Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc. 🐼 Second Quarter 2018

Highlights

Director's Message: A Reflection on Being Grateful

Spotlights:

Meet Rachel Busch: An Adult Professional Living with CdLS

Research Grant Recipient Anupriya Razdan

Super Siblings Maya & Dani



Director's Message



A Reflection on Being Grateful

There is always something to be grateful for. Despite difficult and scary moments along our journey, there are always happy surprises and triumphs.

I've read and heard so many of your stories of small joys and major triumphs: children taking that first step; reaching the milestone of being potty-trained; the positive impact of teaching tolerance and inclusion; beautiful young people attending prom for the first time; or watching a child being in a state of pure delight over some little thing.

I am grateful for the nearly 450 volunteers who support the CdLS Foundation in so many ways. Our Clinical Advisory Board (CAB) answered over 475 of your questions in 2017 and nearly 2,300 in the last 4 years. Regional Coordinators helped us welcome over 100 new families last year and 130 of you raised your hand to help provide emotional support at difficult moments through our Connect-A-Family program. Under the leadership of the Research Committee members, the Foundation has been able to grant over \$260,000 towards gaining a better understanding of how the genetic mutations associated with CdLS manifest into clinical characteristics. Additionally, the research grants have explored potential options to improve the care and medical treatment of people with CdLS through treatment or behavior modifications. The CdLS Foundation Board of Directors and some former board members recently traveled to Connecticut to share their wisdom and expertise on how to advance the mission of the CdLS community forward. You should all be proud that such a dedicated and passionate group of volunteers is giving their time, talent and treasure to ensure the Foundation is viable into the future.

Another reason to be grateful is for the wonderful opportunity to gain a national TV audience to tell our story on PBS. This was made possible through the generosity of donors like you. The individuals with CdLS, their families and the Foundation will have the chance to share our journey with a national audience. The question I need your help answering is "once they have finished watching the program – what do you want the people to think about?" Let me know your opinion, check out our survey on www.facebook.com/CdLSFoundation/ and share what you want the public to know about your journey of raising a child with CdLS.

I am looking forward to meeting as many of you as I can at conference.

Donnie

Bonnie Royster Executive Director

Our Mission

The Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS, and others with similar characteristics, make informed decisions throughout their lives.

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What is On Our Minds



The Cornelia de Lange Syndrome (CdLS) Foundation is never too far away and always on your mind. You might have needed a question answered or helped another family through a difficult time. There has always been a reason that the Foundation has been part of your life, always on your mind.

This year is no different. The Foundation is preparing for the upcoming National Family Conference and Scientific Symposium, which will be held June 27 to July 1 in

Minneapolis. We strongly encourage all to attend, as the benefits are fantastic. The staff are ensuring that all details will be perfect.

Another important area that the Foundation focuses on every year is Awareness Day, which is the second Saturday in May. The goal for Awareness Day is to collectively increase knowledge about CdLS throughout the country. Most people have not heard of it unless connected to a family member. The Foundation offers many opportunities to share information through social media, as well as hosting or joining an awareness activity in your local area.

When the Family Conference ends and Awareness Day is over, the Foundation is still here, on your mind. We want you to know we have more to offer your loved one – we have education that can help your immediate family, your child's health care providers, therapists, teachers and friends. The Foundation has regional meetings and clinics. The support, engagement and empowerment is endless – not only is the Foundation on your mind, but you are on our minds, our collective minds. We will be here for your child and for you.

Join Team CdLS at the <u>Baltimore Running Festival</u>

October 20, 2018

1.800.753.2357



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Meet Rachel Busch: An Adult Professional Living with CdLS

By the time Family Conference wraps up, 33 year-old Rachel Busch has usually lost her voice.

As one of the less than 10 individuals who are part of the Adults with CdLS Network, she was so busy talking to people in the CdLS community about everything from hitting puberty to driving a car that she often forgot to come up for air. But for Rachel, the hoarse voice is worth it: she enjoys being a walking inspiration.



Rachel is one of over 1,600 estimated adults 18 and over (that we are in contact with) who are living with CdLS in the United States. She considers herself "90 percent independent."

For many people in the CdLS community, particularly parents with young children, Rachel believes she is an emblem of strength and hope, reminding others not to live in fear, but in faith that they too can find a meaningful life.

