Dear Parents,

If you have received this New Parent Guide, you have probably received news that your child has Down syndrome. The Central Mississippi Down Syndrome Society (CMDSS) is a non-profit organization comprised of parents who have children with Down syndrome and live in the Central Mississippi area. We have compiled this New Parent Guide to help parents-to-be and new parents who are going through a similar experience.

First and foremost, we want you to remember,

YOUR CHILD WILL BE OK, YOU WILL BE OK.

Secondly, we want you to know, YOU ARE NOT ALONE.

You may feel like you are on an emotional roller coaster ranging from shock, anger, sadness, and grief, all combined with the joy, excitement, and thrill of being a new parent. We have all been on that same roller coaster and have experienced what you are feeling. The parents of CMDSS and the organization are here to offer you whatever support you need. We are willing to visit you at home or in the hospital, or talk to you by phone or email to help answer your questions about life with an exceptional child.

We also understand that having a child with Down syndrome is not what you originally expected and planned, but we assure you that your child is a true gift who will bring more joy, love, and enrichment to your life than you had ever thought possible.

Thousands of children are born each day, and each one is special and unique. Each one will grow up to be far different from what their parents first imagined the day they were born. This is no different for a child with Down syndrome. Your child will bless you in ways that are unimaginable to you right now.

Please take time to read through the New Parent Guide for valuable information. Be sure to read the Reflections section for a personal look at life with a child with Down syndrome from the viewpoint of local families. If any of the stories strike a personal connection with you, we encourage you to contact any parent whose information is listed at the top of their testimonial.

Our New Parent Guide can be found on our website, www.cmdss.org, for quick reference and to share with family or friends.

We have also included a free copy of the book *Babies with Down Syndrome, A New Parents' Guide.* If you did not receive the book with your guide, or have questions at all, please do not hesitate to call us at (601) 385-3696.

Sincerely,

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congratulations

Congratulations on the birth, or expected birth, of your baby! We understand that your baby may have Down syndrome. You probably have a million questions, concerns, and fears right now. That's okay. The most important thing to keep in mind is that this diagnosis is not as "life changing" as the fact that you have a new baby. And, in most ways, your baby will be just like other infants. Every baby needs to be fed, held, and most of all, loved.

There will be challenges in raising your child, but there will also be many, many joys. It's normal to be nervous about what lies ahead, but remember that Down syndrome is a condition your baby has; it is not who your baby is. Now is the time to begin learning all you can about Down syndrome and the local services available to you. This New Parent Guide is a great place to start.

about us

CMDSS is a parent-driven non-profit organization that provides support services for parents of children with Down syndrome and promotes awareness, acceptance, and inclusion of individuals with Down syndrome.

CMDSS programs support more than 350 families in the Central Mississippi area and include:

- **ANNUAL BUDDY WALK/5K RUN**
  Held annually during October in celebration of National Down Syndrome Awareness month, the Buddy Walk attracts more than 1000 walkers and is CMDSS's biggest awareness event and fundraiser, helping to support CMDSS programs.
- **AWARD-WINNING NEW PARENT GUIDE**
  A full-color guide jam-packed with information to help any new parent get started whether they receive a prenatal diagnosis or at birth. It includes the answers to many immediate questions, parent testimonials, and Central Mississippi resource information.
- **NEW PARENT SUPPORT**
  Includes home/hospital visits and phone support from CMDSS families with similar experiences.
- **NEW PARENT DINNERS**
  Hosted by CMDSS periodically to provide new parents the opportunity to get to know each other, share information, and provide emotional support to one another.
- **MOMS' & DADS' NIGHTS OUT**
  These social nights allow parents the opportunity to establish relationships and share ideas with other parents in a casual setting.
- **TEACHER GRANT PROGRAM**
  These grants provide monetary support for classroom education to teachers who have students with Down syndrome.
- **ANNUAL CMDSS AWARENESS CALENDAR**
  This beautiful, full-color calendar promotes public awareness and features local adults and children with Down syndrome.
- **FAMILY SOCIAL EVENTS**
  These events are designed to allow families who have a loved one to interact, share ideas in a social setting, and allow individuals with Down syndrome to establish and grow peer friendships.
- **EDUCATIONAL SEMINARS**
  CMDSS hosts speakers on a variety of topics geared toward educating families and professionals.

Central Mississippi Down Syndrome Society

P.O. Box 935 • Jackson, MS 39205 • 601-385-DOWN (3696)

www.cmdss.org info@cmdss.org

new parent checklist

- ✓ *Enjoy your baby!*
- ✓ Contact CMDSS if you need additional support.
- ✓ Connect with the CMDSS to get a copy of the New Parent Guide and begin receiving communications to learn about local support services, events and information.
- ✓ Be sure to fill out a membership form online at www.cmdss.org or mail the paper registration form. (See Miscellaneous tab)
- ✓ Contact your local Early Childhood Intervention Program (See Resources tab).
- ✓ Apply for the following programs (See Resources tab):
  - Disabled Child Living at Home Program – once approved, your child will automatically qualify for WIC without regard for income.
  - Developmental Disability Medicaid Waiver after qualification for Medicaid for Disabled Child Living at Home.
- ✓ Find a good pediatrician who has experience with children with Down syndrome.
- ✓ Attend a New Parent Dinner sponsored by the CMDSS. These are informal gatherings for parents/families of children with Down syndrome age 5 and under or new to CMDSS. These dinners are held periodically, generally in the months of May and November.
- ✓ Get involved with other CMDSS programs such as:
  - Attending social or educational events.
  - Joining CMDSS in October for the annual Buddy Walk.
- ✓ Check out the CMDSS Calendar and consider sharing your beautiful child.

opening hearts - changing minds

Central Mississippi Down Syndrome Society

welcome to holland

by Emily Kingsley

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this…

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make wonderful plans. The Coliseum. Michelangelo's David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean, Holland?? I signed up for Italy. I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around…and you begin to notice that Holland has windmills… and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy…and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever go away…because the loss of that dream is a very significant loss.

But…if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things…about Holland.

creed of babies
with Down syndrome

My face may be different
But my feelings are the same.
I laugh and cry
And take pride in my gains.

I was sent here among you
To teach you to love
As God in the heavens
Looks down from above.

To Him, I'm no different.
His love knows no bounds;
It's those here among you
In cities and towns

That judge me by standards
That man has imparted,
But this family I've chosen
Will help me get started.

For I'm one of the children
So special and few
That came here to learn
The same lessons as you.

That love is acceptance
It must come from the heart;
We all have the same purpose,
Though not the same start.

The Lord gave me life
To live and embrace,
And I'll do it as you do …
But at my own pace.

the special mother

by Erma Bombeck

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit. This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen? Somehow I visualize God hovering over earth selecting his instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

"Armstrong, Beth; son. Patron saint … give her Gerard. He's used to profanity."

"Forrest, Marjorie; daughter. Patron saint, Cecelia."

"Rutledge, Carrie; twins. Patron saint, Matthew."

Finally He passes a name to an angel and smiles, "Give her a handicapped child."

The angel is curious. "Why this one God? She's so happy."

"Exactly," smiles God, "Could I give a handicapped child to a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel.

"I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she'll handle it."

"I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I'm going to give her has her own world. She has to make her live in her world and that's not going to be easy."

"But, Lord, I don't think she even believes in you." God smiles, "No matter, I can fix that. This one is

perfect - she has just enough selfishness." The angel gasps - "Selfishness? Is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a 'spoken word'. She will never consider a 'step' ordinary. When her child says 'Momma' for the first time, she will be present at a miracle, and will know it!"

"I will permit her to see clearly the things I see … ignorance, cruelty, prejudice … and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life, because she is doing My work as surely as if she is here by My side."

"And what about her Patron saint?" asks the angel, his pen poised in mid-air.

God smiles, "A mirror will suffice."

you are not alone

For parents when they learn that their child has a disability

by PATRICIA McGILL SMITH

If you have recently learned that your child is developmentally delayed or has a disability, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated – and so confused that I recall little else about those first days other than heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the emotions that flood parents' minds when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. This is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some reactions that occur.

Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this

enormous challenge. One of the first reactions is that of denial – "This cannot be happening to me, to my child, to our family." Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of grief and inexplicable loss that one does not know how to explain, or how to deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?" Then other questions arise: "Will he ever learn? Will he go to college? Will he or she have the capability of loving and living and laughing and doing all the things we had planned?"

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is guilt – guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from my bed when she was very young and hit her head, or that perhaps one of her brothers or sisters inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the disability. Guilty feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?" many parents are also saying "Why has God done this to me?" How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?" One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you have never heard before, terms that describe something you cannot understand. You want to find out what it is all about, yet it seems you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge

to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejections can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child – a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they know they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life that you will find that having a daughter with a disability is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources.

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent-helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Children and Youth with Disabilities has listings of parent groups that will reach out and help you.

Talk With Your Mate

Over the years, I have discovered that many parents of a child with a disability don't communicate their feelings regarding problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure that can establish a special communicative bond with them. Talk with significant others in your life – your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Do Not Be Afraid To Show Emotion

So many parents, especially dads, repress their emotions because

they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of children with disabilities who I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn To Deal With Bitterness And Anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet new challenges when bitter feelings are no longer draining your energies and initiative.

Adopt a Grateful Attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake more negative ones.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things that was pointed out to me was that she was (and still is) a very healthy child. The fact that she had had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of the family, too.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom may be your minister, priest, or rabbi. Another may be a good friend or counselor. Go to those who have been a source of strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call, write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out

the "what if's" and "what then's" of the future. Good things happen each day. Take time to "smell the roses."

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports and progress reports.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations many help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Avoid Judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of not knowing what to say, or fear of the unknown. Therefore, others may sometimes react

inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then you do whatever it was you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

Patricia Smith brings much personal and professional experience to the national parent and disability movement. She is currently the Executive Director of the National Parent Network on Disabilities. She has served as the Acting Assistant and Deputy Assistant Secretary in the Office of Special Education and Rehabilitative Services, in the U.S. Department of Education. She has also served as the Deputy Director of NICHCY, where she wrote and first published *You Are Not Alone*. She has travelled to almost every corner of the United States, as well as internationally, to share her hope and experience with families who have a member with a disability.

Mrs. Smith has seven adult children, the youngest of whom has multiple disabilities. She also has an adopted grandson who has Down syndrome.

Jeff Brock, *The Garden*
Courtesy of Mustard Seed, Inc.

Making the decision to have a child – it's momentous.
It is to decide to forever have your heart go walking outside your body.
– ELIZABETH STONE

getting started

Important Things to Know

Insurance & Medicaid

- **STOP! Don't pay your baby's hospital bill yet!**
  Chances are you may already have medical insurance or plans to pay for your baby's hospital bill out of your own pocket. Even if you have great insurance, you will want to consider applying for **Disabled Child Living at Home through the Division of Medicaid** as a supplement to your private insurance.

- With proper documentation and paperwork filled out providing disability details, children with Down syndrome should qualify. Instead of "Down syndrome," Medicaid prefers "Trisomy 21" as the diagnosis. Other details that may be appropriate should be listed (ex. low tone, any heart defects, feeding issues, etc.) If approved, Medicaid will go back for three months and pay most or all medical bills incurred on behalf of your child, including their portion of the hospital bill at birth. The Disabled Child Living at Home Program is NOT based on your income level; it is based on your child's disability. If Medicaid does not initially approve your child, try again! Your child may qualify on appeal, even if an evaluation is needed. (Evaluation options are listed behind the Resources Tab.) Contact CMDSS for advice on appeal. Notify the billing departments of your hospital and doctors to let them know that you are applying for Medicaid. If you go ahead and pay, it may be difficult or impossible to get reimbursment.

Medicaid will pay for a variety of items and services that may not be included in your insurance plan. Even with a great insurance plan, you will have co-pays, prescriptions, deductibles, and limits on therapeutic services, etc. Medicaid will likely cover what your insurance doesn't cover. Medicaid will provide diapers if your child needs them after the age of three. It is worth the time investment to fill out the paperwork.

CHECK BEHIND THE RESOURCES TAB FOR MORE INFORMATION

(WIC) Women, Infants & Children's Nutrition Program

If your child qualifies for Disabled Child Living at Home through the Division of Medicaid, you will also qualify for the WIC program **without regard to income.** This program is designed to provide a monthly package of nutritious food including infant formula, juice, eggs, cheese, cereal, and peanut butter through the age of five. It will also provide breast-feeding support. See contact information behind the Resources tab.

DD (Developmental Disability) Medicaid Waiver

If your child qualifies for Medicaid for Disabled Child Living at Home program, you are eligible to apply for the DD Medicaid Waiver program. The wait list is long, but the benefits provided are worth the wait. Don't delay – get on the list today! This program provides an approved number of hours of attendant care or respite care free of charge in your home to allow you to work or have a time of respite. You can select a caregiver you know and trust with your child. The DD Waiver can also provide Community Care, which would provide free care for your child at a Medicaid-approved facility. Contact information for the DD Waiver program is located behind the Resources tab.

Early Intervention Services

Early intervention is one of the most important things you can do to help your child!

- The State of Mississippi provides FREE Early Intervention services for qualified children with disabilities from birth to three years of age.
- These services include evaluation, education, speech therapy, occupational therapy, and physical therapy.
- It is important to contact an Early Intervention agency as soon as you feel up to it. They can perform an evaluation of your child and give you easy ways to help now with future developmental concerns.
- Your child can receive their FREE Early Intervention services at a certified center, or qualified therapists will come to your home, day care, etc. It is ***your choice*** where your child receives services. If you prefer a private therapy center for early intervention, Medicaid will likely cover the cost.
- At three years of age, contact your public school district for services through age 21.
- Contact numbers for Early Intervention services can be found behind the Resources tab.

What is Down syndrome?

www.ndss.org

In every cell in the human body there is a nucleus where genetic material is stored in genes. Genes carry the codes responsible for all of our inherited traits and are grouped along rod-like structures called chromosomes. Typically, the nucleus of each cell contains 23 pairs of chromosomes, half of which are inherited from each parent. Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21.

This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm - although each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all.

How Common is Down Syndrome?

According to the Centers for Disease Control and Prevention, approximately one in every 700 babies in the United States is born with Down syndrome, making Down syndrome the most common chromosomal condition. About 6,000 babies with Down syndrome are born in the United States each year.

When Was Down Syndrome Discovered?

For centuries, people with Down syndrome have been alluded to in art, literature and science. It wasn't until the late nineteenth century, however, that John Langdon Down, an

English physician, published an accurate description of a person with Down syndrome. It was this scholarly work, published in 1866, that earned Down the recognition as the "father" of the syndrome, although other people had previously recognized the characteristics of the syndrome; it was Down who described the condition as a disability and separate entity.

In recent history, advances in medicine and science have enabled researchers to investigate the characteristics of people with Down syndrome. In 1959, the French physician Jérôme Lejeune identified Down syndrome as a chromosomal condition. Instead of the usual 46 chromosomes present in each cell, Lejeune observed 47 in the cells of individuals with Down syndrome. It was later determined that an extra partial or whole copy of chromosome 21 results in the characteristics associated with Down syndrome. In the year 2000, an international team of scientists successfully identified and catalogued each of the approximately 329 genes on chromosome 21. This accomplishment opened the door to great advances in Down syndrome research.

Are There Different Types of Down Syndrome?

There are three types of Down syndrome: trisomy 21 (nondisjunction), translocation and mosaicism.

TRISOMY 21 (NONDISJUNCTION)

Down syndrome is usually caused by an error in cell division called "nondisjunction." Nondisjunction results in an embryo with three copies of chromosome 21 instead of the usual two. Prior to or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate. As the embryo develops, the extra chromosome is replicated in every cell of the body. This type of Down syndrome, which accounts for 95% of cases, is called Trisomy 21.

MOSAICISM

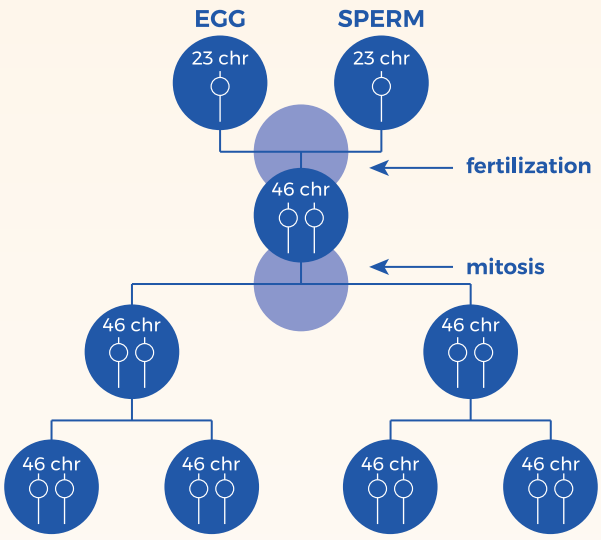
Mosaicism (or mosaic Down syndrome) is diagnosed when there is a mixture of two types of cells, some containing the usual 46 chromosomes and some containing 47. Those cells with 47 chromosomes contain an extra chromosome 21.

Mosaicism is the least common form of Down syndrome and accounts or only about 1% of all cases of Down syndrome. Research has indicated that individuals with mosaic Down syndrome may have fewer characteristics of Down syndrome than those with other types of Down syndrome. However, broad generalizations are not possible due to the wide range of abilities people with Down syndrome possess.

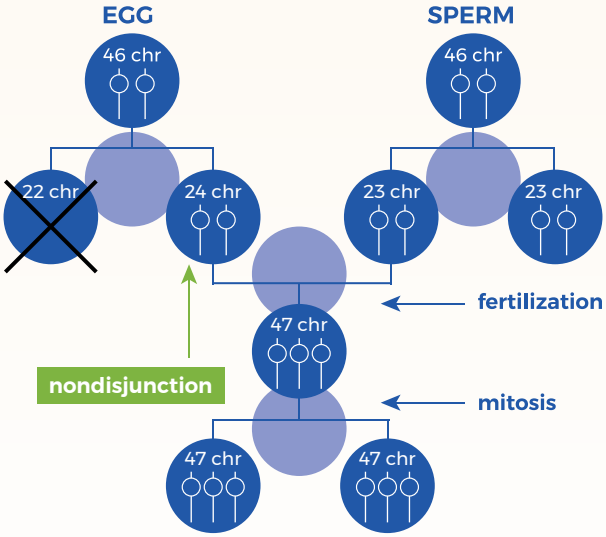
TRANSLOCATION

In translocation, which accounts for about 4% of cases of Down syndrome, the total number of chromosomes in the cells remains 46; however, an additional full or partial copy of chromosome 21 attaches to another

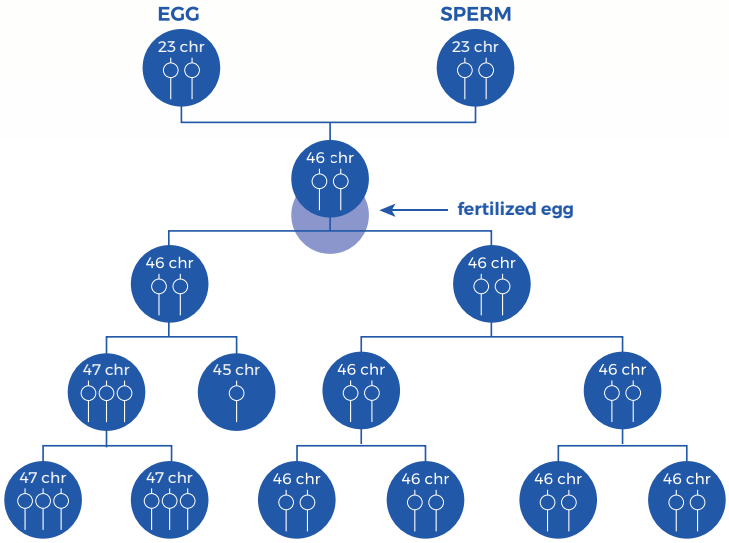
NORMAL CELL DIVISION



TRISOMY 21 (NONDISJUNCTION CELL DIVISION)



MOSAIC CELL DIVISION



chromosome, usually chromosome 14. The presence of the extra full or partial chromosome 21 causes the characteristics of Down syndrome.

What Causes Down Syndrome?

Regardless of the type of Down syndrome a person may have, all people with Down syndrome have an extra, critical portion of chromosome 21 present in all or some of their cells. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.

The cause of the extra full or partial chromosome is still unknown. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome resulting from nondisjunction or mosaicism. However, due to higher birth rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.

There is no definitive scientific research that indicates that Down syndrome is caused by environmental factors or the parents' activities before or during pregnancy.

The additional partial or full copy of the 21st chromosome which causes Down syndrome can originate from either the father or the mother. Approximately 5% of the cases have been traced to the father.

What is the Likelihood of Having a Child with Down Syndrome?

Down syndrome occurs in people of all races and economic levels, though older women have an increased chance of having a child with Down syndrome. A 35 year old woman has about a one in 350 chance of conceiving a child with Down syndrome, and this chance increases gradually to 1 in 100 by age 40. At age 45 the incidence becomes approximately 1 in 30. The age of the mother does not seem to be linked to the risk of translocation.

Since many couples are postponing parenting until later in life, the incidence of Down syndrome conceptions is expected to increase. Therefore, genetic counseling for parents is becoming increasingly important. Still, many physicians are not fully informed about advising their patients about the incidences of Down syndrome, advancements in diagnosis, and the protocols for care and treatment of babies born with Down syndrome.

Does Down Syndrome Run in Families?

All 3 types of Down syndrome are genetic conditions (relating to the genes), but only 1% of all cases of Down syndrome have a hereditary component (passed from parent to child through the genes). Heredity is not a factor in trisomy 21 (nondisjunction) and mosaicism. However, in one third of cases of Down syndrome resulting from translocation there is a hereditary compontent - accounting for about 1% of all cases of Down syndrome. The age of the mother does not seem to be linked to the risk of translocation. Most cases are sporadic – chance – events. However, in about one third of cases, one parent is a carrier of a translocated chromosome.

What is the Likelihood of Having a Second Child with Down Syndrome?

Once a woman has given birth to a baby with trisomy 21 (nondisjunction) or translocation, it is estimated that her chances of having another baby with trisomy 21 is 1 in 100 up until age 40.

The risk of recurrence of translocation is about 3% if the father is the carrier and 10-15% if the mother is the carrier. Genetic counseling can determine the origin of translocation.

How is Down Syndrome Diagnosed?

PRENATALLY

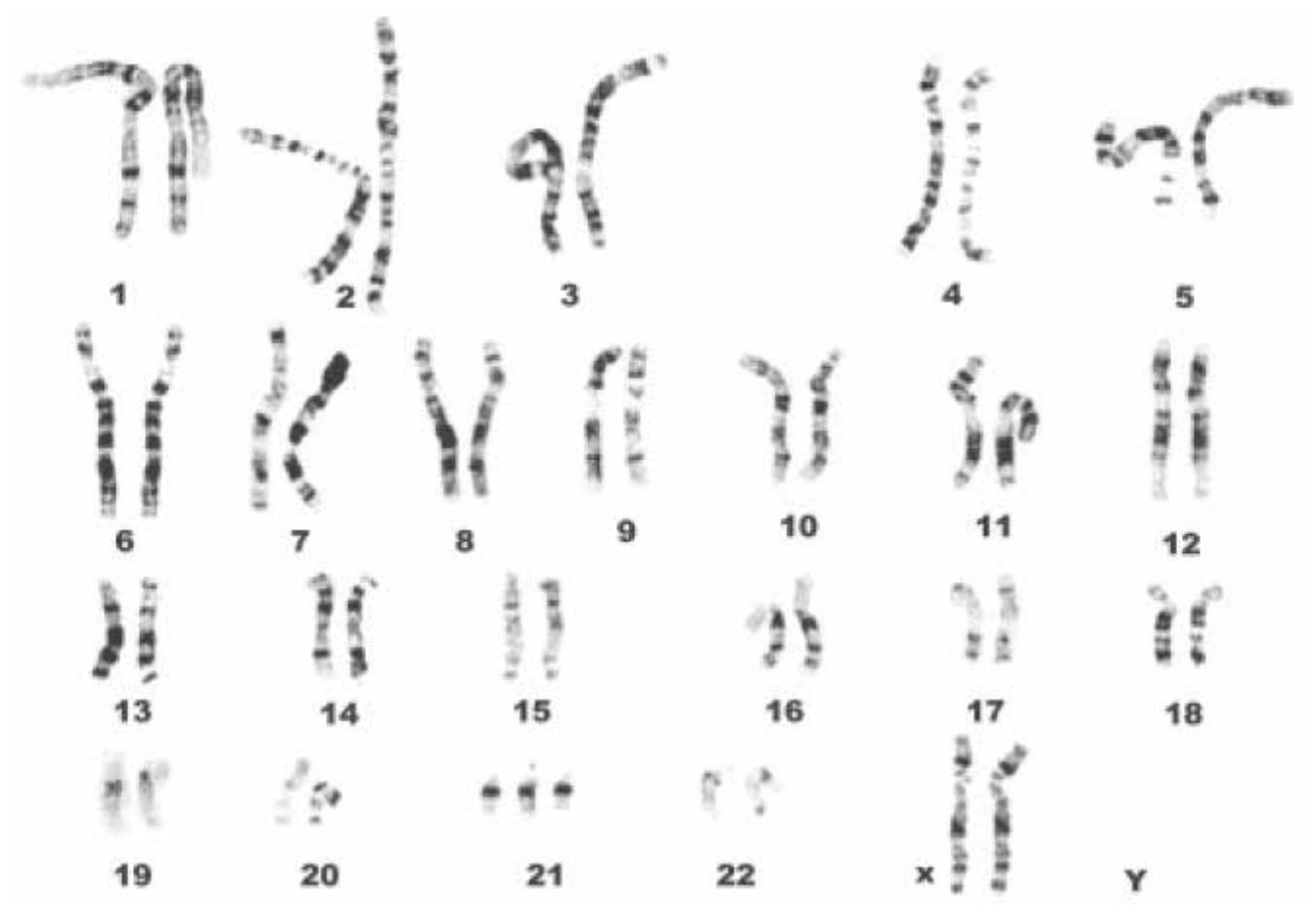
There are two categories of tests for Down syndrome that can be performed before a baby is born: screening tests and diagnostic tests. Prenatal screens estimate the chance of the fetus having Down syndrome. These tests do not tell

Maternal Age	Incidence of Down syndrome
20	1 in 2,000
21	1 in 1,700
22	1 in 1,500
23	1 in 1,400
24	1 in 1,300
25	1 in 1,200
26	1 in 1,100
27	1 in 1,050
28	1 in 1,000
29	1 in 950

Maternal Age	Incidence of Down syndrome
30	1 in 900
31	1 in 800
32	1 in 720
33	1 in 600
34	1 in 450
35	1 in 350
36	1 in 300
37	1 in 250
38	1 in 200
39	1 in 150

Maternal Age	Incidence of Down syndrome
40	1 in 100
41	1 in 80
42	1 in 70
43	1 in 50
44	1 in 40
45	1 in 30
46	1 in 25
47	1 in 20
48	1 in 15
49	1 in 10

KARYOTYPE OF A FEMALE WITH TRISOMY 21



you for sure whether your fetus has Down syndrome; they only provide a probability. Diagnostic tests, on the other hand, can provide a definitive diagnosis with almost 100% accuracy.

