

Down Syndrome Association of Wisconsin



2010 Annual Report to the community



The Down Syndrome Association of Wisconsin, Inc.

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Exceeding Expectations Every Day in Every Way!

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DSAW Self-Advocate Board Member Letter

In late 2006 I was asked to join the DSAW Board of Directors as its self-advocate board member.

As a Board member I have had many opportunities to represent DSAW. In 2007 and 2008 I was privileged to be the Walk ambassador.

My journey to independence in my own apartment came about with DSAW's help and encouragement. I hope to use that experience to advocate for others to find ways to make their dreams come true. My fellow board members listen to my ideas and are patient when it is difficult for me to make them understand. They realize that I can see things from the point of view of someone who has Down syndrome. As a board member I have met many families with young children who seem pleased to see the possibilities for their children. I have seen DSAW reach out to adults and youth with Down syndrome.



The Board members work hard and are very good at what they do. I am proud to be a part of the DSAW Board.

Andrew Gerbitz, Self-Advocate

Friends and Members of DSAW:

As you may know, 2010 marked the 20th anniversary of The Down Syndrome Association of Wisconsin, Inc. (“DSAW”). Twenty years have passed and there has been a sea of change in the way people with disabilities are treated in Wisconsin, the United States and the World. We are confident DSAW had something to do with the increasing awareness and acceptance of individuals with Down syndrome.

Our success has always been driven by the people dedicated to the organization, by those who give their time and talent to further the goal and mission of increased awareness and acceptance. We want to thank all of those involved in this organization. The founders of the organization, former and current staff members and former and current Board members deserve a hearty thank you. In its past, DSAW had been an all-volunteer-driven organization. Without the dedicated service of those volunteers, the organization would not be where it is now and the people who benefit from the organization would be in a different place in their lives.

Our success has been multiplied with the addition of staff members to our organization. The recent and current Board of Directors has made a conscious decision to increase the scope of the services DSAW provides through the use of professional staff members. Our staff members add unbelievable value to our organization for our members. Whether it is meeting one-on-one with caregivers, helping families formulate goals for Individualized Education Programs (“IEPs”), presenting “compassionate care” to child care providers or hospitals, or promoting awareness of Down syndrome by presenting to school children, DSAW and DSAW staff are adding value to our members and the Down syndrome community.

DSAW’s social events for members have continued strong and have increased. Over the past few years, we have added a number of programs such as Lose the Training Wheels and Behavioral Seminars to our list of events. Our traditional events such as the Holiday Party and Summer Picnic continue to be hits. We are adding more events such as a Valentine’s Day Dance to an already-full calendar.

Finally, perhaps the most important thing we did this past year was expand the geographic reach of DSAW into areas of Wisconsin. We now have active chapters in Chippewa Valley, the Fox Cities and Green Bay. Other areas such as Kohler and Janesville have shown an interest in starting more DSAW activity in their communities. Touching the lives of those with Down syndrome and their loved ones is of utmost importance; with the dedicated work of the volunteers in each of these areas across the state, we will continue to foster acceptance and awareness of Down syndrome throughout the state.

The value DSAW adds to your life is reflected in our Annual Report. If you are a potential investor in our organization, please know that your investment - whether monetary, through volunteers, through employment or through in-kind donations - is appreciated. The over 2,500 members of our DSAW community are impacted in a major way by our organization and your contribution.

We appreciate you being a part of DSAW’s success.

Very Truly Yours,

The DSAW Board of Directors

People with Down Syndrome 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 at hospitals and clinics throughout Wisconsin
- Family matching services
- Community education for members and health professionals
- Special events that bring families and individuals together
- Roadmaps to address the most important needs of members



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 across Wisconsin. 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.



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 2010 we saw the power and value of this Chapter model as our Green Bay and Fox Cities Chapters transitioned from emerging entities to financially self sufficient Chapters in just two years.

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.



Down Syndrome Association of Wisconsin

Our History

The Down Syndrome Association of Wisconsin, Inc. was founded by Joan Balliet, a nurse and mother of a child with Down Syndrome 20 years ago. 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 20 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.



Our History

continued

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 re-opened 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 and 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 were 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 2010 five walks were hosted across the state which were attended by 4,000+ walkers.



