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A PHYSICIAN PUBLICATION FROM CHILDREN'S HEALTHCARE OF ATLANTA | **WINTER 2011**

Mending a broken Heart

New Procedure Spares Patient From Another Open Heart Surgery

BRIDGING THE GAP
Pediatric to Adult Care

MYTHS VS. FACTS
Medical Misnomers Revealed

Reader Comments or Questions
Contact the editor at pedsmagazine@choa.org or *pēds*®, 1699 Tullie Circle NE Atlanta, GA 30329.

Children's®
Healthcare of Atlanta

The Heart of the Matter

History: **Christian Banks (pictured at right)** was born with numerous heart defects, which required him to undergo many surgical procedures including a Blalock-Taussig (BT) shunt, bidirectional Glenn shunt and open heart surgery. Yet even with all these procedures, in 2009, cardiologists believed that Christian's pulmonary valve was no longer functioning properly.

Treatment: The Melody Transcatheter Pulmonary Valve procedure to replace the valve was performed in place of an open heart surgery.

Outcome: After Christian's valve replacement, he was able to embark on a cross-country road trip with his parents—hiking many miles through canyons and steep elevations not possible before his procedure.

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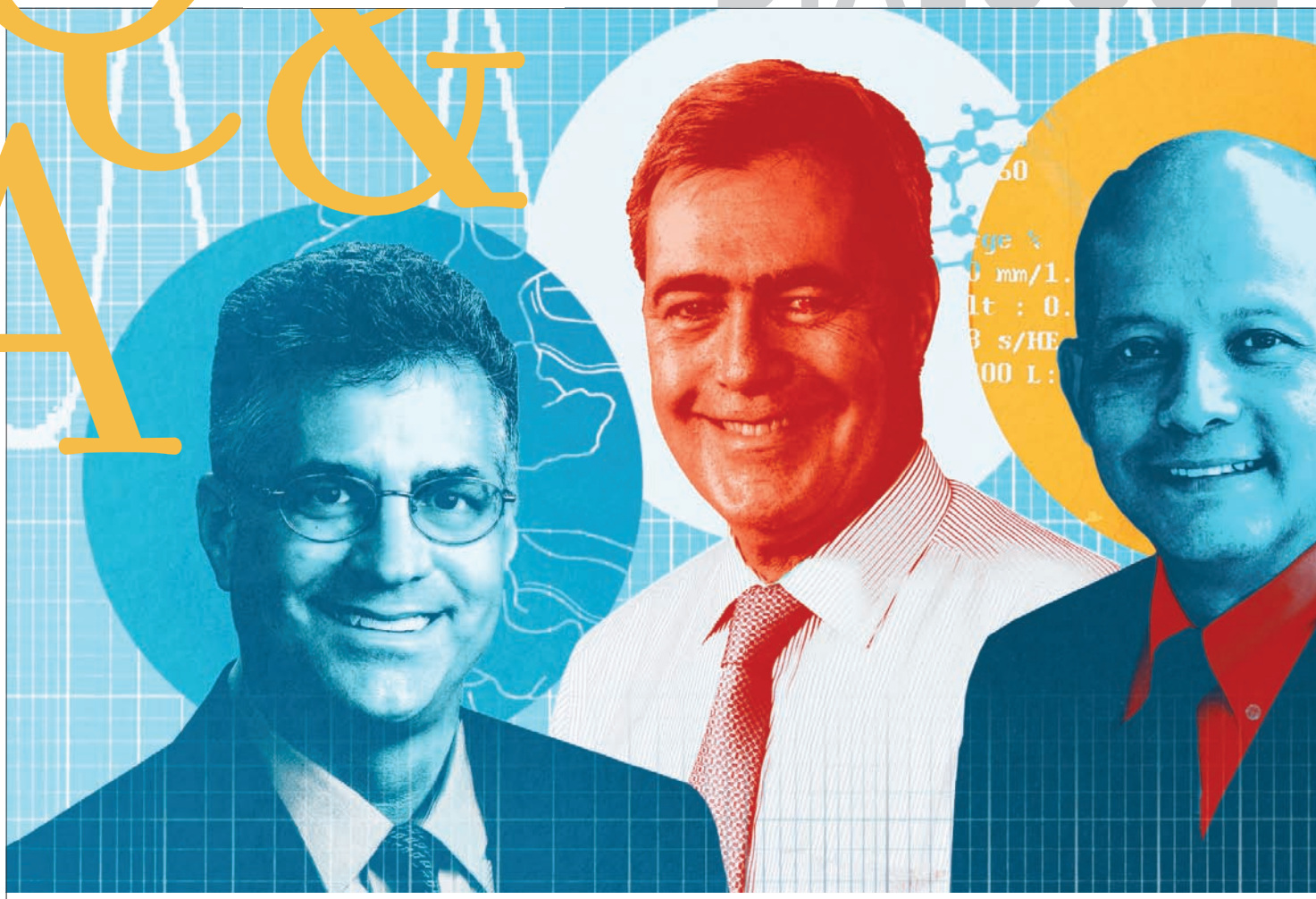
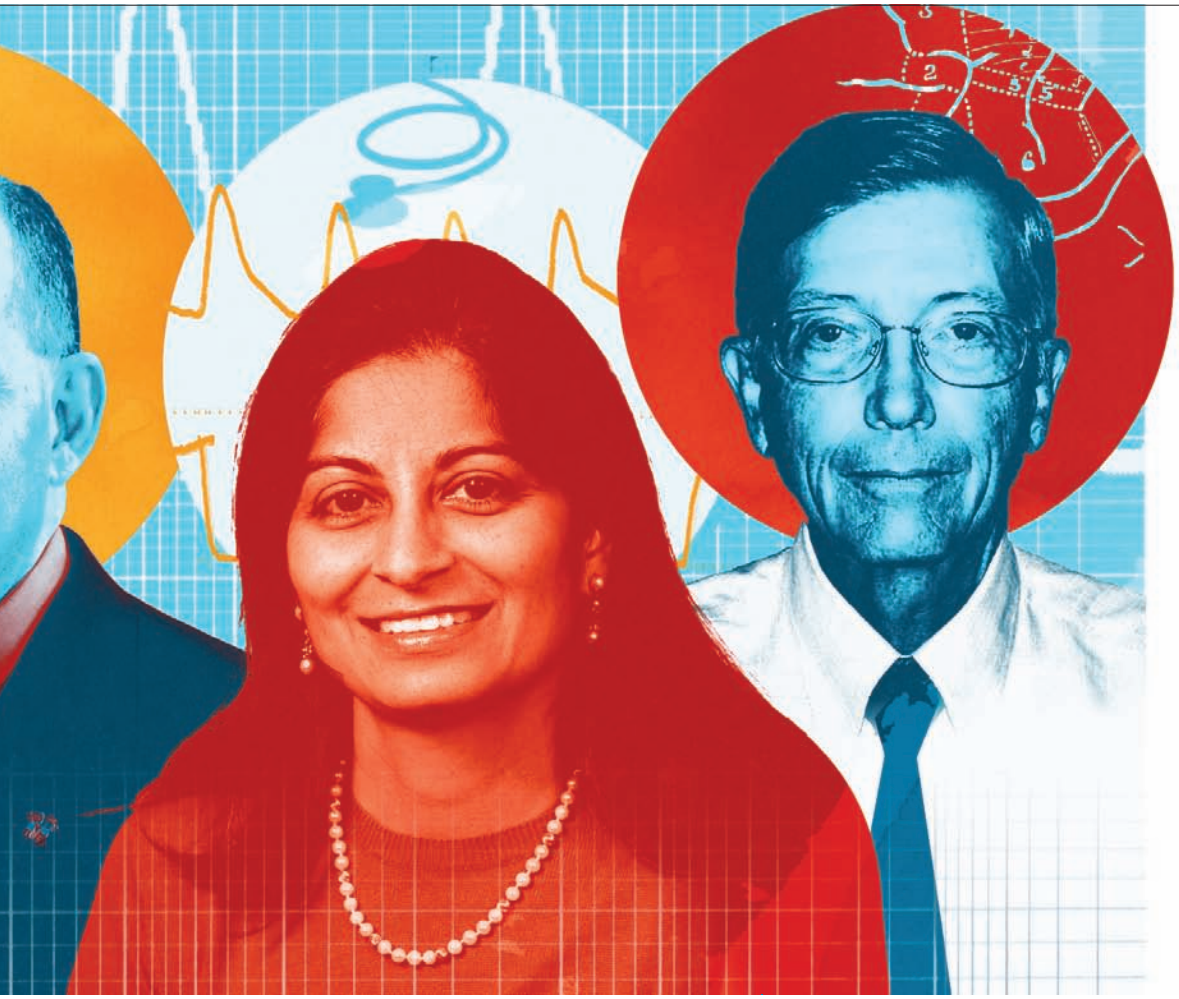
Q&A



GUIDELINES:
Medical Manuals at Work

Guidelines issued by medical societies like the American Academy of Pediatrics (AAP) and others can create tremendous change in medical practice—as well as reduce unnecessary variation. Yet sometimes guidelines lack clarity, or deviation from them may be the best course of action. While not always a magic formula, guidelines certainly have a place in the medical field. But to what extent are they used? Who creates the "right" ones? And what role do they play in reimbursement? All these questions have major implications for a physician and his or her practice.



Dr. Salinas: What are the authoritative sources for guidelines for general pediatricians and pediatric subspecialists?

Dr. Jain: The AAP is the best source but obviously cannot cover all our needs. So I also rely on the Agency for Healthcare Research and Quality's National Guideline Clearinghouse and various subspecialty societies. The Pediatric Infectious Diseases Society/Infectious Diseases Society of America, for instance, released a recent pediatric Community Acquired Pneumonia guideline. There are commercial websites like the emergency medicine-oriented EBMedicine.net. And quality improvement powerhouses, such as Cincinnati Children's, are also good resources.

Dr. Simon: All of these, I think, write very credible guidelines. But here's the problem: inevitably they serve two masters. No.1, they're trying to determine what is the best medicine. But No.2, these societies really don't want to put their members in a defensive position. It's possible for guidelines to be much more definitive about, say, when to get a urinalysis. But a medical society may shy away from doing that whenever they fear that it might hurt significant numbers of the members within their organization in court. That's to the disadvantage of children. So, while guidelines are pretty good, and I certainly read and respect them, I would be a little hesitant to say they are "authoritative," meaning a 10 on a scale of one to 10.

Dr. Elder: www.guideline.gov has a list of all the guidelines submitted by almost every professional organization from around the world. For example, there are 38 by the AAP, 24 by the American Urological Association (AUA) and 172 by the American College of Radiology.[1] In addition, there are a number of guideline commentaries. So for any particular condition, there may be two or three or more guidelines from various organizations.

Dr. Salinas: Do guidelines improve quality of care and reduce unnecessary variation in practice?

Dr. Jain: I do believe that when properly created and applied, guidelines improve both effectiveness and efficiency of healthcare delivery. They reduce variation, and that improves quality.

