I recently read an article on the nature of ideas and the following quote stood out to me: “The search for fresh ideas often leads us to the most unexpected of places. And as most creative people know, the best ideas are usually hidden in either the most obvious or the least expected places.” The best ideas don’t always come out of strategic planning sessions, focus groups or board meetings. Sometimes, the best ideas come from someone who has a spark of an idea and then shares it with others.

A few weeks ago, one of our Teen Group leaders approached me with a spark of an idea by simply saying, “I was thinking about the kids in our Down syndrome community that are graduating from high school. It’s such a huge accomplishment for the senior, their entire family, and I believe the countless teachers that have been champions for their students along the way.” Lucky for us, this mom has a close connection with someone at Lamar Advertising. When she asked him if the DSAGC could honor our seniors on billboards around town, he said yes! Before long, we identified 24 graduating seniors with Down syndrome in our region. We worked with Lamar on the design and in a matter of weeks, we had billboards throughout Greater Cincinnati lined up to congratulate each and every senior. I can’t help but imagine the sense of pride and joy for each graduate and their loved ones seeing their happy faces all over town!

If you haven’t heard or seen our announcement, due to COVID-19 and the health and safety protocols related to large gatherings, we will be celebrating this year’s Buddy Walk on September 12th a unique way (www.buddywalkcincy.org). We have a few details for you in this DS Press, but more details will be coming in the weeks ahead.

The Buddy Walk tagline is “TOGETHER FOR DOWN SYNDROME” so even though we won’t all be in one place physically, we will still be together in spirit, with our teams, in multiple locations throughout the region, celebrating our loved ones with Down syndrome.

Although this year will look different from past Buddy Walks, one of the things I’m looking forward to is hearing and seeing an abundance of creative ideas from Team Captains and participants. Maybe someone will get a spark of an idea that we can all use to celebrate together, even if we aren’t at Sawyer Point. So, let’s Paint the Tri-State, together for Down syndrome!

With Appreciation,

Jim and Violette at the 2019 Buddy Walk
A Letter from Board President, Ashley Barlow

Every cloud has a silver lining. We’ve certainly all experienced metaphorical cloudy weather in the past few months as we’ve faced different struggles associated with the COVID-19 pandemic. We’ve re-worked our support networks, shifted the focus of our goals, struggled to reassess our family values, and learned how to communicate in very new ways. While it’s probably necessary to focus on the struggles to a certain extent to heal from them, real growth can occur when we face stresses like these. Yes, those clouds can be lined in silver.

I was in a pretty bad boating accident when I was a teenager. I awoke in a hospital the day after the accident, and my mom said, “Here’s what we can do. You can be a victim or a survivor. We can focus on everything that happened and everything that hurts; or we can celebrate that you are alive and make the best of it.” As a team, my family chose the latter. We’re survivors. We look for the good. We create the good.

This season at the DSAGC has indeed been full of challenges. I’m so proud of our staff team, volunteers, board members, parents, and self-advocates that have weathered these storms with grace, positivity, and a continued commitment to community. One of my favorite examples involves Adult Matters programming. To keep the audio clear, the leaders of a large Zoom get-together had to mute participants, which obviously limited communication. Finding immediately that the participants needed to communicate with peers, Christy Gregg, our Adult Matters Coordinator, added small group programming and check ins. As a result, our adults got not only the large-group programming but the small-group socialization.

The Buddy Walk will look different this year, but I challenge you to look for the good, to think outside the box, to find that silver lining. Perhaps your revised plans for September 12th expand your outreach to additional groups of people. Perhaps your reach can be felt further because of your use of technology. Perhaps you can specially tailor your celebration to your loved one with Down syndrome. I encourage you to look for the silver as we Paint the Tri-State Yellow and Blue, together for Down syndrome!

Ashley Barlow
DSAGC Board President
This year has brought us a lot of change. But one thing that will never change is our commitment to empowering and celebrating the lives of people with Down syndrome. We will always remain together in that effort. Together, we learn new things, advocate for what’s right, and support each other no matter what. And, nothing brings us together more than our annual Buddy Walk. Thousands and thousands of people come together in downtown Cincinnati from all over the Tri-State to celebrate our loved ones with Down syndrome.

