

# Down Syndrome Association of Wisconsin, Inc.



## 2013 Annual Report to the Community

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# DSAW Self-Advocate Board Member Letter

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As a self-advocate board member of the Down Syndrome Association of Wisconsin, I continue to serve by attending meetings and events whenever I can. I am frequently invited to participate in the peer sensitivity training that DSAW offers to schools. My fellow board members appreciate my input from the viewpoint of someone who has Down syndrome. I consider it a privilege to serve.

This year I became a participant in the IRIS program. IRIS stands for Include, Respect, I Self-Direct. DSAW has helped me to enroll in this program as well as to choose and hire the caregivers I need.

DSAW is also assisting me to transfer the responsibility for the supports I receive from my parents to my siblings. My siblings are learning to deal with government agencies that provide assistance with housing, income, health care, and supportive home care. DSAW is helping to make this a smooth transition.

The services DSAW provides for me are available to all its members. A phone call or email is all it takes.

Sincerely,

Andrew Gerbitz  
Self-Advocate  
DSAW Board of Directors

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# DSAW Board of Directors Letter

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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.

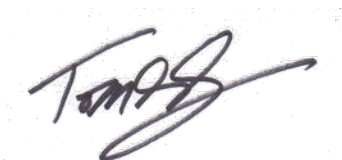
Your investment in our organization, whether as a member, donor or volunteer, allows DSAW to continue to serve as your partner. It allows DSAW to continue providing resources, referrals, support and education about all aspects of Down syndrome from birth to adulthood.

DSAW continues to make significant strides toward our ultimate objective of 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 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](http://www.dsaw.org) for more information about our organization and programming.

Sincerely,



Tom O'Day  
President  
Down Syndrome Association of Wisconsin Board of Directors

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# People with Down Syndrome are Valued and Included

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## **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](http://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
- \* Outreach to medical professionals on how to deliver an unbiased diagnosis
- \* Programming for new and expectant parents
- \* Programming for youth with Down syndrome
- \* Support Circles
- \* Individualized Education Planning (IEP)
- \* Peer Sensitivity Training
- \* Beyond High School, Transition Planning
- \* Support for Housing, Caregivers, Benefits, & Employment
- \* Self Advocacy
- \* DSAW D.A.D.S

## **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.



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# Core Values and Identity

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## **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
- Being 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.

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## Our History

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Joan Balliet, a nurse and mother of a child with Down syndrome, founded the Down Syndrome Association of Wisconsin, Inc. 21 years ago. She 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 22 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 database 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 park, 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 1<sup>st</sup> walk raised \$5,000 and had 75 walkers. In 2011, five walks were hosted across the state, which were attended by more than

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## Our History

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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, several advisory board members wanting to start a Chapter in their community approached DSAW. In 2009, DSAW moved the office into the Marian Center for Nonprofits for cost savings and nonprofit synergy. In 2013 a new Mantra emerged that Wisconsin would become the best-supported state in the country for those with Down syndrome. In 2013 we formally brought DSAW-Children of the Heart - Greater La Crosse Area on board as a new Chapter and transitioned the activities that supported the Greater Milwaukee Area which includes the Counties of Milwaukee, Waukesha, Racine, Kenosha, Walworth, Ozaukee, and Washington to the new Greater Milwaukee Area Chapter allowing the State Organization to focus on truly statewide initiatives such as employment, prenatal outreach, and school peer sensitivity outreach. We followed a successful pilot in 2013 to realize our vision that we all understand the value of those with Down syndrome in our lives and communities. DSAW formally passed a resolution creating DSAW Family Services, which supports DSAW's Vision of full acceptance, full access, full life and full potential by offering services to help those with Down syndrome self-direct their services in Wisconsin.