Dr. Berkowitz: Yes, they're really good, even if they're a little broader than I would like scientifically. But given the political realities of multidisciplinary teams and everything else, that's to be expected. There's certainly no doubt in my mind that, even if the guidelines are a bit watered down for consensus reasons, it is better to do them than not to do them. That's been proven in the literature, and that's why the guideline was made. As a general rule, evidence-based guidelines decrease adverse clinical outcomes, and there's no doubt that it also decreases clinical variance because we have more physicians practicing in a similar way that is also evidence-based.

Dr. Simon: I would go so far as to say guidelines could be the salvation of our medical care system. Unfortunately, we're not using guidelines effectively. Many physicians make medical decisions based on their own experience, when they should be looking at the experience of the profession. And the experience of the profession is found in the medical literature that's subject to peer review and firm statistics. We need to create many more guidelines that are truly authoritative. And we need to create incentives to follow them and penalties for not following them. If that happened, we could significantly reduce the cost of care and improve the quality of care.

The Panel

Daniel Salinas, M.D.
Senior Vice President and Chief Medical Officer, Children's Healthcare of Atlanta and Clinical Professor of Pediatrics at Emory University School of Medicine

Steve Berkowitz, M.D.
Founder and President, SMB Healthcare Consulting

Jack S. Elder, M.D., F.A.C.S, F.A.A.P
Chief of Urology, Henry Ford Health System and Children's Hospital of Michigan; Clinical Professor of Urology, Case School of Medicine; Chairman, the American Urological Association's Guidelines Committee on Vesicoureteral Reflux, which published their recommendations in 1997; Facilitator, the updated AUA Reflux Guidelines Committee, which published their recommendations in 2010

Shabnam Jain, M.D., F.A.A.P
Medical Director for Practice Variation, Children's Healthcare of Atlanta; Director for Quality, Pediatric Emergency Medicine, Emory University School of Medicine

Joseph Simon, M.D.
Medical Director, Call Center at Children's Healthcare of Atlanta

Dr. Elder: Additional research will also do that. One of the things that we [the AUA] did in the 1997 vesicoureteral reflux guidelines was identify the important measurable overt outcomes—for example, scarring from kidney infections, pyelonephritis and so forth. This tells physicians what to focus on when doing clinical research going forward.

Dr. Salinas: What about the adoption of guidelines? What type of national discussions should occur when guidelines are released to promote and facilitate their adoption? Who should be having these discussions? In other words, are guidelines getting the examination and debate they deserve?

Dr. Simon: I think discussions should occur before the guideline is written. My ideal is to create the guidelines with input from three distinct entities. You need the subspecialty society or societies, with their expertise, to come to the table. I think you then need government at the table. They need to be there to keep the specialty societies honest and make sure they're not too influenced by trying to protect their own members. (The problem is, when you put the government at the table, everyone gets suspicious that the government's prime motivation is to reduce costs.) And then one more is needed: a group of medical ethicists to represent the public. They would watch over the specialty societies and government to make sure neither one is forcing an issue that is not in the best interest of patients. So, we need to get input before the guideline is created, not after.

Dr. Elder: The guideline creation has to be an open process. When you develop guidelines, you're in a closed room, it's a closed process. But once you develop them, rather than just publish and implement them, you should submit them for peer review and comments and be fair about making changes. The AAP sent me their (UTI) guidelines about a year and a half ago. I reviewed them and made significant comments, and they made a few changes. They didn't make all the changes I recommended, but that's their prerogative.

Dr. Jain: I'll speak to what should happen after guidelines are published. During the past decade at Children's, we implemented many clinical care pathways and guidelines, but even we are just beginning to systematically evaluate whether they have had any effect, and if not, why. While there is a lot of activity, both nationally and locally, toward guideline creation, their adoption and the rest of the phases (dissemination, education and evaluation) are not being addressed as much as they should be. This needs to be done at the local level, especially in pediatrics, where there is no single national organization overseeing pediatric practice. You also need to re-evaluate and update guidelines every three to five years. They're evidence-based, but evidence changes.

Dr. Salinas: Should guidelines direct what insurers consider medically necessary care?

Dr. Jain: My answer is yes, even though it may appear politically incorrect. If we accept the premise that guidelines are evidence-based, then providers should be accountable for care delivery based on them. For example, if guidelines state that some fancy imaging is not necessary and published literature doesn't support its use either, then providers need to stop using it. Sometimes this happens only when insurance doesn't pay. Of course, this should not be unilateral, nor should it occur the day after a guideline's release. It should happen only after there has been adequate time for education and adoption.

Dr. Simon: If insurance companies come out and say they're going to follow the guidelines, I think that'd be a fantastic thing. That's a tremendous incentive to use the guidelines. But at the moment, they're not there. Here's one way insurance companies could go about getting compliance with guidelines: they could stop looking at individual cases. Doctors shouldn't have to ask an insurance company every

GUIDELINES GENERALLY CAN BE APPLIED ABOUT **80 TO 90% OF THE TIME.**

— Dr. Jain

IN ABOUT **10-20% OF PATIENTS**

A PHYSICIAN'S DISCRETION MAY DICTATE WHEN TO DEVIATE FROM THE GUIDELINE RECOMMENDATIONS, WHICH IS PERFECTLY FINE.

— Dr. Jain

time they want to get a VCUG, for example. Instead, the insurers could say to a doctor, "We're going to audit your charts on a yearly basis. And if we find evidence that shows you followed the guidelines 95 percent of the time, we will keep you on our panel, and we will reimburse the care you order." OK? That's much more efficient, much less labor intensive, much more effective and a tremendous cost savings. It also makes physicians accountable for improving quality of care.

Dr. Salinas: Under what circumstances should a physician deviate from guidelines?

Dr. Jain: If you make a guideline that's too comprehensive—one that attempts the impossible, trying to cover all patients—it may become too cumbersome to use. Most guidelines have exclusion criteria that clearly state when the guideline should not be used. Additionally, guidelines generally can be applied about 80 percent to 90 percent of the time. In about 10 percent to 20 percent of patients, a physician's discretion may dictate when to deviate from the guideline recommendations, which is perfectly fine. In reality, if practitioners are constantly deviating, either the guideline needs re-evaluation and revision, or the providers need education, monitoring and/or disincentives for not following the guideline.

Dr. Simon: That physician's discretion may be based on facts that the guideline did not consider. I'll give you an example. In the UTI guidelines, at no point does it mention foul-smelling urine. But foul-smelling urine is recognized as a risk factor for UTI. So let's say you have a 4- or 5-month-old infant who, per the guideline, does not meet criteria to get a urinalysis. But the infant has foul-smelling urine in addition to fever. He should get a urinalysis because the guideline failed to take that into account. The doctor should make a brief note in his chart saying, "Because of X factor not considered in the guideline, I'm going to do A rather than B." That's all he has to do.

"BUT ONCE YOU DEVELOP THEM (GUIDELINES), RATHER THAN JUST PUBLISH AND IMPLEMENT THEM, YOU SHOULD SUBMIT THEM FOR PEER REVIEW AND COMMENTS AND BE FAIR ABOUT MAKING CHANGES."

— Dr. Elder

"DURING THE PAST DECADE AT CHILDREN'S, WE IMPLEMENTED MANY CLINICAL CARE PATHWAYS AND GUIDELINES, BUT EVEN WE ARE JUST BEGINNING TO SYSTEMATICALLY EVALUATE WHETHER THEY HAVE HAD ANY EFFECT, AND IF NOT, WHY."

— Dr. Jain

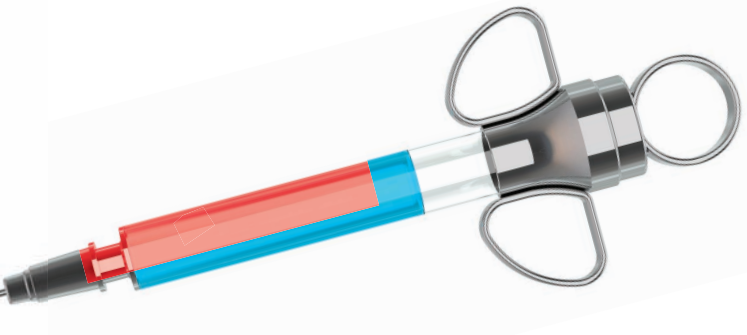
Dr. Salinas: What happens if you just don't like or believe in a guideline and you decide not to follow it? Are there medicolegal risks? Are there risks to the patient? Could there be more financial exposure for the patient based on insurance coverage?

Dr Jain: Regarding financial exposure, if a provider recommends a certain plan, but the patient wants more, "just to be sure," the patient needs to understand he or she may be responsible for the extras. This is part of patient-centered care—we involve patients in informed decision-making, and they are then, at least in part, responsible for their decisions.

Dr. Elder: The patient may want a certain test for his or her own reasons, but the physician's decision has to be evidence-based. One thing about the guidelines: virtually all of them include *why* they're making certain recommendations. They say, "Here are the articles that we analyzed, and here are the tables we created. Here's how we did it, based on our interpretation of the data. Here's why we're making these recommendations." So you need to be conversant in why you're doing something that may be different from the guidelines.

Dr. Berkowitz: I agree. The onus is on the physician to justify not adopting the guideline. Let's say there's some new drug mentioned in the guidelines for your child's condition and your doctor, for whatever reason says, "I just don't practice medicine that way." You don't give your child that drug and your child has a bad outcome. That would be *very* hard to defend. A caveat I want to make very clear is guidelines were never intended to apply to all patients. Patients are too unique. Guidelines were never intended to take the place of an individual physician's judgment on an individual case. Therefore, I expect physicians—in the prudent daily course of medicine—to occasionally deviate from guidelines. If they do, however, I just ask that they document the reason why.

1 www.guideline.gov, U.S. Department of Health & Human Services, Agency for Healthcare Research and Quality. National Guideline Clearinghouse.



Helping Bones to Regrow

Novel procedure may help regrow femoral head in Perthes patients

By Tim Schrader, M.D.

Legg-Calvé-Perthes disease—often known as LCPD or Perthes—is an avascular necrosis in the femoral head of a child. In the natural history of the disease, ischemia of the capital femoral epiphysis causes the head to soften and sometimes collapse. This is followed by resorption of the dead bone and reossification of the femoral head. This head may be deformed, leading to stiffness, pain, osteoarthritis and hip replacement at an early age.

There has been much debate over the optimal treatment for Perthes. Our department has been employing a course of treatment that combines core decompression, commonly used in treating adults with similar conditions, with bone marrow aspirate concentrate (BMAC). This novel technique has shown an impressive ability to speed the healing process among patients in the disease's early stages.

Treatment is rarely required for children younger than age 6 or in cases in which less than half of the femoral head is involved. In those cases, the damage is minimal or is repaired during natural bone growth. For older children, or in more severe cases, treatment generally involves containing the femoral head within the acetabulum (which is unaffected by the ischemia) so it is molded to the correct shape on regrowth. Options include abduction bracing, adductor tenotomy and femoral or pelvic osteotomy.