We have also arranged meetings with educational speakers. A highlight was being able to sponsor a statewide conference in central Wisconsin 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 & 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 2011 we have three Chapters across the state (Chippewa Valley, Fox Cities, Green Bay) and our main office in St. Francis, a suburb of Milwaukee.



2010 Annual Report - Accomplishments

- Created and distributed quarterly newsletter to 550 households
- Created and distributed monthly eBlasts to DSAW listserv with over 500 subscribers
- DSAW Sponsored Family Events included Annual Summer Picnic, Annual Milwaukee Brewers Tailgate Party, July 3rd Rooftop Fireworks Party and Annual Holiday Party
- DSAW Sponsored Community Education Workshop included Youth Behavior Seminar, 2 Part Young Adult Challenging Behavior Workshop, Special Needs Estate Planning Legal Seminar, Special Needs Estate Planning Financial Seminar and Housing for Individuals with Special Needs
- DSAW Sponsored Self Advocate Events included World Down Syndrome Day Financial Management Skills Workshop, IMPACT Day Computer Skills and Financial Skills Workshops and Annual Halloween Dance
- DSAW launched DSAW D.A.D.S. (**D**ads **A**ppreciating **D**own Syndrome) Chapter with a Bowling Party and currently hold monthly meetings
- DSAW co-sponsored its 3rd 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 challenges participated. After one week, camper success rate was at 80%
 - 6-24-2010 - “Depth perception and balance challenges made teaching our daughter to ride a two wheeler more difficult. We are incredibly grateful that DSAW sponsored Lose the Training Wheels and allowed Lydia to experience the “rite of passage” that comes with riding independently. Thanks DSAW!”
Jane & Kerry Winans
- DSAW hosted three major fundraising events including a partnership with the Milwaukee Brewers Wives and the Brewers Community Foundation raising almost \$20,000; 14th Annual Tom Pipines Golf Classic attended by over 130 golfers raised over \$22,000; and, 14th Annual Down Syndrome Awareness Walk attended by over 1,500 individuals with Down syndrome, their families and friends and raised close to \$100,000



- DSAW conducted one Teacher / Community In Service Training in the Medford School District which educated Regular Education Teachers, School District Administration and Community members on issues surrounding Down syndrome and the abilities / expectations of students with Down syndrome
- DSAW conducted one Paraprofessional In Service Training in the Medford School District which provided insight to paraprofessionals on issues surrounding Down syndrome and the abilities / expectations of students with Down syndrome
- DSAW developed and conducted five School Based Peer Sensitivity Presentations to raise awareness and promote acceptance of Down syndrome within the classroom
- DSAW is currently working to coordinate a Self Advocate Group for young adults and adults with Down syndrome
- DSAW conducted ten 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

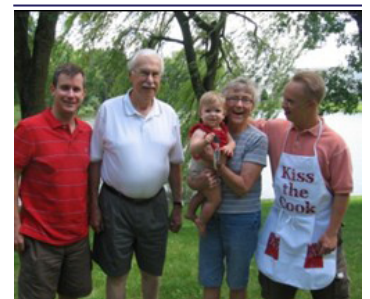
- A mom was concerned the school was not supporting her son appropriately, allowing him to reach his full potential. DSAW staff explained **F.A.P.E.** (Free and Appropriate Public Education), **L.R.E.** (Least Restrictive Environment), how to baseline and write solid **I.E.P.** (Individualized Educational Plan) goals that results in appropriate Supportive Services.

- *8-11-2010 – “I can’t say enough about how much DSAW has brought to our lives. They helped me understanding the IEP process, our rights, and how to work with Quinton’s teachers and school to achieve better communication between us and write goals that we as parents can understand and see progress towards. Thank you DSAW!” - Julie H.*

