



dsaw

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



2016 Annual Report to the Community

*No matter
where you live,
DSAW is here
to help you and
your family.*

Dear Friends,

This past year has been an exciting one for the Down Syndrome Association of Wisconsin. We added two chapters (welcome DSAW-Kenosha, Racine, Walworth and DSAW-Wausau!), and celebrated the historic 20th Anniversary of the Statewide Down Syndrome Awareness Walk and the 10th Anniversary of the DSAW-Chippewa Valley Down Syndrome Awareness Walk. We moved the State Headquarters to a new home in West Allis, and we launched a beautiful new website. We served a record number of families around the state through innovative programs and services (see page 8!).

On top of all this, **we have just finalized DSAW's new 5-Year Strategic Plan**, which will guide DSAW through its planned growth and change over the next 5 years. We will continue to be an organization that is first and foremost built on fraternal support, but we will incorporate new and exciting components into those offerings.



Our programs and services will now be organized around eight areas: Statewide Fraternal Support, Statewide Parent's First Call, Statewide Medical Training, Statewide DSAW-Family Services, Statewide Education Services, Statewide Down Syndrome Awareness, Statewide Advocacy, and the DSAW State Headquarters. Overall, we hope this reorganization sends a crucial message to families and individuals across the state: ***no matter where you live, DSAW is here to support you.***

While we will continue to utilize our effective Chapter system, we have incorporated incremental levels of support from the individual, all the way up to the Chapter level. We believe that in doing so, we can more effectively serve people whether they are in the smallest, most rural areas of the state, or a major metropolitan area like Milwaukee. **We have structured ourselves to serve people across four different "levels"** – Individuals, Parent Groups, Regional Committees, and DSAW Chapters.

In addition to our vital Fraternal Support, DSAW will continue focusing on the key areas that are essential to our mission: Parent's First Call to reach new and expectant parents, Medical Training to educate medical professionals about delivering a fair and compassionate Down syndrome diagnosis, DSAW-Family Services to help individuals with individualized direct services and support, and Down syndrome Advocacy and Awareness. Now, we're excited to add replicable, niche, and model programming to this list.

At our West Allis-based DSAW State Headquarters, we serve the entire state of Wisconsin while piloting replicable programs and services in the Greater Milwaukee Area for implementation by families across the state. We will host programs for families, parents, little ones, and Self-Advocates ages 15 and older.

These exciting programs and services will not solely be available in Milwaukee. **Through our more organized volunteer/fraternal support model, we can launch programs just like these all over the state in the next 5 years.** Programs that help individuals with Down syndrome learn crucial skills and build relationships with their peers, programs that connect families together for fraternal support, and programs that create lifelong community memories.

As we celebrate an amazing 2016, we look forward to a bright future for the individuals and families that we serve in 2017. **Through our programs, services, and events, we're confident that Wisconsin can be the best-supported state in the nation for individuals with Down syndrome.** We hope you continue to join us on this journey.

Gratefully,

A handwritten signature in black ink that reads "Dawn Nuoffer".

Dawn Nuoffer
Executive Director
Down Syndrome Association of Wisconsin



About Us

OUR MISSION

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.

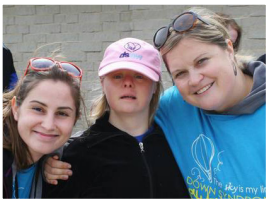
OUR VISION

is to 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.

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, and other virtual support.

Looking for more? Consider gathering a group of parents near you to form a Parent Group!

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 Abbey to start your own!). Parent Groups include the support of the individual level, PLUS Coffee Clubs, Parents Nights Out, Parent Groups (Moms, Dads, Grandparents, Multicultural, etc.), and Play dates.

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, and 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, and More advanced events and seminars.

History

Where we've been...

1990: DSAW was founded by Joan Balliet, a nurse and mother of a child with Down syndrome.



2013: COTH-Greater La Crosse becomes a chapter. Milwaukee becomes a separate chapter.



2008: Green Bay becomes a chapter, and DSAW hosts its first "Lose the Training Wheels" event.

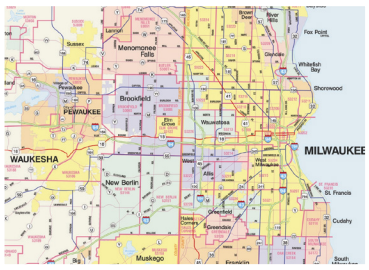
2009: DSAW moves state headquarters to the Marian Center in St. Francis.



2014: DSAW-Family Services is launched. Dawn Nuoffer becomes DSAW's new Executive Director.

1995: DSAW hired its first part-time office manager and began fundraising.

