
Down Syndrome Association of Wisconsin



**2011 Annual Report
to the Community**



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

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DSAW Self-Advocate Board Member Letter

As DSAW’s self-advocate Board member, I continue to work toward awareness, acceptance, and assistance for people with Down syndrome.

I am still living in my own apartment and working as a child care teacher. I can do this because of the support that DSAW helps me keep in place.

This year, as part of the “Take your legislator to work initiative,” DSAW’s president arranged for Governor Walker to visit my place of work. The Governor saw how people with Down syndrome can have meaningful employment.

2011 was also my first year serving on the Wisconsin Board for People with Developmental Disabilities. This experience helps me as a DSAW Board member. I am honored to work with the DSAW Board.

Andrew Gerbitz, Self-Advocate



DSAW Board of Directors Letter

Dear Friend:

Thank you for all you do for individuals with Down syndrome and their loved ones, and thank you for being a supporter of the Down Syndrome Association of Wisconsin (DSAW). We are proud to say that roughly 90% of the funding for DSAW comes from our members, through general donations, membership renewal dues, and our other fundraising events. As our services grow, our goal is to grow revenue through not only our consistent membership support, but also through new, external support as well.

Your investment in our organization, whether as a member, donor or volunteer, allows DSAW to continue to serve as your partner. It allows DSAW to continue providing resources, referrals, support and education about all aspects of Down syndrome from birth to adulthood.

DSAW continues to make significant strides toward our ultimate objective of Wisconsin being the best-supported state for individuals with Down syndrome, along with their loved ones. We continue to provide top-notch services such as:

- Roadmap sessions with families on topics such as IEP's, Benefits, Nutrition, Family Care, Employment, Supported Living, Alzheimer's and Dementia, allowing DSAW staff to provide valuable information and resources to parents and caregivers;
- Distribution of Down syndrome information packets for new and expectant families to hospitals, OB-GYNs and pediatric clinics, genetic counselors, and Birth to 3 programs;
- Monthly e-newsletter and other periodic newsletters to over 2600 households;
- DSAW Sponsored Family Events such as the Annual Summer Picnic, Annual Milwaukee Brewers Tailgate Party, and Annual Holiday Party.

Thank you for supporting the Down Syndrome Association of Wisconsin. Please visit us at www.dsaw.org for more detail about your organization and our programming.

Sincerely,

Tom O'Day
President
DSAW Board of Directors

People with Down Syndrome are Valued and Included

Mission (what we do)

Our mission at the Down Syndrome Association of Wisconsin (DSAW) is simple. We are here to provide support to families and individuals with Down syndrome through education, information, and the exchange of ideas and experiences.

We do that via:

- Our website, www.dsaw.org
- A quarterly newsletter to our members
- New-parent information packets which are provided at hospitals and clinics throughout Wisconsin
- Family matching services
- Community education for members and health professionals
- Special events that bring families and individuals together

Vision (what we want to become)

The vision of DSAW is that we all understand the value of those with Down syndrome in our lives and our communities. We will continue to strive toward full acceptance, full access, full life and full potential.

As a policy, DSAW does not endorse any medical, therapeutic or special education alternatives. We are primarily a volunteer organization that wishes to create an optimistic outlook about Down syndrome for our families and others. The purpose of our website is to provide our members and the general community an educational background about and a source of information on issues related to Down syndrome.



Photo courtesy of Anna Meyer Photography

Core Values and Identity

Core Values (our priorities and how we act)

- Optimism for our families and others
- Equality for those with Down syndrome
- Availability to help our members around the state
- Professionalism, experts on Down syndrome and the needs of members of all ages
- Efficiency in how we leverage time (volunteer hours) and treasure (donations)
- Highest level of financial transparency and integrity
- Conservative to ensure we are here for future generations

Identity (what sets us apart)

To our members, volunteers and donors, DSAW has become a very efficient group of leveraged Chapters supporting Wisconsin, governed by a Board of Directors and led by a small nucleus of paid staff to maximize efficiency and provide technical depth across the state. In 2011, we saw the power and value of this Chapter model, and we doubled our programming across the state year over year.

To our Chapters and Advisory Board Members across the state that provide local support to our members: DSAW is excited to support and partner with you as you grow and become self sufficient in your abilities to support your local community.



Our History

The Down Syndrome Association of Wisconsin, Inc. was founded 21 years ago by Joan Balliet, a nurse and mother of a child with Down Syndrome. Joan was able to pull together a number of families that all shared a passion to help those with Down syndrome in Wisconsin. As one of the founding families 21 years ago, I (Ron Malloy, DSAW's current Executive Director) remember two meetings. At the first meeting, we voted on a name for the organization. Joan was emphatic the name must begin with Down syndrome... because it was felt families searching for information on Down syndrome would first open the phone book and look up Down syndrome. Even today many families still find DSAW through the phone book. The second meeting I remember was a huge picnic where families from all across the state got together to share a potluck lunch, DSAW's first social event.

Dr. David Smith, Joan's husband at the time, had a sister with Down syndrome. Dr. Smith commented that he thought his sister died at an early age due to complications associated with an undiagnosed case of hypothyroidism. Joan, a nurse, and David, a doctor, were married and living in Maryland in 1985 when their son Charlie was born with Down syndrome. One of the first things they learned was that it was hard to get any information on Down syndrome. There was not a lot of support. As a physician, David went to the library and the most recent book he was able to find on Down syndrome was published in the 1950s. David and Joan were unable to find another family with a child with Down syndrome in Maryland. The family eventually found and was able to meet with Dr. Pueschel in Rhode Island, one of the grandfathers of health care for people with Down syndrome.

