

Down Syndrome Association of Wisconsin  
**Parent's First Call Magazine**



Providing resources and support for  
new and expectant parents.



**dsaw**  
**Down Syndrome**  
Association of Wisconsin, Inc.  
*awareness · acceptance · assistance*

# Acknowledgments

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*Everything we do is for you.*





# Congratulations

Your life will be more amazing than you may know!



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*exceeding expectations  
every day in every way*



**dsaw**  
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*awareness • acceptance • assistance*

The Down Syndrome Association of Wisconsin's mission is to provide support to Wisconsin families and individuals with Down syndrome and related disabilities through awareness, education, information, programs, services, and the exchange of ideas and experiences.

We promote the value of those with Down syndrome in our lives and our communities. We continually strive toward full acceptance, full access, full potential, and a full life to make Wisconsin the best supported state for people with Down syndrome and their loved ones.

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## THE DOWN SYNDROME ASSOCIATION OF WISCONSIN

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# Congratulations!

Dear New Parent,

First of all, congratulations on your new baby! As a parent of a child with Down syndrome, I want to assure you that your life with your new child will be more amazing than you may know. As the President/CEO of the Down Syndrome Association of Wisconsin (DSAW), I want you to know that we are so happy to be able to help you, and that we are here for you. Welcome to the Parent's First Call Program. No matter where you live, DSAW is here to help you and your family.

You probably have a lot of questions and are experiencing a lot of emotions. We did too. This magazine and the Parent's First Call Program are designed to help you and your family on your journey in raising a child with Down syndrome. The Parent's First Call Program on page 7 offers Expectant Parent Packs, New Parent Welcome Baskets, and the opportunity to connect with other parents who have been through similar experiences. Our gold-star resources and trained Support Parents can help make your journey a little easier!

This magazine is also full of excellent resources especially for new and expectant parents. We included resources you will need in your first days, such as:

- Page 6 - A definition of Down syndrome
- Page 9 - DSAW partners with local Down syndrome groups and other service providers that offer valuable resources for people with Down syndrome across the state.
- Page 12 - A summary of common health issues
- Page 15 - Help with breast-feeding

The amount of resources that will be thrown at you in the next weeks and months can be overwhelming - this magazine is designed to include all the basics until you're ready to read more.

Finally, other families who have loved ones with Down syndrome can be excellent sources of support. Throughout this magazine, we've included testimonies and encouraging stories from individuals who have loved ones with Down syndrome. Parents, siblings, adoptive parents, and individuals with Down syndrome have contributed stories about their experiences. Take a look to see how Down syndrome has changed the lives of others.

Right now, having a child with Down syndrome might seem overwhelming and a little bit scary. I hope you'll soon discover, as we did, that your child has a life of joy, hope, and opportunity ahead. DSAW is here to help you and your child exceed expectations, overcome obstacles, and achieve your wildest dreams.

Congratulations on your new baby, and welcome to Parent's First Call.

Warmly,



Dawn Nuoffer  
President/CEO  
Down Syndrome Association of Wisconsin



# What is Down Syndrome?

**Down syndrome** is the most commonly occurring genetic condition. Individuals with Down syndrome have an extra, critical portion of the 21st chromosome 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.

**It is estimated that one in every 758 live births will result in a baby with Down syndrome**, representing approximately 5,200 births per year in the United States. There are approximately 250,000 people with Down syndrome in the United States and a few

million people with Down syndrome worldwide. **In Wisconsin alone, there are an estimated 8,000 people with Down syndrome.**

There is a wide variation in abilities, physical development, and behavior of individuals with Down syndrome. Each individual has their own unique personality, capabilities, and talents. With appropriate education, therapy, social support and opportunities, **individuals with Down syndrome can exceed expectations and lead amazing, fulfilling, and productive lives.**

# Letters of Encouragement: Prenatal Diagnosis

Dear Parents,

At 21 weeks pregnant, I was waiting for my husband to pick me up and take me to an ultrasound. This was the big one, we would find out if we were having a prince or princess. I was so excited I could hardly sit still. To try and pass the time, I turned on the television and watched the noon news, where the Executive Director and a self-advocate from DSAW were promoting their upcoming Down Syndrome Awareness Walk. As I listened to them tell their story, I told myself that we should make a donation because they seemed to be helping so many people! Little did I know that soon, DSAW and these two people would become a huge part of my family's life!



The ultrasound started and we were told it was a girl! I was over the moon. But then the tech got quiet and the mood in the room changed. We repeatedly asked if everything was ok and were told that the doctor would be in to talk with us. The doctor came in and told us that they believed our daughter had Down syndrome based on the ultrasound markers. The next hours were a blur. I had an amniocentesis, talked to a genetic counselor, and we were sent home to await the results. Late the next day we received the call: she did indeed have Down syndrome.

January 29, 2009 was an amazing day. Madelyn Rose Stannis came into this world happy and without the health problems that some babies with Down syndrome have. Next thing we knew we were taking this little bundle home with all sorts of instructions, doctors to call and therapists to meet. We felt overwhelmed and anxious but knew with our families and DSAW by our side, we would be just fine.

Maddy is now a spunky, sassy, beautiful 7-year-old that attends a typical second grade class with her friends. She goes to gymnastics and swimming every week, plays with her 18-month-old brother and gives the best hugs that I have ever had. I look back at everything we worried about and what we thought was possible or impossible and cannot believe how my view has changed. She has surpassed so many "expectations" and brought an indescribable joy to our lives and those that she meets.



She has brought an indescribable joy to our lives and those that she meets.

DSAW has supported my family every day since I reached out to them. DSAW has been a tremendous resource for my family, from finding answers to some difficult questions, providing support to me and my husband, and fun social events for my kids! We were immediately welcomed into the DSAW family and felt comfortable right away -- we feel a special bond with these families that we do not have with others and it is remarkable! DSAW is truly changing the way the world sees our family members with Down syndrome and for that I am truly thankful. I know that I do not have to worry about Maddy -- she will go to college, will have a job and live an inspired, fulfilling life!

Sincerely,  
Marita Stannis

# Parent's First Call



## NEW AND EXPECTANT PARENTS

**Congratulations! We invite you to take part in the Parent's First Call Program.** We provide new and expectant parents with unbiased and up-to-date resources on Down syndrome in the form of an Expectant Parent Pack or New Parent Welcome Basket. We also offer the option to be matched with another parent who has been through similar experiences. To request a Welcome Basket/Expectant Parent Pack and/or to be matched with a Support Parent, fill out our Parent Contact Form online at [www.dsaw.org/parentform](http://www.dsaw.org/parentform), email us at [firstcall@dsaw.org](mailto:firstcall@dsaw.org), or call us toll-free at 1-866-327-3729.

