

Managing ADHD: Bridging the informational disconnect between parents and physicians



Stephen Porter, MD, MPH, and Eugenia Chan, MD, MPH

Properly treating attention deficit hyperactivity disorder (ADHD) requires consistent monitoring of a child's symptoms, medications, behaviors and side effects. Paper-based questionnaires from the National Initiative for Children's Healthcare Quality—namely, the Vanderbilt Assessment, a method to establish the frequency of symptoms and diagnose ADHD—have been proposed for use in primary care, with parents as the logical choice to manage this task.

"But this can present challenges, since sometimes these forms gets filled out, sometimes not," says **Stephen Porter, MD, MPH**, a specialist in pediatric emergency medicine and medical informatics at Children's Hospital Boston. "There's very little systematic data

collection going on that can be used to help doctors gauge a drug's effectiveness in ADHD. Physicians solicit bigger, gestalt opinions from parents—like whether a drug is working or not—but don't necessarily drill down to what types of behavior it's working for and why."

Since this pen-and-paper process has been inefficient at capturing information necessary for the routine, systematic monitoring of children with ADHD, Dr. Porter decided to make use of computer technology and the Internet. He collaborated with William Gribbons, PhD, a professor at Bentley College in Waltham, to design a Web-based data entry tool for parents to regularly update doctors about their child's ADHD.

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Pediatric Multiple Sclerosis and Related Disorders Program


Children's Hospital Boston pediatric neurologist **Mark Gorman, MD**, has developed the Pediatric Multiple Sclerosis and Related Disorders Program to care for children and teens with multiple sclerosis (MS), acute disseminated encephalomyelitis (ADEM), optic neuritis and transverse myelitis. The program's team includes a nurse, pediatric neuropsychologist, educational liaison, child psychiatrist, social worker and family advocate.

Traditionally an "adult" disease, pediatricians may not expect to see young patients with MS. However, it is becoming increasingly diagnosed in children and teens, with up to 10 percent of patients with MS first developing symptoms before age 18. Symptoms present in a relapsing-remitting fashion and include:

- vision loss or double vision
- weakness
- numbness or tingling
- clumsiness and difficulty walking
- declining school performance

Pediatricians with patients presenting with such symptoms can refer for further evaluation. Children's specialists conduct a neurologic exam, brain and spine MRIs and a lumbar puncture to determine the diagnosis. Through a close follow-up process, Dr. Gorman and his team pay special attention to distinguishing one-time events, such as ADEM, from recurrent disorders, such as MS. If MS is diagnosed, prophylactic treatment, such as interferons, is offered to reduce relapses and improve the long-term prognosis. If patients do not respond, there are several second- and third-line agents available. If relapses occur, outpatient infusions of corticosteroids are available to avoid unnecessary hospitalizations. Patients with MS and related disorders receive comprehensive care, including a neuropsychology assessment to identify potential learning disabilities and guidance in formulating education plans.

Because MS is a chronic disease requiring ongoing care through adulthood, Children's program helps patients transition to adult specialists.

 Make a referral: 617-355-2758

 More information: childrenshospital.org/ms



Children's Hospital Boston



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A new clinical research volunteer registry

CHB-Connect is a new way to connect individuals—including parents, children and members of the community who may be interested in participating in clinical research studies—with researchers at the hospital.

Individuals who register will be able to select specific medical areas of interest or register as a healthy participant. At the same time, researchers with IRB-approved protocols at Children's Hospital Boston can access the registry's database and contact individuals in the registry to find out if they're interested in participating in specific studies. Registering is fast and secure.

-  Register as a volunteer: childrenshospital.org/connect
-  Register as an investigator: crp-apps.chboston.org/connect

New VUR tool



Hiep Nguyen, MD, director of the Robotic Surgery Research and Training Center, and **Carlos Estrada Jr., MD**, assistant in Urology, have developed a tool to help pediatricians and family practitioners determine the probability of resolution of vesicoureteral reflux.