When David, Joan and Charlie moved to Wisconsin in 1987, Joan had a few years of experience working the system for Charlie. It was not easy. She dreamed that there would be

a statewide organization of support for persons with Down syndrome and their families -- an organization that would educate and help to improve the overall lives of people with Down syndrome. Through her tireless efforts, she was able to pull together families of children with

Down syndrome and start what is now the Down Syndrome Association of Wisconsin. In the beginning, meetings were scheduled to educate as many professionals as possible. David and Joan offered their services to families with a newly diagnosed child with Down syndrome. New Parent packets were assembled and

sent out to as many hospitals, schools and social service organizations as possible. The schools and hospitals needed constant monitoring to make sure they used the information. It was frustrating at times. DSAW was able to create some public service announcements. It was a big step when we were able to place two large billboards showing our pride in persons with Down syndrome, and that they should not be underestimated. The kids were dressed in tuxedos.





In 1995, DSAW was able to hire its first part-time office manager, Polly Daniels, and started fundraising. In 1997, DSAW was able to open an office on the northwest side of Milwaukee in the Endometriosis Association Building. DSAW utilized volunteers in the office. We did our best to include people with Down syndrome serving in the office. We had a large computerized data base of parents and organizations. In 1997, DSAW's two largest fundraising events were launched, the Buddy Walk and the Golf Outing. In 2000, DSAW added a website giving us the ability to educate and support many more people.

Unable to afford the rent, the office was closed for a brief time in 2001 and reopened in 2002. (The office reopened when it was able to find donors willing to underwrite the cost of the office rent.)

Social events were always a big hit. The Christmas party with Santa Claus, which included gifts for all the children, and summer picnics in the parks were a great time for everyone to get together. Fundraisers were always interesting. We staffed one of the food service windows at the old Milwaukee County Stadium. We were able to do one for a Green Bay Packer game when they played in Milwaukee. The Buddy Walks,

now named our Down Syndrome Awareness Walk, started in Milwaukee in 1997. The 1st walk raised \$5,000 and had 75 walkers. In 2011, five walks were hosted across the state which were attended by 4,500+ walkers. In 2000, a statewide conference in central Wisconsin was organized to celebrate our 10 year anniversary which emphasized that we were a statewide organization. The conference was held in Stevens Point, funded by a grant received from the Forest County Potawatomi Foundation. The conference was a huge success. It was soon after that event that Joan Balliet stepped aside and others took over the organization. DSAW is still going today. That is a testament to a strong start, a solid organization, and a definitive need for resources, support and education on issues surrounding Down syndrome.

In 2007, DSAW was approached by several advisory board members to start a Chapter in their community. In 2009, DSAW moved the office into the Marian Center for Nonprofits for cost savings and nonprofit synergy. As we enter 2012, we have four Chapters across the state (Chippewa Valley, Fox Cities, Green Bay, and Sheboygan) and our main office in St. Francis, a suburb of Milwaukee.

2011 Annual Report - Accomplishments

- Created and distributed quarterly newsletter to 800 households.
- Created and distributed monthly eBlasts to DSAW listserv with over 3,500 subscribers.
- DSAW Sponsored Family Events included Annual Summer Picnic, World Down Syndrome Day Water Park Party, Milwaukee Symphony Orchestra Holiday Performance, Annual Milwaukee Brewers Tailgate Party, and Annual Holiday Party.
- DSAW Sponsored Community Education Workshop included Toilet Training and Mental Health and Wellness for Adults with Down syndrome.
- DSAW Sponsored Self Advocate Events included World Down Syndrome Day Valentine's Day Dance and Annual Halloween Dance.
- DSAW D.A.D.S. (Dads Appreciating Down Syndrome) Chapter held 12 monthly meetings; 4 educational seminars: Speech, Respite, Behavior and IEP's; and 3 family events: Halloween Train Ride, Rockin Summer Picnic, and the Brewers Game.
- DSAW co-sponsored its 4th Annual Lose The Training Wheels Bike Camp with The Autism Society of Southeastern Wisconsin. Seventy volunteers and forty young people with Down syndrome, autism and other disabilities participated. After one week, camper success rate was at 80%.
- DSAW hosted three major fundraising events, including a partnership with the 15th Annual Tom Pipines Golf Classic attended by over 100 golfers that raised over \$22,000; and, the 15th Annual Down Syndrome Awareness Walk attended by over 1,700 individuals with Down syndrome, their families, and friends and raised close to \$109,000.
- DSAW conducted one Self Determination Training for Teachers in New Berlin, WI and two IEP Seminars, one in Fox Cities and one in Stevens Point, a sibling workshop, a puberty workshop, a health and mental wellness in adults with Down syndrome seminar and a toilet training seminar.
- DSAW conducted twenty School Based Peer Sensitivity Presentations to raise awareness and promote acceptance of Down syndrome within the classroom.
- DSAW conducted sixty 1:1 Benefits Roadmap Sessions allowing DSAW staff to provide valuable information and resources to parents / caregivers in order to enhance the quality of life of their loved one with Down syndrome. Each session addressed either overcoming a challenge or achieving a dream.