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# 2013 Annual Report - Accomplishments

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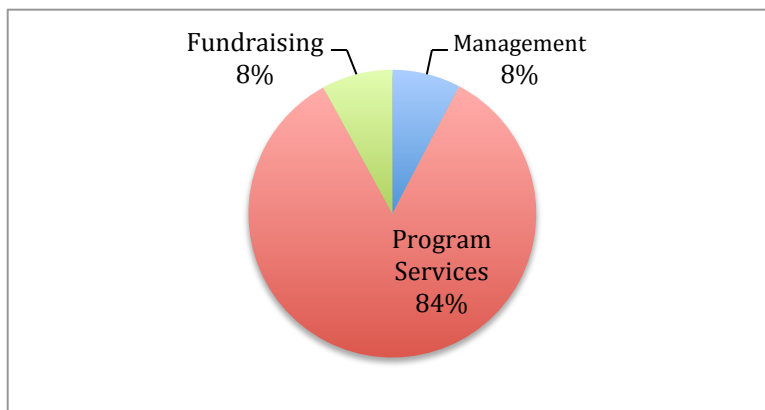
- Chapters Around Wisconsin added two new Chapters in 2013, the Greater Milwaukee Area Chapter and the Children of the Heart -- Greater La Crosse Area Chapter where there are now over 50 volunteer advisory board members across the state delivering high quality programming and support to families across the state. The programming by collective Chapters increased by 50% during 2013.
- Health Care Partnership & Prenatal Diagnosis Education and Medical Outreach updated our Spanish and English new parent packs adding the book "Gifts" to the packet of information and we also distributed the book "Understanding a Prenatal Down syndrome Diagnosis" to hundreds of OB GYNs. Our first grand rounds Physician-to-Physician educational outreach was scheduled in 2013 and will occur in 2014 at the Medical College of Wisconsin. A hands-on nutrition workshop was conducted for 15 self advocates and an educational seminar was held for 70 families on nutrition. Fifty-five families and representatives from 15 schools attend seminars on toilet training and behavior conducted in conjunction with the Down syndrome clinic of Wisconsin.
- iCan Shine™ Bike Riding Camp was conducted for the first time in Waukesha County realizing our goal of rotating the camp through the counties of Milwaukee, Ozaukee, Waukesha and Kenosha Counties annually. In 2014 DSAW plans to sponsor bike camps in the La Crosse and Green Bay areas.
- Our School Partnership Program added on a dedicated "School Peer Sensitivity Outreach Specialist" to present at the rate of one school per week in 2014. DSAW was called in as an expert consultant by two school districts in 2013 to help schools identify successful strategies for students with behavior challenges.
- Dads Appreciating Down Syndrome (D.A.D.S.) welcomed some new DADS in 2013 and conducted educational topics on guardianship, supplemental trusts and sibling support.
- Employment Connect in partnership with UW-Stout conducted a seminar to increase business's awareness of the benefits of hiring someone with Down syndrome that was attended by seven businesses and 15 job-coaching agencies. DSAW is coordinating an employment initiative intended to hire 10% of 50 workers with developmental disabilities at FedEx Smart Post in New Berlin, WI. The first person started working at FedEx this October and DSAW is coordinating the effort to include two government agencies (Include Respect I Self Direct-IRIS and the Department of Vocational Rehabilitation-DVR).
- Topic Specific Roadmap Sessions to help families overcome challenges and achieve dreams supported over 50 one-on-one sessions in 2013 in areas such as school behavior and academic challenges (25), employment (7), adult independent living (10), re-location into Wisconsin (10) and medical (5).
- The 2013 Annual Awareness for Down Syndrome, for the first time attracted 7,000 walkers for every one of the estimated 7,000 people in Wisconsin who have Down syndrome.
- DSAW added a "Nutrition, Health and Wellness" grant in response to our self-advocates asking for more support around maintain a healthy weight and exercise. A new grant to help families with "adoption costs" was also added.
- Volunteer Programs recognized our board members with portraits of a 3 year old with Down syndrome dressed in a tuxedo with his hands raised in celebration captioned with DSAW's vision.

