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A Message to Our Friends

All of us at Nemours, especially those who are on the front lines caring for children, are grateful for the compassionate and generous response of our donors. When someone makes a contribution, it is actually an investment in the future. Whether the giver makes their gift to help improve facilities for patients and families, fund life-saving research, or advance clinical care, they are helping to assure a healthier tomorrow for children.

In this issue of Together, we focus on the specialty of otolaryngology—better known to most of us as ear, nose and throat (ENT). Our specialists in this area go far beyond the more common treatments of ear tubes and tonsillectomies to treat complex, sometimes life-threatening problems. Also presented are the stories of two families who were inspired by their teenage sons to make a real difference through giving.

Thank you for caring about children and giving them a better future.

Sincerely,

Lori J. Counts, Managing Director
Nemours Partnership for Children’s Health

FROM OUR CHAIRMAN

The word “philanthropy” comes from the Greek, meaning “love of one’s fellow man.” Our contributors are showing their love and concern for children through increasingly generous gifts to support the Nemours mission. With philanthropy, we can do even more for children.

When American industrialist Alfred I. duPont established a trust through his will for the benefit of children, it was with the philosophy that everyone should do “what is within his power to alleviate human suffering.” Each of us has that power—to do what we can to ease the suffering of children and improve their lives.

Nemours’ unique Model of Care includes prevention, education, clinical care, and research—all working together to benefit the whole child and his or her family. Through innovative programs combined with research and the latest technologies, we are able to bring the strength of a children’s health system to bear on the treatment each child receives in their local community.

The power of your contribution is this: it substantially increases the ability of Nemours to provide evidence-based, outstanding care for each child and improve their health.

Thanks so much for your support.

Sincerely,

John S. Lord
Chairman of the Board
Meet Dr. Proujansky

An opportunity to build a gastroenterology program from the ground up drew Roy Proujansky, MD, to Nemours/Alfred I. duPont Hospital for Children.

“When I joined the Hospital in 1989, it was growing from a 60-bed hospital that offered only orthopedic care to a full-service institution,” he remembers.

Dr. Proujansky, born in Long Island, New York, earned his medical degree at Northwestern University, Chicago, and completed residency training at the University of Connecticut.

“Today, it has become imperative that we involve the community as partners in achieving our mission. Philanthropy is a critical conversation between our organization and the community.”

He received additional training in gastroenterology and nutrition in the Combined Program at Boston Children’s Hospital, Harvard University and Massachusetts General Hospital. After a two-year research fellowship in infectious disease at Harvard Medical School and a three-year stint at Children’s Hospital of Pittsburgh, Dr. Proujansky came to Nemours in 1989 as Chief of Gastroenterology and Nutrition.

Today, Dr. Proujansky serves as Executive Vice President, Health Operations and Chief Operating Officer of Nemours.

“I have actually had three careers during my 20 years at Nemours,” he remarks. “I was Chief of Gastroenterology for ten years, head of the Practice for seven years, and have been in my current position for the last three. I was also co-Director of Biomedical Research at one point. There is continuous change at Nemours—in the ways we work together, in the health care environment, and more recently, in the economic climate. It has been very positive and moved us forward.”

“Nemours is just great,” observes Dr. Proujansky. “There is an ethos, values, principles and a real commitment to mission, as well as an understanding of the realities of meeting that commitment.” His most prominent memory of his first years at Nemours is of an advanced practice nurse, Millie Boettcher, RN, APN. “It was a huge piece of serendipity that she was here,” he remembers. “Millie was my partner in starting to create a system of care for children with gastrointestinal problems. She was the first of several great people who joined that division.”

“The goal of Nemours is to reach the top tier of children’s hospitals in terms of patient and family satisfaction and quality outcomes,” says Dr. Proujansky. “This is not the same as having the most beds or the highest number of research dollars—it’s about centering everything around the patient. Nemours is able to leverage all of its considerable resources for patients, whether their problem is simple or complex. It’s what makes us unique.”

