



# stories

VOLUME 14, ISSUE 2 • FALL 2009

One family's determination matches that of Duke Children's  
The search for better therapies for neuroblastoma

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# Fifty Years of Keeping Grades Healthy



Photo provided by wral.com

The Hospital School at Duke Children's has been providing a reassuring bridge between home and the hospital since 1959. It is a wonderful distraction amid the tubes, beeping machines, and medicine to be simply a student. The school also symbolizes hope—hope for leaving the hospital behind and returning to a normal life.

For Duke Children's patient Stephen Kirchner it has been a relief to know that when he gets back to school, he'll be right on target. "It's hard enough [for a student] to miss school because of a cold or flu, but can you imagine being in the hospital for two months?" says Stephen's father Robb. "Stephen is in advanced classes and is very goal-oriented. He would never have been able to catch up and would have had to repeat the year."

The Hospital School is part of Durham Public Schools and is staffed by North Carolina certified teachers. Each year, the school serves about 420 children with chronic illnesses, traumatic brain injuries, psychiatric and behavioral disorders, and physical rehabilitation needs.

## Hospital School by the Numbers

**ONE PRINCIPAL**

**EIGHT TEACHERS**  
(Pre-K through 12th grade)

**TWO TEACHERS** available year-round

**30-40 STUDENTS** enrolled at a time

**ONE SECRETARY/BOOKKEEPER**

**\$0 COST** to the patient

The school is a great benefit because it enables patients to continue their studies while undergoing medical treatment. The services of the school may include testing and direct instruction. The Hospital School staff also helps children transition back to their regular schools.

Most of the work is done at bedside for one to two hours per patient, per day. The teachers also instruct students who are outpatients or staying at the Ronald McDonald House. International patients can take advantage of their time in the hospital to learn English and American culture.

"If you are away from school as a child, you are missing what you are supposed to do as a child, which is to continue to learn," says Hospital School principal Rick Lemke, PhD. "We're here to support the educational process and maintain academic progress. These children are forced to lose time because of their illnesses. We feel it is essential to help them stay on track with their learning." ●



## The Pediatric Clinical Social Worker

Clinical social workers are trained, licensed professionals who provide a range of psychosocial services to enhance the quality of care for children, teens, and their families, in both the hospital and the community.

By understanding patient and family concerns, social work professionals join with family members to develop options and plans that meet their child's health, developmental, and emotional needs. The social workers play an important role on the medical team with their intimate knowledge of the patient family's life situation and ability to provide counseling and emotional support.

"The doctors and nurses may get frustrated when mom is never there [in the hospital]," says Anne Kosem, LCSW, a social worker for the pediatric hematology-oncology group. "It's part of my role to help the team understand that mom is a single parent with other children, she has minimal support to help with the other children, and she has to continue to work to maintain health insurance coverage. She's doing the best she can."

Kosem also explains that rarely is cancer the only thing going on in a family. "It is important to understand how they are going to approach this crisis," says Kosem. "When the child is first diagnosed, we do an assessment of the family dynamics, their coping styles, their support system, and additional stressors in their life at the time of diagnosis that helps us determine the best way we can provide support to help the family cope."

The team at Duke developed CARES (Communities Assisting with Resources, Encouragement, and Support)—a program funded by the Pratt Family Foundation to provide education and counsel a patient family's community. The family identifies who is part of their community such as friends, co-workers, or teachers. The social worker then serves as a liaison between the hospital and this group to provide education on how to offer appropriate and meaningful support. Often friends want to be helpful and supportive but don't know where to start. "This takes a lot of pressure off the family," says Kosem. ●



## Group Offers Support for Young Adult Cancer Survivors

Twenty-year-old Rebecca Jester is a student at the University of North Carolina. She is also a cancer survivor.

Jester was diagnosed with leukemia in 2003 and completed treatments nearly four years ago. In addition to the physical toll that cancer brings, there is also an emotional toll, explains Jester. Unfortunately, while there are a number of support groups for adult patients and some for children, there is little to help patients in between.

