



2019 ANNUAL REPORT



MEMBER SPOTLIGHT



Above: The Vogel Family from left to right: Hudson, Sheena, Carter, Paul, and Graham.

THE VOGEL FAMILY

A little bit about the Vogel crew... First off, we have three boys, 4 and under!

Carter, our oldest, is into all things dinosaurs! Just spend some time playing with him and you'll find yourself trying to pronounce lengthy dinosaur names. He adores his youngest brother Graham, but isn't quite sure about his middle brother Hudson yet. Occasionally he'll play ball with Hudson and surprise Graham with big kisses. He loves riding the neighborhood streets on his new big-kid bike and dancing around the house singing his favorite songs from Frozen. Baking, especially when chocolate chips are involved, is a favorite home activity. He is learning Spanish in his first year of 3-School.

Hudson almost left the hospital undiagnosed with an extra chromosome. Hours before discharge, the midwife had to convince the doctors that he had Down syndrome, which lengthened his stay, but with a clean bill of health was on his way home. Hudson excelled at everything from breastfeeding to crawling, constantly amazing the health community. He loves being a big brother. He signs and speaks some words and comprehends a lot – he is very observant. In addition to the support provided by Early On, he also goes to OT and Speech weekly at our local Center of Early Childhood Development. He loves to read, play in water, and ride his bike. He will start 3-School next fall with his older brother.

Graham surprised us with an early arrival at 34 weeks and 1 day. He is also rocking an extra chromosome, which was suspected during the pregnancy along with duodenal atresia, which is the congenital absence or complete closure of a portion of the lumen of the duodenum. It caused an intestinal obstruction which required surgery. He underwent surgery on March 21st which is also World Down Syndrome Awareness Day – we thought that was fitting. He came home from Helen Devos Children's Hospital after a 59-day stay wearing an NG tube. He is now a thriving 1-year old who loves watching his brothers curiously and enjoys snuggling. He also receives care from an Early On team and OT and Speech therapies.

When we received Graham's diagnosis, it was obviously a bit surprising, but we already wrote that chapter of life with Hudson and had a firm grasp on what lay ahead. The best part was that it really meant nothing... Being "that family" and having two children rocking an extra chromosome has impacted and taught us a lot. One of the biggest lessons our boys have shown us is that labels do not define them. They are people first, not the difference.

The Down Syndrome Association of West Michigan was our first exposure to this new world of a "little something extra". After having Hudson, we needed a new kind of support, from people who understood. Through DSAWM-hosted events we have met other families like ours that share the same empathy for the challenges ahead. The first resource I direct parents to who come to me with news of their baby having Down syndrome is DSAWM because this organization has played a major role in our journey with the unexpected.

Sheena Vogel

Sheena Vogel

WHO WE ARE



Empowering Individuals. Supporting Communities.

At the **Down Syndrome Association of West Michigan (DSAWM)** we advocate for and provide services and programming through all stages of life to individuals with Down syndrome and their families. We are committed to creating communities that embrace Down syndrome, empower individuals, and promote opportunities for meaningful lives.

In 2019, DSAWM focused on expanding our community through new partnerships and opportunities to impact members outside our primary service area. While DSAWM serves 12 counties across West Michigan, nearly 75% of our membership lives in Kent and Ottawa counties. Every year we work to expand services for our growing population in Grand Rapids and the surrounding area. In 2019, though, we also increased efforts to implement existing and develop new programs for families in counties including Kalamazoo and Barry. Of the 50 new families we welcomed to the Association during the year, 16 joined from outside of Kent and Ottawa. In Kalamazoo county alone, membership numbers doubled from 2018 to 2019.

As we reflect on the end of the decade, DSAWM celebrates the growth we have achieved and look forward to the endless possibilities and aspirations we have for 2020 and beyond.

Right: Member and our 2016-2019 Intern Allie. Allie continues to work periodically at the DSAWM office to provide communications and programming support.



LETTER FROM THE EXECUTIVE DIRECTOR

‘Unprecedented’ has been the word used to represent the first quarter of 2020, but I know that because of our members, families, volunteers, board, staff, and community partners, our organization will be stronger than ever moving forward. As I look back at 2019, I’m very proud of the accomplishments of the Down Syndrome Association of West Michigan. We increased memberships, expanded programs, and facilitated new relationships with local organizations to benefit our members and their families. More than 2,500 people participated in and were impacted by our programs and events this past year!

Just as important as our programs, however, are the deep friendships and support networks that develop through DSAWM services. Children and young adults develop a sense of belonging while parents and siblings find support and a network of individuals facing similar challenges and joys.

We look forward to an “unprecedented” 2020 as we continue our quest to be the best Down Syndrome Association that we can be!