It is a special day for so many.

This year presents us with an opportunity to expand our reach into the community. In an effort to ensure the safety of over 13,000 participants, we have made the thoughtful decision to celebrate our Buddy Walk a unique way this year! The Buddy Walk will still take place on Saturday, September 12. And while we aren’t able to physically be together at Sawyer Point, we can still remain TOGETHER FOR DOWN SYNDROME while safely celebrating as TEAMS all across the Tri-State!

In a unified effort, we will PAINT THE TRI-STATE YELLOW AND BLUE – wearing our Buddy Walk shirts in solidarity – decorating our neighborhoods with team signs, flags, balloons, and side walk chalk – organizing car parades, family picnics, backyard barbecues, walks with friends and more.

The Buddy Walk may LOOK different, but the feeling of acceptance and celebration will remain the same because Greater Cincinnati is and always will be TOGETHER FOR DOWN SYNDROME.
REGISTER

TEAM CAPTAINS: Before your members can join, you must first sign up your team - so REGISTER TODAY! Then share your page and engage your team members to also sign up!

TEAM MEMBERS: Make sure your Team Captain has created their team page for 2020 and then you can sign up. Remember, registration is free for the Cincinnati Buddy Walk! A great way to Paint the Tri-State is to wear your blue and yellow Buddy Walk t-shirts on Saturday, September 12th.

New to the Buddy Walk? Call Kerin Caudill at 513.761.5400 and she can get you started!

ENGAGE YOUR COMMUNITY

Reach out to your friends, family, neighbors and colleagues to not only join your team, but to also support your team. The Buddy Walk is the largest fundraising event of the year for the Down Syndrome Association of Greater Cincinnati. It brings in the necessary funds to provide support, resources, outreach, advocacy, and programming to thousands of local families in our community. Click here for a quick snapshot of what a Buddy Walk gift supports. We understand that many people have been affected by COVID-19, which may impact their ability to give and willingness to fundraise. Please know we want you to do what feels right for you and your family. Should you have any questions, feel free to reach out to Kerin@dsagc.com.

T-SHIRT WEEK

It’s the most wonderful time of the year at the DSAGC! We will still have t-shirt pick up this year at the DSAGC office. As always, Team Captains will pick up their team shirts. The pick-up process will be modified to align with state regulations and safety guidelines. We will be sure to update you at www.BuddyWalkCincy.org and in Buddy Walk Brief emails closer to the event for specifics on t-shirt pick up.

PAINT THE TRI-STATE

Join us as we PAINT THE TRI-STATE YELLOW AND BLUE on Saturday, September 12! We will share pictures and videos from the community throughout the day on social media. We highly encourage you to interact and share your team celebrations with us! Our local media friends, community partners, and other Cincinnati favorites will be painting the tri-state alongside us because we are all TOGETHER FOR DOWN SYNDROME!

HOW CAN MY TEAM PAINT THE TRI-STATE?

The beauty of paint and color is that it can lead our imaginations and spark creativity. The DSAGC supports 12 counties in Kentucky, Ohio and Indiana. Think about the splash our teams can make in the neighborhoods in which they live, work and play – showing we are all TOGETHER FOR DOWN SYNDROME! Over the next couple of months, we will provide you with ideas, resources, celebration swag and more to help us all celebrate our biggest and most special event of the year.

As always, the health and safety of our community is our top priority. We highly encourage all teams to safely celebrate and abide by the most updated health guidelines as provided by local, state, and federal officials.
We missed seeing everyone at Winton Woods for our annual World Down Syndrome Day 5K/10K/Kids Fun Run, but we very much appreciated the understanding around switching this event to a "virtual" platform. We were THRILLED to see so many of you participating in your own fun, safe, and creative ways! We can't thank you enough for your passion, dedication, and support.

We partnered with Down Syndrome Associations all across the country for a unique Pen Pal program. We held a variety of cooking and baking classes for adults. These classes allowed participants to strengthen motor skills through measuring, whisking, and pouring as well as practice sequencing while following step-by-step directions.
This school year has been exceptionally unique as students and teachers had to quickly adjust to non-traditional instruction due to COVID-19. In an effort to expand learning time, we are offering 1:1 virtual Summer Tutoring with certified special education teachers.

