

# Kids Connection

a monthly newsletter from MUSC Children's Hospital



November 2006

## Letter from the Chair

Dear faculty, Children's Hospital staff and friends,

Imperative to any community-based, nonprofit organization is a strong philanthropic funding stream. Even more importantly is to ensure that the funds raised are managed through stewardship and focus on areas where the funds prove successful for an organization and the individuals served.

At MUSC Children's Hospital, this very important task is given to the Children's Hospital Fund (CHF), originally established by Dr. Charles P. Darby as the Children's Fund. CHF provides the support and management to our generous donors and the funds they raise. Prior to 2001 most of the money raised was used to recruit and support new hires needed in the children's hospital, support research programs, and departments such as social work and child life. These type of support continues on today, however over the years, new and exciting opportunities presented themselves and the scope of CHF's efforts changed.

In 2001, CHF initiated a large capital campaign to secure the necessary donations from the private and public sector to cover the cost of completing our Children's Research Institute (CRI), the largest pediatric research facility in the Carolinas.

This endeavor is one of very few where a single department raised enough money from philanthropic sources to build a facility for anyone who is willing to conduct pediatric research within any given discipline. This might not sound odd because previous philanthropy helped to fund other institutes but the difference is typically that space is dedicated to a single resource or discipline or a single institute, such as cancer. It was never developed from a multidisciplinary approach.

The idea of a single department partnering with the University to provide resources for investigators from other departments was a new paradigm; one that continues to prove itself innovative, collaborative, accountable and cutting-edge—and all for the greatest good of finding ways to provide better health care to our children.

### CHF takes on their next challenge and look toward the future

CHF is now taking on new challenges. The fund, with help from the College of Medicine's dean's office, CHF is helping to provide partial funding for the new neonatal intensive care unit (NICU), slated to be under construction in 2007. As part of the MUSC Children's Hospital



**L. Lyndon Key, MD**  
Professor and Chairman  
Department of Pediatrics

team, the CHF continues to help the department of pediatrics and the CRI recruit and support new talented scientists and clinicians.

The fund which Dr. Darby envisioned serves many projects and supports projects that benefit the department of pediatrics, but also the Children's Hospital at large. Over the next few years, our children's hospital leadership team will be developing a strategy to secure capital that will help us to expand our pediatric facilities.

This year is the first in six years where we have been able to have capital that was not already pledged to the CRI. First and foremost, we will begin recruiting essential faculty in the areas of nephrology, oncology, and gastroenterology. Additionally, projects that will provide new capital for major building projects will begin for the Children's Hospital.

None of these projects would be possible without the steadfast commitment and loyalty from the CHF staff. We have a wonderful staff at the CHF and should always make it a point to support their events, everything from holiday cards to golf tournaments to the Children's Miracle Network. This group is the one that makes it all happen.

- Barbara Rivers (Director of the Children's Hospital Fund)
- Wanda Bazemore (Director of Major Special Events)
- Lauren Kinard (Major Gift Coordinator)
- Courtney Ellicott (Associate Director of Special Events)
- Ann Taylor Guill (Associate Director of Special Events)

Along with the help and advice from Dr. Darby and Maggie Michael, this dedicated core of fundraisers has been the secret to our success.

It is also important to note that the department of pediatrics, the pediatric surgical specialties, and the staff that provide the care within the Children's Hospital, and our support departments are ONE team. For this reason, John Sanders and Dr. Phil Saul are both members on the CHF board, along with an active development committee, Terry Stanley, Jim Fisher, Dean Reves and President Greenberg.

As a team focused on the same mission—to discover better ways to care for the whole child and provide compassionate, child and family-centered services in an environment that fosters innovation, collaboration and excellence—we will certainly achieve our strategic goals for the children of South Carolina.

With such a great team how could we not.

Sincerely,

L. Lyndon Key, MD  
Chair, Department of Pediatrics

## Grants help care-givers better serve the Hispanic community

MUSC's College of Nursing is on the forefront when it comes to knocking down challenges health care professionals face in caring for Charleston's growing Hispanic population.

Deborah Williamson, DHA, associate dean of practice, and Charlene Pope, PhD, assistant professor, have received a two-year grant from the Duke Endowment to fund the Hispanic Health Initiative. Dr. Williamson had also been awarded an additional, five-year Health Resources and Services Administration grant (with Sheila Smith, PhD, RN, as co-investigator). The two grants total more than \$2 million.

The Hispanic Health Initiative has four goals: it aims to improve access to quality healthcare for Hispanic women and their families; develop cultural competence in the nursing workforce; increase recruitment and retention of Hispanic nursing students and faculty; and promote health policy that supports the Hispanic community.

Targeting the Johns Island community, Dr. Williamson, principal investigator for the grants, and her colleagues have teamed with Sea Island Medical Center to enhance services offered at the medical facility.

"This university collaboration with the community health center expands resources to address the health needs of the Hispanic community," she explains. The grant funds a bilingual physician, nurse midwife and pediatric nurse practitioner to provide care to Hispanic women and their children.

Health education is a big component of improving health concerns. The two grants fund health education programs on everything from nutrition to family planning to women's health and infant care.

