



# the up side of downs

*Supporting and  
Celebrating*



*Down Syndrome  
in Northeast Ohio*



Impact Report 2018

*(From top to bottom): Cameron P., Grace P., Dani C.  
Our cover photos were taken by volunteers from the Cleveland Photographic Society. We are grateful for their support.*

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*MindBodySoul Coordinator*

**Barb Waddle**  
*Office Manager &  
Programming Coordinator*

## A Message from our Board Chair and Executive Director



Deirdre Roselli  
*Board Chair*



Toni Mullee  
*Executive Director*

*"Alone we can do so little; together we can do so much."*

This quote by Helen Keller speaks beautifully about a year in which USOD worked with others in the community to expand programming and meet the needs of the 1,000+ families we serve. We were so pleased to offer our Steps to Independence retreat for adults with Down syndrome for the first time in 2018. This program was made possible by our collaboration with the Cleveland State University Occupational Therapy Department, whose Masters level students created curriculum and volunteered that weekend. Our newly created Circle of Support group, which provides support for families dealing with a dual diagnosis of Down syndrome and Alzheimer's disease, wouldn't be possible without the partnership of the Alzheimer's Association. With other organizations throughout Northeast Ohio focused on supporting individuals with disabilities, we brought a ReelAbilities Film Festival to Cleveland in the Fall of 2018. We continue to seek out partners that will enhance our support for individuals with Down syndrome, their families, and communities and those collaborations continue to multiply in 2019. In addition to programs for our families, raising awareness about ABILITY remains a critical part of our work and Artful 21 helps us to share that message with the local community and beyond. Sales increased by 50% in 2018 and the number of small business owners with Down syndrome contributing merchandise to the store grew to 23. We have shipped items from the store coast to coast. In 2018 we reached out to the medical community to create our Medical Advisory Board in order to provide the most crucial information regarding health & wellness as well as the latest on research to our families.

We continue to be grateful to everyone who contributes to the success of USOD—staff, board, volunteers, foundations, sponsors, special event attendees and individual donors. We could not fulfill our mission without you.

Deirdre Roselli  
*Board Chair*

Toni Mullee  
*Executive Director*

**OUR MISSION:** To provide support, education and advocacy for people with Down syndrome, their families, and communities.

**OUR VISION:** The Up Side of Downs is the primary resource for families & communities regarding Down syndrome, where all people with Down syndrome are accepted, included and empowered. USOD envisions a community where people with Down syndrome have limitless opportunities and the ability to pursue their dreams.



# the up side of downs

## PROGRAMS & SERVICES

Family Support	Advocacy	Education	Medical Outreach	Social Programs
Packets & follow up contact for new and expectant parents	Northeast Ohio Buddy Walk	The Learning Program reading and math enrichment for parents and students Pre-K-5 w/ Ds	Medical Advisory Board which provides medical expertise to USOD and those we serve	Bowling Buddies
Sibshop program for siblings ages 7-12	Cleveland Down Syndrome Day	School outreach with IEP teams to facilitate education & support for families	Deliver packets of information to Northeast Ohio hospitals and medical offices	USOD Family Days at area theaters and sporting events
Hospital and home visits to new families	World Down Syndrome Day activities yearly on March 21 (3/21)	Host Educational Conferences for parents and professionals	Provide up-to-date info on the USOD website with relevant medical information	Tee It Up Golf clinics
Growing with 21 Adult Sibling group	Celebrate Down Syndrome Awareness Month each October	Entrepreneur Bootcamp	Present to grand rounds, panels and students in health care fields	Adult gatherings such as monthly karaoke and seasonal dances
Host Northeast Ohio Baby & Toddler Play Groups	Contact local and state legislators to promote Ds initiatives	Down Syndrome 101 training for professionals	Provide medical professional referrals to USOD members upon request	USOD Fall Fun Fests
Host monthly Parent's Night Out gatherings	Spread the Word to End the Word Pledge	Peer Presentations to support friendship and understanding within the classroom	Host medical seminars for families	Mind Body Soul social outings for individuals with Ds, 18+
Family Grants Program offered to USOD families 2x per year	Preferred Language Guide for Ds	Teen Educational Enrichment Network for individuals w/Ds, 13 - 18	Review and promote Ds research studies	USOD Holiday Party
Circle of Support – for families dealing with diagnosis of Ds & Alzheimer's disease	Work with media partners to encourage positive and accurate depictions of individuals with Ds	Strider Bike Camp	Serve on advisory boards for research studies	USOD supported fitness programs such as Adaptive Jazzercise & Buddy Up Tennis
Monthly Grandparent support group	Leverage social media to advocate on behalf of individuals with Ds	Steps to Independence Retreat for individuals w/ Ds, 18+		
Parent to Parent Network Support on Facebook	Sunburst Gala where the achievements of individuals with Ds are celebrated	Summer Enrichment Adventures in Learning Pre-K and up		