Road Map Reviews



Photo courtesy of Anna Meyer Photography



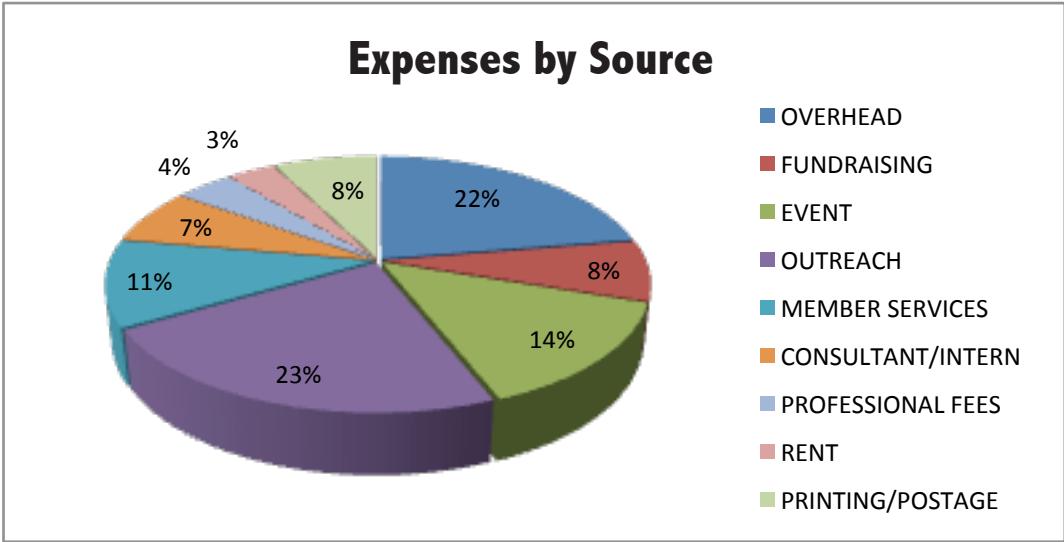
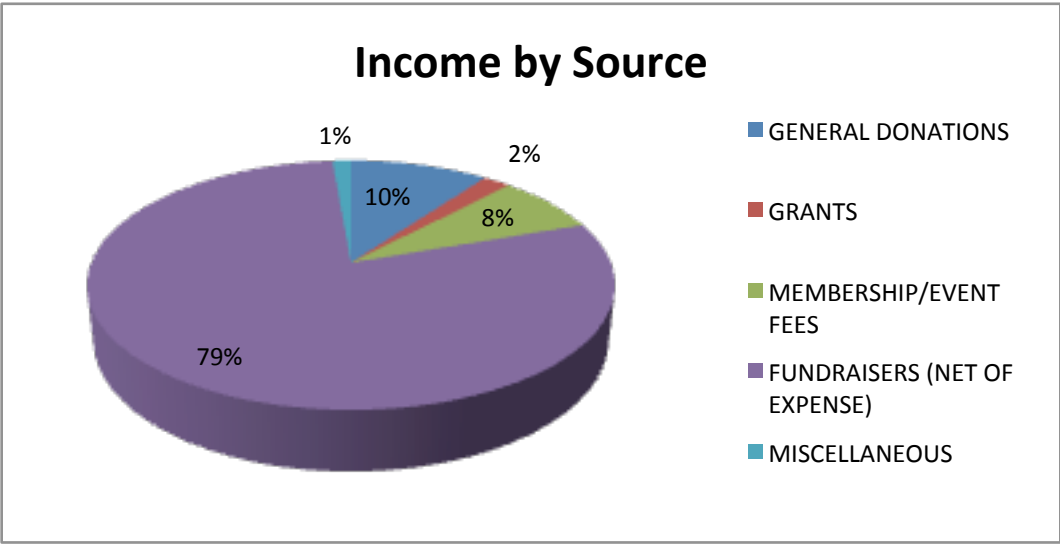
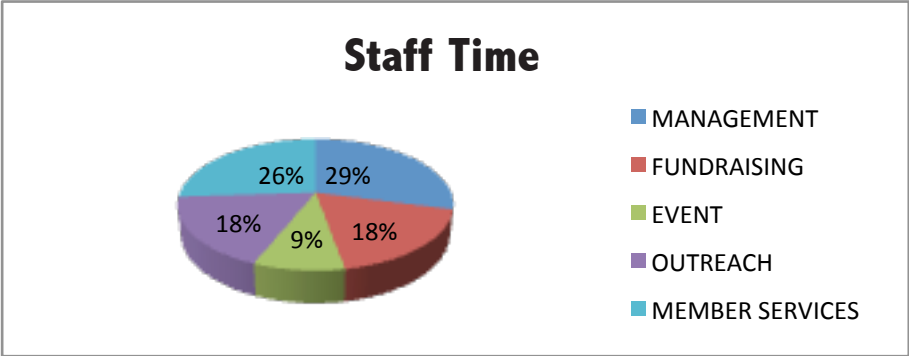
Photo courtesy of Anna Meyer Photography

The IEP Seminar, Road Map Review by Ron Malloy was the first time that I knew exactly what being part of Angelina's IEP Team actually meant. I was inspired to become so much more involved in her goals for now and for the future. Road Map Reviews helped me and showed me that my daughter has rights and deserves to have me on her team as an active player.