For those who don't know her story, Rachel is a force to be reckoned with. She is someone who has never let CdLS stop her from reaching her dreams. Currently, she is working on completing her fourth college degree. She has a part-time job at a restaurant. She has a boyfriend and parents she is very close to. She lives in her own apartment, five miles away from her family, with a spotted pet turtle, black cat and her best friend, Jennifer.

All of these accomplishments do not mean Rachel is impervious to struggle. It's how she chooses to handle those struggles that have enabled her to overcome huge barriers in her personal and professional life. Take college, she is planning to graduate in May 2019 and recently was growing increasingly frustrated when her college's liaison for people with disabilities told her she would have to take online classes.

"What works best for me is having an individual plan and I prefer for someone to be teaching the material to me, rather than online. I have a note taker, I get longer time on tests and have longer time on homework," she said. She noted that she had to carefully assert herself and knock down red tape to make sure she was given what she needs to succeed academically.

Someday, she hopes to figure out "what states offer the best benefits to people with disabilities" and move there.

Once she graduates, Rachel aspires to be a marketing manager. However she understands that much like college she will need to find the right job fit first. "You find a job that will work with your individual needs. It's important to make sure your boss knows those needs and see if they can actually work with you. Some companies are very flexible," she said.



Her big goal: find a job that will provide health benefits so that she no longer has to rely on Social Security. Rachel has become a sort of human encyclopedia of her state's Social Security parameters, both from taking an Introduction to Human Services class in college and practically "living in the Social Security office every month this year." Through this experience, she learned that you can only make up to \$1,000 per month without losing your benefits.

When Rachel turned 19, she accomplished yet another feat: she got her driver's license. "It was terrifying. I told my parents nonstop I didn't want to have a driver's license, but now I've realized that it's ok and I just drive where I

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feel comfortable. I don't drive long distances, or in a big city with more than two lanes or I get overwhelmed," she said, stressing that knowing her limits is key to her driving success.

"With all the disabilities I have, I have high anxiety and frustration. Physically, some days I feel great, some days I don't. Some days I feel like I don't want to do anything, but I just push myself to do it. I do live with a lot of issues health-wise, sinus, upper respiratory, hearing and lung issues. I have choking problems, some days I can't eat food and certain days I can. I get migraine headaches. I also feel like I'm starting to have orthopedic issues in my knees and joints. I don't know if that's normal aging or CdLS or what. I'm struggling with that, and I have balance issues," she said, adding that the frigid Michigan winter isn't helping.

"I probably have every specialist you can think of. You tell me the body part, I will tell you the doctor," Rachel added with a laugh, mentioning she often thinks of herself as a "guinea pig".

Rachel believes individuals with CdLS have high pain tolerances.

"Just today I was cooking soup and I burned myself. Two hours later it hurt and I had no idea what happened," she recalled.

Mentally, on a day-to-day basis, Rachel's moods fluctuate. Some days, she's positive, while other days she's "doing screaming matches with people." The key, again, is being mindful and recognizing that sometimes she needs to remove herself from situations and take a walk or talk to someone in order to calm down. Rachel also makes sure she sees a therapist on a regular basis and recommends adults with CdLS do the same.

One of Rachel's future goals: to join the Board of Directors at the CdLS Foundation.

"My favorite saying is go with the flow and don't stress yourself out," she said, reminding herself, once again, that she must balance her ambition with the ever-important task of self-care.

CdLS Empowerment Team

The Empowerment Team creates a setting where adults with CdLS can come together as a group to support and empower one another in their communities. The team encourages members to socialize, and develop relationships across the country through a variety of opportunities.

Interested in joining the CdLS Empowerment Team? For further information, please contact Whitney Rinaldi at familyservices@CdLSusa.org or call 800.753.2357.



WELCOME NEW FAMILIES

Georgia Toria and son Armani, born December 9, 2017

Iowa Samantha and Michael and son Joel, born April 9, 2015

Michigan Kristin and Joe and son Connor, born May 4, 2017

> **Tennessee** Desma and George and son Zee, born September 21, 2017

Tennessee Molly and Duane and daughter Ariella born June 16, 2015

Wisconsin Michelle and Andrew and daughter Brynn born February 21, 2012

Wisconsin Karla and Scott and son Jaxon born May 14, 2009

Research Grant Recipient Anupriya Razdan



Anupriya Razdan is a second year fellow in child psychology at Johns Hopkins University. She predominantly sees children under 18 with development disabilities such as autism, as well as, complex neurological and psychiatric presentations.