There is an extensive menu of prenatal screening tests now available for pregnant women. Most screening tests involve a blood test and an ultrasound (sonogram). The blood tests (or serum screening tests) measure quantities of various substances in the blood of the mother. Together with a woman's age, these are used to estimate her chance of having a child with Down syndrome. These blood tests are often performed in conjunction with a detailed sonogram to check for "markers" (characteristics that some researchers feel may have a significant association with Down syndrome). New advanced prenatal screens are now able to detect chromosomal material from the fetus that is circulating in the maternal blood. These tests are not invasive (like the diagnostic tests below), but they provide a high accuracy rate. Still, all of these screens will not definitively diagnose Down syndrome. Prenatal screening and diagnostic tests are now routinely offered to women of all ages.

The diagnostic procedures available for prenatal diagnosis of Down syndrome are chorionic villus sampling (CVS) and amniocentesis. These procedures, which carry up to a 1% risk of causing a spontaneous termination (miscarriage), are nearly 100% accurate in diagnosing Down syndrome. Amniocentesis is usually performed in the second trimester between 15 and 20 weeks of gestation, CVS in the first trimester between 9 and 14 weeks.

What Impact Does Down Syndrome Have on Society?

Individuals with Down syndrome are becoming increasingly integrated into society and community organizations, such as school, health care systems, work forces, and social and recreational activities. Individuals with Down syndrome possess varying degrees of cognitive delays, from very mild to severe. Most people with Down syndrome have cognitive delays that are mild to moderate.

Due to advances in medical technology, individuals with Down syndrome are living longer than ever before. In 1910, children with Down syndrome were expected to survive to age nine. With the discovery of antibiotics, the average survival age increased to 19 or 20. Now, with recent advancements in clinical treatment, most particularly corrective heart surgeries, as many as 80% of adults with Down syndrome reach age 60, and many live even longer. More and more Americans are interacting with individuals with Down syndrome, increasing the need for widespread public education and acceptance.

AT BIRTH

Down syndrome is usually identified at birth by the presence of certain physical traits: low muscle tone, a single deep crease across the palm of the hand, a slightly flattened facial profile and an upward slant to the eyes. Because these features may be present in babies without Down syndrome, a chromosomal analysis called a karyotype is done to confirm the diagnosis. To obtain a karyotype, doctors draw a blood sample to examine the baby's cells. They photograph the chromosomes and then group them by size, number, and shape. By examining the karyotype, doctors can diagnose Down syndrome. Another genetic test called FISH can apply similar principles and confirm a diagnosis in a shorter amount of time.

what is Down syndrome

Megan Schmidt, *The Wild Fruit*
Courtesy of Mustard Seed, Inc.

You are valuable because you exist — not because of what you do or what you have done, but simply because you are you.
– MAX LUCADO

feeding

Babies born with Down syndrome can be bottle or breast-fed, but they may require a little additional assistance. Many factors can affect feeding, but the most common ones are due to a small mouth size, low muscle tone, or heart problems, which can make sucking difficult and very tiring.

On the following pages is information to help with bottle and breast-feeding. Another tool to use to help strengthen your baby's suck is the pacifier. The pacifier strengthens oral motor control and helps develop the muscles needed for drinking, eating solid foods, and talking.

When your child is able to begin drinking from a cup, it is important that they use a cup/straw instead of bottles and sippy cups.

In addition, when your child is a little older, your speech pathologist will probably recommend some type of regular facial and oral stimulation so it is helpful if your child becomes accustomed to touching on the face and in and around the mouth at an early age.

A great local source for assistance with breast-feeding is:

Dr. Cris Glick
Mississippi Lactation Services
435 Katherine Drive Suite B
Flowood, MS 39232
(601) 932-6455

Should I Breastfeed or Bottlefeed My Baby with Down Syndrome?

www.ndss.org

You may be aware of the tremendous benefits that breastfeeding provides to newborns. Breastmilk contains natural antibodies that fortify babies' immune systems. This is especially important to infants with Down syndrome, who have higher rates of respiratory and other infections. Breastmilk can also reduce bowel problems, which are more common in babies with Down syndrome, and contains an ingredient known to promote brain growth and development.

In addition, the physical process of breastfeeding strengthens babies' jaw and facial muscles, which helps lay a good foundation for speech and language development, and provides skin-to-skin contact, a form of sensory stimulation that creates neural connections that can facilitate future learning.

There are many great reasons to breastfeed, but whether or not to do so is a personal choice. Some mothers breastfeed exclusively while others bottlefeed. Still others combine the two. There are many factors that play into this decision, including whether or not you feel your body is producing enough milk, whether or not your baby has health complications, and whether or not you plan to return to work soon after delivery.

If you do plan to breastfeed, be aware of certain factors that might make it challenging. Babies with Down syndrome have low muscle tone, so it may be difficult for your baby to "latch on" to your breast at first. As these babies also tend to be sleepier than other infants, you will likely have to make an extra effort to raise your baby's alertness and keep him or her awake throughout the entire feeding. Also, if your baby needs surgery, he or she may require a feeding tube for a short time.

Don't worry, though. There are many organizations and individuals that can help you get started and provide tips for overcoming these and any other challenges you may encounter. These same specialists can help you learn how to pump, store and transport your breastmilk or how to select the right baby formula to meet your infant's needs if you choose to bottlefeed. When it comes to feeding, the important thing is to make the choice that is best for you. Feedings should provide quality time for a parent and child to bond, so they should always be as comfortable and stress-free as possible for both individuals. A meeting with your hospital's lactation specialist is a great place to start learning about what feeding option may be right for you.

bottle feeding

Bottle-Feeding Your Baby

Most babies with Down syndrome grow properly and do just fine in the eating department. But some young babies with Down syndrome have a harder time sucking efficiently, due to their low muscle tone. Their mouths may be less "alert" or ready for feeding, and the extra effort they have to put out to eat gives them less endurance for getting through the whole meal.

Breast-fed babies with low muscle tone can lose interest while waiting for the milk to let down. Some babies with Down syndrome find it harder to latch on to the breast or bottle nipple and maintain a good hold throughout the meal. These babies take many more breaks and end up eating less per feeding than you would expect for the amount of time spent. Swallowing excess air is common because the baby has a less efficient hold on the nipple.

Despite these concerns, babies with Down syndrome and their parents usually find a few tricks that make feedings easier for everybody. This article looks at some techniques that often work.

What Can Be Done?

Babies with low tone may need to be helped to use the muscle strength and control they have. They often prefer to be fed in a way that requires the least effort, rather than using their muscle control. To help encourage muscle strength, you need to "wake them up" or alert them before and during each feeding. Here are a few wake-up strategies; contact your baby's doctor to review the appropriateness of these activities for your child.

Preparation

Start the feeding when your baby is most awake or alert.

See if playing with your baby just before feeding helps increase attention for the meal. Play gentle tickle games with fingers, toys, or kissing around the face and neck. While supporting your baby's head, dance with your baby so head and upper body control is stimulated.

Bounce your baby gently in your lap. Of course, the dancing and bouncing should be done only if your baby can handle that much stimulation and has the head control necessary to participate without getting hurt.

Some parents have found that a cool or tepid bath wakes up their baby before feedings. Others have found that a brisk towel rub helps.

After waking up your baby's body, focus the alerting on the face and mouth area. A cool washcloth on the face or gentle tapping around face and mouth may increase readiness for the bottle.

Some parents have found that gently tickling or stretching the muscles around the lips and cheeks helps wake up the mouth. You can use fingers and washcloths.

Position

Feed your baby in as upright a position as possible. The more your baby is up against gravity, the more active the muscles become. In addition, babies

with Down syndrome seem to be more prone to ear infections. Upright feedings decrease the chance of liquid backing up in the ear canals, reducing the risk of infection.

Be sure that your baby is being fed in a chin tuck position. This position, with the head not too far back and not too far forward, seems to set up the neck and mouth muscles for the strongest sucking response. Try to rest your baby's head – not neck – on your arm when holding during feedings, which automatically tucks the chin slightly. This position also can be achieved with pillows or arm rests.

An angled bottle, available commercially, may be used to keep the baby's head at this angle until the end of the feeding. With a regular bottle, children must tip their heads back to get the last few drops. An angled bottle solves this problem. Cool the liquid.

Temperature may affect the efficiency and speed of your baby's sucking and swallowing. After checking with your doctor, consider starting the baby at room-temperature formula and gradually chilling the formula until your baby can handle it straight from the refrigerator. This can increase not only the baby's interest in sucking but also the amount that is sucked during the meal.

Cheek and Tongue Involvement

Some babies need to be reminded to suck during the meal by having a little attention drawn to their tongues. To increase tongue involvement, try tapping the nipple on the tongue or pressing up and down on the tongue regularly throughout the meal. This may serve to wake up the tongue, but should be discontinued or decreased if it disrupts the meal too much. Cheeks can be tickled, squeezed slightly, or tapped to keep them active during a feeding.

Ask for Help

Babies with Down syndrome have all the basic skills necessary for taking a breast or bottle. The suggestions in this article are intended to increase babies' efficiency and control, so they can progress to more difficult food textures and consistencies.

Some babies with Down syndrome have further medical complications that interfere with good sucking or good nutritional intake. These conditions may require extra assistance. Ask your pediatrician, feeding specialist, or developmental team if you have questions or need more help.

Savannah Wilson, *God's Creation of Animals*
Courtesy of Mustard Seed, Inc.

God will wrap some blessings in disguise. You may have to wait this lifetime to see the reasons with your eyes because sometimes miracles hide.
– BRUCE CARROLL

AAP Guidelines www.aap.org

Down Syndrome Healthcare Guidelines (2011 Revision) Record Sheet*

	Birth	6 mo	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Genetic Counseling[1], Karotype																						
Parent Group Info and Support																						
CBC to R/O transient myeloproliferantive disorder, polycythemia	Parent-to-parent contact, support groups, current books, and pamphlets																					
Swallowing assessment if feeding problems or aspiration																						
Hemoglobin			Hemoglobin annually beginning at 1 year old. If Hg<11, do (a) CRP and ferritin, or (b) Reticulocyte Hemoglobin Content (CHr). If possible risk for iron deficiency, do (a) or (b) regardless.																			
23-valent pneumococcal vaccine[2]																						
Cardiology	Echo[4]														Screen for acquired mitral or aortic valvular disease							
Audiological Evaluation	ABR or OAE	Every 6 months till 3 years of age. Annually thereafter.																				
Ophthalmologic Evaluation	Red Reflex	Appt	Annual ophthalmology appt					Q2 ophthalmology appointment								Q3 ophthalmology appointment						
Celiac Disease Screening					(Only test if signs and symptoms present)																	
Thyroid – TSH, T4	State Screen	Test	Test	Test TSH and T4 annually																		
Neck X-ray (AAI)[3]					✓[3]																	
Dental Exam			Annual Dental Exams. Reassure parents that delayed or irregular eruption, hypodontia are common.																			
Sleep Study by age 4 years	Done prior to 4 years of age																					
Early Intervention																						
Childhood					Discuss self-help, ADHD, OCD, wandering off, transition to middle school.																	
Puberty															Discuss physical and psychological changes through puberty, need for gynecologic care (pelvic exams) in pubescent female							
Facilitate Transition															Guardianship, financial planning, behavioral problems, school placement, vocational training, independence with hygiene and self-care, group home, work setting.							
Sexual development and behaviors															Discuss contraception, STDs, recurrence risk for offspring							
Preventive Care	Annually monitor for signs and symptoms of constipation, OSA, and aspiration.																					

1. Discuss Recurrence Rate of future pregnancies with parents
2. 23-valent pneumococcal vaccine if chronic or pulmonary disease
3. AAI: See AAP Guidelines page 399 - X-rays only if myopathic signs or symptoms ***Peds 2011 ;128 :393-406 Chart by Sie Center for Down Syndrome**
4. Follow up to be determined by Cardiologist

Updated 09/2013

notes

We cannot fashion our children after our desires, we must have them and love them as God has given them to us.

– JOHANN WOLFGANG VON GOETHE

Health Care Information for Families of Children with Down Syndrome

Child's Age: The Prenatal Period (the time before birth)

☐ **Consider testing as desired**

Prenatal testing for genetic conditions is recommended for families who wish information to help them make decisions about a pregnancy. This testing should be done only after information about the tests has been discussed between the doctor and the family, and the family understands the risks and benefits of the testing.

☐ **Counseling**

If Down syndrome (trisomy 21) or any other chromosome change that causes Down syndrome is found by prenatal testing, the family should receive counseling to explain the issues and provide support for the family.

☐ **Prenatal heart testing**

Because there is a high risk of heart problems at birth in Down syndrome, echocardiography (an ultrasound picture of the heart) done during the pregnancy can provide information that may be useful for the remainder of the pregnancy and for the delivery. This information may help with decisions such as where to deliver the baby and the medical services needed late in pregnancy or at delivery.

Health Care Information for Families of Children with Down Syndrome

Child's Age: Birth to 1 Month

☐ **Complete physical examination**

If the diagnosis of Down syndrome was made before birth or suspected after birth, a complete physical examination should be done to confirm the known physical features and to check for any possible associated conditions.

☐ **Genetic testing**

If prenatal testing gave a diagnosis of Down syndrome and if the exam after birth agrees, then no further testing is probably needed in the newborn period. If the physical examination after birth raises the possibility of Down syndrome, testing by rapid (FISH) confirmation and a complete chromosome analysis are needed. The rapid analysis results are typically available within 48 hours, whereas the complete analysis might take 3-5 days for the results. A complete chromosome analysis is needed to provide full information, but to ensure prompt results, both should be obtained unless the complete analysis can be done as quickly as the rapid analysis.

☐ **Counseling**

The prenatal or newborn diagnosis of Down syndrome can cause many concerns for parents. Talking with a medical genetics team (medical geneticist and genetic counselor) or others recommended by your child's doctor may be helpful.

☐ **Feeding**

Infants with Down syndrome sometimes have low muscle control, which can cause feeding problems. For this reason, infants should be closely watched for slow feeding or choking and for good weight gain. Breastfeeding is strongly encouraged, but extra attention may need to be given to positioning and to keeping the baby awake or alert. See Feeding Tab for more information.

CHECK BEHIND THE FEEDING TAB FOR MORE INFORMATION

☐ **Heart**

An echocardiogram (an ultrasound picture of the heart) is needed to check for any evidence of heart disease. This should be done even if a prenatal echocardiogram was done. If issues exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

☐ **Hearing and Vision**

Infants with Down syndrome are at risk for sensory issues, such as eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmology and ENT).

☐ **Thyroid**

Thyroid hormone levels can be too low in newborns and need to be checked (a TSH test). Thyroid hormone imbalance can cause a variety of problems that might not be easy to detect without a blood test.

☐ **Blood Test**

After birth, white and red blood counts can be unusually high in infants with Down syndrome. These blood counts need to be checked.

☐ **Stomach or bowel problems (reflux, constipation, blockages)**

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

☐ **Infection**

Because of an increased risk of infections (especially respiratory infections), infants should be protected from any unnecessary exposures to sick siblings, relatives, or others. It is also recommended to get checked quickly when any infection is suspected.

☐ **Developmental Services**

It is not too early in the first month of life to start to look for the developmental services (sometimes called "Early Intervention") that will be very important in early childhood.

CHECK BEHIND THE RESOURCES TAB FOR MORE INFORMATION

☐ **Resources**

Families of children with Down syndrome will need multiple resources, and now is a good time to start lining them up. Such resources might include specialized medical care, early intervention, physical therapy, and family counseling services.

Health Care Information for Families of Children with Down Syndrome

Child's Age: 1 Month to 1 Year

☐ **Regular well-care visits (check-ups)**

While infants with Down syndrome might need multiple special visits to their doctor and specialty physicians, it is very important that they get regular well-care visits (check-ups). These visits will include checking your child's health, giving immunizations (shots), and building the relationships between the doctor and the family. Developing these relationships will help support the medical and other needs of the child and the family.

☐ **Monitor growth**

It is important to check growth at every visit. Measurements include height, weight, weight for height, and head circumference. Discuss your child's diet, activity level, bowel and urine patterns, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

☐ **Immunizations (shots)**

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

☐ **Heart**

If there were any signs of heart disease in the first month of life, heart monitoring is probably already in place. Heart problems could still worsen or new ones could arise. If concerns exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

☐ **Hearing and vision**

Infants with Down syndrome are at risk for eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmologist and otolaryngologist/ear, nose, and throat doctor or ENT). The eyes should be tested at birth and again at 1 year or sooner if there are concerns. Hearing should be tested at birth and again every 6 months in early childhood to be sure that the baby's hearing is the best possible.

☐ **Thyroid**

Thyroid hormone levels can be too low in infants and need to be checked (a TSH test). Low thyroid levels can cause a variety of problems that might not be easy to detect without a blood test. A TSH should be obtained at birth and again at age 6 months and 1 year.

☐ **Stomach or bowel problems (reflux, constipation, blockages)**

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

☐ **Neck instability**

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done and the results are abnormal, your child may be referred to a spine or neck specialist. It is recommended that the neck be positioned properly for any medical procedures.

☐ **Developmental services**

Developmental services (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.

☐ **Social support services**

Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor the social services that may be available and their benefits.

☐ **Recurrence risk counseling**

Families should get counseling about the possible risk of having another child with Down syndrome, if they choose to have more children. While the risk is usually low, other factors in the family history might be present, so counseling should be done after a complete review of the family history.

Health Care Information for Families of Children with Down Syndrome

Child's Age: 1 Year to 5 Years

☐ **Regular well-care visits (check-ups)**

At the one-year check-up, you should look at the checklists for newborns and infants to be sure everything has been done as recommended. Follow-up on known problems with specialists and be sure that reports are sent to your child's primary doctor.

☐ **Monitor growth**

It is important to check growth at every visit. Measurements include height, weight, body mass index (BMI), and head circumference. Discuss your child's diet, activity level, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

☐ **Immunizations (shots)**

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

☐ **Heart**

The need to see a cardiologist during this age is based on the child's health history and examination. Children with cardiac lesions may need to be monitored even after repair for remaining lesions and development of pulmonary hypertension (high pressure in blood vessels of the lungs).

☐ **Hearing**

Hearing should be checked every 6 months, with audiogram and tympanometry tests until normal hearing is documented by testing of both ears separately (usually by 4-6 years of age). Children with hearing loss should be referred to an otolaryngologist (ear, nose, and throat doctor or ENT). Higher risks of hearing problems can go with middle ear fluid and ear infections. Treatment of middle ear fluid often includes the use of ear tubes.

☐ **Vision**

Vision should be checked at each visit to the doctor and with yearly checkups by a pediatric ophthalmologist (special eye doctor) or a general ophthalmologist who is good with children with disabilities. Crossing eyes or blocked tear ducts might be reasons for quicker action. Early use of eye patches, glasses, or both may help to fix eye crossing while lowering the need for surgery and the risk of vision loss.

☐ **Thyroid**

The thyroid gland is usually normal in babies with Down syndrome. It can stop working normally for half of people with Down syndrome by adulthood. The symptoms of low thyroid can be hard to notice in people with Down syndrome, so a blood test (TSH) is needed every year, or sooner if symptoms change. When there is a problem, treatment is safe and can often be started by your primary doctor.

☐ **Blood tests**

Tests for low iron or anemia (hemoglobin and other tests if needed) should be done every year.

☐ **Stomach or bowel problems (diarrhea, constipation)**

Discuss toilet patterns at each visit, especially any ongoing problems with loose stools or constipation. These are common in children with Down syndrome. Some children with Down syndrome have celiac disease, which is a problem with tolerating some grains, including wheat. Testing can help to identify that condition, and may lead to changes in diet. Celiac disease can affect growth, stooling patterns, and behavior. Let your child's doctor know if your child is having:

- Very loose stools
- Hard to treat constipation (hard or painful stools)
- Slow growth/weight loss
- Belly pain or stomach swelling
- New or challenging behavior problems

☐ **Neck instability**

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done, and the results are abnormal, your child may be referred to a spine or neck specialist. Special neck positioning may be needed for some medical procedures. Let your child's doctor know if your child is having:

- Stiff or sore neck
- Change in stool or urination pattern
- Change in walking
- Change in use of arms or legs
- Numbness (loss of normal feeling) or tingling in arms or legs
- Head tilt

☐ **Sleep issues**

Obstructive sleep apnea is a common problem for people with Down syndrome, especially those with low muscle tone. Some symptoms are obvious (snoring, restless waking at night, daytime sleepiness), but it can be hard to tell just by watching. AAP guidelines recommend that every child with Down syndrome have a sleep study by the age of 4 years. (That testing may be hard to find in some parts of the country.) Treatment can include special breathing equipment or surgery.

☐ **Skin**

Discuss with your child's doctor if your child has very dry skin or other skin problems.

☐ **Brain and nervous system**

Discuss with your child's doctor concerns about neurologic problems, such as seizures.

☐ **Dental**

Delayed and missing teeth are common. Teeth often come in unusual order.

☐ **New treatments**

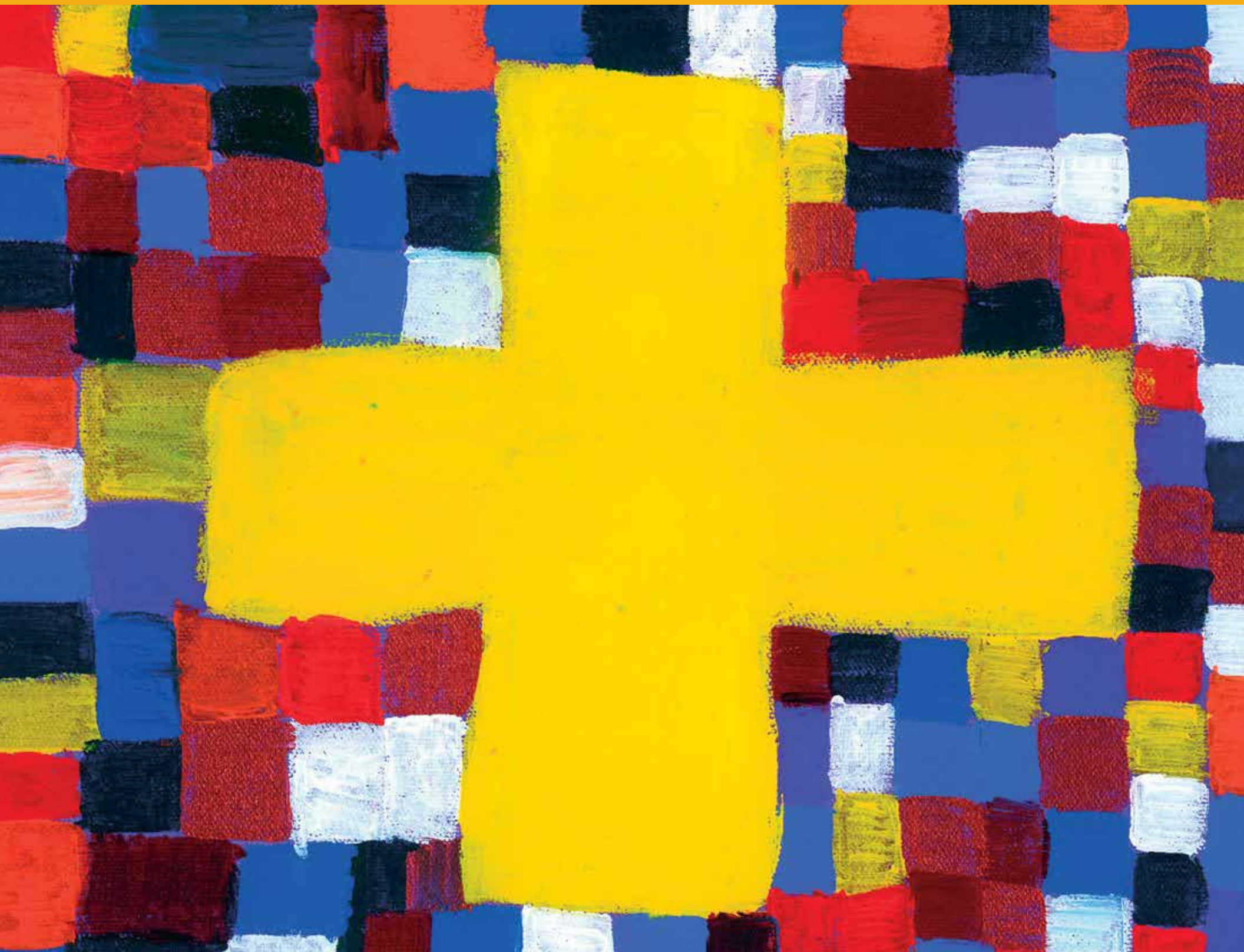
Talk to your doctor about any new treatments or medications you may consider.

☐ **Recurrence risk counseling**

Talk to your doctor about future pregnancy planning and chances of recurrence of Down syndrome and where prenatal diagnosis is available.

☐ **Developmental services (early intervention)**

Review your child's development with your doctor. Referral to local early intervention services and other options for therapy may be needed. Speech progress can be very delayed in children with Down syndrome, but after some delays, most will learn to talk well. Until speech is easier for your child, he or she might need help finding other ways to communicate, such as using sign language, pictures, reading, or using electronic communication tools. Behavior problems are often linked to problems with communication, but may reflect other issues, including ADHD or autism. Language delays or hidden abuse are more common than autism but may be misdiagnosed. Talk with your doctor about how to explain social safety and "good and bad touch" as your child grows older.



Angie Parsons, *Cross of Love*
Courtesy of Mustard Seed, Inc.

There are only two lasting bequests we can hope to give our children.
One is roots; the other, wings.
– HODDING CARTER

dental care

Choosing a Dentist

Anyone that has taken a small child to the dentist can attest that it can be a challenge. A child with Down syndrome is no different, and could present a set of challenges that will require adaptation by the parent/caregiver and the treatment team.

The American Academy of Pediatric Dentistry encourages all parents and other caregivers to help every child establish a dental home by age 12 months. A dental home is the central place where all of a child's oral healthcare needs are going to be comprehensively met. Establishing a dental home early enables the dentist and parents to discuss ways to nurture excellent oral health before any serious problems have had an opportunity to develop.

While children with Down syndrome can be treated in a typical office setting and some general dentists are capable of treating children with special healthcare needs, your child may require the expertise of a pediatric dentist. A pediatric dentist is a "specialist" who has trained for 24 months beyond dental school to learn exclusively how to manage and treat the dental needs of children including children with Special Health Care Needs (SHCN). Their training exposes them to experiences in which they deal with various health concerns of children with SHCN as they relate to their dental treatment needs.

Whether you take your child to a general dentist or a pediatric dentist, the most important thing is to choose someone who can adequately provide the services your child requires.

First Visit

Once you have identified a dental home for your child, the next step is to set up an appointment. A few tips related to this first step are:

1. Familiarize yourself and your child with the practice: Ask if you both could come and meet with the dentist and the staff and see the facility. Some practices are open to this option. This will give your child a chance to be more familiar with the environment prior to getting any type of treatment done.
2. Timing of the appointment: You know your child and their everyday routine the best. Therefore, you can request an appointment at a time of day when you think your child will be the least tired from their daily activities and routine. It is usually recommended to set up an appointment earlier in the day. This will ensure your child is not fatigued and reduces the time spent waiting.
3. Be prepared to discuss all aspects of your child's health with their dentist. Be sure to bring contact information for all your child's healthcare providers so that the dentist can consult and discuss dental treatment plans with them if needed.