Rebecca M., Gettin' Down Central WI, Marshfield, WI



2011 Financial Summary



Down Syndrome Association of Wisconsin, Inc.
Statement of Revenue and Expenses - Cash Basis
For the Year Ended Dec. 31, 2011

	State	Chippewa Valley	Fox Cities	Sheboygan	Green Bay	<u>TOTAL</u>
INCOME						
Donations	\$23,351	\$1,000	\$3,563	\$0	\$620	\$28,534
Grants	4,657	0	0	0	0	4,657
Memberships	6,380	0	0	0	0	6,380
Member Events	6,059	50	0	0	0	6,109
Special Events Revenue	140,690	15,759	65,387	11,445	15,317	248,597
Special Events Expense	(42,718)	(5,832)	(12,374)	(2,231)	(3,534)	(66,688)
Outreach Event Income	5,395	0	0	0	0	5,395
Miscellaneous Income	152	0	0	0	0	152
Interest Income	2,125	0	0	0	0	2,125
Total Revenue	\$146,090	\$10,977	\$56,577	\$9,214	\$12,403	\$235,261
EXPENSES						
Wages	85,254	0	0	0	0	85,254
Payroll Taxes	6,522	0	0	0	0	6,522
Professional Fees	24,242	10	0	0	34	24,286
Advertising	350	0	0	0	0	350
Member Events Expense	18,561	2,418	382	0	234	21,595
Insurance	2,566	0	0	0	0	2,566
Grant Awards	8,189	0	705	0	0	8,894
Equipment Rental & Maintenance	8,827	0	0	0	0	8,827
Outreach Program	6,910	300	4,463	0	0	11,674
Dues & Subscriptions	1,571	0	50	0	0	1,621
Telephone	2,954	553	0	0	0	3,507
Office Supplies	1,268	144	0	0	26	1,438
Rent	7,131	0	325	0	0	7,456
Printing & Publications	6,990	1,161	455	190	540	9,336
Postage	5,818	528	197	0	280	6,823
Travel	1,985	0	0	0	0	1,985
Conferences	1,844	0	0	0	0	1,844
Resource Material	306	0	3,962	0	0	4,267
Miscellaneous Expenses	5,355	284	948	7	38	6,633
Total Expenses	196,643	5,399	11,487	197	1,152	214,878
CHANGE IN NET ASSETS	\$(50,553)	\$5,577	\$45,090	\$9,017	\$11,252	\$20,383
Net Assets, Beginning of Year						425,939
NET ASSETS, END OF YEAR						\$446,322

DSAW Office Staff

The Down Syndrome Association of Wisconsin is staffed by one full-time Executive Director and a part time Office Manager. Each staff member is a strong community advocate and proud parent of a child with Down syndrome.

DSAW staff is focused on delivering value to our members through our many educational and medical outreach trainings, awareness events and social events. Our member services include detailed one-on-one roadmap sessions, our parent connect program and information referrals.

Our staff has significant domain knowledge and hands on experience in the areas of:

- I.F.S.P., Individual Family Service Plan
- I.E.P., Individualized Education Program
- C.L.T.S., Children's Long Term Waiver
- Medical Assistance Personal Care
- Katie Beckett
- Birth to Three
- Early Childhood
- Transition (Elementary, Middle, High School, Community)
- Employment
- Self Employment of People with Down syndrome
- I.R.I.S., Include Respect I Self Direct
- Family Care
- Self Determination
- Community Supported Living
- Supportive Home Care
- Supplemental Trusts
- Peer Sensitivity
- Guardianship
- Transportation
- Dual Diagnosis Autism
- Celiac Disease
- Major Medical (Heart, Duodenal Artresia...)

We do not give medical or legal advice. For the above topics, office staff is able to meet with families and explain a topic in detail, how to apply or access the program and most importantly we are able to specifically talk about how the program will help a person with Down syndrome. We describe these in-depth discussions as roadmap discussions. They typically last two hours and members leave with a detailed understanding of the topic and a roadmap. In other cases, we provide simple informational referrals.

Children of DSAW Staff



Alexis Malloy age 22, with Melissa Daughters of Ron Malloy, DSAW Executive Director



*Kyle Moon age 3
Son of Ellen Moon
DSAW Office Manager*

DSAW Chippewa Valley Chapter



The Down Syndrome Association of WI – Chippewa Valley (DSAW-CV) is a resource in West Central Wisconsin for individuals with Down syndrome, their families, as well as others who support them.

We are here to provide support to families and individuals, as well as professionals in the surrounding communities, through education, information, and the exchange of ideas and experiences.

DSAW-Chippewa Valley has been affiliated with DSAW, Inc. since 2008 and continues to be a growing chapter, always welcoming new families and volunteers.

DSAW-Chippewa Valley
PO Box 3156
Eau Claire, WI 54702

Please call 715-379-0563
Contact person: Amy Standiford
Our email address is: info@dsawchippewavalley.org

Find us on the web at:
www.dsaw.org/chapters-chippewavalley.ASPX
or LIKE our group on **FACEBOOK Down Syndrome Association of Wisconsin Chippewa Valley**



- Sponsored family events that included the Annual World Down Syndrome Day Event, Take Me Out To The Ball Game Night, and the Annual Holiday Party.
- Served over 75 families via email.
- Increased outreach by creating a Facebook group and website.
- Distributed Down syndrome information to new families.
- Collaborated with other local organizations to share education and information with families of children with special needs.
- Supported “Fishing Has No Boundaries.”
- Hosted our 5th Annual Down Syndrome Awareness Walk in Irvine Park which raised over \$16,000.
- Hosted transition Roadmap Sessions presented by DSAW Executive Director, Ron Malloy.