Avascular necrosis also occurs in adults for a variety of reasons, including alcoholism and steroid use. Core decompression has been a longstanding treatment for avascular necrosis in adults, and it is gaining in popularity as a treatment for Perthes as well. In this method, pioneered by Nuno Lopes, M.D., of Portugal, a hole is drilled across the growth plate and into the necrotic bone to vent pressure and form a path to enable growth of new blood vessels.

At Children's, we have had success using core decompression in conjunction with BMAC. In this procedure, bone marrow is aspirated from the iliac crest and placed into a centrifuge, which separates out the buffy coat. The concentrated marrow is then injected into the femoral head using a process developed by Harvest Technologies in Massachusetts, which concentrates the key cells in just 15 minutes. It is hoped that the white cells will differentiate and assist in reossification and revascularization.

The procedure is minimally invasive and can be done on an outpatient basis, and the preliminary results are encouraging. One of our patients, 9-year-old Harrison Gracey, had the procedure done in early June. After six weeks in a double-leg cast, he is undergoing physical therapy and wearing the abduction brace, developed at Children's. By mid-August, an X-ray suggested that the fracture of his femoral head had all but disappeared. Harrison should only require the brace for four months, compared to the one- to two-year time frame typically required for patients who do not have the procedure.

To our knowledge, only a handful of practitioners in the U.S. perform the combination of core decompression and bone marrow injection in Perthes patients. We are currently developing protocols for a multicenter study of this promising procedure.

Tim Schrader, M.D., is Medical Director of the Hip Program at Children's Healthcare of Atlanta.

By Gary Frank, M.D., M.S., and Brian Kogon, M.D.

A Hard Look at Readmissions

Understand them now, so they are not misused later

Reducing preventable hospital readmissions has become a priority of healthcare reform. In the world of adult care, readmissions rates will soon be tied to reimbursement. Similar policies may soon come to pediatrics' doorstep, and our field should start working on readmissions issues now to ensure that the pediatric field is accurately and adequately represented in decisions pertaining to this issue.

Studies of adult medical care suggest that roughly 15 to 20 percent of hospital readmissions are preventable; reducing these readmissions could reduce costs while improving outcomes.[1] Last year's healthcare reform act dictates that starting in fiscal year 2013, Medicare will start to withhold payments to hospitals with higher-than-average readmission rates for certain diagnoses.

But the effort could have unintended consequences. Readmission rates can vary for reasons outside a hospital's control. All-cause readmission rates ignore factors such as the case mix-index, patient demographics including socioeconomic factors, community resources and availability of alternative care settings. Any payment system that attempts to reduce preventable readmissions should adjust for these risk factors. Moreover, studies have shown a tradeoff between a patient's length of stay (LOS) and subsequent readmission in some areas of care.[2, 3] In some cases, it might be more beneficial for hospitals to keep many patients for longer in order to prevent a single readmission. This could increase, rather than reduce, costs.

In pediatrics, readmission rates tend to be much lower than in adults, partly because children suffer from lower rates of chronic disease. Thus, an undue pressure to reduce readmissions could potentially magnify the effect of increasing LOS as compared to adults. Now is the time to study and understand the drivers of pediatric readmissions and its connection with cost, quality and LOS.

At Children's, we implemented several projects to ensure provision of standardized, evidence-based, effective care throughout our complex system. These multidisciplinary efforts often result in new pathways, guidelines and protocols. Typically, we monitor several process and outcome measures including LOS and readmission rates after a new pathway is implemented. Often, we are able to reduce LOS and resource utilization without negatively impacting readmission rates. While we typically find that our LOS and readmission rates compare favorably to our peers, we are somewhat limited by the lack of national benchmarks and published data regarding these outcomes in children.

Dr. Kogon and his colleagues did a retrospective study of readmissions among Children's patients who underwent congenital heart surgery in 2009. Among 685 discharges, 70 patients were readmitted within 30 days. Statistically significant factors for readmission included Hispanic ethnicity, a preoperative diagnosis of failure to thrive and a postoperative hospital stay of more than 10 days.

The study was valuable because it enabled changes in the pre- and postdischarge process aimed at reducing readmissions among patients identified as high-risk. Our readmission rates appear to be lower than typical, but the data is scarce. In the future, we are looking forward to large, multihospital studies for common and uncommon diagnoses in children that set clear benchmarks, and we hope there is a standardized methodology for risk-adjusting such data. Meanwhile, studies like Dr. Kogon's can move the discussion forward. The study has been submitted for publication in the *Journal of Thoracic and Cardiovascular Surgery*.

With enough preparation, the pediatrics field can influence policies tying readmissions and reimbursement to assure that they do not lead to children being kept longer in the hospital than necessary.

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Brian Kogon, M.D., is a pediatric cardiothoracic surgeon at Children's Healthcare of Atlanta and Associate Professor of Surgery at Emory University School of Medicine.

1 *Ashton, C, et al., "The Association Between the Quality of Inpatient Care and Early Readmission," Annals of Internal Medicine, 122, 1995, www.annals.org/content/122/6/415.full.pdf+html; The Clinical Advisory Board interviews and analysis, "Preventing Unnecessary Readmissions: Transcending the Hospital's Four Walls to Achieve Collaborative Care Coordination", Slide 52, 2010 Meeting.*

2 *JAMA. Clinical Characteristics and Outcomes of Medicare Patients Undergoing Total Hip Arthroplasty, 1991-2008, jama.ama-assn.org/content/305/15/1560.full*

3 *JAMA. Trends in Length of Stay and Short-term Outcomes Among Medicare Patients Hospitalized for Heart Failure, 1993-2003, jama.ama-assn.org/content/303/21/2141.full.pdf+html*

By Wolfgang H. Cerwinka, M.D., and Andrew J. Kirsch, M.D.

Life in the 'Stone Belt'

Pediatric stone disease continues to escalate, especially in Southeast U.S.

The incidence of pediatric urolithiasis, or urinary stone disease, has experienced steady growth in recent years, however, it is disproportionately found in the Southeastern U.S. among both adults and children.[1] A multitude of factors, both environmental and lifestyle-oriented, contribute to the consistent and marked increase of these cases in the region, which is widely regarded as the "Stone Belt." In fact, warm and sunny climates throughout the Western world tend to experience a higher incidence of stone disease than colder areas. A 2010 study, which examined pediatric stone cases in the U.S. from 1999 to 2008, revealed an increase of about 10 percent each year.[2]

Children's Healthcare of Atlanta urologists have noted similar upticks in stone disease in recent years. The growing frequency with which pediatric urologists are confronted with these cases, especially in the Southeast, mandates a strict standard of care. The management should be to treat existing stones and prevent future recurrences, as patients with urolithiasis are 35 to 50 percent more likely to experience another episode within five years.[3]

Stone disease begins with the crystallization of urinary molecules when an imbalance of inhibiting and promoting factors is reached. For example, magnesium or citrate qualify as inhibiting factors, whereas dehydration, saturation of molecules such as calcium oxalate, urinary stasis and urinary tract infection are promoting factors. Consequently, an uneven ratio of any of these factors can result in the development of stones. Hypercalciuria, or elevated urinary calcium, is the most common abnormality found in calcium stone formers. It may be caused by increased intestinal calcium absorption, increased renal calcium excretion, or increased calcium resorption from bone.

The Role of Climate and Lifestyle in Stone Development

The impact of this region's climate is significant for many reasons. The warmer temperatures, coupled with a lower average fluid intake, causes children to more frequently become dehydrated. Dehydration is a known cause of urolithiasis because water decreases the saturation of urine with potentially lithogenic molecules. In addition, sunlight exposure increases levels of dihydroxy vitamin D, calcium absorption and urinary calcium concentration, which are strongly related to the disease.

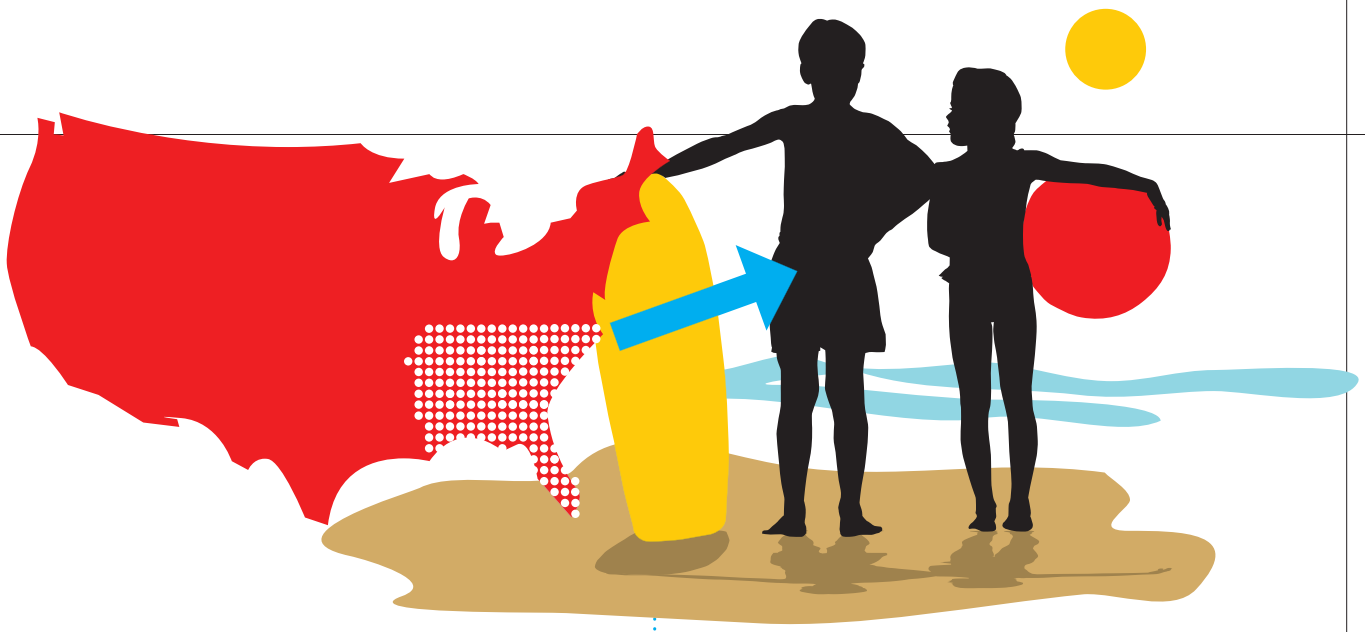
In addition to the effects of environment on this condition, a number of lifestyle decisions can exacerbate the prevalence of urinary stones in children. The Southeastern U.S. has the highest rates of childhood obesity in the country. Obesity and the associated elevated insulin levels are directly linked to stone production, as diets high in salt can also cause calcium build-up in the urine. Of course, genetic predisposition significantly affects a person's likelihood of developing stones, further increasing the risk of stone development in a patient with multiple risk factors, such as dietary considerations like high protein and sodium intake. Fortunately, there are a number of treatment options available for physicians to successfully manage this condition and help prevent its recurrence.

