



DSAWM
Down Syndrome Association of West Michigan

Serving

341
Families

With

316
Individuals with
Down syndrome

Across

12
Counties

2016-2017 Annual Report

The Down Syndrome Association of West Michigan strives to create communities that embrace Down syndrome, empower individuals, and promote opportunities for meaningful lives.





Letter from the Executive Director

The Down Syndrome Association of West Michigan experienced a year of change in 2017, thus giving us our first biannual report for 2016/2017! We have added several new board members and an entirely new staff. Change brings growth and new ideas and we have so many exciting programs and opportunities for our members at DSAWM. It is both an honor and a privilege to serve as the Executive Director. This role has provided me with an opportunity to lead a dynamic organization at a time when there is tremendous potential.

As an organization, we are led by our mission. Our primary goal is to create communities that embrace Down syndrome, empower individuals, and promote opportunities for meaningful lives. Today, the goals of the association have grown to encompass advocacy, education, and public awareness in the West Michigan community.

As you look through this annual report you will see highlights from the previous two years and many pictures of the members and families that we were able to impact. Our focus is to continuously improve our organization and listen to our members. We welcome and value your questions, comments, and concerns in which to better serve you. I'm looking forward to continuing the good work of those that came before me and building a sustainable organization that will be here for those with Down syndrome in the future!

Sincerely,

Jennifer DeVault
Executive Director



Letter from the Board President

Our daughter Katie, my wife Julie, and I joined the DSAWM when we moved to West Michigan from southeastern Pennsylvania at the beginning of 2015. Two years later I joined your Board of Directors and in May of 2017 became your Board President.

Each year your Board examines and approves a budget that aligns our funds with our expenses. This alignment of funds and expenses insures our year-to-year ability to serve the members and to accomplish our mission. Using an annual survey, monthly reports from the DSAWM staff, and contact with our members, the Board listens to you. That information helps us provide 'big picture' guidance to Jennifer about the Association's programs for members, support for families and caregivers, information for the community, and advocacy on behalf of all members. The Board also supports finding, enrolling, and serving new Association members throughout West Michigan.

I want to represent an Association that cares about each member with Down syndrome and each family and caregiver who supports those members. If I am successful, I identify obstacles to members' happiness and remove them. To achieve that success, I devote a part of every day to making life better for our members and every person in West Michigan who meets or interacts with our members.

Sincerely,

Tom Hackett
DSAWM Board President

DSAWM Staff



April Sawhill
Executive Director
thru May 2017



Jennifer DeVault
Executive Director
July 2017-Present

Katherine Key Griswold
Program Director
thru May 2017

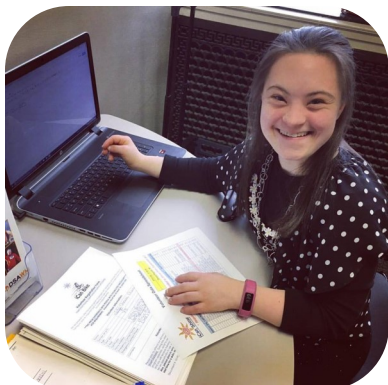


Nate Clark
Program Director
September 2017-Present

Meredith Lange
Communications Director
thru December 2017



Audrey Day
Administrative Assistant
thru November 2016



Victoria Hart
Administrative Assistant
November 2017-Present

Allie Cowden
Intern



DSAWM Board of Directors

June 2016 - May 2017

Maggie McPhee
President

Jim Leach
Vice President

Sean Igoe
Treasurer

Bobbie Blanton
Secretary

Members at Large

Bob Boylen
Diane Estrella
Jill Fouch
Tom Hackett
Andrew Kortesoja
Maureen O'Brien
Roshelle Paul
James Reinhardt
Brad Rivard
Nancy Spanski
Mike Wolff

May 2017 - Present

Tom Hackett
President

Brad Rivard
Vice President

Sean Igoe
Treasurer
May 2017-November 2017

David Wood
Treasurer
November 2017-Present

Roshelle Seals
Secretary

Members at Large

Jill Fouch
Patty Heffernan
Maggie McPhee
Maria Nykerk
Maureen O'Brien
Nancy Spanski
Mike Wolff
David Wood

2016 Highlights



ABLE Documentary

Some of the biggest barriers facing people with Down syndrome are misconceptions about their abilities. In ABLE, West Michigan residents with Down syndrome shared their experiences and hopes for the future. The documentary, produced by DSAWM and GSM Creative, can be viewed on YouTube.