Day of the Appointment

All children are different and your child may or may not enjoy a trip to the dentist. If challenges present themselves, communication between the family, the physician, and the dentist is the key to adapting and overcoming them. Children with Down syndrome may have medical conditions,

such as cardiac disorders or seizure disorders that may need to be treated or considered prior to beginning dental treatment. Both your primary care physician and your dentist can help to create a treatment plan that prioritizes what is most important for your child. Communication should occur between the family and the dentist to establish a good medical history. This will allow the dentist to gain an understanding of your child's needs, and will also allow the family to bring attention to any special concerns they may have regarding their child, such as tactile or auditory sensitivities/aversions. Reviewing the medical history and constructing a treatment plan will greatly increase the likelihood of a successful visit.

Gaining the child's trust is extremely important in the success of the treatment. Consistency and familiarity will increase the chance your child will cooperate in the treatment.

Oral Hygiene

All dentists recommend following the guidelines set forth by the American Dental Association to prevent dental caries. Dental caries, also known as cavities or tooth decay, is the leading cause of tooth loss and tooth-related pain. According to the American Dental Association (ADA), all children should follow these general oral healthcare guidelines:

- Eating a healthy balanced diet and reduce between-meal snacks.
- Brush twice a day with ADA approved toothpaste that contains fluoride.

The process of cleaning your child's mouth should start even before the arrival of any teeth. It is recommended to "wipe" your infant's gums, tongue and inside of their cheeks after each feeding or at least twice a day. Once the teeth erupt, start using a small soft-bristled toothbrush. For most infants and toddlers, a "smear" of non-fluoridated toothpaste is recommended. Use of fluoride toothpaste can be recommended by your dentist based on your child's risk of developing cavities.

Dental Caries (Cavities)

According to the Centers for Disease Control (CDC), "tooth decay (dental caries) affects children in the United States more than any other chronic infectious disease. Untreated tooth decay causes pain and infections that may lead to problems such as difficulties in eating, speaking, playing, and learning." Caries is an infection of the teeth that is caused by specific bacteria, such as Streptococcus mutans. These bacteria invade the oral cavity (mouth) and use sucrose (sugar) present in certain types of foods to produce damaging products (acids). These acids cause destruction and break down tooth structure. When a baby is born, he or she is normally free from infection from these bacteria.

They can however get infected very quickly if they are exposed to the saliva of the mother/caregiver who has a high level of these bacteria in his/her mouth due to the presence of poor oral hygiene and/or cavities. This exposure can occur when a parent kisses the hands of the child who then puts the hand in their mouth, or tasting the child's food, pacifier contamination, etc. It is therefore important for the main caregiver of the child to maintain good oral health, too.

Diet

It is very important to brush/clean your child's teeth, especially after nighttime feeding and to not allow your child to go to bed with a bottle. Baby bottle syndrome or rampant caries are seen frequently affecting the front teeth of children with poor oral hygiene and prolonged exposure to sugary drinks. This is important for all children, and especially important for children with Down syndrome due to the delayed eruption of permanent teeth. Your child may retain their primary (baby) teeth for several years past the typical time frame.

A well-balanced diet is optimal for your child's tooth development and overall wellness. According to the American Academy of

Pediatric Dentistry, nighttime bottle-feeding with juice, repeated use of a sippy or no-spill cup, and frequent in-between meal consumption of sugar-containing snacks or drinks (e.g., juice, formula, soda) increase the risk of caries. Frequent ingestion of sugars and other carbohydrates (e.g., fruit juices, acidic beverages) and prolonged contact of these substances with teeth are particular risk factors in the development of caries. Along with increasing caries risk, increased consumption of sugar-sweetened beverages and snack foods also has been linked to obesity.

Children with Down syndrome may require daily medications. Numerous over-the-counter and prescribed oral liquid medications have been found to have a high sugar content to increase acceptance by children. If given at bedtime, it is important to give these medications before brushing your child's teeth. To motivate children to consume vitamins, numerous companies have made "jelly," "gummy," and "candy-like" chewable vitamin supplements. These are a source of sugar and oral hygiene should be performed after consumption. In addition, cases of vitamin A toxicity have been reported as a result of excessive consumption of candy-like vitamin supplements.

Periodontal Disease (Gum Disease)

Research has shown that individuals with Down syndrome are more prone to gum disease. It is therefore extremely important to maintain excellent oral hygiene at home. Also, discuss with your dentist the option of more frequent "preventive" appointments for your child.

Fluoride

The use of fluoride helps reduce cavities. A small pea-sized amount of fluoride toothpaste is sufficient for children between the ages of 2 and 6 years. Children under 2 years should not use fluoride toothpaste prior to consulting their dentist and performing a caries risk assessment. Now, because most water systems are fluoridated and fluoride works both systemically (drinking) and topically (brushing) it is very important to be aware of your child's fluoride intake. As with anything, too much of a good thing can be harmful.

Too much fluoride can cause dental fluorosis, which is a permanent discoloration of otherwise healthy teeth. The discoloration occurs during the formation of the tooth, which is well before eruption. According

to the CDC, children over 6 years old are considered past the age that fluoride ingestion can cause cosmetically objectionable fluorosis because only certain posterior teeth are still at a susceptible stage of enamel development, and these will not be readily visible. In addition, the swallowing reflex has developed sufficiently by age 6 years for most children to be able to control inadvertent swallowing of fluoride toothpaste and mouth rinse.

Fluoride therapy reduces tooth decay and strengthens the existing tooth structure and the fluoridation of drinking water has had a strong impact on the reduction of caries. Water fluoridation prevents tooth decay mainly by providing teeth with frequent contact with low levels of fluoride throughout each day and throughout life.

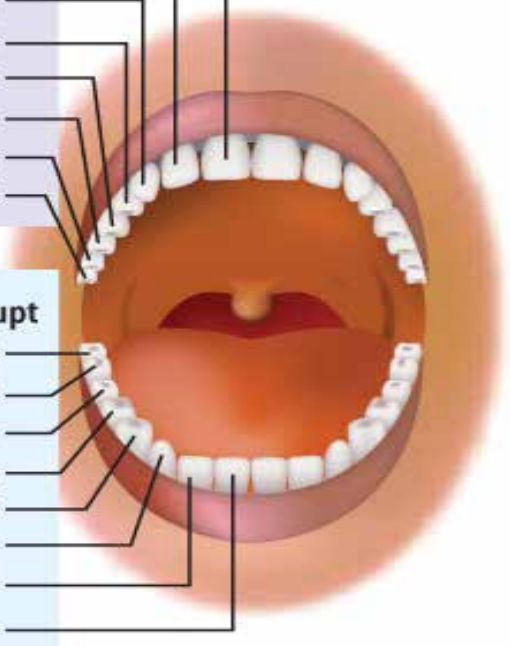
Even today, with other available sources of fluoride, studies show that water fluoridation reduces tooth decay by about 25 percent over a person's lifetime. New moms need to read the label of infant formulas to determine the amount of fluoride in the formula and if fluoridated or non-fluoridated water should be added. Most community water systems are fluoridated and information regarding fluoride levels can be obtained from the water department. Some bottled water has fluoride added and some do not. Single-family well owners can have their water tested for fluoride at a laboratory; local health departments can usually guide you in this process. The CDC also has a website that can be used to determine your water fluoride level; visit the My Water's Fluoride – CDC at https://nccd.cdc.gov/DOH_MWF.

Eruption Sequence

Eruption of both primary and permanent teeth vary greatly from one individual to another. This variability can be seen in children with Down syndrome to a greater extent. The eruption of the first tooth is sometimes delayed in a child with Down syndrome and can be as late as 24 months. The uniqueness of children with Down syndrome does not stop there. It is not uncommon for children to have congenitally missing teeth (oligodontia) or have teeth that

Upper Teeth	Primary Erupt	Permanent Erupt
Central Incisor	8-12 months	7-8 years
Lateral Incisor	9-13 months	8-9 years
Canine (Cuspid)	16-22 months	11-12 years
First Premolar		10-11 years
Second Premolar		10-12 years
First Molar	13-19months	6-7 years
Second Premolar	25-33 months	12-13 years
Third Molar		17-21 years

Lower Teeth	Primary Erupt	Permanent Erupt
Third Molar		17-21 years
Second Molar	23-31 months	11-13 years
First Molar	14-18 months	6-7 years
Second Premolar		11-12 years
First Premolar		10-12 years
Canine (Cuspid)	17-23 months	9-10 years
Lateral Incisor	10-16 months	7-8 years
Central Incisor	6-10 months	6-7 years



http://pidcgr.com/patient-information/your-childs-teeth/tooth-eruption/

are smaller in size (microdontia). This is not necessarily a bad thing and prevents over-crowding in the relatively small size of the oral cavity.

Craniofacial

The oral cavity and more specifically the mid-face region is smaller in size in a child with Down syndrome compared to their typical counterpart. This causes the upper jaw to be small in size and the roof of the mouth (palate) to become narrow thus reducing the overall amount of space needed to accommodate all teeth. This lack of adequate space also affects the amount of available space for the tongue. As a consequence, the tongue "appears" to be larger than normal size and may develop deep creases on the top and side surfaces. Particular attention should be paid to these areas as they can be hard to clean and can get food to accumulate resulting in foul smelling breath.

The smaller dimensions of the mid-face region also contribute to smaller airways. This, accompanied with a large tongue compared to the mouth, can cause mouth-breathing, snoring, and sleep apnea. These can result in problems in how your child's upper and lower teeth relate to each other. The most common issue is "open bite" where their front top teeth do not touch/overlap bottom teeth. An open bite can also be caused by or exaggerated by sucking on a pacifier or sucking on his/her thumb. This should be discouraged and remedied as soon as possible. It will only worsen the problems associated with an open bite. Braces may or may not be appropriate for your child. A pediatric or general dentist can guide you through that decision; however, do not let the fact that your child has Down syndrome discourage you from pursuing braces. Every child wants a beautiful smile and every child deserves a properly functioning bite.

It is the small differences that make each of us so unique and special. If you are reading this New Parent Guide, then you or someone you know has been blessed with a beautiful new baby. So congratulations! Relax and enjoy!! Many talented people are willing to help you with each step of the journey so utilize your resources!

This guide is a reference for new parents and small children, so it is limited in scope. There is a lot of literature/information regarding adults with Down syndrome that is not included. Prevention is always better than cure. Therefore, maintaining good oral hygiene habits greatly reduces the likelihood of having cavities and of contracting periodontal disease. This is only a reference tool and all parents are encouraged to continue to learn about their child's oral health.

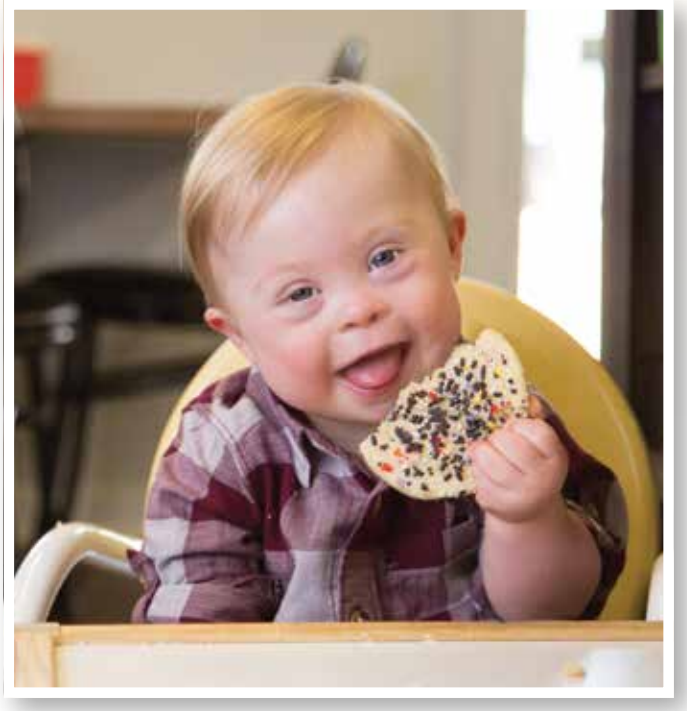
Below is a list of terms that can be used as a reference. The intent of listing these terms is simply for exposure. The more knowledgeable you are, the more confident you will be in preparing for your child's future. Your dentist and pediatrician should be very familiar with the recommended guidelines for care of your child with Down syndrome and will help navigate these unfamiliar waters. Most dental problems can be avoided by simply following the recommended guidelines set forth for any child. Start early! Providing adequate oral hygiene at an early age and having your child become accustomed to the routine will greatly benefit both you and your child in the future. The most important thing to remember is you have a beautiful new baby and enjoy the ride!!

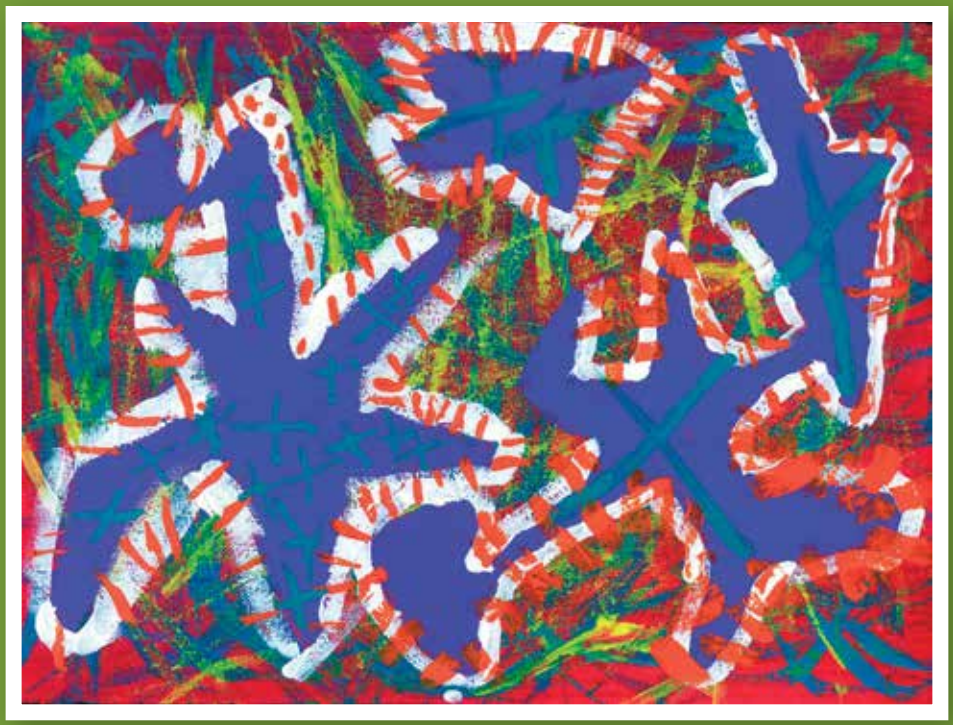
Terms/Definitions

1. **Dental specialties** – The eight specialties recognized by organized dentistry: endodontics, public health dentistry, oral radiology, oral surgery, oral pathology, orthodontics, pediatric dentistry, periodontics, and prosthodontics.
2. **Pedodontics** – The branch of dentistry that deals with the care of children and includes the following: training the child to accept dentistry;

restoring and maintaining the primary, mixed, and permanent dentitions; applying preventive measures for dental caries and periodontal disease; and preventing, intercepting, and correcting various problems of occlusion.

3. **Periodontist** – A dental practitioner who is a dentist who specializes in the prevention, diagnosis, and treatment of periodontal disease, and in the placement of dental implants.
4. **Periodontitis** – Inflammation of the supporting tissues of the teeth, usually a progressively destructive change leading to loss of bone and periodontal ligament.
5. **Gingivitis** – Inflammation of the gingiva (gums).
6. **Microdontia** – Abnormally small teeth. The term may apply to one, several, or all teeth.
7. **Macroglossia** – An enlarged tongue.
8. **Open bite** – When the anterior teeth do not occlude in any mandibular position.
9. **Atlantoaxial instability** – A condition characterized by excessive movement at the junction betwee the first (C1) and second (C2) cervical vertebrae.
10. **Plaque** – It consists of proteins from saliva, microorganisms (bacteria), and other byproducts of the microorganism. It forms on the oral cavity surface, and is a factor in initiation and continuation of dental caries and periodontal disease.
11. **Baby bottle tooth decay** – A dental condition that occurs in children from 1 to 3 years of age as a result of being given a bottle at bedtime, resulting in prolonged exposure of the teeth to milk, formula, or juice with a high sugar content. Dental caries results from the breakdown of sugars to lactic acid and other decay-causing substances. Newer term is early childhood caries.
12. **Bruxism** – The involuntary gnashing, grinding, or clenching of teeth. It is usually an unconscious activity, whether the individual is awake or asleep; often associated with fatigue, anxiety, emotional stress, or fear, and frequently triggered by occlusal irregularities, usually resulting in abnormal wear patterns on the teeth, periodontal breakdown, and joint or neuromuscular problems.
13. **Hypodontia** – A condition characterized by having fewer teeth than normal.
14. **Oligodontia** – A subcategory of hypodontia in which six or more teeth fail to develop.
15. **Supernumerary teeth or hyperdontia** – A dental condition marked by the presence of excessive teeth in the oral cavity.





Jerry Dearing, *Beautiful Shark*
Courtesy of Mustard Seed, Inc.

Faith goes up the stairs love has made
and looks out of the window which hope has opened.
– CHARLES H. SPURGEON

therapy

Children born with Down syndrome may experience weak muscle tone (hypotonia) and joint ligaments that are too loose (ligament laxity). These two conditions lead to excessive joint flexibility. Children with excessive flexibility at their hips may keep their hips very wide apart when lying on their back, lying on their tummy, sitting, and standing. Children that tend to keep their hips in this wide apart position (hip abduction) may not develop the same movement patterns as children who are able to keep their legs positioned closer together. They may have decreased ability to twist their trunk (trunk rotation), poor trunk strength, and less effective balance reactions because they can use the excessive hip motion as a substitute for trunk motion.

One approach to developing more normal movement patterns for children with Down syndrome is to use a figure-eight wrap or Hip Helpers to prevent the children from substituting hip motion for trunk motion. When the hips are gently kept in a more "hips together" position (hip adduction), children develop more normal trunk movement, trunk rotation, weight shifts, and balance reactions. Wearing a figure-eight wrap or Hip Helpers during all floor time as infants and babies can effectively improve the quality of the children's movements as toddlers as well as later in life.

A small percentage of children with Down syndrome experience problems due to their hips slipping a little out of the hip socket (subluxation or dislocation). If you suspect your child is having a problem with hip dislocation, consult your physician. While wraps and Hip Helpers can be a tremendous help for most children with Down syndrome, children with hip dislocation should not use them.

For more information on Hip Helpers, visit http://www.hiphelpers.com/

Oral Motor Skills

Almost all children with Down syndrome will have oral motor issues ranging from very mild to severe. It is recommended by experts that you try to get your baby to suck a pacifier. This may take some trial-and-error to determine the pacifier that works for them, and some babies just won't take a pacifier. Sucking a pacifier will build oral motor control and helps develop the muscles needed for sucking, drinking, eating and speech. When your child is ready to begin drinking from a cup, it is important that they use a cup/straw for drinking instead of bottles and sippy cups.

Muscle Tone

Children with Down syndrome can have low muscle tone and extremely limber joints. This combination delays development in crawling and walking. When your child is lying on his/her back, they may lie with legs and arms splayed open to each side. It will be more beneficial for them to lie on their side with a wedge to keep them from turning to their back. This will keep legs together and arms at mid-line. When holding your baby, try to keep both arms in front of their body, not falling out beside them. Children with Down syndrome should never be held on your hip with their legs forced apart.

Sign Language

Even though your baby may not have a hearing impairment, it is beneficial to teach your baby some basic signs. This will aid in development of both receptive and spoken language. Some simple signs to start with include: more, please, thank you, eat, drink, milk, cracker, etc.

Milestone	Range for Children with Down Syndrome	Typical Range
GROSS MOTOR		
Sits Alone	6 – 30 Months	5 – 9 Months
Crawls	8 – 22 Months	6 – 12 Months
Stands	1 – 3.25 Years	8 – 17 Months
Walks Alone	1 – 4 Years	9 – 18 Months
LANGUAGE		
First Word	1 – 4 Years	1 – 3 Years
Two-Word Phrases	2 – 7.5 Years	15 – 32 Months
SOCIAL/SELF-HELP		
Responsive Smile	1.5 – 5 Months	1 – 3 Months
Finger Feeds	10 – 24 Months	7 – 14 Months
Drinks From Cup Unassisted	12 – 32 Months	9 – 17 Months
Uses Spoon	13 – 39 Months	12 – 20 Months
Bowel Control	2 – 7 Years	16 – 42 Months
Dresses Self Unassisted	3.5 – 8.5 Years	3.25 – 5 Years

Physical Therapy & Down Syndrome

www.ndss.org

by PATRICIA C. WINDERS, PT
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What are some of the challenges that babies with Down syndrome face in their gross motor development?

Children with Down syndrome want to do what all children want to do: they want to sit, crawl, walk, explore their environment, and interact with the people around them. To do that, they need to develop their gross motor skills. Because of certain physical characteristics, which include hypotonia (low muscle tone), ligamentous laxity (looseness of the ligaments that causes increased flexibility in the joints) and decreased strength, children with Down syndrome don't develop motor skills in the same way that the typically-developing child does. They find ways to compensate for the differences in their physical make-up, and some of the compensations can lead to long-term complications, such as pain in the feet or the development of an inefficient walking pattern.

The goal of physical therapy for these children is not to accelerate the rate of their development, as is often presumed, but to facilitate the development of optimal movement patterns. This means that over the long term, you want to help the child develop good posture, proper foot alignment, an efficient walking pattern, and a good physical foundation for exercise throughout life.

What do you do in a typical physical therapy session?

First, I observe what skills the child has already mastered on his or her own. Then I determine what the child is ready to learn next. It's critical that we teach children what they're ready to learn within the next month rather than work on something that's too advanced for them.

Once I know what skill the child is ready to learn, I develop a way to teach him that skill. I break the skill down into its component parts, and then I practice the skill with a variety of strategies to test with which method the child is most successful. The strategies are based on the child's learning style and physical make-up.

Lastly and most importantly, I teach the parents how to practice the skill with their child. The parents can practice the skill when the child is feeling rested and strong, and the skills can be incorporated into the daily routine. Through practice and repetition, the child will develop strength and efficiency, leading to mastery of the skill.

You write that children are typically either "motor-driven" or "observers" by nature. How does temperament impact physical therapy?

Temperament is a person's characteristic manner of thinking, behaving and reacting. I look at a child's pattern of thinking, behaving and reacting when learning gross motor skills. It is my observation that children with Down syndrome fall into two basic categories of temperament: motor-driven and observer. Children who are motor-driven tend to be risk-takers. They like to move fast and tolerate new movements and positions. They do not want to stay in one place and dislike being stationary. Children who are observers are more cautious, careful, and want to be in control. They prefer stationary positions and are easily frightened when learning new movements.

When children who are motor-driven are learning how to walk, for example, they will take risks to take independent steps and will be undeterred by frequent falls. Observers will be more cautious and will only risk independent steps when they are sure of their balance.

Understanding your child's temperament and what motivates him will help you be more effective in helping him learn gross motor skills. You will know in advance which activities he is likely to enjoy and which activities he is likely to resist. Knowing this, you can begin with activities he enjoys and only move on to more difficult ones when he is well rested and motivated to learn.

What are some general tips that parents should keep in mind when working with their child on gross motor skills?

The development of gross motor skills is the first learning task that the child with Down syndrome and his parents will face together. This is an opportunity for parents to begin to understand how their child learns. Use these tips as a starting point to begin to explore your child's learning style.

Determine what motivates your child. Your child is more likely to move when there is something motivating him. For example, he may crawl to get to a favorite toy. When practicing motor skills, your child's success and enjoyment will depend on how you play, what types of toys you use, and where you place them.

Think how your child thinks. Figure out what gross motor skills your child likes to do and then build on those skills. For example, if your child likes to be on his belly, teach him pivoting, crawling and climbing; if he likes to sit, teach him to move into sitting by himself. Children often are motivated to learn skills in a different order and it is OK to follow your child's lead and work on what he is ready and willing to learn.

Set your child up to succeed. Practice skills that your child is ready to learn so that he can accomplish them. Practice when he's at his physical best so that he has the energy, concentration and patience to work on new or emerging skills. Know how to position him and use the best motivators. Lastly, know when to quit. A few well-timed moments when your child understands a new skill and succeeds at it are much more valuable than an hour of struggling that leaves both of you frustrated and upset.

Read your child's cues. Pay attention to how your child is responding to practicing the skills. If it is too hard, make it easier by changing the set-up or giving more support. Practice as long as your child is doing his best. The quality of time you spend practicing gross motor skills is much more important than the quantity.

Treat it as a game. You really want to think of teaching and practicing a skill as a game. First, introduce the "game" so your child feels and tolerates the movement. Second, help your child become familiar with the game and understand what you want him to do. Third, practice the game together and gradually lessen your support. Fourth, progress toward independence. The ultimate goal is for your child to master the game and be able to do it on his own.

Children with Down syndrome have a unique learning style, and we need to understand and respect it. A psychologist named Jennifer Wishart has written extensively on this subject. She says we "could run the risk of changing slow but willing learners into reluctant, avoidant learners." I really customize the work I do with each child. I make sure the physical therapy sessions provide a pleasant learning environment for children so that they are willing learners, and I encourage parents to do the same at home. If your child feels imposed upon, he or she is just going to find ways to resist and avoid learning.

NDSS RESOURCES

- Early Intervention

EXTERNAL RESOURCES

- American Physical Therapy Association
  www.moveforwardpt.com
  Locate a physical therapist and read specialized information on Down syndrome and physical therapy.
- "The Goal and Opportunity of Physical Therapy for Children with Down Syndrome." Winders, Patricia C. (2001) Down Syndrome Quarterly 6(2), 1-4.
- Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals. Patricia C. Winders. Bethesda, MD: Woodbine House. (1997)

Speech & Language Therapy for Infants, Toddlers & Young Children

www.ndss.org

Speech and language present many challenges for children with Down syndrome but there is information that can help infants and toddlers begin learning to communicate, and help young children progress in speech and language. Although most children with Down syndrome learn to speak and will use speech as their primary means of communication, they will understand language and have the desire to communicate well before they are able to speak. Total communication, using sign language, pictures, and/or electronic synthesized speech can serve as a transitional communication system.

Are hearing problems common in children with Down syndrome?

Ear infections occur frequently in infancy and early childhood in all children. But, because of anatomic differences in the ears of children with Down syndrome (narrow and short canals), they are more susceptible to accumulations of fluid behind the eardrum. This is known as Otitis Media with Effusion (OME). These problems result from fluid retention and inflammation in the middle ear; sometimes with infection. The presence of fluid makes it more difficult for the child to hear, resulting in fluctuating conductive hearing loss. Children should be followed by their pediatrician and otolaryngologist (ENT) and visit an audiologist for auditory testing. This testing can be done soon after birth. Hearing testing should also be done every six months until three years of age and annually through age 12 years. Treatment usually involves either an antibiotic regimen or the insertion of tubes to drain the fluid. These recommendations follow

the schedule found in the Down Syndrome Health Care Guidelines.