This June, at the Eighth Biennial CdLS Scientific Symposium in Minneapolis, Anupriya will present her findings from a pilot clinical trial focused on advancing therapeutic options for repetitive and self-injurious behaviors in individuals with CdLS. This presentation marks the first time in Anupriya's career that she will unveil research specifically pertaining to CdLS.

"My first training as a fellow was with a patient with CdLS. That's when I was first exposed to the self-injurious behaviors. I've been reading and building my knowledge base ever since then. My attending doctor also has a long-standing history of working with patients with both CdLS and OCD disorders," she noted.

Anupriya's study focused on examining self-injurious behaviors, like head banging and scratching, and determining if using a "very benign" over the counter treatment that has been used effectively in small studies with autism, could also work for people with CdLS.

"We're hoping to use it in CdLS and self-injurious behaviors to see if it's helpful or not. The whole idea is to inspire bigger and larger scale trials in the field. We don't have a specific treatment available for these behaviors, there is a lot of trial and error, so our hope is that we can find a new novel treatment that will be useful," she added.

Anupriya noted that she is eager to attend her first CdLS Foundation Conference and Symposium this June. She is looking forward to meeting new people, including families and other experts in the field who can continue to expand her knowledge base.

United Healthcare Children's Foundation

As we get closer to Family Conference, it's a timely occasion to think carefully about the various resources that are available to help defray medical costs for our loved ones with CdLS. Whether it's defraying costs to attend a medical conference or needed therapy, we have an idea that may help.

The United Healthcare Children's Foundation (UHCCF) is a nonprofit public charity that strives to enhance either the clinical condition or quality of life of children who have health care needs not fully covered by their commercial health benefit plan.

UnitedHealthcare Children's Foundation

Since 2007, UHCCF has awarded more than 14,000 medical grants valued at over \$35 million to children and their families across the United States. These medical grants can help families pay for children's medical expenses not covered, or not fully covered, by any commercial health insurance plan and state insurance or Medicaid can be secondary. Qualifying families can receive up to \$5,000 per grant (\$10,000 lifetime) to help pay for medical services and equipment that includes physical, occupational and speech therapy, counseling services, surgeries, prescriptions, wheelchairs, orthotics, eyeglasses, and hearing aids.

To be eligible for a grant, children must be 16 years of age or younger. Families must meet certain economic guides, reside in the United States and have a commercial health insurance plan. Grants are available for medical expenses families have incurred 60 days prior to the date of application, as well as for ongoing and future medical needs. There is no application deadline. Parents or legal guardians may apply for a grant at: https://www.uhccf. org/apply-for-a-grant/.

Team CdLS

The Team CdLS events for 2018 kicked off on Sunday, March 18th with a team of 10 individuals who raised funds and awareness. They also diligently trained for the United Airlines New York City Half Marathon.



Participants of Team CdLS were fortunate to receive guaranteed entry into the half marathon due to the Foundation's partnership with the New York Road Runner's Charity Partner program. Each year the CdLS Foundation submits an application for runners to receive guaranteed entry and has been successful in doing so due to the dedication of the runners and their commitment to continuously surpass the fundraising minimum set forth by the Charity Partner program. The March event was goaled to have five runners on the course, and raise \$5,000. The demand to join Team CdLS NYC Half was high and the Foundation was able to secure additional entries, making a team of 10 and raising approximately \$17,000.



Runner Joann B., has participated in the race with Team CdLS since 2016, and shares, "My family is fortunate that our son is surrounded by family, friends, teachers and therapists who all help him

reach the milestones he has. Some children with CdLS and their families are not as fortunate, so fundraising helps me and the CdLS Foundation change the lives of others."