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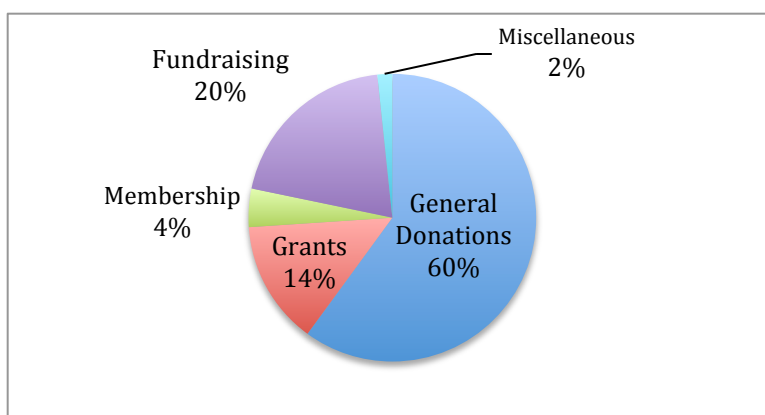
# 2013 Financial Summary

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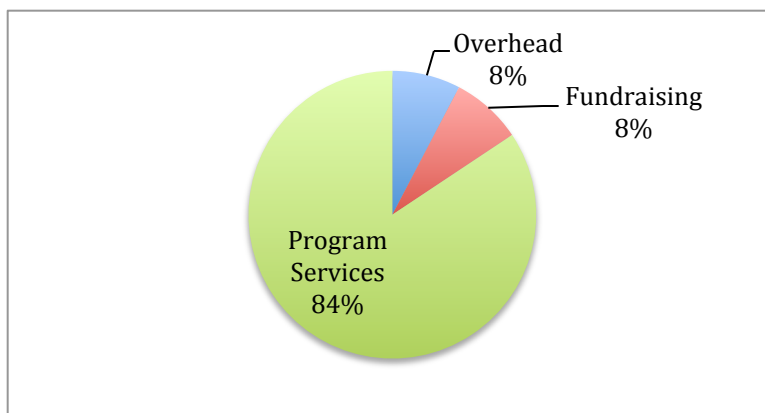
## Staff Time



## Income by Source



## Expenses by Source



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## DSAW Office Staff

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The Down Syndrome Association of Wisconsin is staffed by one full time Executive Director and a part time Office Manager and part time Office Assistant. 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 Atresia etc.)

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 24  
Daughter of Ron Malloy, DSAW Executive Director  
with Anna Couwenhoven, Walk Ambassador*



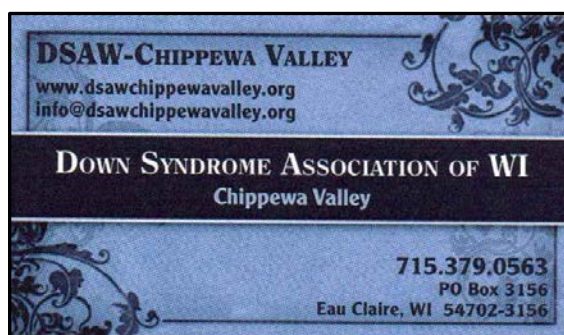
*Kyle Moon age 4  
Son of Ellen Moon  
DSAW Office Manager*

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# DSAW Chippewa Valley

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The Down Syndrome Association of Wisconsin, Inc. – 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.



LIKE our group on **FACEBOOK** Down  
Syndrome Association of Wisconsin  
Chippewa Valley



**Send a Friend Request to:**  
DSAW Chippewa Valley



***"EXCEEDING EXPECTATIONS EVERY DAY IN EVERY WAY"***

**Down Syndrome Association of Wisconsin--Chippewa Valley**

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# DSAW Chippewa Valley

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DSAW-Chippewa Valley sponsored family events that included the Parents Night Out, Annual World Down Syndrome Day Waterpark Event, Chippewa Valley Roller Derby, Bowling and Pizza Party, Ladies Day, DSAW D.A.D.S. Brewer Outing and Tailgate, Art in the Park, Down to Earth Fall Event, and the Annual Holiday Party.