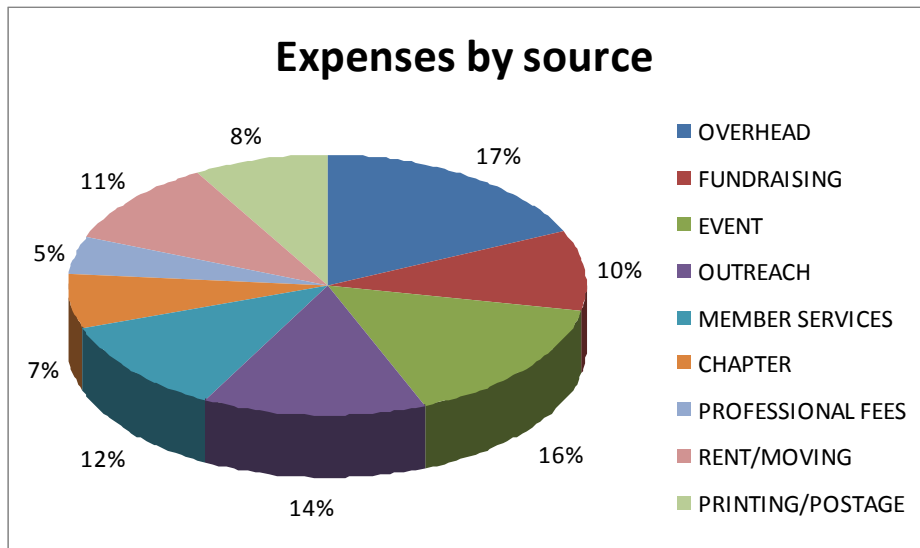
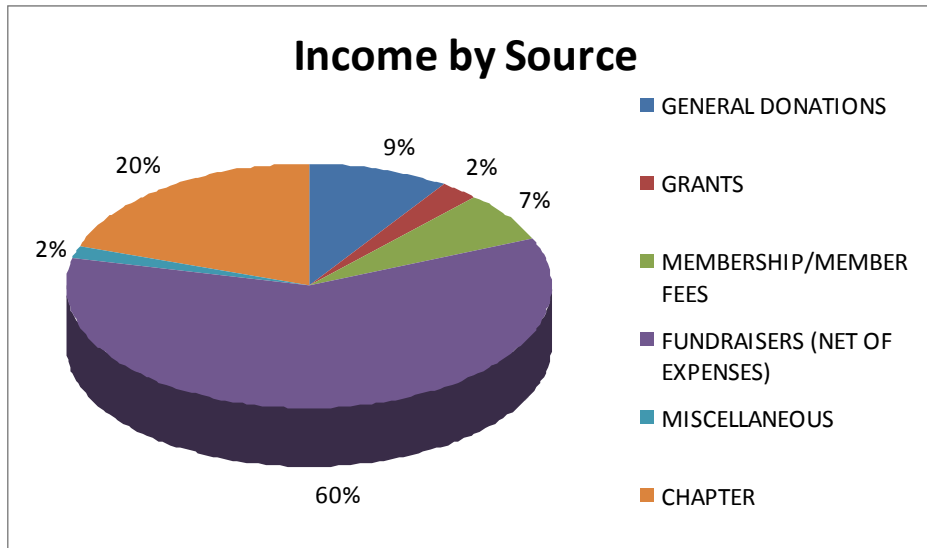
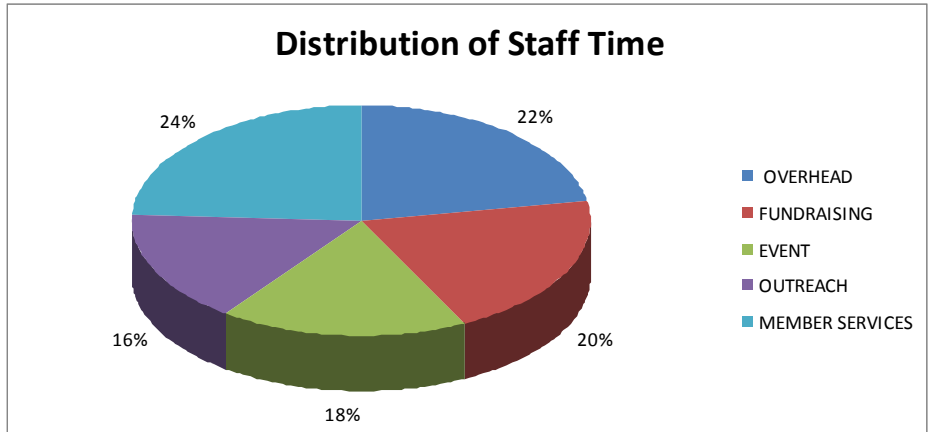


- DSAW has helped members realize adult dreams in areas such as caregivers, employment and housing. Specifically, DSAW helped Andrew realize his dream, challenged by waiting lists and lack of affordable housing in the community where he worked and his friends lived, Oconomowoc, WI. No less than 5 times over a 3 year period he was told there is no housing for you in our city.