This year's team was the largest the Foundation had on the course, and consisted of Joann B. (mom to Stelios); Ashley F. and Christine C. (mother and aunt, respectively, to Lindsey); Sydney L. and Jeremy D. (sister and friend, respectively to Frankie); Isabel T. and Buck S. (sister and cousin, respectively, to Sofia); and Lulu T. and Lauren S. sister and cousin, respectively, to Sofia) who participated as Phantom Runners and assisted in the overall fundraising efforts.



If you or someone you know is interested in participating in a Team CdLS sponsored event or participating in a race independently, contact Kristi Larson at events@CdLSusa.org.

2018 CALENDAR

May 21 New England Golf Tournament Ipswich Country Club Ipswich, MA

June 2 Southwest Region Family Gathering Salt Lake City, UT

June 27-28 8th National CdLS Scientific & Educational Symposium Minneapolis, MN

> **June 28 - July 1** 2018 CdLS National Family Conference Minneapolis, MN

October 6 Midwest Region Family Gathering Denver, CO October 7 2018 Bank of America Chicago Marathon Chicago, IL October 8 Missouri Golf Tournament Tapawingo National Golf Course Sunset Hills, MO

October 20 Baltimore Running Festival Baltimore, MD

November 3 Multidisciplinary Clinic for Adolescents and Adults Baltimore, MD

November 4 TCS New York City Marathon New York, NY

Welcome Aboard

CdLS Foundation Board Members generously volunteer their time and talents to identify new ways we can improve the lives of people living with CdLS and their loved ones. We are pleased to introduce you to three members who have joined us in 2018.

Jennifer Gerton, Ph.D.



Jennifer is a member of The American Society for Biochemistry and Molecular Biology (ASBMB), which awarded her a 2014 Center for CdLS Excellence Award. She is a yeast geneticist and scientist who has worked on structural maintenance of chromosomal proteins. She has

often wondered how she could utilize her expertise to make a difference and contribute to the medical community's understanding of how specific mutations cause disease. Jennifer's first Family Conference was in 2010, an experience that further motivated her as a scientist dedicated to understanding how to impact CdLS. She hopes that she can make her hometown of Kansas City a place where CdLS is quickly recognized without parents wondering for years. At the June Symposium in Minneapolis, Jennifer will be presenting her research regarding how CdLS mutation affects the development of the placenta.

Mike Christie



Mike Christie is Director of Pharmacy and Retail Operations at Walgreens and lives in Massachusetts. His youngest daughter Taryn is 10 yearsold and was diagnosed with CdLS. Having gone through a long journey to eventually find Taryn's diagnosis, Mike is eager to help others in the

CdLS community by raising awareness and funds. Already, he has helped raise significant donations from Walgreens, and is a key driver of awareness building events including New England Golf Tournament and hosting brew and barbeques, which are a personal favorite for Mike as he is often known as the "grill master." Mike is eager to attend the upcoming Family Conference in Minneapolis this June, it will be his third conference.

Arthur Lander



Arthur D. Lander, M.D., Ph.D, is the Donald Bren Professor of Developmental and Cell Biology. He holds joint appointments in the Departments of Biomedical Engineering, and Logic & Philosophy of Science. He serves on the editorial board of BMC Biology, a member of

the American Society for Clinical Investigation, a fellow of the American Association for the Advancement of Science, and a member of the Science Board of the Santa Fe Institute. He holds visiting professor appointments at National Taiwan University and the University of Tsukuba (Japan).

He also had a child with CdLS, who passed away as an infant. Ever since than Arthur has devoted a substantial amount of time to researching CdLS. Through the Foundation, he was able to connect with other scientists and families. Arthur feels that as a Board Member he will be able to give back by keeping families more informed and finding ways to bring more scientists and clinicians into the research side.

CdLS Registry: Enroll Today!

There are so many questions that accompany a diagnosis of CdLS. Questions you have are probably the same as many other families across the country, and world. To get answers, medical professionals rely on information from families to guide their hypotheses and research. This is why the CdLS Foundation has established a CdLS Registry at the Coordination of Rare Diseases at Sanford (CoRDS).



You can help researchers progress forward into determining more about the causes and manifestations of CdLS. For those of you interested in participating in this registry, visit http://bit.ly/CdLSReg to begin the process.

