



**Duke Children's**

# stories

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## In sickness and in health

Duke's Rebecca Buckley, MD, has treated Burns Blackwell since he was an infant for a rare immunodeficiency disease. Dr. Buckley has been there for many of Burns's ups and downs—and even his wedding.

*Read more on page 4*

# Letter from the chairman

Every day I reflect on how very proud I am of the people who make up Duke Children's Hospital & Health Center. Our people make the difference. I am inspired by their brilliance, persistence, commitment to innovation, devoted care for children, and passion for educating tomorrow's pediatric leaders.

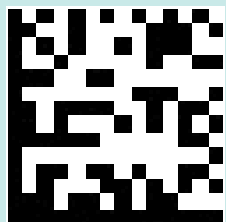
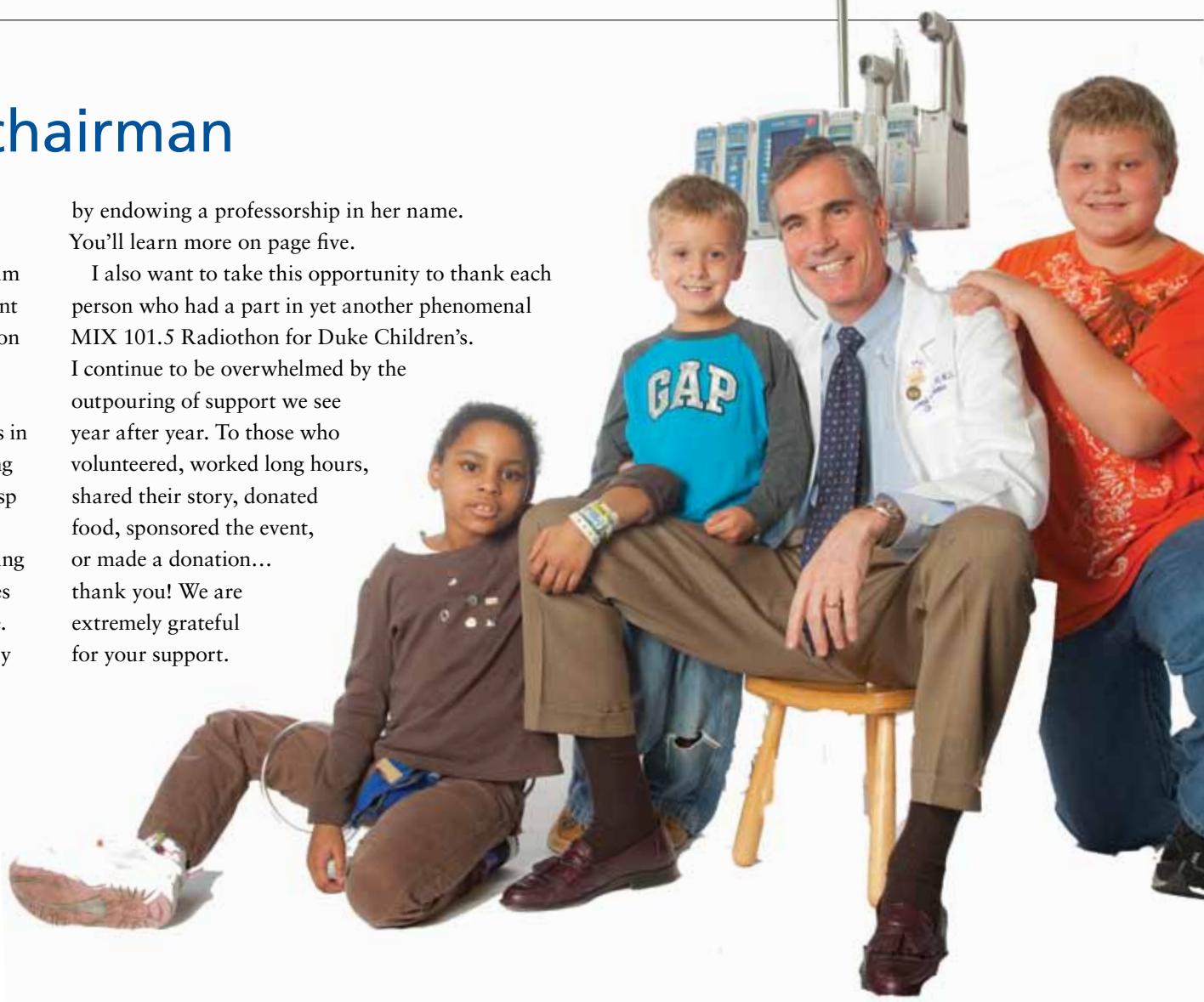
In this issue you will read about our Division of Allergy and Immunology, whose doctors are legends in the field. Division chief Wesley Burks, MD, is leading the way in treating peanut allergies and is on the cusp of a peanut allergy vaccine. Rebecca Buckley, MD, former division chief, is still hard at work today caring for patients with primary immunodeficiency diseases and pursuing research that will transform their care. We hope to honor Buckley's achievements and legacy