Patients with pediatric stone disease must be carefully screened to determine the best course of action. A computed tomography (CT) scan is the preferred initial method for identifying the size and location of the stone(s). This information is vital to appropriate treatment selection.

Outpatient Treatment

Patients who are not experiencing bleeding, fever or excessive pain may be released to handle the duration of the event at home. They should be prescribed appropriate pain and nausea medication for their age and size, as well as an alpha blocker, which has been shown to help stones to pass more easily. The patient and caregiver should also be instructed in the use of a urine strainer, so that the stone(s) can be obtained and analyzed to determine causative factors.

A 24-hour urine analysis is recommended to determine if the urine is deficient in natural stone-preventive substances, including citrate and magnesium. If indicated, supplements of these compounds may be prescribed to reduce the likelihood of future recurrence. In addition, the presence of stone-causing substances in the urine, such as excessive calcium, oxalate, cystine and uric acid, can shed considerable light on possible causes, thus aiding preventative measures.



Inpatient Intervention

Generally speaking, patients with large stones and very young patients are less likely to pass the blockage without surgical intervention. Patients experiencing fever or extreme pain, or those who have already attempted to pass the stone for a significant period of time, should be advised about surgical and other removal options.

Extracorporeal shock wave lithotripsy (ESWL) is feasible when an X-ray study of the kidney, ureter and bladder depicts a stone. Particularly in children whose ureters are too small for standard surgical tools, ESWL allows the physician to noninvasively break up the stone using shock waves while the patient is anesthetized. This option allows the patient to bypass more invasive surgery, although surgical intervention may be required if the stone fragments do not successfully pass.

Ureteroscopy is a surgical option that allows direct visualization of the stone within the ureter and kidney. Size permitting, a basket is used to grasp and remove the stone. Larger stones are broken up using a holmium laser, after which remaining fragments are removed. During this process, an ureteroscope (small caliber endoscope either flexible or semi rigid) is introduced into the ureter via the bladder. A stone basket and/or laser fiber is introduced into the ureter through the ureteroscope. Younger patients face a greater likelihood that the ureter will not accommodate the instrument. In such cases, a stent is placed first to dilate the ureter over a period of one to two weeks to allow introduction of the ureteroscope by a second procedure. Although very effective, this method typically requires multiple surgeries under general anesthesia.

Percutaneous nephrolithotomy (PCNL) is sometimes advised for pediatric patients experiencing a very large stone burden (1.5 to 2 cm or greater). This procedure is an option if the stone is not accessible via the ureter or for patients with multiple stones. Percutaneous access to the renal collecting system is gained under fluoroscopic guidance (nephrostomy tube). The tract is dilated until a tube can be placed that accommodates a nephroscope, which is an endoscope used to look into the kidney. Depending on stone size and composition, various modalities may be applied to break up and remove the stone, such as ultrasound and suction, laser or grasping forceps. A second PCNL will be necessary if the stone was not completely removed the first time. After the procedure is completed, an imaging study, such as CT scan, is obtained to determine that the patient is stone-free prior to removal of the nephrostomy tube.

Open surgeries, such as nephrolithotomy and ureterolithotomy, are rarely performed these days and are indicated in cases of a very large stone burden or anatomical situations, such as ectopic (e.g., pelvic) kidney or ureteral diverticulum, that preclude the use of minimally invasive approaches.

Moving Forward

As clinicians, we cannot rely on encouraged lifestyle changes, such as improved diet and exercise habits, to reduce the number of pediatric urinary stone cases, both in the Southeast and across the country. Proactive measures are necessary to minimize the pain, cost and recurrence of urolithiasis in patients. For example, stone analysis and 24-hour urine analysis provide valuable information regarding underlying causes of urolithiasis. In addition, pharmacologic treatment in the forms of citrate supplementation and thiazides can be effective preventative measures.

To address this issue, it would be prudent for forward-thinking medical facilities to establish a team of specialists, such as Emergency Department physicians, radiologists, urologists and nephrologists, dedicated to the effective diagnosis, treatment and prevention of stones. For this reason, pediatric facilities, particularly in the "stone belt" should encourage ongoing education and communication among these clinicians about ever-evolving treatment and prevention options. It is only with our help and a conscious effort by patients to reduce risk factors that the trend of stone disease in children can be reversed.

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Andrew J. Kirsch, M.D., is a pediatric urologist on staff at Children's Healthcare of Atlanta and Clinical Professor and Chief of Pediatric Urology at Emory University School of Medicine.

1 Hwang, Kathleen, Mason, M.D. & Peters, C.A. (2010). Eur J Pediatr. Surgical approaches to urolithiasis in children. Springer.

2 Epidemiological trends in pediatric urolithiasis at United States freestanding pediatric hospitals. Routh JC, Graham DA, Nelson CP. J Urol. 2010 Sep;184(3):1100-4.

3 National Kidney and Urologic Diseases Information Clearinghouse. (Spring/Summer 2008). Urinary Tract Stones Pose Challenges for Researchers. Editor: Leroy M. Nyberg, Jr., Ph.D., M.D.

By Jeffrey C. Klick, M.D., and Meghan Tracewski, C.P.N.P.

Pediatric Palliative Care:
For More Than End of Life

An interdisciplinary approach to managing patients with life-threatening conditions

In the U.S., palliative care often is synonymous with hospice and end-of-life care. However, many children who receive this type of care also receive therapies directed at curing or improving their disease. As suffering occurs in all stages of disease, even if a cure is likely, palliative care must also be present. In fact, excellent symptom management may actually improve outcomes.

Yet, managing suffering can be challenging. That is why a subspecialty team of clinicians with training and experience managing these challenges is the most effective way to limit suffering and find ways to move care forward.

Building a Base

To this end, Children's Healthcare of Atlanta created an innovative, new department, Pediatric Palliative Care, which consists of a Pediatric Advanced Care Team (PACT)—comprised of three physicians, a nurse practitioner and a social worker. When consulted, PACT works with the patient's care team to learn about the patient, the family and the medical condition. Interventions vary based on the situation but may include: modifying a symptom-management plan; facilitating communication and establishing the child's and family's goals of care; providing additional psychosocial support services; coordinating care; and providing continuity or facilitating transition to home.

Because this subspecialty—especially in pediatrics—is still fairly new, having been officially recognized as a subspecialty by the American Board of Medical Specialists (ABMS) in 2008, the Children's Pediatric Palliative Care Department is poised to play a key role in the national development of this field. During the coming years, we envision the Children's Pediatric Palliative Care Department will:

- Provide vital clinical care, education and training in pediatric palliative care.
- Create a fellowship program.
- Establish appropriate palliative-centered policies.
- Facilitate national and regional advocacy efforts.
- Expand our knowledge through collaborative research.
- Ultimately launch Children's as one of the leading voices in how pediatric healthcare providers identify and treat suffering.

In Practice

One patient in particular at Children's exemplifies how crucial a role palliative care can play. The PACT was consulted to assist in the pain management of a 16-year-old male with metastatic cancer and a tumor compressing

his sciatic nerve. Previously a vibrant young man, he was suddenly unable to walk, was withdrawn and often would not open his eyes all day. Having recently been told that medication would no longer cure his disease, the patient's parents wanted to transfer him to another hospital for experimental therapy. This plan, unfortunately, would most likely not accomplish the cure they were hoping for, and would take him away from his friends and family.

In addition to the patient's pain and inability to function, his family was reeling from the change of prognosis. They were trying to hold onto the hope that had gotten them through the past two years of therapy—the hope of a cure—and were now questioning the faith that was the core of their coping and decision-making. Unfortunately, as a cure was no longer possible, the family could not find anything different to hope for and were not able to move forward.

By developing relationships, fostering communication and understanding of disease, working with chaplaincy and providing aggressive pain management, the PACT helped the family find a way to focus on the patient's life—not his death. They took him home and hoped for the one thing they had control over: for their son to be as well as possible, in body and spirit, for as long as possible.

Through its all-encompassing Pediatric Palliative Care Department and its collaborative work with the system's physicians, Children's will be on the forefront of ensuring other patients experience the significant improvements in quality of life that come from receiving the best in palliative care.

Key Points in Pediatric Palliative Care and Decision-Making

- Managing suffering in children can be challenging as children are not autonomous decision makers and require a third party, often parents, to identify what they are suffering from and to make decisions for them.

- Often the prognosis and course of illness in pediatric life-threatening conditions is ambiguous—not knowing what tomorrow will bring or if a medication might be helpful. This concept can be difficult for families to understand and creates a great challenge in making decisions.

Jeffrey C. Klick, M.D., is Medical Director of the Pediatric Palliative Care Department at Children's Healthcare of Atlanta.

Meghan Tracewski, C.P.N.P., is a nurse practitioner for the Pediatric Advanced Care Team at Children's Healthcare of Atlanta.

TREATING *the* TRANSITION

Individualized strategies help bridge the gap between pediatric and adult care

For teenagers with chronic diseases, a major challenge looms on the horizon: making the transition from pediatric to adult care. From 2005 to 2006, 41 percent of adolescents with special healthcare needs in the U.S. received "the services necessary to make transitions to adult healthcare, work and independence," with the rate even lower for minority children, families with incomes below 200 percent of the federal poverty level, and those who are uninsured or publicly insured.[1] In Georgia, just 37 percent of these patients received necessary resources.[1]

In the face of this sobering statistic, Children's Healthcare of Atlanta implemented individualized programs to address many of the challenges associated with this changeover. These programs are constantly evolving to address differing patient needs and the changing climate of healthcare in the nation. Though these specialty programs are largely deemed successful, cross-departmental analysis of successful transition care programs can offer insights into potential for other disciplines and the system as a whole.

Cancer Survivorship

At the Aflac Cancer Center and Blood Disorders Service of Children's, patients are introduced to transition concepts around the age of 15 by taking ownership of their medical history, and becoming familiar with their health regime, said Karen Wasilewski-Masker, M.D., M.Sc., a pediatric oncologist at the Aflac Cancer Center.

The patient's Survivor Healthcare Plan (SHP) includes a summary of the patient's cancer treatment and guidelines for long-term, follow-up care. The SHP can be securely posted on SurvivorLink (www.cancersurvivorlink.org), a grant-funded website that connects these young patients with their pediatric and adult healthcare professionals, and allows them to communicate with each other and the patient. "Whether the patient will be transitioning to oncology or primary care or a combination of the two," said Dr. Wasilewski-Masker, "they have a roadmap for what needs to be done going forward in terms of surveillance."

Sickle Cell Education

The ideal age for a patient to transition to adult care from the Sickle Cell Disease Clinic at the Aflac Cancer Center is age 18 and a high school graduate, said Anya Griffin, Ph.D., a pediatric psychologist at the Aflac Cancer Center. But the transition process begins as young as age 13 at the annual Sickle Cell Education Day, which includes an interactive teen component where adolescent patients discuss topics including pain management, life and career planning, coping skills and ways to increase self-care responsibilities.