# PRENATAL TESTS

There are many different types of prenatal tests for Down syndrome. In order to best understand what the results mean for you and your pregnancy, it is important to understand which type of test that you received:

- The “triple screen,” “quadruple screen,” “first trimester combined screen,” “integrated screen,” and “contingency screen” are all different types of prenatal screening tests that involve, to varying degrees, blood work and ultrasound findings. These screening tests provide you a risk assessment, not a diagnosis, and the results should be communicated as such. In other words, you should not be told that your child is “positive” or “negative” for Down syndrome. Instead, the results indicate the probability (or chance) that your child will have Down syndrome.
- Current Down syndrome prenatal screening results detect anywhere from 65 to 95 percent of fetuses with Down syndrome.
- A new noninvasive prenatal test (NIPT) involving cell-free DNA is now commercially available. This is a blood test that can be performed as early as 10 weeks gestation. These results are reported as a “positive” or “negative,” although it is important to understand that NIPT is not 100% accurate. This means that expectant mothers who receive a “positive” NIPT result have a significantly increased chance of having a child with Down syndrome; expectant mothers who receive a “negative” NIPT result have a significantly reduced chance of having a child with Down syndrome. In the event of a “positive” NIPT result, invasive diagnostic testing is often recommended by doctors.
- Determining with virtual certainty that your child has Down syndrome requires an invasive test, where a needle is inserted into the pregnant abdomen, or flexible catheter is inserted through the mother’s cervix. Usually administered after the 15th week of pregnancy, an “amniocentesis” analyzes an amniotic fluid sample, which contains fetal cells. The chromosomes of these cells can be tested to determine whether a fetus has Down syndrome. Administered usually 11 to 14 weeks into the pregnancy, “chorionic villus sampling” or “CVS” analyzes a small sample of placental cells. Both tests carry a small risk of miscarriage, and require a discussion with a healthcare provider to discuss the benefits, risks, and limitations of testing.

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## ADOPTION

We understand that not all new and expectant families feel they are able to meet the needs of children with Down syndrome. The National Down Syndrome Adoption Network provides information to birth families who may be seeking alternatives to parenting. The network currently has over 200 registered families, each waiting to adopt a baby with Down syndrome.

You may contact them directly at (513) 709-1751.

## HOSPITAL ASSISTANCE PROGRAMS

DSAW offer a variety of programs to assist with meals and other assistance during your hospital stay. At Children’s Wisconsin in Milwaukee, DSAW offers hospital meal assistance through meal vouchers to families that have a child with Down syndrome who are experiencing an extended hospital stay.

To learn more about hospital assistance programs near you, email [firstcall@dsaw.org](mailto:firstcall@dsaw.org).

# Where to Start: Wisconsin Resources

**Down Syndrome Clinics:** The Down Syndrome Clinics work to ensure individuals with Down syndrome receive best-in-class healthcare and referrals to local healthcare providers.

[www.chw.org/medical-care/down-syndrome-clinic](http://www.chw.org/medical-care/down-syndrome-clinic)

[www.waisman.wisc.edu/clinics/down-syndrome/](http://www.waisman.wisc.edu/clinics/down-syndrome/)

[www.gundersenhealth.org/services/pediatric-care/down-syndrome-clinic/](http://www.gundersenhealth.org/services/pediatric-care/down-syndrome-clinic/)

**Birth to Three:** Birth to Three is Wisconsin's early intervention program for infants and toddlers with developmental delays and disabilities. Through it, your child will receive (in most cases) in-home physical, occupational and speech therapy depending on his or her needs, often at little-to-no cost to your family. <https://www.dhs.wisconsin.gov/health-care-coverage/health-care-coverage/birth-3-program>

**Parent's First Call:** For new and expectant parents of babies with Down syndrome, DSAW offers up-to-date resources (Expectant Parent Packs and New Parent Welcome Baskets), and the opportunity to connect with other parents who have had similar experiences.

1-866-327-3729

<http://www.dsaw.org/pfc>

**Katie Beckett Program Supplemental Insurance:** Children born with DS often experience medical complications at birth, many of which today are corrected with routine procedures. In addition, children with DS will benefit from physical, occupational and speech therapy in their first months and years. The Katie Beckett Medicaid Supplemental Insurance program can cover costs that insurance plans sometimes will not.

<https://www.dhs.wisconsin.gov/kbp/index.htm>

**Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN):** Wisconsin has five Regional Centers dedicated to supporting families with children and youth with special health care needs and the providers who serve them. The Centers are staffed by specialists who can help get answers, find services, and connect you to community resources. Their services are free and private.

<https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>

**Children's Long-Term Support (CLTS) Waiver Program:** The Children's Long-Term Support (CLTS) Waiver Program is a Home and Community-Based Service (HCBS) Waiver that provides Medicaid funding for children who have substantial limitations in their daily activities and need support to remain in their home or community. Funding can be used to support a range of different services based on an assessment of the needs of the child and his or her family. <https://www.dhs.wisconsin.gov/clts/index.htm>

**Supplemental Security Income (SSI):** Supplemental Security Income (SSI) is a monthly cash benefit paid by the federal Social Security Administration (link is external) and state Department of Health Services to people in financial need who are 65 years old or older or people of any age who are blind or disabled and residents of Wisconsin. You can receive the state SSI payment only if you qualify for a federal SSI payment.

<https://www.dhs.wisconsin.gov/ssi/index.htm>

**DSAW Financial Assistance:** DSAW offers Enrichment Grants for DSAW families to help offset the cost of items or services that can benefit the quality of life and development of a person with Down syndrome. In addition, for families who are experiencing an extended hospital stay at Children's Wisconsin in Milwaukee, we offer meal vouchers for family members.

<https://www.dsaw.org/member-grants/>

<https://www.dsaw.org/hospital-meal-assistance-program/>

**Well Badger Resource Center:** Well Badger Resource Center provides a hotline to help families find health information and referrals in a number of areas, including WIC, BadgerCare, Medicaid, Prenatal Health, Adoption Resources, Family Planning, Birth to Three, Katie Beckett, and other resources for children with special needs.

<https://wellbadger.org>

# Letters of Encouragement: Postnatal Diagnosis

Dear New Parents,

First of all congratulations on the birth of your little one! I had a little girl, Sloane, in October 2015 and she spent 19 days in the NICU after birth. We had no idea she had Down syndrome until the neonatologist informed us of his suspicions about 20 minutes after she was born. Here are a few things that I would have loved to have heard from someone in those first days and weeks:

First thing's first... I would have liked someone to tell me to breathe. Although you may question this at times, everything is going to be OK. Just know that family and friends who say something insensitive are coming from a place of love for you and your new bundle. Try hard to always see the love (even when people call your baby "a Down syndrome baby"). Whether you like it or not, you will be a teacher of inclusion and people-first language the rest of your life!



Next up...I am so sorry. Not for your little baby, s/he is a blessing and is absolutely perfect, extra chromosome and all! Rather, I'm sorry that you might be feeling scared or sad when this should be the happiest time in your life. I personally look back on that time and regret that I spent so much of those first few days and weeks feeling sad or scared. I wish I had allowed myself to focus more on the joy of finally having my little girl. I wish I could go back and enjoy my baby and those moments (albeit some difficult ones) more and not worry so much about what the future meant. Because as a new mom now a year out, I realize that no mother knows what the future holds. Despite having many supernatural powers as a mother, a crystal ball predicting the future is not one of them.

