New Pediatric Specialist Guide

The 2006–2007 Pediatric Specialist Guide (PSG), an easy-to-use directory to assist you in contacting the appropriate specialist at Children’s Hospital Boston, is now available. The guide is organized by specialty/subspecialty and provides quick access to basic contact information for our specialists, including telephone and fax numbers, email addresses, office locations and directions/maps to Children’s. In addition, the PSG provides department/division descriptions, guidelines on how to refer a patient, accepted health insurance, and more.

All PSG information is also available online by visiting www.childrenshospital.org and clicking on “Find a Specialist.” Additional information, such as a specialist’s education/training history, professional experience, curriculum vitae and community-based office locations, can be found as part of our online physician profiles.

A “Print-On-Demand” feature allows you to generate a PDF file of the most up-to-date information, whether you’d like to print the entire guide or just one department/division. We also offer a new option to download the PSG—the entire directory or a particular department—to your personal digital assistant.

You will receive a copy of the 2006-2007 PSG by mail. To request additional copies, send your mailing address to marketing@childrens.harvard.edu.

MR-OR in action

When 13-year-old Nichole Paone awoke one chilly morning in November, something just wasn’t right. She’d been lethargic for several days prior, experiencing a tingling sensation in her head and some mild vomiting. But that particular Tuesday, she was looking almost yellow.

Nichole had been in and out of her pediatrician’s office all month, undergoing several tests to determine what was causing her symptoms. When the tests turned up empty, she was eventually referred to a neurologist, but the appointment wasn’t for another few days.

But that wasn’t soon enough for her mother, Michelle, who had been watching her little girl’s symptoms change and get worse over the weeks. So, she brought Nichole to Children’s Hospital Boston’s emergency room later that day.

A CT scan revealed that Nichole had a tumor the size of a baseball lodged in the back of her brain. “The tumor was a juvenile pilocytic astrocytoma (JPA),” says neurosurgeon Liliana Goumnerova, MD. “This is probably the most common tumor in that location in children. There are no known causes of JPA; it is believed to occur sporadically.”

Nichole, who wants to be a veterinarian, took her diagnosis in stride. When told she had a brain tumor, she described, in great detail, a brain operation she had

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Cardiology multimedia library

The Department of Cardiology has created a web-based multimedia library that provides an unprecedented and unique review of congenital heart disease. The site, edited by Children’s Hospital Boston cardiologist Robert Geggel, MD, includes images (electrocardiograms, chest radiographs, diagrams, gross pathology, audio [phonocardiograms] and video [echocardiography, angiography], magnetic resonance imaging, cardiac surgery) to help educate both physicians and families about congenital heart disease.

Visit www.childrenshospital.org/mnm/cvp for more.

Current Concepts in Pediatric Health Care
An online, lunch-time learning opportunity, which is part of a series sponsored by GE Healthcare and MGIC. This complimentary, cutting-edge program featuring Children’s Hospital Boston specialists is intended for primary care physicians, pediatricians, family practitioners, pharmacists and nurses. Talks can be viewed online or through TiP-TV, where available.

April: Update on Childhood Acute Lymphoblastic Leukemia by Lewis Silverman, MD.

May: Pain issues in Pediatric and Adolescent Gynecology: Overlap, Cysts, Tumors, Endometriosis and Congenital Anomalies of the Reproductive Tract by Mark Laufer, MD (See related article on page 3).

June: Angiogenesis-dependent Diseases by J. Attia Follman, MD.

July: Assessing and Treating Pediatric and Adolescent Scoliosis by John Droizas, MD.

August: What to Do When Sciatica Won’t Stop by Janice Ravilis, MD, and Joseph Madan, MD.

September: Evolving Management of Hypothalamic-Left Heart Syndrome: From Fetal to Post-Natal Intervention by Roger Brentbart, MD, and Prudho del Nido, MD.

To register, visit: www.chibpc Pediatric.com.