- *“On February 28, 2010, I moved to my apartment. When Ron says it’s my dream apartment, he’s right on! My patio door windows overlook Willow Pond. Across the pond I can see the large hotel that is part of Olympia. The ski hill and golf course are also visible from my building. I have a washer and dryer in my apartment. Thank you” – Andrew*



2010 Financial Summary



continued

DOWN SYNDROME ASSOCIATION OF WISCONSIN, INC.
STATEMENT OF REVENUE AND EXPENSES - CASH BASIS
FOR THE YEAR ENDED JUNE 30, 2010

	Unrestricted	
INCOME		
Donations	\$ 15,647	
Grants	4,000	
Memberships	5,515	
Member Events	5,737	
Special Events Revenue	139,821	
Special Events Expense	(41,215)	
Chapter Revenue	32,758	
Miscellaneous Income	388	
Interest Income	2,370	
Total Revenue	\$ 165,021	
EXPENSES		
Wages	\$ 82,556	
Payroll Taxes	6,316	
Professional Fees	8,569	
Advertising	871	
Member Events	13,933	
Insurance	1,415	
Grant Awards	2,590	
Equipment Rental and Maintenance	4,242	
Outreach Program	3,621	
Dues and Subscriptions	1,753	
Telephone	2,045	
Office Supplies	1,517	
Rent	9,458	
Printing and Publications	12,203	
Postage	3,361	
Travel	1,031	
Conferences	4,541	
Moving Expense	10,176	
Resource Material	794	
Chapter Expenses	12,299	
Miscellaneous Expense	2,307	
Total Expenses	185,598	
CHANGE IN NET ASSETS	\$ (20,577)	
Net Assets, Beginning of Year	353,300	
NET ASSETS, END OF YEAR	\$ 332,723	



DSAW Office Staff

The Down Syndrome Association of Wisconsin is staffed by one full time Executive Director, a part time Office Manager and a part time Program Director. 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.W., 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
- Supported Living
- Supportive Home Care
- Peer Sensitivity
- Guardianship
- Transportation
- Dual Diagnosis Autism
- Celiac Disease
- Major Medical (Heart, Duodenal Arteresia...)

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 20



Daughter of
Ron Malloy
DSAW Executive Director

Tyler Fech age 13



Son of
Angie Mayer Fech
DSAW Program Director

Kyle Moon age 2



Son of
Ellen Moon
DSAW Office Manager

Down Syndrome Association of Wisconsin

Chippewa Valley Chapter

2010 Events

- World Down Syndrome Day
 - 150 people attended the World Down Syndrome Day event at Action City's Chaos Water Park to celebrate World Down Syndrome Day
- Awareness Walk
 - 700 people attended the Fourth Annual Down Syndrome Awareness Walk. The walk raised \$16,241.



DSAW Walk September 26, 2010

Income \$16,241
Expense \$ 7,367
Profit \$ 8,874



- Holiday Party
 - 75 people attended the First Annual Holiday Party. Santa provided gifts for the children and everyone enjoyed a 2 mile sleigh ride to and from a warm cabin where everyone was able to enjoy a warm beverage or snack.



- MISSION STATEMENT -

- Down Syndrome Association of Wisconsin Chippewa Valley is a local resource for people with Down syndrome and other developmental challenges, their families and others that support them. We are committed to providing support and information in the hope of cultivating awareness, respect and opportunity for those in our community touched by Down syndrome.



