

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

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info@dsaw.org.

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Lastly, thank you to our friends with Down syndrome and their families. 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***



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Down Syndrome
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The Down Syndrome Association of Wisconsin (DSAW) is a non-profit organization with the mission to provide support to Wisconsin families and individuals with Down syndrome 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. No matter where you live, DSAW is here to help you and your family.

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Parent's First Call Program Partners

Wisconsin's Parent's First Call Program brings together local and statewide Down syndrome organizations to ensure that all new and expectant parents receive accurate, unbiased, up-to-date information. If you live near one of these local organizations, please review the magazine insert and/or brochures for information on additional local support.



Down Syndrome Association of Wisconsin

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

www.dsaw.org



Madison Area Down Syndrome Society

The mission of the Madison Area Down Syndrome Society, Inc. is to provide support to individuals with Down syndrome and their families while advancing acceptance, inclusion and opportunity for individuals with Down syndrome in South Central Wisconsin.

www.madss.org



Parent to Parent of Wisconsin

At the heart of Parent to Parent Support is the opportunity for parents raising children with special needs to connect with another parent who has already learned the language and found the resources...someone who has "been there."

www.p2pwi.org



Wisconsin Down Syndrome Advocacy Coalition

The Wisconsin Down Syndrome Advocacy Coalition is a group of Down syndrome organizations in Wisconsin with the mission of advocating on behalf of individuals with Down syndrome in Wisconsin.



Wisconsin Upside Down

Wisconsin Upside Down is dedicated to enhancing the lives of individuals with Down syndrome. The mission of Wisconsin Upside Down is to offer Down syndrome Advocacy, Education, Awareness and Support to families of individuals with Down syndrome and the community.

www.wiusd.org

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 may know. As the Executive Director 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 and our partners are 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 (pg 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 a definition of Down syndrome (pg 6), a summary of common health issues (pg 12), and help with breastfeeding (pg 15), among others. DSAW also partners with local Down syndrome groups and other service providers that offer valuable resources for people with Down syndrome across the state (pg 9 & 32). 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, grandparents, 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 and our partners are 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,

A handwritten signature in black ink that reads "Dawn Nuoffer". The signature is written in a cursive, flowing style.

Dawn Nuoffer
Executive Director
Down Syndrome Association of Wisconsin

A young child with Down syndrome, wearing a blue shirt, is eating an ice cream cone. The child is looking directly at the camera. In the background, there are people and tables, suggesting an outdoor event or fair.

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.**



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, email us at 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.

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) 213-9615.

HOSPITAL ASSISTANCE PROGRAMS

DSAW and the Parent’s First Call program partners offer a variety of programs to assist with meals and other assistance during your hospital stay. At Children’s Hospital of 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.

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

www.waisman.wisc.edu/clinics/down-syndrome/

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, we offer 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/long-term-care-support/services-children/katie-beckett>

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>

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 Member Grants for DSAW Members 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 Hospital of Wisconsin in Milwaukee, we offer meal vouchers for family members.

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

More Resources

DSAW has a large collection of international, national, and Wisconsin-specific resources on a variety of topics related to Down syndrome. To learn more, visit our website.

<https://www.dsaw.org/subject-resources/>
<https://www.dsaw.org/resources-by-county/>

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 pos-

sible. 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.

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.

Congratulations, you hit the jackpot!

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 echocardiogram.** It is important that all children born with Down syndrome, even those who have no symptoms of heart disease, have an echocardiogram 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 echocardiogram. 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 feedings 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 she grows into adulthood. Copies are available on the DSAW website - www.dsaw.org.

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

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 anx-



ious 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

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, daycare 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 motor 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

*Created by Marianne Pastore, RN
MassGeneral Hospital for Children*

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. She 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 (especially fellow dads),

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 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.

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 2:36pm. 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 rollercoaster 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!!



Welcome to Holland

By Emily Perl 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 your wonderful plans. The Coliseum. The Michelangelo 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.

