

Together

SPRING 2017

DELAWARE VALLEY ISSUE
PUBLISHED FOR DONORS AND FRIENDS OF NEMOURS



Inside:
*Surrounding a Family With Support
to Fight for James' Life pp. 4-5*

Nemours Fund for
Children's Health

A Message To Our Friends

Dear Friends,

I am honored to have the opportunity to introduce myself. After nearly 20 years serving missions close to my heart, I am thrilled to be leading the development efforts here at Nemours/Alfred I. duPont Hospital for Children. I often say I wear two hats — one as a professional and the other as a mom. I have three children who received impeccable care here at Nemours, and I draw on that experience daily.

I learned a long time ago that life isn't always fair. To see your child sick and hurting is heartbreaking. I am humbled that so many of you are fueled by your own experiences to get involved, and to do whatever it takes to help another child.



I am constantly touched and amazed by the generosity of you, our donors. Together, we find ways to make tomorrow a better day. Our vision is to inspire generosity for hope and healing. In this issue, you'll meet three of the families that inspire us every day. I invite you to read their stories, share in our vision, and partner with us as we continue to bring hope and healing to so many who need us.

Warmly,

A handwritten signature in black ink that reads "Cathy Kanefsky".

Cathy Kanefsky
Chief Development Officer
Nemours Fund for Children's Health

FROM THE DESK OF DICK CHRISTOPHER



Dear Friends,

As chair of the Delaware Board of Managers for Nemours Children's Health System, I oversee the strategy that we are implementing to serve local families — families like yours. Health care is complex and constantly evolving, but our tactics are only as good as the impact they ultimately have on children.

In this issue, we feature children served by several of our centers of excellence, including orthopedics, cardiology, and cancer and blood disorders. These centers are nationally and internationally competitive, but more important than the accolades are the smiles you see on children's faces when they feel better and on the parents' faces when they can breathe a sigh of relief.

Our founder, Alfred I. duPont, once said, "It is the duty of everyone in the world to do what is within his power to alleviate human suffering." We are truly honored to fulfill that duty, day after day. Thank you for your support.

Sincerely,

A handwritten signature in black ink that reads "Dick Christopher".

Richard T. Christopher
Chair, Delaware Board of Managers
Vice Chair, Nemours Board of Directors

A Voice of Her Own: Shannon's Story

PATIENT STORY

Shannon, with her bright smile and passion for life, has been a patient of Nemours for 16 years. She was born in November 2000 at only 27 weeks, weighing 2.5 pounds. She spent two months at Nemours/Alfred I. duPont Hospital for Children before she could go home.

By the time Shannon was 8 months old, the Nemours team knew she had a form of cerebral palsy. It turned out that she was very medically complex. Before the age of two, she had a gastrostomy tube inserted as well as several eye surgeries.

Shannon was nonverbal, so her family did not know how much she understood them. When she was 2 years old, Richard Lytton, senior speech pathologist at duPont Hospital for Children, decided to test her. He gave Shannon a switch that allowed her to respond to basic questions. Then, he read her a book and asked her questions. Shannon responded correctly every time.

“That’s when we knew she understood us,” says Shannon’s mom, Janine. “We all started crying.”

Shortly after that, Shannon received an assistive communication device, which allowed her to select prerecorded messages and form phrases, word by word. The device used a generic voice — one of only a few voices that are available for that sort of technology.

“I can’t describe what I felt when I heard her say ‘mom’ for the first time,” says Janine. “It sounded like my daughter.”

One of the most incredible moments for Shannon was in 2013, when the researchers at the Nemours Speech Research Laboratory made Shannon her own, personalized voice. They recorded Shannon’s vowel sounds and digitally “mixed” them with the voice of another girl her age, producing a voice that sounded like Shannon.

“I can’t describe what I felt when I heard her say ‘mom’ for the first time,” says Janine. “It sounded like my daughter.”

