

Faces of Hope, Voices of Gratitude

2018 GRATITUDE REPORT



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“Thank you so much. Without your support and donations, our family would not be where we are today.”

– Parent of a patient at Kennedy Krieger



“We greatly appreciate all of you for the kindness and generosity of heart that each and every one of you provides.”

– Parent of a patient at Kennedy Krieger

This year’s gratitude report honors our donors—you and the many hundreds of individuals, families and organizations from around the world who have chosen to give to Kennedy Krieger Institute. Without your generosity, the children and families we serve would not thrive as they do. Without your kindness, we would not be able to give 24,000 patients a year the treatments they need to live their lives to the fullest.

In these pages, we’ve highlighted seven donors and donor families. Their stories are inspiring, thought-provoking and unique—just like your story, and the stories of all our wonderful donors. All of you give to the Institute in special and meaningful ways, and for that, we—and our patients and their families—are deeply grateful.

Here, you’ll read about Jane, who became a patient at the Institute more than 70 years ago, and has included the Institute in her will. You’ll read about Jonathan, currently receiving therapy services at Kennedy Krieger, who has both fundraised and donated directly. And you’ll read about Jesse, who has donated every year since 1973.

You’ll also read about Julie and Alan, who funded a clinical trial of a drug that’s helping kids with the same rare disease as their daughter. You’ll read about Shelly and Joe, tireless fundraisers for a program for young adults with developmental disorders. Liz and Duncan are helping to fund groundbreaking research that will benefit individuals with a very rare form of leukodystrophy. And Nancy and Preston chose to fund an entire wish list of new equipment and services for the Institute’s music and music therapy programs.

Every donor is important to us, and to the children and families who come to us for treatment and hope. Daily, our patients and their families express immense gratitude for being able to receive services and care at Kennedy Krieger. You make that happen. **Without you, we simply could not do what we do.**

Thank you!

The children pictured on the covers of this report are patients and students at our Fairmount campus in Baltimore. From right to left: Matthew R., Channell B., Victor Y., Lydia D., Lillian T., Henry K., Kelphon A., Lillian S. and Jordan G.



The Gift of Music

After taking one look at the teachers' and therapists' wish list, Nancy and Preston decided to fund it all.

Music has always been important to Nancy and Preston Athey. They sing in their church choir, Preston plays the piano, and Nancy is a former board member of a local music organization.

They also seek out ways in which to support music through philanthropy—in particular, funding “things that just aren’t in the budget,” Preston says. In 2017, they funded the production of Kennedy Krieger High School’s first musical, “The Wizard of Oz,” along with music programming at each Kennedy Krieger school—all seven locations. This past school year, they funded the high school’s performance of “Beauty and the Beast,” improvements to the stage at the Institute’s Montgomery County school, and the music therapy program at Kennedy Krieger’s Fairmount school.

“With the musical, the kids could have something to put their hearts and souls into.”

– Preston Athey

“Our motivation for donating comes entirely out of our love for music,” Nancy says, “and our understanding of what music can do for the mind and spirit.”

A couple of years ago, at a philanthropy information session hosted by Kennedy Krieger, the Atheys learned that music teachers and therapists at the Institute’s schools and school programs had compiled a sizable wish list of supplies and opportunities they hoped to offer to students.

For example, teachers needed to rent props, costumes, lighting, sets and more to put on the musical. One of the schools needed a new upright piano. An interactive music system would allow students of all abilities to create their own music.

Above: Students participating in the 2017 Kennedy Krieger High School production of “The Wizard of Oz.”

Left: Nancy and Preston Athey receiving a “Wizard of Oz” poster signed by students.



The Atheys, who live in the Baltimore area, were thrilled to learn they could combine their passion for music with their heartfelt desire to help children. When they looked at the list, Preston says, “we decided to fund it all! We wanted the children to have as much exposure to music as possible.”

At “The Wizard of Oz” musical, “We laughed and cried the whole way through,” Nancy says. Knowing it was much more of a challenge for the students to act and sing than it would have been for students at a typical high school, Preston adds, “We found the entire performance to be truly inspirational.”

72 STUDENTS
taking music classes
at Kennedy Krieger High
School in 2017–2018

Visit KennedyKrieger.org/SchoolPrograms to learn more about the Institute’s educational offerings.