Dr. Proujansky and his wife Michelle are members of The Nemours Society, which recognizes annual donors of $1,000 or more. “Twenty years ago, Nemours felt that we could do it all ourselves,” he comments. “Today, it has become imperative that we involve the community as partners in achieving our mission. Philanthropy is a critical conversation between our organization and the community. It creates a sense of ownership—and we will both be better for it.”
A Walking Miracle

Two-year-old Icylin Shawn Simpson is a walking miracle, having survived many serious threats to her health. She fought through multiple surgeries to beat the odds and inspire everyone around her.

“I had a very difficult pregnancy,” says her mother Jessica. “I was on bed rest and medication after about four months. Then my water broke at 24 weeks.” Although Jessica was on medication to stop labor, Icylin was born 15 weeks early at AtlanticCare Hospital in New Jersey, weighing one pound, seven ounces and measuring only 12 inches long.

The tiny girl suffered many of the problems common to micro preemies, as babies of her weight and gestational age are known. “Her eyes were fused shut, and she had to have a breathing tube put into her throat,” remembers Jessica. “She was also jaundiced and had a Grade 3 hemorrhage in her brain. My husband Shawn and I were warned that she could end up with cerebral palsy, blindness or mental retardation. It was devastating.”

When Icylin was just a week old, she was airlifted to Nemours/Alfred I. duPont Hospital for Children for emergency surgery to repair a perforated bowel. “The doctors also discovered a problem with a heart valve that had to be corrected,” says Jessica “She was very, very ill and had multiple infections.”

Icylin spent the next five months in the Newborn Intensive Care Unit (NICU) at the Hospital. “My daughter was the very first baby to be moved into the beautiful new NICU from the old unit,” says Jessica.

The baby made a high-pitched sound when breathing. When she was examined under anesthesia with a bronchoscope, doctors found a narrowing of the airway. Surgery was performed to give Icylin an external opening for breathing and she was attached to a ventilator. “Shawn and I had to go through training so that we could learn how to care for her,” says Jessica.

“Icylin finally came home. “She had 16-hour nursing care at first,” says Jessica, “but soon I was taking care of her on my own. Gradually, we were able to wean her off the ventilator. During that period, she was constantly sick with infections.”

In March of 2009, Icylin returned to duPont Hospital for surgery to reconstruct her trachea. During the seven-hour operation, Patrick Barth, MD, an otolaryngologist, took cartilage from Icylin’s rib to structure a new airway for the baby. During the two week hospital
stay, Jessica never left her daughter’s side, seeing her two older daughters only once a week. “I cried a lot because I missed them so much,” she says. Icylin once again went home.

“Forty-eight hours later, she was unable to breathe,” says Jessica. “We rushed her to our local emergency department and they sent her back to duPont Hospital. Another bronchoscopy showed that a web of scar tissue was blocking 80 percent of her airway. Dr. Barth cleaned up the area surgically and dilated the airway with a balloon. Icylin had to be brought back to the Hospital each week for repeat bronchoscopies to ensure that the repair was holding and that her airway was open.

Today, Icylin is a friendly, curious toddler who is doing beautifully. All that remains of her long ordeal are some surgical scars and breathing that is somewhat noisy due to air turbulence in her trachea. Her mother says, “My daughter inspires my husband and me and has made our family so strong. Because of Icylin we have learned to appreciate life for what life is and to thank God for each day that he has given us.”

**PHYSICIAN PROFILE**

**Meet Dr. Barth**

Patrick Barth, MD, was originally a communications major at the University of Notre Dame in South Bend, Indiana. “My dad had been in television broadcasting, and that was what I knew,” he says. “One day, I realized that I wanted to do something that would have a more direct impact on people.” Dr. Barth changed his major, completed pre-med classes at the University of Pennsylvania and went on to medical school. He is now an otolaryngologist (ear, nose and throat specialist) at Nemours/Alfred I. duPont Hospital for Children.

“ENT felt like a good fit for my skills,” says Dr. Barth. “My specialty is a little like orthopedics, except they use big tools and we use little tools.” Dr. Barth completed a Fellowship in otolaryngology at duPont Hospital and decided to join the ENT team. “We are truly partners—always available to help each other get through the day,” he says. “We meet every morning to discuss all the cases. The patient benefits from the thought processes of six doctors, not just one.”