Jennifer DeVault
Executive Director



Left: DSAWM staff from left to right: Communications Director & Administrative Assistant Victoria Hart, Executive Director Jennifer DeVault, DSAWMF Fund Development Director Tom DeVault, and Program Director Nate Clark.

Right: Jennifer and Board President Brad Rivard with Kellogg’s mascots at the Member Talent Show presented by Kellogg’s.



DSAWM STAFF + BOARD

STAFF

Jennifer DeVault
Executive Director

Nate Clark
Program Director

Victoria Hart
**Communications Director &
Administrative Assistant**

BOARD LEADERSHIP

Brad Rivard
President

Maria Nykerk
Vice President

Dave Wood
Treasurer

Erica Bode
Secretary

MEMBERS AT LARGE

Lisa Glover
Tom Hackett
Patty Langlois
Maureen O’Brien
Florine Paul
Mike Wolff

INTERN SPOTLIGHT



Above: Intern Molly Vandewater.

MOLLY VANDEWATER

I started working for DSAWM in September of 2019. I was volunteering with my friend, Kylee, and asked Nate, DSAWM's Program Director, if I could get a job there because it was my dream for a long time. They offered me an internship and I was totally excited and happy!

I do a lot of things at work. I copy and shred, put together parenting packets, write thank you notes, and get things ready for dances, fundraisers, and other events. I also do public speaking. I have been on the radio and TV, including an interview with Maranda on WOTV4Women. I also spoke at a special luncheon for grant recipients at Pridgeon & Clay. On Tuesdays, I film Minute with Molly videos for DSAWM's social

media. My favorite things to do as an intern are filming videos and representing DSAWM on TV and radio stations. I love being famous! I have learned to be more flexible and am proud to be a really hard worker who stays focused on my job.

I can't wait to see what my future holds. One of my goals is to have all my friends move into my house with me. I am so excited to get back to my job and I would like to work at DSAWM forever! I am very thankful for my job and all the people who support me.



Above: Intern Cristina Scheuerman with member Jessica at Buddy Up Tennis.

CRISTINA SCHEUERMAN

I am 21 years old and just graduated from Aquinas College with a B.S. in Exercise Science. I live in Zeeland with my parents and two older siblings who both have Down syndrome. My sister Courtney is 31. She loves to worship, dance, exercise, and work. She is currently the manager for the Hope College Women's volleyball team. My brother Drew is 29. He loves basketball, riding his bike, singing, and watching movies. He also gets to help with Zeeland East's girls' volleyball team, as well as the boys' basketball team.

Growing up with siblings with Down syndrome taught me a lot from an early age and shaped me into the person I am today. From watching them compete in Special Olympics to chaperoning the Night to Shine Prom, the special needs community has been a big part of my life for as long as I can remember. I have been involved with

Compassionate Heart Ministries in Zeeland since I was old enough to volunteer, and I participated as a mentor for their Summer Serve Camp. I love spending time with persons with special needs and want to stay involved with the special needs community for the rest of my life.

As a graduation requirement, I needed to find an internship for the year. After some searching, I decided to reach out to the DSA. My parents were very involved with the organization back when it started, but less so as my siblings became older and involved with other activities. I knew I wanted to do something that involved people with special needs, so having an internship at the DSA is amazing! I have greatly enjoyed being part of this organization because it does so many things for its members. Every week, I help with Buddy Up Tennis, Shape Up, and occasionally Cooking Capers. I love attending these programs for the chance to interact with so many wonderful individuals. I have gotten to know a lot of members this year and seeing their smiling faces is the highlight of each week.

2019 HIGHLIGHTS



Above: Member Sanjai with Tony the Tiger after performing a rap at the Member Talent Show.

MEMBER TALENT SHOW PRESENTED BY KELLOGG'S

Through an exciting partnership with Battle Creek-based company Kellogg's, DSAWM invited members of all ages to take the stage in May and showcase their unique talents and abilities at the Member Talent Show. One of our most outgoing members, Jenna Lee, MC'd the lively event which featured exciting performances by 10 members. While many performers chose to sing, the show also featured a rapper, dance troupe, and DJ. Between performances, audience members were invited on stage to take photos and participate in games with Kellogg's mascots. "It was amazing!" said an attendee. "So proud of all the members participating and of all the wonderful community and sponsor support. We hope it's the first of many!"

NEW SUMMER PROGRAMS



Above: Member Drew and his CLS Worker Carol ready to put forth a "super" effort at the Family Fun Run.