Talking about endometriosis

What is endometriosis? Endometriosis is a condition that occurs when tissue similar to the lining of the uterus is found outside its normal location. Common locations of these endometrial implants, or lesions, include the ovaries, fallopian tubes, ligaments that support the uterus, and tissue covering the bladder and rectum. The location of the endometrial implants, and the way in which the lesions affect the pelvic organs, contributes to the symptoms adolescent and adult women may have. Some teens with a lot of lesions have very little pain, while others with a small amount have severe pain.

What causes endometriosis? Although we know that some young women may be slightly more likely to develop endometriosis because female relatives have it, the truth is, we don’t know the cause of this disease. Any woman, anywhere, can get endometriosis.

What symptoms are associated with endometriosis? The most common symptoms include occasional or constant pelvic pain and/or severe period cramps—often referred to as chronic pelvic pain—before, during or after a period. Menstrual cramps are cyclic or acyclic. Teens may experience pain at rest, with exercise, sex or after a pelvic exam. Painful or frequent urination, diarrhea or constipation may accompany the pelvic pain, confusing the diagnosis of endometriosis.

Endometriosis may affect the pelvic organs, contributes to the presence of pain, control the progression of the endometriosis and preserve fertility. Treatment may range from taking medications, such as releasing hormone drugs, such as Lupron, temporarily stop periods by lowering estrogen levels. During laparoscopy, doctors can use special instruments to laser or cautere the endometriosis. Many teens find relief from symptoms after going through this procedure, although over time, some may experience pain again.

Acupuncture, herbal remedies, homeopathy and healing touch are a few alternatives we’ve seen grow in popularity. We’ve also found many of these therapies to be effective. We encourage patients to speak with their primary care doctor or gynecologist before pursuing alternative treatments, as research studies are limited and not every alternative approach has been proven to be safe and effective.

Each month the CWWH hosts an on-line chat about endometriosis, inviting women anywhere in the world to participate. Additional on-line chats are held each month on a variety of topics.

To learn more, visit www.youngwomenshealth.org.

Some common treatment methods include:
• Over-the-counter pain relievers, such as aspirin, acetaminophen, ibuprofen and naproxen sodium can offer relief for some. Others require prescription drugs.
• Oral contraceptives taken continuously relieve symptoms in eight out of 10 patients. GnRH agonists (gonadotropin releasing hormone drugs), such as Lupron, temporarily stop periods by lowering estrogen levels.
• During laparoscopy, doctors can use special instruments to laser or cautere the endometriosis. Many teens find relief from symptoms after going through this procedure, although over time, some may experience pain again.
• Acupuncture, herbal remedies, homeopathy and healing touch are a few alternatives we’ve seen grow in popularity. We’ve also found many of these therapies to be effective. We encourage patients to speak with their primary care doctor or gynecologist before pursuing alternative treatments, as research studies are limited and not every alternative approach has been proven to be safe and effective.
• Eating well and getting enough rest helps the body to manage pain. Exercise often helps to relieve or lessen pelvic pain and menstrual cramps. Practicing relaxation techniques, such as yoga and meditation, help ease pain too.
• Many centers work closely with other health care providers in programs that provide treatment and support for acute and chronic pain. Following an evaluation, services such as biofeedback, physical therapy, TENS (transcutaneous electrical stimulation) and exercise programs, may be offered.

Is endometriosis being researched? Yes. A variety of research is underway around the world. At Children’s, we’ve just finished collecting data on a blood test for endometriosis that may one day provide a less invasive approach to the problem. We are also studying the way complementary and alternative therapies, such as acupuncture, may help manage symptoms alone or in conjunction with other forms of treatment.

Where can young women or parents find more information? The Center for Young Women’s Health is a great resource for young women, parents and health professionals. Their Web site (www.youngwomenshealth.org) includes pages on basic health, nutrition and fitness, emotional health, sexuality and reproductive health. Common questions about endometriosis are answered in sections specific to teens, parents and health professionals. The Endometriosis Association (www.endometriosisassoc.org) is another good resource for more information on endometriosis.
The Next STEP

When he was just one day old, Devin O’Blean had surgery at Long Island Jewish Hospital in New York to correct a twisting of his intestine. But when the problem persisted, an additional surgery was required to remove the damaged segment of his intestine altogether.

