Puke Pediatric Hematology-Oncology Newsletter

Dear Friends,

College campuses throughout North Carolina come alive each autumn with students and the start of a new academic school year. Living and working in an academic



community such as Duke gives us a great sense of the excitement of learning, growing, and improving our world.

This fall, we received a challenge grant of up to \$10,000 in matching donations. We are reaching out to people to ask for their financial support of our mission. We do a lot, but we can do more with your support. At Duke, much of our success in treating children is driven by the foresight of research that is funded by the generosity of people like you.

Duke PHO continues to make important strides in the treatment of childhood cancer. This summer, the work of several of our faculty members has been recognized in top journals describing their groundbreaking research into pediatric leukemias and childhood brain tumors. This research opens the possibility of new treatment options and ultimately leads the way to cures.

Please don't wait for others to step forward. Duke University as a whole was built largely on the generosity of donors, and Duke Pediatric Hematology-Oncology is no different. If you can, please take the time to send us your contribution at the address on page 2 of this newsletter.

As always, I am happy to answer questions about the work we do. Please contact me at dan.wechsler@duke.edu or call me at (919) 684-3401.

With warm regards,

Daniel S. Wechsler, MD, PhD
Chief, Pediatric Hematology-Oncology
DUKE UNIVERSITY MEDICAL CENTER

16 Years & Counting

Making the Best of Every Day

ALYSA HORNE WAS 11 YEARS OLD

when she was diagnosed with acute lymphoblastic leukemia (ALL) at Duke Children's Hospital. Sixteen years later, having successfully finished treatment and gone on to become a nurse at one of Duke University Hospital's clinics, Horne says the first thing she remembers about her time at Duke is that it





ALYSA HORNE, THEN AND NOW.

was Halloween when she first learned her diagnosis.

"That's the first memory I have, of all my nurses dressing up for Halloween. I wouldn't walk when I was first diagnosed; I was really in my shell, I guess, because it was a traumatic experience," she says. "They were trying to get me up to walk, and I remember one of my nurses—her name was Marion and she was dressed up as a maid—and as I went walking, she went behind me doing Hail Marys."

Horne does have other memories of her treatment at Duke: her uncle, a cook, coming in to the hospital to make meals for the staff and patients; finding out she needed a bone marrow transplant and thinking that meant they would take out her bones and put new ones in; getting shots in her legs, a process she disliked so much that her "legs felt like spaghetti" the first time she had to, as a nurse, give a pediatrics patient a shot in the leg.

She also remembers that she'd always wanted to be a nurse, even before she got diagnosed, and that her treatment at Duke only solidified the career path she wanted to pursue when she grew up.

"It definitely made me realize that was what I wanted to do," she says. "I didn't want to do pediatric oncology, I knew that. It brings back too many memories of that. But I realized how important a good nurse is."

Horne works for a surgery clinic today, which means she doesn't administer the same types of treatments that her nurses did when she was a patient at Duke. Still, she says her experience being treated for ALL when she was a kid has better prepared her for the work she does today as a nurse.

"I think you definitely understand compassion," she says. "You have to look at the bright side of things. All of my nurses were wonderful; they were always in there joking with us. They didn't make it sound like it was a drab place to be. There was always something fun going on. You have to find the fun aspects of whatever is going on."

She encourages patients to similarly focus on that optimism as they go through their own treatments at Duke.

"Try to make the best out of every day," Horne says. "Just try to look at the bright side of what is going on and try to spend your time with your family ... and make the best of every day and second you have with each other." •

Duke Fellows

Attracting the Best and Brightest

Holding a child's hand. Testing life-saving drugs. Investigating chromosomes to find the bad guy. Doing whatever it takes to obliterate devastating diseases.

Those are on the short list of what training fellows are doing in Duke's three-year Pediatric Hematology-Oncology Fellowship Training Program. The learning curve is steep and the work important, so Duke looks for the best and brightest applicants.

"I expect the people who will succeed in this field are those who have a thirst for knowledge," says program director Dr. Susan Kreissman, also a professor in the department of pediatrics' Division of Hematology-Oncology at Duke University School of Medicine. "They want to learn, and they have the capacity to know where to go to get information and then can apply that information to patient care."

Although training fellows are seen as novices in the program, they've already graduated medical school and completed a three-year pediatric residency. But, instead of heading to private practice, they've decided to specialize, Kreissman says, and commit to being in training for at least three more years.

Training fellows are matched with families undergoing treatment and become the child's primary care physician. "They're the ones that spend time talking to the family, holding hands, and being the go-between, to support them through what is an incredibly difficult period," Kreissman says.

The fellows work closely with trained oncology specialists on the care of each patient. "The fellow may not know all the answers to the very specific questions about how to change a dose of chemotherapy, but that's what they're here to learn," Kreissman says.

The pediatric hematology-oncology physicians serve as mentors for the fellows, teaching and guiding them, as well as delegating responsibilities. Kreissman went through a similar training program nearly 30 years ago. "If you're in charge of something, you're much more likely to learn it than if you're just doing what somebody else tells you to do," she says.