What effect does hearing loss have on speech and language development?

Speech and language are learned through hearing, vision and touch. Hearing is very important to speech, and studies have shown that speech and language development are negatively affected by chronic fluid accumulation. Children with Down syndrome often have fluctuating hearing loss due to the frequency of fluid accumulation. When fluid is present, hearing is affected; as fluid drains, hearing improves. When children do not consistently hear well, it is difficult for them to learn how sounds and events are related, e.g. the ring of the telephone or someone calling them. It is important for parents to ensure that their child is hearing well. Pediatricians and otolaryngologists have great success in treating fluid accumulation, but treatment requires close monitoring.

How is feeding related to speech and language?

Speech is a secondary function that uses the same anatomic structures used for feeding and respiration. Low muscle tone (hypotonia) affects feeding and will also affect speech. In feeding, children gain practice with strengthening and coordinating the muscles that will be used for speech. If a child has difficulty feeding, it is important that his or her parents seek guidance from a feeding specialist (a speech-language pathologist or occupational therapist who has advanced training). Feeding therapy can to help strengthen the oral muscles, which in turn can have a positive effect on speech.

What other skills are related to speech and language development?

Other important pre-speech and pre-language skills are the ability to imitate and echo sounds; turn-taking skills (learned through games such as peek-a-boo); visual skills (looking at speakers and objects); auditory skills (listening to music, speech, and speech sounds for lengthening periods of time); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving the lips); and cognitive skills (understanding object permanence and cause and effect relationships). The family can stimulate these pre-speech and language skills at home. Parents can contact Child Find (a federal program that identifies the needs of children with disabilities) in their area and ask for speech-language pathology (SLP) services for their child. SLP can help parents learn the skills that they need to help their child begin learning language and using speech.

When will my child say his first word?

Children with Down syndrome frequently begin to use single words between the ages of two and three, but the age of the first word varies. Also, the first true word may be signed, not spoken. Most children with Down syndrome communicate from birth through crying, looking and gesturing. They have the desire to communicate and learn that crying or making sounds can affect their environment and bring them help, play, and attention. Many children with Down syndrome understand the relationship between a word and a concept by 10-12 months of age. However, at that age, a child generally does not have sufficient neurological and motor skills developed to be able to speak. That's why it is important to provide another system so that the child can communicate and learn language before they are able to speak.

What is total communication?

Total communication (TC) is the combined use of signs and gestures with speech to teach language. Total communication provides a child with an output system to communicate when he or she has not yet developed the skills needed for speech. In total communication, adults use sign and speech when talking with the child. The child learns signs in conjunction with speech and uses the signs to communicate. Sign language is a transitional system for children with Down syndrome. Other choices for transitional communication systems are

pictures used on a communication board or in a communication exchange system and/or electronic communication systems which use synthesized speech. Most children with Down syndrome are ready to use a language system many months or even several years before they are able to use speech effectively to communicate. Therefore, a transitional communication system such as sign language, pictures or synthesized voice is frequently needed. A speech-language pathologist and/or augmentative communication specialist (AAC) can help design a transitional communication system for your child. Most children with Down syndrome will use speech as their primary system for communication.

What can parents do to help infants and young children learn speech and language?

Parents are the primary communicators interacting with their babies and young children; thus, parents can do a great deal to help their children learn to communicate. Many of pre-speech and pre-language skills are best learned in the home environment. To help their children develop those skills, parents should:

- Remember that language is more than spoken words. When they are teaching a word or a concept, they should focus on conveying meaning to the child through play or through multisensory experiences (hearing, touch, seeing).
- Provide many models. Most children with Down syndrome need many repetitions and experiences to learn a word. Adults should repeat what a child says and give him or her a model to help reinforce a word.
- Use real objects and real situations. When teaching a concept, parents can use daily activities and real situations as much as possible. They can teach the names of foods as their toddler is eating, names of body parts while bathing the child, and concepts such as under, in and on while the child is playing. Communication is part of daily life.
- Read to their child. They should help their child learn concepts through reading about them, field trips in the neighborhood and daily experiences.
- Follow their child's lead. If a child shows interest in an object, person or event, parents should provide him or her with the word for that concept. There are many milestones as the child progresses toward using speech. The child responds to a familiar voice, recognizes familiar faces, experiments with many different sounds, produces strings of sounds over and over and makes a sound to refer to his or her parents (dada, mama). Many children enjoy looking in a mirror, and increase their sound play and babbling when vocalizing in mirrors. Effective ways to work on these skills at home can be learned through early intervention sessions, through books, workshops and speech and language professionals.

When should speech-language pathology services begin? What is early language intervention?

Speech-language pathology services can begin in infancy. Treatment may involve sound stimulation, language stimulation accompanying play, feeding, oral motor exercises and/or other techniques. It should always include the family as a partner in treatment because the family is the primary teacher of speech and language. Early language intervention (ELI) is the designation given for services provided to infants and toddlers from birth through the end of age two. Speech-pathology services should be part of a comprehensive overall treatment plan for infants and toddlers. This may involve sessions at home or in a center, and may be part of a team approach involving physical, occupational and other therapists working together with the family.

A government-sponsored early intervention program is available in all communities in the U.S. Speech-language and other therapy services are often provided at these programs for eligible children under age three, based on disability and an

evaluation. Most children with Down syndrome qualify for speech-language services. After age three, there may be continuing services sponsored through the school system with an IEP or through community agencies, private practitioners, university clinics, medical centers and other sources.

How do you find a qualified speech-language pathologist?

Qualified SLPs are certified by the American Speech-Language-Hearing Association and licensed by the state. When a professional is certified, they can use CCC-SLP (Certificate of Clinical Competence in Speech-Language Pathology) following their name. This means they have completed a master's degree in an accredited program, have completed required hours of clinical practice internship and passed a national certification examination. If a family is receiving services through Child Find or through the health department or school system in their local area, those organizations will either have professionals associated with them or be able to refer parents to local professionals. Members of local Down syndrome support groups can often refer parents to speech-language pathologists in your area who have experience working with children with Down syndrome.

NDSS RESOURCES

- Early Intervention
- Health Care Guidelines

EXTERNAL RESOURCES

- American Speech-Language-Hearing Association (www.asha.org)
  Provides resources and an online search tool to help parents connect with certified Audiologists and Speech-Language Pathologists
- National Institute on Deafness and Other Communication Disorders Clearinghouse (www.nidcd.nih.gov)
  Conducts and supports research in the normal and disordered processes of hearing, balance, taste, smell, voice, speech and language

BOOKS

- *Early Communication Skills for Children with Down Syndrome*. Kumin, L. Bethesda, MD: Woodbine House. (2003)
- *Kids Like Me…Learn ABCs*. Ronay, L. Bethesda, MD: Woodbine House. (2009)
- *Kids Like Me…Learn Colors*. Ronay, L. Bethesda, MD: Woodbine House. (2009)
- *Talking is Hard for Me! Encouraging Communication in Children with Speech-Language Difficulties*. Reinert, L.N. Bethesda, MD: Woodbine House. (2013)
- *The New Language of Toys: Teaching Communication Skills to Special Needs Children (Third Edition)*. Schwartz, S. Bethesda, MD: Woodbine House. (2004)
- *Speech and Language Development and Intervention in Down Syndrome and Fragile X Syndrome*. Roberts, J., Chapman, R., and Warren, S. Baltimore, MD: Brookes Publishing. (2008)

JOURNAL ARTICLES

- Shott, S.R., Joseph, A., and Heithaus, D. "Hearing loss in children with Down syndrome." *International Journal of Pediatric Otolaryngology* 1:61 (3): 199-205, 2001.

Occupational Therapy & Down Syndrome

by MARYANNE BRUNI, BSC, OT

Occupational therapists (OT) who work with children have education and training in child development, neurology, medical conditions, psychosocial development, and therapeutic techniques. Occupational therapists focus on the child's ability to master skills for independence.

These can include:

- Self-care skills (feeding, dressing, grooming, etc.)
- Fine and gross motor skills
- Skills related to school performance (e.g. printing, cutting, etc.)
- Play and leisure skills

When your child is an infant, your immediate concerns relate to health and growth, development of the basic motor milestones, social interaction with you and others, interest in things going on around him, and early speech sounds and responses.

At this stage, an OT may be involved to:

- Assist with oral-motor feeding problems (this can also be addressed by speech pathologists). Due to hypotonia and weakness of the muscles of the cheeks, tongue, and lips, feeding is difficult for some infants with Down syndrome. OTs suggest positioning and feeding techniques, and can be involved in doing feeding studies, if necessary.
- Help facilitate motor milestones, particularly for fine motor skills. Occupational therapists and physical therapists work closely together to help the young child develop gross motor milestones (e.g., sitting, crawling, standing, walking) OTs work with your child at this stage to promote arm and hand movements that lay the foundation for later-developing fine motor skills. The low muscle tone and loose ligaments at the joints associated with Down syndrome are real challenges to early motor development and occupational therapy can help your child meet those challenges.

When your child is a toddler and preschooler, she will likely have some independent mobility and will be busy exploring her environment. To assist her development you will want to provide her with many opportunities for learning, you will want to encourage the beginning steps in learning to feed and dress herself, you will want her to learn how to play appropriately with toys and interact with other children, you will be encouraging speech and language skills, and you will continue to provide opportunities for refinement of gross motor skills.

At this stage, an OT may become involved to:

- Facilitate the development of fine motor skills. This is an important stage in the development of fine motor skills for children with Down syndrome. Now they will be developing the movements in their hands that will allow them to do many things as they get older, but many children need some therapy input to ensure that these movements do develop. Children do this through play; they open and close things, pick up and release toys of varying sizes and shapes, stack and build, manipulate knobs and buttons, experiment with crayons, etc. Your child may face more challenges learning fine motor skills because of low muscle tone, decreased strength and joint ligament laxity.

An OT can help parents break down the skills so expectations are appropriate, and can suggest positioning or adaptations that might help the child be more independent. For example, a child may have more success feeding herself with a particular type of spoon and dish.

Then your child enters the school system and the focus of your energies changes somewhat again! You can help your child adjust to new routines, you attend school meetings to plan your child's educational program, you focus on speech and communication, you help your child practice fine motor skills for school (such as learning to print), you expect your child to develop more independence in self-help activities, and you search out extracurricular activities that will expose your child to a variety of social, physical and learning experiences.

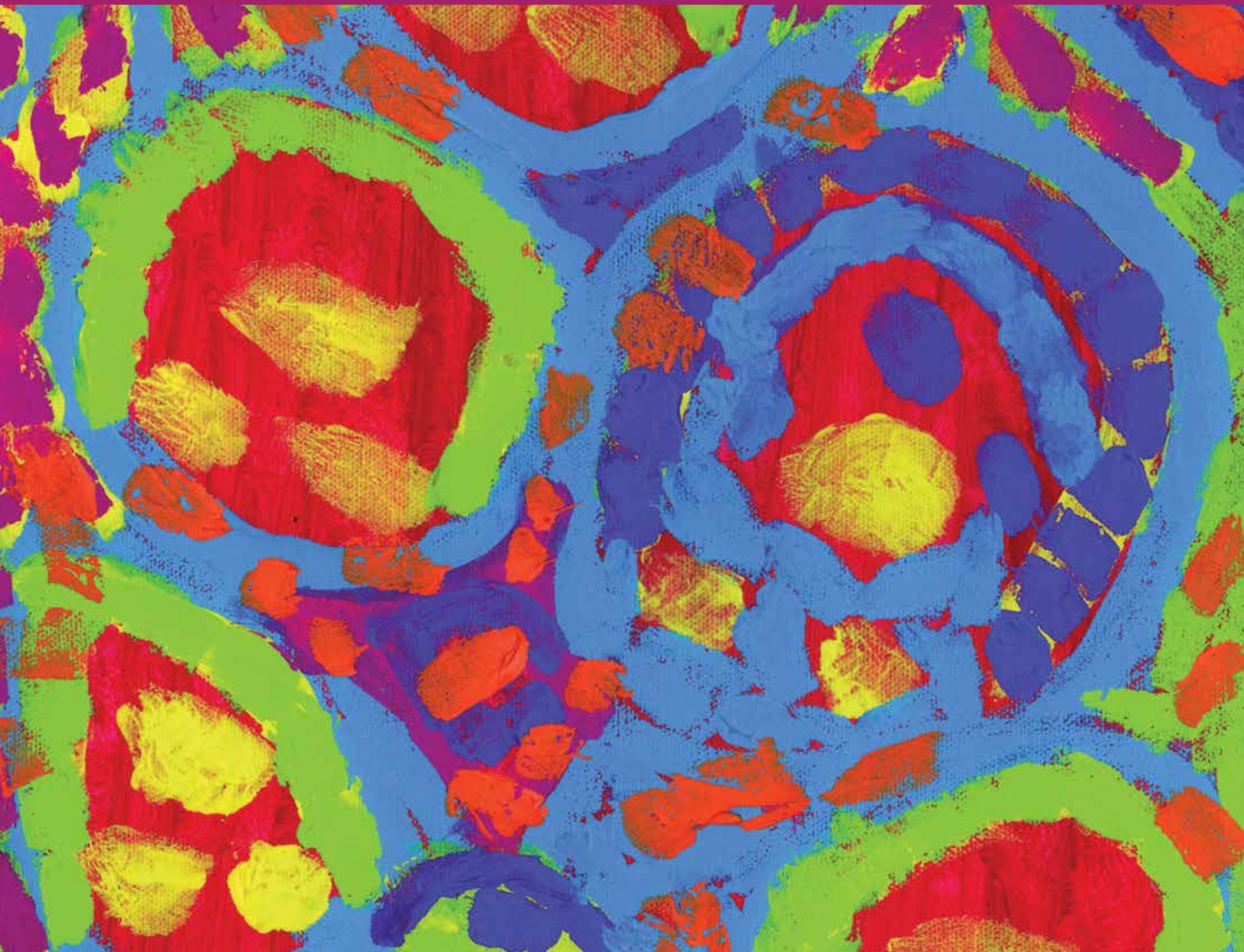
At this stage, an OT may become involved to:

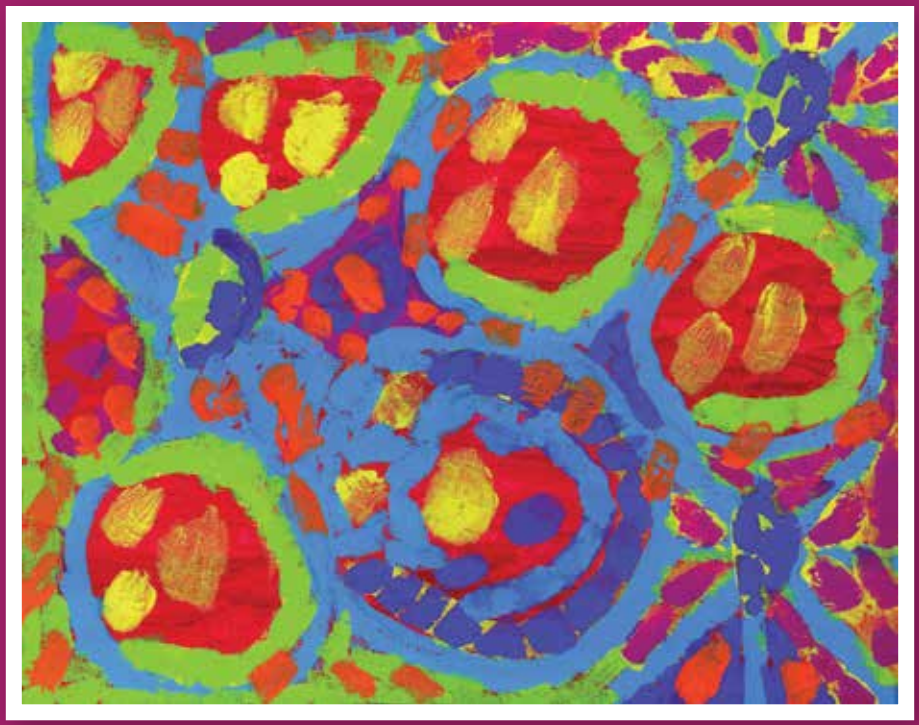
- Facilitate fine motor skill development in the classroom. Many OTs work in the school system and provide programs to help children with Down syndrome learn printing, handwriting, keyboarding, cutting, etc. They will also look at physical positioning for optimal performance (eg: desk size etc.) and assist with program adaptations based on the child's physical abilities.
- Facilitate self-help skills at home and at school. As with all children, our kids with Down syndrome vary in personality, temperament, and motivation to be independent. Some children with Down syndrome have a desire to do things themselves, such as dress and feed themselves. These children may learn these skills by watching others and participating from a young age. Other children may be happy to let others do things for them, and may resist attempts to help them learn these skills. In these cases, an OT may be able to help a parent work out these challenges, while helping the child develop better motor skills to be in self-help skills.
- Address any sensory needs your child may have. Sometimes a parent has a concern about things their child does that may relate to the child's sensory development. For example, a child may excessively put toys in her mouth, she may have poor awareness of her body in space, she may squeeze everything too hard or drop things a lot, or she may not tolerate very well some routines like washing and brushing hair. An OT can offer suggestions to help the child and parents deal with these issues.

As parents we must be concerned with the well-being of our child in all respects. We have so many things to think about and keep track of: medical and dental needs, motor and communication needs, educational needs, advocacy, social and behavioral needs: the list seems to go on and on! We need the help of trained professionals to guide us and to work with our children to help them achieve their potential in life. An occupational therapist is one member of the team that we can rely on to provide professional assistance throughout the growth and development of our children.

OT services can be obtained through Early Childhood Intervention programs, public and private schools, and from private therapists.

Further information about fine motor development can be found in the book *Fine Motor Skills in Children with Down Syndrome*, published by Woodbine House (800-843-7323) in 1998.





Matthew Nichols, *Happy Joyous Free*
Courtesy of Mustard Seed, Inc.

Children are likely to live up to what you believe of them.
– LADY BIRD JOHNSON, *former First Lady of the United States*

estate planning

Proper estate planning is important for any family, but even more so for a family with a child with special needs. Good quality health care and longer life spans for children with disabilities means that plans must be made to preserve public benefits like Supplemental Security Income and Medicaid and to provide a quality of life for many years to come.

Failure to plan leads to a lack of choices. If the family of a person with special needs does not develop a financial plan for the future, state bureaucratic solutions may be imposed on individuals with developmental disabilities. The consequences may not be what the family would choose for their son or daughter with a disability.

It is extremely important to seek legal advice from an attorney who has experience in estate planning for a child with special needs. There are numerous Mississippi and federal benefit programs that may serve the child's needs, including SSI to provide a monthly income payment and Medicaid for medical insurance coverage. The laws and regulations of these programs vary greatly, and a special needs planning attorney can help you navigate and understand their requirements and benefits.

While CMDSS cannot offer specific legal advice or recommendations, the following are some planning steps that experts recommend:

The parents of a child with Down syndrome should establish a Will ("last will and testament") as soon as possible. A Will directs how and to whom your assets will be distributed at your death. You may also name a guardian who would care for your child in the event of your death. Without expressing your instructions about these matters, state law will dictate the share of assets your child will receive, and there may be a conflict between family members over who will have custody of your child.

Many public benefit programs limit their benefits to persons with few assets, and you should be careful in your Will **not** to leave money or property directly to your child with Down syndrome. Instead, a Special Needs Trust should be established for that child, and the trust can be named as the recipient of the child's share of assets. The trust can also be designated as the beneficiary of a life insurance policy or an IRA or other retirement account. (Warning: The IRS has specific rules that allow a trust to be named beneficiary of a retirement account, and you must have a knowledgeable attorney review the trust to make sure it qualifies.) When properly drafted and administered, the assets in the trust will not be counted as the child's assets, and he or she can keep SSI and Medicaid benefits in addition to the funds in the trust for future needs. It is essential to name, as trustee over the trust, a person or bank who will be devoted to the best interest of your child (the trust "beneficiary") and is willing to seek professional guidance about investments and public benefit rules in making payments from the trust.

A Special Needs Trust may be established in your Will, in which case the trust will not exist until your death. Or, you may create a "living" Special Needs Trust that will be in effect now, so that other family or community members can contribute to the trust for your child now if they desire. It is important that other relatives or friends NOT name your child as beneficiary; they should instead leave those assets to the trust. If your child receives an inheritance directly, he or she could be disqualified for SSI or Medicaid benefits and for other services that may require Medicaid eligibility.

The parents of a child with Down syndrome must also plan for their own incapacity or death. A "durable power of attorney" is the legal document that allows you to name the person(s) who will manage your financial affairs – including providing for the financial care of your child – if you later become incapacitated from an illness or injury. The power of attorney must contain certain specific wording to be effective, and it should state any rules or requirements you want your agent to follow in managing your affairs. An adult with Down syndrome may have sufficient legal capacity to do their own power of attorney, thereby expressing their own wishes about who will be able to handle their affairs and how.

Similar to the durable power of attorney, the "advance health care directive" document can name the person(s) who would make medical treatment or health care decisions for you if you become unable to do so. A person age 18 or older with a disability can sign a health care directive if they understand what they are signing.

When a child with a disability becomes an adult, some medical or educational programs may be unwilling to let the parents continue to make decisions for the child. In such cases, it may be necessary to get appointed as guardian for the child. This is a court proceeding that is handled by an attorney who should be able to advise you about the ongoing requirements of law on the guardian.

Some children with Down syndrome are able to live an independent life as adults. Others, however, are unable to manage without assistance. It is impossible to predict your child's future, but with proper estate planning, you can feel comfortable that your child's future needs will be met.

Each family must choose a qualified attorney with whom they are comfortable working. A good place to get started would be contacting an attorney suggested under the "Resources" tab in this New Parent Guide.

CHECK BEHIND THE RESOURCES TAB FOR MORE INFORMATION

able act

The **Federal ABLE (Achieving a Better Life Experience) Act** was enacted in 2014 and is codified as Section 529A of the Internal Revenue Code. It permits states to establish personal savings accounts for persons with disabilities that will not be considered countable resources for Medicaid and SSI eligibility. SSI, or Supplemental Security Income, is the Social Security program that provides a monthly payment of up to $735 (2018) to disabled persons or persons over age 65 whose income is less than that amount and whose countable resources (assets) do not exceed $2,000 (2018).

The disabled individual (or the guardian or conservator for an incapacitated beneficiary) has ownership and control over the distributions from an ABLE account. Payments from the account for what are defined as "qualified disability expenses" will not be taxable income; however, payments for things other than the qualified expenses will be subject to income tax and a 10% tax penalty. Qualified disability expenses are defined as: "education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses."

An individual may have only one ABLE account, and it may be created and/or funded by anyone. A person who contributes to an ABLE account may deduct that contribution from their Mississippi income tax. The maximum that can be contributed to any ABLE account is $14,000 (2018) per year (subject to future increases by Congress).

The **Mississippi ABLE Act** was signed into law in 2017 with an implementation plan to be developed by October 1, 2017, and accounts are to be available to residents by July 1, 2018.

Rebecca Bratley, *Dots Galore*
Courtesy of Mustard Seed, Inc.

When I approach a child, he inspires in me two sentiments; tenderness for what he is, and respect for what he may become.
– LOUIS PASTEUR

resources

Early Intervention Resources

Listed below are programs that are fully funded by tax dollars, so there is no direct cost to you. There are also a multitude of private Early Intervention providers that accept both private insurance and Medicaid for Disabled Child Living at Home, so there is still no cost to you. Some private providers are listed on the following page.

Hudspeth Regional Center
Early Intervention Programs
Provides free evaluations for children birth-three years or older for most Central Mississippi counties.

- **Hudspeth Regional Center**
  (601) 664-6000
  100 Hudspeth Center Dr.
  P.O. Box 127-B
  Whitfield, MS 39193-1032
  www.hudspeth.info
- **Rankin Campus** – (601) 664-6150

Ellisville State School
Early Intervention Programs
Provides free psychological evaluations for children birth-three years or older to determine qualification for their services and therapies.

- (601) 477-9384
  1101 Hwy 11 South
  Ellisville, MS 39437
  www.ess.ms.gov

First Steps
Early Intervention Programs
Provides free evaluations and therapies as needed for children birth-three years old. First Steps is administered through your local county health department. Contact your local health department or call 1-800-451-3903. View information at www.msdh.state.ms.us. First click on Public Services, then Early Intervention under Children's Services.

Boswell Regional Center
Early Intervention Program
Mississippi Department of Mental Health
Provides a continuum of care and services for thousands of Mississippians with intellectual and developmental disabilities.

- (601) 867-5000
  P.O. Box 128 / 1049 Simpson Highway 149
  Magee, MS 39111
  www.brc.ms.gov

Private Early Intervention Resources

Anderson Regional Medical Center
Pediatric Therapy
(601) 553-6703
2000 15th Street
Meridian, MS 39301-4138
www.andersonregional.org *(Click on Pediatric Therapy under Services and Rehabilitation)*

Located near the Anderson Health & Fitness Center on the bottom floor of the parking complex.

Beyond Therapy
Outpatient Therapy
(601) 853-9747
950 East County Line Rd., Ste. E
Ridgeland, MS 39157
www.drayerpt.com/locations/ridgeland-pediatric/

Laskin Therapy
Outpatient Therapy
(601) 362-0859
207 W. Jackson St.
Ridgeland, MS 39157
www.laskintherapygroup.com

Neshoba County General Hospital
Rehabilitation Services
(601) 663-1480
205 E. Hospital Rd.
Philadelphia, MS 39350
www.neshobageneral.com

Rush Foundation Hospital
Rehabilitation Services
(601) 703-4240
1314 19th Avenue
Meridian, MS 39301
www.rushhealthsystems.org/rfh/

Some pediatric patients have been found to progress quicker with the introduction of aquatic therapy because of the play environment and full 360 degrees access by the therapist to inhibit abnormal muscle tone and facilitate weak movement patterns. It is also beneficial for strengthening of muscles especially abdominal muscles as well as good for cardiovascular and pulmonary endurance.

