



# 2016 IMPACT REPORT



the **up side** of  
**d**owns

Supporting and Celebrating  
Down Syndrome in Northeast Ohio



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# A Message from our Board Chair and Executive Director



**Deirdre Roselli**  
*Board Chair*

Over 30 years ago, the Up Side of Downs began as a parent-led organization focused on ensuring inclusion for their children in the schools and in the community as well as providing support to parents as they adjusted to a new diagnosis. Throughout the years, the Up Side of Downs has grown, changed and evolved to meet the needs of the 900+ families whom we support. USOD continues to evolve and as we reflect upon 2016, we are grateful for this opportunity to share our work with you through this report. We simply could not do what we do without our families, our donors, our supporters and our volunteers.



**Toni Mullee**  
*Executive Director*

What a year we had in 2016! We moved to our new Independence location, began The Learning Program in our children's classroom, and opened Artful 21, our gift shop featuring beautiful items handmade by artisans with Down syndrome.

We are grateful for the investment we receive from foundations, corporations, schools, and many individuals and families. All this enables the Up Side of Downs to provide support, education and advocacy to individuals with Down syndrome, their families and communities in 16 counties in Northeast Ohio. THANK 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



# Programs and Services

Family Support	Advocacy	Education	Medical Outreach	Social Programs
Provide packets to new and expectant parents	Northeast Ohio Buddy Walk	The Learning Program reading and math enrichment for parents and PreK-K children w/ Ds	Visit Health Care Providers	Bowling Buddies
Follow up contact to new and expectant parents	Cleveland Down Syndrome Day	School outreach with IEP teams to facilitate education	Deliver packets of information to Northeast Ohio medical professionals	USOD Family Days at area theater 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
Provide packets to NEO hospital maternal health practitioners	Celebrate Down Syndrome Awareness Month each October	IEP support for families	Speak at Grand Rounds and with groups of medical students	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 adult programming for individuals with Ds, 18+
Family Grants Program offered to USOD families 2x per year	Preferred Language Guide for Ds	Mind Body Soul life skills conferences for adults with Ds, 18+	Review and promote Ds research studies	USOD Holiday Party
Monthly support group for Parents of Teens & Adults with Ds	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	Social media presence promoting awareness		Alzheimer's/ Developmental Disabilities awareness	USOD Adults w/Ds Facebook group
Parent to Parent Network Support on Facebook				Artful Adventures for middle schoolers with Ds

# 2016 PROGRAM HIGHLIGHTS

## The Learning Program

In 2016 shortly after moving to our new office, we put our new children's classroom to good use with The Learning Program. It offers three levels of classroom programming for children and their parents and runs from October through June each year. The goal is to empower parents to be advocates for their children and to improve academic outcomes. The program complements formal instruction in literacy and math, and it includes occupational and speech therapy components.

*"Luke is so excited to participate in the Learning Program that each month when we pull into the parking lot he begins to clap and cheer! He has benefitted greatly from the opportunity to learn through play, meet new friends and to be supported in an environment rich with thoughtful educators. The parent sessions have been invaluable as they've provided opportunities to network with other parents of children with Down syndrome (Ds) and have offered information on proven education strategies for learners with Ds and we've gone home from each session with flash cards, handouts and other materials to help Luke build confidence through vocabulary acquisition. Even with limited verbal skills, Luke is able to use the materials for matching exercises and we've incorporated the vocabulary into his*



*augmentative communications device so he's able to execute the vocabulary on his own. Since beginning the program 9 months ago, Luke has been more willing to imitate verbal sounds and in general, is beginning to have emergent skills in this area. We are grateful for the opportunity to participate in The Learning Program; it's something I envision our family participating in for years to come!"*

—Kristin Taylor, mom of Luke

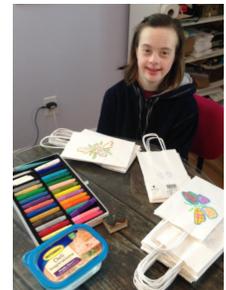


Artful 21 is the new retail store at the USOD office. Located in the Independence Square Shopping Center, the store features a variety of goods made by artisans with Down syndrome and is staffed by self-advocates.

Artful 21 Gift Shop gives creative and entrepreneurial individuals an opportunity to sell their products. Thus, they create their own jobs by having their merchandise accepted on a consignment basis.

