Dear Friends,

The children we serve here at Nemours are remarkable. Take Cian, in Orlando, Florida. He has cystic fibrosis, which requires treatment every single day. Mackenna in Wilmington, Delaware, has juvenile arthritis, so she is often in pain. And Carter and Conner from Jacksonville were quite literally “born into a challenge” — they were conjoined twins. Now separated, they face complex and unique futures.

And yet, despite their struggles, these children have some of the brightest smiles I’ve ever seen. Their parents, despite being tired, are optimistic and hopeful.

At Nemours, we are privileged to help these children and their families.

Philanthropic gifts from people like you help us do even more for these families and the thousands of others who come to us for our expertise. Your gifts help augment patient care, supportive services, equipment, research and more.

With your continued help, we can keep the smiles coming. Thank you for your support.

Warmly,

Lori J. Counts, Operational Vice President
Nemours Fund for Children’s Health

FROM THE DESK OF OUR BOARD CHAIR

Dear Friends,

I’m pleased to serve Nemours as the new chair of the board, succeeding John Lord. Mr. Lord left big shoes to fill (see more on page 9), but I’m determined to do my best for this organization that does its best for so many kids.

After more than six years serving on our board, I know one thing with absolute certainty — Nemours Children’s Health System is one of the best pediatric health systems in the world. We attract the most talented physicians and researchers with the most compassionate hearts.

I’m proud to be part of this organization whose promise is to treat each child as its own. Together, we can change lives.

Thank you for your support, and Happy New Year to you and your loved ones.

Sincerely,

Brian P. Anderson
Board Chair, Nemours
Nemours Celebrates 75 Years
Of Providing Care To Kids

Nemours is proud to celebrate its 75th anniversary of providing care and services to children. The Nemours Foundation was formed in 1936 under the terms of Alfred I. duPont’s will; it began to deliver on his vision in 1940 when the Alfred I. duPont Institute, a pediatric orthopedic hospital in Wilmington, Delaware, opened its doors. Now, Nemours Children’s Health System includes two free-standing and full-service children’s hospitals and more than 50 primary, specialty and urgent care offices in five states.

In Wilmington, Delaware, November 2015 marked the one-year anniversary of the expansion of the Nemours/Alfred I. duPont Hospital for Children. The building was a result of years of planning, which involved close collaboration with patient families. The community raised $25 million for a capital campaign to help fund the construction.

From its opening in November 2014 to November 2015:

- More than 7,400 patients and their families have been admitted and have benefited from our family-centered, single-patient rooms
- More than 47,000 patients have been treated in the significantly expanded Emergency Department

With the expansion open, Nemours is in a state of evolution as it seeks to improve the environment and services it provides to patients and their families. An example of this is the playground outside the outpatient entrance, which was a generous gift from the Auxiliary of the Alfred I. duPont Hospital for Children. Thanks to the support of donors led by Kate Leong, a local mother and children’s advocate, and the Wilmington Flower Market, the playground has evolved into an “all abilities playground,” which offers opportunities for children with varying physical abilities to enjoy the area and equipment.

The interactive Discovery Wall, presented by DuPont, gives children — patients and their siblings — a place to play.

The Anthony N. Fusco, Sr. Atrium provides ample space to host presentations and performances, bringing some much needed fun to children who are receiving inpatient care. (Pictured is Echosmith at the 2015 Help Our Kids Radiothon)
Mackenna’s knee swelled to three times its normal size in September 2014. Her primary care doctor thought she might have Lyme disease, but the test was negative. The situation got even stranger when, a few days later, she woke up with hives all over her body.

At that point, her doctor realized she might have an autoimmune issue, and referred the family to Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware.

Meanwhile, over the course of a few weeks, Mackenna had gone from a child who loved running and playing to “a sleepy bear that wouldn’t get up,” says her mother Kathi. “She had so much pain she didn’t even want to walk.”

Dr. Annemarie Brescia at duPont Hospital for Children immediately knew what was wrong. Tests confirmed it. Mackenna had juvenile idiopathic arthritis.

The diagnosis was hard for Kathi to process. “One day you have a typical kid,” she says. “Then, you are told your child has a condition you’ve never heard of before, and needs a lot of medication.”

“To treat her condition, Mackenna has to take seven low-dose chemotherapy pills every week and get an IV infusion every three weeks. This reduces her arthritis symptoms, but also weakens her immune system, often causing her to miss school for weeks at a time because of infections.

She also takes additional medications and supplements, and does physical therapy to stretch and strengthen her limbs and support her joints. She gets her vision and hearing monitored, because arthritis can impact both senses. She already has some low-frequency hearing loss.

Kathi is extremely grateful for the level of care and support they receive from Nemours. “Dr. Brescia made me feel better,” Kathi says. “She told me ‘you have a healthy little girl, who just happens to have arthritis.’”