Aging Support

Thanks to medical advances, the life expectancy of people with Down syndrome has increased. As a result, families are facing new challenges. Current research shows that half of people with Down syndrome will develop Alzheimer's Disease, showing signs as early as their 30s. To support families on this new leg of their journey, DSAWM and the Alzheimer's Association collaborated to create Aging with Down Syndrome, a support group that invites caregivers to share their experiences and discuss the process of caring for loved ones as they age.



Don't We Already Do Inclusion?

Dr. Paula Kluth – consultant, author, advocate, special educator, scholar, and inclusion facilitator – shared with educators and parents how those concerned about inclusion can create change even when they are not in positions of power. The activities, examples, and illustrations in her workshop helped participants refine their vision and skills in

advocating for inclusive educational environments. “Paula left us feeling inspired and motivated to move in new directions in order to support 100% of our kids,” said one educator. 88 parents and educators from as far away as Chicago and Michigan’s Upper Peninsula attended the day-long conference. 100% of attendees ranked Dr. Kluth as an excellent presenter and said they would use the information presented. One parent raved, “We loved the conference. As new parents, we weren't sure we would get anything out of it. We are SO happy we signed up for it. It was wonderful!”

Medical Outreach

Medical professionals are often the first to communicate to a family their newborn's Down syndrome diagnosis and this experience has a lifelong impact for parents. DSAWM is committed to providing resources and support to medical professionals who are involved in delivering a diagnosis of Down syndrome to new and expectant parents. These resources are available in English and Spanish on our website. In 2016, DSAWM:

- Distributed 230 new and expectant parent guides to 13 West Michigan agencies
- Developed “A Physician's Role: Delivering a Down Syndrome Diagnosis” brochure containing personal stories from our members and information for local medical professionals
- Developed a presentation targeted to practitioners providing a pre-natal diagnosis



Communication Skill Development

In 2016, DSAWM launched therapy focused playgroups for children with Down syndrome. Tiny Talkers and Wordplay provided fun opportunities for speech development for children ages 0-7. Baby Signing Time classes provided families with a valuable communication tool for non-verbal and developing speakers. The success of these programs encouraged DSAWM to consider offering playgroups focused on supporting motor and fine developmental skills in children with Down syndrome.

2017 Highlights

Community Open House

With dozens of new families joining the organization every year, the time had come for DSAWM to find a larger area out of which to operate. In February, the DSAWM office moved into its redesigned space in the Grand Rapids Masonic Center. Friends, families, and community partners were invited to tour the expanded facility featuring a parent lounge and playroom. The open house gave staff the opportunity to meet many new and veteran members, as well as discuss the new programming and service opportunities available with the expansion.



Step Up for Down Syndrome

After three consecutive years of record breaking fundraising and crowds, the Step Up for Down Syndrome Walk has become the largest Down syndrome awareness event in Michigan! In 2017, on its 21st anniversary, Step Up saw the largest crowd in the event's history. Over 1,500 people gathered at John Ball Zoo to celebrate and support loved ones with Down syndrome. 79 teams helped raise over \$135,000 to support the programs and services offered by DSAWM. In 2018, DSAWM wants to hit those numbers out of the ballpark. Literally! The 22nd Step Up for Down Syndrome event will be held on September 22nd at Fifth Third Ballpark.

Self-Advocate Brunch

Advocacy is a powerful tool for change. Few have been more vocal in advocating for the rights and opportunities of people with Down syndrome than Carrie Bergeron. Carrie is a self-advocate, author, motivational speaker, former board member of the National Down Syndrome Congress, and serves on the Self-Advocacy Council. In May, DSAWM members were invited to the Power Your Potential advocate brunch where Carrie spoke about the importance of recognizing ability. "I have taken the 'dis' from disability and made it my ability to advocate for those of us with special needs," she explained. "Those of us with any kind of special needs need to be looked at as human beings because we have the same hopes, dreams, and desires as anyone else."

Food For Thought

In January DSAWM introduced a new learning series aimed at educating parents, caregivers, and self-advocates about the opportunities available to them and their loved ones here in West Michigan. Food For Thought welcomes guest speakers each month to lead presentations on a variety of topics related to Down syndrome. MiAble kicked off the series with a discussion about financial planning, opening the floor to many other topics including IEPs, sibling support, educational advocacy, and healthy living.