As a result, Devin developed short bowel syndrome (SBS), a condition in which patients are without a significant length of their small intestine and are usually deficient in a range of important nutrients, because their intestine cannot absorb enough nutrition from regular food.

Treatment consists primarily of nutritional management to help the remaining intestines adapt and take on the absorption functions that were lost. Many SBS patients get nutrients delivered directly into their stomach or small intestines via enteral nutrition. But in some cases, this is not possible, so patients must get nutrition intravenously through parenteral nutrition (PN). Depending on the length and health of the remaining intestine, nutritional support becomes a lifelong necessity for some patients.

As a newborn with SBS, Devin was put on PN immediately and did well enough to go home after four months. A few days after discharge, however, Devin’s parents noticed a yellow discoloration of his skin and eyes. After consulting with their doctors at Long Island Jewish Hospital, the O’Bleanis traveled to Mount Sinai Hospital, where doctors ran tests and found damage to his liver. It was determined that stapling v-shapes into alternating sides of the bowel will decrease its width and increase its length. Thus, the intestine eventually stretches out and becomes a normal tube, and food is propelled down the tube like a normal piece of intestine.

The O’Bleanis agreed to the surgery, and just weeks later, Devin was back in Boston to undergo a STEP procedure. Following the STEP, his condition improved almost immediately. Devin’s bilirubin level, which was causing his yellow discoloration, began to recede. And while a biopsy taken during surgery revealed some damage to his liver, it was determined that proper nutritional care would be able to reverse it.

“Patients like Devin are complex, but they can be helped if they get the right kind of care,” says Dr. Jaksic, the Short Bowel Syndrome Program’s surgical director. “They present a number of challenges, primarily because their care involves so many different specialties.”

Delivering effective nutrition to patients like Devin demands important contributions from a multidisciplinary team, including gastroenterologists, dieticians, pharmacists and nurses. Dr. Christopher Duggan, MD, MPH, medical director of the Short Bowel Syndrome Program, helps direct how to best to keep kids with SBS growing.

“Devin was pretty malnourished when he got here,” says Dr. Duggan. “The first thing we did was an intensive assessment of his nutritional status and nutrient needs. We were also very aggressive in weaning him from parenteral to enteral nutrition.”

Other team members involved in his care include: Clifford Lo, MD, PhD; Sharon Collier, RD; Julie Iglesias, CPNP; Kathleen Gura, Pharm D; and Denise Richardson, RN.

Today, Devin, an energetic 4-year-old, is back home in New York. Since his STEP surgery in 2003, he has gradually been taken off PN and is now eating everything by mouth. Although Devin sometimes requires extra fluid through his G-tube to supplement his oral diet, it’s a marked improvement for the O’Bleanis family. “The doctors at Children’s gave us our life back—which is Devin,” says Vette.

For more information on Children’s Hospital Boston’s Short Bowel Syndrome Program, visit www.childrenshospital.org/sbs.

To schedule an appointment, call (617) 355-9600.

One STEP at a time
1. Short bowel syndrome causes the bowel to grow wider to absorb nutrients.
   But this can cause life-threatening infections.
2. With the STEP procedure, the bowel is stapled on alternating sides.
3. When complete, the bowel is longer, making digestion easier.

Teenagers’ dieting may affect mothers’ concerns

Teenagers who think their mothers put a premium on thinness may be more likely to worry about their weight and diet frequently, suggest new findings from the Growing Up Today Study, published in the December Archives of Pediatric Adolescent Medicine.

Investigators at Children’s Hospital Boston and Brigham and Women’s Hospital surveyed more than 9,000 U.S. adolescents and their mothers. Overall, 33 percent of girls, 8 percent of boys, and about half the mothers reported frequently thinking about wanting to be thinner. But girls who thought their mothers put too much weight on their own weight or on other people’s, since teens can internalize negative messages, and instead, promote physical activity and sound nutrition.

Children with heart defects can benefit from exercise

Children with serious congenital heart defects are typically urged to restrict their activity, but a pilot study at Children’s Hospital Boston, published in the December Pediatrics, indicates that most of these children can benefit from cardiac rehabilitation.