The store also provides job training and part-time employment at a fair wage for adults in Northeast Ohio, enabling these individuals to meet their personal employment objectives. Artful 21 raises awareness of the talents and abilities of individuals with Down syndrome. By offering products in a retail environment with self-advocates employed in a very visible local shopping center, the store enhances the community's knowledge of Down syndrome and the positive contributions they are making to the community.

**MEET  
APRIL**  
owner of  
April's  
Cottage  
Soaps



April has been making soaps for 5 years. Her product line includes bubble bath, lip balm, lotions, bath salts and more. She also creates greeting cards and gift bags. April's favorite part of the soap making process is painting. She paints her pieces with a glycerin-based soap paint. April's work has been featured in Artful 21 since it opened. "The shop is really nice. I love to sell my soap and bags there. The paychecks are great too."

# USOD SUPPORT

*“Katie Stephens was born on March 29, 2009. She was an unexpected and much loved gift to our world. If we didn’t realize it then, we do now because of the Up Side of Downs. From day 1, our children were connected to the organization and comforted and encouraged by Family Outreach Coordinator, Laurie Kowalski.*



*My involvement came a few months later when I attended USOD’s newly formed Grandparents Group. Looking to be informed so that I could better support our children, I found that I was also given encouragement and support by grandparents who had experienced all the emotions, confusion and misinformation that often surrounds the birth of a child with Down syndrome.*

*Almost 8 years later, I am now a “veteran” of the group and find that I can offer hope to new grandparents. The group is one of my passions, a place where I can voice my concerns and share my joys. It has also become a vehicle through which I am able to invest my time, talents and resources in fundraising events and in growing the group through the New Parent/Grandparent Event, which we undertook several years ago under Laurie’s able leadership. Being a part of this group, building friendships through it, and volunteering because of it has been a personal blessing to me and to my family and to the Down syndrome community of which I am proud to be a part.”*

—Susan Stephens, grandmother of Katie

The Grandparents Group and other USOD support groups are informal and give family members through Northeast Ohio an opportunity to connect, share and support one another.

## MEET ALBERT

*“Albert participates in the Adapted Fitness & Yoga program. When he first started he was a little overwhelmed, but the instructor had a peer buddy in class to help him feel welcome and partner with him for several weeks. From the first class, ‘Jazzercise’ became the highlight of Albert’s week. He loved the music and movement, but the opportunity to socialize with same age peers was something he craved and had been missing. Over time he’s made new friends that he looks forward to seeing each week. As a parent it’s hard to put into words when you know your child is lonely but the opportunities for socialization are limited. This program has been a breakthrough for our family. Tuesday night fitness class is still a weekly highlight and now Albert relishes going to the front of the class and helping lead the routines. During a recent class he was hamming it up next to the teacher and I was trying to prompt him to take his place back with the group. Another participant waves me back and says, “he’s fine, he’s fine.” Among friends. It’s all good.”*



—Anne Waters, mom of Albert

The Up Side of Downs provides a variety of social outings and programs for individuals of all ages with Down syndrome and their families.

## NEW PARENT SUPPORT

*“Nearly 1 year ago, we were blessed with our second child, Andrew. At 2 days old, the hospital doctor brought Andrew back to my room after a short stay in the special care unit and informed us that Andrew had Down syndrome—then she walked out. Obviously my husband and I had a thousand questions, but it was a Saturday and no one at the hospital was able to talk with us. So we searched everything possible about Down syndrome online and ultimately were scared to raise a child with Down syndrome according to the online interpretation.*



*In our search, we realized the Up Side of Downs was available and close to our home. Hence, I called Family Outreach Coordinator, Laurie Kowalski, first thing Monday morning. She met my family for breakfast and did a wonderful job explaining Down syndrome to us—the truths—not the internet interpretation. We quickly learned that it wasn’t going to be as scary as we thought and that there was an incredible support system available at USOD.*

*We are so blessed to be a part of this new family. The New Parent Day was really educational and exciting. USOD celebrated our new babies and our families and made us feel so welcome. The Buddy Walk truly brought tears to my eyes. The amazing coordination and work that was put into the event, along with the incredible support and cheering, just melted my heart. Every month I look forward to the Medina Parent’s Night Out. My son is one of the younger ones of the group and having experienced moms to ask questions to is priceless.*

*USOD has been an amazing support system and has shown me that raising a child with Down syndrome is not scary, but rather a blessing.”*

—Kelly Pappas, mom of Andrew

We are grateful for the hundreds of generous donors,  
friends and sponsors that support our mission.

