



## Taking It Off

COLLABORATIVE PROGRAM STRESSES  
A HEALTHY FAMILY LIFESTYLE FIRST,  
DIET SECOND.

When his mother and doctor told him that his weight was unhealthy and from here on his life was going to change, 11-year old Christopher Ricks saw the writing on the wall. "I was like, Oh my God, I'm going on a diet!" But Christopher's pediatrician referred him to Weigh Smart, a pilot program that takes a no-fault, family approach to weight loss, emphasizing health over diet.

"Weight loss for children is a family affair," says **Kenneth Gelfand**, the psychologist for the program provided by clinicians from the Johns Hopkins Children's Center and the Mt. Washington Pediatric Hospital, where Weigh Smart is based. "We take the stance that it's not the kids' fault, but it has to be treated—and the consequences of not treating it will be to their detriment."

Indeed, between 1980 and 2000, the number of children 3 to 5 years of age and teens over the 95th percentile for weight and height has doubled. For children ages 6 to 11, the rate has tripled. Since 2000, these rates have increased another 5 percent to 17 percent. The consequences for children? Higher blood pressure, insulin and cholesterol concentrations—all pointing to higher mortality.

"If childhood obesity stays at its current levels, for the first time in more than a century the present generation of children will live shorter lives than their parents," says Children's Center gastroenterologist **Ann Scheimann**, a member of the Weigh Smart team.

Over the course of its 13 weekly sessions, Weigh Smart aims to reduce the risks through education, exercise and nutrition. Christopher began reading food labels and keeping a food diary to understand what and when he ate. Realizing that watching TV made him want to eat, he turned off the tube and replaced it with exercise. Today, he's several sizes smaller. And after years of not being able to keep up with his friends, he now plays football and rides a bike with them. His mother, Wanda, who has shed some pounds herself, changed not only Christopher's home life, but the rest of the family's, too.

"I prepare food now for everyone to have just one



**Some children, like Christopher Ricks, are reducing their risks for type 2 diabetes, hypertension and other obesity-related conditions, says pediatric gastroenterologist Ann Scheimann, but too many are not.**

serving," she says. "Today, we all eat together, and we all go to the mall to walk together."

What can pediatricians do? "Address obesity factors before they're fully entrenched," says Lutherville pediatrician **Alan Lake**. "Identify kids at risk—those with a BMI (body mass index) over 85 percent—and refer them for early and aggressive intervention."

Obese children, those with BMI over the 95th percentile, should be further evaluated with blood work to check cholesterol, blood sugar and liver enzymes, Scheimann recommends. For more information, check out the American Academy of Pediatrics' Obesity Prevention Program at [www.mdaap.org](http://www.mdaap.org). For admission criteria for Weigh Smart, visit [www.mwph.org/outpatient/weigh\\_smart.html](http://www.mwph.org/outpatient/weigh_smart.html).

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**George Dover, M.D.**  
**Director,**  
**Johns Hopkins**  
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**Given Professor of**  
**Pediatrics**

## Pediatrics in the 21st Century

We all have a responsibility to look at where pediatrics is going, to teach our residents what their practice will look like. To get at the answers, I turn to one of my own teachers, **Barton Childs**, a preeminent member of our faculty who prides himself on being a pediatrician first and a geneticist second. In *Genetic Medicine: A Logic of Disease* (Johns Hopkins University Press, 2003), he holds that you don't define health by your genes or environment alone, but by the interaction of the two—your gene environment homeostasis.

This hypothesis takes us to something called epigenetics. While genomics is the study of the genetic map, which has allowed us to understand how genes fit next to each other, epigenetics allows us to see how they interact with and talk to each other—and how gene expression is modified by environmental factors. The real excitement is not how genes are actually coded, but how they turn on and off during development and in response to the environment. And we've learned that genes can be turned on and off far easier than we were ever led to believe.

