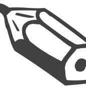
july 2008

a monthly newsletter from MUSC Children's Hospital



LETTER FROM THE CHAIR

Dear faculty, Children's Hospital staff and other friends,

This year has generated some tremendous success in education, research, and new clinical stars. We have worked hard to provide training that will ensure that South Carolina will have a new generation of pediatricians to take care of our children. The Children's Hospital Fund (CHF) has helped us to create our second endowed chair. The CHF has also had gifts and pledges of $3.5 million that we will receive in the coming years to create chairs for research and teaching. We have been able to work with the state to continue funding for the projects that will provide care for children and grants to explore how to better prevent and treat the children and adults in the state. Dr. Singh and Dr. Maria have catalogued the work that is being done within the Darby Children's Research Institute (DCRI). The total funding supported by the DCRI is nearly $29 million. We have started an in-house K12 grant ($200,000 per year from the department to support research training) that will allow us to build training programs to develop future researchers from stars. We have continued to have a very strong General Academic Fellowship Program that has been funded through departmental dollars from medicine and pediatrics, and grants that Paul Darden has been awarded.

Bill Basco, MD, is taking the reins of the Division of General Pediatrics that has been led ably by Routt Reigart, MD, over the past several decades. Dr. Reigart is renowned for his work in environmental toxins, especially lead poisoning. His legacy, however, is measured more in the present and the future, than his own research and clinical success. He has been a tireless educator and a catalyst for academic progress. As Dr. Basco assumes the helm of the Division of General Academic Pediatrics, Dr. Routt will be the senior statesman continuing to teach, study the environment and encouraging those in his division to keep moving forward in all of facets of academic medicine. We welcome Dr. Basco, and we congratulate Dr. Routt for catalyzing academic change in the department.

We look at our current productivity and see opportunities to improve in many ways. A number of the leaders will carry on in the tradition that Dr. Reigart has molded.

Sincerely,

L. Lyndon Key, MD
Chair, Department of Pediatrics

FEATURE STORY
Pediatric Advocacy: *Building Bridges* **PG. 2**

Kids connection

FEATURE STORY

Pediatric Advocacy: *Building Bridges*

Politics and children's healthcare—at first glance, the two seem unrelated. Yet the funding of children's healthcare is largely driven by the legislative process—making it very political. Funding for the state's Medicaid program, the children's health insurance program, and many other children's services is appropriated each year by the legislature. Children have no "legislative voice," and legislators, although well meaning, struggle with multiple priorities.

Making children's health issues a legislative priority is just one of the multiple functions performed by the MUSC Center for Child Advocacy.

"It's challenging—the average legislator doesn't have a lot of knowledge about these (children's healthcare) programs," says Charles P. Darby Jr., MD. *"There are so many competing needs. It is a constant battle for us to move these items up the priority list. There is a long list of groups and organizations fighting for state funds. We just have to convince them that children deserve a good shake."*

And convince them he has. A longtime advocate for children, Dr. Darby's "career" in advocacy began, some would say, when he successfully obtained state funds to build MUSC Children's Hospital. His efforts continue today in his role as the executive director of the Center for Child Advocacy, formed in 2001. The Center for Child Advocacy (CCA) works to provide a variety of government relations, advocacy, Medicaid, service development, and outreach services in support of the MUSC Children's Hospital.

CCA also manages the South Carolina Children's Hospital Collaborative, a non-profit organization made up of the four children's hospitals in South Carolina.

"Protecting some of these programs for children is especially difficult right now, when people are concerned with just staying afloat," notes Dr. Darby. *"When the economy turns down, there's less consumer spending, less sales tax, less state income—less money for these programs."*

Looking out for the little ones

In recent years, Dr. Darby and the CCA have successfully advocated for the following:

- Enhanced Medicaid reimbursement for pediatric specialists. Having adequate reimbursement is critical to providing services. And, notes Dr. Darby, *"this gives children access to the best specialists."*
- The development and implementation of a statewide forensic medical response system for children who are suspected victims of child abuse. This system, known as the South Carolina Children's Advocacy Medical Response System (SCCAMRS) has dramatically improved the quality and quantity of pediatric

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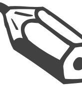
Kids connection



FEATURE STORY

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forensic medical services in the state. *"It's not an easy or inexpensive specialty—it requires photographs, X-rays, lengthy interviews, and often court and mediation,"* notes Dr. Darby.

- Expansion of the state children's health insurance program (SCHIP). CCA worked in partnership with many organizations and legislators to expand health insurance coverage to children in low-income families. Vetoed by the governor and subsequently overridden by the legislature, the expansion is expected to provide health insurance to 80,000 children. *"We were pleased that the legislature had the wisdom and courage to override the governor's veto on SCHIP,"* comments Dr. Darby.