Our “Connecting Through Creativity” classes help relieve isolation through storytelling and creative expression.

World Down Syndrome Day is celebrated on March 21 (3/21) to signify the third copy of the 21st chromosome in people with Down syndrome. Families submitted photos of their loved ones with Down syndrome and shared how they were celebrating 3/21!

Asher was in his element during our Song Circle with Miss Kim! We love staying connected to everyone during the spring through our virtual programs!

Every other week, Miss Julie from Ballet Moves led a dance party to kickoff the weekend! We had over 50 participants at each dance party!
The health and safety of our families, instructors, volunteers, and staff is our top priority. Therefore, we’ve developed a phased approach to reintroducing in-person programming. Through this phased approach, we will continue to maintain safety guidelines as recommended by health experts and government officials. We will continue to learn and adapt in the best interest of our community. We appreciate your patience and understanding as we navigate this transition time together.

Note: Construction on our Empowerment Center is making great progress! Throughout the summer and into the fall, the center will be equipped with the first round of furniture, therapeutic equipment, and educational supplies. We will continue to add additional furnishings as we phase back into in-person programs.

OFFICE / EMPOWERMENT CENTER
The DSAGC office and Empowerment Center are closed to guests.

STAFF SUPPORT & OUTREACH
DSAGC staff will conduct all support services and outreach consultations virtually with few exceptions.

PROGRAMS
All programs are 100% virtual.

COMMUNITY GROUPS / SOCIAL CLUBS
Community Groups and Social Clubs opportunities are 100% virtual.

VOLUNTEERS
There are no in-person volunteer opportunities.

OFFICE / EMPOWERMENT CENTER
The DSAGC office and Empowerment Center is open to families by appointment and scheduled program activities in accordance with the most updated state recommended safety guidelines.

STAFF SUPPORT & OUTREACH
DSAGC staff can conduct support services and outreach consultations to the comfort level of the family / community member. If there is an in-person meeting, staff will abide by state regulations and recommendations.

PROGRAMS
The majority of programs will remain virtual with a select number of programs conducted in person in accordance with the most updated state recommended safety guidelines in place.

COMMUNITY GROUPS / SOCIAL CLUBS
Community Groups and Social Clubs can meet in person at offsite locations only if they abide by the most updated state regulations and recommendations.

VOLUNTEERS
There will be limited in-person volunteer opportunities in accordance with the most updated state recommended safety guidelines in place.
PHASE THREE

OFFICE / EMPOWERMENT CENTER

The DSAGC office and Empowerment Center is open to families in accordance with the most updated state recommended safety guidelines.

STAFF SUPPORT & OUTREACH

DSAGC staff can conduct support services and outreach consultations to the comfort level of the family / community member. If there is an in-person meeting, staff will abide by state regulations and recommendations.

PROGRAMS

Our programs will be a blend of in person and virtual opportunities. All in-person programs will occur in accordance with the most updated state recommended safety guidelines in place.

COMMUNITY GROUPS / SOCIAL CLUBS

Community Groups and Social Clubs can meet in-person at offsite locations and onsite at the DSAGC only if they abide by state regulations and recommendations.

VOLUNTEERS

A reduced number of volunteers will assist with programs and events.

PHASE FOUR

OFFICE / EMPOWERMENT CENTER

The DSAGC office and Empowerment Center is open to families in accordance with state recommended safety guidelines.

STAFF SUPPORT & OUTREACH

DSAGC staff will conduct support services and outreach consultations to the comfort level of the family / community member. If there is an in-person meeting, staff will abide by state regulations and recommendations.

PROGRAMS

The majority of programs will occur in person with a select number of programs available in virtual format. All in-person programs will occur with the most updated state recommended safety guidelines in place.

COMMUNITY GROUPS / SOCIAL CLUBS

Community Groups and Social Clubs can meet in person at offsite locations and onsite at the DSAGC only if they abide by state regulations and recommendations.