"I have faith Kennedy Krieger can improve longevity and quality of life for the children it treats."

- Jesse Brown
(pictured)



Decades of Dedication

Jesse Brown has donated to Kennedy Krieger every year since 1973.

Jesse Brown had always looked up to John F. Kennedy, so after Kennedy's death, he started thinking about what he could do to honor the late president's memory.

A colleague at the U.S. Army's Fort Meade in Maryland, where Jesse worked for 32 years as a medical technologist before retiring in 1993, suggested Jesse

consider donating to Kennedy Krieger Institute, which had recently changed its name from Children's Rehabilitation Institute to Kennedy Institute to honor President Kennedy's support for developmental disabilities research. In 1973, Jesse made his first donation to the Institute, in the amount of \$5.

Since then, Jesse—who grew up on a farm in rural Virginia, served in the U.S. Air Force, and spent 16 years earning his degree at Morgan State University, working while attending school part time—has donated to the Institute every year. He's also established an endowment fund at the Institute to support ongoing research, and



has named the Institute in his will, ensuring his legacy will continue to impact Institute patients and their families in perpetuity.

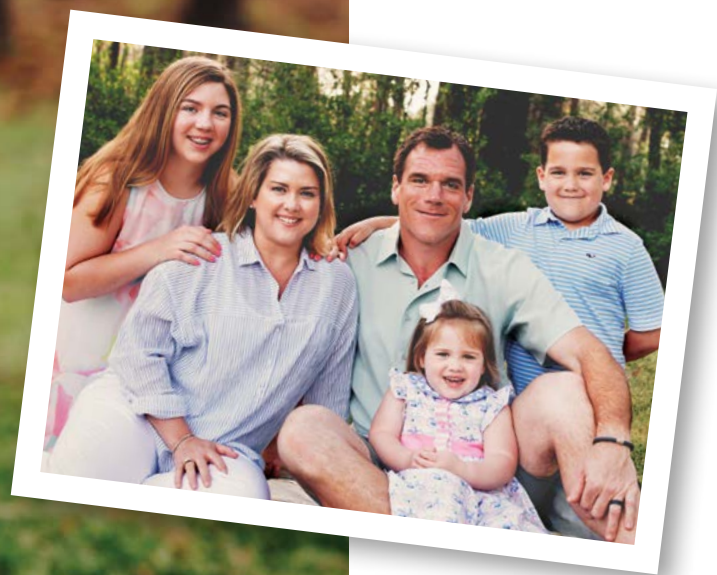
Jesse's donations align closely with his career, which he dedicated to finding more efficient tests for sickle cell anemia, the most common—and often most severe—kind of sickle cell disease. Much of Jesse's work involved laboratory research and writing scientific journal articles.

Thanks to scientific advances made in studying and treating sickle cell disease over the past few decades, Jesse has seen the lifespan of children with the disease increase, and the quality of their lives improve. He hopes research on other diseases and disorders will do the same thing for many more children, and in this, he believes Kennedy Krieger is a leader.

"With the right resources," Jesse says, "Kennedy Krieger can continue to do the important work it's been doing all along to help these children."

Visit KennedyKrieger.org/SCD to learn more about Kennedy Krieger's Sickle Cell Neurodevelopmental Clinic.

132 ACTIVE RESEARCH GRANTS AT THE CLOSE OF FY2017



Left: Anabelle, 12, has Sturge-Weber syndrome, and has been seizure-free for four years. Above: Anabelle with her parents, Julie and Alan; her sister, Penelope; and her brother, Burton, near their home in Virginia Beach, Virginia.

Giving to Find a Cure

A family's decision to fund a clinical trial led to a breakthrough in treatment for the debilitating seizures of Sturge-Weber syndrome.

Anabelle, 12, was only a year old when she had her first seizure. Tests soon showed Anabelle had Sturge-Weber syndrome (SWS), a condition generally accompanied by a port-wine facial birthmark and frequent, debilitating seizures.

As Anabelle grew up, she took a variety of medications, some more effective than others. Many were highly sedative. Yet her seizures continued, and after the worst ones, rehabilitation took up to eight months. She's had to relearn how to talk, walk, read, ride a bike, do math and crack a joke four times.