In September 2008, with funding from a Children's Miracle Network Kids Care grant, Jennifer Walker, MD, a pediatric hematology-oncology fellow, and Laurie Howlett, LCSW, a social worker, created a monthly support group at Duke for cancer patients and survivors ages 15 to 30.

"The group helped me work through pent up emotions like anger and resentment," says Jester. "It also helped me realize that I was not the only one who had these feelings, and they are completely normal."

Howlett says that one of the important aspects of the program is to show the survivors that they are not alone—that others are going through similar situations.

Walker and Howlett are happy that the young adults feel comfortable sharing their stories. During the meetings, the young adults talk to their peers about their experiences with cancer. They regularly hear from guest speakers such as Seema Desai, a Duke nutritionist, who presents information about nutrition both during and after cancer treatment.

Carolyn Koncal, at age 29, is one of the older members of the group. Diagnosed with leukemia 15 years ago, she acts as a mentor to the younger patients.

There are very few support programs of this kind available, so patients come from all over North Carolina as well as parts of Virginia and South Carolina to attend. "This transitional age group is one that's often overlooked, and Dr. Walker's and Mrs. Howlett's efforts to support this group of individuals fills a significant void," says Dan Wechsler, MD, PhD, chief of pediatric hematology-oncology at Duke.

Additionally, Duke offers a parent and caregiver support group that runs parallel with the young adult and adolescent group. This group is open to parents and caregivers of any pediatric oncology patient whether newly diagnosed, in active treatment, or receiving follow-up care.

Both groups meet the first Thursday of each month at Duke Children's Hospital. For more information, call 919-684-3401. ●

“Good things come out of everything...even cancer. Drake’s experience has touched so many people. Others look at how he has handled everything and realize they can face their challenges, too.”

—Dana Hardee, Drake’s mom

# Hope on the Horizon

## for Young Neuroblastoma Patients

A two-year-old with three brothers complains of a sore leg—not so uncommon. A diagnosis of neuroblastoma, however, shakes a family to its core.



**D**rake Hardee, of Grifton, NC, limped through his living room, unable to bend down to pick up objects from the floor. His local pediatricians performed blood tests but attributed his pain to inflammation from a recent bout of bronchitis.

Dana Hardee, Drake’s mom, persisted. “He was getting worse and worse,” she says. “We went to an orthopedist. We went back to the pediatrician for more blood work.”

One by one, frightening diseases were checked off the list—leukemia, juvenile rheumatoid arthritis, lupus. Puzzled, Drake’s pediatrician called Duke Children’s Hospital & Health Center.

An MRI at Duke Children’s presented the Hardee family with a word they had never heard before—neuroblastoma. Drake had a tumor the size of a golf ball on his adrenal gland and evidence of the cancer throughout his body, even in his bone marrow.

Pediatric surgeon Henry Rice, MD, removed the tumor and Drake endured six rounds of chemotherapy and numerous hospitalizations. Still the cancer lingered in his bone marrow.

One more round of chemotherapy followed to ready Drake’s young body for a bone marrow transplant. Drake’s advanced neuroblastoma qualified him for a clinical trial for antibody treatment in New York.

Through it all, Drake exhibited what so many of Duke Children’s patients display—a special kind of determination to beat his disease. “No matter how bad he felt, he would bounce back ready to take on the world,” said Dana.

### Fighting the Good Fight

Today most childhood cancers have a greater than 75 percent cure rate. Neuroblastoma, however, continues to cut short too many young lives, taking with it the hopes and dreams of a family.

All too often, a patient is declared to be in remission only to have neuroblastoma tumors return. Sadly, nearly two-thirds of patients succumb to the disease.

Duke Children’s is working to reverse the devastation of neuroblastoma. A number of faculty have particular interest and expertise in treating neuroblastoma.

Michael Armstrong, MD, PhD, with funding from Hyundai Motor America’s Hope on Wheels, is working to understand how neuroblastoma cells are able to develop resistance to chemotherapy and survive through treatment. The results will be a key to unlock better treatment alternatives.