- DSAW-CV served over 75 families and more than 200 supported members via email.
- DSAW-CV increased outreach through a Facebook group and page as well as the website.
- DSAW-CV distributed Down syndrome information to new families in the area.
- DSAW-CV hosted an Employment Connect Lunch and Learn for local community businesses.
- DSAW-CV offered scholarships for families with a family member with Down syndrome.
- DSAW-CV provided information at the Youth Transition Conference to share information with other community organizations and agencies, as well as people with special needs.
- DSAW-CV participated in and supported local awareness events such as “Spread the Word to End the Word,” “Werner Electric Beard-Off” and the Polar Plunge for Special Olympics.
- DSAW-CV hosted our 7<sup>th</sup> Annual Down Syndrome Awareness Walk in Irvine Park with attendance of 950, which raised over \$25,000.
- DSAW-CV hosted a Roadmap Session presented by DSAW Executive Director, Ron Malloy.
- DSAW-CV will continue to provide scholarships and grants for supported individuals and families.
- DSAW-CV Advisory Board Members attended a DSAW, Inc. Leadership Retreat.
- DSAW-CV will continue to strive towards full acceptance, full access, full life and full potential!!!



*Imagine The PossABILITIES...*



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# DSAW Green Bay Connection

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## 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; in 2013, the walk raised \$20,000. Currently there are approximately 120 members, across five counties in Northeastern Wisconsin. We continue to enjoy growth and recognition in our area.

## In 2013, the Green Bay Chapter of the Down Syndrome Association held the following events:

**World Down syndrome Day Celebration:** In March 2013, 10 families joined us to celebrate World Down Syndrome Day with bowling and pizza. For many of the families in attendance this was their first DSAW-Green Bay event. Everyone enjoyed themselves and many new relationships were formed.

**R-Word/Educator Seminars:** In January 2013, representatives from DSAW-GB met with educators and students at Lincoln Elementary School in Green Bay. It began with an open form with the school staff regarding use of the R-word by staff and students and the impact that it has on families of children with all disabilities. We discussed person first language and the importance of appropriate inclusion options. The staff was very open to our discussion asked a lot of questions and was very appreciative of the information we presented. At the all school assembly, we focused on the word RESPECT, as the staff was concerned about introducing the "R-word" to the younger student body. With the help of a local Special Olympics athlete competing in the 2013

World games, we were able to answer questions about how the students should treat a person with disabilities, what causes disabilities, and we even talked about how disabilities can't always be seen (learning differences). The students were very candid with their questions and enthusiastic about the content. Every student was given a spread the word shirt that also focused on the word RESPECT. The staff stated later that the students got a lot of great information from the assembly.



In May, we presented a Down syndrome specific talk to the members of the Green Bay West Lions. The group requested this talk, as they have members who have a child with Down syndrome. They asked for information about the condition, what advances had been made in education (the average age of this group was 55), and what they can do to help support the family. Overall the talk was well received and many of them were surprised by the information. This talk will be duplicated to another Lions club in 2014.

**5th Annual Down Syndrome Awareness Walk – Held at Lambeau Field:** More than 525 walkers joined us on October 12, 2013 to traverse the route around Lambeau Field to celebrate our loved ones with Down syndrome. Emceed by Devon Ashmann of local radio station WIXX, our walkers enjoyed food, fun, information, and an awesome raffle. Major sponsors included Associated Bank, BayTek, the Green Bay Packers and NFL Alumni Association.

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# DSAW – Green Bay Connection

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**Monthly Play Groups:** Monthly playgroups were held at Kidz Town in Green Bay for families with those affected by Down syndrome. The kids made a lot of new friends and parents were able to develop a strong support network.

**New Parent Packets:** 100 New Parent Packets distributed to local hospitals a collaboration with the Children and Youth with Special Healthcare Needs Clinic at Children's Hospital of Wisconsin – Fox Cities.

