Here for You

YESTERDAY, TODAY, TOMORROW.
Dear Friends,

Last year presented challenges we never could have imagined as the world dealt with the COVID-19 pandemic. When it began, we had no idea that over a year later, the pandemic would have had the devastating impact it has around the world and would continue to present challenges to our everyday lives. Despite obstacles, Up Side of Downs (USOD) staff was up to the task of converting existing programs to virtual offerings and creating new programs to meet the changing needs of children and adults with Down syndrome and their families. The staff provided over 230 hours of virtual programs to over 5,200 participants.

Last year also brought to the forefront many racial inequities and injustices and the need for change. In 2016, Pediatrics Nationwide* released data showing racial disparities in life expectancy for people with Down syndrome. The data showed that average life expectancy for a person of color with Down syndrome was half that of a white person with Down syndrome. The cause for this disparity remains unidentified but this reality calls us to ensure we are doing what we can to meet the needs of all families in our community that include a member with Down syndrome.

*https://pediatricsnationwide.org/2016/05/19/uncovering-racial-disparities-in-down-syndrome

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.
USOD has been offering a range of education enrichment programs for children, from toddlers to teens for several years. In 2020, as the pandemic closed schools and students were taught virtually, families looked for additional supports during this highly unusual learning environment, USOD provided meaningful, interactive and fun materials and education programs virtually for all ages.

Little Learners (18 mos. - 36 mos.), Early Learners (preschool) and Lively Learners (K-5) received materials and access to a Google Classroom full of appropriate activities for ongoing work in-between virtual sessions with USOD educators. Our TEEN group met in 6-week sessions, focused on topics such as friendships, internet safety, and cooking.

The pandemic and its impact on our lives made clear the need for additional programs for adults, so USOD began running two very popular and well-attended programs, Living & Learning with Confidence and Cooking with Confidence. These programs provide interactive classes focused on life-long learning skills and cooking skills using visual recipes in a virtual, yet social environment.

Parent sessions were also conducted on a variety of topics, including a back to school roundtable, mask-wearing strategies, and potty training.

“The Lively Learners program has provided a wonderful boost to Alaina’s development! The curriculum is excellent covering all aspects of learning. We look forward to receiving the packets which are filled with awesome materials that range from being at her current level of learning to a little further ahead so she can be challenged as we revisit them every so often. Additional content is available online, as well. Despite the past year of online learning, Alaina looks forward to the Zoom sessions because she especially enjoys the games. We can’t wait to continue with our 4th session this summer!”

~MARTINA JAEGERS, MOM TO ALAINA

In 2020, USOD expanded programming for adults and created ACES (Able, Capable, Empowered, Strong), which now includes Living & Learning with Confidence, Cooking with Confidence, the Entrepreneur Bootcamp, and Mind•Body•Soul social programs.
The Up Side of Downs welcomes approximately 30-35 new families to the organization each year. Families meet with our New Parent Support Coordinator and are assigned a volunteer parent mentor. Resources and welcome baskets are provided. The past year has made connecting a challenge, but despite that, we continued to meet virtually with and support new families. We also continued hosting Moms, DADS, and Grandparents groups and our Circle of Support, which focuses on programming for families dealing with a dual diagnosis of Down syndrome and Alzheimer’s Disease.

“Rich and the USOD team have been fantastic as we worked through how to care and advocate for our new son, especially in the midst of a pandemic. From a welcome package, to virtual baby sign language classes and financial planning workshops, they have been there for us and willing to answer any questions we had. We got involved in the Buddy Walk in our first year and were able to raise a lot of money with the help of our family and friends to support this wonderful organization! We look forward to many more great years and new friendships developed through our involvement with The Up Side of Downs!”

–BETH & SETH RICHARDSON, PARENTS TO CHARLIE

“I started getting active in the USOD Dad’s Group at the end of 2019. At that time we were meeting monthly in person and it was a great way to connect with fathers like myself who also have children with Down Syndrome. As Covid progressed we unfortunately had to stop meeting in person and began with our monthly Zoom meetings. Although I do miss our in person meetings, the Zoom meetings have been a great way to seek advice from the Dads that are much further along in this journey than myself as well as offering advice or answering questions of the members that are just getting started. Thank you USOD for offering yet another valuable resource for our family!”

–MATT CHERNITSKY, DAD TO ARCHIE
Social Activities

Despite the pandemic we had FUN in 2020! Weekly bingo, No Rulz dance parties, story time and sing-alongs helped everyone connect and enjoy time together. We were also entertained by some of our favorite performers, including Outback Ray and his animal show, magic from the Magic Man, and a Christmas in July visit with Santa and Mrs. Claus. Working with Jacobs Ladder Special Needs Fitness, we hosted twice-weekly workouts to help everyone stay fit despite being home and isolated. We couldn’t host an in-person Holiday Party, an event typically attended by several hundred people, but we made it work with a virtual event that included celebration kits for families and an appearance by Santa and Mrs. Claus.

IN 2020, USOD PROVIDED OVER 125 HOURS OF SOCIAL PROGRAMMING FOR NEARLY 3,000 PARTICIPANTS.