Age-based teen clinics for patients with sickle cell disease are designed around learning the steps for successful transition into adult care at age 18. During clinics, teen patients participate in groups with other transitioning teens for increasing knowledge and self-care. Separate groups for parents are also available to help them with the transition. Teens are seen individually to assess current disease knowledge and other important medical information. At the conclusion of the teen clinic visit, the teen meets with the pediatric team to continue learning these skills.

> *"Our plan is to create a cadre of providers who will help care for these now-adult patients with complex problems that originated as pediatric problems."*
> — Dr. Doelling

At approximately age 17, patients participate in a visit with an adult hematologist, tour the adult sickle cell disease facilities and discuss other resources within Atlanta. The teens then break into groups facilitated by members of both the pediatric and adult sickle cell disease medical teams, as well as adults who have the condition and are able to answer questions about living with it. "It's a very frank discussion of issues related to sickle cell disease that many pediatric providers are unable to fully address, so it is important to have the adult mentors to guide teens along the way," Dr. Griffin said. Finally, the patient comes full circle at a Sickle Cell Education Day during a formal graduation ceremony.

Seventy-three teen patients—40 males and 33 females—went through the program from October 2008, when the Aflac Cancer Center began collecting data about transition care, to February 2011. Ninety-six percent of the patients have an identified adult care physician 12 months after leaving the Aflac Cancer Center's Sickle Cell Disease Clinic, Dr. Griffin said. Patients who participated in the program also have completed at least one initial visit to that new physician.

Transplant Services

In June 2007, the Children's Carlos and Marguerite Mason Transplant Center initiated the Adolescent Kidney Transplant Clinic, an adolescent-focused, multidisciplinary transition clinic for kidney transplant recipients with the goal of improving healthcare self-management and easing transition to adult health services.

"Many of our pediatric transplant patients have been coming to Children's for years," said Shannon Chapman, Program Manager of Cardiac and Transplant Services at Children's. "The staff and way we do things become a familiar routine. Going to an adult center brings new processes, new staff, a lot of change."

Patients between ages 14 to 20 who are at least one year post-transplant are enrolled in the adolescent clinic. Initially, the medical staff sees patients with their parents in the room. Eventually, the teens are seen independent of their parents by a physician, pharmacist, transplant nurse coordinator, social worker, psychologist, and have periodic visits with a nutritionist and child life specialist. Interviews with the

patient focus on adolescent health issues including sexual health, risky behaviors, social support, insurance needs, and medication and treatment knowledge.

An educational transition conference specifically for adolescents and their parents takes place annually. Topics include reproductive health, community resources, college preparation, healthcare reform and healthy lifestyle choices. At age 20, patients tour the Emory Transplant Center, are introduced to staff and schedule their first adult clinic appointment.

To ensure that the transition is smooth, Children's physicians and staff provide detailed medical histories, medical records and insurance information to the new medical team. The Georgia Transplant Foundation also provides valuable resources and assistance to young adult transplant recipients. In addition to the Adolescent Kidney Transplant Clinic, Children's now has separate but similar adolescent clinics for liver and heart transplant recipients.

Cardiac Care

Pediatric cardiologists at the Children's Sibley Heart Center initiate discussions about transition with patients beginning at age 13, and follow a checklist of important issues to address annually, said Michael E. McConnell, M.D., a pediatric cardiologist at the Children's Sibley Heart Center. Dr. McConnell is also Associate Professor of Pediatrics and Assistant Professor of Medicine at the Emory University School of Medicine. Among the discussion topics are: career choices and insurance; sports participation; drug and alcohol abuse; and pregnancy and genetic conditions.

The checklist has been in use since November 2009. Though the Children's Sibley Heart Center has not collected formal data on its effectiveness, Dr. McConnell said that the patients transitioning from Children's to the Emory Sibley Adult Congenital Cardiac Center have a significantly higher percentage of being insured than patients from the general pediatric cardiology community. "It's possible that by taking the time to go over these issues with these patients," Dr. McConnell said, "we are making some progress."

Cardiology patients between ages 13 and 18 also participate in two social outings during the spring and fall to connect with their peers, and attend an annual transition conference in the fall.

Throughout Children's

Since January 2011, Nancy Doelling, M.D., Medical Director for Children's at Scottish Rite, and Cherise Hemmings, Project Manager for Clinical Financial Operations at Children's, have been leading a working group of Children's staff and physicians across specialties to address transition care. By the end of 2012, Children's should have a streamlined process for transition, as well as a support system and partnership in place with adult care providers.

"Our plan is to create a cadre of providers who will help care for these now-adult patients with complex problems that originated as pediatric problems," Dr. Doelling said. "Ideally, we will have a multidisciplinary team, with subspecialties involved, that will oversee a repository of information to offer any group [including adult providers and families of transitioning adolescents] to provide the most up-to-date government service programs including insurance and keep a database."

The transition group will seek funding for the development of a systemwide transition program at Children's. Having such a program will solve many of the current barriers to transition care such as the lack of forums to share best practices; lack of dedicated staff and limited access to adult medical resources with expertise in childhood diseases. "It takes a collaborative effort and a strong administration to identify transition as an overall issue in a healthcare system with shrinking dollars. Our system understands its importance and supports that it needs to be done," said Dr. Doelling.

Shannon Chapman is Program Manager of Cardiac and Transplant Services at Children's Healthcare of Atlanta.

Nancy Doelling, M.D., is Medical Director for Children's Healthcare of Atlanta at Scottish Rite.

Anya Griffin, Ph.D., is a pediatric psychologist at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta.

Michael E. McConnell, M.D., is a pediatric cardiologist at the Children's Healthcare of Atlanta Sibley Heart Center. Dr. McConnell is also Associate Professor of Pediatrics and Assistant Professor of Medicine at the Emory University School of Medicine.

Karen Wasilewski-Masker, M.D., M.Sc., is a pediatric oncologist at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta and Assistant Professor of Pediatrics at the Emory University School of Medicine.

Similar Difficulties

There are many factors involved in transitioning young patients to adult healthcare that cross specialty areas:

Insurance: Between the ages of 18 (legal adulthood) to 25 (the age most private insurance halts coverage for children under their parents' insurance), many young patients fall through the cracks if they and their families are not prepared with new medical coverage.

Physiology of disease and treatment: For example, because children are more susceptible to radiation therapy side effects, young patients are at an increased risk of secondary cancers, said Karen Wasilewski-Masker, M.D., M.Sc., a pediatric oncologist at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta. "Once we cure children, they have a lot more years to get secondary cancers than adults after they're treated."

Emotion: Pediatricians often have developed a long-term relationship with their patients, which can make it difficult to let go.

Patient maturity level: In an adult environment, the patient must be able to talk with physicians about medical and surgical history and current medications as well as taking on the responsibility of making follow-up appointments. This requires a certain level of maturity in the transitioning patient.

1 "Healthcare Transitions for Youth with Special Healthcare Needs: An Analysis of National and State Performance;" National Alliance to Advance Adolescent Health, January 2011

TRADING SURGERY FOR A MINIMALLY INVASIVE PROCEDURE

TRANSCATHETER PULMONARY VALVE REPLACEMENT SPARES CARDIAC PATIENT FROM ANOTHER OPEN HEART SURGERY


Dr. Robert Vincen
Dennis Kim, M.D.

Certain pediatric cardiac patients have a new alternative to open heart surgery—the Melody Transcatheter Pulmonary Valve procedure. In early 2011, Christian Banks underwent this procedure performed by cardiologists at the Children's Healthcare of Atlanta Sibley Heart Center, one of the few pediatric centers in the country and the only one in Georgia able to perform this procedure, providing him a new quality of life.

At scarcely 1 day old, Christian Banks' routine well-baby checkup in the newborn nursery resulted in his immediate transfer to the cardiac intensive care unit at Children's.

"He got down to the nursery, and he was blue and in significant distress," recounted Marty Bova-Banks, Christian's mother. "They pulled him into the NICU and started working. That was our first inkling that there was anything wrong."

Veterans in the medical field, Christian's parents, Marty and her husband, David Banks, a nurse and an emergency department physician, respectively, both thoroughly understood the severity of their son's situation. Their fears were confirmed when the pediatric cardiologist listed Christian's numerous heart defects, including an interrupted aortic arch, stenotic aortic valve, stenotic aortic outflow tract, malformed tricuspid valve, atrial septal defect (ASD) and ventricular septal defect (VSD).

"Essentially, he had a two-chamber heart," Bova-Banks said.

The physicians presented Christian's parents with a couple of options for their child's future, one of which was to continue infusing Christian with prostaglandin until he could receive a heart transplant. Because infant donor hearts are scarce and a heart transplant brings with it a host of new problems and risks, it was a gamble Christian's parents were not willing to take.

Instead, Christian's parents decided on another option—a staged repair of Christian's fragile, damaged heart. It would require multiple open heart surgeries, but this was clearly the best alternative for Christian, given his particular case and limitations.

THE JOURNEY BEGINS

At only 4 days old, Christian underwent his first surgical procedure when a modified Blalock-Taussig (BT) shunt was placed to provide adequate blood flow to his lungs. The infant was wheeled back into surgery on day seven, however, when it became apparent that the shunt was providing too much blood to his lungs. His surgeon had to restrict the shunt to better regulate the flow of blood. One month later, he was sent home to his parents and two older siblings.

Despite his successful surgery, Christian faced significant and growth-impairing feeding problems, necessitating the placement of a feeding tube. At 11 weeks, his oxygen levels dropped alarmingly, at which time his physicians determined that the shunt was probably developing a narrowing when Christian moved his body in certain positions. This troubling development resulted in the early placement of a bidirectional Glenn shunt. Christian, who at the time was one of the youngest recipients of the bidirectional Glenn shunt, recovered well from the surgery. He required no further procedures until 36 months old, when a full repair was completed to restore normal physiology to his heart. At this time, a valved tube was placed to allow blood to move from his heart directly to his lung vessels.

Christian and his family enjoyed seven years without any invasive procedures. In November 2009, a substantial decline in stamina and energy levels raised concerns about his cardiac function. A subsequent echocardiogram revealed increased pressures in the right ventricle, which required open heart surgery to replace the pulmonary valve and conduit that was placed when he was 36 months old. Initially, his physicians hoped that this valve would last about 10 years. Less than two years later, his cardiologist's evaluation suggested the pulmonary valve had calcified and narrowed and was no longer functioning effectively. Christian's parents, who had hoped for a longer surgical reprieve for their son, were disheartened.

"Christian was a candidate for the Melody Transcatheter Pulmonary Valve, designed by Medtronic. This procedure has afforded thousands of patients worldwide the option of avoiding open heart surgery in favor of minimally invasive valve replacement."

Then, Christian's cardiologists at Children's introduced his parents to another cutting-edge possibility for which their son was a prime candidate.

AN IDEAL CANDIDATE

Christian was a candidate for the Melody Transcatheter Pulmonary Valve, designed by Medtronic. This procedure has afforded thousands of patients worldwide the option of avoiding open heart surgery in favor of minimally invasive valve replacement (see sidebar for specific details on the procedure).