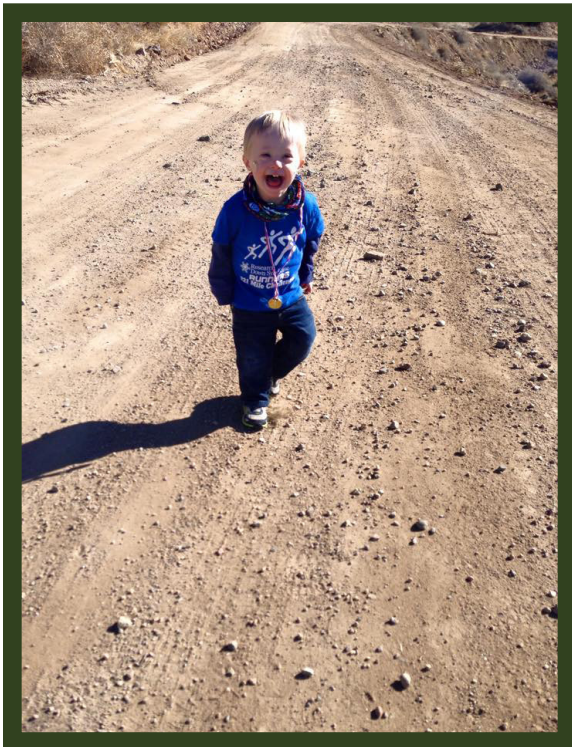
The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

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 never have 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."...

...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.



Dear parents and grandparents,

My 4-year-old grandson, James, calls me Pop Pop, the same name that I called my grandfather, also a James. Three generations spread over so many years, yet so much in common – all 3 with the same first name, young James and I are the first grandchildren in our families, older James and I have the same grandfather name. Yet one difference is that young James has one extra chromosome, a characteristic of those with Down syndrome. It is that difference that has brought our loving family closer together than ever and has expanded our network of friends.

We were thrilled when Dan, our son-in-law, called to announce the birth of James, our first grandchild. When Siobhan, our daughter, called a week later to tell us that James had been diagnosed with Down

syndrome, it took my breath away. That kind of thing always happened to someone else, not us. We recovered very quickly when we saw how well Siobhan and Dan had accepted the challenges ahead of them, and we realized that God had chosen the best parents possible for our grandson. They are living in Colorado so we made a quick visit out there about 2 weeks later.

Since that call, we've learned a lot very quickly. A friend put me in touch with a relative who had started a foundation for Ds research. Siobhan and Dan also followed up and were soon off and running – literally (more on that another time). They also connected with the Rocky Mountain Ds Association, and because I wanted to contribute to the cause, I connected with DSAW.

We've learned that one of the most important roles that grandparents can play is to provide support for the parents of your grandchild. Life is very challenging for them with doctor visits, therapies, school IEPs, DS Association activities, and care for other siblings. More than financial support, they need your moral support, your time to help out, your listening and encouragement, and often just some time for themselves.

James is doing very well. Many of his medical issues have been corrected, and his day care facility has been awesome in its support of inclusion. James adores his little 18-month-old brother named Robert, who in turn looks up to James as his hero. Someday those roles may reverse, but for right now Robert wants to be like James.

We grandparents also have our challenges, questions, uncertainties about the future. At DSAW we are starting up Grandparents Support Groups to address those issues. Please join us. We'd love to hear your stories about your grandchildren.

Sincerely,
James Fackelman

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

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 health-care 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.

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

Dear Parents,

In the beginning, as we were trying to wrap our head around what having a child with Down Syndrome meant to our family, I started to scour the internet in search of resources and “people like us.” That’s when I found DSAW. It wasn’t until we attended our first Down Syndrome awareness walk in Burlington that we realized the strength of the community we just became part of! I remember being so awestruck by how many people--strangers!--came up to talk with us, snuggle Aubrey, and share their story and tips about how to gain access to resources.

For example, one member shared how to contact DSAW to receive meal tickets while Aubrey was at Children’s for heart surgery. We emailed DSAW and they provided meal tickets for our entire stay. We felt taken care of while she recovered. All of this positive connection was exactly what we needed. I then started signing up for more opportunities: a mom’s group, a playdate, the Zoo Walk. With every opportunity came a new connection, a new resource to check out, a new number exchanged. Each experience continues to push us just a little out of our comfort zone...but in the best way possible every time!

We were determined to share the good in our lives because of Aubrey.

In a phrase, Down syndrome has impacted our life for the better! Aubrey has opened the door to connections and conversations that may have never happened without her in our lives. When we received our prenatal diagnosis, both Steve and I, as teachers, reflected on all of the families that we’ve worked with who have approached “different” with the kind of grit and grace that we wanted to. We were determined to share the good in our lives because of Aubrey. She has given us courage we never knew we had--to change perceptions, to overcome obstacles, and to love bigger than we knew we could. Having Down Syndrome in our lives



has helped us recognize more of the beautiful “different” in others. It has changed the way we think about others--about strangers, about our students, and how we want to raise our four-year-old, too. It has given us the chance to slow down and appreciate the small celebrations that we may have never noticed before.