“Our department treats a range of problems—from more routine procedures like ear tubes and tonsillectomies to complex procedures such as cochlear implants and airway reconstruction,” says Dr. Barth. “In airway reconstruction, my area of specialization, the stakes are very high. I try to educate parents beforehand so that they understand the realities of the procedure.”

Dr. Barth and his colleagues are planning an integrated system of care to benefit their patients. “Often the ENT, a gastroenterologist, and a pulmonologist are all caring for the same child,” he remarks. “Collaboration among these specialties and sharing a common operating room would lead to timely solutions to problems, provide a platform for research, and make things much easier for the family.”

“I am very big on technology,” says Dr. Barth. “With our digital system, I am able to share medical images with colleagues or even community pediatricians. Then they can clearly see what I am describing.”

“What I do is very satisfying. We can make a big difference in a child’s quality of life and make an essentially healthy child even healthier,” comments Dr. Barth.
PATIENT STORY

A Way Forward for Kendall

In the moments after Loree Yarbrough gave birth to a beautiful daughter, her joy quickly turned to concern. Her new baby was having trouble breathing.

“It was very upsetting—we were expecting a healthy baby.” Newborn Kendall was transferred to Wolfson Children’s Hospital in Jacksonville. Loree and her husband Jonathan met with Saswata Roy, MD, a Nemours otolaryngologist (ENT).

“Dr. Roy told us that Kendall had been born with her jaw pressing back against the windpipe and a cleft palate—a rare condition called Pierre Robin Sequence,” says Loree. “We were impressed with him from the get-go. He carefully laid out the options for us. Dr. Roy even had a PowerPoint presentation so that we could better visualize what he was discussing. He did not push surgery, but left it up to us. Dr. Roy even put us in touch with another family who had gone through the same thing—it really helped.”

The Yarbroughs chose surgery, rather than a tracheostomy (external airway), for their baby. When she was just sixteen days old, Dr. Roy operated to sever Kendall’s jaw on both sides and install devices to gradually move the jaw forward into the correct position—a process called distraction. “Kendall was on a ventilator and in a drug-induced coma for about a week,” says Loree. “She had to be fed with a tube through her nose because her cleft palate caused feeding problems.”

Kendall came home when she was just over one month old. Two months later, she underwent a second procedure to remove the hardware placed by Dr. Roy. When Kendall was ten months old, she had an additional surgery to correct her cleft palate. “That was a tough recovery,” says Loree. “We had to spoon-feed formula. Eventually she graduated to a sippy cup.” Because of her surgeries and hospitalizations, Kendall was a little delayed in her development, requiring physical therapy to help her walk by 15 months of age.

Today, Kendall is a happy, healthy three-year-old. “She is very smart and can be quite dramatic,” laughs Loree. “Stubborn and feisty are descriptions that come to mind.” Like most little girls, she loves to dance, sing and play with her dolls.

“We love Dr. Roy and wish all doctors could be like him. He is so knowledgeable and down to earth,” says Loree. “I think of him as a friend.”
Meet Dr. Roy

A complete change in direction brought Saswata Roy, MD, into medicine and a career as an ear, nose and throat specialist. Born in India, Dr. Roy moved to Nebraska when he was thirteen years old. “I worked for IBM after I graduated from Grinnell College in Iowa,” he remembers. “After a while, I decided that I wanted to do something I really felt good about. For me, that meant going into medicine.”

He is now part of a team of four ENTs, five audiologists and three speech pathologists at Nemours Children’s Clinic, Jacksonville. “We are one of only four comprehensive ENT centers in the region,” he states.

“About two-thirds of our procedures are ear tubes and tonsillectomies—with the rest more complex, such as cleft palate, cochlear implants, facial plastic surgery and airway reconstruction. Most patients are less than a year old.”