# STEPS

## to Independence

Steps to Independence, USOD's weekend-long retreat for adults with Ds 18 and older, was held for the first time in 2018 on the campus of Cleveland State University. Fifteen young adults attended the retreat. USOD staff members, Barb Waddle & Linda Tarro, worked with the CSU Occupational Therapy faculty and students to plan and conduct the event, which filled up in less than 48 hours. The weekend began with check-in on Friday at the Fenn Tower Dormitory, where everyone stayed for the weekend. Attendees were met enthusiastically by volunteer college friends as they arrived. The group got to know each other and enjoyed a casual dinner and movie at the dorm

*"Going to the Hofbrauhaus was awesome. The party was amazing and I had the best time of my life. I also met many awesome new friends. We called ourselves the Wolf-Pack and put that name on our college dorm door. I can't wait to go back and re-live the awesomeness"*

—JAMIE WHITFORD

that evening. On Saturday, everyone participated in a Zumba class and learned about the benefits of exercise. They also attended sessions on healthy eating, table etiquette, and social relationships. Afterward, the group completed a service project, creating gifts for Buddy Walk top team captains. Later that evening, a fun dinner at Hofbrauhaus was enjoyed by all - and included a conga line! Sunday morning, everyone created a scrapbook of the weekend activities before heading home. For some attendees, this was their first time away from their parents. All attendees left the weekend retreat with new skills and a sense of independence.

*"Steps to Independence was an amazing program. Jamie loved "going to college", just like his siblings did. The CSU students and all the volunteers helped make the weekend non-stop fun. Jamie did not even realize he was practicing important self-help skills as he was too busy making new friends. This program allowed him to stretch his wings a bit. He cannot wait until the next one!"*

—BRIDGID WHITFORD





# early connections



## PARENT MENTOR program

In November USOD started the Early Connections Mentor Program. The purpose of the program is to support new and expectant parents through volunteer mentors in our 16-county service area. Through the program we trained 13 mentors in 2018.

*"The Up Side of Down's Mentor Program was such a blessing for us. We found out about our sweet baby girl's diagnosis when I was about 20 weeks pregnant and we felt so lost and alone. Even though we had wonderful friends and a supportive family, they couldn't understand what we were going through. Meeting with Laurie really helped us to put our fears aside and begin to prepare for anything that our Sweet Caroline might need. She is now our beautiful 4 year old spunky girl and we often wonder why we were so worried about such a little part of her. She is so much more than her diagnosis and we are so blessed to have her in our lives. I am grateful to have the opportunity to participate in the program and to give back. I want to help other families not only grieve the loss of their expected child, which I think is a necessary process, but also to look forward to what their lives will hold and to celebrate with them."*

—JEN COLIADIS



### USOD Medical Advisory Board

The USOD Medical Advisory Board was created and met for the first time in 2018. The board is currently comprised of 10 medical professionals from area hospitals focused on providing care to individuals with Down syndrome and conducting important research that is meaningful to the Down syndrome community. The group meets annually with USOD staff and provides year-round assistance to our organization.



## Artful21.com

Thanks to a grant from the Cleveland Foundation, a new online store was created for Artful 21 in 2018! That helped store revenue grow by 50% in 2018. We also added several new artisans, bringing our total in 2018 to 23. One of those artists is Anna Sladek, owner of Anna's Art. Anna was born in Chagrin Falls, Ohio. She has six brothers and sisters, a mom and dad; all of whom are very supportive of her. Along with creating art, Anna enjoys walks in the metro parks, swimming, fine dining, spending time with loved ones, shopping, fashion, animals, & music. The Zoo, Aquarium, and Art & History Museums are some of her favorite spots. She also loves to spend time in her art studio located in her parents' home where she currently lives. Anna has dealt with a lot of difficulties throughout her life. She was diagnosed with Down syndrome at birth. She didn't walk until she was two years old. When she did walk she was soon running, dancing, swimming, and riding horses. She was very active up until she developed a rare type of arthritis as a teenager. This changed her life dramatically. Mobility became difficult on a daily basis and, as a result, there is no longer any connective tissue between her joints in her fingers. It is a miracle and remarkable she is able to paint at all. Shortly after graduating high school Anna chose to pursue art as her profession. Her family is helping to make Anna's business possible. She truly enjoys art show experiences, restocking cards in shops, and meeting her fans. And of course, painting is her most favorite of all! Anna's greeting cards can be found at the Artful 21 store and at [annasartstore.com](http://annasartstore.com).

## Circle of Support

Many, but not all, people with Down syndrome develop Alzheimer's disease when they get older. People with Down syndrome are born with an extra copy of chromosome 21, which carries the APP gene. This gene produces a specific protein called amyloid precursor protein (APP). Too much APP protein leads to a buildup of protein clumps called beta-amyloid plaques in the brain. By age 40, almost all people with Down syndrome have these plaques, along with other protein deposits, called tau tangles, which cause problems with how brain cells function and increase the risk of developing Alzheimer's dementia. However, not all people with these brain plaques will develop the symptoms of Alzheimer's. Estimates suggest that 50 percent or more of people with Down syndrome will develop dementia due to Alzheimer's disease as they age. People with Down syndrome typically begin to show symptoms of Alzheimer's disease in their 50s or 60s. In order to be responsive to families in our community dealing with a dual diagnosis of Down syndrome & Alzheimer's disease, USOD partnered with the Alzheimer's Association to create Circle of Support. The group meets every 6 weeks and often hosts speakers providing essential information to families.



