

Cub



PENNSTATE



Children's Hospital

Chat

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Help Your Child Live With Asthma

Learn everything you can about this common chronic condition

Parents often make two mistakes when a child has asthma.

First, they don't recognize the symptoms. Who would think that a persistent cough or a string of respiratory infections could be a sign of asthma?

Second, after diagnosis, they avoid giving medications as prescribed. Many assume that the cure could be worse than the condition.

According to **Tracy Fausnight, M.D., assistant professor of pediatrics, Section of Allergy and Immunology at Penn State Children's Hospital,**

"Although a child with asthma may seem to be asymptomatic, the airway inflammation often persists. This is why it is important to adhere to the prescribed medication regimen. Any concerns about medication side-effects should be addressed with your child's provider."

Christy Olson, R.N., has two children with asthma. She admits it took her a while to climb the learning curve. "Even though I was a nurse at the time, I know I under-medicated my children because I was fearful of giving them all that medicine," she says. Today she helps others avoid such mistakes as a nurse educator with the Allergy and Asthma Network/Mothers of Asthmatics.

About 6.3 million U.S. children have asthma. Ms. Olson's advice to parents:

- Seek an asthma evaluation for any



child who has frequent coughing or respiratory infections, such as pneumonia or bronchitis. Other common symptoms include episodes of wheezing, chest tightness, and shortness of breath.

- Learn everything you can about asthma. "The more I learned, the more comfortable I became," she says.
- Work closely with your doctor to develop an action plan for your child. "Make sure your child's asthma is under control, because if it is, he or

she can do anything any other child can do," says Ms. Olson.

- Stick with the prescribed medication plan while avoiding or controlling asthma triggers. Common triggers include exercise, respiratory infections, allergies, and irritants, such as tobacco smoke or cold air. "An allergy evaluation can be helpful in determining potential triggers of a child's asthma," says Fausnight.
- Review your child's treatment needs at school with teachers, coaches, administrators, and nurses. They may not know much about asthma.
- Teach your child to help manage asthma. Depending on age and maturity, kids can learn to avoid triggers, care for medications, and take them. Older children should be as responsible as possible for their own treatment.
- Support your child through difficult times by being relaxed and open about asthma, its symptoms, and its treatments.

"Asthma is an insidious disease, and symptoms can arise when you least expect them. It's important to not let your guard down," Ms. Olson says. ♦

To Learn More

Asthma and Allergy
Foundation of America
www.aaafa.org
(800) 7-ASTHMA



Penn State Children's Hospital Ranks High in Patient Satisfaction

Penn State Children's Hospital ranks higher than 90 percent of children's hospitals nationwide in inpatient satisfaction, according to Press Ganey, a satisfaction-measurement company used by hospitals across the nation.

Children's Hospital also showed significantly improved patient satisfaction at two outpatient facilities: University Pediatrics on Cherry Drive, Hershey; and Children's Heart Group on Nyes Road, Harrisburg.

Over the past year, Children's Hospital has worked diligently in several key areas to improve the experience of patients and their families while at Children's Hospital. Two examples of this include patient meals and spiritual counseling. Now, pediatric patients have more choices when it comes to their favorite foods, including pizza, hot dogs, and macaroni and cheese. A new chaplain



From left: A. Craig Hillemeier, M.D., medical director and chairman; Gil Pak, operations director; Patti Light, R.N., M.S., C.P.N., nurse manager; Sheila Smith, M.S.N., R.N., director of nursing; and Matt Wain, administrator, with various pediatric clinical nurses during a three-day event for patient satisfaction.

recruited specifically for Children's Hospital provides families with increased spiritual and emotional support.

"We couldn't have done it without the help of our patients and families," says **A. Craig Hillemeier, M.D., medical director and chairman,**

Children's Hospital. "Over the past year, we've developed key advisory boards composed of patients, families, and staff that discuss ways we can improve our services. The leadership shown throughout Children's Hospital, which has allowed us to achieve this



Doctors Advised to Wait and See on Ear Infections

Your child may not need antibiotics to get better

Middle ear infections are the main childhood problem that leads doctors to prescribe antibiotics. "Acute *otitis media* is the most common infection in which antibacterial medications are prescribed in the United States," says **Kate Crowell, M.D., pediatrician with Penn State Children's Hospital.** Annually *otitis media* accounts for approximately 20 million office visits and approximately 15 million prescriptions for related antibacterial medications. But until now, there has been little to guide doctors in treating what they call acute *otitis media* with effusion, or fluid in the middle ear.