Also, I wish I could tell myself to take advantage of some wonderful organizations such as DSAW as soon as possible. Try not to get overwhelmed with all the

information being thrown at you...there's a lot. Don't read too far ahead in the books and don't stress if you're not able to look at any of it for months. You are busy feeding and loving your baby, you will get there when the time is right.

**Congratulations,  
you hit the jackpot!**

If you have a spouse or significant other, know that they may react to all of this much differently than you do. Everyone is on their own journey with acceptance. And grief plays a major role too. You have to grieve the life you thought your little one would have because it might be different than you pictured. Or it might not be! No one can tell you what this precious little life will look like, but I'm willing to bet that most likely it will be a million times better than even you could have imagined!

Lastly, the single best thing someone told me after my daughter was born was "Congratulations, you hit the jackpot!" It was the mother of an older child with Down syndrome. And in the moment, that comment stood out to me. It was so completely opposite of what I had expected someone would say to me. Although I didn't quite understand what they meant then, I quickly learned the meaning behind those five words. I wanted to believe that she knew something that I didn't, and my heart really hoped that she was right.

My daughter recently turned one year old, and I know whole-heartedly that I hit the jackpot! She is my teacher, and I her student. In turn, I am learning how to teach my friends and family. And just as my little girl is growing strong and finding her voice, I am learning strength, and I am finding my voice. I am learning what the true meaning of my life is and the reason why I was given this ultimate gift, my jackpot.

Sincerely,

Dani Savick

# TALK ABOUT DOWN SYNDROME



**People with Down syndrome should always be referred to as people first.** Instead of “a Down syndrome child,” it should be “a child with Down syndrome.” Also avoid “Down’s child” and describing the condition as “Down’s,” as in, “He has Down’s.” Down syndrome is a condition or a syndrome, not a disease. People “have” Down syndrome, they do not “suffer from” it and are not “afflicted by” it. “Typically developing” or “typical” is preferred over “normal.” “Intellectual disability” or “cognitive disability” has replaced “mental retardation” as the appropriate

term. The Down Syndrome Association of Wisconsin strongly condemns the use of the word “retarded” in any derogatory context. Using this word is hurtful and suggests that people with disabilities are not competent.

DSAW uses the preferred spelling, Down syndrome, rather than Down’s syndrome. Down syndrome is named for the English physician John Langdon Down, who characterized the condition, but did not have it. An “apostrophe s” connotes ownership or possession. While Down syndrome is listed in many dictionaries with both popular spellings (with or without an apostrophe s), the preferred usage in the United States is Down syndrome. The AP Stylebook recommends using “Down syndrome,” as well.

# Health Issues

## to Address at the Hospital or Soon After Birth

Children with Down syndrome are often at increased risk for certain health problems. Congenital heart defects, increased susceptibility to infection, respiratory problems and obstructed digestive tracts occur with greater frequency among children with Down syndrome. Fortunately, advances in medicine have rendered most of these health problems treatable.

As with all children, you must take an active role in ensuring the best



health care for your child. Some steps that we recommend be taken soon after birth include:

- **Choose a pediatrician who has experience with children with Down syndrome or who is eager to learn.**

The Down Syndrome Association of Wisconsin does not endorse any health care provider. By contacting other parents, you can ask questions about how they selected a pediatrician for their child. You may also ask pediatricians for recommendations of colleagues with experience treating children with Down syndrome.

- **Obtain an echo cardiogram.** It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echo cardiogram in the first 2 or 3 months of life. Symptoms may present themselves as heart failure, difficult breathing, or failure to thrive. The symptoms may not be apparent at first. Most hospitals have the capability to perform an echo cardiogram. It is often most

convenient to take care of this before leaving the hospital.

- **Ensure that the diagnosis of Down syndrome is confirmed via chromosomal karyotyping.**
- **Have your pediatrician check for gastrointestinal blockage.** Some signs of gastrointestinal blockage include vomiting or absence of stools. Again, the symptoms may not present themselves for a period of time.
- **If your child has any feeding difficulties, consult a feeding specialist.**
- **Obtain a hearing test before leaving the hospital.** Some children with Down syndrome have a hearing loss. With new testing procedures this can be detected easily in newborns.

*Obtain a copy of the Down Syndrome Healthcare Guidelines which outline recommended screening tests for your child as they grow into adulthood. Copies are available on the DSAW website - [www.dsaw.org](http://www.dsaw.org).*

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*Please Note: This non-exclusive list is not meant to replace the care and advice of a qualified physician.*

Dear parents and adoptive parents,

Many people are surprised when they find out that Julia is adopted. She doesn't feel adopted to us. She is ours, 100%. She even looks like us. She may have come into this world differently, but since that time, nothing is different. We are glad that people do not know, because we don't need or really want them to know: to us she is our daughter. We share today because we want everyone to know that children with Down syndrome are special. Adopting a child with Down syndrome has been a blessing.

Every couple has their own driving force and life choices to become an adoptive parent, and we had ours: our faith in God. We struggled with having our own child and decided

that adoption was for us. This too ended up being a very challenging road, as many adoptive parents can attest to. When we set out on this journey, we thought we were in control and quickly found out that we were not. After we brought our first adoptive child home, and the mother changed her mind, we found ourselves on an even more difficult path. We struggled with our initial decision, only to be guided back to our original choice: adoption.

We were notified that we were chosen to be Julia's parents on May 5th. She became ours legally eight months later, but she was ours in our hearts the day we were chosen. Although different, she was and is absolutely beautiful!

We both vividly remember the day she was born. Everyone had that look....you know, the look they give you when something isn't quite right. Having a healthcare background, we both knew something was different about Julia. Everyone looked concerned and then shared the list of concerns with us. They shared the diagnosis of Down syndrome. We knew we were chosen for a reason. The agency gave us choices, but we knew Julia was ours. We knew during these discussions that this was absolutely where we should be. We can't say that we weren't scared; scared for her and for us. What health conditions would she have? Would we be able to handle it all? But somehow we just knew in our hearts that it all would be ok. We just had faith.

For anyone who is out there and considering adoption, please know that it is not without its challenges. There are different problems than having your own child, but the end result is still the same. It results in loving parents having loving children. It may result in struggles and tears, laughter and joy. You just never know. No one knows, no matter what path you choose.

**Adopting a child with Down syndrome has been a blessing.**

We would have to say that in the beginning we thought the chain of events occurred because God chose us for Julia, but as we have been blessed to be Julia's parents, we have realized that it was really the other way around....He chose her for us! She teaches us so many things every day. She is loving and kind, thoughtful and forgiving. She loves learning and making people smile. She is the example of compassion and grace -- the kind of person that we all should be. She is just so accepting of everyone! Julia is so strong. She can be sick with eyes and nose draining and still smile as big as the sun when she sees us!!! Julia is amazing! She changes lives every day. We witness it. We are blessed to be a part of her life.