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A Closer look at Mike Christie



Mike Christie, who you read about on the previous page, is a new CdLS Foundation Board Member. Below he talks about what it is like to be the father to Taryn, his 10-year-old daughter who was born with CdLS.

Can you explain what life is generally like for Taryn living with CdLS?

Taryn is mildly affected, which means she has no limb differences, but does have a dislocated left elbow. The cognitive aspect is a challenge. She is a master of deflection, so if you ask her a question about something that she's read, she'll talk for 15 minutes straight, but won't answer the question. It's also one of the things that endears her to every adult she's ever met. She has expressive speech down pat, that's her thing. We see fine motor delays, it's hard for her to write. Something is going on gastrointestinally. She never has the feeling that she has to go to the bathroom. Taryn is on medications for ADHD and when it wears off you can totally tell, she's combative and what we call hangry. The medications manage it pretty well.

What are the most important tools you've learned that have helped you navigate Taryn's educational path?

Make sure that you're going to the meetings regularly and listen to what the teachers have to say because they are with our kids every day. They really have our kids best interests in mind. They will guide you along with what is in the parameters of the Individual Education Plan(IEP). Partnering with teachers makes us successful.

Has your family found anything in particular that has helped with Taryn's learning?

ABC Mouse and her iPad have helped with expressive language and spelling. She's a really good speller. Math apps have also helped her a great deal, she's getting better and better at math because of those. She can work my iPad better than I can and her YouTube search ability is off the charts.

How does Taryn interact with other children at her school?

Taryn has been in school in Ohio, New Hampshire and now Massachusetts. When we move, one of the major factors of where we live is how the special education system is rated and works. Getting into a school system with a highly rated special education program is imperative. Her IEP is extensive and is always being edited every time we have a meeting. She has a typical classroom experience, but she's taken out of class for services like speech. Because everybody is 9 or 10 and she's still in a pull up, sometimes kids can be unkind. However, there are some kids who defend her like this one boy, Tristan, who's a good friend to her.

What kinds of activities do you enjoy in your free time?

I played baseball through college, which paid for half of college. I love getting a chance to play for charity events. In my role at Walgreens and with my CdLS affiliation I played in the 25th anniversary of New England Golf Tournament. I really like barbequing, that's my favorite. If I ever had a second career I'd probably try to start a barbeque restaurant. Lately, I've mentored many leaders in the retail industry, which is very fulfilling when you can kind of guide someone who's moving in their career.

What inspired you to join The Foundation?

For a three year period of Taryn's life, we couldn't find a diagnosis. We heard so many times "failure to thrive", but there was so little awareness of CdLS. If a friend hadn't seen a Perez Hilton fashion update online where someone happened to have a child with CdLS, we never would have known. The thing that drives me to want to be on the CdLS Foundation Board and New England Golf Tournament is to want to help raise awareness for people across the United States.

Super Siblings: Maya & Dani



My name is Maya Okialda-Carter, and I am 19 years old. I work for Seattle Children's Hospital as a Certified Medical Assistant. I live with my parents, and my younger sister, Danika, who was born April 5th, 2008. It was truly a blessing when we found

out Danika was on the way; my mother was considered infertile. When Danika was still in utero, the doctors told us that Danika would most likely have abnormality. She was diagnosed with CdLS at 8 months old.

Danika started out like most children with CdLS; small and quiet. Born prematurely, at 4lb 3oz, she had around 30% hearing, had tubes implanted, which helped improve her hearing tremendously. She also struggled with GERD (acid reflux) and had feeding issues early on. But now, many years later, she eats whatever she can get her hands on! She loves birthday cake and chicken (but not together, of course).

We also never thought she was going to walk, and we were partially right. Because one day, she didn't get up and walk. She ran. Ever since then, she hasn't stopped moving and exploring.

While going through the motions and figuring out what CdLS meant for our family, we were struck with another medical experience that would change our lives again. In 2011, my mother was diagnosed with advanced thyroid cancer. She was treated and in remission later that same year, but we all struggled a lot with the reality of cancer and it's toll it had on my mother. This time of our lives, was when I stepped in and became "Mommy Maya". I cared for Danika as much as possible. When I wasn't at school, I was babysitting and tending to her needs. I sacrificed a lot of time with friends but do not regret any days I decided to spend with my sister instead.