What does all this mean for pediatricians? With the increasing ability to manipulate gene expression early in the disease process, pediatricians will be the genetic deprogrammers in the 21st century. In other words, as patients' first physicians, we'll be the ones most responsible in helping patients avoid adult-onset diseases. As Dr. Childs predicts, individual variability will increasingly play a role—we'll be treating children and not diseases. In a new form of preventive medicine, we'll see earlier diagnosis of both common and rare disorders, and therapies we can only imagine right now. This is an incredibly exciting era, the real key to unlocking the impact of genetics on medicine.

Thank you, and enjoy this issue.

## Freeing Up Nurses' Hands



**While waiting to hear the results of her young patient's latest lab results, nurse Sharon Welsch leans in for a heart-to-heart with 8-year-old Brittany Falcone.**

Nursing is hands-on, but it's ears-on, too. Whether in the PICU, ED or a med-surg unit, nurses are constantly making, taking or waiting for calls regarding doctors' orders, lab results and other critical information. But at the same time they're being pulled away from the bedside. So how do you manage communications and patients at the same time?

One answer may be found in a mobile communication system recently piloted by nursing staff on a Children's Center unit. Using a wireless headset and an automated "voice agent," the system is designed to allow nurses to make or take an important call at the same time they're at the bedside. "They can use this voice agent when they need to be heads-down on a task," says **Lynne Brotman**, a researcher at Avaya, the company that designed the system. "You don't have to sit by the phone or wait for the page."

But doesn't that open up the nurses to endless calls, some that can wait? Brotman explains that all calls come pre-announced through the voice agent, which acts as a sort of personal assistant in screening calls. Nurses have different availability settings to choose from and can specify which callers may interrupt them. They can set their system at "high access," for instance, but block calls from outside the hospital. In the blocked mode, callers may leave a message or be trans-

ferred to a unit.

What did the study find?

Of the 36 nurses in the six-week pilot, 75 percent agreed the system enabled them to do their job more efficiently, 71 percent said the system contributed to increased productivity, and 82 percent said the system improved the efficiency of paging services and receiving callbacks. Rather than have to go to the nurses station and search through a three-ring binder for different services, nurses were able to program and voice activate the most frequently paged medical services.

Among nurses' feedback: "It was great to be able to walk into a room and continue care without worrying about missing a phone call."

The system, however, was not glitch-free. While 61 percent said the voice agent was easy to use, lack of experience with voice recognition systems made some users uncomfortable. Having to remove the headset every time to use a stethoscope was another issue. Also, the headset design was not optimal for voice recognition in a noisy nursing unit.

"One thing we learned is that you need higher-quality headsets designed to minimize the impact of environmental noise," says Brotman. She adds that flip-up ear pieces on the headsets may be the solution for easier stethoscope use.

For more information, call 908-696-5149. ∴

# Homing in on Histiocytosis

Likely all pediatricians have heard about histiocytic disorders at one time or another, especially LCH, or Langerhans cell histiocytosis, and most have come across a case either in medical school, residency or private practice. Still, many may be asking themselves, as pediatric oncologist **Robert Arceci** did at a recent Grand Rounds, how you get your arms around the constellation of symptoms this rare, complex disorder presents, and detect and treat it in a timely manner.

“A variety of diseases must be ruled out quickly to commence with treatment,” says Arceci. “You’ve got a limited time from diagnosis to get these patients into treatment. If you don’t, the mortality can be very high (80 percent to 100 percent at five years) in some forms of the disease.”

The challenge is that this neoplastic myeloproliferative disorder presents differently in adults and children, and differently among different-age children. Older children more commonly are afflicted with a single bone lesion called eosinophilic granuloma, which surgeons tend to scrape out. However, there’s a 50 percent chance the lesion will return. A toddler typically presents with more chronic skin involvement behind the ears, along with bone disease, erosions around the gums, and painful lumps and bumps on the scalp. An infant typically presents with a rash that won’t go away, prompting a call to the dermatologist. Even if the rash does go away, half of these infants will go on to progress with other significant manifestations.