Dr. Roy believes strongly in educating families. “They must know exactly what’s going to happen,” he says. “There has to be a two-way relationship and a mutual understanding. I always encourage parents to seek a second opinion. They have to be at peace with their decision.” Dr. Roy shares PowerPoint presentations about most surgeries with parents whose children will be having complex operations. He also connects families whose children have already had surgery with those who are facing the same thing. “They can share everything—the good and the bad,” he says.

“The biggest thing at Nemours is that doctors can treat everyone exactly the same way, regardless of their resources or medical insurance,” says Dr. Roy. “That’s very important to me. The work our team does is a labor of love. The stakes are so high for these little kids.”

PHYSICIAN PROFILE

Meet Dr. Roy

Saswata Roy, MD, Pediatric Otolaryngologist, Nemours Children’s Clinic, Jacksonville

Hear We Go!

Children with hearing disorders were the winners in the first annual Hear We Go 5K Run/Walk on the grounds of Nemours/Alfred I. duPont Hospital for Children and Nemours Mansion & Gardens. The May event drew more than 350 people and raised net proceeds of more than $12,000 to benefit children with hearing loss and assist with hearing conservation programs.

Hear We Go actually has a historic connection to Nemours. Our founder Alfred I. duPont suffered from profound hearing loss throughout his life. Today, Nemours is able to offer significant assistance to children with hearing loss—from cochlear implants to speech and language therapies—while pursuing research studies to discover even better treatments.

“Community support for this event was outstanding,” says Robert C. O’Reilly, MD, pediatric otolaryngologist. “We thank all of our sponsors and participants. The funds raised will support related research and clinical programs at the Hospital and help educate patients and families about hearing loss and hearing conservation. The story of Mr. duPont and his deafness served as the inspiration for this event. We hope to continue to build on this success by hosting the event each May.”
Saying Thanks by Giving

Gordon and Cindy Kaiser are grateful to Nemours. “We were so happy to be approached about giving,” says Gordon. “It gave us an opportunity to say thank you to all the folks that helped our son.”

Gordon, a money manager, and Cindy, an attorney specializing in business transactions, are the parents of two teenage sons, Tom and Will. “During Will’s freshman year in high school, he became very sick,” remembers Cindy. “His kidneys just stopped working.”

The Kaisers brought their son to Nemours/Alfred I. duPont Hospital for Children, where Will was diagnosed with FSGS/nephrotic syndrome, an autoimmune disorder affecting the kidneys. The usual treatment, high doses of steroids, did not help as much as the doctors hoped. It took months to stabilize Will’s kidney function. “Will had lots of visits to the emergency room and several hospitalizations,” says Cindy. “The team of nephrologists, other doctors and nursing staff were really wonderful.”

Seven months later, Will woke his parents in the middle of the night. “He had found a lump on his collarbone,” says Gordon. Will was diagnosed with Hodgkin disease, a type of lymphoma. “It sounds crazy, but we were almost relieved to hear that he had cancer—because we were told that Hodgkin disease could be treated successfully,” says Cindy. Will underwent chemotherapy and radiation. Amazingly, these treatments finally arrested the kidney disease. “We will probably never know how Hodgkin disease and the kidney problem were connected,” says Gordon.

Today, Will is a 19-year-old college student, apparently free of disease. “It was a very frightening thing for him to go through,” says Gordon. “We will never forget the kindness of the nurses, doctors, therapists and others at duPont Hospital who helped him.”

Gordon and Cindy are Cornerstone Partners in The Nemours Society. “We recognize that it’s good for the community to support the Hospital. It also gives us a way to express our gratitude.”

Your Gift Mends Tiny Hearts

Net proceeds from our 2008 black-tie gala, A Night at Nemours, provided support for a newly completed cardiac catheterization laboratory at Nemours/Alfred I. duPont Hospital for Children. The state-of-the-art lab is able to provide higher resolution cardiac images and lower exposure to radiation, while enabling surgeons and cardiologists to work more effectively and efficiently. Cardiac catheterization procedures close abnormal holes in the heart; open narrowed blood vessels and valves; and correct heart rhythm abnormalities, in many cases, making heart surgery unnecessary. The young patient is often able to go home later the same day.
A Promise for the Future

Dick Hykes is a man of many interests. After a long career in banking, he taught finance at Drexel University in Philadelphia. One of his favorite spots in the city is Laurel Hill Cemetery, the resting place of many famous Philadelphians. Mr. Hykes also admires Nemours Mansion & Gardens. “I’ve always been interested in architecture and design,” he says.