-  More information: childrenshospital.org/vur

Robotic surgery Webcast




Watch **Hiep Nguyen, MD**, co-director of the Center for Robotic Surgery, perform an intravesical ureteral reimplantation procedure using robotic-assisted surgery to correct vesicoureteral reflux in a 6-year-old patient. Also, learn more about procedures employing the *da Vinci* Surgical System, such as pyeloplasty, continent urinary diversion and bladder augmentation.

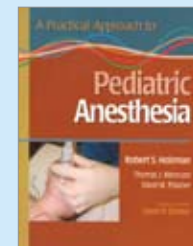
-  Check it out: childrenshospital.org/webcasts

Screening for CMV

Congenital cytomegalovirus (CMV), a common virus transmitted *in utero* and present in one out of every 200 births, often results in permanent hearing loss. When diagnosed promptly after birth, anti-viral medications can often prevent or slow down the progression of the hearing loss. **Margaret Kenna, MD, MPH, FACS**, associate in Otolaryngology, is part of the CMV Task Force, a coordinated team of physicians and audiologists at Children's, Beth Israel Deaconess Medical Center and Brigham and Women's working on an initiative to screen babies for CMV infection.

-  If you suspect CMV in a newborn or if a patient has failed a newborn hearing test and needs further evaluation: 617-355-6832 or 617-355-8852

A Practical Approach to Pediatric Anesthesia



By **Robert Holzman, MD, FAAP**, and **Thomas Mancuso, MD, FAAP**, of Children's Department of Anesthesiology, with David Polaner, MD, FAAP.

This new edition of the comprehensive guide to pediatric anesthesia focuses on the pediatric patient, clinical and operational aspects of pediatric anesthesia, and anesthetic management of normalities and abnormalities of organ systems.

Quick and Easy Recipes for Teens



Children's Center for Young Women's Health (CYWH) has released the second edition of its cookbook,

which offers 120 recipes with detailed nutrition information analyzed by Children's nutritionists, health guides and several vegetarian and ethnic recipes. The book is \$24.95 and all proceeds support CYWH programs.

youngwomenshealth.org/cookbook.html

The Menstrual Cycle and Adolescent Health



Edited by **Catherine Gordon, MD, MSc**, of the Bone Health Program, with five others.

This volume features the results of a meeting held at the National Institutes of Health to advance the goal of having the menstrual cycle accepted and understood as a marker of general health in adolescent girls.

blackwellpublishing.com

Social anxiety disorder

Joseph Gonzalez-Heydrich, MD, chief of Children's Hospital Boston's Psychopharmacology Program, specializes in mood disorders, problems with impulse control, developmental disorders and psychosis. Here, he discusses diagnosis and management of social anxiety disorder (social phobia).

What are the typical features of social anxiety disorder?

Those with social anxiety disorders have an intense and persistent fear of situations in which they're exposed to unfamiliar people or scrutiny. In social situations, they're afraid that people are looking at them, and overestimate the chances that people are going to reject them or that they're going to be embarrassed. Exposure to these situations provokes anxiety responses like panic, freezing, blushing, tantrums, crying and clinging. People with social anxiety disorder tend to avoid these situations for obvious reasons. Over time, this gets in the way of social development and can become a real cost to them in terms of education, family functioning, employment and overall happiness.

How are children affected by social anxiety disorder?

The rate in children is thought to be 0.5 percent to 4 percent. In adolescents, it may be as high as 7 percent. It's not known why certain children are affected, but it's thought that it may be hereditary. Parents with panic disorder, for example, have a higher rate of children who have social anxiety disorder.

Is it more common in boys or girls?

It seems like it's more common in girls, but if you look in treatment settings, there are more boys than girls. It's not known why that is, but it's probably because being more socially inhibited and shy, even extremely shy, is more acceptable in girls. So boys are more likely to be identified and get referred for treatment.

How early can it be diagnosed?