“People used to think this was a relatively minor disease that came and went for a while and eventually never came back in children,” says Arceci. “As we followed these patients longer, we saw the disease recur later in life.”

Also, an infant can have a skin rash one day, and the next day full-blown disease—skin rashes, diarrhea, failure to thrive, premature eruption of teeth, enlarged liver and spleen, along with skull lesions.

Says Arceci bluntly: “It just explodes.”

Arceci explains that children with histiocytosis carry a defect in their immune system that results in uncontrollable growth and proliferation of the macrophages of the body. With the accelerator on and no brakes, the car keeps going



**“You’ve got a limited time from diagnosis to get these patients into treatment.”**  
—Robert Arceci, M.D.

faster and faster. The body fills up with these macrophages, resulting in damage to all organs, including the brain. Systemic chemotherapy to attack this inflammatory process, at doses less than those used for leukemias and sarcomas, can be effective and is usually much better tolerated. But the intervention must be fast to avoid the chronic recurrences and potentially devastating, long-term sequelae—lung and liver disease, craniofacial abnormalities and neurocognitive problems.

“It really breaks your heart,” says Arceci. “You want to find a way to intervene early, to help these patients and families, who often feel like orphans because of the rarity of these disorders.” ∴

## Continuing Education Schedule

June 16

**Pediatric Endocrinology for the Primary-Care Clinician**

Thomas B. Turner Building  
Johns Hopkins Medicine

September 28–29

**Pediatrics for the Practitioner Update 2006**

Thomas B. Turner Building  
Johns Hopkins Medicine

# Catching CF Early

About 70 percent of individuals with cystic fibrosis are diagnosed by 1 year of age, about 20 percent by age 10, and the other 10 percent after age 10. Sometimes family history or an intestinal obstruction related to meconium ileus will tip off the pediatrician early on, but most often it's coupling the classic symptoms of a chronic cough and failure to thrive that drives the diagnosis. But by then, says Hopkins pediatrician **Beryl Rosenstein**, serious damage may have already been done.

"We have some patients who unfortunately were not diagnosed until age 3, 4, 6 or 10 and who had evidence of significant lung disease," says Rosenstein. "Catch these kids early and you can favorably impact the clinical course and maybe even survival."

A new newborn screening program, starting in Maryland in July, will help pediatricians detect the disease and intervene in early infancy. Before newborns are discharged from the hospital, their dried blood spot-collected for newborn screening will be used to measure levels of a pancreatic enzyme called trypsinogen,

which is usually substantially elevated in newborns with CF. A positive result can be followed up with a diagnostic sweat test. This means 90 percent of individuals with CF will be diagnosed before 1 month of age. They will form a different group of patients for pediatricians like Rosenstein—CF patients who have no signs of pulmonary damage or malnutrition.

"They will have somewhat unique needs," says Rosenstein. "The focus will be on education and counseling for families, and monitoring patients for problems early on as they develop."

In conjunction with the screening, the Children's Center has developed a new clinic for these newly diagnosed newborns. Families will learn nutritional strategies and airway clearance techniques early on, while Rosenstein and his colleagues stay on the lookout for organisms like *Pseudomonas aeruginosa*. Once colonized in a young CF patient's airways, *P. aeruginosa* can quickly become a permanent resident and lead to signifi-



**A newborn screening test for CF means patients will be diagnosed and treated earlier, reducing their risk for pulmonary damage and malnutrition.**

cant lung damage. Patients with the organism are known to suffer steeper declines in pulmonary function and infections requiring IV antibiotics and hospital stays.

"It's been shown in recent years that if you can pick up *Pseudomonas* by airway cultures as soon as it starts to colonize, there's a window of opportunity to eradicate the organism with intensive oral and aerosolized antibiotic therapy," says Rosenstein. "We have a treatment protocol to fight it."