*"Cecily is the second of our four children. She has Down syndrome. She was diagnosed with the early onset of dementia in early 2017, when she was 44 years old. Our family's objective is to enable her to live the remainder of her life in a dignified manner as she is cared for in a respectful and loving environment. The USOD Circle of Support is our choice as the most effective way to educate ourselves on an ongoing basis about the intersection of Down syndrome and Alzheimer's disease. The combination of Down syndrome and Alzheimer's disease results in extraordinary challenges. Medications, for example, often have unintended results. Behaviors that signal unmet needs are nearly impossible to unravel. USOD's Circle of Support significantly increases our ability to exchange information and experiences with others facing similar challenges and serves to calm our fears about Cecily's future."*

—FRANK AND JANET BERKOPEC



# BUDDY WALK®

Congratulations to Our Top Teams from the 2018 Buddy Walk®

## TOTAL MONEY RAISED



Kayla's Kingdom  
\$19,026.60



Cooper's Crew  
\$9,808



Asher's Dashers  
\$8,987

## TOTAL TEAM MEMBERS



Team Crestview  
156



Kayla's Kingdom  
151



Greyson's Homies  
108

## What's Happening in 2019

Our first **Teen Educational Enrichment Network** classes began this year. This program focuses on academic support and life skills for individuals with Down syndrome ages 13 and up.

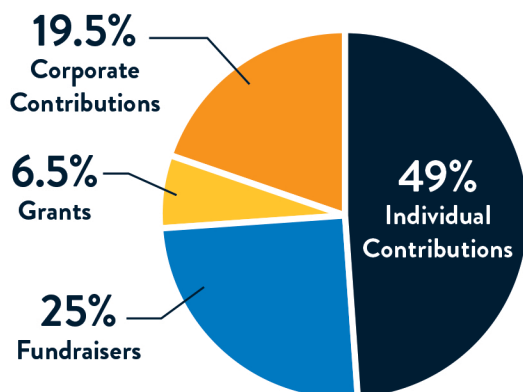
We are hosting an **Entrepreneur Bootcamp**, with financial support from the Burton D. Morgan Foundation, for self-advocates 15 and older interested in exploring self-employment. The program will run twice per year.

We were pleased to present well-known expert and author **Terri Couenhoven** early in the year for a weekend sexuality education workshop for individuals with Down syndrome and their parents, caregivers, and educators.

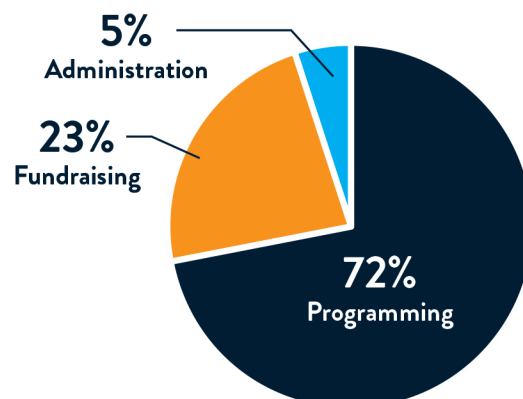
We are creating **community groups** in some of the counties we serve to provide more support to families in these areas. Community group leaders will be given a budget to create programming for those we serve in Summit, Stark and Lorain counties in 2019.

USOD is now a member of **ADA Cleveland**, a coalition of agencies and organizations that share in the mission to provide greater access and opportunity for individuals with disabilities.

## USOD BY THE NUMBERS



2018 USOD INCOME



2018 USOD OPERATING EXPENSES



*Supporting and Celebrating  
Down Syndrome in Northeast Ohio*

6533-B Brecksville Road  
Independence, OH 44131

p: 216.447.USOD (8763)  
f: 877.353.USOD (8763)  
e: [info@usod.org](mailto:info@usod.org)  
[www.usod.org](http://www.usod.org)

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Non-profit Org.  
U.S. Postage  
**PAID**  
Cleveland, OH  
Permit #434



Discover beautiful, handcrafted artwork,  
jewelry, stationery and more at Artful21—  
a unique gift shop filled with treasures created by  
individuals with Down syndrome. Your purchase supports  
these artisans and their small business ventures.

Shop Online at [www.artful21.com](http://www.artful21.com)

Visit us at 6533-B Brecksville Road, Independence, OH 44131

Follow Us:



19th Annual Northeast Ohio

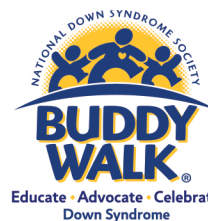
# BUDDY WALK®

*Supporting & Celebrating Down Syndrome*

**SATURDAY, AUGUST 24, 2019**  
**CLEVELAND METROPARKS ZOO**

Rain or Shine  
Registration 7:30am  
BUDDY WALK® 9am

Registration includes  
all-day admission to the  
Zoo & Rainforest!



Register online at [usod.org](http://usod.org)

*Mission: To provide support, education and advocacy for people with Down syndrome, their families and communities.*