"The primary reason that it is special is it takes the place of an open surgical procedure," explained Dennis Kim, M.D., Ph.D., pediatric cardiologist at the Children's Sibley Heart Center and Assistant Professor of Pediatrics at Emory University School of Medicine. "A patient can have the same results as a new valve implantation without the need for sternotomy or being placed on the heart/lung bypass machine."

"To date, more than 2,500 Melody devices have been implanted worldwide," said Robert M. Vincent, M.D., C.M., Director of the Children's Sibley Heart Center Catheterization Lab and Professor of Pediatrics at Emory University School of Medicine. "It's an alternative for selected patients who would otherwise need a surgical procedure."

"Although it is still a relatively new procedure, research suggests that a Melody Transcatheter Pulmonary Valve may have a lifespan of roughly a decade before being replaced with another conduit or valve, which is similar to surgically placed valves," Dr. Kim said.

"Although it is still a relatively new procedure, research suggests that a Melody Transcatheter Pulmonary Valve may have a lifespan of roughly a decade before being replaced with another conduit or valve, which is similar to surgically placed valves."

"The Melody valve does not completely eliminate the need for surgical replacement of pulmonary valves or conduits. We hope that we can reduce the number of open heart surgeries that will be required. In some situations, we may be able to put another Melody valve inside the previously placed Melody valve," Dr. Kim said. "Depending on the circumstances, it is possible that two or even three Melody valves could be replaced before requiring open surgical replacement."

The procedure was launched in Europe in 2006 to great success among the adult and pediatric congenital heart defect population. In 2010, the U.S. Food and Drug Administration (FDA) approved the technology with a humanitarian device exemption (HDE) designation after reviewing trial data compiled by test centers in the U.S. It is currently approved for adult and pediatric patients with narrowed (stenotic) or leaky (regurgitant) right ventricular outflow tract conduits or bioprosthetic valves. It is most often employed in patients with pulmonary atresia, tetralogy of Fallot, transposition of the great arteries, truncus arteriosus and double outlet right ventricle, all of which may have severe associated abnormalities of the pulmonary valve or right ventricular outflow tract. Also, patients who have undergone a Ross procedure for aortic valve disease will require a different pulmonary valve to be placed because the patient's own pulmonary valve is put into the aortic valve position as a replacement with this procedure. Ideally, pediatric patients under consideration for the procedure should have a bioprosthetic valve or conduit that is large enough to handle the device, which can be expanded between 16 and 22 mm. Typically, this means that the previous surgery for the pulmonary valve occurred in late childhood or early adolescence.

"To be considered, the patient will have had previous surgery in the area of the pulmonary valve and have a significant amount of recurrent narrowing, leakage, or both," Dr. Kim said. "It is not recommended for patients who have particular geometries of the pulmonary valve area that may be too large or too small to appropriately hold the Melody valve in place. In fact, only about 15 percent of patients who have had reconstruction of the right ventricular outflow tract might be suitable."

TAKING THE PLUNGE

Christian was deemed an excellent candidate for this advanced technology. Key factors were his age, size and recent valve replacement, which was large enough to accommodate the Melody valve.

"When the physicians met with us they were really excited about it," Bova-Banks said. "Christian was on the front end of the Melody valve in Atlanta for children. We were so fortunate he could be a part of this pioneering technology."

Christian's valve replacement was in May 2011. The first words out of the then 12-year-old's mouth after waking up from the four-hour procedure were "Can we go home now?" Before the procedure he could hardly handle his home's steep driveway. Within weeks of his discharge, he embarked on a cross-country road trip with his parents and four siblings. During the trip, he hiked miles every day through canyons, steep elevations and forests, none of which he could have accomplished prior to receiving his Melody valve.

Although Christian certainly appreciated the 31-day trek across the country, he is most pleased with his improved athletic ability.

"I played baseball in the spring, and after having the procedure, I could play so much better," Christian said. "I was able to run around the bases and steal second and run a whole lot faster to first base than I could have done before my surgery."

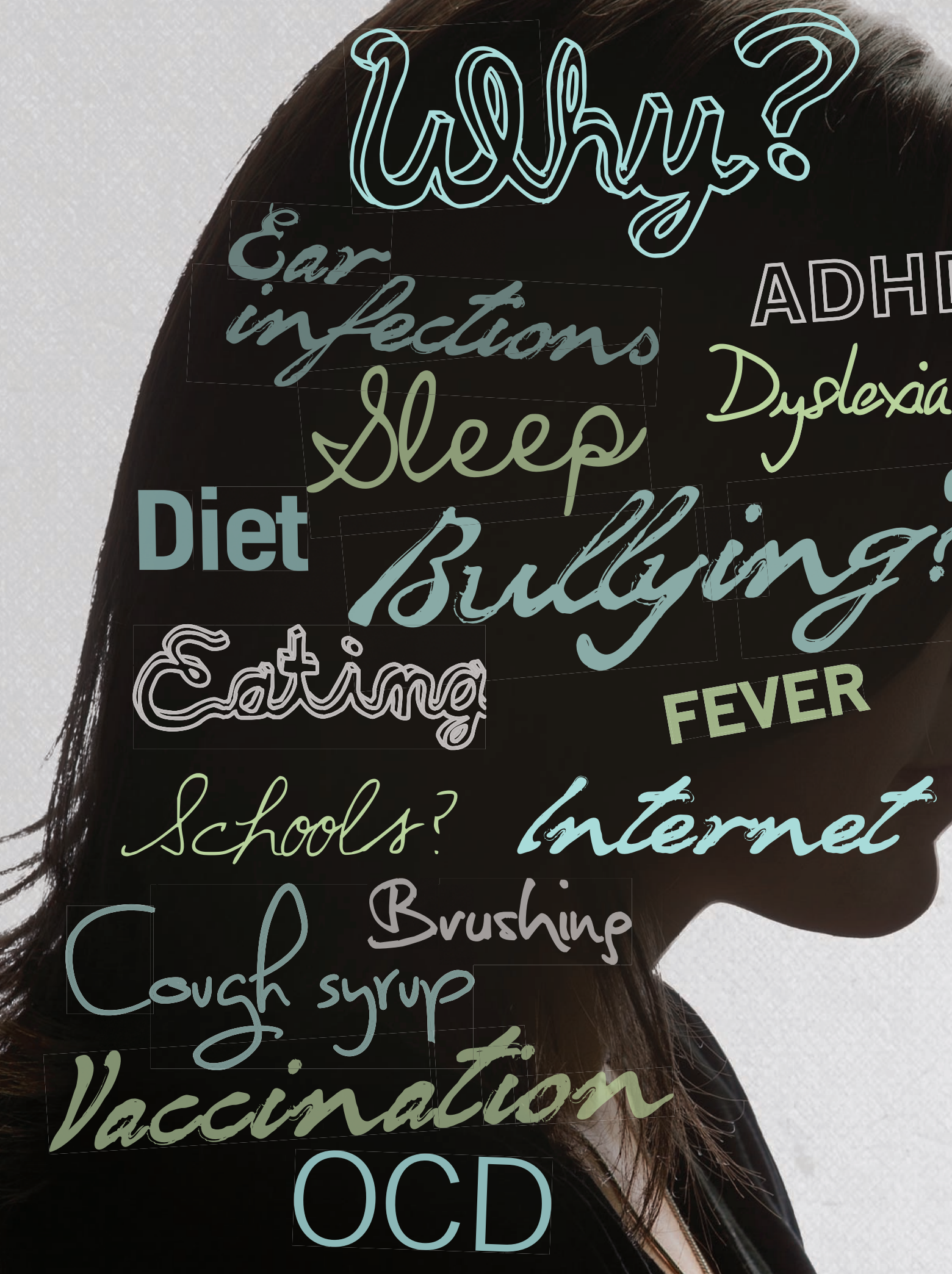
HOW IT WORKS

Once a patient is identified as an appropriate candidate for a Melody Transcatheter Pulmonary Valve, he can be educated on the process itself. Generally, the procedure takes two to three hours.

For Christian Banks, it was longer because he required additional stent placement prior to the Melody procedure. The procedure begins when a small access site allows a catheter to be inserted into the patient's femoral (groin) vein. The vein serves as a roadway for the catheter containing the Melody valve to be guided to the heart. The balloons contained in the Melody valve are inflated once the valve has been correctly positioned. The valve then expands and allows blood to flow unobstructed between the right ventricle and lungs. The catheter is then removed and dye injections are used to confirm that the device is working as it should.

Dennis Kim, M.D., Ph.D., is a pediatric cardiologist at Children's Healthcare of Atlanta Sibley Heart Center and Assistant Professor of Pediatrics at Emory University School of Medicine.

Robert M. Vincent, M.D., C.M., is Director of the Children's Sibley Heart Center Catheterization Lab and Professor of Pediatrics at Emory University School of Medicine.


Why?
Ear infections
ADHD
Dyslexia
Sleep
Diet
Bullying?
Eating
FEVER
Schools?
Internet
Brushing
Cough syrup
Vaccination
OCD

Fighting Fear *with* Facts

PEDIATRICIANS CAN HELP PARENTS SORT RISKS AND BENEFITS, MYTHS FROM FACTS

When the latest health scare buzzes through the online world, it is likely to ripple into your practice. Arsenic in apple juice? Mercury in vaccines? Dangers of antidepressants during pregnancy? It is natural for parents to harbor anxieties about their children's health, but in the Internet age, addressing fears and separating the real risks from the misconceptions is more important than ever.

My child has an ear infection and needs an antibiotic.

FACT: EAR INFECTIONS OFTEN SUBSIDE WITHOUT TREATMENT. THE AMERICAN ACADEMY OF PEDIATRICS RECOMMENDS THAT ALL INFANTS YOUNGER THAN 6 MONTHS SHOULD RECEIVE ANTIBIOTICS FOR OTITIS MEDIA, WHILE THOSE OLDER THAN 6 MONTHS SHOULD RECEIVE ANTIBIOTICS ONLY IF THEIR SYMPTOMS ARE SEVERE OR IF THEY HAVE UNDERLYING MEDICAL CONDITIONS, SUCH AS DOWN SYNDROME OR CLEFT PALATE.[2]

"These days, parents have access to more information than ever before," said Jennifer Shu, M.D., a pediatrician with Children's Medical Group in Atlanta. "The problem is they don't always know how to relate the information they get online to their own child's situation."

The information age has transformed the doctor-patient relationship, in some ways for the better. Having access to more information empowers parents to be participants in care decisions.

But when a parent is worried about her child's ear infection and searches online, she may find a scary headline such as: *Could a type of ear infection make a child obese?* Or, *1 in 5 kids with colds develop an ear infection.* Or the parent may learn on Wikipedia that an ear infection can result in a perforated eardrum, mastoiditis or bacterial meningitis.

"There are pros and cons to having all this information at your fingertips," said Dr. Shu, who is also editor of the Healthychildren.org website of the American Academy of Pediatrics. Children's Healthcare of Atlanta also maintains an informational website for parents with a glossary of pediatric health conditions at www.choa.org/childhealth.

