Pediatricians working closely with parents of children who have difficulty learning in the classroom can make a significant difference in the child’s long-term educational trajectory. “Children who are having difficulties in school, whether it’s with an academic subject or with processing and understanding new information, need to have an evaluation,” says Esther Sinclair, Ph.D., a UCLA educational psychologist.

In many cases, these difficulties are the result of learning disabilities, which, according to UCLA clinical psychologist Martha Jura, Ph.D., generally are defined in terms of “unexpected underachievement”—that is, it is not explained by intellectual level, inadequate schooling, or emotional status.

Diagnosing the problem is only the first step. The next task is to develop specific school interventions. The federal Individuals with Disabilities Education Act (IDEA) defines a variety of disabilities, including learning disabilities, that school systems must address by providing special services under certain circumstances, and requires, in the most general sense, that children with disabilities be given access to a free and appropriate public education.

In many cases, learning disabilities defined under IDEA in terms of a discrepancy between ability and achievement overlap with learning disorders as defined in the Diagnostic and Statistical Manual of Mental Disorders. In some instances, though, “a learning disorder diagnosed in hospitals and clinics is not always defined as a disability by the educational system,” notes Dr. Jura. Both describe a significant discrepancy between expectation and achievement. However, a learning disability commonly requires specification of the underlying processing problems, while a learning disorder does not. Both definitions have exclusionary criteria, indicating that the discrepancy or shortfall is not accounted for by one of several problematic conditions such as sensory impairment or mental retardation, or environmental or cultural disadvantage.

Federal procedures around learning disabilities are subject to change, driven in part by economic and practical realities—many public school
new law. “This is all in flux, which makes it difficult for pediatricians to know how best to advocate for their patients.” Dr. Jura notes.

The first step a pediatrician should take when a patient is identified with learning issues is to urge parents to discuss concerns with the child’s teacher, who can offer less formal interventions. If necessary, the family can seek a formal evaluation from the home school to determine whether the child qualifies for special education. If the child is eligible, parents, teachers and school system representatives establish an Individualized Education Program (IEP) to ensure appropriately specialized services.

Parents should be encouraged to learn what constitutes an adequate learning evaluation. Dr. Jura says. Since the goal of most assessments is to obtain services for children who need them, this can depend on the definition of learning disability being used. In the old discrepancy model, the evaluation focuses on intellectual, cognitive and achievement testing to establish a discrepancy between ability and achievement, and, commonly, the underlying processing problems. In the new response-to-intervention model, the inquiries and testing will be much more specific, involving, for example, curriculum-relevant measurements. Assessments and increasingly intensive interventions, starting in class and in small groups, will precede any IEP evaluation. In either case, Dr. Jura notes that beyond simply ruling out any conditions that might preclude children from receiving services, any comprehensive evaluation should look at anxiety, depression and attention, or any other factor that might negatively affect learning. It is important to keep the big picture in mind, she says: the focus of any assessment should be on the child and not criteria. “Whatever the school’s perception and rules, the parents have their own point of view. If they see that something is wrong, all they want is for it to be understood and fixed. Ideally, a good evaluation is a road map for doing this,” she says.

Whatever model or plan the school uses, parents always have the option of requesting an IEP evaluation if they are concerned about their child’s schooling. Just because an evaluation is scheduled doesn’t mean the family’s problems are over, Dr. Sinclair notes. It often is up to the discretion of the district team to decide which students are learning disabled and in need of services. “It is naïve to assume that every child with problems is going to get special help at school,” says Dr. Sinclair. “Schools follow a narrow definition of learning disability so that only those with the greatest need get attention. If a child doesn’t meet the district’s criteria for special education, there tends to be limited discussion about other avenues for help. Yet, the parent knows something still is not right.” In such cases, parents can seek evaluations and recommendations through professionals in the community, though these may be expensive.

Most commonly, teachers have referred children for evaluation sometime during the third grade, at which time the emphasis in school shifts from acquiring skills to learning information. “Because schools have limited resources, it has been almost impossible for a young child [with a learning problem] in first or second grade to get identified,” Dr. Sinclair says. “But the sooner a problem is addressed, the more likely it is to be overcome.”