Most diagnoses are made in adolescence when it's obvious that children are not doing the things developmentally that they should be doing—they're not going out with peers, they're avoiding talking with classmates and with people in authority, they're not joining teams or clubs. However, social anxiety can be detected in children as young as 8. In fact, if a child presents with clear social anxiety disorder before age 11, it is likely to persist into adulthood and referral for treatment is recommended. If it presents in adolescence, there's a greater chance that it will remit with experience over time.

How does social anxiety disorder differ in children vs. adolescents?

In children, it manifests itself with freezing, selective mutism (refusing to speak in public), tantrums or never leaving the mother's side at a birthday party. Adolescents exhibit symptoms like not participating in after-school activities, never talking in class or they'll never return something in a store or talk to a person of authority for fear of being embarrassed. Seventy-five percent of adolescents with social anxiety disorder report no or few friends, 50 percent have no extracurricular activities and 10 percent refuse to attend school regularly.

What symptoms should pediatricians look for during an office visit?

Children and teens often deny their symptoms, so it's important to ask the parents. Basically, you look for extreme shyness that's causing significant interference with a child's normal development and quality of life. Questions should include: Does Johnny avoid going to parties or joining clubs? Does Johnny avoid talking to classmates or to people he doesn't know well? Is he bothered by blushing? Does he avoid being the center of attention? If the answers are positive and the child is not doing things that are developmentally appropriate for his or her age, then it's worth referring to a psychotherapist for formal evaluation.

How is social anxiety disorder treated?

The first line of treatment for mild and moderate social anxiety disorder is psychotherapy to give the child tools to deal with the anxiety. The therapist will look at the child's distortions—people are looking at me all the time, they think what I say is stupid—and will help the child develop automatic ways of dealing with these thoughts, and help him understand that maybe there's another way of thinking about his distortions. Exposure is also a part of treatment. For a child whose anxiety is so strong that you can't get him to fully engage in psychotherapy, then selective serotonin reuptake inhibitors (SSRIs) are the first line.

What are the best medications?

So far, SSRIs have proven to be the most effective and may be used as long-term treatment to reduce anxiety. Other medications are effective as short-term solutions. For example, a child with school-refusal may benefit from a Benzodiazepine, which can help lower the anxiety and allow the parent to at least get the child out the door. It's important to note, however, that Benzodiazepine should only be used as a bridge. Also, the use of any medication should be part of a comprehensive program where there's another person handling the psychosocial treatment and can see whether the medication is helping or not and at what point the child can start coming off the medication.

Are there other treatment options?

Medication and psychotherapy can help lower anxiety, but if you don't have a plan for getting a child back into the world, then you just have a child who's less anxious and sitting at home. You need to expose him by having him go to a party, join a club, make new friends and have a good time. Those experiences weaken the social anxiety and help treat the disorder itself.

-  More information: childrenshospital.org/psychopharmacology



Joseph Gonzalez-Heydrich, MD

Program spotlight: Pediatric lung transplants

The Pediatric Lung Transplant Program at Children's Hospital Boston focuses on evaluating, transplanting and providing long-term care for children and young adults with chronic lung diseases. Since the program's inception in 1990, 60 bilateral, single and heart-lung transplants have been performed, making it one of the busiest pediatric transplantation programs in the country.

Program basics:

- The multidisciplinary lung transplant team includes a pulmonologist, cardiologist, cardiothoracic surgeon, anesthesiologist, immunologist and nutritionist. Pediatric experts from other sub-specialties at Children's join the care team as needed.
- Child Life Specialists, psychologists, social workers and resource specialists provide supportive care before, during and after transplant.
- As part of the Pediatric Transplant Center, patients benefit from a collaborative, interdisciplinary team of transplant specialists who share knowledge across disciplines to optimize treatment and follow-up care.