It’s hard to believe, but in five years, Aubrey will be entering kindergarten. Our hope is that her teachers see her strengths and use them to build her up. Our hope is for Aubrey to be meaningfully included, for her thoughts to be valued and her contributions recognized. We hope for friendships--sweet kindergarten friendships, honest and true.

To realize this vision, though, we can’t walk this journey alone. Our hope is that we, along with all of the wonderful people involved with DSAW, continue to build awareness, fight for access to the best resources to build Aubrey’s foundation, and continue to blow the ceiling off of possibilities for our daughter and others with Down Syndrome!!

Warmly,
The Pratt Family

Dear Parents,

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 babysitting 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 babysat 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 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 children in my community. I love my job! I must earn the required number of credits to keep my 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 have been recognized as a good spokesperson or advocate for others who have disabilities. I have been invited to speak at conferences, fundraisers, and schools. I like to share my experiences, and I am often told that 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. 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.

I have an amazing life.

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

Down Syndrome Association of Wisconsin

Statewide Fraternal Support & Programming

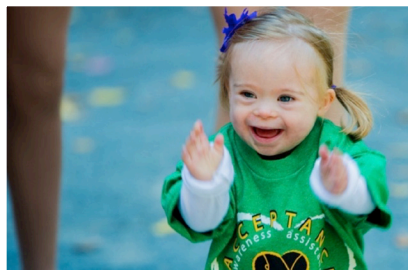


No matter where you live, DSAW is here to help across your loved one's lifespan! We offer you statewide support on four levels, depending on your community: Individual, Parent Groups, Regional Committees, and Chapters. DSAW currently has chapters in Milwaukee, Kenosha/Racine/Walworth, the Fox Cities, Green Bay, La Crosse, Chippewa Valley, Sheboygan, and Central Wisconsin. Additionally, DSAW provides executive, administrative support for the Madison Area Down Syndrome Society. Our Parent Support Groups and Regional Committees extend outwards from these chapters and locations. Visit www.dsaw.org/chapters to find support near you.



Statewide DSAW Program Models

DSAW pilots replicable program models at our State Headquarters in West Allis, and then replicates successful programs to locations around Wisconsin. DSAW Program Models include Transition and Activities of Daily Living; OT, PT, Speech, Behavior, and Music Therapy Programs; Safety, Relationships, and Dating; Family Resource Day/Night; Wellness; Siblings; Computer, Reading, and Math Literacy; and more.



Statewide Parent's First Call

Parent's First Call offers information about Down syndrome for new and expectant parents; the opportunity to talk with other parents about emotions and questions; parent groups; assistance navigating medical and early intervention services; referrals to local and national resources, and much more. We offer a hotline and email address for new and expectant parents to receive immediate information, and we send prenatal parent packs and welcome baskets, too!



Statewide 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.

Programs and Services

Statewide DSAW-Family Services



DSAW-FS provides private, public, and IRIS (Include Respect I Self-Direct) supported services to adults and young adults with Down syndrome, other disabilities and their families to achieve a full and independent life in the community. DSAW-FS focuses on individualized, customized solutions to help any person in the state of Wisconsin overcome obstacles and achieve their dreams. Services include: personalized goal development; identification of benefits, housing, employment, transportation and caregiving assistance to achieve our client's goals; crisis and back-up support; budget coordination and implementation of the final support plan; as well as social connections and support circles. DSAW-FS also specializes in one-on-one Roadmap Sessions.

Statewide Education



DSAW offers statewide educational resources to help families, medical professionals, workplaces, students, and the general public learn more about topics related to Down syndrome. Our educational programs include Workplace / Peer Sensitivity Training; seminars, conferences, and teacher in-services; statewide webinars on various topics; and the DSAW Speakers Series.

Statewide Awareness



DSAW works to raise awareness and promote inclusion, diversity and acceptance of people with Down syndrome in our communities and in our lives. We do this through seven annual Down Syndrome Awareness Walks around the state, our resource directory, Parent's First Call Program, and mass communications strategies to raise awareness of Down syndrome in Wisconsin.

Statewide 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.

Our Fraternal Support Model

No matter where you live, DSAW is here to help you and your loved one!