by endowing a professorship in her name. You'll learn more on page five.

I also want to take this opportunity to thank each person who had a part in yet another phenomenal MIX 101.5 Radiothon for Duke Children's. I continue to be overwhelmed by the outpouring of support we see year after year. To those who volunteered, worked long hours, shared their story, donated food, sponsored the event, or made a donation... thank you! We are extremely grateful for your support.



Joseph W. St. Geme, III, MD  
Chair, Department of Pediatrics



Use your smartphone to scan this code and take a tour of Duke Children's Hospital & Health Center.

Or visit [dukechildrens.org](http://dukechildrens.org) and click on "Giving."



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## Q&A with Wesley Burks, MD

Wesley Burks, MD, is the Kiser-Arena Professor of Pediatrics and chief of the Division of Pediatric Allergy and Immunology. Burks's research is helping us better understand the mechanisms of adverse reactions to foods. He and his collaborators have identified the important components of peanuts that are part of the allergic response. Additionally, they are working on several different types of immunotherapy for the treatment of food allergy, primarily peanut allergy.

### Q. What is the most common allergy?

**A.** The house dust mite is the most common allergy. In the United States the most common food allergies are milk, egg, and peanut, with peanut allergy being the most serious.

### Q. Why do food allergies seem so prevalent today?

**A.** One theory that has developed about the increasing prevalence of allergies is called the hygiene hypothesis. This theory states that exposure to allergens in the environment early in life reduces the risk of developing allergies by boosting immune system activity. Conversely, early exposure to a relatively clean environment would sway the immune system toward allergy-promoting responses. Clean environments are simply part of our modern society,

but a super clean environment is really not necessary. It's okay to get infections, to retrieve food from a relatively clean floor, and to let your children play in the dirt.

### Q. What course of action should parents take if they suspect a food allergy?

**A.** Atopic dermatitis, or skin rash, in the first six months of life might indicate the presence of a food allergy. Be aware of when symptoms develop, and talk with your pediatrician. It is uncommon for a child to have a life-ending allergic reaction before adolescence. It is not clear why adolescents more commonly have these reactions, so that question is being studied. It could be hormonal factors, risk-taking behavior (that is, an adolescent eating a food that he knows he's allergic to) or other factors we do not understand now.

### Q. How can you tell if your child has an allergy or if recurrent infections are the root of the problem?

**A.** If a child is having recurrent symptoms (more than eight times a year) of wheezing, runny nose, itchy watery eyes, or sneezing, parents should talk to their pediatrician. If a fever is present with these symptoms, the likely diagnosis is infection, not an allergy.

### Q. Should parents avoid giving babies certain foods?

**A.** If there is a history of food allergies in the family, we recommend that a mother breastfeed and not introduce any solid foods to a baby until he or she is at least four months old. ●



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## Four titans of allergy and immunology

Duke Children's allergy and immunology specialists pioneered treatments and continue to advance the field

Open a medical textbook on allergy and immunology and you will see that many chapters have been written by Duke Children's physicians. Rebecca Buckley, MD, Wesley Burks, MD, Michael Frank, MD, and Louise Markert, MD, PhD, are all legends in the field. Their research is transforming the lives of patients. The knowledge they share is helping to spread advances worldwide.



### Trailblazers

Families travel from all over the world for treatments pioneered here at Duke Children's. Whether it is Markert's thymus transplant to cure complete DiGeorge syndrome, Buckley's bone marrow transplant to treat severe combined immunodeficiency disease, or Burks's food allergy immunotherapy, parents come to Duke in search of a miracle for their children.

From the life-saving to the life-altering, the allergy and immunology teams offer priceless answers to complex problems.