### FOUNDATION SUPPORT

The Catanzarite Foundation  
The Cleveland Foundation  
Conway Family Foundation  
Different Needz Foundation  
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Gertrude F. Orr Trust Advised Fund of  
Akron Community Foundation  
Global Down Syndrome Foundation

The GROW Foundation at Hathaway Brown  
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### IN-KIND SERVICES

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### TOP 10 BUDDY WALK FUNDRAISING TEAMS

Amazing Macee's Marchers  
A.J.'s Amigos  
Beckett's Buddies  
Callen's Buddies  
Cooper's Crew  
Greyson's Homies  
Ian's Idols with Grayson's Groupies  
Kayla's Kingdom  
Super Joe's All Stars  
Sophia's Sidekicks

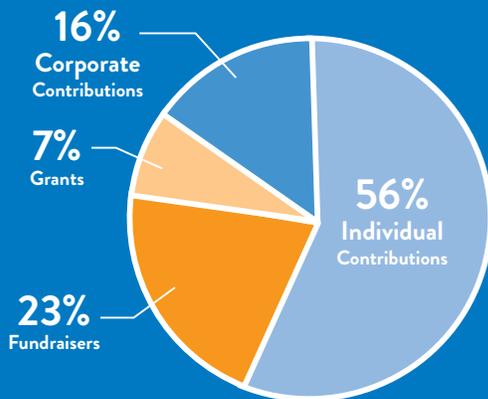
*Special thanks to  
Dempsey Scheiman & Associates  
for hosting their annual golf  
outing in support of the Up Side  
of Downs. 2016 marked their  
23rd annual outing for USOD.*

## 2016 HIGHLIGHTS

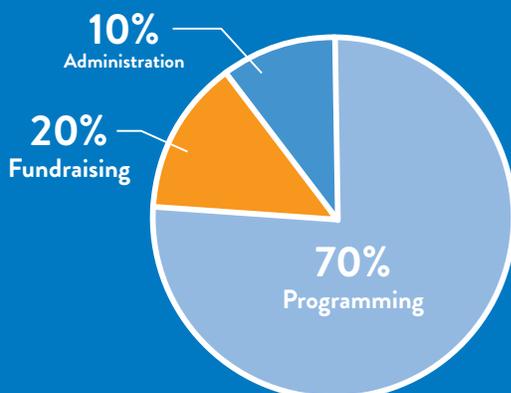
- We moved into our new office space on May 1! With this move we doubled our space and added our children's classroom, general programming space, and retail store
- We opened Artful 21, a retail store featuring the work of 14 artisans with Down syndrome, staffed with self-advocates
- We began the Learning Program in our children's classroom – with 4 full classes of our children from preschool to grade 3
- We had a record-breaking Buddy Walk at the Cleveland Metroparks Zoo with over 6,000 in attendance!
- 60 Family Grants were awarded, totaling over \$29,000
- We began a new partnership with the Cleveland Clinic pediatric department, which is helping us get critical information about our services to parents throughout Northeast Ohio
- We started a SibShops program for siblings ages 7-12
- We were named Affiliate of the Year for 2016 by the Down Syndrome Affiliates in Action, a nonprofit trade association representing over 80 Down syndrome associations in the U.S. and abroad

## USOD BY THE NUMBERS

### 2016 USOD INCOME



### 2016 USOD OPERATING EXPENSES



## WHAT'S HAPPENING IN 2017

- Two USOD brochures are now available in Spanish
- We will once again hold the Buddy Walk at the Cleveland Metroparks Zoo. This year's walk is on Saturday, August 26th
- We are partnering with other local organizations in NE Ohio to present the Transition Boosters series focused on the transition from school to adult life for youths with disabilities
- We are an official internship site for the Occupational Therapy Assistant Program at Bryant & Stratton, and we are working with their students and staff on programming while providing interns with the knowledge and experience to work with children with Down syndrome in the future



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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The Up Side of Downs is proud  
to have been named  
***2016 Affiliate of the Year***  
by Down Syndrome Affiliates in Action

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