Wanting Anabelle to have the best care possible, her parents, Julie and Alan Faneca, began bringing her to Dr. Anne Comi, director of the Hunter Nelson Sturge-Weber Syndrome Center at Kennedy Krieger Institute, when Anabelle was 1 1/2 years old. Under Dr. Comi's care, Anabelle has been seizure-free for four years.

But in 2014, when Anabelle was recovering from her last seizure, and Julie and Alan didn't know what the future would hold for Anabelle, Julie read a news story about a child suffering from severe seizures. The child's parents were treating her with marijuana oil.

Julie asked Dr. Comi if the oil might help individuals with SWS. Dr. Comi soon had an idea: Isolate just one

chemical—cannabidiol—from medical marijuana, and use it to treat the epileptic seizures of SWS.

Dr. Comi needed to conduct a clinical trial to determine cannabidiol's efficacy in treating seizures in patients with SWS before she could prescribe it. Almost without hesitation, Julie and Alan agreed to fund the study. Of the study's five participants, three experienced a drastic reduction in seizures.

"Alan and I are ecstatic with the outcome" of the study, Julie says. "We're just so glad to be able to help other children who, like Anabelle, are living with Sturge-Weber syndrome."

Julie and Alan have continued to support SWS research at Kennedy Krieger. Currently, they're helping fund a trial that tests how well oral sirolimus treats cognitive impairments in patients with SWS, and they recently provided funds to support a postdoctoral fellow working in Dr. Comi's laboratory.

Visit [KennedyKrieger.org/SturgeWeber](https://www.kennedykrieger.org/SturgeWeber) to learn more about the Institute's Hunter Nelson Sturge-Weber Center.

67 CLINICAL TRIALS
took place at Kennedy Krieger in 2017



Left: Camille at her family's home in Washington, D.C., baking up an M&M's cookie cake.

Above: Shelly and Joe Galli, with their daughters, Francesca, Camille and Bella.

Below: Camille and Francesca (prom co-organizer) at the Montgomery County school's first prom, in 2015.

Funding a Brighter Future

Shelly and Joe want to help as many young adults about to age out of special education funding as possible.

Ever since their daughter Camille, 19, was a little girl, Shelly and Joe Galli have worried about her future. Diagnosed with autism when she was a toddler, Camille has attended Kennedy Krieger's Montgomery County school for children with developmental disorders since she was 10. "We love the school—the quality of education and support offered by the staff is so amazing," Shelly says. "The kids are respected and have a community, but when they turn 21, state funding to attend the school ends."

Knowing that young adults with autism and other related developmental disorders often struggle to find employment, and can benefit from further education and vocational training after turning 21, Shelly and Joe met with Dr. Robin Church, the Institute's vice president for educational programs, to find out how they could help get an over-21 program started at the school.

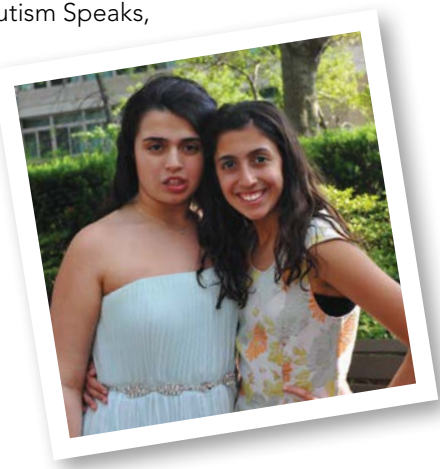
"Dr. Church said if we raise the money, she'll make it happen," Shelly says. Since last summer, Shelly and Joe have raised nearly \$800,000, both for the over-21

Fundraising in support of programs for individuals with autism is not new to the Gallis. Their oldest daughter, Bella, 21, has fundraised for Autism Speaks, and their youngest daughter, Francesca, 17, helped organize and fund the first prom for Camille and her classmates at the Montgomery County school three years ago. The prom has since become an annual event funded, in part, by the Bike to the Beach foundation.