## **Projected 2014 Events:**

- Monthly Parents Nights Out with provided day care
- Monthly Playgroups
- 2014 World Down Syndrome Day Family Celebration
- R-Word/Peer Sensitivity/Educator Sensitivity Seminars
- iCan Shine™ Bike Camp
- 6th Annual Down Syndrome Awareness Walk



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# Down Syndrome Association Wisconsin-Fox Cities

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**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](http://www.dsawfoxcities.org)

**Email:** [info@dsawfoxcities.org](mailto:info@dsawfoxcities.org)

**Facebook group:** Down Syndrome Association  
Wisconsin Fox Cities



**Parent Network Coordinator:** Maria SteenePoorte, [maria@dsawfoxcities.org](mailto:maria@dsawfoxcities.org)

## **DSAW-Fox Cities Advisory Board:**

Maria SteenePoorte, *President*

Shanna Buettner

Debbie Merkel, *Vice-President*

Sherry Nedens

Michelle Zoromski, *Treasurer*

Sara Pingel

Karen Domer, *Secretary*

Tim Verboomen

Melanie Baeten

**DSAW-Fox Cities History:** DSAW-Fox Cities became a new chapter of DSAW in February 2010, and formed an Advisory Committee of 5 individuals in January 2011. DSAW-Fox Cities then formed an Advisory Board of 8 individuals in January 2012.

## **DSAW-Fox Cities' 2013 scheduled monthly events:**

- 3rd Tuesday DS Walk Committee meeting & Advisory Board meeting
- Mom's Night Out

## **2013 Annual Events:**

- 3rd Annual DSAW-Fox Cities World Down Syndrome Day Celebration
- 1st Annual DSAW-Fox Cities Summer Pool Party
- 4th Annual Down Syndrome Awareness Walk
- 2nd Annual DSAW-Fox Cities Holiday Party



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# Down Syndrome Association Wisconsin-Fox Cities

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## DSAW-Fox Cities' accomplishments from January through December 2013:

- Totaled 120 families on the supported family database
- Communicated with 99 supported families on the private Google email group
- Contacted 938 individuals on the DS Awareness Walk email list
- Distributed the monthly e-newsletter to 200 families and organizations
- Raised \$59,000 before expenses at the 4th Annual Down Syndrome Awareness Walk with 1450 walkers
- Distributed 21 Down syndrome information packets 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 60 books for new parent Down syndrome information packets for a total of \$600
- Distributed 35 "Understanding a Down Syndrome Diagnosis" and "Delivering a Down Syndrome Diagnosis" pamphlets to local medical professionals.
- Donated 6 Signing Time Classroom Edition kits to local schools for a total of \$1,800
- Frequently submitted *New Materials Suggestions* to local public libraries to update Down syndrome resources
- Donated shirts to 13 schools in the Spread the Word to End the Word campaign for a total of \$3,600
- Donated grocery/gas gift cards to two families experiencing extended hospitalization for total \$200
- Sponsored 13 sports participation scholarships totaling \$985
- Sponsored two performing arts participation scholarships totaling \$200
- Sponsored one individual for the iCan Shine™ camp for total \$400
- Sponsored participation of parents in national Down syndrome conferences for total
- Created 1one new scholarship opportunity for summer camp participation
- Sponsored two applicants for the Timothy Ditter Post-Secondary Education Scholarship
- Sponsored Handwriting Without Tears workshop & take-home kits for 36 attendees for total \$10,000
- Sponsored toilet training and behavior workshop led by Alice Belgrade
- Hosted CESA presentation of FAPE and IEP
- Hosted Development and Sexuality Workshop serving 17 parents.
- Hosted a hospitality room at an indoor Halloween party for families of kids with special needs
- Sponsored the 3rd annual World Down Syndrome Day Celebration at Monkey Joes for 29 families
- Sponsored the 1<sup>st</sup> annual Summer Pool Party at Doyle Park Pool for 15 families
- Sponsored DSAW-Fox Cities tables for our families to attend local fundraising dinners of other community organizations that also serve families of individuals with special needs
- Sponsored a Down Syndrome Awareness Team in the Green Bay Marathon