### Excellence as a standard

Burks is chief of the Division of Pediatric Allergy and Immunology and credits much of the division's success to its first chief, Susan Dees, MD. Dees's commitment to the highest level of clinical care and research set the standard. Dees trained Buckley, and Buckley trained Burks.

"Our work as researchers makes us excellent doctors for these children. I am so proud of the people I get to work with every day. I am excited to think about what they have accomplished and what is still to come," Burks says.

### Sharing knowledge

Like many physicians and scientists at Duke Children's, the allergy and immunology teams are active presenters, authors, and collaborators. Scientists and doctors come from all over to learn from them as well.

"To really make a difference and help children takes a lot of people," says Burks. "We want to share as much as we can to move advances forward."

### The next generation

Over the past 60 years, more than 100 aspiring specialists from as far away as Australia have received extensive training in allergy and immunology at Duke Children's. The Pediatric Allergy Training Program was established by Dees in the early 1940s and became widely recognized as an excellent program for clinical training in the field. Over the years this important tradition has been upheld, and the program has been expanded to include immunology, and more recently, molecular biology training.

"It has been an honor to learn directly from the immunologists who have essentially written the textbook on immune deficiency and its treatment, Dr. Rebecca Buckley and Dr. Louise Markert," says Edwin H. Kim, MD, third-year fellow in allergy and immunology. "Similarly, I have been taught and mentored by one of the world leaders in food allergy, Dr. Wesley Burks. These faculty and others at Duke have been great role models in their balance of research and life-long learning combined with incredible clinical skills. They have fostered a scientific curiosity that I will carry throughout my career. I will cherish these relationships forever."

"Training those who will follow us is our lasting impact," says Burks. "It is incredibly worthwhile to invest in people, knowing they are going to be amazing at what they do and help so many children." ●



## Responding to the need

Pediatric nurse practitioners are vital to allergy and immunology care

The number of children with food allergies has doubled in the last decade, increasing the demand not only for advances in research, but also for specialized care in this area. The medical community responded by expanding the role of pediatric nurse practitioners to provide more comprehensive health care services. Today, certified pediatric nurse practitioners, or CPNPs, work to examine, evaluate, treat, and educate children suffering from severe allergies and immune deficiencies.

Ginger LaBelle was the first CPNP to be hired by the Duke Children's Division of Allergy and Immunology in 1978. In a sense, she has grown with the field as it has evolved with the transforming landscape of pediatric medical care.

Today there are four CPNPs in the division, and their responsibilities vary with their subspecialty (allergy, immune deficiency, food allergy research, and thymic evaluation and transplant). For example, LaBelle conducts "food challenges" and gives patients supervised amounts of food in gradual, incremental doses in the safe setting of the hospital.

Another CPNP in the division, Stephanie Gupton, works with Louise Markert, MD, PhD, to coordinate thymus transplants for babies born with complete DiGeorge syndrome. This congenital immunodeficiency disease leaves babies defenseless against infection due to the absence of the T-cell-producing thymus gland.

The other two CPNPs in the division, Pam Steele and Deb Sedlak, perform peanut desensitization studies and coordinate the management of patients referred for primary immune deficiency.

This team of nurse practitioners has helped make Duke Children's a world leader in allergy and immunology. "A lot has been learned about allergy and immunology within the last 20 years," says LaBelle. "There is so much new information all the time."

CPNPs at Duke Children's stay up-to-date by attending several meetings a week to discuss the most recent advancements, interesting cases, research, and journal articles from around the world. Armed with the latest information, CPNPs in the Division of Allergy and Immunology work with physicians to provide assessment, education, disease management, treatment, and research. ●

For appointments for children,  
please call 919-668-4000.

Physicians requesting consultations  
or making referrals should call the  
division office at 919-684-9914 or the  
Duke Consultation and Referral Center  
at 800-MED-DUKE (800-633-3853).



# On the groom's side

## An adult patient at Duke Children's refuses to let a rare disease crash his wedding

In 1979 the family of two-year-old Burns Blackwell learned he had a rare, multi-generational disease known as chronic granulomatous disease (CGD). This was the same disease that claimed his grandmother's brother as a toddler—in fact, at the same age as Burns's diagnosis. Burns's family was immediately referred to Duke Children's Hospital & Health Center to see Rebecca Buckley, MD—the beginning of a long and meaningful relationship.