Educators hope that shifts in identifying and dealing with students with learning problems will facilitate exactly this process. At this point, however, nothing is certain, and pediatricians should not wait for parents to bring up their child’s learning problem during office visits. “Pediatricians may need to do some probing to find out how things are going in school,” Dr. Jura says, and perhaps might ask specifically about reading because of its importance in school and life, and about problems with attention, which can negatively affect both academic achievement and social behavior. If both the parent and pediatrician are concerned, then the parent should be encouraged to talk with the teacher and school psychologist about options for addressing the student’s needs. Over time, the pediatrician and parent can work together to figure out how to pursue solutions in the school and/or the community.

Recommended reading
Sudden Death in the Athletic Child

The death of a well-conditioned young person during athletic participation is both tragic and disturbing. Sudden death among athletes usually relates to an unsuspected congenital heart condition, most commonly hypertrophic cardiomyopathy. Although rare—approximately 100 incidents occur each year—these deaths have generated a great deal of publicity and have moved many in the medical community to advocate screening young athletes for cardiovascular abnormalities prior to participation in competitive sports.

“An even split exists among specialists in arrhythmia management as to whether or not we should be doing screening studies for young athletes, and there are passionate people on both sides,” says Kevin Shannon, M.D., pediatric cardiologist and co-director of the UCLA Cardiac Arrhythmia Center.

Dr. Shannon argues that the most effective way to identify athletes at risk is with a thorough personal and family history and evaluation, and referral of patients with suspicious findings for specialized testing. The evaluation should determine whether there is a family history of sudden death and/or cardiovascular disease in anyone under 30. Any history of unusual accidents—for example, a family member who drowned in a small amount of water or died in a single-car accident without any known cause for having lost control of the vehicle—also should arouse suspicion.

Certain symptoms also may indicate the need for further evaluation. While fainting episodes are not uncommon among adolescents, they are unusual enough to warrant an electrocardiogram. Other than shortness of breath, nearly all exercise-induced symptoms—palpitations, vision changes, nausea and chest pain—warrant follow-up. Patients should receive a careful cardiac exam and Valsalva maneuver, both looking for murmurs. Most patients with hypertrophic cardiomyopathy have a murmur, even if they don’t have obstruction, Dr. Shannon notes.

Dr. Shannon assesses the percentage risk that a patient with suspicious findings has a particular disease. “There is not always a definitive diagnosis, although we’re getting better, particularly with the availability of genetic screening,” he explains. In determining whether to recommend participation in competitive sports, he multiplies the percentage risk of the patient having a particular disease by the percentage risk that, if the patient does have that disease, participation would trigger a fatal event. “Occasionally, after looking at the family history, other family members’ findings and the severity of the patient’s findings, I might decide that even if the patient has the disease, it is such a mild form that his chances of sudden death are trivial and he should be allowed to participate,” Dr. Shannon says. “However, most of the time, when suspected disease exists and you multiply those two percentages, you wind up with a number too high to let the child compete.”

The most difficult patients to keep from participating are those with “gray-zone” findings—a small risk, often without a definitive diagnosis. “For a lot of adolescents, even if you tell them there is a 5 percent chance of dying if they play, they want to play,” Dr. Shannon says. “They feel invincible.”

Even when risk factors for sudden death prevent patients from competing, conditioning remains important. For patients he prohibits from participation, Dr. Shannon conducts treadmill tests to gauge their ability to exercise and show them the level they should not exceed. Most are advised to remain involved in recreational sports in which they won’t feel compelled to continue when they become tired.

Those who advocate routine cardiovascular screening for all young athletes point to studies that show screening does detect patients with hypertrophic cardiomyopathy who would otherwise have been cleared to play. But Dr. Shannon notes that none of these studies was blinded or randomized; he also argues that the conclusions have been based on the false assumption that any abnormality detected is a death prevented. “The risk of dying if you have hypertrophic cardiomyopathy is not 100 percent. If you find the disease in an athlete, you are not necessarily preventing a death,” he says. “In addition, if you restrict that person from athletic participation, it doesn’t guarantee that the person won’t die from the disease.”

Screening all young athletes with echocardiograms would almost certainly identify some individuals with clear risk factors for sudden death who should not be participating. At the same time, for every positive finding there might be 10 to 20 athletes with borderline findings that would require expensive follow-up evaluations. During the evaluation time, he says, many would be restricted, and some might be told they can’t participate even if they were not found to have a disease. Due to liability concerns, “even when these athletes are cleared to participate, coaches and schools often don’t want to take that chance,” Dr. Shannon says.

Rather than routinely screening all young athletes, Dr. Shannon encourages greater emphasis on a thorough pre-participation history and physical. “For many of these athletes, this is the only time they will see a doctor during their adolescence,” he says. “This provides an opportunity not only to screen them for sudden-death risk factors, but to counsel on all areas of risk avoidance.”