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# DSAW-Sheboygan and Surrounding Counties

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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, Wisconsin, 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](mailto:joy@dsaw.org)



## 2013 Events

DSAW Walk – October 12, 2013

Attendance: 200+ Walkers and Bean Bag Participants

## Looking to 2014 and 2015:

The DSAW Sheboygan Chapter is in the growth stage and is looking to expand our Advisory Board to best serve our constituents. We want to hear from you! Families and individuals who would like to share their ideas on programming they would like to see in our communities.



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## DSAW – Children of the Heart-Greater La Crosse Area

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The Down Syndrome Association of Wisconsin – Children of the Heart – Greater La Crosse Area is proud to serve as a resource to families in La Crosse, Monroe, Vernon, Juneau, and Adams Counties in Wisconsin. Due to our close proximity to our neighboring states, we also provide resources to families in Southeast Minnesota and Northeast Iowa.

Our vision 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.

DSAW-COTH-GLA is here to support families. We support and advocate for children and adults in a wide age range. We are respectful of the choices families are making based on the phase of life they are currently in.

Children of the Heart (COTH), La Crosse's first group for family and friends of people with Down syndrome, was founded in 1996. The group provided an opportunity for families to support each other through social functions and information sharing. As the membership grew and the needs of the members changed, Children of the Heart began to realize the benefits of being part of a larger organization. In April 2013, Children of the Heart officially became a chapter of the Down Syndrome Association of Wisconsin. We are looking forward to working with DSAW to continue to raise awareness of the ABILITIES of people with Down syndrome.



DSAW-COTH-GLA  
PO Box 796  
Onalaska, WI 54650  
(866) 327-DSAW

Our email address is:  
[info@dsawlacrosse.org](mailto:info@dsawlacrosse.org)

Find us on the web at: [www.dsawlacrosse.org](http://www.dsawlacrosse.org)

Find us on Facebook: [www.facebook.com/dsawlacrosse](https://www.facebook.com/dsawlacrosse)



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## DSAW – Children of the Heart-Greater La Crosse Area

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- DSAW-COTH-GLA sponsored three educational presentations in 2013.
- DSAW-COTH-GLA attended a fishing outing hosted by the North American Squirrel Association (NASA) at their private pond. Fifteen NASA volunteers assisted 54 people in catching trout and then prepared a meal of fish for everyone afterwards.
- DSAW-COTH-GLA hosted a Christmas party social attended by 72 people, representing 25 families.
- DSAW-COTH-GLA sponsored a Down Syndrome Awareness Walk attended by approximately 850 people and raising a net profit of just over \$18,000.
- DSAW-COTH-GLA sponsored a monthly music therapy group hosted by Life in Harmony Music Therapy giving our parents of our youngest members a chance to socialize on a monthly basis while engaging their children in a fun and therapeutic activity.
- DSAW-COTH-GLA served 63 people on our closed Facebook group.
- DSAW-COTH-GLA served 66 people through our email distribution list.
- DSAW-COTH-GLA distributed baby bags with our contact info and a gift book to local hospitals as a congratulatory gift to new parents.
- DSAW-COTH-GLA distributed \$2,700 to supported families through the Family Enrichment Grant program.
- DSAW-COTH-GLA sponsored five “Roadmap Sessions with Ron” 1:1 educational sessions for area families.



In addition to continuing our 2013 programs mentioned above, we have the following new programs planned for 2014:

- iCan Shine™ Bike Camp
- Awareness events: World Down Syndrome Day Celebration, marketing campaigns within the local media throughout the year
- Two Peer Sensitivity Trainings in area schools
- Developing a Self-Advocacy Program for older teens and adults
- Developing a Speech Initiative to help families access private speech services and to provide several educational presentations related to speech topics
- Distribute a quarterly newsletter to share information
- Build interest in our website and public Facebook page

2014 promises to be a year of growth for DSAW-COTH-GLA. We are excited to enrich the lives of people with Down syndrome in the Greater La Crosse area.