CGD is a primary immunodeficiency disease (most common in males) affecting the white blood cells, which, left untreated, can claim life within the first few years. The white blood cells can "surround" infections but are powerless to kill them. So when the cells die, the infection is released back into the body. Burns is particularly susceptible to fungal and bacterial infections. He has to have medicine to fight infection because his body cannot do it alone.

At age 10 Burns had a serious fungal infection that required a seven-week hospital stay—something no child should have to go through. Later, the creation of an outpatient service now known as the Valvano Day Hospital in the Children's Health Center transformed his care.

Instead of being an inpatient for treatment of infections, he could stay at home and come in daily for outpatient care. Burns and his family wouldn't realize how important that would be until just over a year ago.

In February 2010, Burns became quite ill and began a battle—his hardest yet—which would last nearly 10 months. Patients with CGD show signs of infection, but cultures to determine the specific germ are often negative, making treatment difficult. "Most of the time we don't know exactly what we are fighting, but the doctors always find a solution," says Burns, now 34. "Normally after three to four months the battle would be over. This time I wasn't improving."

In May doctors located an infection in his spleen, but scans and tests were inconclusive as to the type of germ causing the infection. So Burns began a daily six-to-10-hour regimen of antifungal medicines in the Valvano Day Hospital. He endured many reactions and side effects. Still Burns remained positive and strong. He and his fiancée Laura Mills counted down to their September wedding, along with the staff at the hospital...all hoping he would be well enough for the big day.

"One of the first things I grew to love about Burns was his amazing strength," says Laura. "He tackles everything in life wholeheartedly. When I first learned of his illness, I did not know what to expect—I had never heard of CGD. But thanks to his patience and the kindness of all the staff at Duke Children's, I was taught about the immune deficiency and treatment that was consuming our days. And even though it was taking up most of our time together, we did not let it shape our lives."

***"She's the first person I called when I got engaged."***

—Burns Blackwell, of Rebecca Buckley, MD

Burns was given time off from treatment for the wedding. The staff in the Day Hospital threw a surprise party the Thursday before the wedding. With the care of a home health team to provide him potassium and fluids over the weekend, Burns went home to Greensboro to enjoy the celebration with family and friends.

"I had more energy those two nights than ever before in my life," says Burns. "We had an amazing wedding. Dr. Buckley attended and sat with the family in the second row. Our honeymoon was four days at a Chapel Hill hotel so I could be close to Duke Children's. I paid greatly for being off the medicine for several days, but I wouldn't trade it for the wonderful experience of my wedding. We danced all night."

Still, the infection was not under control, and Burns had to return to his regimen of care...his daily visits to the Day Hospital.

The toll of the treatment was becoming unbearable, and Burns asked for surgery to remove his spleen. Buckley had managed his disease for more than three decades, rarely having to resort to surgery. "Other people with this disease are all cut up, having multiple surgeries to remove infections," says Burns. "That is not Dr. Buckley's style. Quality of life is very important to her."

Buckley agreed that surgery might be the only option. She left to give a talk at a conference, staying in close touch with Burns. After her lecture, she was discussing Burns's condition with two investigators at the National Institutes of Health. They had just discovered a new germ, one that is resistant to the antibiotics that would typically be used in a patient with CGD.

Buckley quickly called Burns—two days prior to his surgical consultation—to give him the news. They tried a new course of treatment, with an antibiotic directed against the new germ, and Burns was feeling better within three days.

"I don't know how my life would be different without Dr. Buckley," says Burns. "She knows more about me than I do. She's like a grandmother to me. She's the person I call when I don't feel well." ●



Burns and new wife Laura pose with Rebecca Buckley, MD





## Rebecca Buckley, MD

### Giving hope to children with primary immunodeficiency diseases

Rebecca Buckley, MD, is a pioneer of pediatric immunology. Buckley's interest in medicine started early. She remembers well calls her physician father received at home while she was growing up. After graduating from Duke University, Buckley followed in her father's footsteps and received a medical degree from the University of North Carolina. She returned to Duke for residency, fellowship training, and further specialization in immunology. She joined the faculty as an instructor in pediatrics in 1961, received a National Institutes of Health Fellowship Award in 1964, and began her research. Buckley served as chief of the division from 1974 to 2003. The field of immunology was emerging right along with Buckley, and she was present for many of the advances.

"I feel privileged to have been a part of it all, to be along to see so much happen," says Buckley. "Every week or month there was a new discovery that could lead to more advances."