By addressing the questions and concerns of parents, pediatricians may be able to improve compliance with treatment instructions, ease anxieties and strengthen the doctor-patient relationship. Dr. Shu suggests asking parents to provide their specific questions on the forms they complete when they check in for an appointment. This allows the pediatrician to target the discussion in the exam. Dr. Shu also often asks an open-ended question such as: "What are your concerns today?"

Help Parents Weigh Risks and Benefits

Some parental concerns about procedures or treatments are grounded in actual risks. In fact, informed consent prior to procedures often incorporates a laundry list of frightening possibilities. Pediatricians can help alleviate the concerns of parents by putting the risks into perspective.

"When children need surgery, parents are often more afraid of the general anesthesia than the procedure itself," said Rick Bonner, M.D., Executive Medical Director of Physician Practices at Children's Healthcare of Atlanta. "They worry that their child will be awake but unable to speak (a plot line of a recent movie) or that the child will be in pain during the procedure."

"We reassure them that their child is going to be well cared for by pediatric anesthesia providers," Dr. Bonner said. "Someone from our staff monitors the child at all times. We never leave the child's side."

For a healthy child, anesthesia is typically safer than the drive to the hospital or surgery center, he said. "Children with an underlying medical condition, such as asthma, diabetes or Down syndrome need special care but still can safely receive general anesthesia," said Dr. Bonner, who is also Medical Director of the Children's Surgery Center at Meridian Mark Plaza in Atlanta.

Parents may also have trouble identifying the risks and benefits of radiological procedures. Recently, a parent brought her child to Dr. Shu because of a stubbed toe and she wanted an X-ray to see if it was broken. But because no treatment was required for the toe, even if it were broken, Dr. Shu reassured the parent and offered suggestions about safe pain relievers and ways to protect the toe while it healed naturally.

But, according to Dr. Shu, if a parent comes in with a child who was momentarily knocked out while playing soccer, a computed tomography (CT) scan might be warranted to make sure there was no concussion—especially since the child would be at risk of further injury after returning to the soccer field.

If imaging is clinically indicated but the parents are reluctant, Dr. Shu explains the need for the scan compared with the small risks of radiation. She tells the parents that the radiation technicians will make sure to focus only on the injured

Mercury in vaccines causes autism.

FACT: AN INSTITUTE OF MEDICINE PANEL FOUND NO CAUSAL RELATIONSHIP BETWEEN VACCINES CONTAINING THIMEROSAL AND AUTISM.[3]

I should stop taking antidepressants if I become pregnant.

FACT: THE FOOD AND DRUG ADMINISTRATION WARNS THAT PAROXETINE (PAXIL) HAS BEEN ASSOCIATED WITH FETAL HEART DEFECTS IN THE FIRST TRIMESTER.[4]

THERE ARE ALSO SOME RARE RISKS OF PULMONARY HYPERTENSION IN NEWBORNS IF THE MOTHER TOOK A SELECTIVE SEROTONIN REUPTAKE INHIBITOR (SSRI) DURING THE SECOND HALF OF PREGNANCY.[5] AT THE SAME TIME, PREGNANT WOMEN WHO STOP TAKING ANTIDEPRESSANTS ARE AT RISK OF RELAPSING INTO DEPRESSION.

"My 2-year-old is congested and needs cold medicine."

FACT: THE FOOD AND DRUG ADMINISTRATION CAUTIONS THAT INFANTS AND CHILDREN YOUNGER THAN AGE FOUR SHOULD NOT BE GIVEN OVER-THE-COUNTER COLD OR COUGH MEDICINE BECAUSE OF CONCERNS ABOUT SAFETY AND EFFICACY.[1]

WEBSITES PARENTS CAN TRUST

Children's Healthcare of Atlanta: www.choa.org/childhealth
MedlinePlus: www.nlm.nih.gov/medlineplus/healthtopics.html
American Academy of Pediatrics: www.healthychildren.org
The Nemours Foundation: kidshealth.org/parent/

part of the body and will cover up areas that are sensitive to radiation," she said.

Allay Fears by Offering Alternatives

Sometimes, even when you have explained the risks and benefits of a treatment, parents remain reluctant. There can be ways to modify your usual recommendation to address their concerns.

"For example, parents who are fearful about their infant receiving too many vaccinations may feel better if they aren't given on the same day," said Dr. Shu. "Or a parent who does not want to give antibiotics to a baby for an ear infection may have the option of watching and waiting for 24 hours. The likelihood of an infection escalating quickly in an infant younger than 6 months is much greater than in children age 2 or older," she said.

"As long as he's getting better, you don't need to treat [the baby]," Dr. Shu advises parents. "If the fever goes higher, you need to treat the child right away. You also could ask the parents to bring the child in the next day to make sure he is improving," she said.

It is hard to have enough time in the typical patient visit to counteract all of a parent's possible misconceptions. But parents do appreciate some background about the medication or treatment you're prescribing—or not prescribing. "It can be helpful if the doctor says, 'If it were my child, this is what I would do,' and discuss why," said Dr. Shu.

If a parent is incompatible with an approach and resistant to medical advice, suggest a doctor who would be a better fit.

While treatment choices may vary, one maxim always holds true: "Doctors need to advocate for the child," Dr. Shu said.

Jennifer Shu, M.D., is a pediatrician with the Children's Medical Group in Atlanta.

Rick Bonner, M.D., is Executive Medical Director of Physician Practices at Children's Healthcare of Atlanta and Medical Director of the Children's Surgery Center at Meridian Mark Plaza, LLC. He is also a practicing pediatric anesthesiologist.

1 *U.S. Food and Drug Administration. Public Health Advisory: FDA recommends that over-the-counter (OTC) cough and cold products not be used for infants and children under 2 years of age. www.fda.gov/drugs/drugsafety/postmarketdrugsafetyinformationforpatientsandproviders/drugsafetyinformationforheathcareprofessionals/publichealthadvisories/ucm051137.htm. Updated Feb. 23, 2011. Accessed Sept.27, 2011.*

2 *American Academy of Pediatrics Subcommittee on Management of Acute Otitis Media. Diagnosis and management of acute otitis media. Pediatrics May 2004; 113:1451-1465.*

3 *Institute of Medicine. Adverse effects of vaccines: Evidence and causality. Washington, DC, The National Academies Press; 2011.*

4 *U.S. Food and Drug Administration. Public Health Advisory: Paroxetine. www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHeathcareProfessionals/PublicHealthAdvisories/ucm051731.htm. Dec. 8, 2005. Accessed Sept.27, 2011.*

5 *U.S. Food and Drug Administration. Information for healthcare professionals: Paroxetine (Marketed as Paxil). www.fda.gov/Drugs/DrugSafetyPostmarketDrugSafetyInformationforPatientsandProviders DrugSafetyInformationforHeathcareProfessionals/ucm085313.htm. Updated July 20, 2010. Accessed Sept. 27, 2011.*

Jay E. Berkelhamer, M.D.

ACGME Resident Guidelines Require a Fostering of Teamwork

Pediatric residents average 80 duty hours a week and have one 24-hour period away from the hospital. If you add in sleep time, that leaves them with about two to three hours each day for things like everyday activities and independent learning. All of that makes for a busy life. Yet, it is common for the senior physician staff to reminisce about the good old days when they were residents, working even longer periods and without adequate sleep. Clearly, the hospital has become a more intense environment with more complicated and sicker patients. Extraordinary scientific advances and new technologies have also added to the daily challenges of clinical practice. It ultimately became necessary for the Accreditation Council on Graduate Medical Education (ACGME) to regulate the number of duty hours to protect the safety of our patients and the health of our residents.

Capping the total hours for each resident has resulted in many creative adjustments in the on-call schedule and a considerable amount of shift work. Often, residents leave their patients to other residents to manage after they admit them. Daytime residents assume responsibility for part of the hospital stay, but then hand off their patients again when they leave for continuity clinic or finish their shift. We know there are inherent problems with so many transfers of responsibility. More formal sign-out rounds have become standard in most programs. The ACGME residency requirements state that "transitions of care are critical elements in patient safety and must be organized such that complete and accurate clinical information on all involved patients is transmitted between the outgoing and incoming individuals and/or teams responsible for that specific patient or group of patients." The introduction of computerized medical records with order entry capability has facilitated the multiple hand offs, as well.

Patient care in the hospital is too complex and must incorporate an approach that includes group think and accountability to the care team while taking individual initiative and responsibility for timely, consistent, personal, error-free care.

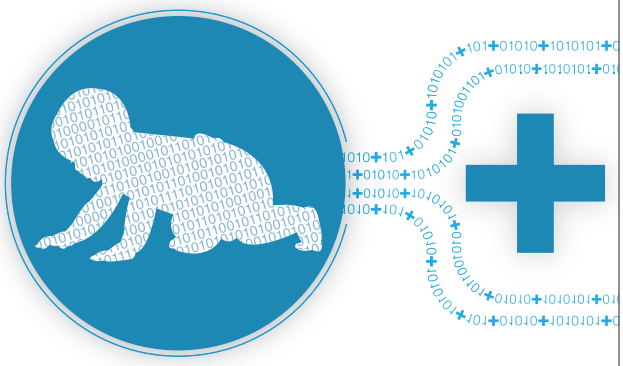
The quality of patient care depends on a high-functioning team of doctors, nurses and others who participate in the various efforts to deliver services to the child and her family. All members of the team have a role to play and must know when they are a critical component of ensuring the optimal outcome for each patient. Being a skilled participant in teamwork is a learned skill. In the past, most physicians learned to take responsibility for their patients in a personal way by functioning as the captain of the ship—acting congenial to all who helped care for their patients, but consistently calling all the shots in a take-charge manner. Our residents modeled these behaviors and matured into leaders with similar approaches and skill sets as their admired attendings. I am concerned that the reminiscing of our more senior physicians is, in part, a longing for the days when each doctor was the captain of his own ship and unilaterally made all the decisions while caring for his hospitalized patients. Truly, those days are gone. Patient care in the hospital is too complex and must incorporate an approach that includes group think and accountability to the care team while taking individual initiative and responsibility for timely, consistent, personal, error-free care.

Sleep deprivation may be less of an issue today, but becoming an effective team member is more difficult and paramount to ensuring the best patient care outcomes. The residency curriculum is crowded already, but I believe it is time to add a formal teaching module on how to function as a team member in a complex environment, such as in a children's hospital. We might benefit by adapting the training programs of other industries, such as the NASA curriculum designed to help astronauts become part of a highly functioning team.

Jay E. Berkelhamer, M.D., is a senior physician consultant on staff at Children's Healthcare of Atlanta. He also is Editor Emeritus of pēds and past president of the American Academy of Pediatrics.

STRENGTH IN NUMBERS

Neonatologists create new database with broader data on rare disorders



Neonatologists at 26 tertiary and quaternary children's hospitals, including Children's Healthcare of Atlanta, have a new tool to help improve their patients' outcomes—the Children's Hospitals Neonatal Database (CHND).