The program's first year is a clinical year, in which fellows work directly with the patients. The last two years are largely dedicated to research.

"We've had our fellows working to look at new ways to use cord blood stem cells that may help treat not just bone marrow diseases, but other diseases," Kreissman says. "Our fellows are doing research in the laboratory trying to either understand how AML (acute myeloid leukemia) develops or how to switch off a gene that causes rhabdomyosarcoma." Another fellow had



SUSAN G. KREISSMAN, MD

the opportunity to identify a new drug for hard-to-treat brain tumors, she says.

As program director, part of Kreissman's job is to keep the coffers filled with stellar candidates so advances in pediatric hematology-oncology at Duke continue.

"I think one of the reasons people go into pediatric hematologyoncology is because of the intensity of the relationships that they form with

the parents and the patients," she says. "When a child is critically ill and in a life-threatening situation, those bonds are important. As a young physician, it's a really powerful experience to have the ability to care for someone at that level."

It can be hard, too. That's one of the reasons the three-year period is split between patient care and research. "We're trying to improve our training so that our fellows are not only well trained, but that they're happy and well-balanced, to attract new people who are medical students or residents who are working with our fellows," Kreissman says.

That includes having research options that fellows can be excited about. Kreissman says that when she was in training, fellows were expected to do research in a basic science laboratory, but that now there is an opportunity for many different kinds of research.

Opportunities include researching initiatives on psychological/social supportive care, or how physicians deliver care and explain test results. Global health research is another emerging research field, as is research to improve the standard of care across pediatric institutions.

"When you have a good mentor and a project that the fellow is interested in, great things happen," Kreissman says. "It's important we continue to have a source of people who are motivated and dedicated to something that's extremely difficult, but also extremely rewarding."

Christa Gala is a freelance writer in North Carolina and writes about business for regional and national publications.

How to Reach Us:

PEDIATRIC HEMATOLOGY-ONCOLOGY OFFICE: (919) 684-3401 EMERGENCY/WEEKEND PHONE: (919) 684-8111 EMERGENCY/WEEKEND BEEPER: (919) 970-7661 CHILD LIFE: (919) 668-4204

Duke Pediatric Hematology-Oncology welcomes your input, support, and comments. Please contact Dan Wechsler, MD, PhD, at dan.wechsler@duke.edu or write us at Duke PHO, DUMC 102382, Durham, NC 27710.

Meet Your Caregiver: Julie Wickel



JULIE WICKEL AND HUSBAND BEN WICKEL

Some people find their calling late in life, maybe after putting in a few years at college or in a different career. But Julie Wickel knew she wanted to work in the medical field from a young age, having worked in clinics in high school and during her undergrad years at Wake Forest, including stints

doing clinical work in India and Africa.

Today, Wickel is a physician's assistant (PA) at Duke's pediatrics hematology-oncology unit, where she says she enjoys the all-encompassing work that her job entails. "I like the fact that you get to work with doctors, as well as nurses," she says. "That's really what drew me to PA versus another specialty in the medical field: the team approach to patient care."

That team approach includes interacting with patients and their families and consulting with attending doctors, nurses, and special teams like child life specialists to better treat each patient. Wickel collects patient histories, conducts physicals, reviews labs, talks through plans with attending doctors, and communicates treatments to patients and their families.

She says the interaction with patients is her favorite part about being a PA at Duke.

"I love the fact that I get to know them and I get to know their families and I get to hear about their lives outside of Duke and outside of treatment," she says. "Every time a child finishes their chemotherapy treatment is so rewarding. One of the first patients that I had recently completed their therapy, and it was so neat getting to see her finish after having watched her walk through the whole course of her treatment."

Wickel, who enjoys reading, being outdoors, and hiking and traveling with her husband, Ben, in her spare time, says that even though she's been working in medicine for several years, she's still learning from her patients every day.

"I've been able to see the resilience and the courage that kids have facing these kind of huge illnesses and diseases that impact their lives," she says. "It's taught me a lot about courage and about strength, getting to watch them face their diagnoses with a lot of courage, strength, and hope." •

Philip Rosoff: Hope for the Long Term

While most attending doctors on Duke's pediatrics hematology-oncology unit specialize in certain diseases and commit much of their time to researching treatments in their laboratories, Philip Rosoff spends most of his time in the library.

Of course, Rosoff's office is in the library, and he has good reason to be there: Rosoff is the director of clinical ethics for Duke University Hospital, and specifically studies the allocation and distribution of scarce resources, or "rationing."

He describes his studies as figuring out "how one allocates these types of resources or stuff or even people in as fair a way and as equitable a way as possible," like deciding how to ration out ventilators in an influenza pandemic or divvying up scarce chemotherapy drugs. He's published papers on the topic and is also writing a book.

But Rosoff also spends one full day a week in the outpatient clinic treating oncology patients, and says he makes himself available to his patients whenever needed. In addition, he's in charge of the long-term follow-up program at Duke. "I've had an interest in that for years and years and years, mostly because, when I was in training, lots of people didn't want to see those patients, or lost interest in seeing those patients after they finished their treatment," he says. "I didn't think that was the right thing to do, so I kept on following them and they're very interesting. I think they need that kind of help."