DSAW Chippewa Valley Chapter cont.

- Participated in local awareness events such as the “Spread The Word To End The Word” and “Dress Down For Down Syndrome” campaign, along with the Polar Plunge for Special Olympics
- Provided scholarships and grants for supported individuals and families
- Board members attended a Leadership Retreat
- Will continue to strive towards full acceptance, full access, full life and full potential!



DSAW Green Bay Chapter

The **vision** of the Down Syndrome Association of Wisconsin-Green Bay Connection (DSAW-GBC) is that we all understand the value of those with Down syndrome in our lives and our communities.

We continually strive toward *full acceptance, full access, full life and full potential.*

Our group is based in Green Bay, WI but has families in many surrounding communities, including Pulaski, Kewaunee, Sturgeon Bay, Greenleaf and Two Rivers. We are a growing group, recently becoming a chapter of the Down syndrome Association of Wisconsin. In 2011, community donations made in honor of Miki Greaves funded the Miki Greaves Memorial Scholarship Fund which assists with community inclusion of those with Down syndrome.

Primary contact in Green Bay is Samantha Platkowski, 920-713-8784, sam@dsaw-gbc.org.

2011 Events

DSAW Walk – October 6, 2011

Walk Income: \$ 15,316

Walk Expenses: \$3,533

Walk Profit: \$11,783

Miki Greaves Memorial Scholarship: \$787.98

Projected 2012 Events:

Trust & Family Planning	Playgroups
Seminar	Mom/Dad's night out
Christmas Party	Summer picnic
Parent's night out	IEP Training

History

The Down Syndrome Association of Wisconsin – Green Bay Connection has been in existence since the early 1990's. Formed by a small group of parents as a networking and support group, and funded by the local ARC, the group gained members quickly. In 2003, the local ARC discontinued support of the group and organizers began looking into ways to raise money to keep activities accessible to all families. In 2008, the group became a regional chapter of the Down Syndrome Association of Wisconsin. In 2009, the first Down Syndrome Awareness Walk was held, raising over \$2,000.00. In 2011, the walk raised over \$11,000.00. Currently there are approximately 100 supported families across five counties in northeastern Wisconsin.



DSAW Fox Cities Chapter

DSAW-Fox Cities Mission/Vision: We are here to provide support to families and individuals with Down syndrome through education, information, and the exchange of ideas and experiences.

DSAW-Fox Cities serves families of individuals with Down syndrome in the Fox Cities area, specifically in Outagamie, Winnebago, and Calumet counties.

Address:
DSAW-Fox Cities
PO Box 2232
Appleton, WI 54912
Website: www.dsawfoxcities.org
Email: info@dsawfoxcities.org
Facebook group: Down Syndrome Association Wisconsin Fox Cities

Parent Network Coordinator and DSAW-Fox Cities Advisory Board Chair:
Maria Steenpoorte, maria@dsawfoxcities.org

DSAW-Fox Cities History: DSAW-Fox Cities became a new chapter of DSAW in February 2010, and formed an Advisory Committee of 8 individuals in January 2011.

DSAW-Fox Cities' current schedule of monthly events:

- 2nd Saturday Gathering for families
- 3rd Tuesday DS Walk Committee meeting & Advisory Board meeting
- 4th Friday Summer Play Date
- Mom's Night Out

DSAW-Fox Cities' accomplishments from January through December 2011:

- Totaled 95 families on the supported family database
- Served 80 families on the private Google email group
- Served 150 families and organizations with the e-newsletter
- Hosted a total of 43 social or educational events
- Raised \$62,000 at the 2nd Annual Down Syndrome Awareness Walk with 1,200 walkers
- Sponsored the 1st annual World Down Syndrome Day Celebration at Wild Air for 22 families





- Participated in the annual Building for Kids Children's Parade
- Hosted a room at an annual community Halloween party for kids with special needs
- Donated 180 books for the Down syndrome information packets for a total of \$1,800
- Distributed 35 DS information packets to new and expectant families in collaboration with NE Regional Center Children & Youth with Special Health Care Needs to reach families at hospitals, genetic counselors, perinatologists, pediatric and OB clinics, and Birth to 3 programs
- Donated 14 Signing Time Classroom Edition kits to local school districts for a total of \$2,800
- Donated grocery/gas gift cards to 3 families experiencing extended hospitalizations for a total of \$300
- Donated \$1,200 of t-shirts for 6 schools in the Spread the Word to End the Word campaign
- Sponsored 5 sports participation scholarships totaling \$335
- Sponsored 1 individual for the Lose the Training Wheels camp for a total of \$400



DSAW Fox Cities Chapter cont.