St. Dominic's Outpatient Rehabilitation
Aquatic Therapy
(601) 200-4920
St. Dominic's Outpatient Rehabilitation
970 Lakeland Drive Suite 23
Jackson, MS 39216
http://www.stdom.com/services/rehabilitation/aquatic-rehabilitation/

Medical/Financial Resources

Medicaid for Disabled Child Living at Home

Children with Down syndrome will likely qualify for Medicaid for Disabled Child Living at Home. Medicaid Regional Office locations can be found on the Department of Medicaid website: www.medicaid.ms.gov, scroll down and click on the paragraph underneath Medicaid Office Locations. A partial list of counties:

Rankin, Simpson, Smith
Brandon Regional Office
Phone: (601) 852-0477
Fax: (601) 825-2184
3035 Greenfield Rd.
Pearl, MS 39208

Copiah, Lincoln, Lawrence
Brookhaven Regional Office
Phone: (601) 835-2020
Fax: (601) 835-5429
1372 Johnny Johnson Dr.
Brookhaven, MS 39601

Covington, Jeff Davis, Marion
Columbia Regional Office
Phone: (601) 731-2271
Fax: (601) 736-7924
501 Eagle Day Ave., Ste. A
Columbia, MS 39429

Forrest, Lamar, Perry
Hattiesburg Regional Office
Phone: (601) 264-5386
Fax: (601) 261-1244
6971 Lincoln Road Extension
Hattiesburg, MS 39402

Hinds, Madison
Jackson Regional Office
Phone: (601) 978-2399
Fax: (601) 956-4264
5360 I-55 North
Jackson, MS 39211

Attala, Holmes, Leake
Kosciusko Regional Office
Phone: (662) 289-4477
Fax: (662) 289-4477
160 Highway 12 North
Kosciusko, MS 39090

Green, Jones, Wayne
Laurel Regional Office
Phone: (601) 425-3175
Fax: (601) 425-9441
1100 Hillcrest Dr.
Laurel, MS 39440-4731

Clarke, Lauderdale
Meridian Regional Office
Phone: (601) 483-9944
Fax: (601) 486-2988
3848 Old Hwy 45 North
Meridian, MS 39301-1517

Jasper, Newton, Scott
Newton Regional Office
Phone: (601) 635-5205
Fax: (601) 635-5213
9423 Eastside Drive Extension
Newton, MS 39345-8063

Kemper, Neshoba, Noxubee, Winston
Philadelphia Regional Office
Phone: (601) 656-3131
Fax: (601) 656-7950
340 Main Street
Philadelphia, MS 39350

Claiborne, Issaquena, Sharkey, Warren
Vicksburg Regional Office
Phone: (601) 638-6137
Fax: (601) 638-7186
3401 Halls Ferry Rd., Ste. 1
Vicksburg, MS 39180

Holmes, Humphreys, Yazoo
Yazoo City Regional Office
Phone: (662) 746-2309
Fax: (662) 746-2645
110 N. Jerry Clower Blvd., Ste. A
Yazoo City, MS 39194

(Medical/Financial Resources continued)

ID/DD Medicaid Waiver

If you qualify for Medicaid for Disabled Child living at home, you are eligible to apply for the ID/DD Medicaid Waiver program. This program can provide free childcare for your child in your home or in a Medicaid-approved facility.

- **Hudspeth Regional Center** serves most Central Mississippi counties.
  (601) 477-5887

- **Ellisville State School** serves most South-Central Mississippi counties.
  (601) 477- 5887

WIC

You automatically qualify for WIC if you qualify for Medicaid for Disabled Child Living at Home. WIC will provide free formula and nutritious foods from birth to age five regardless of income.

- **Mississippi Department of Health**
  Women, Infants, and Children's Nutrition Program (WIC)
  805 S. Wheatley Street
  Ridgeland, MS 39157
  (601)-991-6000
  1-800-338-6747
  www.msdh.state.ms.us

Social Security Benefits for Children with Disabilities

It is possible that your child will qualify for Social Security based on his/her disability and your family income.

- **Social Security Field Office**
  100 W. Capitol St., Room 401
  Jackson, MS
  1-800-772-1213

National Resources

National Organizations

- **National Academy for Child Development (NACD)**
  1-801-621-8606
  www.nacd.org

- **National Down Syndrome Congress (NDSC)**
  1-800-232-NDSC
  www.ndsccenter.org

- **National Down Syndrome Society**
  1-800-221-4602
  www.ndss.org

Additional Websites

- **www.dsd-health.com**
  Created by Len Leshin, M.D., pediatrician and father of a son with Down syndrome. It contains great information on health-related issues faced by children with Down syndrome.

- **www.nathhan.com**
  National Challenged Homeschoolers Associated Network (NATHHAN). NATHHAN's purpose is to provide support and information for homeschooling families with special needs children.

- **www.reecesrainbow.org**
  Reeces Rainbow advocates and finds families for orphans with Down syndrome and other special needs by raising funds for adoption grants and promoting awareness through an online community.

- **www.ndsan.org**
  National Down Syndrom Adoption Network provides information to birth families who may be seeking alternatives to parenting as they prepare for the arrival of their child.

Other Helpful Resources

Abbie Rogers Civitan Camp
A camping experience for children and adults with significant disabilities.
50 Fieldstone
Hattiesburg, MS 39402
(601) 859-5290
www.abbierogerscivitancamp.org

ARC of Mississippi
The ARC promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetime.
704 North President Street
Jackson, MS 39202
(601) 355-0220
www.arcms.org

Camp Bratton Green
Camp Bratton Green offers Special Sessions including Camp Able a ministry of Gray Center. Sessions include camp offerings for campers ages 10+ with Down syndrome or other genetic disorders.
1530 Way Road
Canton, Mississippi
http://www.graycenter.org
office@graycenter.org
(601) 859-1556

Camp Lake Stephens
Camp Lake Stephens, a United Methodist Camp and Retreat Center, is committed to being a place where children, youth, and adults can encounter God and respond in faith to God's call to transform the world.
117 Camp Lake Stephens Drive
Oxford, MS 38655
Phone 662-234-3350
Fax 662-234-3883
cls@camplakestephens.com
www.camplakestephens.com

Central Mississippi Down Syndrome Society (CMDSS)
The mission of CMDSS is to provide support, education, enrichment and resources to individuals with Down syndrome and their families.
PO Box 935
Jackson, MS 39205
(601) 385-DOWN
cmdss.org

The Children's Center for Communication & Development – USM
Provides complete evaluations and therapies in all disciplines for children from birth to five years of age, all at no cost to parents.
The University of Southern Mississippi
Institute for Disability Studies
J.B. George Building 109
118 College Drive, #5092
Hattiesburg, MS 39406-0001
(601) 266-5222

Clinton, MS Parks & Recreation ABILITIES PROGRAM
The ABILITIES Programs includes a variety of sports, events and activities scheduled throughout the year for individuals ages 6+ with disabilities. Includes: TOPSoccer, Tennis, Challenger League Baseball, Basketball and Bowling
300 Jefferson Street
Clinton, MS 39060
(601) 924-6387
www.clintonms.org/departments/therapeutic-recreation/challenger-league-program/

Junior Auxiliary of McComb Camp Sunshine
Junior Auxiliary of McComb is a non-profit organization that strives to help individuals with special needs enjoy a camp experience.
juniorauxiliary@ymail.com
http://najanet.org
Betsy Murrell, Director
Phone 601-810-2828

Hope Hollow
Hope Hollow works to enrich the lives of children and adults with special needs by providing fun, meaningful camps and programs in a Christian based environment filled with love, adventure, compassion, and fellowship.

910A Catlett Road,
Canton, MS 39046
(601) 859-5290
www.hopehollowms.org

Joni and Friends
Joni and Friends works together with local churches and organizations, forming outreach programs throughout the community and ministering hope and the message of Christ to those who face daily challenges of life with a disability.

(601) 594-0148
http://www.joniandfriends.org/jackson/

Little Lighthouse
The Little Light House is a tuition-free Developmental Center that has been making a difference in the lives of hundreds of children with special needs.

P.O. Box 13662
Jackson, MS 39236
(601) 956-6131
www.llhms.org

Magnolia Speech School

733 Flag Chapel Road
Jackson, MS 39209
(601) 922-5530

Mississippi Coalition for Citizens with Disabilities
The MSCCD is a coalition of organizations and individuals who have joined to advocate for and promote the full and equal participation of all Mississippians with disabilities in all aspects of life.

2 Old River Place, Suite M
Jackson, MS 39202
(601) 969.0601
www.msccd.org

Mississippi Department of Education
Office of Special Education

359 Northwest Street
Jackson, MS 39201
www.mde.k12.ms.us/ose

Mississippi Parent Training and Information Center
Provides information, resources, support and training that allows you to help your child meet his or her educational goals. It also includes resources for what he or she needs to lead a productive and independent adult life.

2 Old River Place, Suite M
Jackson, MS 39202
(601) 969-0601
www.mspti.org

MSU – T.K. Martin Center for Technology and Disability
The Mission of the T.K. Martin Center for Technology and Disability is to ensure that persons with disabilities are able to continually benefit from technological solutions and advances in the field of assistive technology.

Mississippi State University
P.O. Box 9736
Mississippi State, MS 39762
(662) 325-1028

Project Start

Project Start provides on a loan-basis appropriate technology-related services for Mississippians with disabilities.

P.O. Box 1698
Jackson, MS 39215-1698
1-800-852-8328
(601) 853-5249
www.msprojectstart.org

Ridgeland, MS Parks & Recreation Special Needs Programs

304 Highway 51, Ridgeland MS
(601) 853-2011
www.ridgelandms.org/city-departments/recreation-and-parks/

HOOPS

HOOPS Basketball is a program designed for children with special needs. Games are held in January and February utilizing volunteer coaches and assistants.

TOPSoccer

This spring and fall soccer program is offered to children ages 5 and up who are mentally and/or physically challenged. Registration occurs in the summer and winter.

TOPSoccer Jamboree

TOPSoccer Jamboree is designed for boys and girls ages 5-18 with special needs. This event provides a day of fun while teaching basic soccer skills.

RideABILITY

RideABILITY is a NARHA member therapeutic riding center that proudly serves the Jackson, MS metro area. They offer classes that help build confidence, balance, strength and coordination while students learn to ride horses.

RideABILITY
P.O. Box 5061
Brandon, MS 39047
(601) 750-6735

Special Olympics of Mississippi

Offers a variety of sports opportunities for individuals with special needs.

15 Olympic Way
Madison, MS 39110
(601) 856-7748
www.specialolympicsms.org

University of Alabama Intellectual Disabilities Participation Registry

The purpose of the Intellectual Disabilities Participant Registry is to engage with families of children and adults with intellectual disabilities interested in participating in psychological research studies. The studies that they work with address topics such as memory, language, and learning. Families can help researchers better understand intellectual disability and how to meet its challenges by enrolling in the participant registry.

Box 870348
The University of Alabama
Tuscaloosa, AL 35487
(205) 348-4253
www.uaidpr.ua.edu

Willowood Developmental Center

Willowood provides a daycare setting where children with or without disabilities can learn in an inclusive environment with developmentally appropriate learning centers.

1635 Boling Street
Jackson, MS 39213
(601) 366-0123

Check your local parks and recreation department for special needs programs!

Suggested Professionals

Inclusion on this list should NOT be considered an endorsement of any kind by the Central Mississippi Down Syndrome Society, either expressed or implied. CMDSS families have recommended these resources, which are provided for informational purposes.

Attorneys Specializing in Special Needs Trusts/Wills

Richard Courtney, CELA
Frascogna Courtney, PLLC
4400 Old Canton Road, Suite 220
Jackson, MS 39211
(601) 987-3000
1-866-ELDERLAW
www.frascourtlaw.com/courtney.php
rcourtney@frascourtlaw.com

Linda Bounds Keng
Jones Walker
190 E. Capital St., Suite 800
Jackson, MS 39201
(601) 949-4960
lkeng@joneswalker.com

Financial Consultants

Bill Stone
EFP
1501 Lakeland Dr., Suite 250
Jackson, MS 39216
(601) 206-0006
(601) 540-3031
bstone@wostoneadvisors.com

Eddie Carlisle
Medley & Brown
795 Woodlands Pkwy, Suite 104
Ridgeland, MS 39157
(601) 709-4400
eddie@medleybrown.com
www.medleybrown.com

Breastfeeding / Lactation Consultant

Dr. Cris Glick
Mississippi Lactation Services
435 Katherine Drive Suite B
Flowood, MS 39232
(601) 932-6455

Endocrinologist

Dr. Naznin Dixit
The University of Mississippi Medical Center
2500 N. State Street
Jackson, MS
(888) 815-2005

Dentistry

Dr. Lubna Fawad
The University of Mississippi Medical Center
2500 N. State Street
Jackson, MS
(601) 984-6100

Dr. Sarah Carlisle
Colony Dental
119 Colony Crossing Way
Suite 780
Madison, MS 39110
(601) 605-1410

Dr. Susan Fortenberry
Dr. Lee Cope
Pediatric Dentisty
5315 Hwy 18 West
Jackson, MS 39209
(601) 922-0066

(Suggested Professionals continued)

Dentistry (continued)

Dr. Nathan Beavers
Beavers Pediatric Dentistry
119 Colony Crossing Way, Suite 140
Madison, MS 39110
beaverspediatricdentistry.com
(601) 856-5313

Pediatric ENT

Dr. Mark Reed
Dr. Jeffrey Carron
University Physicians/ENT
764 Lakeland Drive
Jackson, MS
(601) 984-5160

Pediatric Opthalmology

Dr. John McVey / Dr. Robert Mallett
Jackson Eye Associates
1200 North State Street
The Belhaven, Suite 330
Jackson, MS 39202
(601) 353-2020

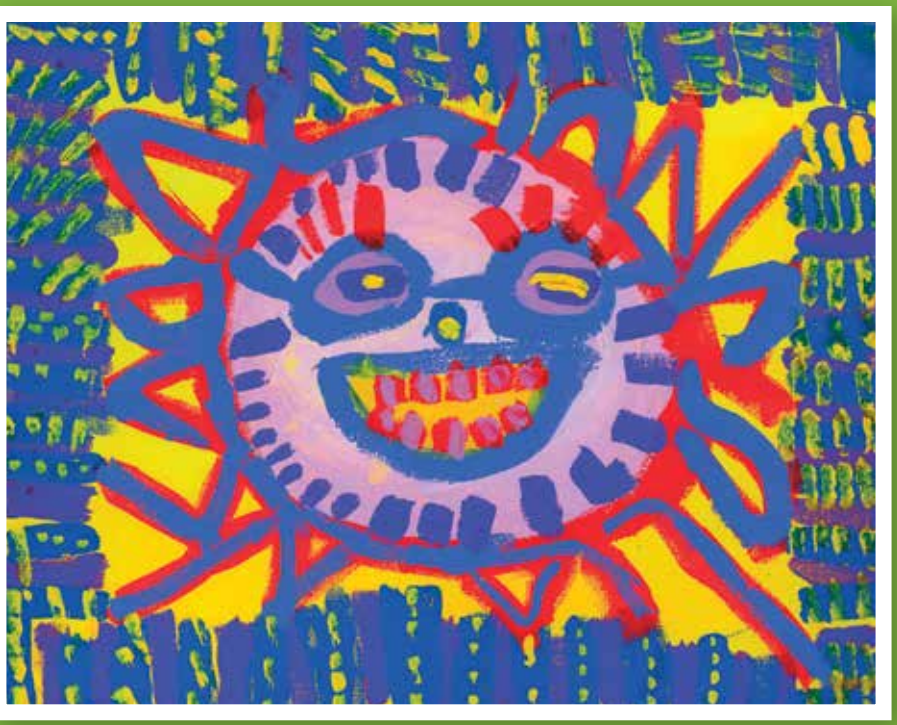
Dr. Nils Mungin
Director of Pediatric Opthalmology
University of Mississippi Medical Center
764 Lakeland Drive
Jackson, MS 39216
(601) 984-5020

Pediatric Cardiology

Dr. Aimee Parnell
University of Mississippi Medical Center
2500 N. State Street
Jackson, MS
(601) 984-5250

Dr. Jennifer Shores
University of Mississippi Medical Center
2500 N. State Street
Jackson, MS
(601) 984-5250

Dr. David Braden
MS Children's Heart Clinic
1190 N. State St., Suite 200
Jackson, MS 39202
(601) 965-6100



Will Terry, *Summertime Clown*
Courtesy of Mustard Seed, Inc.

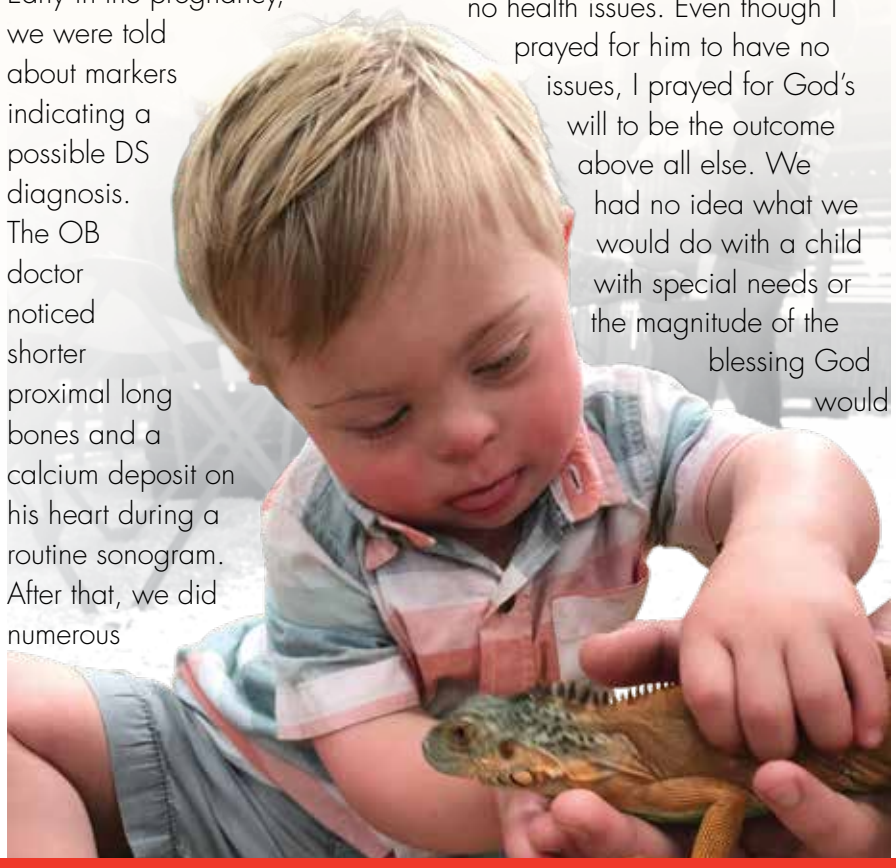
Children are our most valuable natural resource.
– HERBERT HOOVER

Asher Baucom

by BRIAN BAUCOM | (601) 906-0230

My wife, K'Anna, and I are parents to Bren, Asher and Ella. Asher has Down syndrome, a diagnosis that has changed how we see special needs. That diagnosis has done nothing to slow down our little boy. As I write this, he is dancing to the music from *Moana* with his sister's shoes on his head and trying to sword fight the bird on there with a light saber. He has definitely changed the way we look at our lives.

Early in the pregnancy, we were told about markers indicating a possible DS diagnosis. The OB doctor noticed shorter proximal long bones and a calcium deposit on his heart during a routine sonogram. After that, we did numerous sonograms with multiple specialists, and the experts told us that we had around a 1 in 8 chance of our child being born with Trisomy 21. We were worried and scared, but we thought that 12.5 % was a really good chance of "beating the odds." We prayed and had everyone around us praying that Asher would be born as a "typical" child. I wanted Asher to be a normal son. I personally prayed for him to be born with no health issues. Even though I prayed for him to have no issues, I prayed for God's will to be the outcome above all else. We had no idea what we would do with a child with special needs or the magnitude of the blessing God would give us when he was born.



When Asher and his twin sister, Ella, were born, they spent three weeks in the NICU. After they were stable, we wanted to know if Asher had "Downs." The doctor told us that it appeared he did. We still weren't convinced, and the staff did a chromosomal test for confirmation. One of the nurses that worked in the NICU came into the room to tell us that everything would be okay and she had a son with Down syndrome. We were appreciative, but it still hadn't "registered" that we had a child with special needs. So, we kind of rejected anything she said. Then, the doctors told us that he would need open-heart surgery for an AV Canal defect. We were floored, but the NICU staff at River Oaks Hospital did a great job at getting us the resources we needed for our journey.

After we left the hospital, my wife and the nurse became friends. She told us about The Little Lighthouse, and the Central MS Down Syndrome Society. My wife did an incredible job to get him on the list for "The Lighthouse," becoming involved in the CMDSS and beginning early

intervention therapy. Also, we began preparing for his open-heart surgery. During a meeting with the surgeon, he told us that he had been praying about this case from the time he got it. He told us that he was very confident in his skills, but he was not God. It was another time that we would have to wholly trust in the Lord with the outcome of our lives. All of the glory is to God, the surgery was a complete success. After the surgery, Asher grew stronger and stronger, and his personality began to blossom into the child we know today.

He started school at The Little Lighthouse in 2015. Since then, he has become a social butterfly. The teachers and therapists at the school have done an awesome job at loving him like their own. They go to great lengths to teach and love him, especially when he is in full "Asher mode." Between the therapists at "The Lighthouse," and his other therapists, he has made incredible strides in his physical, speech and occupational skills. Asher comes home daily showing us his new signs and songs that he learned at school. He's accomplishing many milestones that are largely in part to our family at The Little Lighthouse.

Asher is the greatest blessing that we wouldn't have asked for, but we wouldn't change him for the world. His vibrant personality has changed our lives and the lives of many around him in just a few short years. He loves to love people and puts a smile on everyone's face with his enthusiasm. Likewise, he loves to worship the Lord, dance anytime a beat drops, and if he gets a platform (an open spot in circle time or an opportunity), he'll preach with the best of them. His favorite pastimes are eating dirt, running from us and knocking the folded clothes off of the table. He is all boy and everything you would expect from a boy. He's my little buddy. I look forward to the things we get to do in the future (hunting, walking through the woods, playing on the tractor, sports, anything he wants to do.) The only limitations he has on his life are the ones that we place on him. We are extremely blessed to have been given him as our son.

asher baucom

Brady Bennett

by MARK BENNETT | (601) 503-0742

In September of 2003, our only son, Brady Bennett, was welcomed into our family.

It only took a few minutes after birth that the doctor diagnosed Brady with Down syndrome, and right there Brady Bennett made his first splash in this world.

The news was rather shocking to say the least, and many concerns flooded our minds. We were so convinced that something negative had happened, to the point, I wrote a testimonial for the original New Parents Guide and compared Brady's birth experience to the actual terrorist attack on 9/11. I look back on that and I have to laugh, but truly the comparison was of similar feelings. Brady's birthday, 9/9/03, was just a few days before the 2-year anniversary of 9/11, and I guess the memory of how we felt the day of the attacks was still fresh on my mind! For me it was a great sense of fear like never before, then concern for our family, and then just the unknown of what was gonna happen next!!

Looking back, I bet my testimony scared some new parents with that comparison, but the truth is, I had the same feelings when we received Brady's diagnosis.

We had no time to prepare or educate ourselves, so having a child with special needs was the unknown to us and made us feel the same fear of what this would really mean for us on a day-to-day basis. My questions to myself were how is this diagnosis going to affect my family, will I be a great parent for him, and will he have a happy full life? This caused some anxiety for us initially. We quickly moved past these fears with the unconditional love and great joy Brady gave us, and we look back often and think how silly we were.

It has now been 13 years later, and having Brady has made our family wonderful. We feel now that nothing negative happened at all. Something wonderful definitely did!! My family was made better that day. Brady has been an awesome part of this family and

even though he's our only son, it can't be much different raising any other boy. He has his own personality with the things he likes and the things he does not like! He loves his family, has his friends that mean the world to him, can shoot some mean basketball, loves to play board games, bowling, golf, swimming, music, dancing, the beach, loves good food and if it was up to him, he would eat Mexican every night! He truly enjoys every day to the fullest!

He has sisters older and younger, and they play, tease and live life together as any siblings would. We raise him the same as our girls and expect him to do his best every day just as we do our girls. He makes us laugh a lot, but like all teenage boys, he can test your patience for sure. It makes us so proud that he's our son. It warms my heart that his personality is what it is, and we love what he brings to our family! Yes, Brady made a splash the day of his birth, but he's made plenty of splashes since. Like any kid, he loves life, and we all stumble through

together and learn new things and overcome obstacles. That's just this wonderful life. Our life wouldn't be the same without the joys and splashes of Brady Bennett!!

Thirteen years later we are continuing to see that Down syndrome is just a diagnosis, but Brady is just our awesome son that we are so wonderfully blessed to have been given!!!

Walt Clingan

by BETH CLINGAN | (601) 540-2927

When my husband and I got pregnant, we were so excited and couldn't wait to start a family. We never in a million years thought that our child would have Down syndrome, and I'll never forget the moment I found out.

It was just another normal day when my mother, who sells ultrasound machines, invited us to her house to try out her newest machine and practice on me before an upcoming show. Instead of looking at our sweet baby with joy and excitement, my mother told us that we should take the ultrasound pictures that she took to my next appointment and show my doctor. She would not tell us why at the time, but we could tell that something was definitely wrong.

At my next appointment, we were referred to Maternal Fetal Medicine. Not long after that appointment, we decided to have an amniocentesis to confirm if our child had Down syndrome or not. My husband and I both agreed that no matter what the results showed, we would never want to terminate the pregnancy. We just needed to be able to prepare ourselves, both mentally and emotionally.

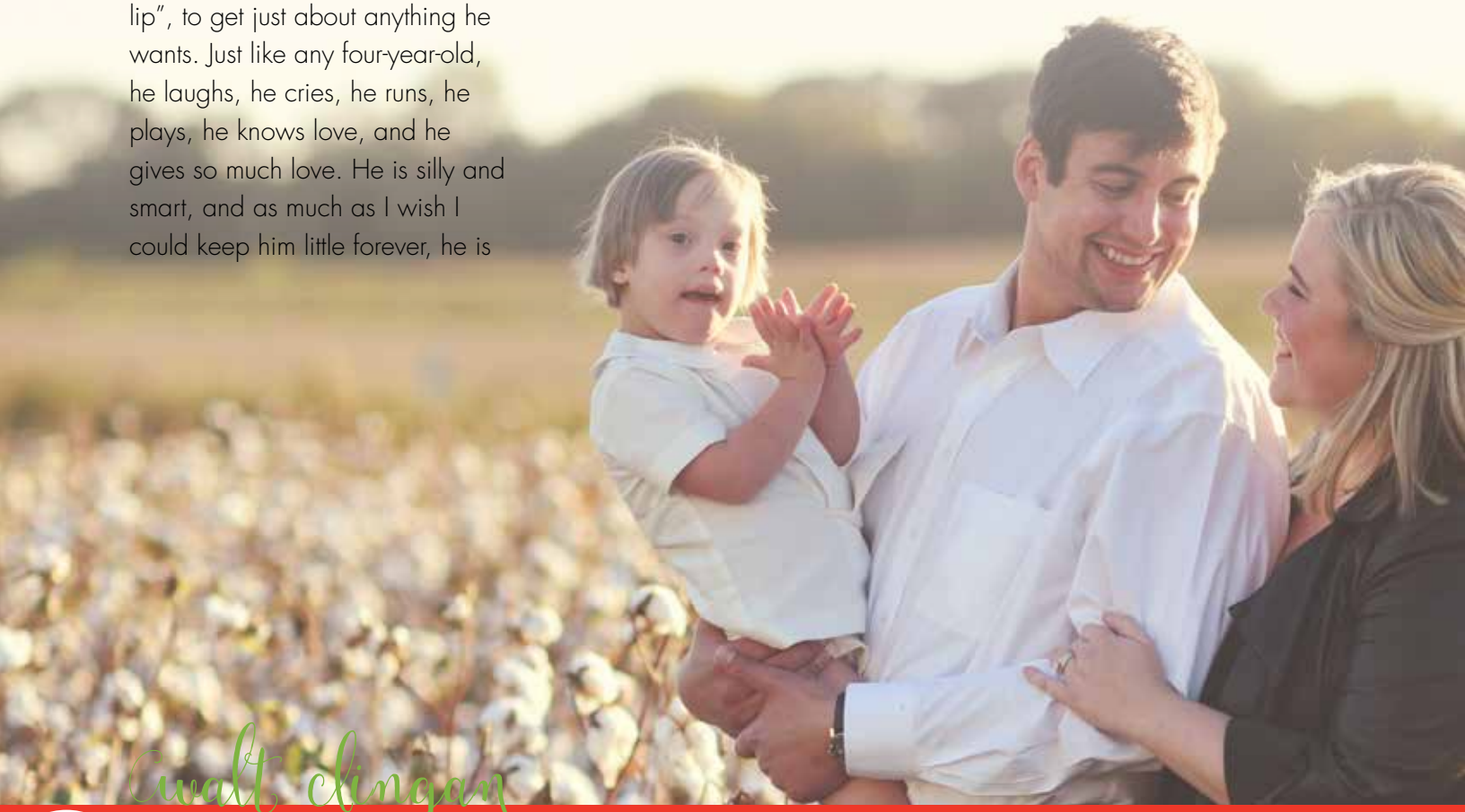
A few weeks later, I got the call confirming the results: our baby has Down syndrome. I still remember where I was, what I was doing, what the weather was like, and who was around me – I remember everything about that moment. The world completely stopped turning during that phone call. I think I was in shock, and I certainly wasn't ready to hear that news. I calmly thanked the doctor for calling, hung up the phone, and continued what I was doing like nothing happened. It wasn't until I had to say those words out loud to my husband later that night that it really started to sink in - our baby has Down syndrome. At that moment, we felt so many emotions. While we agreed that we would love our baby no matter the results, it was easier said than done. We were devastated. We were terrified - not only for our baby, but for ourselves. I stressed myself wondering what kind of life he would have and the effects this condition would have on the rest of our lives. It just didn't seem fair.