#### In search of perfection

Buckley's most notable work has been with patients diagnosed with severe combined immunodeficiency disease (SCID). These patients are born without T-cells, which are necessary to fight infection, and invariably die early in life unless they receive a treatment that will allow T-cells to develop. For the first 15 years of her career Buckley watched sadly as these babies died, because the common belief was that they would need a perfectly matched donor for a lifesaving bone marrow transplant. If the match was not perfect, the donor T-cells would fatally attack the baby.

"I was determined to find an answer for these children," says Buckley. She perfected a process of removing T-cells from the donor marrow and transplanting it into the SCID patient. This meant that parents, who typically are only half-matched, could provide bone marrow for their children. The stem cells from the parental bone marrow would become functioning T-cells that would not attack the baby and would repair the child's immune system. Buckley also has not used chemotherapy prior to these bone marrow transplants. "These children didn't need it because they are born with no T-cells that could reject the graft. The chemotherapy would have resulted in a higher mortality and left them unable to have children of their own someday."

#### Watching them grow

Buckley has performed transplants on 168 babies. The procedure has a 94 percent success rate when done in the first three months of life. "Translating discoveries in the lab to the care of patients and seeing these babies thrive has been the highlight of my career," Buckley says.

Buckley's daughter, Beth Buckley, says that it is precisely that—watching babies grow up—that has motivated her mother. "I believe what is different about her accomplishments is what drives them—a desire to save lives and prevent illness by expanding the frontiers of her scientific discipline. This drive to excel is selfless, not career-minded."

#### Ensuring longer and better lives

Several years ago the Immune Deficiency Foundation named Duke a National Center for Excellence for Primary Immunodeficiency Disease—a designation honoring the work of Buckley and other Duke experts.

Buckley's most recent accomplishment was election to the National Academy of Sciences, which is among the highest honors a scientist can receive. She also has served on the Immune Deficiency Foundation's Medical Advisory Committee. She presented before the North Carolina Newborn Screening Advisory Committee, encouraging approval of the federal recommendation that the state adopt newborn screening for SCID. At the conclusion of her presentation, the state committee voted unanimously to recommend that North Carolina add the SCID test to the state's newborn screening panel.

"For the families who are unaware of a family history, something as routine as childhood vaccinations could be deadly for a baby with SCID," says Buckley. "When caught early, some primary immunodeficiency diseases can be successfully treated. But unless they are screened for, they don't become known until the patient is dreadfully ill."

All of her successes came as part of a life well-balanced. Buckley and her husband Edward Buckley, MD, an immunologist, raised four children.

"Mom was somewhat of a pioneer of the working woman, juggling a demanding work life as well as a family," says her daughter, Kathy Hatter. "Among my friends at school I was the only one whose mother worked and could not do carpool. This was a pain sometimes, but it was mostly a source of pride because we knew her work was important and that her patients had longer and better lives because of her." ●



### Going the distance for a miracle



**John Patchett is a miracle.** His life took an unexpected turn before he was even born when testing confirmed his mother's greatest fear—her unborn baby was diagnosed with a genetic disorder of the deadliest sort.

John had severe combined immunodeficiency disease (SCID). This rare disease, characterized by a diminished number of T-cells, had taken the life of many of his male relatives. John's mother, Carrie, began a national search to find help. Her answer came in the form of a pioneering physician-scientist at Duke Children's Hospital & Health Center.

To ensure immediate treatment upon the birth of her son, Carrie relocated from Texas to Durham, North Carolina. The delivery was normal, and just days after he was born, John was given a transplant of Carrie's bone marrow, a procedure Duke's Rebecca Buckley, MD, had

been performing for 20 years. Three months later, tests revealed that John had developed a functioning immune system.

Through pioneering medical treatment John received at Duke Children's, he has thrived—escaping the tragedy that had gripped his family for years.

#### HOW YOU CAN HELP

We want families like the Patchetts to have hope for tomorrow. We want to endow a professorship in pediatric allergy and immunology to honor Buckley's lifetime of accomplishments and to ensure that her legacy of achievement and excellence continues for generations. You can get involved by contacting us at **919-385-3141** or [dukekids@notes.duke.edu](mailto:dukekids@notes.duke.edu).

# Giving also runs in the family

Thirty-two years ago, at age two, Burns Blackwell was diagnosed with chronic granulomatous disease (CGD), a life-threatening immunodeficiency disease. His life was saved when he came under the care of Rebecca Buckley, MD (see story on page 4). To show their appreciation over the years, his family has made gifts to Duke Children's. The gifts were made in honor of Burns's grandmother, Mary Burns Detgen, through the Detgen family business, Terminix. That support has continued consistently since 1984.