- Sponsored participation of parents in two national Down syndrome conferences for a total of \$1,100
- Created 2 new scholarship opportunities for visual arts and performing arts class participation
- Frequently submitted New Materials Suggestions to local public libraries to update DS resources
- Switched to a new website provider for a cleaner looking website with easier web maintenance
- Formed a formal chapter Advisory Board of 8 individuals

DSAW-Fox Cities' plans for 2012:

New Outreach programs:

- Distributing 50 booklets "Understanding a Down Syndrome Diagnosis" and pamphlets "Delivering a Down Syndrome Diagnosis" to local medical professionals June 2012

New Social Events:

- Sponsoring tables at local fundraising dinners/ events of organizations that also support our families February, March, October 2012

New Education and Awareness events and programs:

- Donating \$4,000 of t-shirts to 11 schools for the Spread the Word to End the Word campaign March 2012
- Hosting CESA presentation of FAPE and IEP February 2012
- Sponsoring Handwriting Without Tears workshop & donation of materials to attendees July 2012



DSAW Sheboygan Chapter

The vision of the Down Syndrome Association of Wisconsin Sheboygan and Surrounding Counties is that we all understand the value of those with Down syndrome in our lives and our communities.

We continually strive toward full acceptance, full access, full life and full potential.

Our group is based in Sheboygan, WI, and we support families in Manitowoc, Fond du Lac, Dodge and Sheboygan counties. We are a growing group, recently becoming a chapter of the Down Syndrome Association of Wisconsin in 2011.

Primary contact in Sheboygan is Joy Bosch, 920-979-5560, joy@dsaw.org

2011 Events

DSAW Walk – October 13, 2011

Attendance: 300 Walkers

Walk Income: \$ 9,334

Walk Expenses: \$997

Walk Profit: \$8,337

Looking to 2012 and 2013:

In 2012, the Sheboygan Chapter plans to make available grant and scholarship dollars that will provide funding to educational and recreational activities such as toilet training and summer camps for parent respites. Sheboygan will also purchase the books “Understanding A Prenatal Down Syndrome Diagnosis” as part of their prenatal outreach program to get the books in the hands of OB-Gyns and new parents.



Board Members

Andrew Gerbitz, Self Advocate **adgerb@charter.net**

Andrew Gerbitz is from the town of Oconomowoc. He is the first self advocate to hold a position on the DSAW board. Andrew graduated from high school twice, once from home-school in 2002 and again from Mukwonago High School in 2004. While at MHS, Andrew was a member of the swim team.

He is a certified child-care teacher and is active in Special Olympics basketball and swimming. Andrew is a voting member of his church and serves as an usher. Andrew has worked as a self advocate in the past for other groups and the DSAW board is thrilled to count him as our own! His insight is priceless.



Tom O'Day, President **tommyoday@hotmail.com**

Tom O'Day is a native of Wauwatosa, Wisconsin and now lives in Milwaukee's North Shore. Tom is an attorney with a health insurance company in the Milwaukee area. Tom worked for a large law firm prior to his current position where he specialized in labor and employment law, as well as education law.

In addition to his J.D., Tom holds a Masters Degree in Education Leadership and Policy Analysis from the University of Wisconsin. His studies and past practice included analysis of state and federal education law, including the Individuals with Disabilities in Education Act (IDEA), the No Child Left Behind Act (NCLB) and state and federal education finance policies. He earned his Bachelor of Science degree in political science from the University of Wisconsin-Madison in 2001, with distinction and as a member of Phi Beta Kappa.

Tom also has experience in state government in legal, policy and campaign roles. Tom has worked in every branch of state government in various capacities for the Supreme Court of Wisconsin, the Wisconsin Department of Commerce, the Wisconsin legislature, and the Governor's Office.



Nicole Cook, Treasurer

Nicole Cook lives in Mequon, Wisconsin with her husband Jack and their daughter, Lily. Nicole is a tax senior manager at Deloitte in the Private Client Advisor Group. Nicole graduated from Central Michigan University in May of 2000 with a Bachelor Degree in accounting and moved to Milwaukee shortly after graduation.

Nicole has participated in events for various organizations through Deloitte, such as Junior Achievement and Big Brothers Big Sisters. She served as the DSAW camp coordinator for



the 2008 Lose the Training Wheels Milwaukee Camp. She is looking forward to helping DSAW as a member of the finance committee and will continue to assist with the planning of several events.

Nicole enjoys traveling and running in her free time.

Brian Perhach, Vice President

Brian Perhach is a native of Wauwatosa, WI and now lives in Whitefish Bay with his wife and three sons. Brian is an attorney with Gray & Associates, LLP specializing in bankruptcy law and creditor rights. Brian earned his undergraduate degree from UW-Stevens Point and his J.D. from Marquette University. Brian became involved with DSAW after the birth of their second son. Brian also serves on the DSAW Golf Committee.



Marita Stannis, Secretary **mstannis@live.com**

Marita Stannis grew up in New Berlin and currently resides in West Allis with her husband and daughter, Madelyn. Marita is a Health and Safety Professional at Caterpillar. She graduated from the University of WI-Whitewater with a Bachelor Degree in Occupational Safety and Health. Marita became involved with DSAW after the birth of her daughter. She also serves on DSAW's Medical Outreach Committee. Marita enjoys spending time with her family and traveling in her free time.



Pete Loeffel, Member at Large

Pete Loeffel lives in Wauwatosa with his wife, Jennifer, and two daughters, one of whom has Down syndrome. He received his Masters in Library and Information Science from the University of Wisconsin-Milwaukee and is Director of the St. Francis Public Library. He is a member of the Society for American Baseball Research and enjoys running, reading and hiking.