Our precious Walt was born on November 7, 2012, and that was the first day of the rest of our lives. That was the day we fell completely in love with our son – the one we had feared we would not be able to truly love. He was absolutely perfect. Of course, we were still afraid of the future and the many unknowns that we would face, but holding him and seeing him for the first time made all of those fears fade away, at least for a while. There have

been many hard days since Walt made our family complete. But for every hard moment, there are multiple amazing and wonderful moments. Moments that I wouldn't trade for the world. We've seen him overcome more than some will overcome in a lifetime. We've seen him work so incredibly hard to reach a milestone that comes so naturally to other children. But he does it with a smile on his face and never gives up.

Walt has taught us so much about patience, perseverance, and unconditional love. Today, he is the happiest, sweetest, and most mischievous four-year-old I know. He can do so many things I never thought were possible. He has learned that he can use his "pouty face", or as I like to call it, "the lip", to get just about anything he wants. Just like any four-year-old, he laughs, he cries, he runs, he plays, he knows love, and he gives so much love. He is silly and smart, and as much as I wish I could keep him little forever, he is

becoming more and more independent and opinionated every day. He lights up the room and can make anyone's day so much brighter. He is so cherished, and we could not love him more. He is our Walt, and we cannot imagine how boring life would be without him. We thank God every single day for giving us this blessing we never knew we wanted.



Walt Clingan

Kate Cox

by TISHA COX | (601) 941-9448

God brought our Kate, also known as Katie-bug, into our lives on December 20, 2011! To our surprise, we were informed that there was a possibility that she may have Down syndrome but would need genetic testing to confirm. I wish I knew on that day what I know now. I wouldn't have been worried so much and would have embraced the news that day. Kate has been just like my other two kids other than moving on to the next stage a little bit slower, which has been nice because I truly get to enjoy each stage. She loves to sing, dance, read, jump on the trampoline and most of all, likes to play with her brother and sister. She brings a smile to everyone she comes in contact with because she is always smiling. She loves to hug and never meets a stranger, and her laugh is contagious. Our lives would be dull without Kate. She loves everyone and judges no one. She is excited about starting Kindergarten this fall and showing her new teacher that she can say her ABC's and knows all her colors.

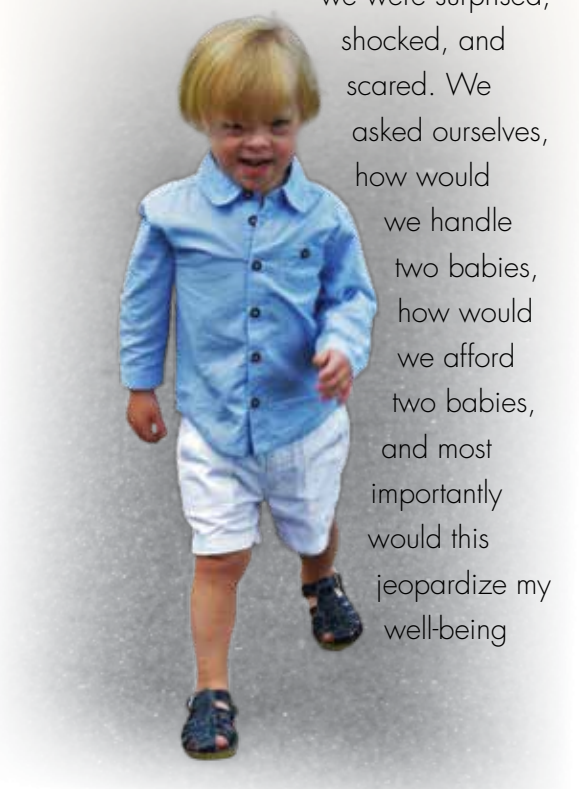
kate cox

Solon Carter Dobbs IV

by LYNDI DOBBS | (662) 816-2729 | lyndidobbs@gmail.com

My husband and I had been married for seven years before deciding we were ready to have a child, or at least we thought we were as ready as we would ever be. We had enjoyed our time together, worked on our careers, and traveled as much as possible.

Fast-forward two years later…we discovered we were pregnant! We were ecstatic and joyful and giddy with excitement. We go for our first ultrasound and discover that there is not just a Baby A but a Baby B as well. To say the least, we were surprised, shocked, and scared. We asked ourselves, how would we handle two babies, how would we afford two babies, and most importantly would this jeopardize my well-being carrying multiples?



At 36.5 weeks, my blood pressure began to creep upwards. My OB-GYN decided that is was best to go ahead and induce labor. After a very easy delivery, we met Adeline Claire Dobbs and Solon Carter Dobbs IV. Both appeared to be healthy and happy right after the delivery. Both were sent to the well baby nursery for the first night. The next morning the neonatologist thought it would be best to send Solon down to the NICU for closer monitoring. He was having some difficulty maintaining body temperature, and his blood sugars were a bit low. No need to panic…just to be safe.

A week later, Solon was still in the NICU, and the doctors decided to order further testing, including chromosomal testing…just to rule everything out. Two days later we received the news. Yes, your son does have Trisomy 21, and I am sorry we missed it earlier. So now…we have a 2-week-old daughter at home and a 2-week-old son with Down Syndrome in the NICU. I was immediately contacted by CMDSS, given references and resources, and instructed by our NICU case manager on our next steps.

Like so many families in our situation, we struggled to balance the grief, anger, happiness, and a burning desire to obtain more information. We quickly recognized that CMDSS and the many families involved in the organization were not only able and willing to offer comfort, but knowledge as well. Knowledge can be a curious thing. Many times I have found that it is not only *what* I am told or learn, but also *when* that can make the difference. Some facts need to be learned quickly, despite the sting, yet other information comes only when we are ready for it to be absorbed.

Solon and his twin sister just celebrated their third birthday, and as I reflect on our time together I recognize the importance of the connections made with the caring and compassionate individuals

linked to CMDSS. These families share in our struggles and our triumphs. For me, the lesson is simple – I have been given two beautiful children, and our journey has led us to a group of people who offered us information and community. As I look into my son's eyes and hold him close, I can only ask, what more could a mother want?

Zoe Beth Edwards

by MONICA & CLAY EDWARDS | (601) 720-8074

For nine months, my husband and I had been expecting a perfect, healthy baby girl. We had every test tell us that's what we could expect. So when Zoe Beth was born and we were told we needed to run genetic tests, we were devastated. What just happened? What about our perfectly healthy baby we had watched growing for the last 9 months? How does this happen? Was she going to be okay? Is this my fault? What did I do wrong? Will she ever walk? talk? go to school? I had so many questions. I was so afraid. I needed answers! One of the nurses put me in touch with a social worker who brought me a book and a binder. She said, "These are from the Central Mississippi Down Syndrome Society. I think you might find some of this information helpful." I said, "Thank you." I spent hours reading and rereading every single page.

I needed to know, what does Down syndrome mean for us? I would give anything to be able to go back and talk to myself in those first days, so I could say, "It means everything is going to be okay. It means you're going to take your time growing up. It means your baby girl is going to do everything your baby boy did, she might just need a little extra encouragement and time to get it done."

The worst feeling in those very early days was the fear of the unknown. My imagination was so much worse than anything that we have actually experienced. I absolutely grieved the loss of the child I thought I would have. I focused so much on all of the things I thought she would never be able to do. All of the things I thought she could never be. But I refused to let myself stay in that place. I had to find out what was possible!

Our experience has been something kind of wonderful. I wish I could have imagined how amazing she is. When I first heard the words Down syndrome, I never imagined Zoe Beth running up to her friends at school and church to give them big hugs. I never imagined running and chasing her across the front yard in a full sprint. I never imagined standing on the edge of the pool as I (and 100 of her biggest fans!) clapped and cheered her to the finish line of her first race in a swim meet. I never imagined her singing and signing "Twinkle, Twinkle Little Star." I never imagined her saying, "I looooooovvveee yooouuuu!!!" over and over again.

Four years after we received Zoe Beth's diagnosis, this is where we are. We are the proud parents of a happy, healthy, amazing 4-year-old. She goes to school 3 days a week. She loves swimming for the Sealions Swim Team, a fully inclusive team of almost 100 kids, where she is one of two swimmers with Down syndrome. She loves jumping on her trampoline for hours at a time. She loves books more than life, and although she can't actually read just yet, she will recite a story to you with all the enthusiasm of a Juliard-trained stage actor. Her favorite sign is "bathtime" and her favorite food is a red bell pepper cut into strips. Life is good.

I think one of the greatest decisions we made was joining the Central Mississippi Down Syndrome Society. We went to our first Buddy Walk when Zoe Beth was just 9 weeks old. Through this organization, we were put in touch with families of older children who we could learn from, but we also met parents of children the same age as Zoe Beth. Those families have become more than friends, they are our extended family. They are more than a support network cheering each other's kids on; we are a team helping to spread awareness and make this community a better place for our kids. I'd like to encourage you, when you are ready, to reach out and connect with people in this community. We can help answer questions, and hopefully ease fears. The best thing about this community, it is so full of love. We hope to see you around.

zoe beth edwards

Hayden Elliott

by KELLY & DEANNA ELLIOTT
Kelly: (601) 238-6802 | *Deanna:* (601) 601-668-3223

Having two older sons, I know the joy that comes with having a baby. I also know the pain, sadness, and disappointment that comes with finding out your new baby has a disability. January 29, 2010, is a day I will never forget. The excitement and thrill, the oohs and ahhs, and the "Oh, he looks just like his brothers, Peyton and Conner." I remember how quickly that excitement went away after being told that our precious baby boy had Down syndrome. In that very moment, I felt that someone had ripped my heart out. I thought there was no way this could happen to me, to us. Kelly and I were normal people, we were a normal, Godly family, went to church, and I taught in a Christian school… this was a mistake. I had not planned this.

Although, most things those first few months were a blur. I do remember crying myself to sleep at night for months. I remember someone telling me about a school for special-needs babies/children (The Little Light House), and I needed to get his name on the list immediately. I remember everybody telling me that God gives special kids to special people. I thought if I heard that one more time, I would scream. I did not want my child to be special, and I did not want to be special. I worried about how people would treat Hayden, how our friends

would treat us, and how my family would treat him. I wondered if my family would love him as much as his older brothers … I know these feelings may seem strange, but if you are reading this, chances are you are a new parent of a precious baby who happens to have Down syndrome, and you may be feeling this way too. Little did I know on January 29, 2010, just how special Hayden truly was and the undeniable impact and joy he would bring to our family's lives and all those that are fortunate to meet him.

Not long after Hayden was born, a friend texted me a verse one morning… Jeremiah 29:11 – *"For I know the plans I have for you," declares the Lord, "plans to prosper you and not to harm you, plans to give you a hope and a future."* Little did I know how much I would lean on that verse the next few years. In the days ahead for you it may not be obvious, but I assure you the lessons and pure love your child teaches and shows you will far outweigh the worry, anger, and fear you may be feeling now. And though it won't always be easy and certain, I can predict the blessings you receive will be much more than you could have ever expected.

hayden elliott

Nia'Brooke French

by VENICA KNIGHT | Vknighto8@yahoo.com

Nia'Brooke is our ray of Sunshine even on cloudy days. At first we didn't know what to expect from her diagnosis of Down syndrome. We were thinking the worst, but later found out that GOD gave us the best. She is a very loving child and doesn't let challenges get in her way. I found that allowing her to be enrolled in daycare, aftercare, and school in classes with typical children helped with her development tremendously. Each day we are learning that there is #Nothingdownaboutit, and we as parents are #theluckyfew.

Jared Giles

by DEBORAH & ROBERT GILES | (601) 373-5011

The opportunity to share our story is appreciated, and we hope that it will inspire families and parents of children with Trisomy 21 chromosome known as Down syndrome. After learning that Jared had Down syndrome, my questions were, "What will his quality of life as an adult be like?" and "Will he be able to contribute, in some way, to society?"

Jared, now 22 years old, continues to transition from school to daily living and community involvement, with assistance and a circle of supports. He participates in the Home and Community Based Services offered through the Department of Mental Health where he learns and practices pre-vocational tasks to acquire skills needed for future employment. In addition to the pre-vocational skills training and community services, Jared likes playing with his game system, YouTube and sports. He participated in the Special Olympics winter and summer state events, earning a gold medal in basketball skills and silver medal in bowling. Jared also participates in the Challenger League, a sports league for individuals with disabilities. Jared is active. He has a busy schedule and loves to socialize, especially at dances, with his peers. He recently became a cell phone user, and the touch screen cell phone has helped to improve his ability to communicate. Jared also serves as an usher at his church and looks forward to his responsibility.

So despite Jared's many surgeries and medical conditions, heart disease and Hirschsprung's disease, being the most critical, we manage to live life to its fullest. We encourage others to explore all opportunities, discover possibilities, and research issues and concerns thoroughly; focusing on medical concerns, needed occupation and speech therapy, education, and balancing daily living with socialization and peer related activities. Become active in organizations, support groups and advocate on behalf of your loved one and other individuals with disabilities.

Reading about Jared's journey so far and at this point in his life, I hope, will inspire you and affirm to you that your loved one is capable and expects you to help him or her achieve based on their abilities.

Even as an adult, when Jared leaves home each day, he still says "Love you Momma, Love you Daddy," and we tell him we love him. We are grateful that he has a structured environment to learn and grow along with many supports that were once nonexistent for individuals with disabilities. As we grow as a family, we continue to feel God's love and protection over our lives.

jared giles

Savannah Hartung

by DEBBIE HARTUNG | (601) 624-4868

I had just turned 40 and was pregnant with my second child when I received a phone call from my doctor that would change my life. "Debbie, you're having a girl and she has DOWN SYNDROME." I went to a specialist, who gave me a piece of paper with a list of possible problems, all in technical terms. He said we had to make a decision whether or not we wanted to keep our baby. My first impulse was NO, I don't want to do this. A million reasons went through my head of why I could not keep this baby. But thank God for my now ex-husband, Richard. We sat down, and I began to pour out my reasons why I should terminate this pregnancy. Very calmly, he said, "In theory, legally, I have always thought a woman has the right to choose, but now that it is my child, I'm just not sure." I called my obstetrician back, and said, "Please help me, Richard wants to keep the baby, and I'm scared." Her words saved my baby and me. She said, "I have seen sick children, and these are usually not sick children. They are truly a blessing, they seem to have been given something extra to make up for anything they might lack."

Sixteen years after Savannah's birth, as I look back at that terrified pregnant person I was, how I wish I could have shown her the future. I believed the positive things I read on the Internet HAD to be biased, that they couldn't REALLY be being honest by saying they were happy with their "special needs" child. But I am here to tell you that raising my Savannah has been an absolute JOY.

I'm not saying life has been perfect. Yes, she was sickly for the first 5 years of her life. She was very small, and whenever she got a cold her tonsils would swell and we'd end up in the ER getting a breathing treatment of Epinephrine to reduce the swelling (chronic croup). And she did have a heart cath at age 3. But through all these procedures, you never saw a sweeter, more pleasant child. I sang Twinkle-Twinkle and Wheels on the Bus at least a million times to keep her calm, and as long as I was calm, she always followed suit.

I took her to ballet at 2, dance and gymnastics at 3, and cheer at 5, just like I did her sister. And I made her stand in her spot, pay attention to the teacher and participate, just like I did her sister. And she did. She played t-ball and soccer. We flew on planes, went on cruises, traveled all over the country in my mini-van, and she even snorkeled at 7 when her 11-year-old sister was too scared.

I fussed at her when she was bad. I made her apologize when she did something wrong. I never "assumed" she didn't understand or "couldn't help it". I treated her

just like I did my other child. I have expectations for both. They are not the same, but they are fair and tough. Everywhere I go, people tell me she is the sweetest child they have ever known. She is polite, respectful, and just full of joy. I wish I could say that I made her that way, but I didn't. God did that.

I just get to enjoy it. All I can say is, don't sell your kids short by limiting what you "think" they can do; they may surprise you. Let them try. Let them fail, pick them up, and keep them going, just like all your kids. God gave me the greatest gift I'll ever receive. He gave me a person who always sees the good in everyone. Who loves me the minute she wakes up until the minute she goes to sleep. He gave me a best friend for life. He gave me a little glimpse into what Heaven will be like where everyone is good and kind and full of joy. So I sit here 16 years later and say…Thank you to Richard
for seeing the light and helping me see it as well and thank you to God for giving me a gift I totally did not deserve. And to my Sweet Savannah (Vanna) I love you with all the heart a mom can love with…thank you for being mine !!!!!

savannah hartung

Wilson Helms

by SARA & JOEY HELMS | (662) 910-0077

The day Wilson was born our life changed forever, but I had no idea how beautiful of a journey would unfold. In the beginning, there were tears shed over the shock, concern for his health, and what the future looked like for us as a family. Little did I know how normal things would be, how Wilson would thrive, and how we would find joy in the unexpected. We started from infancy in therapy that has given Wilson the tools to reach his potential. Now, those therapists have become more like family. The milestones that take a little longer to achieve cause for huge, jump-for-joy, celebrations. We waited longer than most kids to hear Wilson talk, but now he loves belting out "Happy Birthday to You." "Hey, everybody" is his go-to greeting in public, and he leaves out no one, and at times his smart mouth will even wind him up in time out. Through Down syndrome, we have found there is a great support group in our community, and I've made lifelong friends who I often look to for support and encouragement.

Most importantly, our sweet, outgoing, and adorable Wilson is leading a happy, fulfilled life. If you ever have the pleasure of meeting Wilson, it's very evident by his infectious smile and laugh. Five years have passed quickly. I find myself learning from Wilson daily and thanking God for the extra chromosome that has made us enjoy life a little more.

Julia Hogue

by COURTNEY HOGUE | (601) 594-7290

My third pregnancy was progressing well, just as my other two had. I was 31 years old, not considered high risk. Therefore, it was my choice not to have the genetic blood test done. Even at 18 weeks, everything looked good, measurements normal. However, at my 30-week check-up, our sweet girl had fluid on one of her lungs and other red flags that something was abnormal. At that point, we were filled with fear, not only that there might be something 'wrong' with our baby, but for her life as well. We left the doctor's office determined to name her, not knowing what the future held. Through amniocentesis, Julia was diagnosed with Down syndrome. We were heartbroken, mourning the loss of expectations for our unborn child. Never having spent much time around anyone with Down syndrome, we feared the unknown, feared Julia would not be able to use her imagination, to be independent, to play and be loved by her "typical" peers. We automatically wrote off college, marriage, things most consider milestones in a successful life. With all these thoughts, fears, and disappointments, I will confess her birth was not a joyous moment, at least not as joyous as it should have been. However, it did not take long for us all to fall deeply in love with sweet Julia.

Had I known then what I know now, I believe I could have found more joy in giving birth to this unique individual. Julia is just that, an individual, more similar to my other two children than different. She is the most independent child, always wanting to do things by herself, whether she can or not! As she has gotten older, it has become very clear that Julia can definitely participate in imaginative play. I often hear her in her room carrying on conversations with her dolls and animals. She is in a regular preschool class as well as a regular dance class. Julia has been welcomed with open arms by her classmates and participates in the same activities as the rest. Julia is full of life. She does not hold a grudge and loves unconditionally. She gets upset when she doesn't get her way just as any child (and some adults). She is feisty, loving, silly,

and quite the problem-solver. I do not know whether or not she will go to college or get married, but I do know these are milestones that I do not doubt she can achieve one day. It may take Julia longer to reach her milestones, but it makes the triumphs that much greater and makes me appreciate the little things we often take for granted in life. Julia has opened my eyes to how precious our lives are and filled my heart with compassion for those around me. Through Julia and the community of parents and other children I have met over the past 6 years, I have come to realize that we are not special. Everyone has something going on in their lives from a child with a disability, a parent with a life-threatening illness, a friend struggling with depression. We are all in this journey called Life together. I think it was completely normal for me to mourn the shattered expectations for my child when I first got her diagnosis. However, finding friends through the CMDSS and other outlets, I found community and comfort in the fact that we were not alone.

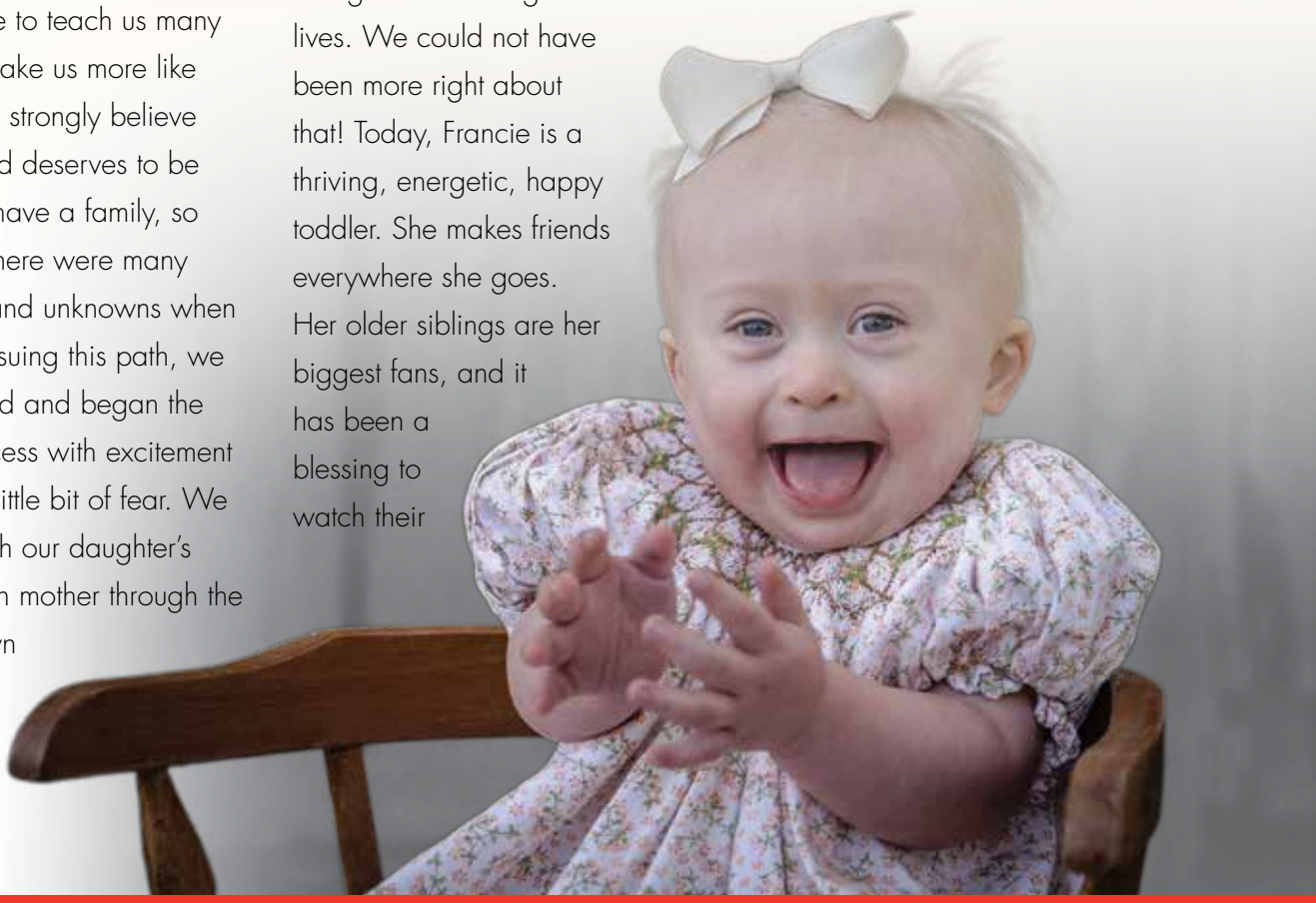
julia hogue

Mary Frances "Francie" Howie

by DAVID & CARRIE HOWIE | (601) 212-4743

When our third child was very young, we began to feel a call from the Lord to adopt a baby with Down syndrome. At first, the thought of adding a child with special needs to our already full plate felt overwhelming. However, we quickly realized what an honor it would be to have a precious child with Down syndrome in our family. We knew that this child would have so much to offer and that the Lord would use him or her in our family's life to teach us many lessons and make us more like Him. We also strongly believe that every child deserves to be loved and to have a family, so even though there were many uncertainties and unknowns when it came to pursuing this path, we moved forward and began the adoption process with excitement mixed with a little bit of fear. We connected with our daughter's wonderful birth mother through the National Down Syndrome Adoption Network, and we built a relationship with her over the next several months while we anxiously awaited our baby's birth.

Mary Frances Howie (Francie) was born on October 4th, 2014, and we fell head-over-heels in love with her from the moment we met her. When we looked into her beautiful face, we knew that whatever challenges the future may hold would pale in comparison to the joy that this little girl would bring into our lives. We could not have been more right about that! Today, Francie is a thriving, energetic, happy toddler. She makes friends everywhere she goes. Her older siblings are her biggest fans, and it has been a blessing to watch their relationship develop. Having a sibling with special needs has been wonderful for our older children, and they're learning to be kind and accepting of all people. Francie attends weekly physical, speech, and occupational therapy, and she works extra hard to reach her milestones. She has taught us so much about determination and never giving up. When she reaches a new milestone, whether big or small, we celebrate it.