New Staff

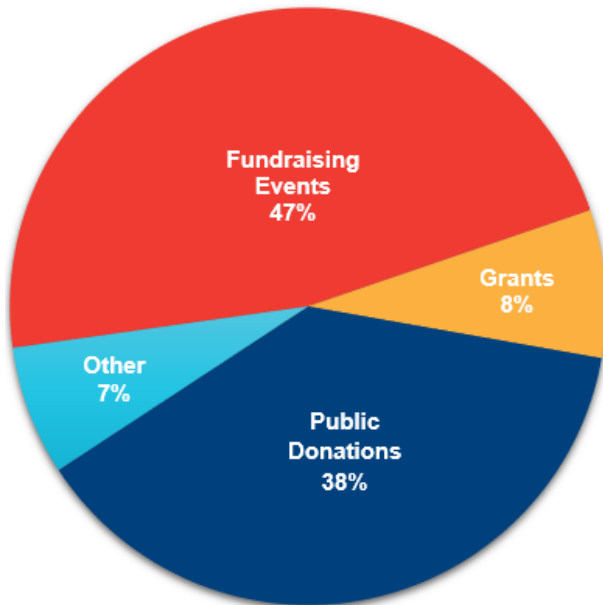
In late Spring, DSAWM experienced a complete staff turnover. As veteran staff departed the organization in pursuit of other exciting opportunities, a new group of passionate individuals took their place. Jennifer DeVault became the first new DSAWM face as the organization's Executive Director. Nate Clark joined a few months later as the new Program Director and Victoria Hart followed shortly after in the role of Administrative Assistant. The staff has learned a lot about DSAWM and the West Michigan Down syndrome community over the past year and are truly honored to serve such a passionate and giving community.

Financial Report

2016

Financial Highlights

- Highest earning Step Up for Down Syndrome event in DSAWM history with a donation total of \$150,000
- Highest earning Step Up For Down Syndrome team in event history with \$16,000 raised by Natters Matters
- Gazelle Sports Foundation selected DSAWM as the recipient of a \$5,000 grant to support iCan Bike Camp



Income Total: \$285,835

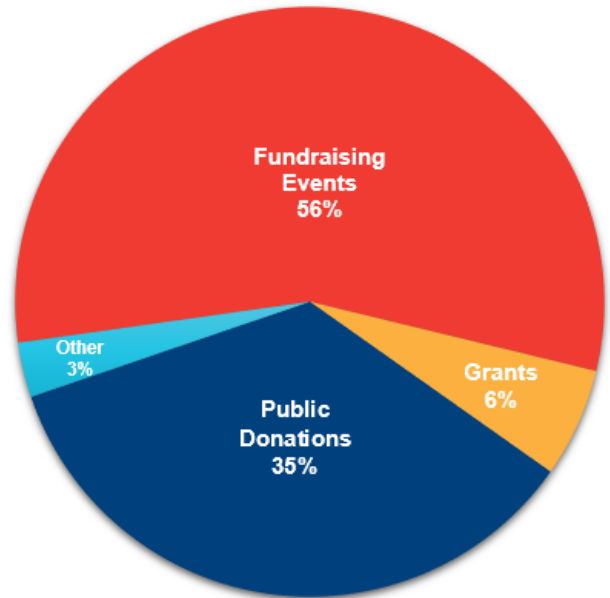
*Member Dues, Program Fees



2017

Financial Highlights

- Program fees were eliminated for members in 2017. Members will continue to receive free access to DSAWM programming in 2018.
- Event Fundraising increase of 13% compared to 2016
- 263% increase in 3rd party fundraiser gifts compared to 2016



Income Total: \$234,353

*Member Dues, Miscellaneous



2016 Statement of Activities

Support and Revenue

Fundraising Events	\$134,875
Grant Revenue	\$22,500
Member Dues	\$6,597
Program Revenue	\$14,437
Public Support	\$109,426

Total Support and Revenue	\$285,835
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Expenses

Program Services	\$165,430
Management and General	\$129,945
Fundraising Costs	\$7,894

Total Expenses	\$303,269
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Endowment Fund

Investment Income	\$30,552
Unrealized Gain/Loss	\$27,791

Change In Net Assets	\$62,514
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Net Assets, January 1st	\$995,412
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Net Assets, December 31st	\$1,057,962
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2017 Statement of Activities

Support and Revenue

Fundraising Events	\$132,244
Grant Revenue	\$12,930
Member Dues	\$6,618
Public Support	\$82,561

Total Support and Revenue	\$234,353
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Expenses

Program Services	\$86,686
Management and General	\$101,892
Fundraising Costs	\$6,992

Total Expenses	\$195,570
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Endowment Fund

Investment Income	\$41,944
Unrealized Gain/Loss	\$98,647

Change In Net Assets	\$168,850
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Net Assets, January 1st	\$1,057,962
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Net Assets, December 31st	\$1,226,776
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Foundation



The Down Syndrome Association of West Michigan Foundation (DSAWMF) provides a permanent source of principal to ensure funds will be available in the future to support individuals with Down syndrome, their families, and the organizations that support them. DSAWMF is a not-for-profit organization funded by cash, securities, and assets, and is independent from DSAWM. Though a separate entity, the Foundation supports the Association's mission of empowering individuals with Down syndrome and supporting their communities.