One thing I love most about my sister is her energy and cleverness. Most kids her age love to color or draw, but Danika really loves to write. She will write words, big or small, whether she understands what they say or not. She somehow always gets her point across: "Maya Danika Sleep You Room", usually means "sleepover time!" and how can I say no to that?

She also really enjoys dancing and singing to songs she doesn't know all the words to. Nothing stops her from feeling the beat or singing her heart out. She is just like any other kid her age; lively, kind of obnoxious, but special.



I chose to work in the medical field with pediatrics and enjoy working with children with special needs. I decided to commemorate these medical experiences with my family in a tattoo. I designed it myself, and the idea stems from the Unilome, a traditional Buddhist tattoo. The

tattoo is meant to symbolize the path to enlightenment and happiness, and I took the idea and switched it up. I wanted the CdLS logo to be the main shining jewel, sitting at the top, while the ribbon represents my mother's cancer battle. The olive branches symbolize new life, and new beginnings, which God certainly has given to us. The cascading heart beat monitor line simply demonstrates that we face struggles, but life goes on.

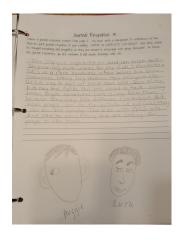
It has been an honor to learn more about CdLS and to be a sibling of a child with CdLS. I can't wait to continue supporting this community and all it offers to families across the nation.

> Share your Mailbag or Super Sibling Story! Send your story and photo to outreach@CdLSusa.org.

Mailbag – Carter Larson

Carter Larson's 7th grade Language Arts project was to read a social issues book that left a resounding impact on his life. His teacher asked Carter and his classmates to write reflections throughout the process about how he could relate to the story. Carter choose *"Wonder"* by R. J. Palacio and found that Auggie's story was one that had very special meaning to him.

He writes below:



"This story called *"Wonder"* is important to me and I can relate to it because my mom works for the CdLS Foundation. CdLS is a rare syndrome where babies are born sometimes looking very different than everyone else. The kids may be deaf, not talk or can't walk. Some of the kids may have eyelids that look closed or have missing limbs.

People sometimes look away from them because they may look different like Auggie. But what people see on the outside is not what they are on the inside. The kids with CdLS are kind, can be very funny and are looking for people to like them."

Did you know?

The CdLS Foundation has **Medical Specialty Cards**. These cards provide valuable care information in the following specialties: behavior, cardiology, dentistry, development, gastroenterology, gynecology, neurology, ophthalmology, orthopaedic, and otolaryngology.

Contact Lynn Audette at families@CdLSusa.org to request your own Medical Specialty Card(s), which you can also share with your child's care team members. To the right you'll see an example of the behavior card. CdLS Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

Behavior

• Autistic-like symptoms and autism may be present.

• Behavioral assessment if issues arise, including ADHD, self-injurious behavior, aggression.

• Be aware that individuals with CdLS may develop anxiety and depression.

• Self-injurious behavior may be related to an untreated medical condition, the most common being gastric reflux. The frequency with which unsuspected reflux has proven the basis for behavioral change has led us to strongly recommend that every person with the diagnosis of CdLS be given an evaluation for gastroesophageal reflux disease (GERD) which may include pH probe/impedance study, nuclear medicine scan and/or endoscopy.

• It is important that individuals with CdLS be evaluated and followed at some regular interval for gastroesophageal reflux (GER). Unexplained pain/discomfort or acting out may be due to an underlying medical condition. Management and treatment guidelines are available www.cdlsusa.org

• Ensure that the family has the CdLS Medical Alert Card, available from the CdLS Foundation Web site, which would be helpful in an emergency situation (e.g. risk for volvulus).

> Support organization information should be given to the family whenever a diagnosis is made: The CdLS Foundation 1-800-753-2357 www.CdLSusa.org.

 $^{ig \leqslant}$ Cut this out and share with your child's doctor.

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Donations from 01/1/18 - 03/31/18 Gifts that Count -In Honor/Celebration

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Abigail Busk Jennifer and James Busk

Adam Jackson Sara and Rodney Lair

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September 12, 1997 – January 31, 2018 Daughter of Kim and Ken Lesher 101 Marcur Lane Monaca, PA 15061

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