Recommended reading
The Challenge of Cleft Lip/Palate

The nearly 7,000 babies born each year in the United States with an orofacial cleft will face issues beyond cosmetic appearance that encompass feeding, dentition, hearing and speech. Although the rehabilitative process can be lengthy, the coordinated efforts of an interdisciplinary team can greatly enhance the probability of successful outcomes for these children.

Clefts of the lip and/or palate result from incomplete development of the face or mouth, and occur in approximately 1 in 600 births. The resulting defect can range from a slight notch-like deformity to complete clefts of the lip and palate. In approximately 50 percent of cases, both the lip and palate are involved. Cleft lip and/or palate sometimes are associated with syndromic conditions, and diagnostic testing may be performed to rule out the presence of other physical or cognitive and developmental problems. However, the majority of clefts are non-syndromic, and most children will not experience any developmental delay.

Feeding is the most immediate challenge faced by parents of a newborn with a cleft. A baby with a cleft lip may have trouble making a good seal around the nipple to suck, and with a cleft palate the mouth cannot be closed off from the nose so little or no suction can be created. With patience and some adaptive techniques, breastfeeding an infant with a cleft lip may be possible, points out pediatrician Yoshio Setoguchi, M.D., co-coordinator of the UCLA Craniofacial Clinic. However, breastfeeding a baby with a bilateral cleft lip and palate is almost impossible. For mothers who are unable to or do not wish to breastfeed, there are specialized bottles and nipples available. Mothers also can be taught how to best position their baby during feeding—an upright or semi upright position is best—to minimize the amount of milk or formula that might flow through the open cleft into the nose or eustachian tubes.

It is not always clear why a cleft occurs but the majority of non-syndromic clefts appear to be due to a combination of genetics and environmental factors that may include use of tobacco, drugs or alcohol during pregnancy. Nutrition during pregnancy also may affect the incidence of clefting, as may some medications, such as the anticonvulsants phenytoin and sodium valproate and the antimetabolite methotrexate. Folic acid supplementation prior to conception and during pregnancy has been shown to reduce the incidence of clefting.

A cleft can be detected by ultrasound as early as the 16th week of pregnancy, but often it is not picked up on a routine exam, particularly if it is not expected. A Level II or “targeted” ultrasound that looks for specific markers of a suspected condition is more accurate in detecting a cleft, while a 3D ultrasound is the most accurate of all.

The risk of clefting increases with the number of affected relatives, particularly if some have syndromic forms. Clefting also is more prevalent among some racial and ethnic groups—1 in 500 births among Native American, Asian and Hispanic groups; 1 in 700 births among people from European roots; and 1 in 1,000 births among those of African ancestry. Only a geneticist can, after a thorough genetic study, give a family an accurate probability rate. Such an assessment is vital to establish the risk of recurrence in subsequent pregnancies, says Katrina M. Dipple, M.D., Ph.D., a pediatrician and geneticist and co-coordinator of the UCLA Craniofacial Clinic.

Team Approach Is Vital

Children with a cleft lip and palate need the expertise of an interdisciplinary medical team. In addition to requiring plastic surgery to repair the opening, interventions to correct issues with teeth, hearing and speech are necessary, as well as addressing children’s psychological development as they mature. At the UCLA Craniofacial Clinic, the team includes plastic surgeons, geneticists, pediatricians, neurosurgeons, otorhinolaryngologists, orthodontists, oral surgeons, dentists, speech pathologists, audiologists and social workers. Other experts can be called in if required.

“A coordinated approach is essential,” notes plastic surgeon James P. Bradley, M.D. “As a plastic surgeon, I can focus on reconstruction, but the other specialties are needed to address such problems as hearing or subtleties...
process usually starts in two weeks after birth and begins with a custom-fitted denture—the molding plate—that is placed into the baby’s mouth and causes the bones of the upper jaw at the midline, and reconstructing the throat muscles. The most significant reason for repairing the palate is to preserve speech, explains plastic surgeon Henry K. Kawamoto Jr., M.D., D.D.S. “A child can have a hole in the roof of his mouth and still be able to eat OK—they adapt,” he says. “But with a cleft palate, they will never be able to communicate in terms of speech. Repairing the palate is, for that reason, very important.”