We have never tried to hide the fact that our daughter has been diagnosed with Down syndrome. This has led several individuals to reach out to us when they or a loved one has been brought the possibility or actuality of Down syndrome. On this journey, we have been able to show people how absolutely awesome our children are! We have been able to demonstrate an important role they play in our life and in theirs, showing acceptance, kindness and love. We hope that we have helped them to know that their child has a great deal of potential and that this diagnosis does not define who they will be. Life just wouldn't be the same without Julia or any of our loved ones with Down syndrome!

With love,  
Julie and Jorge Aguilar



# Questions About Birth to Three



## What is Birth to Three, and what is its purpose?

Birth to Three is Wisconsin's Early Intervention program. The concept of "early intervention" is quite simple. If a child with a developmental delay receives proper help early on, problems in the future may be minimized. A child, his/her family, and the educational system will benefit by the reduced need for long-term intervention throughout the child's school years.

## What kinds of things will my child with Down syndrome do in Birth to Three?

Your child will participate in a variety of activities planned by licensed therapists, teachers, and nurses. The setting for these activities -- which are designed to provide physical, occupational, and speech therapies as needed -- may include regularly scheduled home visits, play group activities, individual therapy at home, day-care or hospitals, or other combinations that work for your family. Your child's record will be kept confidential.

## Will I have any say regarding my child's participation in any of these therapies?

Absolutely! After eligibility is determined (and most children with Down syndrome usually qualify), the Individualized Family Services Plan (IFSP) is written with help from the parent(s) and services begin.

## When should my child start Birth to Three Services?

Some families choose to enjoy their babies and adjust to life with a new little one before jumping in. Others choose to start therapy right away. Ideally, a baby would start therapies within the first 8 weeks of life if that works in your family schedule.

## Is there an age limit to receiving Birth to Three services?

The age limit is newborn to three years.

**Pediatric Physical Therapy (PT)** is the treatment of children with physical disabilities by a licensed professional physical therapist who is educated and trained in the diagnosis and treatment of children with physical disabilities. The goal of PT is to improve care and provide a treatment program to obtain or restore the highest level of independence and function in quality of movement, walking, strength and endurance, gross motors skills, posture, positioning for functional skills, coordination, and mobility for the child with the disability.

**Pediatric Occupational Therapy (OT)** is the treatment of children with physical, emotional, and/or intellectual disabilities from birth to 21 by a licensed occupational therapist educated in a variety of diagnoses and therapies for such children. The goal of OT is to help make learning possible by helping children develop the underlying skills that will lead to independence in personal, social, academic, and vocational activities. This includes remedia-

tion of difficulties the child may encounter with ADLs (Activities of Daily Living) such as dressing, grooming, feeding, etc.

**Pediatric Speech Therapy** addresses the child's complete communicative needs. This often begins with the development of non-verbal communicative skills such as attending to the speaker and the activity, taking turns, and making appropriate eye contact. It is designed to help with speech disorder, often referred to as articulation or phonological disorders - problems with the way sounds are made or how sounds are sequenced to form words; oral-motor problems resulting in difficulty producing speech sounds; and delays in feeding skills. A speech-language pathologist is a specialist in the normal development of human communication. The Certificate of Clinical Competency (CCC) assures you that a speech-language pathologist has been qualified to provide clinical services by the American Speech-Language Hearing Association (ASHA).

# Breast-feeding Your Baby

## BREAST-FEEDING BASICS

All babies benefit from breast-feeding or receiving breast milk. Breast-feeding can:

- Promote eye and brain development.
- Lower the risk of Sudden Infant Death Syndrome (SIDS).
- Improve mouth and tongue coordination, which will help speech skills.
- Create a special bond with your baby.

There are, however, special benefits for babies with Down syndrome:

- Babies with Down syndrome have a higher risk of infection. The mother's body makes antibodies, which she passes on to her baby during breast-feeding. Antibodies help protect your baby against infection.
- Breast milk is very easy to digest, and this is helpful for infants who may have stomach problems related to Down syndrome.
- Skin to skin contact during breast-feeding helps stimulate babies who have low muscle tone, or weak muscles.

## GETTING STARTED

When any baby learns to breast-feed, it takes time and patience. Getting off to the best start helps you and your baby succeed with breast-feeding.

- Start breast-feeding as soon after birth as possible.
- Have skin to skin contact with your baby as much as you can. Touch helps increase the breast-feeding hormones. A baby is also likely to begin rooting or nuzzling at the breast and may actually latch-on when having skin to skin contact.
- Feed your baby often, 8 to 12 times in 24 hours, including feedings during the night.
- Get comfortable before you start to feed.
- Position your baby so their body and chin are well supported. This is especially helpful for a baby with low muscle tone. The nurses will help you with this in the hospital.
- Know where to go for help and support after you leave the hospital.

## IS MY BABY GETTING ENOUGH MILK?

You can be sure your baby is getting enough milk if you watch for the following:

- Your baby should be breast-feeding 8 to 12 times in 24 hours.
- After a week, your baby should have 6 to 8 wet diapers and 3 bowel movements that are yellow, soft and seedy.
- Your baby with Down syndrome should gain at least 4 ounces per week.

## BREAST-FEEDING CHALLENGES

Babies with Down syndrome may face some special challenges that might affect breast-feeding. There are many things you can do to work through these challenges and have success.

### Low muscle tone

Your baby may have low muscle tone, or weak muscles, especially in their tongue and lips.

To help babies with low muscle tone during breast-feeding, do the following:

- Keep your baby's body and chin well supported.
- Support the base of your baby's head with your hand. Too much pressure on the back of your baby's head can cause a poor latch.

### Sleepiness

Your baby may be extra sleepy, which can affect feeding patterns. Babies who fall asleep may also not get enough milk, especially the end milk or "hind milk." End milk has extra fat and calories which help your baby to grow.

- Dim the lights in the room so your baby doesn't have to close his or her eyes against the light.
- Remove all of your baby's clothing except the diaper to help keep him or her alert.
- Wash your baby's face with a wet cloth
- Gently stroke and talk to your baby during the feed.
- Compress and massage your breast while breast-feeding. This will help the milk flow and keep your baby interested in breast-feeding.



### **Tongue Thrusting**

Babies with Down syndrome may have a protruding tongue that pushes against your nipple. To help these babies breast-feed, try the following:

- Wait for your baby to open wide (like a yawn) with his tongue forward and down.
- Gently press down on your baby's chin. Opening the jaw will help the tongue come forward.
- Teach your baby how to keep his or her tongue down. Put your index finger on the center of your baby's tongue. Push down and gently pull your finger out.
- Allow your baby to suck on your finger so he develops rhythmic sucking rather than biting.