Now 16, Shannon still goes to the Nemours Cerebral Palsy Clinic. She also sees neurology, pulmonology, gastroenterology, ophthalmology and rehab medicine.

“Shannon views Nemours as an extension of home,” says Janine. “And that’s incredible, since she has needed muscle lengthening procedures, bone density treatments, serious back surgery, and physical, occupational and speech therapy.”



Shannon and her mom, Janine, enjoying time at home.

Shannon still faces a lot of challenges. She needs help to sit up and she cannot feed herself. She needs a wheelchair to get around, and she has seizures. But none of that stops her. She loves going to school, stopping at Starbucks and playing soccer for kids with special needs. She has gone to dance camp. She loves amusement parks — the scarier the ride, the better. She loves being with friends and attending concerts. And most of all — she enjoys talking!

Nemours has embarked upon a campaign to create an Endowed Chair for Cerebral Palsy. This reliable source of income would help Nemours improve clinical care, research and education for families with children impacted by cerebral palsy.

An anonymous donor has generously offered to jumpstart our fundraising. They are matching community donations, dollar-for-dollar, up to \$750,000. We have raised more than \$334,000 to date, but we need your help!

To make a donation, visit [Nemours.org/GivetoCP](https://nemours.org/GivetoCP). While there, you can watch a video about Shannon, narrated by Shannon.

For more information, contact Melissa Chirinos at melissa.chirinos@nemours.org or (302) 298-7551.

The Fight of His Life: James' Story

In November 2014, when James was 3 years old, he started showing signs of a cold. He had just started preschool, so his parents figured he had caught something from one of his classmates. But his fever did not go away. On Thanksgiving, they decided to take him to the hospital. James had an excessive white blood cell count, and the family was sent to Nemours/Alfred I. duPont Hospital for Children. It was there that the family received the news: James had acute myeloid leukemia (AML).



James is glad to be back home.

A Terrifying Diagnosis

AML is a very aggressive form of childhood cancer. Though the survival rate for childhood cancers overall is 90 percent, survival rates for AML are much lower and have plateaued, despite maximally aggressive therapy.

The family was shocked. James' mother, Tatiana, said that the Nemours hematology/oncology team, led by Andy Kolb, MD, was supportive in all the right ways.

"They provided a lot of information, but they also asked what they could do for us," she said. "They let us have our cry too. They knew we needed our grieving time."

James' diagnosis, already more than any family should have to bear, was complicated by the fact that he has autism. He is largely nonverbal and struggles to explain feelings like stress and anxiety.

The progression from the autism diagnosis to the cancer diagnosis was heartbreaking for the family. "When we learned our son had autism, we had to process that he might not have a job and might not get married," Tatiana said. "Then, when we were told he had cancer, we had to process that he might not survive."

Treatment started right away. The care extended beyond the expert physicians and included social work, psychiatrists and the palliative care team. Everyone took the time to get to know James and his unique needs.

James' diagnosis, already more than any family should have to bear, was complicated by the fact that he has autism. He's largely nonverbal and struggles to explain feelings like stress and anxiety.

The family stayed in the hospital for five months. James was cleared to go home in the summer of 2015. When they arrived at their house, they still had leftovers from Thanksgiving dinner in their fridge, which Tatiana said seemed strangely appropriate, because their previous life had stopped the minute James was diagnosed.

The Cancer Returns

Unfortunately, one year after James went home from the hospital, his cancer returned. It was the summer of 2016, and

Tatiana was eight months pregnant with their second child.

This time, James needed a bone marrow transplant, which is usually considered a last resort because it requires eradicating the immune system. James only had a 50/50 chance of surviving his relapse, even with the transplant.