The study enrolled 19 children, ages 8 to 17, in a 12-week program of stretching, aerobics and weight/ resistance exercises. All the children had cardiac disease severe enough to consider restricting their activity, and all showed reduced function on exercise tests, but none had test findings that might raise a safety concern, such as arrhythmias or chest pain. Still, all 16 children who completed the program had undergone heart surgery or a nonsurgical procedure in the past, and 11 of the 16 had just one functional ventricle.

The hour-long sessions, held twice weekly, were tailored to the children’s interests and included dance, calisthenics, kick boxing and jump rope. Balls, music, games, relay races and age-appropriate prizes helped keep the kids motivated and sessions were moved outdoors whenever possible. Heart rate was checked initially and two to three times during each session. A pulse oximeter and external defibrillator were available on site, but were never needed, since there were no adverse events.

At the program’s end, 15 of 16 children had significantly improved peak work rate, peak oxygen consumption, or both—their hearts pumped more blood with each beat, and their muscles used more oxygen. Functional improvements were as high as 20 percent on some parameters.

Children’s cardiologist Jonathan Rhodes, MD, who led the study, believes that some of the reduced exercise capacity in children with congenital heart defects is due to inactivity. In this pilot study, he notes, fewer than 10 percent of children with diminished exercise capacity had conditions that made it dangerous to exercise. “With the approval of a pediatric cardiologist, and after careful exercise testing, exercise is generally safe and tolerable,” he says.

Follow-up exercise testing, roughly 7 months after program completion, showed that participants’ cardiac benefits were sustained, whereas non-participating children had a slight decline in cardiac function. Participants reported exercising more in the past and had higher behavioral, emotional and self-esteem scores.
New network services

The Division of Genetics is now seeing patients at Children's Hospital Boston at Waltham. To schedule an appointment, call (781) 216-2100. In addition, geneticist Jonathan Picker, MBChB, MSc, PhD, will begin seeing patients at South Shore Hospital this March. To make an appointment, call (781) 331-4715.

The Hearing Technology Center opens at Children's Hospital Boston at Waltham on February 21. Headed by audiologist Mary Ellen Coran, MA, CCC-A, the center will professionally fit and dispense hearing aids and assistive listening devices for teens and adults with sensorineural hearing loss. To schedule an appointment, call (781) 216-2100.

MR-OR — continued on page 6

While anesthesiologist Craig McClain, MD, managed Nichole's anesthesia, Dr. Goumnerova removed Nichole’s tumor using her usual metal surgical tools instead of the non-metallic instruments that must be used in previous MR operating rooms. And before Dr. Goumnerova closed the wound, radiologist Caroline Robson, MB, ChB, chilled the MRI from its deck to scan Nichole's brain to determine if the entire tumor had been resected. And in fact, it had.

"Nichole's case is a perfect example of how the new MR-OR can be used to benefit our patients," says Dr. Goumnerova, citing that 12 patients have now undergone procedures in the cars identical to the images we obtained during her surgery was very good, so we were able to interpret them accurately to see if the tumor has been completely removed, therefore avoiding additional procedures."

By 11 a.m. Nichole was out of surgery and recovering in the ICU, and by 2 p.m. that afternoon, she was already up and walking to the restroom with the help of her mother and her nurse. She spent just three additional days in the hospital before returning home.

BecauseNichole experienced a mild problem with coordination on her left side affecting her arm and leg after surgery, Nichole has since completely recovered. "She was out of school for about a month, but that mostly has to do with the holidays," says Michelle. "And she's already caught up on all of her school work. You look at her, and you'd never even know she'd just had brain surgery. It's truly amazing."

Nichole returned to Children's in January for a follow-up visit with Dr. Goumnerova and was given a clean bill of health. "Nichole has recovered wonderfully from the surgery," says Dr. Goumnerova. "Her examination was normal, and she can return to her usual activities without any restrictions. Generally, these tumors tend to complete removed, so Nichole's long-term outcome is expected to be excellent."