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## DSAW – Greater Milwaukee Area

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In late 2013, DSAW started the Greater Milwaukee Area Chapter to offer dedicated support for individuals with Down syndrome, their families, and others who support them in the following counties, Milwaukee, Waukesha, Racine, Kenosha, Walworth, Ozaukee, and Washington.

DSAW- Greater Milwaukee is proud to have their first Annual Down Syndrome Awareness Walk on May 4, 2014 at the RecPlex in Pleasant Prairie featuring Emmy Nominated Rachel Coleman! There is an expected turnout of about 200 walkers. There will also be other events held throughout the year including a summer picnic, Halloween dance and a Holiday party for all members. Many services are provided to the members as well, like individual IEP and Roadmap sessions as well as group seminars and educational events.

DSAW- Greater Milwaukee is always welcoming new families and volunteers! If you would like more information please contact the office at 414-327- 3729 or via email at [info@dsaw.org](mailto:info@dsaw.org)





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## Board Members

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### **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, he 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 specializing in employment law, government affairs and school law in the Milwaukee area.

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.

### **Andrea Zahn, Treasurer**

Andrea Zahn is a native of Brookfield and now resides in Waukesha. She is the Director of Sales and Marketing for The Iron Horse Hotel in Milwaukee. 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 sales and marketing to help DSAW. Andrea also chairs 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.



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## Board Members cont.

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### **Mike Knoebel, Vice President**

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. Professionally, Mike is the Program Manager for Pro Unlimited, overseeing the contingent labor program for Briggs & Stratton. Mike got involved in DSAW after the birth of his son, Matthew age 7, and was actively involved in helping launch the DSAW D.A.D.S. group. In his free time he enjoys reading, golf, and volunteering at Saint Dominics in Brookfield.



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

Marita Stannis resides in New Berlin with her husband, Kevin, and daughter, Madelyn. Marita graduated from the University of Wisconsin- Whitewater with a Bachelors Degree in Occupational Safety and Health and is a Health and Safety Professional at Caterpillar. Marita became involved with DSAW after the birth of her daughter taking on different roles including Secretary of the DSAW State Board of Directors and the Chairperson of DSAW's Medical Outreach Committee. She enthusiastically took on the role of President for the Greater Milwaukee Chapter as a way of helping individuals with Down syndrome and their families in her own area. Marita enjoys spending time with her family and traveling in her free time.



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

Mike Bare is a native of Manitowoc, Wisconsin, and currently resides in Verona with his wife. Mike is Research and Program Coordinator 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 political 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.



### **Pete Loeffel, Member at Large**

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





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## Board Members cont.

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### **Liz Streubel, Member at Large**

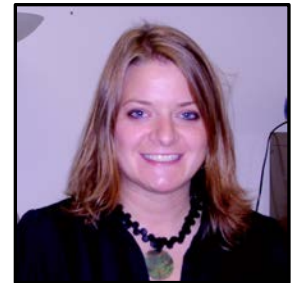
Liz Streubel lives in Whitefish Bay with her husband Vince, her two children, and dog. She is a special education teacher for the West Bend School District teaching special education at Jackson Elementary for grades kindergarten through fifth. Liz graduated from the University of Wisconsin Madison with 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. She enjoys consulting with families and schools on IEPs, Functional Behavior Assessments, and developing Behavior Intervention Plans.