What the program offers:

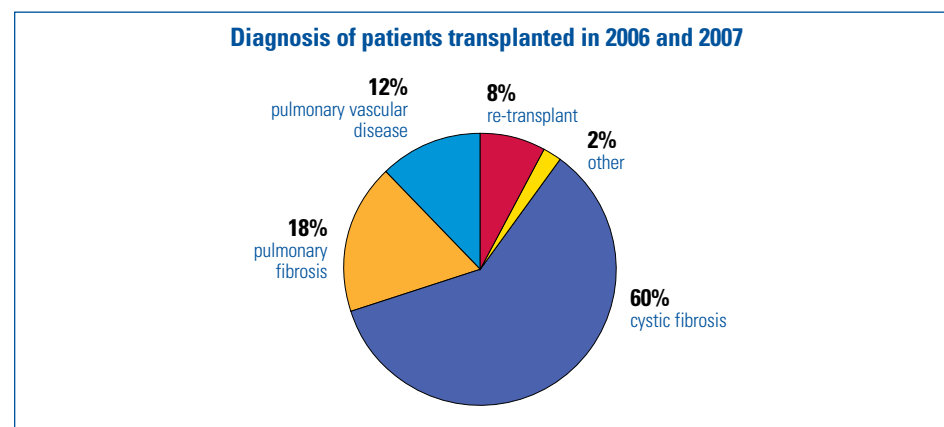
- Patient evaluation and pre-transplant care.
- Placement on the national organ transplant waiting list and coordination of donor services; arrangement of supportive care, including mechanical bridge to transplant (extracorporeal membrane oxygenation), when necessary.
- The expertise of the largest and busiest pediatric cardiothoracic surgery program in the country.
- Interaction with a number of highly specialized programs at Children's, such as the Cystic Fibrosis Center, Pulmonary Hypertension, Pulmonary Vein Stenosis, Infant Lung Disease and End-Stage Lung Disease programs.
- Focused post-transplant care addressing topics like medical compliance, returning to school and the transition to adulthood.

Research studies underway:

The pediatric lung transplant team is involved in a multi-center drug study evaluating inhaled cyclosporine in the prevention and treatment of chronic rejection. They are also examining the relationship of exercise and rehabilitation to outcomes in pediatric lung transplantation, and are part of an innovative drug clinical trial for patients with pulmonary vein stenosis at Children's.

As a member of the International Pediatric Lung Transplantation Collaboration, the team is evaluating quality of life in pediatric lung transplantation patients, right ventricular remodeling after lung transplantation for pulmonary hypertension and the role of respiratory infections in lung allograft survival.

Basic science studies and lung transplant models currently focus on evaluating mechanisms of rejection and possible novel therapies to improve long-term graft survival.



MEET THE TEAM



Gary Visner, DO,
medical director



Craig Lillehei, MD,
surgical director,
transplant surgeon



Francis Fynn-Thompson, MD,
cardiothoracic
surgeon



Debra Boyer, MD,
pediatric
pulmonologist

Make an appointment:
617-355-6681

More information:
childrenshospital.org/lungtx



Dario Fauza, MD

Repairing spina bifida *in utero* with neural stem cells

Delivering neural stem cells (NSC) into the spinal cord *in utero* could enhance the treatment of spina bifida, according to researchers at Children's. The team modeled spina bifida in fetal lambs—similar in weight and size to a human fetus—dividing the fetuses into three groups. The first received no surgery, the second had standard surgical repair and the third had surgery and an infusion of NSC to the spinal cord. Initial evidence of ongoing spinal cord repair was found in the third, experimental group.

Dario Fauza, MD, associate in Surgery, who led the study, sees this as an improvement on simply covering the neural tube opening to prevent further insult to the spinal cord, which is the only procedure offered to date. Next, he plans on examining various NSC sources and cell-delivery methods to generate longer-term data and get a better grasp of this method's usefulness in humans.

Defective motor neurons, not muscles, cause eye movement disorder

Duane syndrome is an inherited complex eye movement disorder affecting one in 1,000 people, rendering them unable to move one or both eyes outward. Contradicting the accepted belief that this is due to muscle defects, researchers at Children's, led by neurologist **Elizabeth Engle, MD**, senior associate in Neurology, have identified a gene mutation in Duane syndrome that results in improper development of the nerves controlling eyeball movement.