1997: DSAW opened its first office on the northwest side of Milwaukee.



2010: Fox Cities becomes a DSAW chapter. DADs group launches. First Peer Sensitivity Trainings are held in schools.



2015: Board approves creation of DSAW-Wausau and DSAW-Racine chapters.



2000: DSAW launched its first website.



2011: Sheboygan becomes a chapter.

2012: Prenatal Medical Outreach begins in response to new blood tests that cause record termination rates.



2016: Parent's First Call Program launches. DSAW moves State headquarters to West Allis and launches replicable menu of programs and services. 20th Anniversary of the Statewide Down Syndrome Awareness Walk. DSAW debuts new website.

2007: The chapter system begins with DSAW's first chapter, Chippewa Valley.

...and where we're going

Programs and Services

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. Click here to learn more about these four levels and to find support and programming near you.

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.

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.

Programs and Services

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.

Statewide Headquarters



DSAW's West Allis-based State Headquarters serves the entire state of Wisconsin while piloting replicable programs & services in the Greater Milwaukee Area. Our full menu of programming includes Young Leaders Academy, tween and teen groups, parent/grandparent groups around a variety of topics, and more. In addition, the DSAW state headquarters houses the offices of our state staff.

Administrative Staff



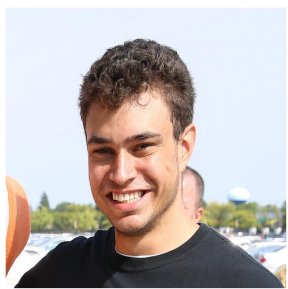
Dawn Nuoffer: Executive Director

Dawn became DSAW's Executive Director in December 2014. Her previous experience includes the creation of housing for homeless and disabled veterans, the opening of wrap-around resource centers providing employment and training support, benefits assistance, financial assistance, and a full spectrum of counseling and holistic services for individuals in poverty. She has dreamt big dreams and worked hard with passionate individuals to bring those dreams to fruition for the betterment of some of society's most vulnerable populations --- dreams like a not-for-profit café which trains veterans in the food service and hospitality industry, or state of the art kitchens training individuals with disabilities and barriers to employment. Dawn has one daughter, Abby, who is 12 years old and has Down syndrome.



Abbey Nicholas: Director of Marketing & Development

Abbey has been with DSAW since February 2015, and took on her current role in May 2016. She has a Bachelors of Arts in Social Welfare & Justice from Marquette University, and a Master of Science in Management from the University of Notre Dame. She brings extensive experience in marketing, fundraising, communications, and design to the team. Abbey fell in love with working with and for people with special needs during her time at Marquette, and is thrilled to advocate for people with Down syndrome in this role.



Chris Due: Office, Program and Events Assistant

Chris is a Milwaukee native and 2015 Graduate of Xavier University. Chris has experience working in numerous non-profits, and just recently finished a one-year fellowship with AmeriCorps. Chris has a skill for reimagining programs and events that people with Down syndrome and their families love, and is currently in the midst of creating a new menu of programs and services for DSAW's West Allis-based State Headquarters.

Casey Atkinson: Green Bay Program Manager



Casey and her family moved to Green Bay in June of 2014 after her husband took a position with the Green Bay Packers. She quickly met Melissa Moody, who was then serving as the DSAW-GBC Board Treasurer and Walk Coordinator. With Melissa's help, Casey was hired as the iCan Shine Bike Camp Coordinator for that summer. After conducting a successful first event, she was asked to move into the role of Program Manager for the chapter. Prior to this role, Casey was the Medical Outreach & Adult Programming Coordinator and Buddy Walk co-chair at the Up Side of Downs in Cleveland.

Casey and her husband have three children, Tori (8) who has Down syndrome, Lillian (5) and Garrett (4) and our loyal chocolate lab Riley.

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2016 by the Numbers

- 1. Launched the Parent's First Call Program, offering resources, support, parent mentors, and welcome baskets for new and expectant parents. We supported new families around the state through this innovative program.**
- 2. Introduced our new Statewide Fraternal Support Model, allowing DSAW to serve every person in Wisconsin, no matter where they live!** In 2016, we provided ongoing support and programming to 4,500 supported-families across the state.
- 3. Directly combated the rapidly increasing termination rates for fetuses with Down syndrome as a result of advancements in prenatal testing by training more than 600 medical professionals in five major health systems across the state in the last three years.**
- 4. Served 250 individuals with Down syndrome and other special needs around the state with DSAW-Family Services' "roadmaps," transition services, Support Broker Services, Employment Services, the creation of 5-year plans, and just about anything families need across their lifespan in a 1:1 setting.**
- 5. Hosted 7 Down syndrome Awareness Walks across the state with more than 6,500 walkers, runners, racers, rollers, and strollers... WOW!!!..Combine that with the thousands more volunteers, donors, and supporters...well, you have a person for every 8,000 people with Down syndrome in Wisconsin!!! (Chippewa Valley, Fox Cities, Green Bay, La Crosse, Milwaukee, Racine, and Sheboygan - WE LOVE YOU!!).**
- 6. Moved the DSAW State Headquarters to a central location in West Allis. This office serves the entire state of Wisconsin while piloting replicable programs and services in the Greater Milwaukee Area.** We've launched a large menu of programs for families, parents, little ones, tweens, and Self-Advocates ages 15 and older. Look for programs and services just like these in YOUR area in the next 5 years.