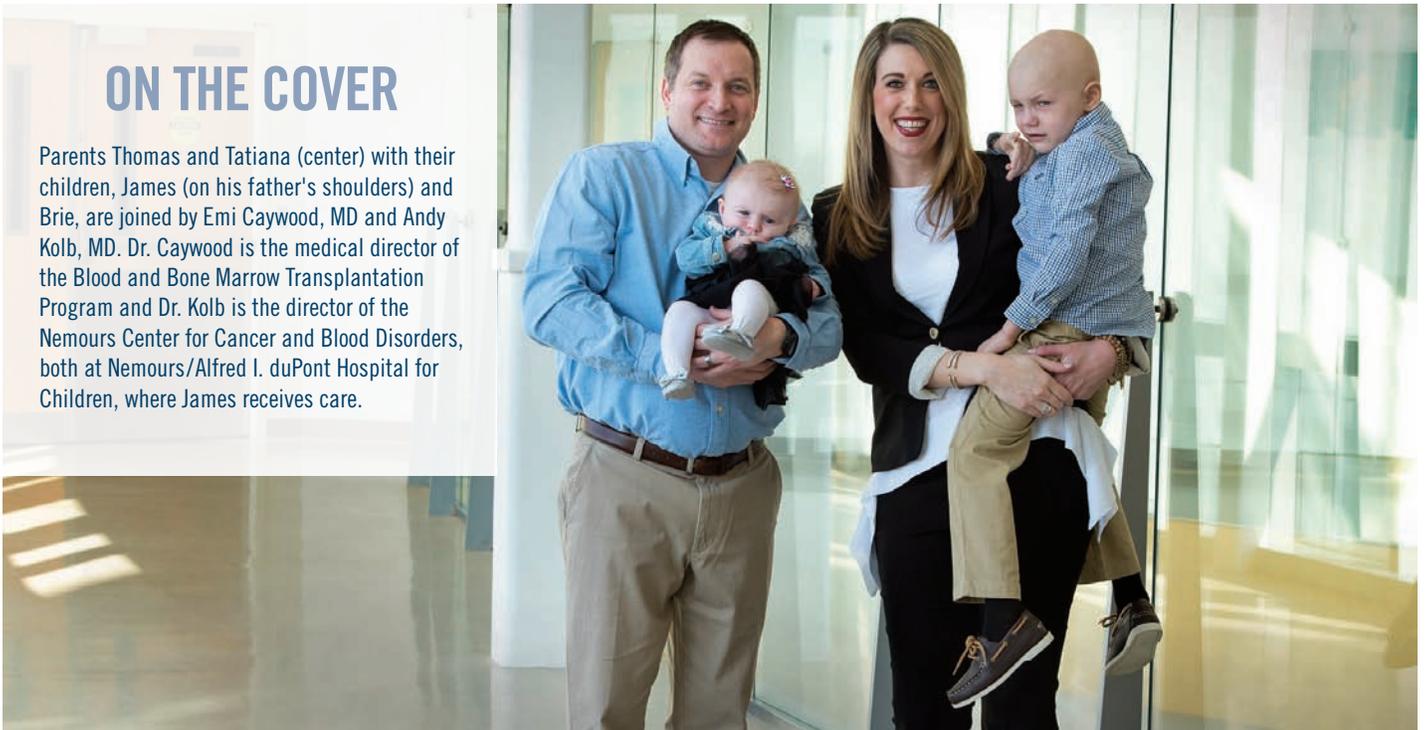
Incredibly, there was a donor match in the national directory. Nemours timed James' treatment around Tatiana's birth plan, so that everything went as smoothly as possible. "We brought our pack-and-play into his hospital room, and that just became our new normal," Tatiana said.

After his immune system had been demolished, James had his bone marrow transplant. His little body could not handle it, and he had a life-threatening reaction. His care team was compelled to put him into a medically induced coma. "We were preparing for him to die," Tatiana said.

But James did not die. He pulled through, and they woke him up from his coma on Christmas morning.

ON THE COVER

Parents Thomas and Tatiana (center) with their children, James (on his father's shoulders) and Brie, are joined by Emi Caywood, MD and Andy Kolb, MD. Dr. Caywood is the medical director of the Blood and Bone Marrow Transplantation Program and Dr. Kolb is the director of the Nemours Center for Cancer and Blood Disorders, both at Nemours/Alfred I. duPont Hospital for Children, where James receives care.