We offer various levels of support depending on your location throughout the state:

Individual



DSAW has resources for YOU, even if you are not near a Parent Group, Regional Committee, or Chapter. We can support you through:

- DSAW-Family Services
- Roadmap Sessions
- Referrals & Resources
- Webinars
- Conferences & Seminars
- Workplace / Peer Sensitivity Training
- In-Services
- Parent's First Call
- Membership
- Statewide Advocacy
- Statewide Awareness
- Medical Training
- Other virtual support

Parent Groups



Parent Groups can form in any town or location in Wisconsin - you just need a group of parents who want to meet regularly. DSAW will help you market

the event and make it visible to parents in your area (email firstcall@dsaw.org for information on starting a Parent Group in your area!). Parent Groups include the support of the individual level, PLUS:

- Coffee Clubs
- Parents Nights Out
- Parent Groups (Moms, Dads, Grandparents, Multicultural, etc.)
- Play dates
- Other virtual support

Regional Committees



Regional Committees are strategically located around multiple Parent Groups. In addition to the benefits received by individuals and Parent Groups, Regional

Committees have leaders that help plan larger events in your area, such as:

- Picnics
- Holiday Parties
- World Down Syndrome Day Event
- Small Fundraisers
- Dances
- Teen Club/Young Leaders.

DSAW Chapters



DSAW Chapters are strategically placed in major metropolitan areas that can sustain large-scale programs and services. In addition to the benefits of

individuals, Parent Groups, and Regional Committees, DSAW Chapters have access to:

- Member Grants
- iCan Bike Camp
- Awareness Walks
- Chapter-specific staffing
- More advanced programming
- More advanced events and seminars

No Parent Groups, Regional Committees, or Chapters near you? Start your own Parent Group! Email firstcall@dsaw.org to learn more.

Find support near you at www.dsaw.org/chapters

Dear Parents,

Our journey with Down syndrome started on January 23, 2005 when our beautiful baby girl “Daeja” was born. The surgeon who delivered her by c-section at 35 weeks told us that he saw some Down syndrome characteristics and that he would be calling in a geneticist to do a chromosome test on Daeja.

Her dad and I waited patiently for the results. Since we knew very little about Down syndrome, we became nervous not knowing what the road ahead would be like for our daughter. Two days later we were informed that our Daeja did indeed have Down syndrome. Because we received the diagnosis postnatally, we didn’t have time to mentally or physically prepare ourselves, but we knew she was our special baby and she deserved to be happy no matter what!



We became very eager to learn about life with Down syndrome and the tools we needed to make sure our “Daeja” would live a happy, healthy and successful life in spite of her extra chromosome. Of course we were told all of the things our daughter wouldn’t do compared to typically-abled children, and how hard it would be for her to do this and that. But in my mind, I had already claimed VICTORY over everything she would face in this life. Daeja has Down syndrome, but Down syndrome is not who she is! Yes, we have had some challenging obstacles (which is to be expected) but there has not been one obstacle that we have not overcome.

**I had already claimed
VICTORY
over everything she would face**



Daeja attended Penfield Children’s Center at 3 months old, graduated from Birth to 3, and started school. She remained in Penfield’s childcare until age 7. Daeja received Occupational Therapy, Physical Therapy, and Speech Therapy while she was there, which was very important for her growth and success.

In 2014 Daeja had open heart surgery at Children’s Hospital to close two holes and repair one valve. Surgery was successful and recovery was amazing. Daeja has no restrictions and is very active.

Although very shy, Daeja is a member of Girl Scouts, has a job in the food court of her school, and also has a daily responsibility to help another child with special needs. Daeja is an awesome swimmer and a fast runner -- she runs in the special track league for MPS annually in which she always wins 1st-3rd place. She didn’t even start walking until she was 2 years old and couldn’t run until she was 3 years old! That’s what I call “progress.” Daeja is also very smart and doing great academically in all areas of study. It takes patience, but our friends with Down syndrome can do and be whoever they want to be and reach every goal they strive for. The sky is the limit!

This journey with Down syndrome requires a lot of unconditional love and patience. Remember, patience is rewarding. When we focus on progress over perfection, the road is much easier!

All the best,
Lamona, DS mom



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

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



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



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



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

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



Madison Area Down Syndrome Society

The mission of the Madison Area Down Syndrome Society, Inc. is to provide support to individuals with Down syndrome and their families while advancing acceptance, inclusion and opportunity for individuals with Down syndrome in South Central Wisconsin. www.madss.org



Wisconsin Upside Down

Wisconsin Upside Down is dedicated to enhancing the lives of individuals with Down syndrome. The mission of Wisconsin Upside Down is to offer Down syndrome Advocacy, Education, Awareness and Support to families of individuals with Down syndrome and the community. www.wiusd.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



Wisconsin Down Syndrome Advocacy Coalition

The Wisconsin Down Syndrome Advocacy Coalition (WIDSAC) is a group of Down syndrome organizations in Wisconsin with the mission of advocating on behalf of individuals with Down syndrome in Wisconsin.

*exceeding expectations
every day in every way.*



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





Down Syndrome Association of Wisconsin

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