Francie truly blesses our family every day in more ways than we could have imagined when we first started down the road of adoption. We wanted to love a child who needed a family, but little did we know that we would be the ones on the receiving end of the sweetest blessing. Being Francie's family is a privilege, and we are so thankful that we didn't let fear hold us back from the joy of having Francie in our lives. When we look at Francie, we don't just see Down syndrome or a diagnosis. We see our sweet daughter with her own unique set of strengths and challenges, just like the rest of us.

francie howie

Kaylen Kellis Jackson

by LONNIE & MONICA JACKSON | (601) 373-9462

God blessed Lonnie and me with a beautiful baby girl name Kaylen "Kaybug" Jackson. I found out five months into my pregnancy that something was wrong. My regular OBGYN could not figure out what was wrong, so we were sent to an ultrasound specialist. My first pregnancy was great with no complications, so I felt no need to worry about this pregnancy. I opted out of all the screenings for abnormalities and went on with my pregnancy. My OBGYN sent me to a specialist at Baptist Hospital, and he could not figure out was going on either. He said to my husband and me, "Something is wrong, but I don't know." So more testing and more doctors. I finally saw a doctor who was one of the best pediatric cardiologists in the state of Mississippi at the time, Dr. Jennifer Shores. After hours of observing and pictures, she narrowed it down to the wire. Kaylen was diagnosed with truncus arteriosus of the heart and Down syndrome. Yes, I was torn and confused at the same time, but ironically, weeks before finding out all of this information, I stated to my co-worker that no matter what's wrong with her, she is mine and I would love her unconditionally. I cried one day on my way home with all sorts of thoughts good and bad. I was worried for her, and she was not even born yet, because I knew how cruel the world can be. In that instance, I told myself I was going to do all I can and be the best mother for her. I had no clue on how to take care of a child with special needs. I met some really great people or shall I say another family through CMDSS. They showed us that it was going to be okay. They were always there to answer questions, and guide and direct us to the help we needed. We realized God had blessed us with something so precious and rare that she had to be treasured.

Kaylen arrived in this world January 27, 2011 at 11:49 am. She was as perfect as I imagined. Kaylen has brought great joy and excitement into our life. Kaylen's personality is one of a kind, which just adds to her uniqueness. She loves music, playing patty cake, itsby bitsy spider and she really loves light-up toys. Kaylen also has a brother who just adores her and lets her get away with anything. She loves to hug and kiss on him and of course boss him around. She has her daddy wrapped around her finger, and well, as for me, I treat her no different than a typical child just lots and lots of redirecting with love.

Tanner Knotts

by ALICIA & KEN KNOTTS | alicia@knottsfamily.org

Tanner Knotts is the youngest of three children. As one can imagine, he has them (and the rest of us) in the palm of his hand. His sisters, Loden and Elizabeth, were nine and six when Tanner completed our family.

During my pregnancy, we were referred to the geneticist for testing. We had been through it before and really didn't think much more than at our age it was a precaution. The test revealed a bit more than we anticipated – we would be having a boy with Trisomy 21 - Down syndrome. At first our spirits were crushed. We were scared, worried, overwhelmed. What would life be like for us and for him? We had imagined so many things for our son and now to find out it would not be anything as we had hoped, dreamed… what? We didn't actually know. Ken and I knew of other families with a child that had Down syndrome but did not have a lot of knowledge. We told our immediate family and just a few close friends about Tanner's diagnosis, and we studied. I dove into life and medical; Ken chose finance, insurance, benefits and estate planning. We both got to know Shawn Wilkerson with CMDSS, the New Parent Coordinator. We had lunch and talked and spent a ton of time getting to know all about support. But in the end, it was clear – we were just having a baby and with two other children at home, it was just going to be ok.

The big day came. Tanner entered the world on July 9, 2007, at 5 lb 2 oz and decided he would get to know the staff at Baptist for a few weeks before making his grand appearance at home. Yeah, he was small, and no, he didn't like to eat, but he was just a baby. We still had doubts and had a second genetic test because he just didn't display the physical characteristics we expected. Those tests affirmed his diagnosis, which didn't matter to us; he was just Tanner. The day we brought him home we drafted an email to our friends and family to let them know he was home and to share his diagnosis. We made it clear that we would be raising a son named Tanner and not a condition or diagnosis, and we certainly didn't want him to be treated any differently than other children. The responses were all over the board, but the ones that we recall most were the congratulations.

See, regardless of the diagnosis – he was still just a baby, our son Tanner, and he was home.

Unfortunately, medical issues continued, and he decided to do time at Arkansas Children's Hospital at five months old for his heart condition. Despite initially showing no signs of heart issues, he had them, and we had to get it fixed. Again, support out of this world came from ACH's staff, our family and friends. Almost overnight, he started gaining the weight he needed, and in short order he was trying to stow away in Ken's suitcase he was packing for business trips. He was a boy, all boy.

We didn't expect to have a a child with special-needs, it's not something you dream about when you're planning the perfect family. What we've discovered through the years is there is very little perfect planning – especially when it comes to children and family. God gives special gifts to special people. We're still trying to figure out what makes us special enough to deserve the package we got. And boy does this package pack a lot of extras – love, laughter, smiles, giggles, all sports, focus, determination and most of all energy!! But we're sure glad we got him!

Today Tanner is involved in numerous activities through school and beyond. He spends time daily with the children in his 3rd grade class as well as the friends with special-needs he loves so much. He is reading, spelling and working addition and subtraction. He plays basketball, soccer, baseball and football. Tanner is an avid bass fisher, awaking every Saturday morning asking when he will get to hit the water.

We researched and thought a lot about what Tanner's future would hold, and we were extremely wrong in those initial thoughts. Our life may be at a different pace, but it's our pace. We have learned to appreciate, enjoy and love the little things in life. Tanner and so many of his friends with Trisomy 21 are achieving things the public never thought possible 30, 20 or 10 years ago. It's not all the kids; it's the support of organizations like CMDSS who provide support and a place for parents to talk about what is working and how to get your child involved.

Our story is about Tanner, and he happens to a little more special that the average child.

tanner knotts

Lily Lape

by BRENT & KRISTIN LAPE | (601) 951-8776 OR (601) 953-0730

"We believe that Lily has Down syndrome…" were the words spoken by our Neonatologist as I stood in the well-baby nursery holding the tiny fingers of our beautiful newborn little girl, and I honestly do not remember what was said after that. I do distinctly remember the immediate questions that went spiraling through my head. Why us? Why our little girl? We were in our late 20's… this only happens to older folks! I went from being a proud dad to feeling like a victim…to feeling like I had literally been punched in the gut and couldn't catch my breath. God and I had a lot of talks over the next few days and by "talks," I more so mean me shouting and not doing much on the listening side.

My turning point came after spending some quality alone time with our new beautiful little girl, Lily. I was playing peekaboo with her and even with only being a few days old … she was so attentive! I remember laughing at some of her funny facial expressions and then stopping in my tracks as Lily just sat there staring at me. It was almost like she was telling me through this simple look "Daddy…we are going to be just fine," and probably also saying "Daddy… you are some kind of goofy!"

Running also became my therapy as I used it to collect my thoughts and also to show off our beautiful little girl. In just over a few years of being in the running community, Lily isn't known to the running folks as "that girl with Down syndrome"…they know her as that spunky little Lilybean.

Lilybean is now 4 years old and currently attending Madison Preschool and is thriving! She spends the rest of her day at daycare (for anyone worried…yes…our kiddos are accepted/included at a typical daycare). Lily has now been going to Madison County Gymnastics in a typical class for over a year now and is doing great! A few lessons we have learned from Lilybean:

1. Enjoy life and take your time! Lily might have taken a little longer to achieve some milestones, but that made us enjoy each and every moment that much more. And man did we celebrate each and every milestone!

2. Lily and her other friends that rock an extra 21st chromosome are truly more alike than different. We tend to focus so much on the differences that we don't realize how much more we

all are truly alike. And Lilybean is no different.

3. Live in the present. All of the amazing therapists and teachers and doctors are doing the legwork to ensure our kiddos are prepared for tomorrow. The biggest mistake I made as a parent was worrying so much about the unforeseen future. Little did I realize that no parent knows what the future holds for their child. Lily has taught us to enjoy today and embrace each and every moment. Tomorrow will take care of itself.

There's really no sugarcoating it, getting that unexpected diagnosis 4 years ago sucked. My wife, Kristin, and I both mourned the child and the future that we thought we had just lost. Little did we know then that we didn't lose anything. We gained a missing piece from our life that we didn't know we truly needed or that we were missing. Once you realize that it really is just an extra chromosome, you will realize how truly more alike than different your child is. I had a "veteran" parent of a child with Down syndrome tell me shortly after Lily's diagnosis that we had won the lottery. It didn't take long to realize how right she was. Lily has truly taught me more about life and love than I ever imagined was possible.

Please feel free to reach out to myself, Brent Lape, or my wife, Kristin Lape, if you would like to talk or have any questions!

lily lape

Wayne McDowell

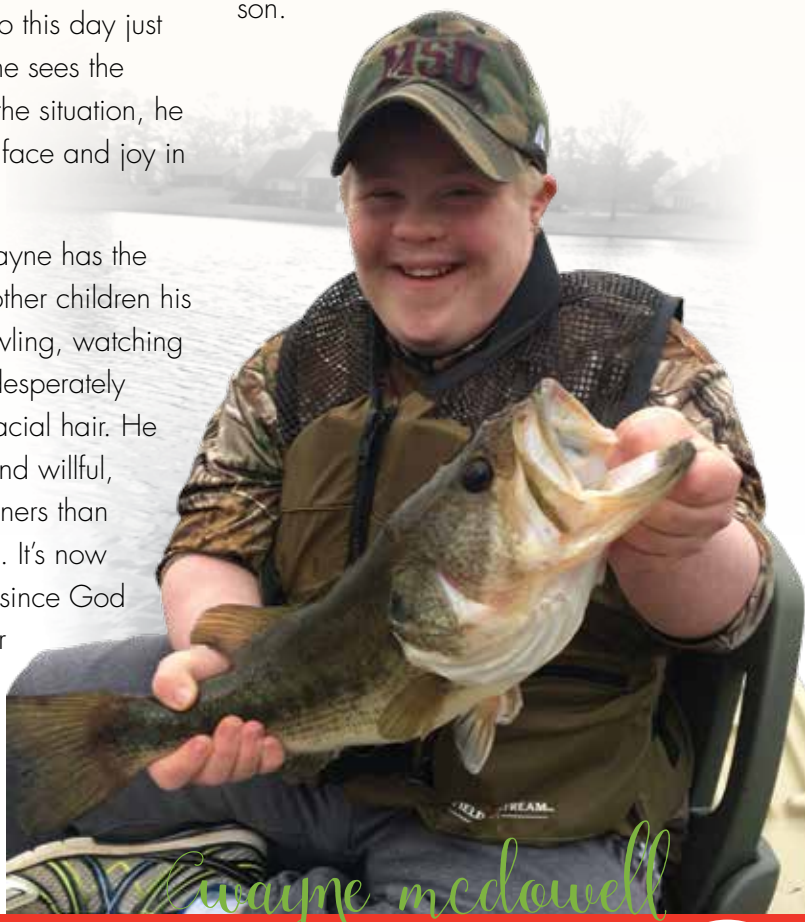
by JONATHAN & KIMBER MCDOWELL | (601) 506-9734 OR (601) 951-7775

When I was younger, I would look at parents with children with Down syndrome and feel sorry for them. I actually remember hearing a parent refer to their child as "special" and I just thought it was an easier way for them to deal with what had to be a sad situation. Well, on the afternoon of March 1, 2002, I found out first-hand what "special" REALLY means.

We didn't know we were going to have child with Down syndrome, and to say we were shocked would be an understatement. My wife began crying, and I stood in silence trying to imagine how I would cope with this unexpected and disappointing news. In those few minutes, sitting in the recovery room with my wife, I literally imagined all the things I wouldn't be able to do with my son; sports, hunting, fishing, and watching him turn into a "real" man. Amazingly though, it was me that turned to my wife and said the boldest statement I had ever made in my life; I told her she had five minutes to cry and that was it, because we weren't being fair to our son. I asked her, "Who are you crying for, him or us? He doesn't know he has Down syndrome, and we are going to treat him just like any other child, until he needs special treatment." After nineteen long days in NICU, we took our little boy home.

The first few years were definitely challenging, as our son battled with pneumonia, and we learned the ins-and-outs of raising a child with Down syndrome. My wife and I have had to keep each other going from time to time, but that's the way life is in general. Throughout all those difficult times, it still amazes me to this day just how joyfully Wayne sees the world. No matter the situation, he has a smile on his face and joy in his heart.

As a teenager, Wayne has the same interests as other children his age. He loves bowling, watching television, and is desperately working to grow facial hair. He can be stubborn and willful, but has better manners than most children I see. It's now been fifteen years since God blessed us with our son, and I still think back to my initial worries about what my son wouldn't be able to do as he grew up. I honestly feel ashamed that my priorities and values were so low back then. My son doesn't see race, wealth, or status; he sees and shows love for everyone he meets. He greets everyone with a hug, and leaves them with a smile. He spends hours talking to God, not for himself, but for others. You see, I have learned that my son is "special"; Wayne sees the world as our Father in Heaven would have us all see it, I am truly blessed to call him my son.



William Frederick McFadden

by MANDY & ROBERT MCFADDEN | (601) 408-4081

Oh, sweet mama … I recognize those tears. You're probably still processing the fact that you've landed in Holland. We landed there, too, with our third son, Will. I want to tell you about a few of the windmills, tulips and Rembrandts we have encountered in the last eight years.

Wilster is learning to read and write, counts fairly well, and speaks a little Martian, but we're working on it! He dresses up like a super hero most days. He loves to watch movies and jump on the trampoline. He loves to RUN, swim and jump from the diving board (as long as he has his floaties on – if not, he is a starfish on daddy's face)!! He LOVES going to Civitan camp every summer!! He is currently preparing to receive his first communion, and has already made his first confession—he is mostly innocent and sweet but as the middle of five children, let's say he makes his presence known! He tells me all the time that Jesus is in his heart while putting his fingers over his chest in the heart shape. I have no doubt, little man! He loves taking hilarious selfies and playing on "WillBlueiPad". He sings and dances a lot. Life is a party! He loves to play his ukulele and guitar. I can't wait to hear the concerts we are about to have with Will on lead guitar, Bella on piano, Bo on Trombone, Eli on Violin and Hannah on jinglebells – anyone know an agent?

On the day he was born, I was filled with such a mix of emotions. I was so in love with that BEAUTIFUL boy … he took my breath away. I was already prepared for the fact that he would be born with Down syndrome and a heart defect that would require open heart surgery. But instead of fearing for his life at the time, we were honestly full of FAITH that it would all work out; that God would use Will's life to glorify Himself, and to ultimately bring each of us closer to Himself — that's why we called him "God's Will."

The 11 weeks before his birth were a whirlwind of gathering information, going to doctor's appointments and meeting new people – and tears. There were SO many tears, y'all. I was sad. God what is Your Will?!?! He answered me – "Be not afraid!!" I wasn't mad or disappointed, but the unknowns scared me. I loved him even MORE than I did before we found out about his perceived "imperfections." So many questions: Would he look like his beautiful brothers? Did I do something wrong that caused sticky chromosomes or the heart defect? Would my friends/family accept him and remain in our lives? Would we have the help and support that we may need? Oh God, what will we need?? Guilt, pain, sadness … because, a mother's love.

We mothers of children with Down syndrome are in a kind of

sisterhood. No one else can quite understand what is in our hearts, what mothering feels like to us – even to our typical children. Motherhood to me after God's Will is very different than before. If I could go back and tell my sobbing, pregnant self something, it would be ***"Congratulations! You are now part of the cool mom's club – you are one of the truly lucky ones!!!"*** And after the confetti and balloons settle I would say: "You did nothing to cause Down syndrome or the heart defect. In fact, you did something right and God saw fit to gift this little dude into your family. You are blessed!" He has never been alone. WE have never been alone. He is surrounded by people who love him, even people I don't know personally. People don't pick on Will – if anything, he may be one of the most popular kids in his school! In public, strangers are moved to come talk and interact with us BECAUSE of Will! New friendships forged BECAUSE of Down syndrome are uniquely special. We just get it. Connect through social media—it will help for when you just need someone to relate to but can't get out. We are here for you, Sweet mama.

Thank you, God, for this precious gift. He is so loved and so perfectly placed in the center of our family—two big brothers to pull him up, two bossy baby sisters to push him along and nurse him to health when he needs it. I don't deserve any of them, but I pray that we can continue to take good care of them as long as God entrusts them to us. As I type this, Will is "helping" his six-year-old sister Bella practice her tap dance to "BreakyBreakyHeart." Sing it Wilster! The Macpack party resumes! Maybe our agent is stuck on a plane to Holland…

Will Mcfadden

Henry McNeer

by DAWN MCNEER | (601) 720-6266

Receiving a diagnosis of Down syndrome was the last thing I expected on my journey through parenthood, yet, that is exactly the diagnosis we received when Henry was born. I was scared and heartbroken because I thought I knew what that meant. Truth is, I was the one who was in the dark. As I began to educate myself on what Down syndrome really is, I found out there is so much "information" that is outdated and depressing and wrong, and I hope that by sharing our experience with Henry, we will give a glimpse of what Down syndrome truly is. I fell in love with Henry the first moment I held him, and he continues to surprise and inspire me daily. Henry is a big brother and a little brother, he has cousins who love him and grandparents who adore him. Henry attends school at The Little Lighthouse, and at 5 years old, he has accomplished so much! At the end of the day, Down syndrome is just a diagnosis. It is a part of who Henry is, but does not define him. He is smart and beautiful, funny and ornery, loving and stubborn, sweet and independent. He is many things, just as we all are. He is a gift, a blessing I didn't know to ask for, but grateful our family received.

henry mcneer

Leighton Myrick

by LISA MYRICK | (601) 695-2423

It's hard to sit down and write about all of the emotions surrounding my beautiful daughter's birth. Just putting it into words is difficult because from the very beginning she was making her presence known in a very big way! Leighton Olivia Myrick was born January 30, 2009 at 11:10 a.m. She was beautiful and absolutely perfect. When she was born, we were unaware that she had Down syndrome, so to say the first couple of hours were crazy is an understatement. Over the next few hours, they spent time examining her, performing tests and trying to keep us abreast of the developments. It would actually take several days to get the results back, so the next few days and nights were spent anxiously watching and praying over our little one.

Over time, we tried to relax and begin our lives as new parents. In most cases, that is easier said than done, and of course ours was no different.

As therapy and early intervention appointments became a common thing for us, we began to realize that raising her was going to be just like raising any other child. Of course it comes with challenges, some large and some small, but no one ever said raising children would be easy. The big things didn't seem as big as they did in the beginning, and the accomplishments were worth celebrating no matter how big or small. We got to watch her grow and achieve things they said she wouldn't or couldn't. She beat the odds then and continues to do that today.

Leighton is now 8 years old and a 2nd grade student at First Presbyterian Day School. She loves swimming and riding horses and, of course, does not like boys.

leighton myrick

Parker Pittman

by KATHERINE PITTMAN | (601) 580-5782

Parker's story is one of unexpected, but immeasurable blessings. The first unexpected blessing with Parker came in the form of a surprise pregnancy. With 3 years of marriage under our belts in June of 2009, we discussed the idea of starting a family, and by Christmas we were telling our family and friends that Baby Pittman would be arriving in August 2010. With the excitement of a new little life, we began to verbalize our dreams for our child: athletics, colleges, careers, and even physique. Our Baby Pittman was already destined for greatness! Just two short months after Christmas, Baby Pittman shared his identity of Baby BOY Pittman with us, revealing his place of honor as the first male grandchild on my husband's side of the family. We were tickled with excitement. On this same day, we completed a blood test to screen for Down syndrome, Neural Tube Defect, and Spina Bifida, since my husband's parents had endured the tragic loss of an infant son with Spina Bifida. Our doctor assured us that our baby looked great on the ultrasound; therefore, this test would just further confirm his perfection. I left the doctor's office that day, and when I did, I left the thought of the results of that blood test there too. I didn't think about it one bit, until a phone call came to my cell phone roughly two weeks later. It was my nurse, who's also my oldest sister. Her words struck me. That seemingly insignificant

blood test came back showing that my baby had a high risk of Down syndrome. "How could this be?" I thought. "I'm only 25," I reassured myself. The next day we found ourselves in the office of the Prenatal Diagnostic Center, having a detailed ultrasound. And to our surprise, more unexpected news came our way. Shortened femurs. Possible esophageal atresia. Echogenic foci. All these words, combined with my blood test results, gave us a 25% chance of our baby having Down syndrome. Our doctor offered the amniocentesis, which I tearfully accepted, explaining to my husband that I couldn't wait until August to find out for sure. The next 10 days it took to get the results seemed to lull on, feeling like 20 days instead of 10. At the end of that 10th day, the phone call came. I answered immediately, and the words I heard on the other end of the phone became another unexpected, immeasurable blessing, Down syndrome. At that moment in time, I couldn't see this news as a blessing. I was grieving my dreams and was fearful of the future. I was bitter at the thought of the challenges and struggles my child was sure to face in his lifetime. Our pregnancy progressed, and Parker's birth came in true fashion, unexpectedly with an emergency cesarean section immediately following my 38-week check-up. The moment Parker came into the world, my grief was no more. We weren't sad when we saw the Palmar crease in his little hand or the epicanthal folds on his eyes. Truthfully, we didn't notice those things. We just saw Parker, our baby boy. Our future athlete, future college student, future big brother, and strong, healthy little man. Our hearts were and are still overflowing with love for our son. Andy and I decided during those early days that Down syndrome would never define or limit Parker. Today, at six years old, Parker is the light of our families, our star tee-ball player, and a caring big brother to our youngest son, Ridge. We know there's no limit for Parker Wilson Pittman, our unexpected, immeasurable blessing.

parker pittman

Finn Roberson

by TRACE ROBERSON | (601) 919-7579

In 2015, we were the parents of 4 children ages 1-6 when we decided to get pregnant one last time. Boy were we surprised to hear it was twins! One boy and one girl who were growing together and seemed healthy. We spotted a tiny mark on the boy's heart at 24 weeks and were assured it was perfectly typical and we had nothing to worry about. A specialist confirmed the same thing and over and over we heard "healthy babies." Until one unnecessary blood test called a DNA screen said otherwise. It was hard to hear that one of our children would have Down syndrome. All the once kind, reassuring doctors started to talk about tests and options, and it was heartbreaking to repeat our wishes to continue on without testing or procedures over and over to the medical community. Nothing had changed, and yet everything had. Worry and fear flooded our hearts for this baby and his siblings and the tears fell despite our best efforts to hold them back. Jay and I never prayed for Finn not to have Down syndrome, but we had to let ourselves mourn for a short time. Mourning seems like a strong word, but that's what we did. We grieved over the typical baby that seemed lost, the one our imagination conjured up, even though God had different and better plans for us. As soon as that "make believe baby" was gone from or hearts, Finn became the baby we dreamed about and longed to meet along with his twin sister! We began learning and researching, educating all the young doctors that did scans on the twins what a wonderful life children and adults with Down syndrome can lead. We made it our goal to change as many minds in the medical community as we could about Trisomy 21. By the time Piper and Finn joined our family we were elated to welcome them! Our nurses were

wonderful, they spoke of the soft sweet feel of having a baby with Down syndrome in your arms and how they almost melt into you. They were so right! In addition to the healthy arrival of the babies, we got to reveal to our friends and family that we had delivered twins! We kept it secret the whole pregnancy.

It's not all roses and pixie dust. Finn faced heart failure and reflux at 2 months old. We were lucky, and medication helped him minimize symptoms and continue hitting milestones. By 6 months his growth had slowed, and he needed surgery to repair a hole in his heart. We were all afraid but knew Finn was in capable hands at UMMC and with God watching him. At 12 months, you can hardly see Finn's scar, he's babbling and crawling, pulling to stand, signing and sitting up by himself. His physical therapists are additional people in his life who love him. We are constantly in awe of how hard he works and how bright he is. People respond to Finn with kindness and celebration of his differences everywhere we go. We still say that we never mourned Finn or cried over his diagnosis. We simply let go of a future that was never ours in the first place, and held tightly to this better path God had in store for us. Your child will never be typical, but they will be amazing. He or she will change how you see the world, but mainly for the better. Your baby will take the scenic route to walking or talking or reading, but when they get to those things, you will have so many precious memories of the journey you took there together. Without a moments hesitation, I can say I would never change Finn. I might wish things came more easily for him sometimes, but that is all, and what parent doesn't want that anyway? Connecting to other parents who understand the frustrations and celebrations of Down syndrome is so important! Jay and I now laughingly share with people how we were told multiple times we had less than a 1:800 chance of having a baby with Down syndrome. We truly hit the jackpot!

Congratulations!

finn roberson

Chandler Smith

by KRIS SMITH | (601) 249-9747

My name is Kris Smith, I am 39 years old. I live in McComb, MS, and I work for the McComb Fire Department and cut grass on my days off. I have been married to Megan for nine years, and we have two little girls, Madeline (7) and Chandler (5). First things first, if you are reading this, I would like to tell you "CONGRATULATIONS" on having a new baby. When Megan and I were pregnant with Chandler, we were sent to Jackson to see a specialist about her kidneys. That is when we heard "hole in the heart" and "Down syndrome." We had an amnio done and were told the results would come back in 12 days. I think I prayed every night during those days that she would not have Down syndrome. When the results came in, I was cutting grass when Megan got the call from our doctor. You guessed it, our baby did have Down syndrome. I thought my life was over. I tried to stay strong for Megan, I cried when she wasn't looking and thought God had punished me for something I had done in my younger days. Boy, looking back, I was the one with the problems!

Today, I wouldn't have it any other way. Chandler is the best thing that has happened to this family! Everything you are feeling or have felt is okay. It is hard being a parent of a child with special needs, but at the end of the day, it is the biggest reward you will ever receive. I am proud to be a dad of a child with Down syndrome!! Chandler has

had open heart surgery and is one tough little cookie. She gives her big sister a run for her money and everywhere we go, she is the life of the party! I called a guy from the CMDSS book that had been sent to us from our doctor and it was so reassuring to talk to a DAD of a child with Down syndrome and that had been where I was about to go. So, if you need someone to call, I am more than happy to talk to you! Good luck and know that everything is going to be okay!

chandler smith

Caitlyn Stewart

by DOUGLAS STEWART | (601) 260-6087

When Caitlyn was born with Down syndrome, I was worried about her health more than the Down syndrome. She had a heart defect, and as a new parent not knowing what to expect, it was unsettling. She had two heart surgeries, but I was assured by her doctors that the success rate was 97-100%. As expected, she did well, and has been a healthy child other than a hospitalization for pneumonia once. But, even "typical" children get pneumonia, right?

Time solves many worries and challenges. Caitlyn is entering kindergarten as a nearly 5-year-old in the fall and still has many more years of school, but getting started right before her 2nd birthday gave her a great head start. When she first moved from the nursery to a regular Sunday School class at church, I knew she had more experience in a classroom setting than the typical kids in the room.

A truth often said is that the people of Mississippi are very generous. There have been many programs that help Caitlyn. CMDSS, funded through the generosity of Mississippians, was great for connecting us with other families with young children that were experiencing similar issues. More help came from lots of sources – whether it be the Medicaid program that helps defray the cost of healthcare to the tuition-free schooling she initially received first at the Little Light House, and later at Madison County Preschool. They all made life a little easier and were much appreciated.