Funding from an anonymous donor will also accelerate the basic science understanding of these elusive tumors.

A promising new compound called I-MIBG can selectively irradiate neuroblastoma tumors sparing surrounding tissues from damage. Duke Children’s has two lead-lined rooms where the radioactive neuroblastoma-seeking compound I-MIBG can be administered.

The complexity of maintaining neuroblastoma trials with I-MIBG requires a dedicated coordinator—the missing piece in making this program a reality at Duke Children’s.

Fortunately, grants from St. Baldrick’s Foundation and Medical Services Association have allowed Duke Children’s to hire a nurse practitioner/clinical research associate to facilitate the program, catapulting Duke Children’s toward becoming a part of the New Approaches in Neuroblastoma Treatment (NANT) consortium. Currently, out of the 14 centers that can offer I-MIBG treatment, none are in the Southeast. Patients in our area have to travel great distances to receive treatment. Duke Children’s will soon be able to offer families a much closer option.

Drake, now almost five, is still undergoing treatment at Duke Children’s and in New York. For his family, this concerted effort to better understand and battle neuroblastoma provides hope that a cure is on the horizon for Drake and the many children battling this cancer. ●





## Celebrating a Life Dedicated to Children

Clementine Carlaftes was born in New York City but grew up in Miami with her adoptive mother. She received bachelor's and master's degrees in education from the University of Miami and dedicated her life to early childhood education both as a teacher and as an elementary school principal.

So it is no surprise that such a woman, having no children of her own, would leave her estate to a children's charity. But those who did not know Carlaftes well may have been surprised that she left her entire estate—nearly \$500,000—to Duke Children's Hospital & Health Center.

"Clementine was very frugal—nothing fancy in her house, no extravagant clothes," says Ruth Irvin, development officer for Duke Medicine. "She did love cars and had a collector's edition car, which she referred to as her baby. We were all surprised by the amount of her gift."

Carlaftes first became acquainted with Duke in 1996 through the Palm Beach Forum—an event organized by Duke Medicine Development and Alumni Affairs. Later she came to Durham to see a physician and quickly became friends with a number of staff members in the development office and at the hospital.

"We all quickly took a personal interest in Clementine," recalls Brenda Rimmer, an events



planner with Duke Medicine. "She was fun-loving and intellectually curious. We became her friends...and her family."

Along the way, Carlaftes declared she would leave her estate to Duke Children's, but would never say how much. It was obvious that she was genuinely concerned about the well-being of our pediatric patients.

Carlaftes was touched by an organization and its people, and by giving to Duke Children's, she followed her heart. Though never a patient or family member herself, she saw the miracles nonetheless. Her care and concern for Duke's pediatric patients lives on, as the Pediatric Cardiac Intensive Care Unit family waiting area has been named in her honor. How appropriate that even after her death, she continues to provide help and comfort for children and families as she did in life. ●

## A Missed Shot Becomes a Slam Dunk for Duke Children's

George Grody, a Duke 1981 graduate and avid basketball fan, perched on the edge of his chair making bids on a 1992 championship basketball rim on [dukebasketballreport.com](http://dukebasketballreport.com). He lost the bidding at the last second, but he and Duke Children's won in the end.

The auction was in memory of two sisters, Laurel and Ashley Matkins, who had passed away from cystic fibrosis. Their photo and story were prominently placed on the auction home page where Grody would continuously enter his bids. When Grody's adrenaline from the bidding war receded, he contacted Duke Children's.

Grody was then working for Procter & Gamble. He had lived and worked all over the world but considered Durham his home, if only emotionally, and his retirement would bring him back there. He wanted to help a charity in Durham with a Duke connection. The basketball rim auction and a subsequent tour of Duke Children's put all the pieces together.

Early in Grody's career a trusted mentor advised him to always leave everything you touch better off than you originally found it. This has become Grody's mission in both his career and his retirement, which he spends teaching at Duke and serving the community. This will be his legacy.