Thomas and Tatiana with their son, James, and daughter, Brie.

Shortly after that, Dr. Kolb told the family that James' bone marrow transplant was "100 percent engrafted." That meant their son had a brand new immune system, and was not producing any more detectable leukemia cells.

Family-Centered Care

"Having an ill child can be a very isolating experience," says Tatiana. "The Nemours team surrounded us with support. Harriet, a volunteer, would bring me coffee and just visit with me. The nurses brought me a cake on my birthday and made sure I took time for myself. It was so heartwarming."

Tatiana notes that the presents they exchanged on Christmas morning came from the hospital's "Snowflake Station," which Child Life stocks with toys that have been donated by the community.

"Having an ill child can be a very isolating experience," says Tatiana. "The Nemours team surrounded us with support."

Optimism for the Future

James was released from the hospital in January 2017. He is largely home-bound, because he is immuno-compromised, but just being back home is an incredible step for their

family. He receives physical therapy and recently started a home schooling program.

In a few months, they will know if the bone marrow transplant "stuck." Though James' future is still uncertain, the family is persistently hopeful. They dream of a day when they can do simple things like go to the playground or to the beach, or even out to a restaurant. They know that, with Nemours, they are receiving the best possible care. Tatiana said, "We could have gone anywhere, but I wouldn't put our son's life in the hands of anyone else."

Advancing pediatric cancer research is critical to find better treatments and ultimately cures. When James had his life-threatening reaction to his bone marrow transplant, the drug that saved him came from a study that Nemours helped to develop.

The Nemours Center for Cancer and Blood Disorders is an international leader in the field of pediatric cancer research, and donations help them do so much more for children like James.

You can donate at [Nemours.org/give](https://www.nemours.org/give).

“Your daughter needs a new heart.”

We heard those words when our little Caralynn was only 6 months old. It rocked us to our core. How could we face the reality that our daughter’s heart would be removed from her tiny body and replaced with another one?

The Nightmare Began

Cara had restrictive cardiomyopathy, which meant the walls of her heart did not soak up fresh, oxygenated blood the way they should. The disease progressed rapidly. Only five months later, Cara was admitted to the Cardiac Intensive Care Unit at Nemours/Alfred I. duPont Hospital for Children. She was placed on the list for a heart donor.

Cara received a transplant after an incredibly short wait of 12 days. Unfortunately, the donor heart never reached full function. She had to be re-listed for another heart. We did our best to celebrate her first birthday, which fell on Thanksgiving that year.

The Berlin Heart

Less than one month later, Cara underwent another harrowing surgery to place a right-side Berlin Heart bypass machine in her failing body. As time passed, we celebrated Christmas, New Years, anniversaries and birthdays, always with the same prayer — that they would not be our last with Cara.

The Second Transplant

On January 21, 2012, our daughter received her second donor heart. In true Cara fashion, she emerged from the surgery victorious. She was discharged from the hospital three months later. She had 17 different medications and needed continuous oxygen, a feeding pump and IV infusions ... but we were *home*.

Strength in Recovery

Cara began to improve by leaps and bounds. She relearned to crawl, sit on a toddler bike, feed herself, use sign language and generally command the household! We knew the first year post-transplant would be the most risky, and we lived each day to the fullest.

Sudden Tragedy

Nothing could have prepared us for August 8, 2012, when Cara unexpectedly suffered a sudden cardiac arrest and passed away in our arms. Words cannot describe our grief. Just like that, her battle was over.

Caralynn’s Legacy

We know there is nothing her care team could have done differently. Everyone did everything they could for Cara. She inspired them, because she was so close to death so many times, and would always pull through. Her blue eyes shone brightly even in the darkest of hours.



