

Kids Connection

a monthly newsletter from MUSC Children's Hospital



January 2007

Letter from the Chair

Dear faculty, Children's Hospital staff and friends,

2006 was a very good year. We made changes that solidified our position as the premier Children's Hospital in the region. It is a good time to look at all the modern miracles that we have from computerized imaging, simulation labs, and electronic records. Against this mountain of mechanization, however, the healing touch, the open mind, and the attention to what the patient is feeling remain the tools that get things done. This means that we need to continually hone our minds to see, hear, process and direct the wealth of technological miracles.



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

I would like to see medical education continuing to allow us to work with the patient as the main learning venue. My resolution this year is to try to help each student, resident, and practitioner to appreciate the need for judgment and processing the cues that are difficult to quantify mixed in with some good old common sense.

I note that there are many individuals who know many facts, but do not have a framework of systematic knowledge to guide their decision making. Evidence-based medicine is a powerful tool. It allows us to develop and follow protocols that will help

to eliminate errors. However, each protocol must be tailored to take into account the social, physical and mental makeup of the patient.

While looking forward to the future of this New Year, I want to remind every student of medicine from 20-90 years old that if physicians miss the lessons of the past taught by professors, records, articles and texts, they will not be able to use the miraculous power of the human mind and the depth of feeling within the human heart to reach a decision. Remember, that it is the ability to make people feel better, which is the true work of the physician. Let us never strive to diagnose and treat without understanding the whole patient. If we do, the human element will be lost.

Sincerely,

L. Lyndon Key, MD
Chair, Department of Pediatrics

January 2007

The Autism Queen

Jane Charles is called the autism queen, though she is of a soldier fighting on the frontlines than a ruler dictating from on high.

The developmental pediatrician is widely respected as an expert on the screening, diagnosis and management of autism. She is, among other things, director of MUSC's Carolina Autism Resource Evaluation, or CARE Center, one of three statewide that she helped to establish several years ago.

"I worked together with the Autism division, the state agency that provides services to persons with autism, to develop a series of diagnostic clinics to serve three areas of the state—Greenville, Columbia, and Charleston," she explains.

At MUSC's CARE clinic, Dr. Charles and her team see children suspected to have an autism spectrum disorder. "We screen kids who are not developing as they ought to be, who are not walking, talking, learning or behaving in school as they should," she says.

The CARE clinic offers screening, diagnosis, assessment and management by a team composed of a developmental pediatrician, school psychologist and educational specialist.

"This team of physicians and specialists provides evaluations as well as management and education support," says Dr. Charles. The team helps with developing treatment plans and effective learning teaching skills, works closely together to assess the child's needs and skills, and recommends the best possible plan for service and training.

By going on home and school visits, Dr. Charles takes her work with these children a step further.

In particular, she attends Individualized Education Plan meetings for children who are having a lot of problems. "If I'm managing medication for them, that can be a big part of the entire picture. I really like to meet the teachers, see the classrooms, see the kids in school. It's very helpful for me to be able to visualize the child in the school setting."

"You really need a whole team to be involved with these kids to make sure they're getting the right help; that we're all on the same page," explains Dr. Charles, who lectures widely

at schools and annual meetings across the state to teachers, school psychologists, speech and occupational therapists, parent support groups and education experts as well as to physicians, nurses, medical students.

Kids with developmental disabilities have complicated learning and behavioral issues, she says, and frequently have medical problems associated with the disability.



Dr. Charles

Recognizing that much of the difficulty is in physically getting these children into the office for medication, Dr. Charles now intends to travel to them. She will soon open a monthly clinic at North Charleston High for students with severe to profound mental retardation, and another at Burns Elementary for kids with behavioral problems.

Dr. Charles also set up a diagnostic clinic for pediatric residents at MUSC to help teach them how to recognize and screen kids with autism. "They get first-hand experience with children with autism, and it ensures that they can have autism in their differential diagnosis," she explains.

Along with clinical psychologist Dr. Laura Carpenter, PhD, Dr. Charles has also set up a third autism clinic.

"We now have 24 autism diagnostic evaluations per month," she says, "and we're still swamped, with a six-month wait list."

Around the country, many autism programs are equally challenged, some with wait lists as long as two years.

In response to concerns over a growing number of children with autism, Dr. Charles is one of two principal investigators in a study looking at the prevalence of the disorder. Funded by the Centers for Disease Control with a recently renewed, 10-year grant, the scientific study is largely translational, says Dr. Charles.

"It's really a public health project, a surveillance study to inform the public so they can use the information to come

January 2007

up with treatment strategy and intervention,” she explains. “To inform the appropriate organizations so they can plan for adequate services. For instance, to help school districts plan teachers, and health care providers plan programs. The results of the study will help these groups predict how much money they’ll need for services, to plan for the financial impact.”

“We’re translating information for the public,” says Dr. Charles. “It’s research from the bedside to the community.”

It’s clear that a larger number of kids with autism are being identified, and a larger number are receiving services from the public.

“Current thinking is that it’s due to earlier identification and better awareness,” she notes. “There’s also been change in diagnostic criteria—it’s become more relaxed, so it’s easier to get a diagnosis.”

There is also probably a true increase in the numbers, says Dr. Charles, perhaps related to environmental triggers. The federal government is beginning to fund research to look at the effects of environmental toxins on child development.