For more information on our MR-OR, visit www.childrenshospital.org/mr. To schedule an appointment in the Department of Neurosurgery, call (617) 355-6009.

Detecting CO

• When buying a CO detector, check for the UL approved label.
• Digital display models show the CO level, rather than simply beeping.
• Install CO detectors in a central area on every floor and near sleeping areas.
• Detectors should be placed at least five feet above the ground, as CO rises.
• Hard-wired and plug-in models won't work during a power outage.
• Like smoke detectors, batteries need to be replaced every year.
• CO detectors lose sensitivity over time and should be replaced every five years.

Source: Consumer Reports, 2005.

How do detectors work?

CO detectors can be purchased at most hardware stores, can be hardwired, battery-operated or plugged-in.

Most beeps when levels have been at 70 ppm for an hour, or sooner if levels are higher. Although symptoms usually go unnoticed at this level, if the alarm sounds, immediately open windows and doors for ventilation, leave your home and call 911 immediately before symptoms or unconsciousness occur.

How can you prevent exposure?

It’s important to have your fuel-burning appliances inspected by a qualified professional at least once each year. But the most important thing you can do is to have a CO detector in your home.

When a sleeping 10-year-old girl died in her home last year because a snow drill blocked an outside vent, the state of Massachusetts passed “Nichole’s Law” requiring all residential buildings to be equipped with CO detectors. Other states have passed similar laws.

30:2

New CPR guidelines

In November 2005, the American Heart Association released new CPR guidelines. They now recommend that all rescuees employ a chest compression-to-breath ratio of 30:2 on all victims from infants (excluding newborns) to adults, with no increased flow rate to the heart, brain and other vital organs.

When parents tuck their children into bed at night, they usually feel assured that they’re as safe as can be. But what if a “sleeping killer” could be on the loose in some homes, putting the whole family at risk of illness or even death?

What is carbon monoxide? Carbon monoxide (CO) is a gas that is produced when fuel—gasoline, propane, natural gas, oil, wood, or coal—is burned. CO is extremely dangerous to people when emitted in an enclosed, unventilated area, such as a home or garage.

What happens during poisoning? Both children and adults can become very ill and even die within minutes or hours of exposure. Pregnant women, their unborn children, babies, heavy smokers, and people with anemia, heart or lung disease may be affected more quickly or seriously. Symptoms and effects vary between individuals, even at the same level of CO exposure, but people typically experience flu-like symptoms, including: dizziness, fatigue, weakness, headache or vomiting, trouble breathing, confusion, ringing in the ears, heart fluttering, gastrointestinal complaints, increased blood pressure, or bright red or pink skin, mucous membranes or nails.

Death from CO poisoning can result even if none of these symptoms occur. In some cases, people fall unconscious before ever feeling ill. Some CO poisoning victims have described drifting in and out of consciousness, but being completely immobilized and unable to get themselves out of the area.

How many people die from CO exposure? According to the Journal of the American Medical Association, 1,500 Americans die every year from accidental exposure to CO, and there are more than 10,000 injuries each year.

Although most CO poisoning happens during a one-time sudden incidence, it is possible to suffer from chronic CO poisoning. This is when someone is exposed to low levels over weeks or months (for instance, due to a faulty oil-burning furnace), and experiences symptoms over that time.

How do you prevent exposure?

It’s important to have your fuel-burning appliances inspected by a qualified professional at least once each year. But the most important thing you can do is to have a CO detector in your home.

When a sleeping 10-year-old girl died in her home last year because a snow
DID YOU HEAR?

The center for Communication Disorders, under the leadership of Howard Shane, PhD, is now seeing patients at Children's Hospital Boston at Waltham.

The center combines five programs in audiology, augmentative communication, and speech and language pathology to serve the needs of infants to adolescents (and some adults) with speaking or hearing impairments.

To schedule an appointment, call (781) 216-2100. For more information on services available, visit: www.childrenshospital.org/ccd.

Pediatric Views

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The information in this newsletter should not be taken as medical advice, which can only be given to you by your personal health care professional.

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