"Improving care also means helping the Hispanic community navigate and access the US health care system," says Dr. Williamson, explaining that her team networks with various agencies to provide all these different health education programs. "It's very basic information, such as when to use the phone code 911, when to use the emergency room. But it's important."

Also made possible by the grants is a "Mom's Morning Out" program, a collaborative effort that includes the Charleston County School District, Trident Literacy Association, and Midland Park Community Ministries.

"This program combines educational and health services to improve the well-being of immigrant women and children," says Dr. Williamson.

The program provides school readiness training to children of Latino descent, ages two to three, who reside in the Midland Park Elementary school district; at the same time, their mothers receive ESL and health awareness education classes.

English classes are a second goal of the program, yet they're important, says Dr. Williamson. "Immigrant mothers are often socially isolated, and this helps improve and possibly prevent that."

A pilot program, "Mom's Morning Out" could be a model for other schools and districts, hopes Dr. Williamson.

"I would like to see more partnerships like this one in the community for children," adds Dianne Inman, Program Coordinator and director of the Pediatric Nurse Practitioner Program at MUSC College of Nursing.

Also funded by the grants is radio talk show guest Dr. Vanessa Diaz, of the Department of Family Medicine at MUSC, who covers a variety of health topics, including health concerns for children, on local Spanish radio station EL SOL.

The initiative also funds programs to improve cultural competency in the nursing work force. "That competency extends beyond caring for Hispanics to apply to caring for any patient in the hospital system that's not of your culture," Dr. Williamson points out. "It's particularly important for nurses, who are there with a patient all day. Cultural norms affect healthcare behaviors and therefore outcomes; part of being a nurse is being respectful of differences."

Increasing recruitment of Hispanic or bilingual students and faculty is another component of the Hispanic Health Initiative. "Less than five percent of physicians in this country are Hispanic, and just two percent of nurses are Hispanic," notes Dr. Williamson. "While 14 percent of our nationwide population is Hispanic."

Initiative personnel are working with community colleges, high schools, and the SC Area Health Education Consortium (a national program focused on building a pipeline for healthcare providers). Dr. Williamson hopes the grant will help increase the number of Hispanic students interested in health-related careers, particularly nursing, and the number of bilingual and Hispanic nursing faculty.

Health policies that support Hispanics are also a goal. Developing interpreter services is key. "It's very difficult to get equal care if you don't speak the language," says Williamson.

The number of interpreters at MUSC has increased from one to 15 over the last five years. Accessible interpreter services mean family members are not placed in inappropriate situations, says Dr. Williamson.

"Often when a Hispanic family comes in, it's a child who speaks the best English," she notes. "If a child is called upon to translate, it puts the child in an awkward position of relaying sensitive information. It changes family dynamics by altering the parent/child relationship. Also, children may make mistakes that can result in errors in medication or treatment." Federal guidelines, the CLAS standards, require competent and trained interpreters in healthcare settings.

"These grants make it possible for us to expand limited resources through collaborations with educational institutions, hospitals and community-based organizations," says Dr. Williamson. "Immigrant populations bring new energy and talent to our communities. Children born to immigrants are US citizens. We can choose to create a culture of poverty for these young citizens, or we can provide basic health and education services that are necessary for their success as adults in our culture."

## Letter from the Medical Director



**J. Philip Saul, MD**  
Medical Director  
Director, Pediatric Cardiology

This time of the year, early fall, is often a little quieter in the Children's Hospital. Elective summer procedures are done, and the onslaught of winter's infectious disease season hasn't quite begun. The weather is still warm, the grass green and all the trees still have their leaves. So it is hard to think about our winter season being just around the corner. Yet, the season is now approaching fast.

Flu shots are being offered, the emergency room is getting busier and our beds more full, reminding us of the need for expansion. Planning is currently ongoing for adding another patient bed unit.

Our adult colleagues in the heart and vascular center will be moving to their new facility in late spring 2007, vacating up to 100 beds in the main hospital. This gives us the opportunity to both expand our bed capacity and provide some flexibility for reconstruction and refurbishing of our current inpatient units.

Further, we are moving along with plans for a brand new Neonatal ICU which will consolidate all our Level 2 and 3 beds in a single location on the 6th floor.

All of these activities are exciting, but also stressful due to the added work of detailed planning which must be accomplished. Kudos to all our faculty and staff for their active participation, which I know will lead to a brighter future for the Children's Hospital and its patients.

## Update from the Administrator



**John Sanders, MHA**  
Administrator  
MUSC Children's Hospital

### *New Leadership in the Children's Hospital*

After conducting a national search for a director of perinatal services, I am very happy to announce that Vicki von Ehrenfried has joined our leadership team.

Vicki comes to Charleston after serving as the director of Women's Services at Northeast Baptist Hospital in San Antonio, Texas. Vicki has a unique background with experience in obstetrics as well as pediatrics in level III nurseries. Her responsibilities will be to direct the operations of all obstetrical services and nurseries.

Also joining our leadership team is Beth Thelan, manager of 7B, our hematology and oncology inpatient unit. Most recently, Beth was a clinical instructor in Aiken at the University of South Carolina. She has prior management and clinical experience with pediatric hematology and oncology services. We are very excited to have Beth with us, and we're certain she'll take us to another level in providing care to a very special group of children.