### **WHAT IF MY BABY IS NOT BREAST-FEEDING?**

Some babies might not breast-feed while at the hospital. Your medical staff can help you create an individual feeding plan to make sure your baby gets all the nutrition he needs to grow and thrive. After you leave the hospital, you will meet often with your pediatrician who will help make changes to the feeding plan as needed. During this time, it is important to build and protect your milk supply. Building a milk supply usually happens if your baby is breast-feeding a lot. If your baby is not breast-feeding, the medical staff will help

teach you how to get a double electric breast pump and how to pump your breasts. In the end, some babies do not breast-feed. However, giving your baby your breast milk from a pump will still give your baby all the wonderful benefits.

### **SUPPORT**

Your nurse in the hospital will help you with breast-feeding. They will also arrange a visit with a lactation, or breast-feeding, consultant during your stay. The more help and support you have, the more successful you will be. It is important to check with your pediatrician to see if they have a staff member who can help with breast-feeding or make a referral to someone who can. Ask your nurse in the hospital for available resources. Zipmilk.org is a great website that can provide you with Lactation Consultants, La Leche League Groups and other support groups in your community.

*This document is intended to provide health related information so that you may be better informed. It is not a substitute for a doctor's medical advice and should not be relied upon for treatment for specific medical conditions.*

Dear Parents,

I am a recently retired career firefighter and had over 30 years putting on the gear and answering the call. I was 51 when my son was born. My wife Beth and I tried for over a year to get pregnant, and had lost the pregnancy on two previous attempts, so Beth was monitored closely when Henry came along.

We found out at our 5 month scan that Henry had Down syndrome. The doctor saw markers and we decided to have an amniocentesis performed, which confirmed the diagnosis. We were initially shocked and devastated. "How could this happen to us?" We knew little, like most people, about Down syndrome and worried about our child's quality of life. However, it did not take long to learn and realize that these children were special gifts from God and that we were truly blessed to have been chosen as parents for Henry.

The first DSAW event we attended was when Henry was a year old. It was the annual DSAW Zoo Walk at the Milwaukee County Zoo. We were astounded at the number of people in attendance along with all the booths set up by various support organizations. Everyone we encountered was friendly, supportive and most had children of their own, or knew someone who had a child with Down syndrome. It was then we learned that there were support groups sponsored by DSAW for parents including Mothers groups and a Dad's group.

Fraternal support has been very important for us. I attend the monthly Greater Milwaukee Dads Appreciating Down Syndrome (DADS) meetings on the first Thursday night of each month. We meet at the New Berlin Ale House. It is a place where fathers, uncles, adult siblings, and male caregivers can talk about concerns and questions they may have regarding their kiddos. It is always rewarding to see new attendees, the anxiousness on their faces and how it changes to relaxation and comfort as they come to realize they are not alone and that we all share many of the same experiences. To fathers in the Milwaukee area, consider attending a meeting and checking it out. You may find that it is something that really improves your attitude and helps in coping with many issues a father of a typical child does not have to cope with. To those in

other parts of the state, consider starting your own group! DSAW would be happy to make that happen.

I always believe that events in our lives happen for a reason. I also believe that when life gives you a gift or a challenge, that one must accept it and that we must proceed with our best efforts. I had never thought in my life that I would have another child at my age let



Henry has a special purpose in life and we would not change anything.

alone a child with Down syndrome. It has opened my eyes to the beauty in life, as well as to what is most important: tolerance, understanding, patience and most of all, the love of a child. Yes, it is a struggle every day and I sometimes stumble in my attempts to be the perfect father. But along with my wife, other families and support groups like DSAW and DADS Group, being the father of one of these precious and special children only proves to be a privilege and a joy. Henry has a special purpose in life and we would not change anything.

If you are a dad reading this I sincerely hope we see you at a DADS meeting soon! I believe you will find it a fun, enjoyable and informative organization where you will make new friends.

Sincerely,  
Kevin "Max" Wisniewski

# Baby Announcement

It can be hard to know how to announce the birth of your baby to friends and family. Take a look at our sample birth announcement to give you some ideas:

Hello everyone,

We are happy to report the birth of Evan Michael. He joined us yesterday at 2:36 pm. Mom is recovering well and is likely headed home tomorrow. Evan weighed in at 7 lbs 1 oz and was 19.5 inches long.

We'd also like to share some additional news we learned shortly after he was born - Evan has been diagnosed with Down syndrome.

The last day has been an emotional roller coaster but we are all doing well. After spending some time learning more about DS, we know that Evan will be a wonderful addition to our family and we are looking forward to watching him reach his own milestones just as his sister has done herself.

We realize that our announcement may prove a little awkward for some - some we've told in person have a hard time knowing what to say. "Congratulations" works just fine! The past 24 hours have made us realize how lucky we are to have the support of many caring family and friends and we look forward to sharing Evan with everyone.

If you'd like to learn more about Down syndrome, we encourage you to check out online resources, such as the Down Syndrome Association of Wisconsin or the National Down Syndrome Society. After reading about DS, we hope you'll know, as we do, that Evan can and will have an amazing life.

We promise to report back soon with pictures and an update!

# Letters of Encouragement: Prenatal Diagnosis Support Group

Dear Parents,

Our story began with finding out we were pregnant in the fall of 2020 in the middle of the pandemic. We were elated to be expecting and especially because this had not happened easily for us. Between my health issues, fertility treatments and the pandemic this was nothing short of amazing. At the beginning of our second trimester some testing results came back. We received a call on our second wedding anniversary that our baby was very likely to have trisomy 21. This news completely took us by surprise and it took us time to process. The new additional unknowns and concerns the medical professionals were presenting us were overwhelming



to say the least. My husband accepted our reality faster than I did. I grieved the child and life I had imagined and really struggled with all the unknowns.

Fast forward...It's been a year since our prenatal diagnosis and looking back I wish I could have told myself it truly would be alright. Honestly, so much better than alright...down-right incredible and amazing. Hands down our daughter, Kate, is the absolute best thing that has ever happened to us. What I found

hardest was I didn't yet know my child. At the time I regretted doing the testing because I thought having her in my arms would make the news easier to accept. Looking back, I am glad I had the time to allow myself the space to emotionally do a lot of the work ahead. Somehow the unknowns are easier for me to handle now that she is here. I can hold her, look into her eyes and each day learn more about her developing personality. This was my first pregnancy and although I had a ton of experience with babies and children I had yet to parent my own. Taking one step at a time is what we decided was our plan for the pregnancy. I'm a natural planner and so had to slow myself down and not think too far ahead because that is what troubled me most.

The truth is life for every baby has unknowns but somehow learning her diagnosis had me feeling like I

needed to have it all figured out and there is nothing realistic about that. I quickly dove into all the wonderful resources our genetic counselor shared with us and stumbled upon this prenatal support group that met virtually. I signed up and have not missed a meeting yet even after birth and our stay in the NICU.