One of the training components of the new over-21 program will be a cafe where program participants can practice and hone their baking, culinary and business skills. This means a lot to the Gallis, because Camille loves to bake. She's a stellar cookie-maker who wants to learn how to make all kinds of confections, Shelly says. There are also plans for a greenhouse, where students will learn how to grow herbs, which will be used in the cafe.

The cafe, like the over-21 program overall, "will be a viable way for these young adults to earn money and start a wonderful career," Shelly says, "and do it on their timeline."

Visit KennedyKrieger.org/Over21 to read more about postsecondary transition programs at the Institute.



587 STUDENTS served by Kennedy Krieger school programs in 2016–2017

program and for the school itself, by asking people whom they know are in a position to give, to give what they can. They've been thrilled by the response, and they're excited that the new program, named CORE Foundations, is slated to start this fall, with up to 12 participants.

2017 Gallery of Gratitude



Every year, Kennedy Krieger holds a special gathering for members of the Kennedy Krieger Society. Attendees of the 2017 Society party included hosts Wendy and Ben Griswold (above left), Jim and Mary Keely (above right), Pattie and Mike Batza (below left), and Christine and Bill Heaphy (below right).



At the Baltimore Running Festival, participants of Team Kennedy Krieger raise money for the Institute with every mile they walk, run or cycle. Last year's team (pictured below) raised \$123,321.



Above: ROAR for Kids 2017's colorful mascots. Left: Landon Brown, the winner of ROAR for Kids' Cara Becker Youth Fundraising Award in 2017, raised more than \$2,300—more than any other child or teen raising money through ROAR last year—for Kennedy Krieger's Bennett Blazers.



(Left to right) Alex Shek, John and Kim Greeley, Rob Shek, and Jay and Shelley Cortezi at the 2017 Fall Fete, an annual fashion show at Green Spring Station where patients and staff walk the runway.

Baltimore Area Toyota Dealers donated two Toyota vans and a Prius to the Institute in 2017 for staff member use. With fold-out chairs, the vans are accessible to individuals using wheelchairs.



Right: Lainy LeBow-Sachs, Kennedy Krieger's executive vice president of external relations, accepts a check from Dave Garbarino, Baltimore market president for BB&T Corporation, for title sponsorship of the Institute's 2017 Festival of Trees. Below: Jim Anders, Kennedy Krieger's chief operating officer, and his family at the festival.



At the October 2017 Art of Giving fashion show, attendees—including (left to right) Dana DiCarlo, Dawn Moore, Christiana Donahue and Bari Fore—helped raise more than \$43,000 for Kennedy Krieger and the Baltimore School for the Arts.



Hats & Horses, an annual Derby-style fundraising gala, raised close to \$280,000 in 2017 to buy cutting-edge robotic devices for patient rehabilitation. Attendees included (above, left to right) Doug and Erin Becker, Dara and Charles Schnee, and Dana DiCarlo and Wes Moore; and (below, left to right) Linda and Howard Miller, Toni Hiers-Johnson and Rob Johnson, and Steve and Joy Sibel.



Paul Siegel (left) organized a dine-out-for-Sturge-Weber-syndrome event in Baltimore in October 2017, with help from Al DeCesaris (right). Through the event and a T-shirt fundraiser, Paul has raised more than \$3,500 for Sturge-Weber research.



- SAVE THE DATES AND JOIN US!**
- Sept. 7, 2018: Fall Fete
 - Oct. 10, 2018: Judy Woodruff D.C. Event
 - Oct. 20, 2018: Baltimore Running Festival
 - Nov. 23–25, 2018: Festival of Trees
 - April 27, 2019: ROAR for Kids
 - May 3, 2019: Hats & Horses



Left: Jane Neer, at home in Richmond, Virginia.

Above: Jane and Dr. Winthrop Phelps, Baltimore, c. 1951.

Below: Jane, skiing in the 1970s.

A Lasting Legacy

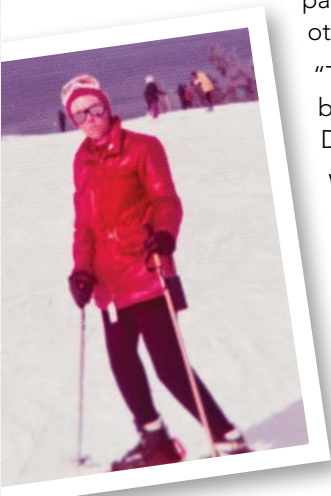
Jane Neer's connection to Kennedy Krieger spans more than seven decades. By including the Institute in her will, she'll continue that connection for decades to come.