In retirement, Mr. Hykes has found many satisfying pursuits. He enjoys biking through beautiful Lancaster County, Pennsylvania, and loves animals. Mr. Hykes has given a number of young people the opportunity to travel abroad and quietly helped friends in need. “I’ve accumulated enough that I don’t really care about living anything other than a very simple lifestyle,” he remarks.

As he learned about the Mansion and Gardens, Mr. Hykes became more aware of Nemours/Alfred I. duPont Hospital for Children. “I spent a lot of time researching Nemours,” he says. “It is a rock-solid organization—honest, intelligent and foresighted. There is a sustainable quality there. That was important to me, as well as what you do for children. This place is special to me—I always feel like I’m entering another world.” Mr. Hykes has recently become a Hospital volunteer.

Mr. Hykes, an alumnus of Haverford College, recently brought a group of students from Haverford College Research Institute to visit Nemours Center for Childhood Cancer Research. “These promising students are all from poor families. Seeing the lab gave them an opportunity to meet young scientists from many backgrounds and to see a future for themselves,” he says.

A member of The Nemours Society, Mr. Hykes has made a commitment to leave a portion of his estate to Nemours. The Nemours Partnership for Children’s Health is proud to recognize this commitment by honoring him as a member of The Carillon Society.

Plan Your Legacy for Children’s Health

Did you know that you can make a significant contribution without affecting current income? Your bequest will help Nemours care for sick and injured children, construct new facilities and advance life-saving research. If you would like to plan a legacy for children’s health, contact Amy Bielicki of the Nemours Partnership for Children’s Health at (302) 651-4298 or e-mail abielick@nemours.org.

Be sure to request a copy of Giving Wisely, Saving Lives, our guide to planned giving. You may also visit www.nemours.planyourlegacy.org to access a wealth of information.

PLANNED GIVING

Dick Hykes poses outside Nemours Mansion & Gardens, a catalyst for his generous gift.

“I’d like to see more research into the diseases that take children’s lives,” he says. “It’s such a shame that some of these kids never get an opportunity to experience anything.”

“Nemours is wonderful. I’ve not found an organization I admire more,” says Mr. Hykes.
Something to Cheer About

Jeff and Andy of Tri-State CheerNastics have supported Nemours since 2006 through their Cheer for Charity tournament.

Four oversized checks, each made out to Nemours/Alfred I. duPont Hospital, decorate the walls of the office at Tri-State CheerNastics. Andrew Hoff and Jeffrey Martino, co-owners of the business, are enthusiastic proponents of the Hospital.

Graduates of the University of Delaware, Jeff and Andy brought together their respective expertise in cheerleading and tumbling to form Tri-State CheerNastics. They knew there was a need for quality instruction in tumbling and gymnastics. “We saw a niche,” says Jeff, “It was an easy decision.”

“One of our biggest challenges is to help kids and parents set reasonable, attainable goals,” says Andy. More than 450 children, teens and adults are instructed by Tri-State’s staff at their facility in New Castle in gymnastics, tumbling and cheerleading from 22 instructors. “Most people have no idea how big the sport has become,” comments Jeff.

In 2006, Jeff and Andy decided to start a regional tournament called Cheer for Charity, “We wanted to take something the teams would be doing anyway and use it to benefit a local charity,” says Jeff. “My wife suggested duPont Hospital.” Since that time, Tri-State has donated almost $82,000. “A lot of our kids and parents share their own stories about the Hospital, so we have gotten a lot of positive feedback about our gifts,” says Andy.