Mackenna, now 8, is very mature for her age. She says her “invisible” condition has caused her to understand the struggles that many other children have. She says, “People need to know that sometimes sick kids don’t look sick.”

Kathi says, “All I know is, our girl could barely walk last year and now she’s doing cartwheels, thanks to Nemours.”
Fighting To Breathe

When Lynda was 19 weeks pregnant with her son Cian, doctors suspected that he might have cystic fibrosis (CF), a genetic disease that causes persistent lung infections and progressively limits the ability to breathe.

At that point, Lynda and her husband discovered that they were both carriers of the CF gene, which meant that their son had a 25 percent chance of having the disease.

Lynda knew Cian had CF as soon as he was born. He had trouble digesting food, his skin had an odd, grayish color, and he was losing weight.

Cian was officially diagnosed by Nemours physicians when he was 3 weeks old. Treatment started immediately. His parents learned how to do his therapies, which included tapping him on his chest and back to break up the thick mucus in his lungs. “We were determined to do all we could to give our son the fullest possible life,” Lynda says.

He was very sickly as an infant. He had pneumonia six times in his first year of life, always needing IV antibiotics to recover. He had stomach surgery at 5 months old, to prevent dangerous reflux issues and to put in a feeding tube.

Now 9 years old, Cian takes 23 to 27 pills a day to loosen the mucus in his lungs, prevent infection and help him digest his food. He does chest therapy at least two times per day, for 30 minutes each time.

He still gets sick a lot, but it is more manageable because of some new medications. Cian enjoys playing competitive soccer, which has increased his lung function.

“One of the many things I love about Nemours is they listen to patient families and truly take their advice on decisions big and small,” Lynda says.

Lynda says Cian is strong willed. “I feel like he was born with that trait to help him with his CF. He’s a fighter. And he needs to be.”

Lynda has served on the Family Advisory Council for Nemours since 2007, and has served as co-chair since before Nemours Children’s Hospital opened in 2012. “One of the many things I love about Nemours is they listen to patient families and truly take their advice on decisions big and small,” she says.

About Cystic Fibrosis (CF)

For people who have CF, a defective gene causes a thick build-up of mucus in the lungs, pancreas and other organs. In the lungs, the mucus clogs the airways and traps bacteria leading to infections, extensive lung damage and eventually, respiratory failure. In the pancreas, the mucus prevents the release of digestive enzymes that enable the body to break down food and absorb vital nutrients.

To imagine how children with CF breathe, think of breathing through a narrow straw, like ones used to stir coffee.
PATIENT STORY

Carter And Conner: Close, Even In Separation

Formerly conjoined twins are doing well, thanks to a collaborative team in Jacksonville.

Carter and Conner are Nemours celebrities of sorts. Cameras and reporters are poised to follow their every move in Jacksonville, Fla. and that is pretty serious star status, considering they both just turned 1 year old.

Carter and Conner were born as conjoined twins—the first set of successfully separated conjoined twins born in Northeast Florida. When the boys were born in December 2014, they shared their small intestine, had two livers and bile ducts that were fused together.

Only hours after their birth, they were transported to Wolfson Children’s Hospital, Nemours’ hospital partner, where Nemours surgeons performed emergency surgery to repair a potentially life-threatening condition called a ruptured omphalocele, in which the boys’ shared small intestine protruded through a weak area of the abdominal wall.

On May 7, 2015, Carter and Conner underwent a 12-hour surgery to separate the boys. The 17-member surgical team was led by highly skilled pediatric physician specialists from Nemours locations in Florida and Delaware. The team was led by:

• Daniel Robie, MD, chief of pediatric general surgery at Nemours Children’s Specialty Care, Jacksonville
• Nicholas Poulos, MD, pediatric general surgeon at Nemours Children’s Specialty Care, Jacksonville
• Carolyn Bannister, MD, chief of pediatric anesthesiology at Nemours Children’s Specialty Care, Jacksonville
• Stephen Dunn, MD, division chief of solid organ transplant at Nemours/Alfred I. duPont Hospital for Children

It has been a long road to recovery, but on November 30, 2015, Conner was discharged from the hospital to Brooks Rehabilitation, where he will undergo inpatient rehabilitation — the next step on his journey home.

“Carter and Conner are miracle babies. We are blessed to be their parents,” says Michelle, their mom.
Conjoined twins are extremely rare, with estimates ranging from one in every 100,000 births to one in every 200,000 births.

The boys have been cared for by nearly 200 healthcare professionals including neonatal and pediatric critical care nurses, pediatric respiratory therapists, rehabilitation therapists, Child Life specialists, pediatric chaplains and other health care disciplines.

“Both Carter and Conner are doing remarkably well,” says Dr. Daniel Robie, chief of pediatric general surgery.