Recently Burns's parents, Harden and Derry Blackwell, also made a significant personal pledge. All this has been done in support of the woman and the team they credit for Burns's remarkable life.

"It is easy and with great pleasure that we give back to Duke Children's because of everything Dr. Rebecca Buckley has accomplished for Burns over the past 32 years," say Derry and Harden. "The high level of compassion and care from Dr. Buckley and the entire staff at Duke Children's exceeds anything one could expect. We strongly believe this care has enabled Burns to achieve the highest quality of life possible with CGD."

By honoring Buckley's research they know they are helping not only Burns, but the thousands of families facing immune diseases who seek hope at Duke Children's each year. Fueling the research engine will uncover new answers for those battling CGD and other primary immune deficiencies.

### Thankful for an answer

The family tradition of supporting research in allergy and immunology extends to Burns's great-aunt, Elisabeth Burns Nimocks. Elisabeth's brother, Robert "Bobby" Owen Burns Jr., died at age three of CGD, although his death was shrouded in mystery at the time. It was not until Burns was diagnosed many years later that the family had some closure as to why little Bobby was taken from them at such a young age.

Though Elisabeth never knew Bobby, the emptiness she felt was very real. To learn she might lose her great-nephew as well was heartbreaking. "Burns is one of the bravest people I have ever seen," says Elisabeth. "And when Dr. Buckley entered the picture, it was like Superman stepping from a phone booth. We were thankful to know, finally, what we were dealing with and that there was someone who knew how to take care of Burns."

"We think the world of Dr. Buckley," says Elisabeth. "When my mother passed away, we designated memorial gifts to support Dr. Buckley's work."

Elisabeth established an endowment at Duke Children's Hospital in her brother's name: The Robert Owen Burns, Jr. Fund. This fund was established as an operational endowment for the Division of Allergy and Immunology in the Department of Pediatrics.

In addition, the Nimocks Family Foundation makes annual gifts toward the current expenses needed to support research in immunology to help unlock answers for families like their own.