**Kate is the absolute best thing that has ever happened to us**

I am overwhelmed with gratitude when thinking about what the prenatal Down syndrome support group means to me. I feel so incredibly lucky that I found this group of women shortly after our prenatal diagnosis. They have helped me navigate a wide range of difficult emotions by listening and openly sharing their experiences. As well meaning as our family and friend support circle is they naturally just can't offer what I get from these Moms. I feel blessed beyond measure to have a group of women who truly understand and whom I can learn from. These women validate my feelings and offer their own unique perspectives sometimes giving explanations to my own feelings I haven't yet found the way to verbalize. The space is safe and often everyone is at a different emotional place. It feels comforting to both be supported but also offer support now that my daughter is here and no longer the youngest. There is so much healing in that.

This connection has allowed me to be present in other relationships and in ways I am not sure I would have been if I hadn't stumbled upon this gem. The support, knowledge and resources shared have helped me build new parenting confidence and I have a small intimate community to take questions, concerns and emotions about now and the future. Having this lovely support group in my life has been one of the greatest blessings.

Sincerely,  
Nicole Kuehn

# Letters of Encouragement: Prenatal Diagnosis Support Group

Dear Parents,

When reflecting on my experience from the moment of sitting in the ultrasound room hastily googling the meaning of “max NF” to laying in an operating room holding a fierce but content newborn son, I experienced a rainbow of emotions with hues changing each moment depending on the situation. Somewhere in between the chaos of those first two months following our prenatal diagnosis, I stumbled upon the DSAW Prenatal Support Group. Enter Ambivalence. I recognized that I should connect with others but the idea of speaking with strangers was scary and a bit daunting. The one thing I had gained from ALL the posts and readings is that each individual with Down syndrome is unique and needs can vary person to person.



I knew I was going to need guidance navigating this journey which included accepting the path that was put before me. I admit that I didn't eagerly attend my first DSAW prenatal meeting. The idea of the group was intimidating but I also craved connection to those who understood my experience. Reflecting back, I think I needed someone to tell me that it was going to be okay. Relief. My first meeting I felt accepted and heard. It was helpful to have positive and negative emotions/thoughts validated. I was supported in my thoughts of being upset and frustrated. I was NOT alone, and I found individuals who could

understand all the uncertainty better than my friends, family, and spouse (he initially struggled with the diagnosis). Finally, Peace. I think I also had an underlying goal prior to joining the group, which was to find peace with the diagnosis. I have observed from the group that we all find this peace, but it comes in different forms and at different times.

Each day he brings us more joy than the day before.

Fast forward 18 months, my hues are mostly bright. I have found my rainbow representing the hope I have for my son's life. I also know that there are better times to come as each day he brings us more joy than the day before. The journey was numbing at the onset, but the feeling of love pours from my soul. I am so thankful that I have had the opportunity to learn from my fellow group members as well as to share my experience.

Sincerely,  
Erin Plumley



## Virtual Prenatal Diagnosis Support Group

DSAW hosts a completely non-judgmental support group for women who have recently received a prenatal Down syndrome diagnosis and wish to seek personal support. The group is for women in various stages of their pregnancy and decision-making journey. We welcome everyone, regardless of any decisions made, to attend our judgment-free group. Join us as we gather to provide support and share our experiences.

For more information go to:

[www.dsaw.org/prenataldiagnosisgroup](http://www.dsaw.org/prenataldiagnosisgroup)

Dear parents and siblings,  
When my brother George was born, I was four. Expecting a fun little brother, I got a little baby who couldn't yet do anything on his own. I learned to help my parents change diapers, feed him, and provide him with everything babies need. As he grew older, he crawled around the house and began to grow and learn. At the time I didn't understand Down syndrome, or that he would need extra help in things.

When we decided to teach George sign language, I found it unnecessary. I thought he would just learn to speak. Once the whole family could string together words, it became apparent that this was necessary after all. He knew what we were saying, and now he could answer us. My most prominent memory of my family using sign language was when George was about two and he still couldn't speak, I had turned off his favorite show, Teletubbies, and changed it to another show. He immediately started signing at me to stop, and that I was being mean. Then he proceeded to crawl into our kitchen and tell my parents that I hurt him and that he needed help. It was funny seeing him yell at me with his hands.

Our family used our hands to communicate until George was about five -- we used hands and words to help him understand. Some days we would go the entire day without saying a word, and other times the entire day

just talking. I think growing his vocabulary before he could speak helped him a lot learning other things. When I helped teach him to read, he knew the words and he was able to sound them out nine times out of ten. He learned at the pace of someone his age, and was able to speak pretty clearly.



Growing up with a brother with special needs, I needed to learn with him in order to help him. We would teach each other new things every day, and when we were able to communicate, it was like nothing could stop our sibling powers. I helped him talk, walk, read, and anything he needed, I was there. His special needs never stopped him. Everything that was supposed to stop him, only made him stronger.

Sincerely,  
Sophia Westcott



# Testimonial

## My name is Andrew Gerbitz

I have an amazing life. It seems that I was born at exactly the right time. I had the advantages of early intervention, inclusion, and transitioning.

I am told that soon after I was born in 1983, my parents took me to a center for early intervention. Therapists worked to give me a good start. They told my mom how to hold and position me so that my low muscle tone would improve. During the first three years of my life (called Birth to Three) physical, occupational, and speech therapists worked with me.



In 1988 when I started kindergarten, I was in a classroom with kids who had no disabilities. That was really important. It is called inclusion. That is how my education continued, almost always alongside students without disabilities.

Around the year 2000 when I was in high school, lots of attention was focused on what happens after high school, like jobs. That is called transitioning. It is important to know what you are going to do when your public school education ends.

It is also important to set high expectations. Before I had a paying job, I volunteered at Old World Wisconsin (an outdoor historic museum not far from my parents' home). Eventually I was hired there. I cleaned the

restaurant. I was good at it, well-liked by my employers, and paid fairly well. However, it was not my dream job. My parents and I were looking for meaningful work within my community.

Next I volunteered at an early intervention center and later had a paying job there. I also started baby-sitting for my young nieces and nephews. In 2002, I decided on a career in child care. There were plenty of people who said I would never get hired, but I did not pay a whole lot of attention to them. I had high employment expectations and worked to make my dreams come true. My sister-in-law and my mom taught me, one step at a time, how to care for my nieces and nephews.

The next step to fulfill my employment dreams was to get certified for child care. I enrolled in my local high school where I could get classes in child care. I was able to do that because people with disabilities can continue their public school education until they reach their twenty-first birthday. I was able to spend three semesters at Mukwonago High School. I swam on the swim team, and I took one of my nieces to the prom. (Not one that I baby-sat for. You see, I have one niece who is the same age as me.) I finally completed my certification through the Early Education Station by correspondence.



My first job was not a good fit for me, so I gave two weeks' notice and then I quit. That was very discouraging, but I did not give up my employment dreams. I continued to work at another center and

# “I live an amazing life”

remained there until it closed. By that time I was working at my present job.