Following up with patients every year after they've been

treated at Duke is a "won-derful" process, Rosoff says, because he's developed long-term friendships with many of them. "These are very often kids and young adults who I've known for 17 or 18 years and watched them grow up," he says. "It's great."

Rosoff says the ability of pediatric oncologists across the globe to collaborate with each other and work toward advancing cures for cancers



DR. PHILIP ROSOFF

has made it so that more patients have hope for a long-term success story.

"I can say that when I started my fellowship training in 1980, the outcomes for the cure rates for many different types of pediatric cancer were not even close to what they are now," he says. "But now we can say that kids with acute lymphoblastic leukemia have an average of 80 percent of cure, whereas when I started out it might have been 50 percent. That's a big change. It didn't happen overnight; it's been incremental. But that's pretty amazing. It's pretty amazing how many patients go on to be long-term survivors."

More Than Physical Care

Duke's Pediatric Quality of Life program offers additional support for PHO patients.

Duke's Pediatric Hematology-Oncology unit has world-class doctors, nurses, and other staff members delivering top-shelf care to patients across the hospital. But physical care isn't the only treatment Duke provides for children at the hospital.

Duke's Pediatric Quality of Life program is increasingly leveraged to give children with complex, chronic, or potentially life-limiting diseases the resources they need to have a better quality of life. Whether it's through treating pain or non-pain

symptoms; supporting a patient, family, or staff in complex decision-making; hosting educational activities to give new skills to caregivers; or helping a child transition home at the end of life, the program aids patients and families throughout the treatment process.

"Families are often surprised at the range of possibilities available to respond when we ask the question, 'How can we improve your quality of life today?'" says Raymond Barfield, a physician with

Duke's PHO unit who heads the Quality of Life Program at the hospital.

There are three different facets to the Quality of Life program: clinical service, education, and research. Barfield says Duke's Quality of Life program has fostered partnerships with medical teams, social workers, child-life specialists, chaplains, nurses, and patient resource managers to incorporate evidence-based practices that augment the primary team's care of a patient. "We view our role as a partnership, and never as a replacement for anyone on the team," he says.

He adds that there is a misperception that the Quality of Life Program is only for patients at the end of life.

"While this is a very important part of our work, we also work with children who have chronic or complex diseases that may not be life-limiting, but that significantly impact their quality of life," he says. "Even in situations where a disease may be life-limiting, we like to be involved early if at all possible. Developing a relationship with a patient and family helps enormously when we do have to assist a child at the end of life."

Barfield originally got involved with Quality of Life programs when he worked at St. Jude Children's Research Hospital in Memphis, where he helped build its offering.

"At one point in my career, when I was doing bone marrow transplants, I realized that the tools I had to manage the biological aspects of a child's disease were not enough," Barfield says. "I had received very little training in pain management, communication, decision making, and care at the end of

life. So I began taking course after course in these areas, and attached myself to mentors who taught me more about this aspect of caring for children and their families."

Duke's Quality of Life program evolved out of physician Margarita Bidegain's "palliative care order set," which she had created to support patients in the NICU. In 2008, a team of physicians, nurses, and other staff members—including more than 70 volunteers from around the hospital—developed a

strategic plan for a Quality of Life program. After the program rolled out to the PICU, bone marrow transplant, and other units, Cheryl Thaxton joined as Pediatric Quality of Life nurse practitioner and program coordinator and built the program even further. Today, Quality of Life is consulted by every division in the Children's Hospital.

The Quality of Life program at Duke is continuing to improve through developing evidence-based practices, educational events for the

staff, advancing knowledge through research, and partnerships with philanthropists who fund parts of the program, Barfield says. For the fall of 2014, in partnership with UNC, the program is planning the first annual pediatric pain and palliative care course for regional providers.

Patients and families can get involved with the program via a Pediatric Quality of Life Consult order in the EMS. There is also a QOL pager for when questions arise: 970-HELP.



(L TO R) MARGARITA BIDEGAIN, RAYMOND BARFIELD, AND CHERYL THAXTON HELP SPEARHEAD DUKE'S QUALITY OF LIFE PROGRAM.

Duke Pediatric Hematology-Oncology would like to gratefully acknowledge some of the grants received by our faculty and trainees in recent months. Some grants cover multi-year periods and all are enormously important to our research efforts.

V Foundation Research Award

Dan Wechsler, MD, PhD

St. Baldrick's Infrastructure Award Mike Armstrong, MD, PhD **Hyundai Scholar Award** Ashley Hinson, MD

Duke KidsCare Grant Wait Aumann, MD

Duke Pediatric Hematology-Oncology—recognized by US News and World Report as the 12th highest ranked Pediatric Cancer Program in the USA

Duke PHO needs assistance big and small. To help, please contact Kathy Greenwell, administrative assistant, Duke PHO, at kathleen.greenwell@duke.edu.