*"I feel like I am helping children and honoring my late brother."*

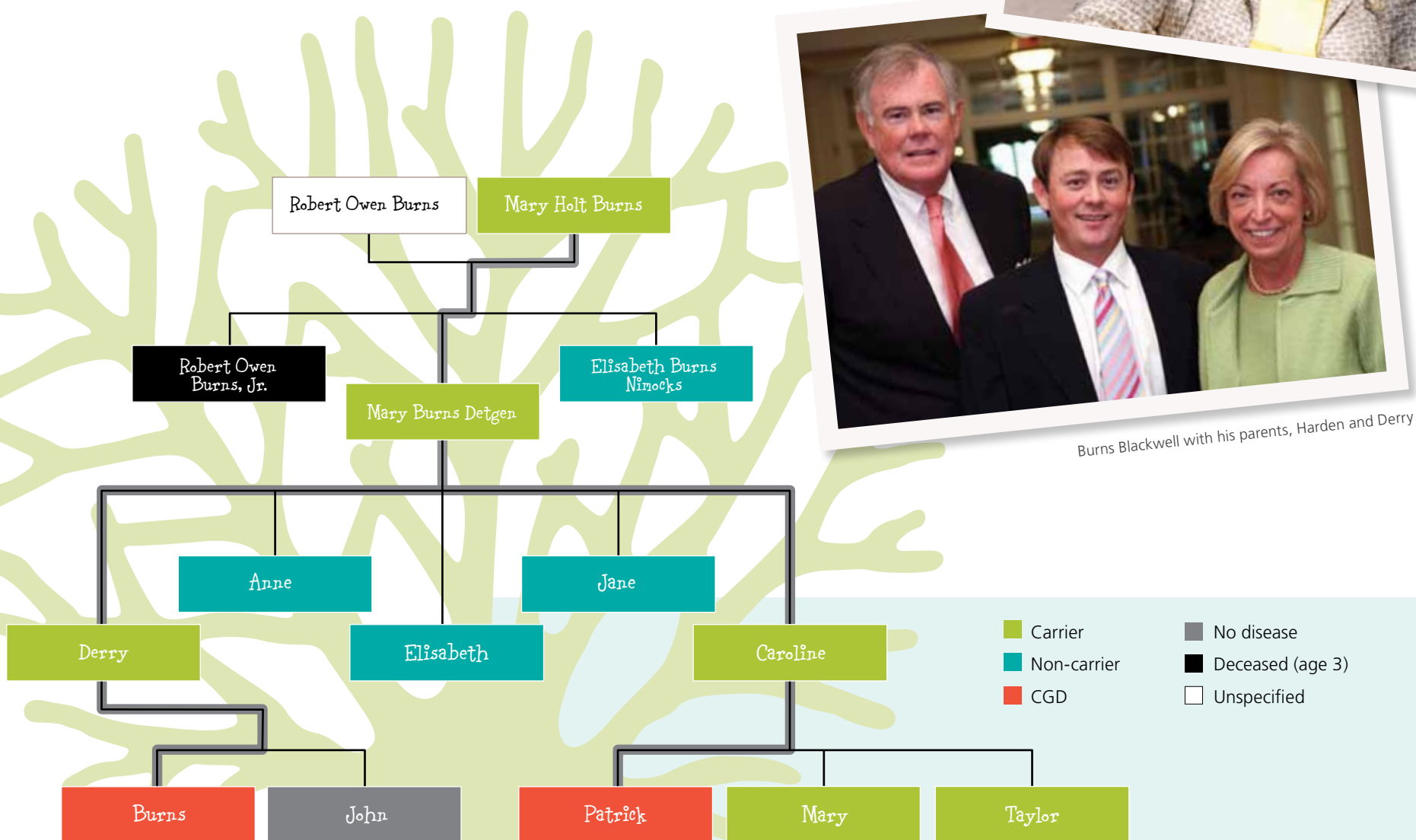
—Elisabeth Nimocks



Elisabeth Nimocks (right)



Burns Blackwell with his parents, Harden and Derry



Burns Blackwell's family tree reveals the origins of his chronic granulomatous disease (CGD). In this family, CGD is carried by females and affects males. Burns's great-aunt Elisabeth was not a carrier for CGD as her mother and sister Mary were. Her children would be spared the disease. Anne, Jane, and Elisabeth have children as well—none affected by the disease. Burns's brother John does not have CGD, but his cousin Patrick does. Because Burns is older, the family genetics were understood by the time Patrick was born. So when Patrick had a life-threatening illness at just a couple of days old, his mother's decision to come to Duke Children's saved his life. Patrick is now a junior in high school.



# THANKS A MILLION

## For a record-breaking Radiothon

At the conclusion of the 17th annual MIX 101.5 Radiothon for Duke Children's Hospital & Health Center on February 17, Joseph St. Geme, MD, chair of the Duke Department of Pediatrics and chief medical officer of Duke Children's Hospital, and Bill and Lynda of the MIX 101.5 morning show announced a three-day fundraising total of \$1,224,053. MIX 101.5 listeners, sponsors, patient families, and hundreds of volunteers came together to make magic happen for Duke Children's.

The three-day Radiothon for Duke Children's broadcasts live from the lobby of the McGovern-Davison Children's Health Center and raises more money per capita than any other Children's Miracle Network Hospitals Radiothon in the world. We are grateful to be part of such a generous community.

Over the past 17 years, MIX 101.5 and its listeners have raised more than \$13 million for Duke Children's Hospital & Health Center. Mark your calendar for next year's Radiothon set for February 14-16, 2012.