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CHIPPEWA VALLEY

Chippewa Valley Chapter

continued

We Offer:

- - SOCIAL
 - It is always fun to get our children together and share experiences. Regularly scheduled get togethers include: World Down Syndrome Day events, Awareness Walk, summer pool party and picnic, family social outings, and educational meetings.
- - FINANCIAL
 - We provide aid for local families in need who would like to participate in conferences and educational programs.
- - EDUCATIONAL
 - Scheduled speakers keep our group and the community informed on current Down syndrome related topics. Our newsletter offers current stories and important news, as well as a calendar of upcoming events.
- - OUTREACH
 - We provide an opportunity for parents to receive advice from other parents of children with Down syndrome who have faced many of the same challenges. Parent contacts are available to support and encourage. We will provide or help you find information to help you make informed decisions. In 2010 we provided Down syndrome related books that were distributed in New Parent Packets to local hospitals.
- - ADVOCACY/AWARENESS
 - Take advantage of our resource materials and contacts to help your advocacy endeavors. Participation in our annual Awareness Walk is a great way to get together with the local Down syndrome community while promoting awareness. In 2010 we added a number of new books to our resource library that were borrowed by our members and hosted our 4th annual Down Syndrome Awareness Walk.

Contact us at:

info@dsawchippewavalley.org

(715) 379-0563



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CHIPPEWA VALLEY

Down Syndrome Association of Wisconsin

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 2010, 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

2010 Events

DSAW Walk - October 3, 2010

Walk Income \$ 9,972

Walk Expenses: \$2138

Walk Profit: \$7,834

Miki Greaves Memorial Scholarship: \$787.98

Projected 2011 Events:

Trust & Family Planning Seminar

Christmas Party

Parent's night out

Playgroups

Mom/Dad's night out

Summer picnic

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 2010 the walk raised close to \$8,000.00. Currently there are approximately 90 members across 5 counties in northeastern Wisconsin.



Down Syndrome Association of Wisconsin

Fox Cities Chapter

Down Syndrome Association Wisconsin-Fox Cities

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

Down Syndrome Association of Wisconsin-Fox Cities (DSAW-Fox Cities) became a new chapter of DSAW in February, 2010. DSAW-Fox Cities serves families of individuals with Down syndrome in the Fox Cities area, specifically in Outagamie, Winnebago, and Calumet counties. Families residing outside these three counties are served on a case-by-case basis.

DSAW-Fox Cities
PO Box 2232
Appleton, WI 54912

Blog: <http://www.dsawfoxcities.blogspot.com/>

Website: www.dsawfoxcities.org

Facebook group: Down Syndrome Association Wisconsin Fox Cities Connection

Parent Network Coordinator and DSAW-Fox Cities Advisory

Committee Chair: Maria Steenepoorte, maria@dsawfoxcities.org

DSAW-Fox Cities' schedule of monthly events:

- 2nd Saturday gathering for families
- 4th Friday summer play date
- Advocacy/Support/Networking meeting
- Mom's Night Out
- Dads Appreciating Down Syndrome (DADs)Fox Cities

DSAW-Fox Cities' 2010 accomplishments:

- Served 70+ families via email group
- Served families and community via blog
- Increased outreach by creating a Facebook group and website
- Frequently submitted New Materials Suggestions to local public libraries to update resources
- Collaborated with NE Regional Center Children & Youth with Special Health Care Needs to reach hospitals, genetic counselors, perinatologists, pediatric and OB clinics, and Birth to 3 programs
- Increased distribution of Down syndrome information packets (from 20 to 53) to new and expectant families
- Donated 180 books to be included in the Down syndrome information packets
- Donated 6 Signing Time Classroom Edition kits to local school districts
- Doubled monthly scheduled events
- Held 30 social or educational events
- Participated in Building for Kids Children's Parade, and a community Halloween party for kids with special needs
- Hosted the 1st Annual Down Syndrome Awareness Walk which raised over \$60,500



Fox Cities Chapter

continued

DSAW-Fox Cities' plans for 2011:

New Outreach Programs:

- Care packages for families with major hospitalizations of individuals with Down syndrome

New Social Events:

- Sponsor party at Wild Air to celebrate World Down Syndrome Day which is March 21, 2011.