Speech Therapy Begins

Children generally begin speech therapy between the ages of 3 and 5 years. An additional surgery may be required between the ages of 7 and 10 to improve speech. During that period, the adenoids begin to involute—reduce in size—which is a natural process that occurs in all children. In children with cleft palate, however, the adenoids act as a sort of cushion that allows for a seal of the palate during speech production, Dr. Shapiro explains. For these children, articulation may worsen as the adenoids shrink, and they might sound as though they have an open, un-repaired cleft palate. An operation such as pharyngoplasty may be necessary to tighten the seal, or the child may require more intensive speech therapy.

Children with a cleft may have dental issues such as supernumerary, ectopic, rotated and missing teeth, and extensive orthodontics will be required. Generally, the first phase of treatment is at about age 7 to 9 years, explains UCLA orthodontist James F. Mulick, D.D.S., M.S.D. At that time, an appliance is used to widen the jaw and to improve the shape of the dental arch prior to placement of an alveolar bone graft, followed by second-phase treatment after eruption of the permanent canines/secondary molars. Additional orthodontic treatment may continue until young adulthood.

With a comprehensive and coordinated approach to care that includes close alliance with the community-based pediatrician as well as the family, the outlook for children born with a cleft is very positive.

Recommended reading


Byrnes AL, Berk NW, Cooper ME, Marazita ML. Parental evaluation of informing interviews for cleft lip and/or palate. Pediatrics. 2003 August; 112(2): 308-313.
Living with Food Allergies

For parents of the 3 million school-age children with food allergies, daily life can be a frustrating struggle to find a diet that won’t ignite a distressing reaction.

Food allergy affects multiple aspects of a child’s health, as well as that of the family as a whole, notes Talal A. Chatila, M.D., chief of the UCLA Division of Immunology, Allergy and Rheumatology. “Parents experience a dilemma about which foods to allow and which foods to avoid. These issues extend beyond the family, to the school and the community. As physicians, we need to manage all of these aspects of the problem with a comprehensive care approach to prevention and therapy,” he says.

Severe food-allergic reactions account for about 30,000 emergency room visits and 150 to 200 deaths every year. While any food can potentially be the source of an allergic reaction, peanuts, eggs, milk, shellfish, wheat, tree nuts, soy and fish together account for about 90 percent of all food allergies. The reaction occurs most often when the body’s immune system produces immunoglobulin E (IgE) antibodies in response to antigens in the offending food, triggering the release of histamine, prostaglandins and leukotrienes. Symptoms can range from the relatively mild, such as tingling in the mouth or hives, to swelling of the tongue and throat, respiratory impairment, drop in blood pressure or loss of consciousness. Gastrointestinal reactions are not uncommon. In extreme responses, anaphylaxis and death can occur. Symptoms typically begin within minutes to two hours.

Early onset of atopic dermatitis, often at around 2 months of age, is one sign of a potential food allergy. Babies with severe eczema, or with persistent vomiting or diarrhea that does not resolve with formula change, and babies who fail to thrive, can benefit from a thorough evaluation to pinpoint specific food allergies or to rule out food sensitivity and thus avoid unnecessary restrictions while allowing the pediatrician to proceed to other diagnoses.

Food allergies can be difficult to accurately diagnose and challenging to manage. It is not uncommon for skin tests to indicate multiple sensitivities but not all might be clinically relevant. Likewise, says Maria Garcia-Lloret, M.D., co-director of the UCLA Allergy Clinic, a positive result on the RAST (or radioallergosorbent test) blood test for IgE antibodies “does not necessarily mean that the child is allergic to the substance in question.” Levels of specific IgE can predict the likelihood of a generalized reaction for certain foods, but for many others the presence of specific IgE in the blood does not indicate a clinically meaningful allergy. Eliminating a particular food from the diet should not be recommended on the basis of a RAST test alone.

An accurate history, including a complete family history, is very important for correctly diagnosing a food allergy. A diary kept over one to two weeks that lists all foods consumed, reactions and how long before onset also will, along with a physical examination and lab tests, assist in determining what, if any, food or foods are causing symptoms.

If a practitioner is facing a complex food-allergy issue or is uncertain or uncomfortable about a diagnosis, it is best to refer to specialized care, such as that available at the UCLA Food Allergy Clinic. The clinic is a comprehensive resource that offers the expertise of an immunologist and a nutritionist trained in dealing with food-allergy issues. In addition, the clinic can provide resource materials both to physicians and to members of the community.