For more than 20 years, neonatal intensive care doctors in perinatal centers or birthing hospitals have had resources, such as the Vermont Oxford Network Database, in which to document their treatment and patient outcomes. Meanwhile, referral-only hospitals like Children's did not have a single database that focused on infants with rare disorders, congenital anomalies or surgical problems, as opposed to those whose health issues stemmed primarily from prematurity.

"We were frustrated that there were no databases for the types of patients we take care of—those with the rare disorders that we see maybe 10, 20 or 30 times a year," said Francine D. Dykes, M.D., Medical Director of Neonatal Services at Children's Healthcare of Atlanta at Egleston.

Five years ago, Dr. Dykes, along with neonatologists from around the country, created the Children's Hospitals Neonatal Consortium (CHNC). Their primary goal: to create a database that could turn a small sample of documented cases into a data set large enough to impact physicians' practices.

"For example," Dr. Dykes said, "in 2010, Children's only treated 14 infants with gastroschisis, while other hospitals in the CHNC treated about 185 patients with this condition. So for our physicians, the ability to access documentation on that many cases is invaluable."

The consortium's executive committee strategized for two years before they partnered with the Child Health Corporation of America (CHCA) to develop the data collection tool, which launched in June 2010.

While basic data is gathered for all patients in the Children's Neonatal Intensive Care Units (NICUs), the abstractors also collect more detailed information on disorders, such as:

- CHRONIC LUNG DISEASE
- DIAPHRAGMATIC HERNIA
- GI DISORDERS, INCLUDING ABDOMINAL WALL DEFECTS, BOWEL ATRESIAS/STENOSES, MALROTATION VOLVULUS AND NECROTIZING ENTEROCOLITIS

The consortium chose to focus on some of these disorders, such as diaphragmatic hernia, because they are rare and will benefit from a larger pool of data. Other conditions, like the GI disorders, were chosen because they are common and the physicians wanted to improve their management as soon as possible.

The data fields cover information such as demographics, diagnoses and treatments, detailed central line data, ventilator days, infections, alternative interventions, length of stays and treatment outcomes. Eventually, the CHND will have access to another CHCA database, Pediatric Health Information System (PHIS), to examine data about drugs and dosages, X-ray statistics and surgical procedures.

As of Sept. 26, 2011, there were 17,574 closed cases logged in the database, which is structured so each hospital can examine its own practices and outcomes and compare them to those of the other member hospitals. A case is considered closed when the patient has been discharged from the NICU, all patient data has been collected, and the file is complete.

In addition, the consortium plans to continually expand the scope of the diseases being studied.

"The CHND allows us to compare our performance with other participating hospitals—to learn from one another and translate those learnings into clinical practice," said John Zetzsche, Vice President of Quality and Medical Management at Children's. "The research opportunities will also enable us to improve patient outcomes."

Toward that end, the CHNC has a data-use committee that will help researchers utilize the database. There is also a quality committee, which will use the data to make improvements like decreasing infection rates, increasing survival rates, and putting more efficient, effective techniques into practice.

The potential is as great as the number of hospitals enrolled.

"It is on its way," Dr. Dykes said. "This tool will allow us to do what they do in the perinatal center hospitals and really make some changes in what we do with our patients."

Francine D. Dykes, M.D., is Medical Director of Neonatal Services at Children's Healthcare of Atlanta at Egleston and Associate Professor of Pediatrics (Neonatology) at Emory University School of Medicine. Dr. Dykes also is a member of the CHNC Executive Committee.

John Zetzsche is Vice President of Quality and Medical Management at Children's Healthcare of Atlanta.

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FEB. 3

Asthma Care and Education (ACE)

DESCRIPTION: This updated train-the-trainer program will provide the latest pediatric asthma information including the current National Institutes of Health (NIH) guidelines for the Diagnosis and Management of Asthma. All participants will receive the Asthma Care and Education (ACE) flip chart, a teaching tool with color pictures for educating children, parents and staff about asthma management.
LOCATION: Children's Healthcare of Atlanta Office Park, 1680 Tullie Circle, NE, The Learning Center
CONTACT: Nancy Richardson, 404-785-7843

MARCH 16 TO 17

18th Annual Echocardiography Conference

DESCRIPTION: The objective of this activity is to familiarize sonographers with the spectrum of common forms of congenital heart disease in children and adults. Attendees will have the opportunity to individually examine anatomic specimens with a variety of cardiac defects. Additionally, actual patients will be available for small group scanning and detailed discussion of specialized imaging techniques.
LOCATION: JW Marriott Atlanta Buckhead
CONTACT: Allison Krawczyk, 404-785-7744

APRIL 14 TO 15

New Horizons in Pediatrics

DESCRIPTION: The purpose of this conference is to update pediatric practitioners about the treatment of children and medical conditions that affect them. The conference will benefit pediatricians, family practice physicians, physician assistants and pediatric nurse practitioners. Nurses and other health professionals involved in the care of children may find the information useful and are welcome to attend.
LOCATION: InterContinental Buckhead Atlanta
CONTACT: Nancy Richardson, 404-785-7843

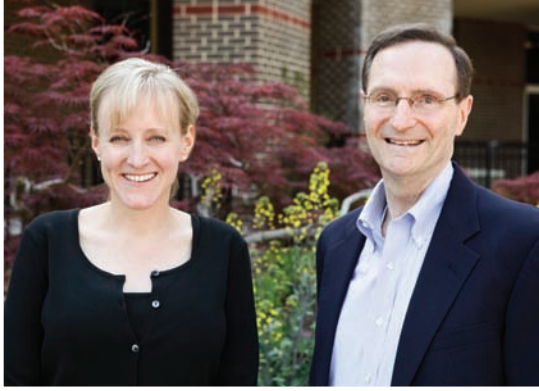
APRIL 28 TO 29

Managing the Pathway of Youth Sports Injuries: From Field to Return to Play

DESCRIPTION: This unique one and a half day conference will follow the pathway of five different sports injuries on a case-by-case basis. Each case will include presentations from certified athletic trainers, primary care physicians, orthotists, radiologists, surgeons and physical therapists as they demonstrate how to integrate their expertise into the care of the patient.
LOCATION: Georgia Tech Hotel and Conference Center
CONTACT: Allison Krawczyk, 404-785-7744

CASE IN POINT

By Deborah J. Andresen, M.D., F.A.A.P., and Julius Sherwinter, M.D., F.A.A.P.



A Teenage Female's Case History as Window to Rare Condition

A 15-year-old female presented with two months of intermittent shortness of breath and chest pain, and one month of dizziness and brief episodes of syncope. She was seen by her primary medical doctor (PMD) initially and prescribed an albuterol inhaler, which did not help her shortness of breath or chest pain. After a subsequent visit to the PMD with ongoing symptoms, she was referred to cardiology, where an EKG and cardiac evaluation were normal. Her symptoms were aggravated when standing or upon exertion. A diagnosis of neurocardiogenic syncope was entertained and increased fluid intake encouraged.

During the month prior to admission, she also complained of cold intolerance and headaches associated with nausea, as well as an 8-pound weight loss despite a reasonable appetite. Her symptoms of dizziness and headaches worsened after being hit in the head by a ball while playing dodgeball. She suffered disorientation but no loss of consciousness. Screening labs, including a CBC with differential, CMP and urinalysis were normal and an appointment with neurology was arranged. An EKG was repeated and was, once again, normal. She had multiple stressors, including bullying at school, parental divorce and recent transfer to a new high school. Her grandmother reported that the patient slept a great deal and seemed to lose interest in activities she previously enjoyed. Anxiety with panic attacks and depression were considered. Her pediatrician referred her for counseling.

Symptoms continued and, on a subsequent visit to her PMD, she experienced a syncopal episode while in the office and was referred to the Children's Healthcare of Atlanta Emergency Department. There, her blood pressure was 84/52 with a pulse of 128. She was alert and her physical exam was unremarkable except for tachycardia (with no murmur) and capillary refill of three to four seconds. She was given 2 liters of normal saline I.V. and her BP improved. Further history revealed an unusual craving for saltine crackers for one month prior to admission. Significant labs included a sodium 128, potassium 5.3, Chloride 95, bicarbonate 22, BUN 31 and Cr 0.9. CBC was normal. Capillary blood gases revealed a pH of 7.17, pCO_2 53, with a base deficit of -9.

The differential diagnosis was broad and included dehydration, vasovagal syncope, postural orthostatic tachycardia syndrome (POTS), cardiac disease, endocrine issues (e.g., adrenal insufficiency and SIADH), malignancy, infection, inflammatory bowel disease and eating disorders.

A cortisol level was obtained and was depressed at 0.3 (afternoon normal values range 1.7 to 14.1). The diagnosis of adrenal insufficiency was strongly suspected in view of the hyponatremia, hypotension and hyperpigmentation (noted on closer examination of her skin).

TO LEARN THE FINAL DIAGNOSIS AND TREATMENT, VISIT US AT WWW.CHOA.ORG/PEDS.

Deborah J. Andresen, M.D., F.A.A.P., is a pediatric hospitalist at Children's Healthcare of Atlanta and Director of Academics for the Children's at Scottish Rite hospitalist group.

Julius Sherwinter, M.D., F.A.A.P., is Section Chief of Pediatric Nephrology at Children's Healthcare of Atlanta and Chairman of Physician Continuing Medical Education at Children's. He is also Clinical Associate Professor of Pediatrics at Emory University School of Medicine.

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A Network of Nine

Leading the Nation in Pediatric Cardiac Research

The Emory+Children's Pediatric Research Center, which is a collaboration between Children's Healthcare of Atlanta and Emory University School of Medicine, joins eight other core sites across the nation and Canada as part of the federally funded Pediatric Heart Network (PHN). Together, these leading institutions will work to advance the study of congenital and acquired heart disease in children.

"As a core site, our center will play an important role in designing and implementing the major clinical studies in pediatric cardiology," said William Mahle, M.D., Medical Director of Clinical Research at the Children's Sibley Heart Center. "We will have more support, more resources available and a solid infrastructure that will raise the quality of research we are doing."

Funded by the National Heart, Lung and Blood Institute, the cooperative network of research centers will receive $19.6 million allocated during a five-year period to support two primary studies to be determined through a proposal process. The core sites will follow predetermined protocols for each study, collecting the same data and treating patients similarly to ensure the accuracy of findings.

"As a core site, our center will play an important role in designing and implementing the major clinical studies in pediatric cardiology."

At the forefront of the Emory+Children's PHN efforts are Dr. Mahle and William Border, M.B.Ch.B., M.P.H., Director of Noninvasive Imaging and Medical Director of the Cardiovascular Imaging Research Core (CIRC) at the Sibley Heart Center. This team will recruit study participants from Atlanta and the surrounding areas who, prior to the PHN designation, traveled hundreds of miles to participate in trials for congenital or acquired heart diseases.

"Our patients will get to take part in some of the highest quality research in the country," Dr. Mahle said. "The PHN designation confirms that children in Atlanta have access to both a first-rate health system and a leading child health research institution."

William Mahle, M.D., and **William Border, M.B.Ch.B., M.P.H.,** are both pediatric cardiologists at Sibley Heart Center and Associate Professors of Pediatrics at Emory University School of Medicine.