At four, Caitlyn is doing many of the things that any other child does. She understands everything we say, attends school, and loves dressing up as a Disney princess. I never realized that she could have such a great sense of humor – she loves to kid you. She loves to clean the house and knows the controls of an iPad as well as any adult.

When we found out our little girl could have Down syndrome, I never thought of praying for her to be different. Prayers were said to have the strength to handle it. God puts people in Caitlyn's path as part of His answer to provide that strength.

caitlyn stewart

JoEllen Talley

by ALLISON TALLEY | (601) 500-2142

From *"JoJo and Me"* by Allison Talley

JoEllen is thriving now. She's in a regular 3rd grade class, participates in just about every activity that typical children do, and most recently she was a princess in the Miss Mississippi Pageant. She doesn't even know that she is different. You'll find that you didn't know you could love someone so much!

I'm JoEllen Talley's mom. We call her JoJo. The best way to tell you, as a new parent, how I feel about JoJo is to share excerpts from my personal journal entries from the days when JoEllen was born. I put them in chapters because when she's old enough, we're going to write a book together (yes, she's nine years old and can write just like every other nine year old). We'll call it "JoJo and Me." She's just like me in every way, and I love her so much. I thank God every day for her and can't imagine a life without her. I couldn't be prouder of my child and though you may not fully understand it now, you'll feel the same way – soon.

Chapter 1: The Story Begins

I couldn't have been happier to find out that at age 42 I was pregnant again. We had an eight-year-old son, but another with a nice space in-between sounded ideal to us. I knew the statistics about genetic odds over age 40 (actually 35 is the age they start scaring you with them), but 1 in 100 didn't sound concerning to me at all. I wouldn't bet on a horse with those odds. Actually, I'm the unluckiest person in the whole world so the chances of me hitting the 1 in 100 were even more impossible. (This rate actually diminished to 1 in 80 as I was later informed at my delivery). At any rate, I read what I was expected to, but early on decided against any form of test that would give me bad news half way through my pregnancy. Besides, my doctor was a friend, and she promised to give me any tidbit of information she could capture from a sonogram that looked concerning to her.

One day as I went on my 6:00 a.m. two-mile walk, I really didn't feel like finishing. I came home, contemplated my "sick day" call to the office, and realized that I was in labor. It was all too familiar. It was almost a month too soon. This was not right at all. I all of a sudden became scared, for the first time in a long time. My husband was almost to work by now. It was 7:30 and traffic was awful at this time of day. I'd never get him, and if I did, there's no way he'd be able to make it home in time to pick me up. It was a 30 minute drive to the hospital.

"Hey, what's up? I made a quick stop at Lowe's to pick up a part for the dryer. Need something?", he said. Lowe's was only five minutes

away. This was another carefully crafted piece of the plot for us that day. Something was definitely not right.

Chapter 2: So I'm the 1 in 80?

I've always believed that good hair skips a generation. That's why when I saw her for the first time I didn't notice how many fingers or toes or even if she was breathing or not, I was overwhelmed with joy that she'd be the one in our family with perfect hair. She'll be able to wear it with or without bangs, straight or in curls, and it's not stringy or fine. Beautifully brown and perfect!

JoEllen seemed so advanced when I met her. She instantly knew how to nurse. She didn't cry, and she had a beautiful little round face. She weighted 7 pounds 7 ounces, which I thought was pretty good for being nearly a month early. The nurses swept her away to clean her up, and I wasted no time calling all of my closest friends to tell them about my most recent experience (and to brag, I suppose, about natural childbirth even though it was completely accidental). Life was good now.

Then it came. There's no easy way to tell someone that your child has a genetic disorder, so the doctor just came right out and said it - "we think your child has Down syndrome."

"But," she said, "she's going to be high functioning." What the heck does that really mean? It's a term I'd hear a lot over the next few weeks. It's actually a classification for people with Down syndrome, and a not-so-accurate one at that.

The only thing I said for the rest of the consultation of which I can remember hardly any of anymore was "so… I'm the 1 in 80."

I'm the 1 in 80, the lucky 1 in 80.

Mary Catherine Vanderloo

by BETH | (601) 906-9501

If you are reading this testimony, it is most likely because we share something in common in our lives. We were blessed with having a child with a little extra – an extra 21st chromosome – and so much more.

My name is Beth Vanderloo. I am a pediatric speech-language pathologist, wife and mother to three beautiful children: Elizabeth, 9 yrs. old; Thomas, 7 yrs. old; and, Mary Catherine, 6 yrs. old.

On March 11, 2011, our third child, Mary Catherine, was born. We were excited to find out we had another precious girl. While I was in recovery, Mary Catherine was being examined by the neonatologist. They then told my husband that they suspected she may have Down syndrome. Though numerous sonograms were performed throughout my pregnancy, nothing showed any suspicion of Down syndrome, and I had a normal pregnancy. My husband came and shared the doctor's thoughts, then brought Mary Catherine in to me. I took one look and knew right away their suspicions were correct, and later testing confirmed her diagnosis. Hearing those words changed my life forever.

Although I have years of experience with treating children of various diagnoses, to know it firsthand was extremely hard to accept. Not me, not us! It felt like something was taken from me, as if my pregnancy was all a lie; I was blindsided with the news. What would her siblings think, my family, my friends? I thank the Lord every day for my husband, Matthew, who never once viewed anything about her diagnosis as negative. All that mattered to him

was that she was ours and she would be no different than her siblings.

Mary Catherine was born with an ASD (a heart defect that resolved itself on its own, without any surgery), but other than that, is very healthy. She ate well, slept well and, all in all, was a very easy baby, just like her siblings. We came home with her two days after her birth, and I began to go into "therapist mode". I began researching and trying to do all I could to figure out what we needed to do that would help her reach her fullest potential. Although I was busy with research, I continued to struggle with accepting her diagnosis and cried often.

After going back to work and talking with other parents about their journey and watching our Mary Catherine meet skill after skill did I began to see her as Mary Catherine, not a child with Down syndrome. Mary Catherine is so much more than that little diagnosis. I look at her and literally cannot get enough. I can hardly wait to see her precious face every afternoon in carpool when I pick her up from school. Her first words when she gets in the car are, "Hey Mama, Bit Bit and Tom?" Asking me "Are we going to get Elizabeth and Thomas next?" (which we are). She adores her siblings more than anyone, and they adore her back. She has taught and continues to teach them the joy and appreciation of all human life. How no matter who you are, what color your hair is, how tall you are, we are all different in many ways, but all the same in the image and likeness of God, and that is all that matters in our world.

When I look back, I often feel a sense of guilt as to how I felt at the time of her birth and for some time after. I know now that it was just part of the process for many parents to experience, and that is ok. If you have these struggles in the beginning, I can assure you 100% that you will realize how blessed you and your family are.

I could not imagine life without our Mary Catherine. We are privileged as parents, and I can certainly say that God has gifted our family with our precious child, just as He gifted us with her siblings and just as He has gifted your family.

So in closing, I thank God for allowing me to say, "Yes me!" Thank you for allowing me to hear those words and for changing my life. What I thought was the worst day of my life would turn out to be the BEST day, and every day with her and her siblings is a BEST day!

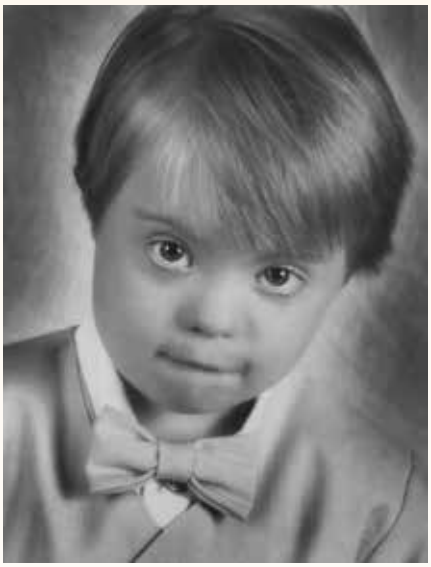
Please contact me with any needs you may have. It is a joy and privilege to meet new parents of children with that extra chromosome.

Cmary catherine Cvanderloo

Cole Waites

by SHELBY WAITES & VAN WAITES | (601) 942-4984 | (601) 942-4985

Every loving parent, whether their child has a disability or not, wants their children's lives to be both mentally and physically struggle-free (as much as possible). There is nothing that can show a parent's vulnerability more so than when their children are presented with challenging circumstances. When Cole was born, we were totally unprepared for the diagnosis of Down syndrome. Neither of us knew anything about DS and felt utterly helpless as we came to realize the impact and all it entailed. The intense emotion was surreal. At the time, it felt like a dream from which we would wake and everything would be as we anticipated. I just knew that the neonatologist was wrong when he told us he suspected our baby had DS, and I told him so. Cole was such a beautifully perfect baby boy. After all, he didn't look like he had DS to us. No, it just couldn't be true. Nevertheless, as the day grew closer to the confirmation of the test that would conclusively reveal the diagnosis, we prepared ourselves to accept what we really already knew in our hearts. As I think back to that day and the tears we shed and



the sadness we felt, I only wish I knew then what I know now. In reality, we should have celebrated because little did we know how blessed our lives had just become. Literally, we had hit the jackpot – the most beloved and cherished gift had been bestowed upon us. God had given us our own little angel on earth to love … our own little ray of sunshine to teach us compassion and acceptance and to make each and every day brighter and to fill our lives with bountiful laughter and immense happiness. God had blessed us with an extra special measure of love and favor in the form of a very precious treasure. He had allowed us the privilege of being the parents of a special needs child – one of His greatest creations – our son, Cole. We are so blessed to be one of the lucky ones. Yes, I said lucky! It is quite the honor because not every parent is chosen to serve. So, to you I say CONGRATULATIONS for being one of the chosen ones. As hard as it may seem to fathom – you have just received one of the greatest gifts ever! Welcome to the most wonderful team on earth.

As the days went on, it took time to research and determine the best possible care and approach for our sweet baby, but with the help of those who had been down the same path before us and through other supportive organizations, books and internet research (which we were told not to do, but we did it anyway) we learned, day by day, the unique circumstances our child would face, and we made ourselves experts in the field. Today, it is just second nature. It is not overwhelming because we continue to take it one day at a time. We keep learning and seeking guidance on how best we can help our child succeed. And one day, you will be able to encourage, enlighten and congratulate other parents just as

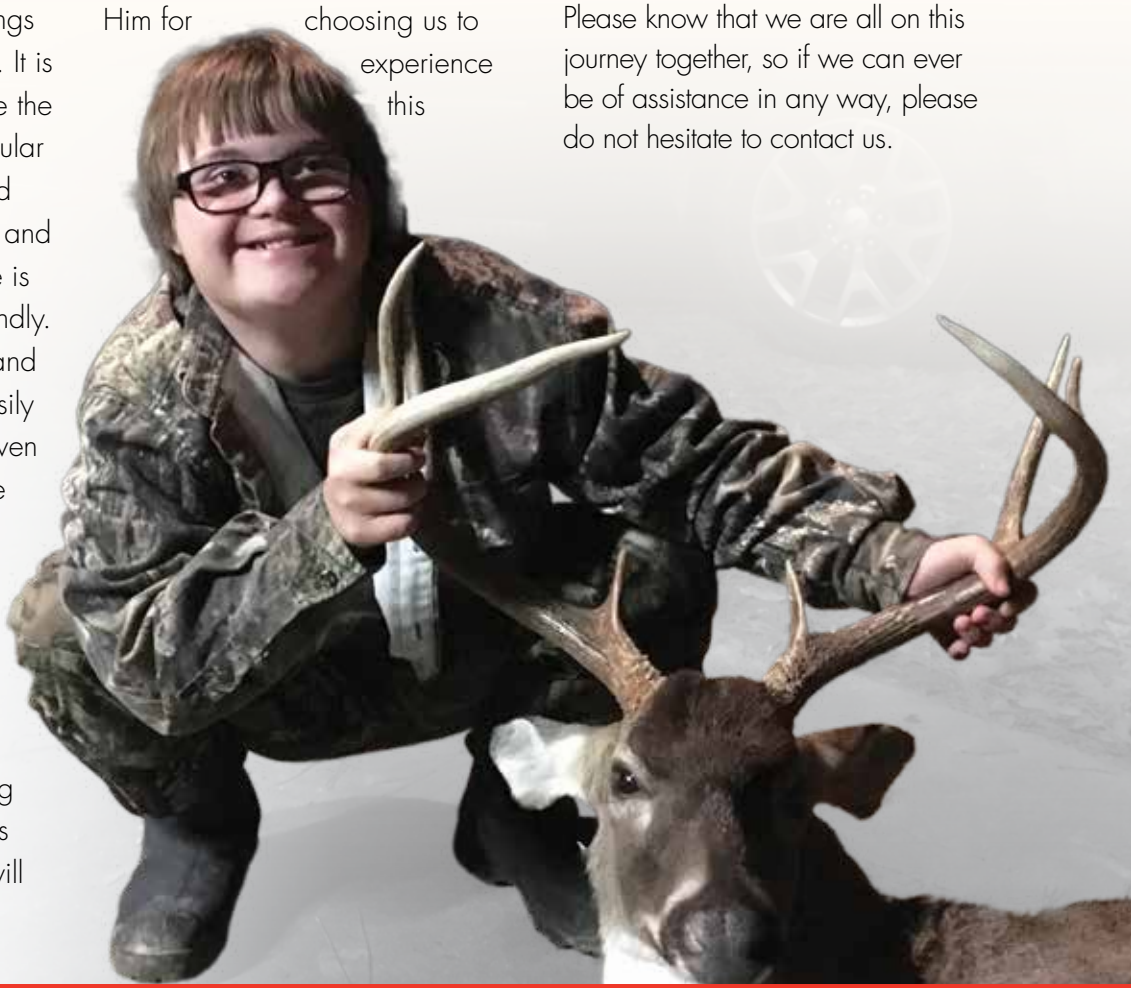
we are doing for you now.

Truly, in a lot of ways we, as society, are the "handicapped" ones because Cole has taught us so much more than we will ever be able to teach him about what is really important in life. In addition, the accomplishments we initially thought Cole would never reach are all notions of the past because he has surpassed each and every one and more! Do some accomplishments take a little longer to reach? Sure, but isn't that true of us all? Nobody runs a race at the same pace. Upon others learning of the diagnosis, the words, "I'm sorry" come forth, to which I say that there is no need in the world to be sorry because Cole is one of the best blessings that has ever happened to us. It is my humble pleasure and quite the honor to raise such a spectacular child of God. Our 14-year-old son is funny, smart, thoughtful and extraordinarily handsome! He is compassionate, kind and friendly. He has quite the personality and is very social. He forgives easily and does not hold grudges even when his feelings are hurt. He never considers anyone less of a person than he. Cole loves unconditionally and is accepting of all. He is not arrogant or proud. He does not see color or nationality, rich or poor, young or old. He sees no differences at all. No matter what – he will always be your friend. He is quite the sportsman and athlete as his hobbies include playing with Nerf guns, WWE, football, basketball, swimming and hunting. He also enjoys cooking and hanging out with friends.

We are so blessed that the Lord allowed us to be the parents of such an amazing boy. Our lives are so much richer and fuller because of our sweet Cole. One of the greatest fortunes in life God so graciously bestowed to us. Let that sink in for a minute. I will say it again … one of the greatest fortunes in life God so graciously bestowed to you and me! I sincerely believe that God has a plan for everyone's life and I thank Him for choosing us to experience this wonderfully unique path. My character and faith have been transformed to a level that I may have never reached had I not experienced this journey which has opened my eyes to so much. So, once again, CONGRATULATIONS and welcome to the most wonderful club you will ever have the honor in which to serve. And hang on. You are definitely in for the most fabulous ride of your life. This experience will fill you with more determination and joy than you've ever imagined. It just simply confirms God's love, devotion and adoration for us, which we, in turn, provide to our children. Truly, it is all worth it and more.

Please know that we are all on this journey together, so if we can ever be of assistance in any way, please do not hesitate to contact us.

cole Cwaites



Matthew Weiss

by JEAN WEISS | (601) 750-3291

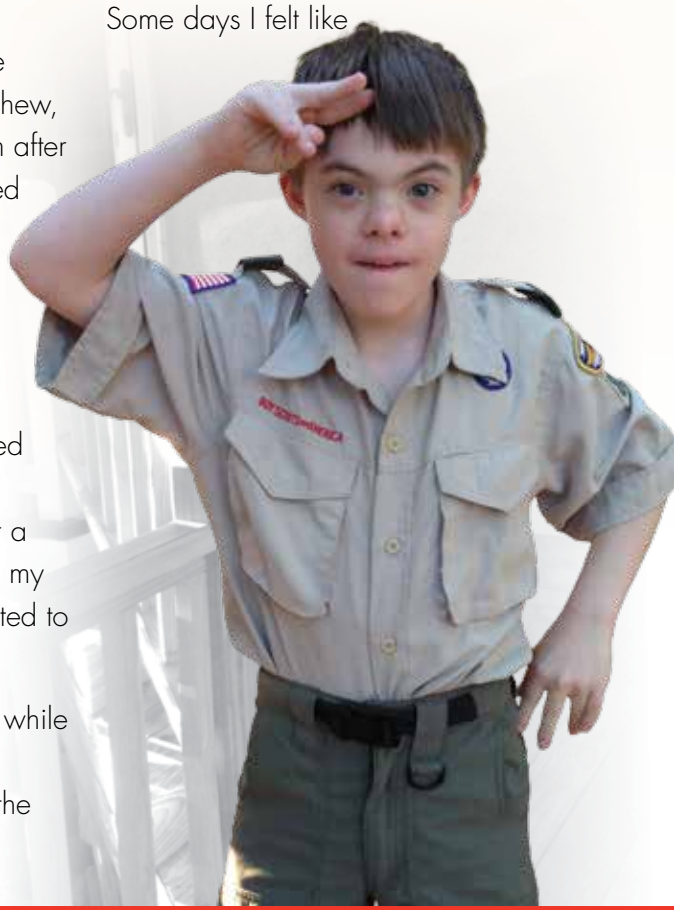
When I first found out I was pregnant, I was in shock. Matthew was our third child, and our older kids were already nine and seven years old. My husband was thrilled, but it took me a few days to adjust to the idea. Soon, we were both overjoyed and I could easily say, this must be God's will and that He must have gotten tired of us waiting around to decide on a third child. When I went into labor, Chuck and I quietly went to the hospital on our own and had the easiest delivery of the three. We have no family in Mississippi, and we didn't even tell friends we were going to the hospital, but we were so excited to call family in New York and Illinois to celebrate. A few hours later, I was encouraging Chuck to go home and get some rest. He was making one last call when the door opened and a doctor and a number of nurses walked in, stood awkwardly around the end of the bed and gave us the news that it was a good chance that Matthew had Down syndrome…then they walked out and left us in shock. So there we were, alone on a Saturday night at the hospital, and we started another round of phone calls to share the news.

There were a lot of tears that night. I didn't really know what Down syndrome was, but I knew that it wasn't what we expected or wanted. Sometime in the night, we were informed Matthew was having trouble breathing and they were taking him to the NICU and they suspected a likely heart problem. I have to say there were times that night that I truly despaired. I didn't want this, and I didn't think I could deal with this. Chuck and I had never felt so alone, but we made a commitment that we were in this together.

We ended up spending three weeks in the NICU with Matthew, and it wasn't a heart problem after all, but a colon problem called Hirshsprung's disease. It ended up being a bigger issue for a few years than the Down syndrome. I remember the first time I left the hospital without him, I cried all the way home. The Down syndrome part was no longer a problem in my mind. He was my baby, I loved him, and I wanted to bring him home.

The best advice we received while I was in the hospital was that how we present Matthew to the world is the way the world would treat him. We took that to heart, and it worked out really well for our family. Daily emails the first few weeks with health updates signaled to our friends and family how they should respond and support us.

There were moments of tears, anger, grief, and sadness during that first year that were mixed with the joy and happiness of having a new baby. That is perfectly normal and we each worked through it at a different pace and way. Some days I felt like



someone had placed me in an alternate universe where everyone else was exactly the same, but our lives were upended and would never be the same. Then I realized lives are changed by babies and you can dwell on the difficult parts or you can celebrate and focus on the joy of it. It just took me a while that first year for that lesson to sink in.

Matthew is a teenager now, and has changed our lives in so many ways. He was not what we expected, but none of our children turned out how we expected. He has brought us so much joy. He has taught his older brother and sister compassion and caring, and they adore him. Matthew can be so very funny and so very stubborn. He is active in boy scouts and his dad is determined that Matthew will someday achieve Eagle Scout just as he and Matthew's older brother had. He is active in our Catholic church, having made his First Communion and he's on his way to making his Confirmation with his peers. He is also involved in our church youth group and attends religious education classes. He brings a smile to faces wherever he goes, and wouldn't it be great if we all had that natural ability?

Our dreams and wishes for Matthew are no different than for our older kids. We want them to be happy doing whatever that means for them, and they are each very different and very unique. He will never achieve academically to the level of his siblings, and that's ok. He is happy and achieving what he can achieve. It is so clear that none of our three children has turned out to be what we expected, and isn't that part of the fun (and sometimes angst) of being a parent? We love, we nurture, we watch them grow and give them wings to fly in their own direction. Matthew is going in his own direction, and we are enjoying the journey he is taking us on.

If I had to give my younger self some advice from my older self, I would tell myself to relax and enjoy your new baby. It's ok to accept help, and it also helps friends and family to be included. Share that baby with others, and let them fall in love too! I'd also get involved with other families who have a child with Down syndrome. Learn from them and ask questions. There was no CMDSS or New Parent Guide when we had Matthew, which is one of the reasons why we started the group and put this guide together. Shared knowledge only makes you stronger.

Congratulations on your new baby! I look forward to meeting you and watching your sweet baby grow up. Feel free to call me if I can help, answer questions, or support you and your family in any way.

Cmatthew Cweiss

Amelia White

by TAMAH WHITE | (601) 942-6563

Congratulations! If you are reading this, then you have probably just had a beautiful baby placed in your arms. What a miracle and gift from God! In Psalm 139:13-14, it says, "For you created my inmost being; you knit me together in my mother's womb, I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well."

And oh, how I know full well that His works are wonderful. Our sweet Amelia was born August 2011. We did not know that the road we have gone down existed, but how grateful and blessed we have been to be on this journey! There are countless numbers of people we have met because of Amelia, that have not just become friends, but who are now a part of our family.

Amelia adores her big sister, Abigail. She is her constant sidekick. They are each other's biggest fans. They can be found having dance parties and singing at the top of their lungs, painting nails, playing school, jumping on the trampoline, playing soccer, or cuddling up in a chair reading books.

Some of Amelia's favorite things to do are go to church, school, and attend ballet class. She loves playing with friends, riding in Pa Pa's golf cart, going to the park, playing and reading with her grandmothers, swimming, playing in the sand, and trips to Chick-fil-A. She is always the first to make a friend and the first to comfort you and give a hug.

Amelia has added so much joy to our family. Her sense of humor keeps us laughing, and her tenacity motivates us. She has taught us to love without borders, and to look beyond the surface of others. Her enthusiasm and energy for life spurs us on to want to live life to the fullest just as she does.

Just as Psalm 139:13-14 states, "His works are wonderful and we know that full well …" because of Amelia!!

amelia White

Caroline Michele Wilkerson

by SHAWN WILKERSON | (601) 750-5901

It was the spring of 2001 when Bob and I found out that not only were we expecting, but that I was carrying twins. It was an exciting, but frightening, time in our lives because I had trouble carrying the pregnancies of our older two sons to term. Doctors recommended we "reduce" this pregnancy by one to increase our chances of a successful pregnancy. That was not an option for us; after being told years earlier that we would be unable to conceive again, we knew that these children were gifts from God.

The pregnancy was not without complications, and I spent months on bed rest praying for healthy babies. My maternal-fetal specialist did two ultrasounds each week, and was reassuring that all looked fine. Then, on October 9th, our life's journey took an unexpected detour. Born just over six weeks early, the babies were examined and deemed to be premature, but otherwise perfect. Because of my age, while still in the delivery room, I asked for reassurance "Do either of them have Down syndrome?" My question met with a resounding "No, they look great!" The wall of self-protection that I had built around myself just in case the answer had been different came tumbling down. I was on top of the world!

It was the following day after I saw Caroline without the cap she had worn to keep her temp up, without the CPAP tube that had run across her face to help with breathing, and with her eyes open for the first time, that I saw what looked like traits of Down syndrome. Although I didn't show it, I honestly felt like I couldn't breathe when the nurse confirmed that they suspected the diagnosis. It was not that I did not want her or love her. In fact, the opposite was true – because of my love for Caroline, I could not bear the thought that she may struggle. Bob and I thought we were educated people, and even though he is a physician, neither of us felt equipped to help her. There wasn't a CMDSS at the time or a New Parent Guide that told how to help Caroline. This led to uncertainty,

which led to an abundance of fear. Bob and I are Christians and know that the Bible tells us to turn over our worries to God, but I'll be honest, I struggled with this. I was consumed with worry about the unknown struggles she could face. What I did know and what held me together in the early days is the fact that I know that God doesn't make mistakes and He intended for Caroline to have Down syndrome and that her life would have great purpose. The life scripture Bob and I chose for Caroline when we dedicated her life to God is Jeremiah 29:11 "'For I know the plans I have for you,' declares the Lord, 'Plans to prosper you and not to harm you, plans to give you hope and a future.'"

If you are reading this reflection of my life with Caroline and you are the parent of a newborn who is afraid of the future, I wish your life could be fast-forwarded for just a few months. I promise you will see that your child will be more like his or her peers than unlike them. Caroline is smart, beautiful, funny (the girl LOVES to tell knock-knock jokes), she enjoys ballet, cheer, snow skiing, tubing, reading, laughing, and most anything any other child enjoys. She DOES, however, abhor being outside in the sweltering heat, as most southern divas do! Caroline loves completely no matter the color of your skin, sexual orientation or religious affiliation, forgives easily, cares deeply about others, and will immediately stop whatever she is doing to pray for someone in need. She feels a closeness to God that is hard to explain. In fact, I am convinced that God wants all of us to be more like children with Down syndrome.

With Caroline's birth, God sent our life on a different path – not a bad path, just a different path. Yes, she has Down syndrome, but she is SO MUCH MORE than that. She has blessed our lives and made us appreciate everything about life more than we ever could have without her influence. Every day, I am so thankful to be her mother. You will see this with your own baby – you are in for untold blessings and a wonderful adventure.

caroline wilkerson

notes

Charlie Winstead, *My Designs*

Courtesy of Mustard Seed, Inc.

Your child is not your masterpiece... your child is not even truly yours... they are a precious loan, and each one has a unique path toward serving God. Your job is to help them find out what it is.

– ANONYMOUS

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If you'd like to be included on our mailing list so that you'll know about upcoming CMDSS educational and social events, please register online at www.cmdss.org or fill out the form below and mail to: CMDSS, P.O. Box 935, Jackson, MS 39205.

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Child's Name:_____ Birthdate: _____

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If in reading our New Parent Guide, you wish to make recommendations for additional information, make corrections, or simply wish to comment on the content of the guide, please contact:

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