I have worked at the YMCA at Pabst Farms in Oconomowoc in the child care center for the past ten years. I work with four- and five-year-old certification. I am CPR trained. I take classes in first aid, shaken baby syndrome, and other child care related issues.

About six years ago I moved out of my parents’ home and into my own apartment about two miles from where I work. That was one of the most exciting days of my life! I always wanted to live on my own. Sometimes I ride my bike to work and to shops and my bank. Sometimes my caregivers drive me where I want to go. I would like to be able to drive myself, so I took an online driver’s education course and got my temporary license. I am eager to do some real driving!

The Y where I work gives free membership to staff, so I get to swim and work out there every day. I have lots of friends who work there. It is a safe place for us to hang out together. We all love our jobs! The Y sponsors the Special Olympics sports that I participate in. I am especially proud of my two gold medals for swimming the 400m freestyle. I hope to go to Special Olympics National someday.

I am good at it. With lots of help from my support team at Down Syndrome Association of Wisconsin - Family Services, I have started Andrew’s Voice, a motivational speaking business. Please take a look at my website – [www.AndrewsVoice.com](http://www.AndrewsVoice.com). Starting a business is not easy, but I am eager to help others who have disabilities.



Living my amazing life requires lots of scheduling. This is very difficult for me. For many years my mom helped me with my schedule, but she knew this was something I needed to learn to do without her. DSAW-Family Services developed a scheduling tool which I can use with my smart phone. I still receive scheduling help for about one hour a week. That is OK.

Living my amazing life requires other help, too. I write checks to pay my bills, but balancing my checking account is very hard. My friends at my bank keep my account balanced. DSAW – Family Services works with IRIS to make sure my caregivers are paid. My brothers and sisters help me with things like taxes and the forms I need for housing and insurance. My nieces and nephews help, too. Hannah designed my business website and works on marketing. Cora keeps track of my passwords. Aaron maintains my bike. Others take me out to dinner or to sports events. Still others make sure I am being responsible with social media.

I have many people to thank for making my amazing life possible. Thank you for giving me the opportunity to tell you my amazing story.

Warmly,  
Andrew Gerbitz



I have been recognized as a good spokesperson or advocate for others who have disabilities. I have been invited to speak at conferences, fund-raisers, and schools. I like to share my experiences, and I am often told that

# DSAW Services Across the Lifespan

## Parent's First Call for New and Expectant Parents

### Welcome Baskets and Expectant Parent Packs

DSAW provides baskets to new and expectant parents filled with books, community resources, and fun goodies for our new families.

### Support Parents & Support Groups

DSAW matches new and expectant parents with Support Parents - other parents of children with Down syndrome who have walked in their shoes, and can provide friendship and support. DSAW also offers Support Groups, including our Prenatal Diagnosis Support Group.

### Resource Libraries

In addition to the resources listed in this magazine, DSAW offers full resource libraries online for new and expectant parents.

## Children's Services

DSAW provides one-on-one services, programs, and classes for children ages 0-17 with Down syndrome and related disabilities.

### Free Programs

DSAW has a large menu of free programs for children with disabilities. We offer Music Therapy, Tiny Tots, Stream Team, and more!



### DSAW Connects

Children ages 10+ who are able to use Zoom technology independently are also invited to participate in our DSAW Connects classes! We have virtual classes focused on topics ranging from social skills to cooking to sports. Visit [www.dsaw.org](http://www.dsaw.org) to learn more and register for DSAW Connects programs.

### One-on-One Services

DSAW staff also provide one-on-one daily living skills training at home and/or in the community. We work with your family to accomplish your child's goals and help them to achieve their dreams! We can work with children on skills such as learning to count money, easy meal prep/kitchen skills, safety, social skills, self-care, potty training, and more!

### Family Events

*DSAW's chapters and locations around the state host fun family events throughout the year, such as picnics, holiday parties, and our Down Syndrome Awareness Walks.*



*DSAW also offers Adult Services, Employment Services, and Aging Services. Visit [www.dsaw.org](http://www.dsaw.org) to learn more about these other service areas!*

# Educational Services

## Webinars

DSAW hosts statewide webinars on a variety of topics! Webinars allow you to access the latest information without ever leaving your home. We also keep recordings of previous webinars for you to access anytime.



## Seminars and Conferences

DSAW regularly hosts world-renowned speakers to educate parents, medical professionals, and community members on the latest information about Down syndrome. Topics include potty training and behavior, delivering a diagnosis, puberty, IEPs, and more.

## Workplace & Peer Sensitivity Trainings

Are you a teacher who wants to educate your class on Down syndrome and other special needs? Are you a parent who wishes your child felt more included amongst their peers?



Would your school district like in-service training for your teachers about how to teach individuals with Down syndrome? Are you a manager who wants your employees to have the skills and knowledge to treat people with Down syndrome with dignity and respect, or would you like to create a positive, supportive work environment for your typically-abled employees and employees with special needs alike? DSAW is here to help! We offer customized presentations to schools, workplaces, and other institutions to provide education and resources about Down syndrome.

## Medical Training

Recent advancements in prenatal testing have resulted in skyrocketing termination rates for fetuses with Down syndrome as balanced and unbiased information struggles to keep pace. DSAW conducts continuous statewide medical trainings and webinars, provides gold star resources and state-specific resources for medical professionals and the public, and engages in statewide marketing campaigns to educate the public on the importance of individuals with Down syndrome.

## Advocacy Services

DSAW works hard to make sure that the voices of individuals with Down syndrome and all disabilities are heard throughout Wisconsin. DSAW is a member of several statewide Down syndrome and disability advocacy groups and regularly works to mobilize DSAW members to support changes in our state that will support individuals with Down syndrome and other special needs.



*Learn more about our programs, services,  
and events online at [www.dsaw.org](http://www.dsaw.org)*

# DSAW Events

## Family Events

DSAW chapters across the state host regular family events to encourage the fraternal support that DSAW was founded on. Events include World Down Syndrome Day celebrations (March 21st each year!), sports games, family picnics, pool parties, fall festivals, holiday parties, and more. DSAW chapters also host events specifically for parents and siblings, such as Parent's Nights Out and Sibling Workshops.



## Down Syndrome Awareness Walks

DSAW hosts eight Down Syndrome Awareness Walks each year. These annual walks draw more than 8,000 walkers, volunteers, donors, sponsors, and partners across the State under one collective mission – to raise awareness and promote inclusion, diversity and acceptance of people with Down syndrome in our communities and in our lives. DSAW walks take place in August-October - visit our website to find the closest event to you!

## Golf Outings

DSAW hosts Golf Outings in the Milwaukee and Madison areas each year. These events draw people from around the state to support our mission and participate in a fun day of golf. Visit our website for more details.