The clinic also has the capability to measure pulmonary function in infants, and to intervene early. Knowing there's an association be-

tween poor nutrition in the first year of life and susceptibility to respiratory infections, clinic staff are raising the bar on nutritional status for these patients, too. Counseling will be offered to parents who may be shocked to learn their seemingly healthy newborn has CF.

"In the past, the child wasn't thriving and the parents weren't getting an answer," says Rosenstein. "With newborn screening, we should detect CF before there's any damage."

For more information, call 410-955-2795, or visit the Johns Hopkins CF Center Web site at [www.hopkins-cf.org](http://www.hopkins-cf.org).

## A Lifeline of Support for CF Families

Over sandwiches and salad in a Johns Hopkins boardroom, 12 parents share experiences in caring for their children with CF. They problem-solve the issues, like a daughter refusing to take her meds, but also share the joys of everyday life—preparations for a prom, a vacation with no trips to the ED.

At this parent support-group meeting, organized by the Johns Hopkins Cystic Fibrosis Center, the parents with older children encourage **Lisa** and **Eric Haack**, whose infant child Aidan was recently

diagnosed. When Lisa says, in disbelief, that their SUV isn't big enough to carry all the equipment their child needs for a three-day trip—the routine trappings of babyhood plus the CF vest, the inhalers and all the medications—the group laughs appreciatively. These parents know. As one mother says, "We've all been there."

This understanding community and wry laughter in the face of an overwhelming chronic illness are a balm for the parents' raw worries. "This is so good for

us," Lisa tells the group. "Everyone is so calm. You've all gone through what we're going through."

They have. Yet these parents have been isolated from one another, for the most part, due to the risk of CF patient-to-patient transmission of respiratory infections. CF clinic nurse coordinator **Donna Peeler** and social worker **Janelle Kellum** launched the group last December as a regular forum for clinic parents. For more information, call 410-955-5816, or visit [www.hopkinscf.org](http://www.hopkinscf.org).

# With Nerves, Regenerating a Smile

In his pediatric plastic surgery practice, **Rick Redett** often performs facial nerve surgery on children with congenital facial paralysis. He takes a sensory nerve from the leg, ties it onto the facial nerve, drapes it across the face and transfers a muscle to control the corner of the mouth. The outcome: a smile, although results vary and get worse with age.

“We’ve reached an impasse where people are still only getting a certain percentage of return of function after nerve grafting, which isn’t that good,” says Redett. “There’s nothing we can do surgically right now—we can’t use different instruments or different sutures or higher-power magnification. So the next advance will be on the molecular level.”

Redett works on that level whenever he’s not in the OR—trying to find a way to improve peripheral nerve regeneration. He explains that surgeons always repair nerve injuries using sensory, as opposed to motor, nerve grafts because of the abundance of sensory nerves in the body. Also, sensory nerves are somewhat more expendable. Removing a sensory nerve will leave a numb patch in the part of the body from which it is taken, but it won’t paralyze a muscle like the removal of a motor nerve will.

Redett, along with orthopedic surgeon **Thomas Brushhart** and neurologist **Ahmet Höke**, set out to prove that motor nerve grafts work better on motor nerves and that sensory nerve grafts regenerate better in sensory nerves. Their paper, describing their experiments using pure motor nerves and pure sensory nerves in rats, published in the *Journal of Neuroscience* (October 2005), provided the definite proof they sought.

Given that using motor nerves is impractical in humans, however, how do you improve nerve regeneration? The team’s next step was to analyze the different growth factors, called neurotrophins, that support motor nerves and sensory nerves. The neurotrophins



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—Rick Redett, M.D.

are found in Schwann cells, the main support cells to the nerve that make myelin. “Our idea is to take a sensory nerve, using it as a graft, and change the Schwann cell to produce motor neurotrophins,” explains Redett. Using an adenovirus, the group plans to transfect the Schwann cell to produce a different set of neurotrophins, turning the sensory nerve graft into a motor nerve graft.