VOLUNTEERS

A typical number of volunteers will assist with programs and events.
In addition to these new program options, we continue to provide support, resources, and outreach. While we can’t wait to see everyone again at our in-person programs and events, we remain committed to our mission and are still available to support each family and their unique needs during this time.

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**AGES 0 - 5**

- **EXPRESSION THROUGH ART**  
  Art Therapy Opportunity
- **FUN IN THE SUN MUSIC MAKING**  
  Music Therapy Opportunity
- **PRESCHOOL READINESS**  
  Educational Opportunity
- **DANCE PARTY WITH MISS JULIE**  
  Recreational Opportunity
- **ICE CREAM SOCIAL**  
  Social Opportunity

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**AGES 6 - 12**

- **CHEERLEADING WITH COACH DEB**  
  Recreational Opportunities
- **DANCE PARTY WITH MISS JULIE**  
  Recreational Opportunity
- **FUN IN THE SUN**
- **HEALTH & SAFETY IN THE KITCHEN**
- **GAME TIME**
- **LET’S EXPLORE THROUGH SCIENCE**  
  Occupational Therapy Focus
- **COOKING WITH CHEF MILES**  
  Life Skills Opportunity
- **EXPRESSION THROUGH ART**  
  Art Therapy Opportunity
- **ICE CREAM SOCIAL**  
  Social Opportunity
- **SUMMER TUTORING**  
  Educational Opportunity  
  (registration closed)

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**AGES 13 - 17**

- **CHEERLEADING WITH COACH DEB**
- **DANCE PARTY WITH MISS JULIE**  
  Recreational Opportunities
- **FUN IN THE SUN**
- **HEALTH & SAFETY IN THE KITCHEN**
- **GAME TIME**
- **LET’S EXPLORE THROUGH SCIENCE**  
  Occupational Therapy Focus
- **COOKING WITH CHEF MILES**  
  Life Skills Opportunity
- **EXPRESSION THROUGH ART**  
  Art Therapy Opportunity
- **ICE CREAM SOCIAL**  
  Social Opportunity
- **SUMMER TUTORING**  
  Educational Opportunity  
  (registration closed)

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**AGES 18 & UP**

- **BAKING WITH CHEF DANIEL & CHEF JORDAN**  
  Life Skills Opportunities
- **BROWNIE MAKING WITH CHEF DANIEL & CHEF JORDAN**
- **FUN IN THE SUN**
- **HEALTH & SAFETY IN THE KITCHEN**
- **FIRE SAFETY**
- **LAUNDRY SKILLZ & DRILLZ**  
  Occupational Therapy Focus
- **EXPRESSION THROUGH ART**  
  Art Therapy Opportunity
- **MARTIAL ARTS WITH COACH JEFF**
- **DANCE WITH COACH DEB**
- **DANCE PARTY WITH MISS JULIE**  
  Recreational Opportunities
- **ICE CREAM SOCIAL**
- **BINGO NIGHT**  
  Social Opportunities

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Learn more & register at www.dsagc.com/virtual.
Complete Atrioventricular Septal Defect

By: Marty Tomlin, MSN, APRN, RN, University of Cincinnati Medical Center | DSAGC Health Advisory Board Member

Congenital heart defects (CHD) are reported to affect from 40-60% of babies diagnosed with Down syndrome compared with approximately 1% in the general population. The complete atrioventricular septal defect (AVSD) is the most common type of congenital heart defect in individuals with DS with a 45% prevalence. It occurs during pregnancy with the abnormal development of the valves (tricuspid and mitral valves) between the heart’s upper and lower chambers (atria and ventricles) and the walls between the chambers (septal walls).

The complete atrioventricular septal defect is characterized by a large hole in the center of the heart which allows blood to flow between all four chambers of the heart. This hole occurs where the septa (walls) separating the two top chambers (atria) and two bottom chambers (ventricles) normally meet. There is also one common atrioventricular valve in the center of the heart instead of two separate valves – the tricuspid valve on the right side of the heart and the mitral valve on the left side of the heart. This common valve often has leaflets (flaps) that may not be formed correctly or do not close tightly. This defect allows blood to flow where it normally should not go and may result in a lower than normal amount of oxygen for the individual. Extra blood also can flow to the lungs which can force the heart and lungs to work hard resulting in congestive heart failure and pulmonary hypertension.