Update from the Administrator



John Sanders, MHA
Administrator
MUSC Children’s Hospital

Children’s Hospital Rated High

Every two years, *Child* magazine surveys children’s hospitals across the country and ranks them based on clinical outcomes, research and programs available. MUSC Children’s Hospital has always done well and this year is no different. On January 9, *Child* magazine will publish their rankings and our Children’s Hospital will be listed in the top 40!

This year’s survey was a little different in that it was open to all full member hospitals in the National Association of Children’s Hospitals and Related Institutions (NACHRI). The rankings were more competitive than ever due to the objectivity of the new survey tool and the excellent care being provided by so many hospitals.

There are several specialty areas that are evaluated in the NACHRI survey and I am excited to report that the MUSC Children’s Hospital Emergency Department ranked ninth in the country. This honor is well deserved by a very dedicated staff that has developed a truly exceptional program. The community recognizes and appreciated the family centered care that is given to our patients and families and we will continue to plan for a new expanded emergency department. Thank you and congratulations to all!

Children's Research Institute News Brief



Bernard L. Maria, MD, MBA
Executive Director
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**Thomas C. Hulsey,
ScD, MSPH**
Director of Pediatric
Epidemiology

Understanding translational research

Defining translational research can be confusing because it's a broad-based definition of a process that applies to multiple disciplines and not a specific end point, says director of pediatric epidemiology Dr. Thomas C. Hulsey, ScD, MSPH.

"It's a new discipline that describes the process by which two traditionally independent disciplines—basic and clinical science—now work collaboratively to improve human health," says Dr. Hulsey.

Translational research is a dynamic cycle that reinforces the linkages between basic laboratory research, epidemiology studies, and clinical trials. It's the critical bridge between a better understanding of biological processes and the etiology, diagnosis, prevention, treatment, and outcomes of specific health conditions.

"What that means is that now the clinician begins to think more about how new information from biomarkers might be related to disease processes she's treating, while the basic scientist might think additionally about how the process he's studying contributes potentially to certain diseases," says Dr. Hulsey.

The National Institutes of Health acknowledged that improvements in human health were not keeping up with independent investments they'd been making in basic and clinical research, says Dr. Hulsey. To achieve a more efficient return on this investment, a new discipline in clinical and basic research was needed. The result: translational research.

As a new discipline, there is a shortage of accomplished translational research teams, since traditional programs train basic and clinical researchers as independent disciplines. To overcome that obstacle, new training programs are vital. New training programs ensure a steady supply of translational researchers, as well as qualified mentors in translational research.

"That's one of the things we're working on for the current Master of Science in Clinical Research (MSCR) program," explains Dr. Hulsey. "We're developing new courses and rotations to include a translational research approach as well as a clinical one."

The Southeastern Pre-doctoral Training in Clinical Research (SPTCR) T32 award for predoctoral students was specifically designed to include strong clinical and translational components, notes Dr. Hulsey, co-PI of the award and program director.

Programs specifically in the DCRI and Pediatrics are working to promote translational research methods through seminars and greater opportunities for interaction between scientists. "The GCRC sponsors a monthly seminar, and the DCRI has followed suit with specific children's issues," he notes. "The DCRI has taken on a formal role in supporting translational research in pediatrics."

Since translational research is a process, it's vital that it be supported through infrastructure. "It requires a corporate behavioral change," says Dr. Hulsey.

He's excited about how Dr. Jane Charles and her colleagues are applying translational research to autism research at MUSC. Recently the US government announced it was earmarking additional new funds specifically to target the disorder.

"The inclusion of translational research money would provide a greater opportunity to include information on mechanisms that might underlie the development of this disease," he points out. "So we can go beyond observing, recording, and documenting autism, to the inclusion of more mechanistic kinds of information that will help us further understand autism and related disorders even more than we do today."

"That could move research studies like the one Dr. Charles is conducting away from being traditionally public health, to also incorporate medical models of prevention and treatment."

Evidence-Based Tip



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

Practice Guidelines

In its book *Guidelines for Clinical Practice*, the Institute of Medicine defines practice guidelines as “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.” They are sometimes called clinical guidelines or clinical practice guidelines, but their purpose is the same: to guide practitioners, patients, and health care administrators to the best possible care.

Are practice guidelines evidence-based?

Systematic reviews and meta-analyses form the basis for an increasing number of practice guidelines. Besides strength of evidence based on valid and reliable studies, guidelines should be clear as to patient populations to which they may be applied—important in pediatric practice—as well as being stated in unambiguous language. Ideally, all practice guidelines would be based on a thorough review of the best available evidence. This is often the case. However, some practice guidelines are based on expert opinion. When consulting a guideline, check to see how the guideline was established.

Where to find practice guidelines

The American Academy of Pediatrics has subject-specific committees and sections that issue guidelines based on the work of a committee of experts in the related fields. New guidelines are published in the AAP journal, *Pediatrics*, and must be renewed every five years to be considered in effect. Click here (http://aappolicy.aappublications.org/practice_guidelines/) to access the current guidelines.

In addition to practice guidelines, the AAP also offers evidence-based technical reports and links to AAP-endorsed guidelines developed by other organization. Click here (<http://aappolicy.aappublications.org/>) to view.

Another excellent source for practice guidelines is the National Guideline Clearinghouse. Developed by the Agency for Healthcare Research and Quality (AHRQ), the content is international in scope, and is searchable by keyword and you may browse by disease, condition, treatment, and issuing organization. Each guideline is graded for its level of evidence and references supporting the recommendations are linked. Click here (<http://www.guideline.gov/>) to learn more.

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