According to Dr. Engle, a popular but unproven hypothesis says that human disorders could arise from growing nerve fibers incapable of migrating to the right location, due to errors in axon guidance. She and her team identified a unique mutation in the gene CHN1, which results in an overactive signaling molecule, $\alpha 2$ -chimaerin. This, in turn, disconnects the response of lower motor neurons to growth signals, so they aren't appropriately targeted to the relevant eye muscles.

Dr. Engle describes her findings, published in the August 8 issue of *Science*, as "a nice example of an error in the development of a very simple motor circuit." And since vision requires precise, coordinated eye movements, congenital disorders like Duane syndrome are a sensitive indicator of such errors, she adds. By first understanding the wiring of such simple circuits, she hopes to eventually gain insight into neural circuits of a more complex order.



Vijay Sankaran, an MD-PhD student

Predicting sickle cell disease severity

Patients with sickle cell disease may suffer from frequent and severe pain or they might have a mild form of this disease; symptoms vary greatly and are not easily predictable. But now, research led by **Guillaume Lettre, PhD**, a researcher in the lab of **Joel Hirschhorn, MD, PhD**, in Endocrinology at Children's Hospital Boston, and **Vijay Sankaran**, an MD-PhD student in the lab of **Stuart Orkin, MD**, in Hematology/Oncology at Children's, have found five new gene variants that may prove useful in predicting sickle cell disease severity.

These variants influence the levels of fetal hemoglobin, which are high at birth but gradually decline as the switch is made to adult hemoglobin. Past research at Children's showed that in sickle cell disease, the more fetal hemoglobin is retained, the more benign the patient's symptoms.

Dr. Lettre describes this study as a first step toward an improved understanding of fetal hemoglobin regulation in sickle cell patients, while cautioning that the clinical usefulness of these variants has yet to be validated. An eventual understanding of the factors behind varying fetal hemoglobin levels could allow doctors to ameliorate the pain crises and other severe symptoms of sickle cell disease, and pave the way for better, more targeted therapies in the future. The researchers reported their findings in the August 19 issue of the *Proceedings of the National Academy of Sciences*.

American Academy of Pediatrics**October 11 to 14****Hynes Convention Center
Boston, MA**

Mark your calendars because the AAP will be in Boston this year. Visit us at booth 1140.

More at AAPexperieNCE.org

Children's Hospital Boston will host two events:

- Children's Alumni Event at the Prudential Center Skywalk Observatory on October 11, from 5 to 8 p.m.
- Tour of Children's newest clinical building and Emergency Department on October 12, from 11:30 a.m. to 2:30 p.m.

Review and Update 2008 Cerebral Palsy**October 17, 7:30 a.m. to 5:30 p.m.****Longwood Inn
123 Longwood Avenue
Boston, MA****Fee:** Physicians \$50; others \$25**Credits:** TBD

Description: To provide a review of current knowledge regarding the assessment and treatment of children with cerebral palsy.

Special guest speaker: Professor H. Kerr Graham from the Royal Children's Hospital, Melbourne.

Pediatric Epilepsy: The Whole Picture**October 25, 8:30 a.m. to 3 p.m.****Children's Hospital Boston at Waltham
9 Hope Avenue
Waltham, MA**


Topics: What You Don't Know About Antiepileptic Drugs, Epilepsy Management, Sibling Support Strategies, Neuropsychological Assessment of Children with Epilepsy

Advances in Pediatric Health Care**November 5****Four Points by Sheraton Hotel****1125 Boston-Providence Turnpike
Norwood, MA**

Credits: 6.25 category 1 credits towards the American Medical Association Physician's Recognition Award

Fee: \$75

Topics: Risk Taking Behaviors in Adolescents, Office Assessment of Sports Injuries, Common Head and Neck Puzzles, Office Interviewing and Screening of Adolescents, Substance Abuse, Pediatric Head Trauma, Hypertension

 Full agendas and registration: childrenshospital.org/cme

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Managing ADHD

The program guides parents through each step of reporting the relevant information on ADHD, with a built-in mechanism to ensure that questions aren't skipped over.