“Mel likes exercise because its two days a week and she likes all the exercises. Her favorite is the goddess pose. She liked seeing her friends on Zoom and she misses getting together with them. Exercise was fun and her friends made her laugh. She likes saying the prayer at the end. She was so happy to go to the beach and see her friends the best part was Rich jumping in the water.” –BRENDA DELUCA, MOM TO MELANIE
### Programs & Services

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<th>Family Support</th>
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<th>Social Programs</th>
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<tr>
<td>In-person and virtual hospital and home visits to new families</td>
<td>Northeast Ohio Buddy Walk</td>
<td>Wiggle, Giggle &amp; Learn (18 mos.-36 mos.), Early Learners (preschool), Kinder Kickstart &amp; Lively Learners (K-5) education programs</td>
<td>Medical Advisory Board which provides medical expertise to USOD and those we serve</td>
<td>Bowling Buddies</td>
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<td>Transition Boosters partner agency - programming for families of transition-age youth</td>
<td>Cleveland Down Syndrome Day</td>
<td>School outreach to facilitate education &amp; IEP support for families</td>
<td>Deliver packets of information to Northeast Ohio hospitals and medical offices</td>
<td>USOD Family Days at area theaters and sporting events</td>
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<tr>
<td>Early Connections parent mentors, welcome baskets and packets for new and expectant parents</td>
<td>World Down Syndrome Day activities annually on March 21 (3/21)</td>
<td>Educational seminars &amp; roundtables for parents and professionals</td>
<td>Provide up-to-date info on the USOD website with relevant medical information</td>
<td>Tee It Up Golf clinics</td>
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<tr>
<td>Support &amp; programs for siblings of all ages</td>
<td>Celebration of Down Syndrome Awareness Month each October</td>
<td>ACES (Able, Capable, Empowered, Strong) adult education programs</td>
<td>Present to grand rounds, panels and students in health care fields</td>
<td>Adult gatherings such as monthly karaoke and seasonal dances</td>
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<td>DS+ support for families of an individual with Down syndrome &amp; autism</td>
<td>Contact local and state legislators to promote Ds initiatives</td>
<td>Down Syndrome 101 training for professionals</td>
<td>Provide medical professional referrals to USOD members upon request</td>
<td>USOD Fall Fun Fests</td>
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<td>Host DADS, MOMS, Grandparent and Baby &amp; Toddler Playgroup gatherings</td>
<td>Spread the Word to End the Word Pledge</td>
<td>Peer Presentations to support friendship and understanding within the classroom</td>
<td>Host medical seminars for families</td>
<td>Mind Body Soul social activities for individuals with Ds, 18+</td>
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<tr>
<td>Family Grants Program offered to USOD families 2x per year</td>
<td>Preferred Language Guide for Ds</td>
<td>Teen Educational Enrichment Network for individuals w/Ds, 13 - 18</td>
<td>Review and promote Ds research studies</td>
<td>USOD Holiday Party</td>
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<td>Circle of Support – for families dealing with diagnosis of Ds &amp; Alzheimer’s disease</td>
<td>Work with media partners to encourage positive and accurate depictions of individuals with Ds</td>
<td>Living &amp; Learning with Confidence &amp; Cooking with Confidence – adult life skills programming</td>
<td>Serve on advisory boards for research studies</td>
<td>USOD fitness programs such as 321 Fitness, Adaptive Jazzercise &amp; Yoga</td>
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<td>La Familia del síndrome de Down del Noreste de Ohio. &quot;De Familia a Familia&quot;</td>
<td>Leverage social media to advocate on behalf of individuals with Ds</td>
<td>Book Bundles – free resources for area schools</td>
<td>Steps to Independence Retreat for individuals w/ Ds, 18+</td>
<td>Strider Bike Camp</td>
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<td>Parent to Parent Network Support on Facebook</td>
<td>Sunburst Gala where the achievements of individuals with Ds are celebrated</td>
<td>Entrepreneur Bootcamp</td>
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*Programs are currently provided virtually and in-person with the safety of our participants at the heart of each offering.*
Ongoing programming with the safety of our participants at the heart of each offering.

Creation of a mural titled, “More Alike Than Different” celebrating individuals with developmental disabilities in Cleveland in partnership with the Bellaire Puritas Development Corporation, CLE City Council member Brian Kazy and other organizations that support families and individuals with developmental disabilities. We will unveil the mural in October.

Diversity, Equity, & Inclusion Initiative: A DEI Task Force has been created to develop and implement a DEI Plan that enables USOD to be thoughtful and intentional about our commitment to advancing Diversity, Equity & Inclusion for all stakeholders.

New classes and social opportunities for adults with Down syndrome through A•C•E•S Buddy Walk 2021 – this year’s walk is being held on Saturday, September 18th at Lake Metroparks Lake Farmpark. You can attend in-person, or virtually wherever you are!

What’s Happening in 2021

USOD BY THE NUMBERS

2020 Revenue: $543,886.15
2020 Expenses: $557,917.21
2020 Ending Net Assets: $847,304.92

*Financial information provided prior to audit
Supporting and Celebrating Down Syndrome in Northeast Ohio

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

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.

21st Annual Northeast Ohio BUDDY WALK®
Supporting & Celebrating Down Syndrome
One mile walk to promote the acceptance and inclusion of all people with Down syndrome.

SATURDAY, SEPT. 18, 2021
Lake Metroparks Farmpark
Kirtland, Ohio

Shop Online at www.artful21.com
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Register at usod.org

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