Caralynn Titter

Making Hospital Stays More Colorful for Teens

In January, the Alicia Rose Victorious Foundation and A.C. Moore partnered to provide a mobile, fully-stocked Art Cart to the Child Life team at Nemours/Alfred I. duPont Hospital for Children. The cart will give hospitalized teens additional opportunity for creativity and expression.



Pepe Piperno, owner and CEO of A.C. Moore (second from left), and Gisele DiNatale, co-founder and executive director of The Alicia Rose Victorious Foundation (fourth from left), present the cart to the Nemours Child Life team.



Mandy and Josh Titter (right) and their son, Ryan, (front) enjoy a Phillies baseball game with Roy Proujansky, MD, EVP of Nemours and chief executive of Delaware Valley Operations, and Stephen Dunn, MD, chair of the Department of Surgery, duPont Hospital for Children.

After she passed, we founded *Heart of Hope – The Caralynn Titter Foundation* to help other families going through a heart transplant journey. We support duPont Hospital for Children. Through this work, we make sure Cara’s blue eyes shine on.

You can support the Nemours Cardiac Center and help children like Cara. Visit Nemours.org/give and select “Delaware Valley Heart Care.”



Betty M. Kennedy

In Memory of Betty M. Kennedy (1922 – 2016)

Betty was a lifelong resident of York, Pa., who loved the mountains and enjoyed time in her garden. She made a generous planned gift to the hospital because of her fondness for children and her desire to help those with special needs.

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Natasha, Nemours patient

Your Gift Helps Children:

- **Give online at Nemours.org/give.** Consider becoming a “Hospital Hero” by making a monthly credit card gift of \$15 or more.
- **Mail your gift to** the Nemours Fund for Children’s Health, 1600 Rockland Road, Wilmington, DE 19803. Make checks payable to “Nemours.”
- **Plan an event to benefit Nemours.**
- **Consider Electronic Funds Transfer (EFT).**
- **Donate appreciated securities.**
- **Include Nemours in your estate plans.**
- **Check with your company for matching gift opportunities.**

Call us at (302) 651-4828 to speak to a gift Associate about the options above.

As always, 100 percent of your gift goes to help children because of the support from the Trust created by Alfred I. duPont.

If you wish to have your name removed from the list to receive this communication or future fundraising requests supporting the Nemours Fund for Children’s Health, please email giving@nemours.org or write to us at: Nemours Fund for Children’s Health, 1600 Rockland Road, Wilmington, DE 19803.

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Have Fun and Help Kids!

Join us for our upcoming events:



A Night at Nemours

Friday, June 16, 2017 • 6 - 11:30 p.m.
Nemours Estate • Wilmington, Del.

Our annual gala will benefit The Swank Autism Center at Nemours/Alfred I. duPont Hospital for Children. The Nemours Fund for Children's Health will host an elegant evening with cocktails, dinner and dessert by ROUGE Fine Catering. After dinner you can slip into your dancing shoes and enjoy the sounds of the FM Band.

Tickets to *A Night at Nemours* are \$300 per person. Not able to join us for dinner? Consider attending our "after party" beginning at 9 p.m. where you can enjoy cocktails, dessert and dancing for \$100 per person.

Visit Nemours.org/gala for more information.

Help Our Kids Radiothon

September 6 - 7 • 6 a.m. to 6 p.m.
Anthony N. Fusco, Sr. Atrium at
Nemours/Alfred I. duPont Hospital for
Children • Wilmington, Del.

Save the date for our 7th Annual Help Our Kids Radiothon, sponsored by Delmarva Broadcasting. This two-day event benefits the duPont Hospital for Children. Over the past six years, this event has raised more than \$1 million!



A Round for the Kids

Monday, October 23 • DuPont Country Club, Wilmington, Del.

Save the date for our 8th Annual Golf Tournament. Participants will enjoy a light breakfast, lunch and snacks on the course and a celebratory meal with awards. Proceeds will benefit duPont Hospital for Children.