Eugenia Chan, MD, MPH, assistant in Medicine and an ADHD specialist, helped develop the program. She hopes that teachers will also use it to provide input on a child's behavior at school. Ideally, teachers' feedback would help doctors manage cases, but they are even less likely than parents to respond to the standard paper questionnaire. Dr. Chan thinks the Web-based system will motivate more teachers to provide feedback on a regular basis.

The project is being piloted at Children's. Parents are randomized to use either the new electronic program or the standard paper questionnaire, and their responses are analyzed to gauge whether using the computerized system results in either different data or a different experience. "We're finding out what works for parents and what doesn't," Dr. Porter says. "But parents feel that this is something designed for them, not a generic black-and-white form."

Dr. Porter would like to expand the program to become part of the patient portal—an electronic data exchange and medical record system developed at Children's. "ADHD is supposed to be owned by primary care, but it leaves a lot of primary care doctors with questions about the right things to do," he says. "Ideally, ADHD care should use data that's shared and owned by parents, primary care physicians and a referral place like Children's, where specialists could offer insight based on information from parents."

 More information: childrenshospital.org/adhd

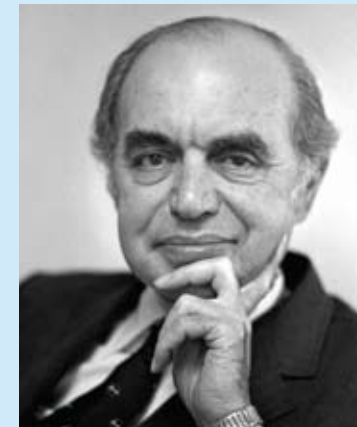
ADHD: UNMET NEEDS

The needs of children with behavioral health conditions differ from those with physical conditions, and the current primary care system may not be handling this special group's needs as successfully, according to a study led by **Sara Toomey, MD**, clinical fellow in General Pediatrics at Children's Hospital Boston. Dr. Toomey examined whether children with attention deficit hyperactivity disorder in a medical home had fewer unmet needs than children with asthma. "Medical home" is defined by the American Academy of Pediatrics as care that is, among other things, accessible, family-centered, continuous and comprehensive.

For the study, her team analyzed the National Survey for Children's Health (2003), which is composed of 25-minute telephone interviews in which parents were asked about their child's needs in three categories—medical care, prescriptions and mental health—and about attributes of the care received. They found that children with ADHD were nearly four times as likely to have an unmet need as children with asthma. They also found that although having a medical home was associated with fewer unmet needs for children with asthma, for children with ADHD who also had a medical home, there was no such decrease.

Inadequate access to mental health providers, along with primary care's structure—short visits and lack of reimbursement—may be among the reasons for this difference. "Our study suggests that innovations are needed in primary care to better meet the needs of children with ADHD and, by extension, children with other behavioral and mental health conditions," Dr. Toomey says. The study was published in the August issue of *Pediatrics*.

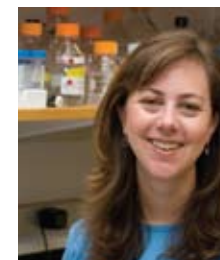
In memoriam: Julius Richmond



Former Chief of Psychiatry at Children's Hospital Boston **Julius Richmond**, 91, died in July. He held joint appointments as director of the Judge Baker Children's Center and chairman of Psychiatry at Children's from 1971 to 1977. He was instrumental in forming the hospital's inpatient psychiatric service (which is named in his honor) and initiated many of the hospital's advocacy and community outreach efforts.