Both boys have a lot of therapy and follow-up care in their future, but their physicians have high expectations for each of them.

“Both Carter and Conner are doing remarkably well,” Dr. Robie says. “We are looking forward to the news that they are home and thriving, and living the normal lives we expect them to have.”

Support For Bereaved Siblings

Kids with Confidence (KWC) is a Delaware Valley nonprofit organization dedicated to helping kids cope with various challenges, giving them their best chance to grow into confident, healthy adults. In recent years, KWC has generously supported the palliative care program at Nemours/Alfred I. duPont Hospital for Children. Gifts from KWC support a Child Life specialist who is devoted to helping children as they navigate the grief of losing a brother or sister. The Child Life specialist is trained to understand the different ways children deal with loss and helps them develop coping strategies specific to their needs, often providing a creative outlet for dealing with emotions through art, music and play. Support from KWC was also essential for launching a unique weekend bereavement camp hosted by Nemours in October 2015. “Camp Molly” is unique to the region and provides support and healing for children whose siblings have passed away.

Carter, the smaller of the twins, is still at Wolfson Children’s Hospital. He is doing well, but needs additional recovery of his intestine function and stomach function before he can be discharged. His doctors are optimistic that he will be following his brother in the near future.

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Q&A With Mary Mehta, MD
Chief Medical Officer, Nemours Children’s Clinic, Pensacola

How long have you been with Nemours?
I started in April 2004, as a cardiologist at Nemours Children’s Clinic, Pensacola (NCCP). So, 11 years.

As chief medical officer, do you still see patients?
I do. Five days per week, for half the day. I see patients both in Pensacola and in Orlando. My area of expertise is pre-natal diagnosis.

What are the primary components of your role as chief medical officer?
I provide executive leadership for NCCP, and I oversee development across the Florida Panhandle. I manage our relationships with local care providers, including those in the Panhandle, Tallahassee and southern Alabama. I work closely with the leadership of Sacred Heart Hospital, for initiatives related to children’s health.

What is unique about Pensacola, from a health system perspective?
Well, we live in a beautiful piece of the country with beautiful beaches. But, the median income here is low, so we see a lot of patients whose families are economically challenged.

We cover a lot of ground, because we are the only pediatric specialists for hours in any direction, until you get to New Orleans or Birmingham or Atlanta. The families are really grateful we are here. It feels like a family here at NCCP, as well as in Pensacola in general. We also serve a lot of military families from all across the country because they come to Pensacola for training.

What do you see for the future of Nemours in Pensacola?
We need to expand our services. In this area, there are simply not enough providers for pediatric subspecialty care. We don’t want adult providers to be the default for our children.

What is your top fundraising priority right now?
At the clinic, we are fundraising for two digital radiology machines, which provide high quality imaging. This equipment works quicker than the equipment we currently have, and will reduce wait time. It will also reduce exposure for children, which is always ideal, especially for kids who are routine visitors because they have recurring or chronic conditions.

We are always fundraising for equipment so we can increase our outreach. In communities such as Pensacola, you often have to meet families where they are for follow-up appointments, because of transportation challenges.

How can people get involved?
You can contact Jodi Gup, development manager, at (850) 505-4797. We’d be happy to talk about opportunities to support Nemours in Pensacola!
A Little Brother With A Big Heart

Jake is a special boy who has experienced some profound sadness in his life. His older brother, Noah, passed away in September 2009 at age 20.

Noah was tall, dark and handsome with ice-blue eyes and a playful, larger-than-life personality. He was an avid sportsman, playing lacrosse and hockey. He was always healthy, so when he hurt his leg during spring training for lacrosse in 2008, his family thought it was just a sports injury.

When Noah had an MRI, doctors discovered his injury was much more serious. Dr. Mihir Thacker, an orthopaedic surgeon at Nemours/Alfred I. duPont Hospital for Children, diagnosed Noah as having osteosarcoma — a rare bone cancer. He had a tumor behind his knee that needed immediate attention. Noah went through chemotherapy, led by Nemours pediatric hematologist, Robin Miller, MD. Dr. Thacker performed a long, multi-hour surgery to save his leg.

Despite these efforts, Noah passed away the day after his 20th birthday. Throughout his ordeal, Noah’s courageous spirit never faltered.

Jake and his family and friends wanted to do something to honor Noah. They wanted to do something simple, but impactful, to support the nurses and staff who had been so loving to Noah. Jake decided to raise funds to remodel the offices where Noah’s nurses did their paperwork.

Jake attended Thurgood Marshall Elementary School in Newark, Delaware, from kindergarten through 5th grade. For three years, they did a “Crazy Mixed-Up Day” as a fundraiser. For a small donation, kids could come to school wearing mismatched, silly clothes. Jake chose this theme because Noah had a great sense of humor and was very artistic and cheerful. Noah would have approved.