After an exciting start to the summer with the Member Talent Show and our participation in the Amway River Bank Run—DSAWM was selected as a charity partner and raised over \$8,000—we looked forward to hosting a new slate of programs. In June, we held a Fishing Derby. Despite the rain, 11 members joined us at Gun Lake to learn fishing techniques and try their hand at making the catch of the day. The sun was shining a few weeks later when we welcomed 38 participants to the Family Fun Run. The superhero-themed 1-mile run/walk was organized by our enthusiastic River Bank Run Road Warrior Britany Spangler with professional timing kept by Egress Endurance. Health and fitness was also an important component of our Buddy Up Tennis Camp in July. Athletes aged 10 and older enjoyed the week-long program where they further developed their tennis skills and experienced new activities ranging from sports to the arts.

STEP UP FOR DOWN SYNDROME

Step Up For Down Syndrome was record-breaking in 2019! Over 1,500 people joined us in September at Fifth Third Ballpark for our annual fundraiser and Michigan's largest Down syndrome awareness event. In celebration of our rock 'n' roll theme, "Rockin' an Extra Chromosome", the day featured live music with performances from members, an autograph signing station, and photos with Elvis. With the support of 78 teams—including our two largest teams to date, Down to Defend with 134 walkers and Fist Bumps for Callen with 133 walkers—the event raised over \$135,000 for DSAWM programs and services.

Below: Team Fist Bumps for Callen at Step Up For Down Syndrome.



COOKING UP A STORM

Teens and adults with Down syndrome who participate in our Cooking Capers program learn culinary terminology, cooking methods, measurements, and kitchen safety as they craft a healthy meal. The program is one of our most popular with over 30 members participating each season. Demand has grown so much that to accommodate we opened two new sessions in 2019. Two groups now alternate time in the kitchen in Grand Rapids and another group meets biweekly in Kalamazoo. This expansion would not have been possible without the support of Meijer and partnerships with Grand Valley State University's Clinical Dietetics students and Western Michigan University's Student Dietetics Association. The financial and volunteer contributions of these organizations allowed over 45 unique members to participate in 2019 and learn skills that encourage self-sufficiency and independence.



Above: Member AJ and a student volunteer from WMU's Student Dietetics Association at a Kalamazoo Cooking Capers class.

LA POSADA

With the support and outreach of members Diane Estrella and Niurka Diaz, DSAWM served 25 Spanish-speaking families in 2019. The relationships built over the year culminated in December with the first annual La Posada event. La Posada is a Christmastime festival traditionally celebrated in Latin countries that brings neighbors and communities together to socialize, share food, and celebrate the season. The event's success, attended by 59 people, was encouraging and we look forward to creating more opportunities for our Spanish-speaking families to engage with programs and services in the coming year.



Above: Member Anna and her sister preparing treat bags for our first annual La Posada.

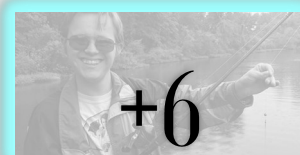
2019 BY THE NUMBERS



Families served across 12 West Michigan counties.



New members welcomed, compared to 49 new members in 2018.



New programs offered in 2019:

1. Member Talent Show
2. Fishing Derby
3. Buddy Up Tennis Camp
4. Kalamazoo Cooking Capers
5. Grand Rapids Cooking Capers: Group B
6. Shakin' It with Sammy



People attended 12 events held in 2019.



Unique members participated in at least one of 15 programs offered in 2019. In total, programs were attended by 1,499 people, including members, parents, and siblings.

2019 FINANCIAL REPORTS

THE ASSOCIATION (DSAWM)

REVENUE	DOLLARS	% OF TOTAL
Fundraising Events	\$123,298	45.3%
Public Support	\$120,009	44.1%
Grants	\$22,371	8.2%
Member Dues	\$6,517	2.4%

TOTAL REVENUE \$272,195

EXPENSES	DOLLARS	% OF TOTAL
Programs & Services	\$182,868	62.5%
Fundraising Costs	\$57,021	19.5%
Admin & Management	\$52,640	18%

TOTAL EXPENSES \$292,529

THE FOUNDATION (DSAWMF)

REVENUE	DOLLARS	% OF TOTAL
Unrealized Gain (Loss) on Endowment Fund	\$159,319	54.7%
Fundraising Events Endowment Fund	\$80,497	27.7%
Investment Income	\$46,047	15.8%
Public Support	\$5,118	1.8%

TOTAL REVENUE \$290,981

EXPENSES	DOLLARS	% OF TOTAL
Programs & Services	\$86,960	84.9%
Admin & Management	\$13,443	13.1%
Fundraising Costs	\$2,000	2%

TOTAL EXPENSES \$102,403



Left: Program Director Nate, members Molly and Adam, and Executive Director Jennifer join local TV personality Maranda for a special segment highlighting the Cooking Capers program.

Right: Member Octavia at Friends Just Like Me.



THE 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 and their families. 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.