In the last year, Jeff and Andy decided to take their generosity to a new level. They made a $100,000 pledge to the Hospital’s Pediatric Intensive Care Unit, with an initial gift of $32,000—the proceeds of the 2009 tournament, which attracted 160 teams from the mid-Atlantic region. “We knew from the start that we picked a great charity,” says Andy. “It was important to us to help our own community.” The Nemours Partnership for Children’s Health is grateful to these two young entrepreneurs for their loyal support and generosity.

To learn more, visit www.tristatecheernastics.com

Your gift helps children:

- Make a secure, online contribution by credit card. Go to www.nemours.org/give.
- Mail your gift to: Nemours Partnership for Children’s Health, 1600 Rockland Road, Wilmington, DE 19803, made payable to “Nemours.”
- 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.

Note: All gifts are processed through this office.
The B+ Foundation

Andrew McDonough was an elite soccer player, straight-A student, and affectionate son, brother and friend. “He did everything with joy,” remembers his father, Joe. “He was always trying to make someone laugh or feel better when they were down. Andrew was everything I wanted in a son.”

Two days after playing four soccer matches in one day, Andrew became very ill. Suspecting appendicitis, his parents brought him to Nemours/Alfred I. duPont Hospital for Children. Instead, the diagnosis was leukemia. During his 167-day hospital stay, Andrew experienced severe complications, including cardiac arrest and sepsis (an overwhelming infection of the bloodstream). “We moved into his hospital room,” says his mother Chris. “The community rallied around him and supported us, too.”

“We always thought that we would take him home,” says Joe. “Even at the end, our son told us he was undefeated.” On July 14, 2007, Andrew’s brief journey on earth ended. He touched so many people,” remembers Chris.

Joe, Chris and their daughter Ali decided to start a foundation in his memory. “B positive was Andrew’s blood type, but it was also his attitude toward life,” says Joe. Soon The B+ Foundation was raising money through 5K runs, a golf tournament, and other events.

The Foundation’s goals are to provide financial support to families of critically ill children, fund pediatric cancer research, spread the B+ message, and help others to “Live Like Andrew”—set goals, try your best, show affection and be comfortable with yourself.

Recently, The B+ Foundation awarded a grant of $250,000 in support of the Nemours Center for Childhood Cancer Research. The funds have assisted in establishing a robotic High-Throughput Screening laboratory to help discover new drugs for pediatric cancers. “We thought our money could go a lot farther in this start-up effort at Nemours,” says Joe. “My hope is that in the future, kids will think of childhood cancer in the same way we think of polio today. My happiest day will be when we can shut down The B+ Foundation.”

For more information on The B+ Foundation visit www.BePositive.org.

COMMUNITY PARTNERS

The McDonough family honors their son by inspiring others to “Live Like Andrew.”

HOW TO DONATE

- Include the Nemours Partnership 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 stock or property. Give us a call at (888) 494-5251 and our staff will assist you in making arrangements.

- Remember, 100% 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 Partnership for Children’s Health, please e-mail giving@nemours.org or write to us at: Nemours Partnership for Children’s Health, 1600 Rockland Road, Wilmington, DE 19803.
Vroom, Vroom... We Have a Winner!

After months of wishing on the part of 780 hopefuls holding tickets for the raffle of a Harley-Davidson™ Fat Boy® Motorcycle, the big day finally arrived in September when a drawing was held at Nemours/Alfred I. duPont Hospital for Children. Michelle Williams, whose son Ethan is being treated at the Hospital, was the lucky winner of the bike, generously donated by Concordville Nissan-Subaru in Concordville, Pennsylvania. Nemours Partnership for Children’s Health is grateful to all who purchased tickets for the raffle, which raised $17,000 to benefit children.

Kids Take Flight with Southwest®

Southwest Airlines is helping children who need medical care at Nemours/Alfred I. duPont Hospital for Children and must come from a distance. Complimentary roundtrip passes will be given to families with limited resources. The total value of the passes available to the Hospital is $30,000. Nemours Partnership for Children’s Health thanks Southwest Airlines for this wonderful contribution. It will surely make coping with the serious illness of a child a bit easier for families.