2016 by the Numbers

7. Hosted Member Events and Socials across Wisconsin such as: a statewide celebration of World Down Syndrome Day, Holiday Parties, Halloween Dances, D.A.D.S. Support Groups, Brewer Outings, Summer Picnics, Valentines Socials, Family Resource Nights, Family Bowling Parties, Pool Parties, and so much more. We had a BLAST creating fraternity and raising awareness of the value of individuals with Down syndrome in our lives!



8. Hosted, and partnered to host, educational seminars and webinars on a variety of topics including: Potty Training, Behavior, IEP planning, Alzheimer's & Down Syndrome, Speech Therapy, "Sensational Brain," "Parent's First Call" Training, "Talk Tools," Puberty/Sexuality, and MORE! (A HUGE thank you to our partners who join us in this work).



9. Through DSAW's Peer Sensitivity Training, we trained students at 7 different elementary schools in La Crosse, Fox Cities, Madison, Milwaukee and in Racine. Upwards of 2,000 children were trained on what Down syndrome is, what it isn't, and how to be a good friend to someone with Down syndrome.



10. Donated thousands of "Spread the Word to End the Word" Campaign t-shirts to schools all over the state to end the use of the "R" word.



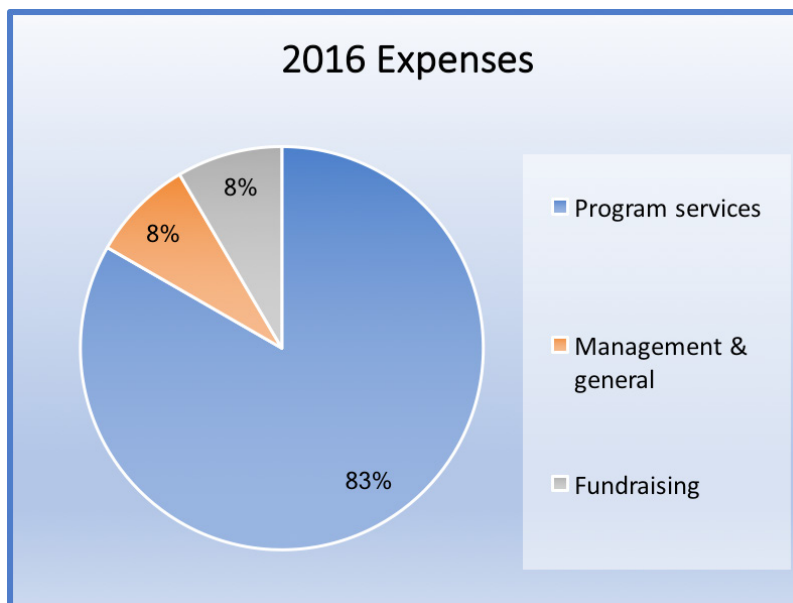
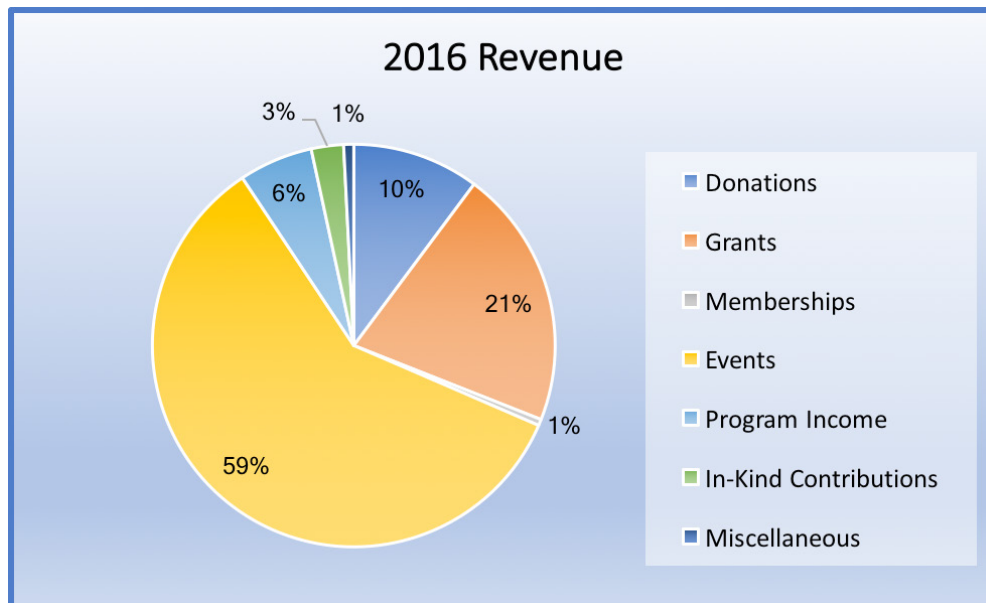
11. Advocated for rich futures for individuals with Down syndrome through the creation of the Wisconsin Down Syndrome Advocacy Coalition (WIDSAC). WIDSAC is a partnership between "Down syndrome" organizations in Wisconsin focused on legislative advocacy, maintaining high standards in Wisconsin's long-term care system, and getting fair, accurate and unbiased information in the hands of newly diagnosed families across the state.