In 1941, when she was only a month old, Jane Terrell Neer made her first trip to Baltimore, for an appointment with Dr. Winthrop Phelps. Jane had been born with athetoid cerebral palsy, which affected movement along the entire right-hand side of her body. Her father, a prominent surgeon in Richmond, Virginia, knew if anyone could help his daughter, it was Dr. Phelps, who in 1937 had founded the Children's Rehabilitation Institute, which later became Kennedy Krieger Institute.

As a child, Jane made monthly trips to Baltimore to see Dr. Phelps, who "was like a second father to me, always encouraging me to live as normal a life as possible." Dr. Phelps explained that Jane's relatively mild cerebral palsy condition could make it hard for others to understand her physical disability.

"Throughout my life, I've found that to be true," Jane says. "I'm so grateful to Dr. Phelps for explaining that to me."

When Jane was preparing for a postgraduate year of study in Switzerland, Jane told Dr. Phelps she planned to learn how to ski. "My mother was horrified," she says, but Dr. Phelps said, "Well, why not!" As it turned out, all it took was a little lift added to one of her ski boots and skis, and Jane was off down the slopes.



Dr. Phelps' successor at Kennedy Krieger, Dr. Charles E. Silberstein, continued to be there for Jane. In 1992, following his advice, Jane underwent a total hip replacement. After months of recuperation, she returned to work and threw a "Hip, Hip, Hooray" party to thank those who had helped her recover. Dr. Silberstein and his wife travelled all the way from Baltimore to Richmond to attend—a thoughtful act Jane will never forget.

Dr. Silberstein also oversaw Jane's month-long therapy "boost" in 2011, when Jane traveled to Baltimore every other day for physical therapy.

Recently, Jane joined the Winthrop Phelps Society, a group of donors who pledge to include Kennedy Krieger in their estate plans.

"I just wanted to give back to Kennedy Krieger for the wonderful care Dr. Phelps and Dr. Silberstein provided," she says. "I don't think I could have made it without them. They were just the perfect doctors for me."

Visit KennedyKrieger.org/Jane to read more of Jane's story.





Above: Alex and Sarah (Jon's brother and wife), Jon, Phyllis and Sidney (Jon's parents), and Amanda (Jon's sister) at the 2016 Baltimore Running Festival.

Left: Jon with his Kennedy Krieger doctor, Dr. Philippines Cabahug (left), and therapists, Beth Myers (middle) and Alison Staples (right).

From Patient to Donor

Once Jon was on the path to recovery, he knew what he had to do next: help his fellow patients—many of them kids—get their lives back, too.

Two years ago, Jonathan Bresler started having dramatic back pain, strange neurological symptoms, and—whenever he tried to sit or stand—spasms. After his left side suddenly became weak, his wife, Sarah, a nurse, took him to the hospital. It was his first time checking in to an emergency room.

Jon, then 28, soon found himself in the neuro-intensive care unit, reviewing an MRI with a doctor. An intramedullary tumor—a benign mass, very difficult to access—was putting pressure on his spinal cord, threatening paralysis, and had just started bleeding, leaving Jon with no sensation from the chest down.

Jon, a hedge fund manager who lives in Washington, D.C., spent a month at The Johns Hopkins Hospital recovering from the bleed. He selected New York University's Langone Medical Center for surgery to remove the tumor and,

"Right from my tour of the Institute," he says, "I could tell how passionate everyone was about the work they do." The Institute's dedication to spinal cord recovery impressed him, as did its program in aquatherapy, something his surgeon had recommended.

After two rounds of therapy at Kennedy Krieger, Jon's back on his feet. He also has a new passion: helping his fellow Kennedy Krieger patients get better, too.

"While I was doing my rehab, it was very humbling to look around the gym and see the other patients," he says. "Many of them were in situations that made mine look trivial, yet they were still there every day, working just as hard as I was.

"I saw a lot of children, and I thought to myself: 'These kids deserve to have a normal, happy life.'"