Mike Bare, Member at Large **mike@mbare.org**

Mike Bare is a native of Manitowoc, Wisconsin, and currently resides on Milwaukee's East Side with his wife. Mike is a research consultant for the Community Advocates Public Policy Institute. He specializes in energy, housing, and health care policy research, and is



Board Members *cont.*

an expert on the intersection of policy with politics and the legislative process. Mike has an extensive grassroots politics and government background, having worked for and provided consulting to several campaigns. He also served as an aide to former U.S. Senator Russ Feingold in his Washington, DC office, and as the Research Director for his 2010 campaign. Mike holds an MA in political science from American University, where he was President of the Graduate Student Council. Mike has been a longtime volunteer for Special Olympics, and other disability organizations.

Liz Streubel, Member at Large

Liz Streubel lives in Whitefish Bay with her husband Vince and their dog Daisy. She is a special education teacher for the West Bend School District teaching special education at Jackson Elementary for grades kindergarten through second. Liz graduated from the University of Wisconsin Madison with a Bachelor of Arts degree in English and went on to earn a Master of Education Degree in Special Education from the University of Wisconsin Oshkosh.



Liz specializes in providing inclusive environments for students with disabilities. She is an advocate for inclusion and the benefits of creating a school community where all students are included and welcomed. She is a trained Reading Recovery Advocate and a Certified Non-Violent Crisis Intervention instructor for her district. She has spoken at WOTA (Wisconsin Occupational Therapy Association) Conferences and with parent groups on the benefits of inclusive education services.

Amy Bontempo, Member at Large

Amy Bontempo is originally from Green Bay, WI and currently resides in Milwaukee with her husband Tony, their daughter, Ave, and dog, Tank. Amy earned her Bachelors Degree in Social Welfare from the University of Wisconsin- Milwaukee and is licensed through the state of Wisconsin. Amy has been employed by Penfield Children's Center in Milwaukee for over 10 years.



Amy is a Birth-to-Three Service Coordinator, supervises the Parent Mentor Program, and is Penfield's Family Program Coordinator. As Penfield's Family Program Coordinator, Amy is in charge of special events, educational programs, and social events. Amy serves on The Children's Service Society of Wisconsin's Volunteer Respite Program Advisory Board and has helped in implementing respite events for the Spanish speaking community in collaboration with Alianza Latina and their Down syndrome Support Group.

In her free time, Amy enjoys spending time with her family and friends.

Mike Knoebel, Member at Large

Mike Knoebel grew up in Waukesha and currently resides in Menomonee Falls with his wife Cherie and three children. Mike graduated with a Bachelors Degree in business Administration from Lakeland College, and is currently a partner at Techstaff, a search firm specializing in recruiting engineering and technical professionals. Mike got involved in DSAW after the birth of his son Matthew, age 5, and was actively involved in helping launch the DSAW D.A.D.S. group. In his free time, Mike enjoys reading, golf, and volunteering at church.



Andrea Zahn, Member at Large

Andrea Zahn is a native of Brookfield and now resides in Waukesha. She is a Financial Advisor with Merrill Lynch Wealth Management specializing in Non-Profit Management, Special Needs and Family Planning. Andrea graduated from the University of Wisconsin Stevens Point in 2007 with a degree in Political Science and moved to Washington, DC shortly after graduation for four years. Upon her return, she quickly became involved with DSAW, Wisconsin Women's Entrepreneurs and the Special Olympics Young Professionals Board.



Andrea is looking forward to using her experience from DC in nonprofit management and event planning as well as her current experience in the financial industry in helping DSAW. She has become a member of the DSAW finance committee. Andrea's strong connection to the special needs community stems from having several family members who are special needs teachers. In her spare time, Andrea enjoys baking and spending time with her boxer puppy.

Anthony Iracki, Member at Large

Anthony Iracki is a native of Michigan who earned his degree in History and Political Science from Ferris State University. Prior to living in Milwaukee Anthony lived in Baton Rouge, Louisiana, working full time for the YMCA. Anthony continues his work for the YMCA as an Area Aquatic Director overseeing two YMCA centers in the Milwaukee Area. Anthony became involved with DSAW after exploring opportunities to continue giving back to the communities he lives and works in. Outside of DSAW Anthony also mentors through the Sponsor a Scholar Program which aims to provide academic, personal and financial support to disadvantaged students who wish to pursue post-secondary education.



Currently, Anthony resides on Milwaukee's East Side and enjoys swimming, live music, biking The Oak Leaf Trail, and experiencing the different cultures of the city through festivals and other events.

Board Members *cont.*

Patrick Murtaugh, Member at Large

Patrick Murtaugh grew up in Winnetka, IL, and currently lives on the East Side of Milwaukee. He works in Institutional Equity Sales at Robert W. Baird & Co. after earning his B.S. in Business Management with a concentration in Finance from the Carroll School of Management at Boston College. Patrick became involved with DSAW to honor the life of his uncle who lived with Down syndrome and for his nephew.

He also serves as a Board Member for Milwaukee's East Town Association and on the Advancement Committee for Catholic Charities of the Archdiocese of Milwaukee. Patrick enjoys golfing, skiing, and traveling in his free time.



Sandy Siira, Member at Large

Sandy is currently a Managing Director of Human Resources with FedEx and has held executive level human resources positions over the past twelve years.

Sandy earned a master's degree in Labor Relations and Human Resources from the University of Wisconsin-Milwaukee and a bachelor's degree in Business Management and Professional Communication from Alverno College. Sandy enjoys spending time with family, serving the community, appreciating nature, and physical fitness activities. Sandy supports numerous local organizations by sharing her gifts of time, talent and treasure.