Grody retired from Procter & Gamble after 26 years of service. He moved to Durham in September 2007 with his two black labs, Coco



and Jil. Now George serves as chair of the Duke Children's National Board of Advisors. Already a loyal donor, George wanted to be sure that he could continue to support the great people and the great mission of Duke Children's even after he was gone. For Grody, a bequest to Duke Children's was an easy decision.

"I want to ensure that the things that are important to me are taken care of. My bequest will help ensure the best care will be available at Duke for the children and families of Durham and beyond," says George. "If you find an organization that means a lot to you, the best way you can keep your vision alive is to plan for when you can no longer make a personal impact. You're never too young to think about a planned gift to show how much you truly care about an organization." ●

## CHARITABLE GIVING

### What Makes Sense Right Now?

The past year and a half has been a stressful time for many Americans as the financial markets batter our investments, savings, and retirement plans. But history has shown us that these down times often are a source of great opportunity.

Planned giving presents many options that benefit you and Duke Children's. Planned gifts can offer you tax savings, provide you with a lifetime income, support an elderly loved one, or help pay for your child's college education. So while giving you comfort and security, your planned gift is supporting the missions of care, advocacy, research, and education at Duke Children's.

Here are just a few of the most popular examples of planned gifts.

#### CHARITABLE GIFT ANNUITY

This is a simple agreement between you and Duke Children's, whereby we pay you a lifetime annuity in exchange for a charitable gift. The amount of this annuity depends on market interest rates and the age of the beneficiary. Under certain circumstances, a large portion of the income from the annuity can be tax-free or taxed at lower capital gains rates.

#### CHARITABLE REMAINDER UNITRUST

You can establish a trust that pays you income based on the market value of the trust assets each year. Such a trust provides an excellent hedge against inflation because if the market value of the trust assets increases, so will your income. You may also claim a charitable deduction on your income taxes.

#### RETIREMENT PLANS

There is yet another way to reduce your taxes with a gift to Duke Children's. IRAs and other retirement plans are usually subject to both income and estate taxes at your passing. If you name Duke Children's as a beneficiary for all or a portion of your retirement plan, you may make a generous gift and realize important tax savings for you or your heirs.

#### BEQUESTS

Some of Duke Children's largest gifts have come to us under the terms of a donor's will. Today's federal estate tax laws favor charitable bequests.

- **Specific bequests** provide for a specific dollar gift or specific assets to be given to Duke Children's.
- **Residuary bequests** provide for a gift to Duke Children's of all or a portion of the remaining assets of your estate after all specific bequests have been paid.

It is easy for an attorney to change your will or trust to include a gift to Duke Children's.

To learn more about planned gifts, please contact the Duke Children's Office of Development. ●

## Want to Help?

Great things are possible because of you! If you are interested in supporting Duke Children's Hospital & Health Center, please contact our Development Office.

919-667-2563

[dukekids@notes.duke.edu](mailto:dukekids@notes.duke.edu)  
[dukechildrens.org](http://dukechildrens.org)



## Teddy Bear Ball to Honor Radiothon Team, Past Chairs

The 20th Teddy Bear Ball will be a splendor of teddy bears, holiday spirit, and special recognitions. The ball, which will have a storybook theme this year, will honor those who have made a significant impact on the event and on Duke Children's.

The Teddy Bear Ball will honor a collection of past chairs of the event who have come together to chair the anniversary year.

Samuel Katz, MD, and Michael Frank, MD, will be honored for their contributions to the department of pediatrics. Both served as chairs of the department and continue to make a significant impact on children's health care both at Duke Children's and around the world.

Finally, we will honor MIX 101.5 and Capitol Broadcasting for a tremendous 15-year, \$10.7 million fundraising effort through Radiothon. The Radiothon team, including Bill and Lynda from the morning show, will attend along with Ardie Gregory, general manager for MIX 101.5 and Capitol Broadcasting CEO Jim Goodmon.