### **Amy Bontempo, Member at Large**

Amy Bontempo resides in Milwaukee with her husband, daughter, and dog. Amy earned her Bachelors Degree in Social Welfare from the University of Wisconsin-Milwaukee and is a licensed Social Worker through the state of Wisconsin. Amy has been employed by Penfield Children's Center in Milwaukee for over 12 years. Amy began her career at Penfield as a Birth-to-Three Service Coordinator. Amy is now the Manager of Family and Community Engagement. Responsibilities include managing the Parent Mentor Program, Family Programs, Kohl's Building Block Outreach and Education Program, and Volunteer Services for the agency. Amy has held positions on DSAW's Advisory Board, the State Board, and currently is Vice President of the Greater Milwaukee Chapter.



### **Kerry Laurin**

Kerry Laurin lives on Milwaukee's East Side with her husband. She is a research analyst for Heartland Advisors and is a CPA and a Chartered Financial Analyst. Kerry graduated from Marquette University with a bachelor's degree in English and Secondary Education. She received her Master's degree with a concentration in Accounting from the University of Wisconsin – Milwaukee. Kerry became involved in DSAW through co-workers at Heartland. In her free time she enjoys travel, running and wine tasting.

### **Sandy Siira, Member at Large**

A Milwaukee area native, Sandy Siira is currently a Managing Director of Human Resources with FedEx and has held executive level human resources positions over the past fourteen 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. Also, a professional coach, Sandy has been certified by the International Coaching Federation. 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 includes board member of St. Coletta Day School of Milwaukee, United Way of Waukesha County's Developing Self-Reliance committee member, Alverno College Alumnae board member and student assessor at Alverno College.



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## Board Members cont.

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### **Jim Fackleman**

#### **Jeff Kallio**

Jeff Kallio is a native of Hartland and now resides with his wife and two daughters in Mequon, Wisconsin. He is currently Managing Director and Chief Compliance officer for Racon Capital Partners, an SEC registered alternative investment firm headquartered in Milwaukee. Prior to joining Racon, Jeff managed the finance and banking division at Stark Investments, which at the time was one of the world's largest hedge funds. Jeff is a graduate of Marquette University Law School and the University of Wisconsin Milwaukee. He is a member of the Wisconsin State Bar. Prior to joining the DSAW state board, Jeff actively served on the DSAW finance and audit committee.



#### **Nicole Cook**

Nicole Cook lives in Bayside, Wisconsin with her husband Jack and their children, Lily and William. Nicole is a tax senior manager at Deloitte in the Private Company Services 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.

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# DSAW Family Services, Inc.

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In 2012 the DSAW State Board authorized a pilot where DSAW would provide paid services to providers such as the Wisconsin IRIS Program (Include Respect I Self Direct) which supports adults with Down syndrome in Wisconsin self direct their community based supports and to provide services to different counties across the state through their Family Support Programs that provide supports to children in Wisconsin.

Following a tremendously successful pilot engagements in 2013 DSAW formally passed a resolution to offer Support Broker services, Family Governed Coordinator and Community Supported Living Services to individuals in Wisconsin who want to self direct their supports as part of the Wisconsin IRIS Program through a new organization named DSAW Family Services. DSAW Family Services is also offering services to coordinate group buys of Speech Therapy Blocks of time for our Chapters, conducting Independent Functional Behavior Screens and Independent Behavior Intervention Plans to School Districts around the state, as well as providing Consumer Education and Training Seminars through the Family Support Program.

The new board of Directors for DSAW Family Services is:

**Ellen Trytek, President**

*Chief Marketing Officer, Clifton Larsen Allen*

**Mark Andres, Vice President**

*Lead Attorney, Blommer Peterman, SC*

**Jill Boyle, Treasurer**

*CPA, Schenck SC, Non-Profit Specialization*

**Jill Van Calister, Secretary**

*Management and Leadership Executive*

**Joe Malloy, Member**

*Accounting Manager*



DSAW-FS helps people like Noah realize his dream of going to college.

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# Top Individual, Corporate and Foundation Donors

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\* Donors listed in alphabetical order.

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Eric Trau  
UAW Local 469  
United Health Group  
US Bank  
Utphall Construction  
Phyllis Verhaalen  
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Daniel Wollner  
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Wisconsin Athletic Club  
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