This defect can be surgically corrected. The atrial and ventricular septal defects are repaired with a patch. The single atrioventricular valve is separated into right and left components and the valves are reconstructed into a tricuspid valve and a mitral valve. The separated valves are attached to the patch.

The left atrioventricular valve (the mitral valve) is partially closed with sutures to reduce regurgitation or leakage. Surgery should be done before there is permanent damage to the lungs from too much blood being pumped to the lungs.

Individuals with Down syndrome who have undergone surgical repair of a complete atrioventricular septal defect are not cured. The most common complication is a leaky mitral valve. This condition occurs when the mitral valve does not close completely so that it allows blood to flow backwards through the valve (mitral regurgitation). A leaky mitral valve can cause the heart to work harder to get enough blood to the rest of the body and may have to be surgically repaired.

A child or adult with a repaired AVSD should have regular follow-up visits with a cardiologist to ensure the heart is working well and to monitor for any complications. With proper treatment, these individuals grow up to lead healthy, productive lives.

Also, because many babies with Down syndrome have congenital heart defects, all infants with Down syndrome should have an echocardiogram to look for any type of congenital heart defect.

References available upon request.
Virtual Greetings from the Thomas Center! Life has turned upside down and it can be hard to see when life will feel more stable and predictable. COVID-19 and the incomprehensible death of George Floyd have impacted us in many ways. It can be overwhelming at times. We have seen stress, challenges, as well as amazing resilience during this time.

You may be wondering what is going on with the Thomas Center during this time and how have we adapted to the world of telehealth. I am proud to report that the Thomas Center team members have excelled in embracing this new way of providing care. We have been doing team visits and individual visits through telehealth. Families get a link to an app that then allows us to meet up on Microsoft teams. This platform can include many people at one time, somewhat like zoom, but with greater security. The families who have participated have been amazing at working with us to help us see the accomplishments of their children. We have also been able to set up visits with single providers (such as nutrition, OT, PT, speech-language pathology, psychology, social work, and medical providers). Gretchen Carroll has remained available for school questions and concerns and has participated in school meetings virtually. The transition program is also working through telehealth and on-site visits.

As we move into the summer, we will continue to offer telehealth care when appropriate. We don’t want to delay care for issues that need to be addressed. Sometimes that means we need to see children directly rather than through a computer screen.

We have started increasing on-site care as well. We recognize that it can be a little scary to think about coming on site for care. I want to reassure you that Cincinnati Children’s as a whole is taking safety and care very seriously.

If you do come on site, you will find things have changed. We are limiting those who come to bring no more than 2 adults with the child and no siblings. When you enter, there will be a screening area. Here all members of your party will be asked questions about symptoms and exposure to COVID-19, have temperatures taken with a touchless thermometer (over the forehead), and provided masks. You are allowed to wear your own mask if you prefer. If a child cannot wear a mask, they will not be required to wear this, but everyone else (adults and care providers) will be expected to keep their mask on while in the building. We have developed a social story for children if you would find that helpful.

All staff are also screened when they come to work. As always, we are washing our hands (or using hand sanitizer) prior to and after care and rooms and materials are wiped down between patients. We have added wearing masks at all times and using goggles for patient care.

Finally, if you are looking for more information, Cincinnati Children’s Hospital has a good webpage with up to date information (www.cincinnatichildren.org/patients/coronavirus-information).

We look forward to continuing to serve you, whether virtually or in person. We are all new at this. When we lean on each other and learn from one another - we will become stronger. I am personally grateful for the opportunities to walk alongside families in their journey as it has made me a better provider, a better parent, and a better person.
Families Needed for Older Children Adoption

By Stephanie Thompson, Director of the National Down Syndrome Adoption Network

The National Down Syndrome Adoption Network had a great year in 2019. We helped with the adoption of over 25 children with Down syndrome into adoptive families.

At present, we have 45 families on our registry - families who are home-study ready, and want to adopt a child with Down syndrome. In order to be included on our registry, you must have a home study, which is a legal document that approves you to adopt.