Jake’s fundraising, in combination with donations to the Noah Memorial Fund established with the Nemours Fund for Children’s Health, raised more than $6,000 to complete the renovations.

The new workstation provides the nurses with a more updated and comfortable environment, and it showcases some of Noah’s original artwork.

Hitting The Road For Pediatric Cancer

The Iron Pigs Motorcycle Club is a nonprofit motorcycle club for law enforcement officers and firefighters in the Orlando area. In 2014, they collaborated with Nemours Children’s Hospital (NCH) for the first Pigs Against Pediatric Cancer Ride, bringing together 300 motorcycles and raising more than $5,000. In 2015, their event was even more successful, raising $13,000 for NCH!

Save the Date for the 2016 Event: Saturday, April 16, 2016
Congratulations, John Lord

Decades from now, Central Florida will likely still be known for its world-class attractions. Thanks to the efforts of Mr. John Lord, the area will also be known as a destination for exceptional pediatric health care.

Mr. Lord serves on the board of directors for The Nemours Foundation, and is the immediate past chairman of the board. He is also a trustee of The Alfred I. duPont Testamentary Trust.

Mr. Lord played a critical role in bringing Nemours Children’s Hospital to Orlando. He counts the opening of that hospital as one of his proudest philanthropic achievements. He was intimately involved in recruiting some of the best pediatric specialists and physician-scientists in the nation to ensure that all children have the best care possible.

Mr. Lord is a tireless advocate for children. He helped raise millions of dollars and has volunteered thousands of hours for a variety of organizations in the region. He credits his wife Carolyn, a philanthropist and active community leader in her own right, for being part of this journey with him and for inspiring him daily.

On November 13, Mr. Lord received the 2015 H. Clifford Lee Lifetime Achievement Award from the Association of Fundraising Professionals Central Florida Chapter. The association’s highest honor recognizes the personal and professional contributions made by the recipient to better the community.

Your gift helps children:

- Make a secure, online contribution by credit card at Nemours.org/give.
- Mail your gift to: Nemours Fund for Children’s Health, 1600 Rockland Road, Wilmington, DE 19803, made payable to “Nemours.”
- Check with your company for matching gift opportunities.
- Remember a friend or family member with a memorial gift. You can also honor someone special or mark an important occasion with a gift. Notification (but not the amount) will be sent to the person you specify. You may make a tribute gift online or call us with your credit card information: (888) 494-5251.
A Passion For Early Childhood Education

The Chartrand Foundation Supports Nemours ReadingBrightStart.org.

For the Chartrand family in Jacksonville, their philanthropic passion is early learning and quality education. In 2006, their family foundation was established with a mission to “improve educational opportunities for children in Duval County, through strategic investments that encourage and support early learning and strengthen the public educational system.”

With a recent gift to support ReadingBrightStart.org, an initiative of Nemours BrightStart!, the Chartrand Family is helping Nemours reach more families and prepare all children to enter kindergarten. ReadingBrightStart.org is a website Nemours launched to increase the reach of the Nemours BrightStart! program that provides evidence-based tools to help struggling young learners achieve reading readiness. ReadingBrightStart.org targets parents of children from birth to age 5 and offers self-conducted screenings to gauge a child’s skill level as well as activities to build pre-literacy skills.

Evidence shows that reading ability is the single strongest predictor of adult health. However, many children across the country struggle to read. The Chartrand family believes in the power of the Nemours BrightStart! tools and the website, and offered the gift to help Nemours promote its program, through online and traditional marketing. “Nemours BrightStart! is a remarkable program, and now is the time to bring it to scale, to ensure it reaches as many parents of young children as possible,” says Meredith Frisch, director of Early Childhood Initiatives at the Chartrand Foundation. “We hope, through our foundation’s gift, to reach thousands of young children and to positively impact their futures by ensuring they enter school prepared to succeed.”

- Include the Nemours Fund for Children’s Health in your estate plans. The Carillon Society honors individuals who have informed us of their intentions.
- Consider Electronic Funds Transfer (EFT) if you are a regular contributor or would like to become one. Call our office at (888) 494-5251 to have a monthly contribution charged to your credit card. This can be discontinued at any time.
- Donate appreciated securities. Give us a call at (888) 494-5251 and our staff will assist you in making arrangements.
- Remember, 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 e-mail giving@nemours.org or write to us at: Nemours Fund for Children’s Health, 1600 Rockland Road, Wilmington, DE 19803.
Wishing You Health And Happiness For The New Year

On behalf of the children and families we serve here at Nemours, we wish you a very Happy New Year.

We are able to do so much more for patients and families because of your support. From one-time gifts to multi-year pledges to planned gifts, there is a multitude of ways to help our kids. And 100 percent of donations go to children.

For more information, contact us at (888) 494-5251 or email giving@nemours.org.