Annually, DSAWMF hosts The Winners Cup, a Kentucky Derby themed party and auction. Every year the event raises around \$100,000 for the Foundation. A portion of The Winners Cup proceeds support the many programs and services that DSAWM provides to its members. The 2019 Winners Cup will be held on May 4th at Kent Country Club.



2016

\$55,000

Gifted to DSAWM

\$2,100

in Community
Giving

2017

\$25,000

Gifted to DSAWM

\$4,000

in Community
Giving

2016-2017 Board of Directors

Bob Boylen
President



Sean Igoe
Treasurer

May 2017-November 2017

David Wood
Treasurer

November 2017-Present

Members at Large

Bill Blanton
James Cook
Cameron Dolbow
Jaimie Lomonaco



Upcoming Focus



Skill Building Series

DSAWM is excited to announce a new program coming in Spring 2018. The Skill Building Series will give young adults the opportunity to learn, practice, and discuss the skills necessary to transition to a more independent adulthood. Disability Advocates of Kent County will partner with DSAWM for the first program, centered on self-advocacy and employment. Participants will be introduced to skills including communication, decision making, problem solving, personal rights and responsibilities, and job preparation.



Summer Programming

2018 will have a full summer programming line-up with the return of Rapid Runners, iCan Bike Camp, Buddy Up Tennis, and the Adaptive Water Ski clinic. In addition to these popular programs, DSAWM will also bring a series of day camps to the lakeshore and Kalamazoo! In Grand Rapids, DSAWM will partner with Grand Valley State University to offer a weekly playgroup focused on occupational therapy. The Member Picnic will return as well to Tunnel Park in Holland at the end of July. Visit dsawm.org/calendar for a complete summer schedule and updates!



Step Up For Down Syndrome

The 22nd Annual Step Up For Down Syndrome Walk will be held on September 22, 2018 at Fifth Third Ballpark. Now in its 22nd year, Step Up is a celebratory event that invites DSAWM members and the public to show their love, support, and appreciation for the Down syndrome community. The impact of the event grows every year and in 2018, for the first time in the history of DSAWM's largest fundraiser, Step Up will have a title sponsor — Dan Vos Construction Company. It's never too early to start forming your team or fundraising! Visit dsawm.org/donate to show your support today.

Important Dates

2018 looks to be an exciting year for DSAWM. Mark your calendars with these important dates!

- **May 16: Friends Just Like Me @ Grand Rapids Children's Museum**
- **July 29: Member Picnic @ Tunnel Park, Holland**
- **September 22: Step Up For Down Syndrome @ Fifth Third Ballpark**
- **December 2: Member Holiday Party @ Frederik Meijer Gardens**

Stay Connected

Join the Mailing List

dsawm.org

Social Media



/DownSyndromeAssociation
ofWestMichigan

@DSAWM

Thank You!

DSAWM thanks all of the fantastic donors who made contributions in 2016 and 2017. Over the past three decades, the organization has grown from just six couples meeting in a Grand Rapids basement to serving more than 300 families across West Michigan. Your financial gifts have allowed DSAWM to continue to grow and make a real and lasting impact in the West Michigan Down syndrome community. Thank you for your support. We simply couldn't do it without you!



Ways To Give

Financial Giving

Interested in making a personal contribution to DSAWM? Maybe you would like to donate in honor or memory of a loved one. Or perhaps you want to get everyone involved by hosting a fundraiser to benefit DSAWM. Every dollar is appreciated and supports the vital programs and services offered to members!

Give online at
dsawm.org/donate

Mail gifts to
DSAWM
233 Fulton St. E, Ste 124
Grand Rapids, MI 49503

Volunteer

With dozens of programs offered year-round, there is always a need for an extra set of hands. Whether it's checking in participants at the Step Up For Down Syndrome walk, serving cookies at our Holiday Party, or speaking to a new parent about the opportunities available to them, DSAWM can always use YOU!

Visit dsawm.org/volunteer.

Become a Member

Do you have a loved one with Down syndrome? Join DSAWM! Becoming a member of the Down Syndrome Association of West Michigan connects you with Michigan's largest Down syndrome support network, programs for individuals with Down syndrome, and resources for families and professionals.

Visit dsawm.org/membership or call 616-956-3488 for more information.



EMBRACE
Down
syndrome

EMPOWER
individuals

PROMOTE
opportunities
for meaningful
lives



DSAWM

Down Syndrome Association of West Michigan

Empowering individuals. Supporting communities.