“If we can get a sensory Schwann cell to change its phenotype and become a motor Schwann cell, our next question will be, Does that nerve graft improve function in a rat? If so, that would be translational research you would take into the clinic.” ∴

## Research Briefs

### EDs Score Poorly

A mock-drill study conducted in a third of North Carolina’s emergency departments revealed that nearly all failed to properly stabilize injured children during trauma situations, according to a team of researchers at Johns Hopkins Children’s Center and Duke University

Medical Center. The study’s lead author, Hopkins anesthesiologist and critical care specialist **Elizabeth Hunt**, noted that 31 of the 35 EDs in the study failed to order proper administration of IV fluids, and 24 of 35 did not either attempt or succeed at accessing a child’s bloodstream through

a bone, a critical alternate avenue for rapidly delivering fluids and medicines to sick children whose veins may have constricted due to hypothermia or blood loss. “This study,” says Hunt, “gives us very specific targets for attempting to improve stabilization procedures for children.”

# A Pediatrician Hardly Out to Pasture

Cherry the cow picks up speed across the pasture as she nears the door of **Mel Stern's** barn in Highland, Md. While she digs into her super-sized supper of grain, Stern carefully wipes clean her udders and prepares to milk her. Cherry has provided Stern and his family with gallons of milk a day for two years now.

"It might be time for her to take a rest," he quips, patting her.

No so for pediatrician Stern. In the thriving private practice he operates out of his house, just up the hill from the barn, there's always a child to see, a family to help, a greater good to serve. An active member of the American Academy of Pediatrics, whose Maryland Chapter named him Pediatrician of the Year in 2002, he has helped bring about multiple pieces of child and family-friendly legislation and implement public policies to improve children's welfare.

"I can't help myself," he admits. "Anyone who knows me knows I wear multiple hats. If I see something wrong, I need to fix it."

In a career that has encompassed two stints in academic medicine—at the University of Southern California in the early 70s and subsequently the University of Maryland in the late 70s—Stern left each for practice in a community where he could do some good, maybe harvest a few fruit trees. In his first, he was the sole pediatrician for a farming community of about 60,000 in Sunny-side, Wash., 250 miles from the nearest tertiary care facility. "I was the beginning



Mel Stern has a hold on Cherry and contemporary pediatrics.

and end of pediatrics," he says. "I've never worked so hard in my life."

Today, well into caring for a second generation of patients in his Howard County, Md., practice, Stern has watched his role as primary care provider shift to one more on par with the specialists. "Specialists' primary role was once to support the provider," he says. "Today, we have this growing phenomenon of a medical marketplace, a 'commodity' approach to health care. The system is losing its central focus—the patient. It's a constant struggle to try to pull together all the fragmented aspects of a child's care into one comprehensive package when you have separate entities providing it."

Technology may play a role in closing the gaps, but it generally needs resizing to fit a pediatric practice. As a member of the AAP's Task Force on Medical Informatics, Stern has helped develop standards essential and unique to pediatric electronic medical records (EMRs), creating a common medical home for kids. "We have a near embarrassment of riches in terms of medical resources around here," he says, "but not the integrated, mobilized medical community to deliver it comprehensively."

At day's end, his patient families have sustained him and been "incredibly supportive" of his activism, he says. The year

the bill requiring insurers to provide well-child benefits passed, state delegates were calling Stern to say they were going to vote for it, so could he please ask his patients to stop calling!

"Having families who allow you to focus on what's best for their children," says Stern. "That's a good reason to come to work in the morning."

He smiles as he adds that those office hours begin right after he's milked the cow and fed the chickens: "The setting might be rural, but living within a 30-mile radius of NIH and five major medical teaching institutions, I could never say my practice is rural. The combination has been both enriching and challenging—a good balance." ∴