New Education and Awareness events and programs:

- IEP Workshop presented by DSAW Director, Ron Malloy
- Visual Learning Seminar presented by GiGi's Playhouse
- Spread the Word to End the Word campaign
- Sponsorship of 20 Kids on the Block Down syndrome presentations by the Arc Fox Cities to local schools
- Donation of books to preschools, childcare centers and church nurseries

New scholarships and Grants:

- 10 scholarships of \$200 available for the Lose the Training Wheels camp
- Sponsorship of speaker's fees for local workshops and conferences
- 40 sponsorships for participation in local sports leagues, for up to \$50 per sports participation fee
- 4 scholarships of up to \$2,500 for continuing education of individuals with Down syndrome
- 20 grants of up to \$250 for families to attend Down syndrome conferences and workshops



“Endless possABILITIES”



“FRIENDS”



“2010 DOWN SYNDROME AWARENESS WALK TEAMS”



Awareness Walk Team & Retired Board Member
Photos courtesy of Chrissy k-g Photography

Retired Board Members



Barb Balistreri
Joan Balliet
Andria Boyd
Kelly Brown
Heidi Dauer
Bill Dowsett
Charisse Erickson
Kevin Fech
Angie Fech
Ellen Feider
Bea Gerbitz
Enno Gerbitz
Mickey Harris
Ron Irwin
Maureen Keyes
Christa Kochanski
Julie Loyo
Robbin Lyons
Robert McIntyre
Michael McNally
Basil Mercado
Brian Nagai
Bob Neja
Robert Ochowicz
Jon Reetz
Carole Shafer
David Smith
Sue Stellhorn
Nancy Valkenburgh
Bruce Webster
Brian Young
Gary Zanoni

* Best efforts were made to capture retired board members and we apologize in advance if anyone was inadvertently omitted.

Board Members

Interested in attending a board meeting or joining our Board of Directors? Let us know!

Tom O'Day, President

today@gklaw.com

Tom O'Day is a native of Wauwatosa, Wisconsin and now lives in Milwaukee's North Shore. Tom is an attorney with Godfrey & Kahn, S.C. specializing in labor and employment law as well as education law. Tom currently holds the position of DSAW's President.

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 current practice include 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. 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.



Brian Perhach, Vice President

Brian Perhach lives in Whitefish Bay with his wife and three sons, one of whom has Down syndrome. 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.



Marita Stannis, Secretary

mstannis@live.com

Marita Stannis grew up in New Berlin and lives in West Allis with her husband Kevin and daughter Madelyn. Marita is a Health and Safety Professional at Bucyrus International. She graduated from the University of Wisconsin-Whitewater with a Bachelor Degree in Occupational Safety and Health. Marita became involved with DSAW after the birth of her daughter who was born with Down syndrome. She also serves on the DSAW Medical Outreach Committee.



continued

Pete Loeffel, Member at Large

Pete Loeffel lives in Wauwatosa, where he lives with his wife, Jennifer, and his 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 the 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 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.



Mary Pearson, Member at Large

pearson.mary@uwlax.edu

Mary Pearson PhD is currently an assistant professor of special education in the Education Studies Department at the University of Wisconsin La Crosse. Mary is originally from Utah, where she completed her Bachelor's of Science in significant disabilities, and her Master's of Education focused in developmental disabilities and secondary transition. She taught special education for 7 years in Utah, working with many students with Down syndrome and other disabilities. Mary also has worked extensively with people with developmental disabilities in group homes, respite care, and recreational activities. Mary has spent years as a private or peer tutor, and feels lucky that many of her former students and their families consider her a friend. Mary moved to Kansas in 2006 to complete her doctoral work at the University of Kansas, focusing in research, developmental disabilities, secondary transition, and teacher education. She was able to work extensively with the University of Kansas teacher education program and the Transition Coalition while there, and assisted in supervising and teaching future teachers in special education and conducting inservice activities as well. Mary is excited to serve on the board of the Down Syndrome Association of Wisconsin!



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ON THE UP WITH DOWN SYNDROME
Newsletter is published Quarterly by
The Down Syndrome Association of WI, Inc.

DSAW's *mission* is to provide support to families and individuals with Down syndrome through education, information and the exchange of ideas and experiences.

DSAW's *vision* is the understanding of the value of people with Down syndrome in our lives and the community. We will continue to strive towards full acceptance, full access, full life and full potential.

DSAW's *policy* is not to endorse any medical, therapeutic or special education alternatives. DSAW is a volunteer group consisting of people who wish to create an optimistic outlook about Down syndrome for our families and others. The purpose of this newsletter is to provide a source of information to the community and members on issues related to Down syndrome.

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