45 families may sound like a good amount of families for our registry, but let me explain further how our process works. Close to 90% of the situations we help with are newborn, private adoptions. That means that birth families have contacted us, considering an adoption plan.

When an expectant or new family contacts the NDSAN, we provide a safe place and listening ear for them to share their diagnosis story and process their thoughts and emotions. We then provide updated information and resources about Down syndrome. Families also have the option to connect with other families and/or local supports. This begins the process of families deciding to parent or make an adoption plan.

The remaining 10% of the situations we help with are older child adoptions, either private, or public adoption through the foster care system.

And this is where you come in!

Yes, we may have 45 families on our registry, but an overwhelming majority of those families want to adopt a newborn. More families are needed who feel called to adopt an older child, age 12 years old and up.

A family who wants to adopt an older child may have the following parameters:

- The potential adoptive parents (that’s you!) may be over the age of 40
- The potential adoptive family be “Empty Nesters”
- The potential adoptive family may have children older than the age of 12

Most children in foster care who are older do best when they are the youngest or only child. This is because they have been through a LOT of transitions in their life; they will need to be in a family where they are given the most attention for the first few years.

One of the ongoing goals of the NDSAN is to always have a diverse and wonderful pool of adoptive families on our registry, from every state across the US.

This is where you come in. We are seeing an increase in older kiddos. We need families who feel called to provide a forever home to these children.

You’ve probably never thought about adopting an older child with Down syndrome. It probably never occurred to you that it may even be needed.

So I am here to plant that seed with you.

First, take a look at our website, ndsan.org. You’ll find it’s a great introduction to what the National Down Syndrome Adoption Network does for birth and adoptive families. Take a look at the Adoption Process section for a little more information on how we work.

Second, head over to our Foster Kiddos page, https://www.ndsan.org/adoption-process/children-in-foster-care/, to see all of the children currently in foster care, who are ready to be adopted into a forever family. Please know that older children in private care situations are kept confidential and only shared with families on our registry.

Third, head over to our Facebook page, facebook.com/dsadoption. Make sure to “Like” the page. You will see posts about adoption resources, stories from families who have adopted, and children who are in public custody who need families. If you do not feel called to adopt, please consider sharing their posts!

Fourth, contact me. You may have questions about the adoption process, or you may just need to talk about this “feeling” that you have after reading this article. I would be happy to talk with you and answer any questions, and if you decide to take the journey of adoption, I will walk you through the process. Feel free to email me at stephanie@ndsan.org or call me at 513-709-1751.
Congratulations, Class of 2020!

We partnered with our good friends at Lamar Advertising Cincinnati and the Abel Family to showcase graduating seniors with Down syndrome in our Greater Cincinnati area. Individual billboards were displayed all over town highlighting their milestone. In addition, we shared their accomplishments on our social media pages throughout May and June.
Thank you, Penn Station!

During the first three weeks of March (March 1 - 21), Penn Station locations host a Round Up for Down Syndrome campaign. Customers are able to round up their purchase to support their local Down syndrome organization. This campaign was launched in 2019 in the Cincinnati and Dayton markets. Because of its success, all Penn Station locations across the country participated in this year’s campaign.

This year, the campaign raised more than $30,000 for the Down Syndrome Association of Greater Cincinnati! Overall, more than $160,000 was donated to 33 Down syndrome organizations through the Penn Station Round Up for Down Syndrome Campaign. In addition to the money donated by customers, Penn Station also made a very generous donation to the National Down Syndrome Adoption Network, a program of the DSAGC.

Thank you to Penn Station and all those in our DSAGC community who participated in this campaign. Your support benefited not only our own community, but is making a difference in the lives of people with Down syndrome in dozens of other communities around the country!
The DS Press is published four times a year. The purpose of the DS Press is to share current information about various topics relating to Down syndrome and to publicize the activities of the DSAGC. The DSAGC does not endorse, recommend or support any particular regime, therapy or treatment. We welcome articles from parents, professionals and other interested parties.

The mission of the Down Syndrome Association of Greater Cincinnati is to empower individuals, educate families, enhance communities and together, celebrate the extraordinary lives of people with Down syndrome.