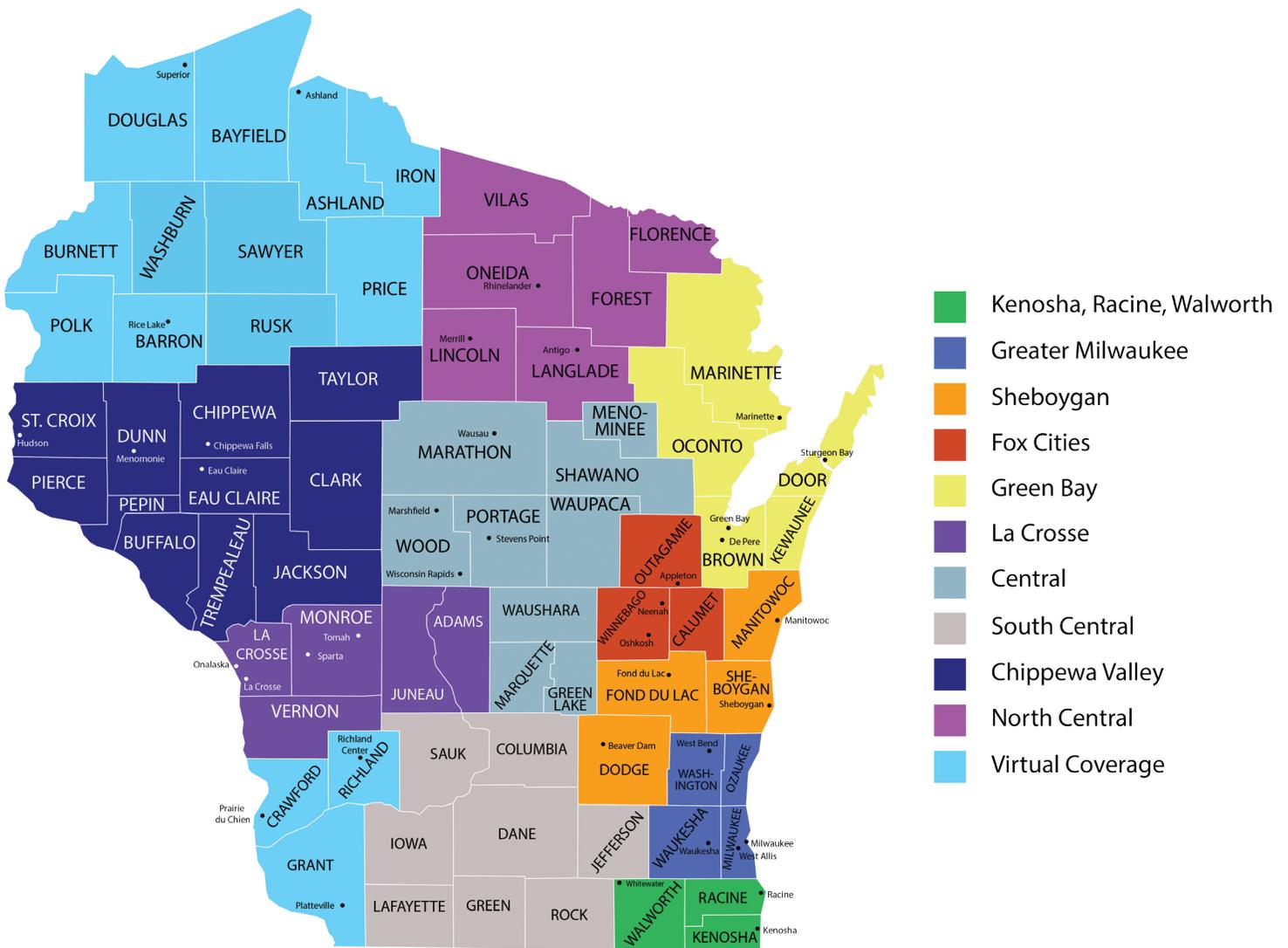


# DSAW Locations

No matter where you live, DSAW is here to help you and your loved one! We offer a variety of in-person and virtual programs, services, and events to serve all of our families.

The majority of DSAW's in-person programs, services, and events, happen near our DSAW Chapters, which are based in Milwaukee, Sheboygan, Green Bay, Appleton, Wausau, La Crosse, Madison, and Eau Claire. Chapters support these cities as well as families in the surrounding counties.

Visit [www.dsaw.org](http://www.dsaw.org) to find a chapter and local events near you!



*Learn more about our programs, services, and events online at [www.dsaw.org](http://www.dsaw.org).*

# Recommended Books



**Down Syndrome Parenting 101**

By Natalie Hale

**Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives**

Edited by Kathryn Lynard Soper

**Common Threads: Celebrating Life with Down Syndrome,**

By Cynthia Kidder and Brian Skotko

**The Parent's Guide to Down Syndrome: Advice, Information, Inspiration,  
and Support for Raising Your Child from Diagnosis through Adulthood**

By Jennifer Jacob and Mardra Sikora

**What I Want You To Know: Messages of Hope and Joy from your Baby**

By RA Hudson

**Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome**

By Nancy McCrea Iannone and Stephanie Hall Meredith

*Request a DSAW Expectant Parent Pack or New Parent Welcome Basket to  
receive many of these titles. [www.dsaw.org/pfc](http://www.dsaw.org/pfc)*

# National Down Syndrome Resources



## National Down Syndrome Society

The National Down Syndrome Society (NDSS) is the leading human rights organization for all individuals with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. [www.ndss.org](http://www.ndss.org)



## National Down Syndrome Congress

The mission of the National Down Syndrome Congress (NDSC) is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome. The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome. [www.ndscenter.org](http://www.ndscenter.org)



## Global Down Syndrome Foundation

The goal of the Global Down Syndrome Foundation is to significantly improve the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy. Global works to educate governments, educational organizations and society in order to affect legislative and social changes so that every person with Down syndrome has an equitable chance at a satisfying life. [www.globaldownsyndrome.org](http://www.globaldownsyndrome.org)



## Down Syndrome Diagnosis Network

The mission of the Down Syndrome Diagnosis Network is to connect, support, and provide accurate information for families with a Down syndrome diagnosis. [www.globaldownsyndrome.org](http://www.globaldownsyndrome.org)

# Wisconsin Down Syndrome Resources



## Down Syndrome Association of Wisconsin

The mission of the Down Syndrome Association of Wisconsin (DSAW) is to support Wisconsin families and individuals with Down syndrome through awareness, education, information, programs, services, and the exchange of ideas and experiences. [www.dsaw.org](http://www.dsaw.org)



## GiGi's Playhouse

GiGi's Playhouse Down Syndrome Achievement Center's mission is to change the way the world views Down syndrome through national campaigns, educational programs, and by empowering individuals with Down syndrome, their families and the community. [www.gigisplayhouse.org](http://www.gigisplayhouse.org)

Down Syndrome Achievement Centers  
educate. inspire. believe.



**dsaw**

**Down Syndrome**  
Association of Wisconsin, Inc.  
*awareness • acceptance • assistance*



***exceeding expectations  
every day in every way.***



**Down Syndrome Association of Wisconsin**

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