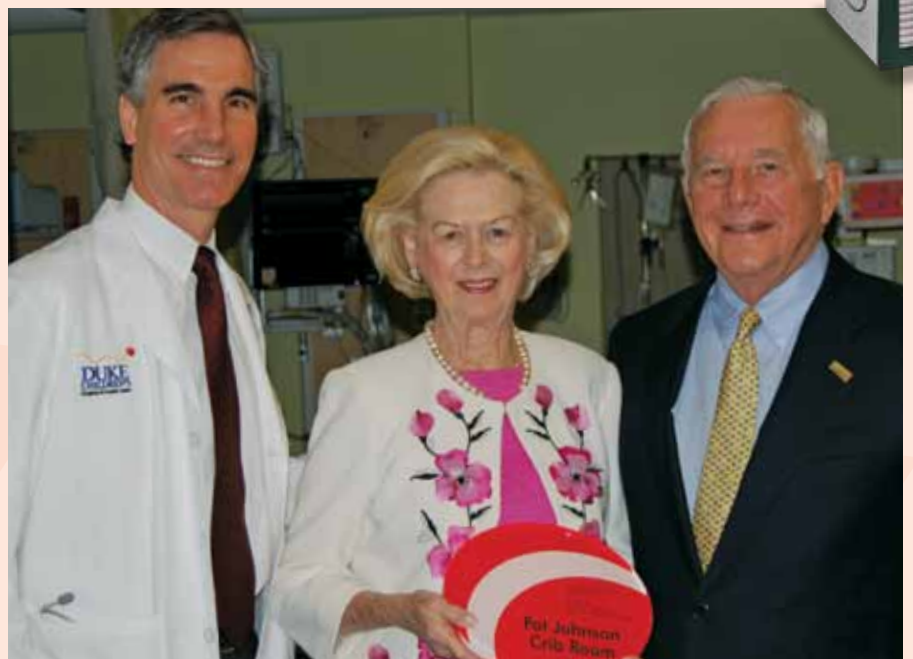
## Tribute Giving

### Looking for a thoughtful way to honor someone special?

Birthdays, weddings, anniversaries—these celebrations of life, love, and happiness commemorate special moments of one's life. But what if you could spread that joy to someone else? What if celebrating your birthday meant that an entire family could celebrate the life of a child?

Consider making a tribute gift to honor a family member or friend, memorialize a loved one, or thank someone whose care made a difference for you and your family at Duke Children's. They've changed your world, and now they will forever change the world for someone else.

This year, make your special day, or the special day of a loved one, even more meaningful—make it a day of miracles. Honor the person you care about with a special gift to Duke Children's.



Jason Rodri, a third-grader at Cathedral School in Raleigh, turned nine years old last October. He and his parents decided that instead of gifts he'd ask birthday party guests to make gifts to charity. Without hesitation Jason selected Duke Children's Hospital & Health Center. "They saved my cousin Bayden Collins's life," Jason says. "My invitation included information about Bayden's kidney transplant and let people know they'd get to meet him at the party." Jason was so proud to contribute \$272 to support pediatric nephrology.

*"Ever since my wife, Pat, took a tour of Duke Children's last fall she has been so excited and impressed by what is being done there. She talks about it all the time. When it came time for her birthday, I thought making a gift in her honor would be such a nice surprise. To make it even more special, the crib room in the Pediatric Cardiac Intensive Care Unit was named for her. That part of the tour had a lasting impact on her."* —Dick Johnson



## State champ!

Just days after her birth, Jayla developed a rash all over her body and began having seizures. She was initially thought to have just a calcium imbalance but ultimately was diagnosed with DiGeorge syndrome, an extremely rare disease that affects fewer than 10 babies born in the United States each year. The disease is characterized by the absence of a thymus gland and oftentimes parathyroid deficiency (resulting in a low calcium level) and congenital heart disease.

Born without a thymus gland, which is responsible for the "education" of T-cells that build our immune system, Jayla could have died from exposure to the smallest germ. Her family was referred to Duke Children's Hospital & Health Center, and doctors set out to save Jayla's life.

Months after receiving treatment, a biopsy revealed a "super positive," the first sign that the transplanted thymus Jayla received was working.

After living in total isolation for the first years of her life, today Jayla lives worry-free. She beat initial life-expectancy odds of just one year and is now attending preschool. She loves giving hugs, listening to stories, and being around her sisters and classmates. And now she has a big honor to celebrate, too.

Jayla has been selected to represent all the sick and injured children of North Carolina in the Children's Miracle Network Hospitals' Champions Across America program. Jayla and her family will travel to visit North Carolina Congressmen in Washington, DC, and then to Florida to participate in the annual celebration event at Disney World.



## Children's Miracle Network Hospitals

### A new look for Children's Miracle Network logo

Duke Children's Hospital & Health Center is a member of Children's Miracle Network Hospitals, an organization that was founded by Marie Osmond and John Schneider with the goal of helping as many children as possible by raising funds for children's hospitals.

Children's Miracle Network Hospitals' most recognizable symbol and greatest fundraising tool is its red and yellow Miracle Balloon icon. The logo and icon received a sleek, modern look for 2011.



### New phone numbers

As of June 9 the Duke Children's Development Office phone numbers have changed. You can now reach us at **919-385-3141** with questions about giving opportunities.

# Stories



## The heavy hitters

Duke Children's allergists and immunologists are writing the book, offering answers, and making life's big—and small—events possible for patients