We want the very best staff to work at MUSC Children's Hospital because our kids deserve the best. Vicki and Beth are two examples of the energetic team we have in the Children's Hospital. The passion shown by our management team, staff and physicians is electric and I only see bright things for our organization going forward.

## Children's Research Institute News Brief



**Bernard L. Maria, MD, MBA**  
Executive Director  
Darby Children's  
Research Inst.



**Inderjit Singh, PhD**  
Scientific Director  
Darby Children's  
Research Inst.

### *DCRI Adds New Researcher with Expertise in Polycystic Kidney Disease*

Excited about the Charles P. Darby Children's Research Institute's commitment to basic research, scientist Dr. Darwin Bell recently relocated from the University of Alabama at Birmingham to set up his lab in the DCRI.

"I had visited the DCRI at Dr. David Ploth's urging, and felt really excited about what's going on, about the emphasis on growth and new research," says Dr. Bell, a pediatric nephrologist. "It really appealed to me to become part of what I see as a medical school on the rise."

Dr. Bell's lab in the DCRI focuses on polycystic kidney disease (PKD), the most common genetic, life-threatening disease. It affects more than 600,000 Americans.

"It's a very prevalent disease which results in kidney failure," explains Dr. Bell.

Polycystic means multiple cysts; with PKD, there are multiple cysts on each kidney. Growing and multiplying over time, these cysts cause the kidney to enlarge. Ultimately the diseased kidney shuts down, making dialysis and transplantation the only forms of treatment.

Dr. Bell's lab is studying the individual cells of these diseased kidneys. "PKD is by-and-large a disease of the cilia, the fingerlike projections on the cell which act like antennas. We are trying to understand the function of cilia in cells, to grasp how these 'antennas' work," says Dr. Bell.

"We're hoping to identify how the loss of cilia structure affects function, how it causes cysts to be formed in the kidney," he continues.

The disease has two forms – autosomal dominant PKD is the most common, affecting about one in 500 adults. Recessive PKD is less common, but affects newborns, infants and children, having a devastating effect on kidneys and other organs.

Dr. Bell's lab aims to identify and show therapeutic agents and modalities that would either prevent cysts from forming in the kidney, or reduce their size and number.

Impressed with the DCRI's resources, including new and well-planned labs and facilities, Dr. Bell says he's challenged to pursue avenues of collaboration.

"We're using sophisticated confocal and imaging techniques that we think have a wide application for other kinds of research, too, in terms of diseases such as hypertension," says Dr. Bell. "I'm excited about the opportunity to collaborate with other scientists on other diseases that affect children."

In the future, he anticipates working with Dr. Bernie Maria to tackle Joubert's Syndrome, another cystic disease with a neural and kidney component. "Hopefully we can find out something that would be of benefit in the next few years."

## Evidence-Based Tip



**Laura Cousineau, MLS**  
MUSC Library  
Dept. of Pediatrics  
EBM Faculty

### *Understanding the Numbers: How to Interpret Statistics in a Study*

Authors of studies can measure their results in several ways. To know whether or not the results are important enough to either change or reinforce our current standard of care, we need to be able to understand those numbers. In a therapy question, those numbers should be able to tell us how large the treatment effect was, and how precise the effect was.

#### **How large was the treatment effect?**

There are three important statistics that help us to understand how effective our intervention was in comparison to either placebo or the alternate treatment, relative to the outcome we selected.

- Relative Risk is a ratio, not a proportion. It tells us whether the outcome occurs more or less frequently in the group that used our treatment compared to the comparison group. It is derived by comparing the percentage of people experiencing the outcome in the intervention group to the percentage of people experiencing the outcome in comparison group.

- Risk Reduction can be relative or absolute. Relative Risk Reduction is a larger number than Absolute Risk Reduction. Both are expressed as a proportion, and the greater the percentage, the larger the effect of the treatment. For questions of harm, one can use Relative Risk Increase and/or the Absolute Risk Increase.

- Number Needed to Treat (NNT) is a number derived from the Absolute Risk Reduction, and tells how many patients would needed to be treated before one would receive the benefit of the treatment. A NNT of five would mean that five patients would have to be treated in order for one patient to avoid a bad outcome. Likewise, Number Needed to Harm (NNH), is the number of patients who would need to be treated before one patient experienced the harmful side effect.

#### **How precise was the treatment effect?**

Conducting a study is like having a freeze-frame in the total moving picture of how well our intervention works. Did we get enough to see the big picture? The Confidence Interval tells us the range of what we would expect our results to be if we did this test again and again. If the lower end of the range is big enough to show our treatment made a positive difference, then we have enough people in our study to get that big picture. How likely is it that we would get the same results if we did this study again? Most studies are reported with a 95 percent confidence interval. This means that 95 percent of the time, when we repeated this experiment, the result would fall within our range.

Often, these numbers are given and explained in the report of study, and it is not necessary to do the calculations yourself. However, being aware of what these numbers mean can help you in your critical appraisal of treatment claims.

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