The wheels on the bus go round and round: *work continues*

The federal government matches every state dollar spent on Medicaid with three dollars. Likewise, the federal government matches every state dollar spent on SCHIP with four dollars. So it doesn't make economic sense to reduce state funding, explains Dr. Darby, especially when you consider that the healthcare will still be provided. *"We try to get them to spare Medicaid. We have to keep our hospitals and our emergency rooms open, and we won't turn a child away. The state ends up paying for these services, and it costs them more without the federal matching funds."*

Initiatives for the coming year include:

- State funding for the three developmental evaluation centers (DECs), which face closure due to impending changes in Medicaid reimbursement. Children are referred to a DEC for a multidisciplinary evaluation of a suspected developmental or behavioral disorder. An accurate diagnosis is essential in identifying appropriate early intervention services.
- An increase in the cigarette tax. Unlike adults, children are more price-sensitive to the cost of cigarettes. The number of children smoking generally decreases as the price of cigarettes increases. *"In addition, we'd like to expand the SCHIP program and cover more uninsured children,"* says Dr. Darby.
- Preserve funding for the SCHIP program and move its legislative language into permanent law.
- Work with Medicaid to preserve and restructure the state's three medically fragile children's programs, facing possible closure pursuant to changes in federal policy. These programs serve medically fragile children, providing all needed services in one setting. *"It's very cost effective,"* explains Dr. Darby.
- State funding for the South Carolina Children's Advocacy Medical Response System.

Advocacy is the bridge that connects the disparate worlds of children's healthcare and politics. The MUSC Center for Child Advocacy, in partnership with the South Carolina Children's Hospital Collaborative will always have more "bridges."

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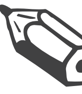

CHILDREN'S RESEARCH INSTITUTE NEWS BRIEF

Just for children: *advocating for research specific to kids*

Once upon a time, what was good and true for adults was thought to be good and true for children, just on a smaller scale—halved, usually. A full dose for adults, a half-dose for kids, and so on.

But that was old-school thinking. These days, we know better.

Children can't be treated as if they're small adults, says John Raymond, MD, vice president for academic affairs and provost of MUSC.

"There are differences in their metabolisms, and medications and treatments can interfere and interact differently with the hormonal aspects of their growth development," says Dr. Raymond.

Research specifically for children helps determine these nuances, he adds.

Yet historically, we've shied away from children's research, concerned about the risks.

"Unintentionally, this has hurt children. Adult studies don't necessarily help determine what works for children. We can generally assume they'll be effective for kids, but we don't really know."

"The effectiveness of therapies for children has been under-investigated," he notes.

Research—and advocates for children's research—are hurrying to make up for lost time.

In response, the National Institutes of Health has been making a concerted effort to include children in studies where they've traditionally been excluded.

It's an effort long overdue for those lobbying for children's research.

"Children are our future," says Dr. Raymond. *"They have the longest life span ahead of them, so it makes sense to preserve the quality and length of their lives by maximizing the effectiveness of their therapies."*

Yet he cautions that children have special ethical needs: *"They may not have the cognitive capacity or life experience to make informed decisions about treatment options."*

"We have to be absolutely clear about the risks and benefits of these therapies. These are the people who most desperately need our help."

As one of MUSC's chief academic leaders, Dr. Raymond places importance on difficult-to-treat diseases. He references the new treatment for childhood brain tumors that Dr. Bernie Maria is investigating.

"Because the biology of the developing brain is different from the adult brain, it's vital to have this research, and to be able to get closer to curing these diseases without damaging the child."

It takes compassionate, dedicated physicians like Dr. Maria, notes Dr. Raymond.

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CHILDREN'S RESEARCH INSTITUTE NEWS BRIEF

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"Treating these children and driving this research is so important. These researchers need to be frontline pediatric physicians, in my opinion—they are the healthcare providers who interact most closely with children and their families, so this makes them better advocates and better able to balance the risks with the possible benefits of these new treatments."

Nowhere is this balance of care and advocacy for children more at work than in the DCRI. "It's one of the few places in the country where such a broad array of outstanding basic scientists are working side-by-side with pediatric clinicians to target serious childhood diseases, including diabetes, heart disease, rheumatological disorders — all of which are different in children who are still growing than they are in adults."

Children are our future, he notes. "And that's a very good reason to advocate for research specifically for them."

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

Bernard L. Maria, MD, MBA
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A special thanks to the following individuals for their efforts in putting together Kids Connection each month.

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