For the past two years, Jon has participated in the Baltimore Running Festival's 5K race, jogging some of the way, walking the rest, and raising money for Kennedy Krieger with every step. He and his wife have matched every dollar he's raised through the event, and many of his friends and family members—including his parents, Phyllis and Sidney Bresler—including his many contributors.

Visit KennedyKrieger.org/BRF to learn more about the Institute's Baltimore Running Festival team.

\$123,321

total amount raised for Kennedy Krieger through the 2017 Baltimore Running Festival

on the advice of doctors at Johns Hopkins, Kennedy Krieger Institute's International Center for Spinal Cord Injury for rehabilitation.



Above: Liz and Duncan Ferguson with their children (left to right), Lucia, Bella, Marco and Christopher.
Left: Marco plays at the pool during a family vacation.

Helping From Miles Away

The Fergusons were inspired not only by their son, but also by others working to find a cure for their son's rare disease.

When Marco, 7, was a baby, the only hint of his rare genetic condition was the slightly-larger-than-typical diameter of his head. Once he was walking, he began getting painful leg cramps, often several times a day.

An MRI revealed Marco might have LBSL, short for leukoencephalopathy with brainstem and spinal cord involvement and lactate elevation, a progressive disorder. A blood test confirmed the diagnosis.

Marco's parents, Liz and Duncan Ferguson, wanted to learn all they could about LBSL. Duncan, a surgeon, helped the rest of the family understand what having LBSL meant: Marco's mitochondria were unable to manufacture all the energy his cells needed to stay alive. "The initial diagnosis was grim," he says.

"We hope to help those with LBSL live full and independent lives."

- Duncan Ferguson

Research on the internet led them to discover A Cure for Ellie, a nonprofit founded by Beth and Michael McGinn to raise money for LBSL research at Kennedy Krieger

Due to the extreme rarity of LBSL, Marco's family found that no doctors in New Zealand, where the family lives, had any clinical experience with the condition.

Institute. The McGinns, whose daughter Ellie has LBSL, put the Fergusons in touch with Dr. Ali Fatemi, director of the Institute's Moser Center for Leukodystrophies.

A "cocktail" of supplements and nutrients keeps Ellie's mitochondria going, while researchers like Dr. Fatemi study LBSL, with the hope of one day developing a cure. Marco is now on a similar cocktail, and his legs are mostly cramp-free.

In 2015, after attending a conference in Australia, Dr. Fatemi visited the Fergusons' home to meet with Marco and his family. Hearing Dr. Fatemi talk so passionately about his research and vision for a future in which LBSL can be cured, and in gratitude to the McGinns for connecting them with Dr. Fatemi, the Fergusons were inspired to match, dollar for dollar, whatever the McGinns raise each year for LBSL research.

"We wanted," Duncan says, "to contribute to and support the tireless efforts of the McGinns to raise the profile of this condition and help drive the pursuit for a potential cure."

Visit KennedyKrieger.org/MoserCenter to learn more about the Institute's Moser Center for Leukodystrophies.

Kennedy Krieger diagnoses and treats more than 800 DISORDERS

Thank you for donating to Kennedy Krieger Institute. Your gifts help us—and thousands of other kids at Kennedy Krieger—live our best lives, every day. Your generosity gives us the chance to reach our potential. Your kindness means the world to our parents and caregivers, and to us.

Thank you so much.



Many thanks to the children and families pictured throughout this report. They—like all our patients and their families—are the inspiration for what we do.

The preceding lists include individuals, foundations, corporations and community groups whose tax-deductible gifts or pledge payments were received between January 1, 2017, and December 31, 2017. The greatest possible care was taken in preparing this record. If any omissions or inaccuracies are found, please accept our apology and advise us of any corrections by contacting the Office of Philanthropy via the contact information below.

For information about giving to Kennedy Krieger, please visit **HelpKids.KennedyKrieger.org** or contact the Office of Philanthropy:

Kennedy Krieger Institute Office of Philanthropy
707 North Broadway, Baltimore, MD 21205
Main line: **443-923-7300**
Toll-free: **888-512-KIDS (5437)**

To read the stories from this report online,
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To learn more, get involved and stay connected,
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