Some of the support Sandy gives includes being a board member of St. Coletta Day School of Milwaukee, committee member of United Way of Waukesha County, volunteer catechist for the Milwaukee Archdiocese, and student assessor at Alverno College.



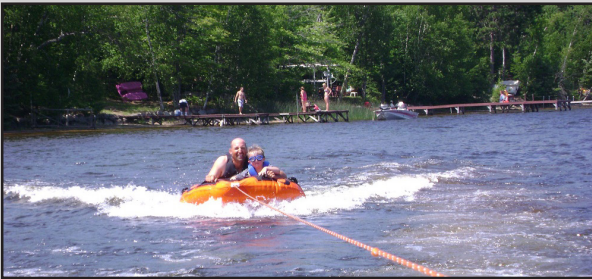
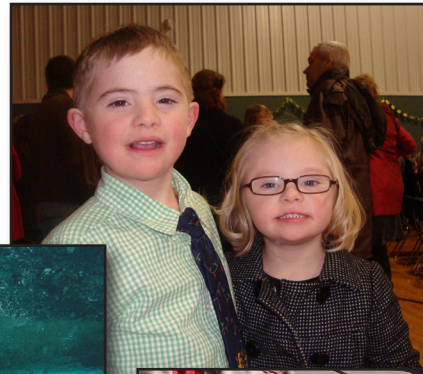
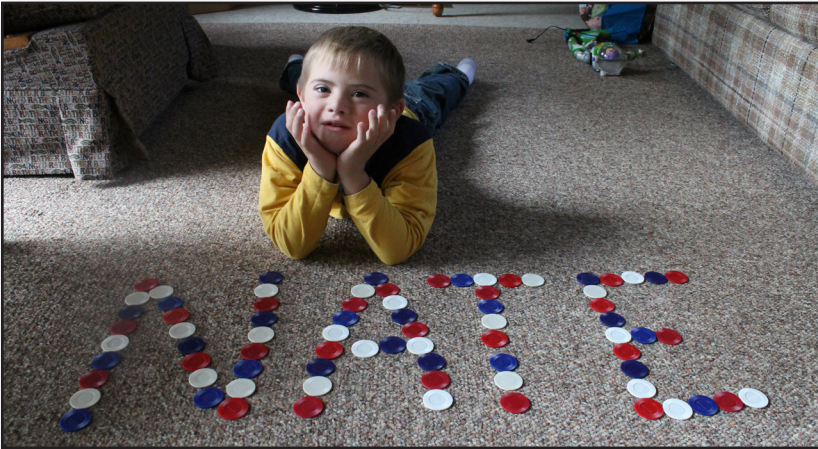
Nate!

Full Acceptance

Full Access

Full Life

Full Potential



New Program

Prenatal Diagnosis Education and Medical Outreach Program

Down syndrome is by far the most common chromosomal abnormality; therefore, the Down syndrome community is the first to address how the lack of information, quality of information, and personal physician bias impact decisions made by expectant parents.

Other disability groups will monitor and learn from the actions or inactions of the Down syndrome community. When genetic counselors and physicians were surveyed about giving a prenatal diagnosis of Down syndrome, 15% of genetic counselors and 37% of physicians used their own personal bias to sway an expectant parent's decision on how to react to the diagnosis.

Studies by the Special Olympics and by The American Congress of Obstetricians and Gynecologists (ACOG) show that:

- 81% of medical students report, “not getting any clinical training regarding individuals with Down syndrome.”
- 58% of medical deans say such training is not a high priority.
- 45% of The American Congress of Obstetricians and Gynecologists fellows and junior fellows rated their training as “barely adequate or non-existent.”
- Only 28% of ACOG fellows felt “well qualified” in prenatal genetic counseling.

In 2012, we will pursue grants to fund our Prenatal Medical Outreach program. This program will position DSAW to be a resource to medical professionals by training them to give a balanced and unbiased, accurate and up-to-date, and compassionate diagnosis of Down syndrome to expectant parents. Dr. Brian Skotko will conduct Grand Rounds where he will go around a hospital and talk to obstetricians about a new test called MaterniT21™ PLUS and Down syndrome. Each physician will be formally invited to attend lunch with Dr. Skotko to learn more about MaterniT21™ PLUS, how to deliver a compassionate diagnosis and how to talk about what Down syndrome is and isn't. Physicians and geneticists will be given tear-sheets provided by DSAW which will include valuable information on what it means to receive a Down syndrome diagnosis and give expectant parents contact information for DSAW to get more accurate up-to-date information on what the diagnosis means.

When doctors deliver a prenatal diagnosis of Down syndrome, he or she will give the parent(s) one of these informative sheets. Printed on the cardboard back of the pad will be information for doctors on how they can receive up-to-date balanced information on a Down syndrome diagnosis. We will also provide expectant parents with informative Down syndrome pregnancy packages and then provide them with new parent packages (available in English and in Spanish), a supportive and understanding community of parents of children with Down syndrome, and educational programs to help them become effective advocates for their children.

In 2012, we expect this new program to serve 200 families from a variety of cultural and socio-economic backgrounds across the state. Three new blood tests are now available that identify an unborn baby with Down syndrome with 97% - 100% accuracy depending on the test, with no risk to the baby.

\$500+ Corporate and Foundation Donors

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