Financials

This data represents the audited financials for 2015.

Total assets: \$565,806
Total current liabilities: \$44,051
Total net assets: \$521,755



The Down Syndrome Association of Wisconsin raises funds through the annual appeal, grant writing, employee giving, special events, and estate planning & bequests.

DSAW is 100% funded by private individuals and concerned corporate citizens and foundations that believe just as we do that with appropriate investment and just the right amount of supports, our loved ones can accomplish amazing things!

Meet the Aguilar Family



We never knew anyone personally with Down syndrome before Julia was born. The diagnosis was somewhat scary and the books we read when we found out the diagnosis were even scarier. They focused on accepting the diagnosis, the challenges she would have and how she would be different. Not one of those books said “Congratulations on your beautiful baby and wonderful human being!” The health care professionals, although kind, also focused on the challenges. Family and friends didn’t know what to say. They were very supportive, but at the same time they also didn’t know what to say. Their first words after we told them the diagnosis was often “I’m sorry.” We knew it was awkward and they all meant well. We are here to tell you, while we are many things, sorry is not one of them.

Down syndrome is just a diagnosis. It does not define who Julia is or who she will be. She may not be typical, but we wouldn’t want her to be. It is true that it often takes our children longer to learn, or walk, or talk and it is true that they have distinct genetic features and health care issues. But it is also true that our children have unique personalities that teach acceptance, patience, perseverance, loyalty, forgive-

ness, kindness, and a capacity for unconditional love like no other. Our lives will never be the same because of this amazing little girl and her ability to brighten any room and any day with her smiles, snuggles, hugs and laughter! She is so proud when she learns a song, a line in a movie or a new dance move. When we pick her up from school each day she runs to us with open arms and a smile of pure sunshine. She changes our lives every day. She changes others’ lives every day. We witness it. We are truly blessed.

As we continue on this journey, we are so grateful for the Down Syndrome Association of Wisconsin. DSAW has brought us together with other families who understand Down syndrome and just how amazing our children are. DSAW gives us a community to reach out to with questions, whether it be on dealing with behaviors, health care concerns, access for our children, or where to find a dance class for Julia! Jorge has found community in the D.A.D.S. (Dads Appreciating Down Syndrome) group where they socialize and talk about all kinds of topics and resources.

DSAW continues to show us how individuals like Julia are more alike than different. They teach us how to deal with the many common misconceptions about our children and how to make sure they have the support they need to live their lives to the fullest and to be accepted for who they are, not defined by their diagnosis!

As we think about Julia’s future, we are hopeful and excited. Our dreams are probably not much different than any parent. We want Julia to remain healthy. We want her to build positive relationships with her friends and succeed at school. We want her to learn how to ride a bike and participate in outside activities like dance, swim and sports. **We want her to be happy and to feel loved and accepted-for who she is.**

DSAW will continue to be available as a resource for her IEPs at school. They will provide a network of friends who understand our children’s unique challenges and offer suggestions on how to navigate these challenges successfully. They will continue to give us information on how to get Julia into activities and learn how to ride a bike. **There are exciting changes ahead for the Down Syndrome Association of Wisconsin, from increasing their programming throughout the state to increased education and resources for our loved ones. We are so thankful for the support we’ve received, and are looking forward to a bright future with DSAW’s help.**

Meet the Pratt Family

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!



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!!

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Thank You!



This annual report is available to the community at www.dsaw.org



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