Vigilance Is Essential

There is no cure for a food allergy, and strict avoidance of allergy-causing foods remains the only certain prevention. Parents of children with a severe allergy who are at risk for anaphylaxis always should carry an EpiPen. Teens and young adults who are allergic to peanuts or tree nuts and also have asthma appear to be at increased risk for severe or fatal allergic reactions. There should be a clearly defined written plan of action—including a list of symptoms and doctor’s treatment instructions—for handling accidental ingestion, and others who are commonly around the child, such as teachers, school nurses and daycare workers, also should be educated about how to handle an emergency.

Food allergies can be difficult to accurately diagnose and challenging to manage. It is not uncommon for skin tests to indicate multiple sensitivities but not all might be clinically relevant.

Allergenic products can show up in all kinds of foods and parents should be vigilant about reading ingredient labels of any processed food. In January of 2006, the Food and Drug Administration enacted regulations requiring that food labels clearly state if food products contain any ingredients that have protein derived from the eight major allergenic food groups.

Avoiding an allergenic food is not terribly problematic if a child is found to be allergic to just one type of food, but sensitivity for multiple foods is not uncommon. “Suppose the parent of a child who has a positive skin test for 12 different foods keeps that child on a very restrictive diet and stops all of them—the child is going to become malnourished,” Dr. Chatila says. “It’s not an atypical scenario.” Perhaps of those 12 foods, only two or three are clinically relevant.

A double-blind, placebo-controlled food challenge is the gold-standard test to ferret out which sensitivities are clinically relevant. A food challenge, Dr. Chatila cautions, should only be carried...
out in a medical environment and under strictly controlled conditions. “This is a test that requires a comprehensive medical setup. We want to avoid precipitating a severe reaction, hence it is essential to have a hospital’s resources behind you,” Dr. Chatila says.

Allergies On the Rise

Like other allergies, the incidence of food allergy is on the rise. Studies have indicated that the number of children under 5 years old who are allergic to nuts, for example, doubled between 1997 and 2002, to 1 in 125. “We are seeing more food-related conditions such as eczema, allergic esophagitis, allergic gastroenteritis and urticaria,” says Dr. Garcia-Lloret. It is not clear why the incidence of food allergies is increasing. Increased exposure to peanuts or peanut-containing products early in life has been implicated in some studies. Other studies suggest it has to do with food processing—maybe roasting peanuts rather than boiling them alters the proteins in a way that makes them more allergenic. In addition, lifestyle appears to be a determining factor. The increased incidence of food allergies is being observed predominantly in Western industrialized countries like the United States, Great Britain and Scandinavia.

“Maybe because we are living in cleaner environments, or maybe because of pollutants we weren’t exposed to before, or maybe because of antibiotics taken early in life, the bacterial composition of the gut has changed, leading not only to an abnormal permeability, but also to an altered interaction between the mucosal immune system and ‘harmless’ foreign substances such as foods,” Dr. Garcia-Lloret says.

If that is the case, one therapeutic approach to addressing food allergies might be through probiotics—re-colonizing the gut with beneficial microflora in an effort to prevent the onset of food allergies. A fellow in UCLA’s Food Allergy Clinic is, in fact, initiating research in this area. Researchers elsewhere are examining the efficacy of herbal approaches to prevention and treatment. While conventional allergy shots are not effective in the treatment of food allergies, protocols of oral desensitization are being presently investigated. “Interest in the study of the pathogenesis of food allergy has risen exponentially in recent years,” Dr. Garcia-Lloret says. “We can reasonably expect that in the next few years, the management of food allergies will extend well beyond the EpiPen and dietary restrictions.”

While food allergies in adults tend to be life-long, many children do grow out of allergies, Dr. Garcia-Lloret notes. “The chances of becoming tolerant to a particular food depend on the age of onset and on the food in question. Children who had a food allergy before 3 years of age should be retested in grade school. Some children follow restricted diets when, in fact, they are no longer allergic and can begin to enjoy foods that once were off-limits,” she says. On the other hand, children and adolescents with no prior history of food allergy who begin to experience symptoms such as recurrent hives or gastrointestinal disturbances may have developed an allergy to a certain food.

All of which serves to illustrate that there are no easy answers when it comes to food allergies.

Recommended reading


Download information for parents and families about topics you’ve read here, including food allergies.

http://healthcare.ucla.edu/mattel/health-tips
To contact any of the doctors referred to in this issue, or to correspond with a Mattel Children’s Hospital at UCLA specialty pediatrician, click the “contact us” icon on our website, www.mattel.ucla.edu, or call 1-800-252-4933

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