You can be a part of the glitz and glamour of the Teddy Bear Ball hosted by Joe St. Geme, MD, Bill Fulkerson, MD, and Victor Dzau, MD. Join us at the Durham Marriott Convention Center on Saturday, December 5. Tickets and sponsorships are available by contacting 919-667-2562 or [dukekids@notes.duke.edu](mailto:dukekids@notes.duke.edu).



## Quilting a Fairy Tale

The campers at Camp Kaleidoscope—Duke Children's summer camp for chronically ill patients—lent their talents to create an adorable and cozy quilt for the Duke Children's Teddy Bear Ball. With fabric markers in hand, the campers took on the challenge of sketching and coloring their favorite storybook characters. They also added a handprint to the fabric for the back of the quilt. Their unbridled creativity soon became a lively explosion of color.

The quilt and other artistic pieces from the children will be auctioned at the Teddy Bear Ball on December 5 to raise money for Duke Children's.



## Care to Grow On

Duke's Long-Term Cancer Survivor Clinic helps childhood cancer survivors along the journey to adulthood

Philip Rosoff, MD, knew he had a different outlook on pediatric cancer when he was still a fellow, just starting out.

"Patients who had been cured would come in for annual checkups," he says, "and nobody wanted to see them."

Rosoff did. In fact, he went on to establish the Duke Long-Term Cancer Survivor Clinic in 1996—one of the nation's few multidisciplinary clinics that follow childhood cancer survivors into adulthood.

As he says, "It is wonderful to see these people grow up."

That they are growing up is the good news. Since the early 1960s, pediatric cancer survival rates have gone from 28 percent to more than 75 percent.

The bad news is the unpredictable costs to your health of that survival.

Thoracic radiation treatment for Hodgkin's disease, for example, has left young women with significantly elevated risk for breast cancer. Children surviving cancer may encounter special problems at school. Growth and development are often stunted by chemotherapy drugs and radiation, and many chemotherapy drugs cause stresses to the heart muscle that over the long term can lead to cardiovascular disease.

Recently, Rosoff saw two patients treated for the same rare type of facial tumor. One, treated when she was 15 with heavy radiation, came in with her husband and wanted a pregnancy test. All was going well for her.

An hour later, Rosoff saw a boy who had been irradiated when his face was still growing, at age three or four. "It's now almost a year after his second recurrence of thyroid cancer from the treatment." The boy also has vision and hearing problems related to the radiation.



Still, Rosoff sees hope: "He's studying aerospace technology."

He's also visiting the clinic, a reason for hope in itself. As Rosoff noted in a 2006 *New England Journal of Medicine* article, despite survivors' propensity to develop chronic health problems, long-term follow-up care is still "the exception rather than the rule."

And the many patients who don't visit a clinic like Rosoff's may not see practitioners who would know to be on the lookout for the consequences of survivorship.

"If you're 65 years old [when you're diagnosed]—and we know the average time to many complications is 20 years—you won't have to worry as much," Rosoff says. "But if you're 15 years old, you're going to be a young adult, in the prime of life."

About half the patients seen in the clinic today are adults. Rosoff sees those under age 19, while adult oncologist Carlos DeCastro, MD, serves the older survivors, some of whom are now in their 40s and 50s.

Above all, the clinic has pioneered the treatment of cancer survivors—not just cancer.

## Cancer Center to Offer Adult Patients One-Stop Cancer Care



Duke University Health System has embarked on plans to construct a new building that will transform cancer research and patient care. The new facility will be dedicated solely to the multidisciplinary care of cancer patients and will consolidate adult cancer-related services including imaging, diagnostics, support resources, and clinical research in one convenient location.

The new Cancer Center is expected to open in 2012.

## Stay Connected with Duke Children's

Visit [dukechildrens.org](http://dukechildrens.org) for links to our Facebook page and to sign up to receive our e-newsletter, *On the Ball for Children's Health*.

You can also make a gift to Duke Children's online at [dukechildrens.org](http://dukechildrens.org).



**Duke Children's**

A newsletter for friends of Duke Children's Hospital & Health Center

# Stories

**Finding Hope**  
Promising treatments  
for devastating diseases