Every May, DSAWMF hosts the Winners Cup Benefit, a Kentucky Derby themed party and auction to benefit the Foundation. Since its inception, the event has consistently raised over \$100,000. One of the event's live auction items is a paddle raise in direct support of DSAWM's services. In 2019, bidders donated \$16,750 to the Member Financial Assistance program. Parent and member Crystal Lovell spoke in support of the program and shared the relief it has provided towards her daughter's medical expenses over the years. Over \$130,000 was raised overall, making 2019 the highest grossing event in the benefit's history!

IN 2019, DSAWMF GRANTED \$46,750 TO DSAWM. AN ADDITIONAL \$4,000 WAS GRANTED TO ARTS IN MOTION AND THE GRAND RAPIDS CIVIC THEATER.



Left: DSAWM member Eric and his parents, Susan and Rick, at the DSAWMF Winners Cup Benefit.

DSAWMF BOARD OF DIRECTORS

BOARD LEADERSHIP

Robert Boylen
President

Jennifer DeVault
Executive Director

Thomas DeVault
Fund Development Director

Robin Zondervan
Treasurer

MEMBERS AT LARGE

Cameron Dolbow
Tom Hackett
Brad Rivard, DSAWM
Representative
Jim Scarlett

UPCOMING FOCUS

SUMMER PROGRAMMING

We are eager to make up for the lost time hanging out with our friends and enjoying one another's company! As we begin a gradual return to normal this summer, DSAWM is excited to welcome back members to some of our favorite programs and events.* We will kick summer off in July with iCan Bike Camp, where instructors, staff, and hundreds of volunteers come together to teach children with disabilities how to ride a two-wheeled bike. The Member Summer Picnic in Holland will follow at the end of the month. August will then be dedicated to Oh Baby, our annual baby shower to welcome new members to our community, and preparing for our biggest event of the year: Step Up For Down Syndrome.

STEP UP FOR DOWN SYNDROME

Join us this fall for 'Step Right Up' For Down Syndrome! Our annual fundraiser and Michigan's largest Down syndrome awareness event will be held on Saturday, September 26th at Fifth Third Ballpark.* The family-friendly celebration is open to all individuals with Down syndrome, their families, friends, and thousands of local supporters. As a direct result of event sponsorships, team fundraising, and generous public donations, DSAWM is able to continue providing educational resources, informational programs, parent support networks, financial assistance, and social events for our community. This year, we invite you to 'Step Right Up' for a carnival-themed celebration that will feature acrobats and circus performers, skill-testing games for all ages, and a bounty of exciting prizes. Registration will open at dsawm.org in June. We hope you to see you there!

**Programming and events are tentative and subject to change this summer and fall as we continue to monitor COVID-19 guidelines from the MDHHS and CDC. Updates will be shared on our website, Facebook page, and via email as they are made.*



Left: Communications Director Victoria and member Addison enjoy face-painting at the Member Summer Picnic.

Right: Members Jack, Jay, and Jason having their photo taken with Santa at the Member Holiday Party.



IMPORTANT DATES (Tentative)

ICAN BIKE CAMP

July 13th-17th
at Special Olympics Michigan

MEMBER SUMMER PICNIC

July 26th
at Tunnel Park in Holland

OH BABY

August 22nd
at Grand Rapids Children's Museum

STEP UP FOR DOWN SYNDROME

September 26th

MEMBER HOLIDAY PARTY

December 6th
at Grand Rapids Public Museum

THANK YOU!

DSAWM thanks the generous donors who made contributions in 2019. Over the past three decades, the organization has grown from just six couples meeting in a Grand Rapids basement to now serving over 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 could not do it without you! A special thanks to the following donors who made gifts of \$1,000 or more in 2019.

BDO USA, LLP	Gordon Food Service	Paper Plane Therapies	Robert Boylen
Jeff Bode, Realtor with Bellabay Realty	Herman Miller Cares	Pridgeon & Clay	Jeffrey & Sally Harold
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	Miller Johnson	Jeff & Erica Bode	Aaron & Jodi Veldheer
	PADNOS	Mr. & Mrs. Drew Boersma	

GET INVOLVED

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 or mail your contribution to**

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

DSAWM also accepts bequests and gifts of stocks. To learn more, contact us at 616-956-3488.

VOLUNTEER

With dozens of programs offered year-round, we're always in need of volunteers. Whether it's checking in participants at Step Up, serving cookies at our Holiday Party, or swinging a racket with members at Buddy Up Tennis, your helping hands are appreciated! **Visit dsawm.org/volunteer to join our volunteer roster.**

BECOME A MEMBER

Do you have a loved one with Down syndrome? Join DSAWM and get connected with Michigan's largest Down syndrome support network, programs for individuals of all ages, and resources for families and professionals. **Visit dsawm.org/membership or call 616-956-3488 for more information.**



DSAWM is 501(c)(3) nonprofit and an accredited charity with the Better Business Bureau. All donations are tax deductible.



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