As a result of all of these efforts, Dr. Richmond was asked by President Johnson in the 1960s to implement the Head Start program. He served as the first director of the federal program for at-risk preschoolers, which now provides educational and health services to more than 25 million children. He then went on to become surgeon general under the Carter administration, where he worked to fund community health centers, migrant centers and primary care programs, and to offer grants for public health initiatives. He also took on tobacco companies, lobbying for stronger warnings about health risks on cigarette packages and acting as an expert witness in several class-action suits against the tobacco industry.

"Dr. Richmond had a rare combination of vision, practical know-how and an incredible warmth and caring for all he worked with," says colleague **William Beardslee, MD**, chief emeritus of Psychiatry. "He was an extraordinary listener who was wonderful at bringing different groups of people and perspectives together. He had an indefatigable optimism and incredible energy to make the world better for children."



Elizabeth Brown, MD, a nephrology fellow, has been awarded a post-doctoral fellowship by the NephCure Foundation Research Scientific Grant Program. She will study the cause and identify treatments for focal segmental glomerulosclerosis and Nephrotic Syndrome.



Mark Gorman, MD, a neurologist, has established the new Neuroimmunology Program at Children's, one of the only pediatric programs of its kind in the country. The program focuses on children affected by rare disorders of the immune system, such as "dancing eyes syndrome," central nervous system vasculitis and Hashimoto's encephalopathy. The team includes a pediatric neuropsychologist. Consultations with pediatric specialists in Rheumatology, Endocrinology and Oncology are available.



Carlos Estrada, Jr., MD, assistant in Urology, recently won the Young Clinician Award, which is given by the Center for Integration of Medicine and Innovative Technology to outstanding doctors who also want to pursue a career in research. The goal of Dr. Estrada's current study is to develop and evaluate novel approaches for functional tissue engineering as they relate to addressing the lack of optimal clinical therapies for the treatment of bladder dysfunction.

Q: What is the current view on dietary supplements for children?

A: Studies suggest that approximately 30 percent of children under 18 use supplements, from multivitamins and vitamin C, to iron, ginkgo biloba, echinacea and ginseng. Supplements can be divided into two major groups: complementary dietary supplements and ergogenic aides.


It's imperative that physicians give informed messages about supplements. For instance, telling an adolescent athlete that all ergogenic aides are ineffective is inaccurate. To cultivate a trusting relationship, we need to be able to give athletes accurate information on safety and effectiveness. On the other hand, they need to be aware that the supplement industry is not governed by the same regulations that the pharmaceutical industry is held to. There have been reports of contamination (including heavy metals) and inconsistent dosing, even from batch to batch within the same brand.

I tell athletes and parents to be wary of any product that claims "weight loss, increased energy or increased alertness," as these products may contain stimulants. These can have exotic or benign sounding names like ma huang, guarana, paullina cupana or zoom. There are thousands of supplements on the market and very few physicians can keep up with the safety or effectiveness profile for each one. In general, children and adolescents should be encouraged to get their vitamins and minerals through a balanced diet rather than supplements.



I'm frequently asked about calcium. Children ages 4 to 8 should have at least 800 mg per day and ages 9 to 18 should be taking in at least 1,300 mg per day. Children with chronic diseases or with a previous history of stress fractures may need higher levels of calcium, up to 1,500 mg per day. Calcium carbonate (like Tums) is a simple way to get calcium if the child isn't getting enough in her diet.

— **Michael O'Brien, MD**
Primary Care Sports Medicine, Dance Medicine

 [A fact sheet about nutritional abuse: childrenshospital.org/nutritionalfacts](http://childrenshospital.org/nutritionalfacts)

PediatricViews

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Editors: **Gina Colavecchio, Alison Dargie, Erin Graham** | Contributors: **Michael Coyne, Matt Cyr, Nancy Fliesler, Lesley Niccolini, Alissa Poh, Nikki Shimshock** |

Designer: **Jeffrey Jalovec**

300 Longwood Avenue, Boston, MA 02115 | 617-355-6000 | URL: childrenshospital.org/views | Email: Pediatric.Views@childrens.harvard.edu



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