"What we now know is 90 percent of these infections will get better without using antibiotics, if we just watch the child, and let the illness run its natural course," says Richard M. Rosenfeld, M.D., M.P.H. Rosenfeld co-chairs the American Academy of Pediatrics (AAP) subcommittee on *otitis media* with effusion. Since just 10 percent of kids will need antibiotics,

"we're exposing a large number of children to the side effects" for no cause. Further this contributes to the problem of increased antibiotic resistance.

The AAP and American Academy of Family Physicians (AAFP) set up a panel to study ear infections in kids 2-months-old to 12-years-old. Here's what those doctors had to say:

- "The doctor should decide to use antibiotics with input from the parents. But both should think about watching the child for a few days first," says Ted Ganiats, M.D., co-chairman of the AAP/AAFP panel. That holds true as long as the child does not have a very high fever or other severe problem. Observation has been advocated for all otherwise healthy children with an uncertain diagnosis and for children older than 2-years-old with a certain diagnosis but without severe symptoms.
- The doctor should ask about pain, and prescribe acetaminophen or ibuprofen when needed. "Treating the child's pain is the key step the

Top 10

The following Children's Hospital physicians were named the Top 10 Patient Satisfaction Physicians from July 2003 to June 2004:

- **Mark Baker, M.D.**, general pediatrics
- **Andrew Freiberg, M.D.**, hematology/oncology
- **Brandt Groh, M.D.**, rheumatology
- **Roger Ladda, M.D.**, genetics
- **John Myers, M.D.**, cardiovascular surgery
- **John Neely, M.D.**, hematology/oncology
- **Barbara Ostrov, M.D.**, rheumatology
- **Daniel Rifkin, M.D.**, pulmonology
- **Diane Schuller, M.D.**, allergy/immunology
- **Steven Wassner, M.D.**, nephrology

high level of patient satisfaction, has been truly extraordinary."

Sheila Smith, M.S.N., R.N., director of nursing at Children's Hospital, credits the efforts of the multidisciplinary team in making Children's Hospital a highly satisfied patient facility. ♦



doctor can take," Ganiats says.

- The doctor should be frank with parents about the certainty of the diagnosis. That may help parents weigh their treatment options. "Unfortunately the diagnosis of acute *otitis media* can be difficult," says Crowell. "It requires a rapid onset of symptoms in conjunction with a middle ear effusion and signs of middle ear inflammation."
- If the child fails to improve after two or three days without antibiotics, it's time to use them.
- Parents should be taught about prevention. Bottle-feeding, pacifiers, and cigarette smoke can raise the risks for these infections.
- Doctors should tell parents that they don't know enough yet about alternative medicine and ear infections to back such treatments. ♦

Autism Has Many Faces

A team of experts can help pin down a diagnosis

What does autism look like? Even for an expert, the answer is not always clear. That's because autism isn't just one disorder. Instead, it's a spectrum disorder—a set of issues that can be mild, severe, or anywhere between.

Children with autism may have high or low IQs. They may be chatty or silent, outgoing or shy, good or bad students. They may or may not have unusual talents. Some are easygoing, while others have severe behavioral issues.



What do they have in common? Delays or disabilities when it comes to social skills such as ordinary conversation, eye contact, and emotional understanding of others. Most children with autism also share delays in motor skills.

Most experts agree that early intervention is a key to treating autism. But how can parents spot problems that might lead to a diagnosis?

Developmental pediatrician Adrian Sandler, M.D., is medical director of the Olson Huff Center in Asheville, N.C. He says you can see red flags (*see list below*) that might point to autism in a child as young as 1-year-old.

Robert Naseef, Ph.D., a psychologist and author, suggests that parents who suspect autism seek an evaluation. "A team evaluation is ideal. You get different perspectives from professionals in areas including psychology, speech, occupational therapy, and physical therapy.

"You certainly want an evaluator with a good background in the autism spectrum—a child psychologist, developmental pediatrician, or neurologist—who can do a careful observation. Expect a lot of questions," Naseef says. "A good evaluation is more than a label. It will help with interventions."

There is no standard test or treatment, and no cure. But many therapies can help. Once parents place their child in a good education program, they often mix and match approaches to meet the child's needs.

Treatment, especially when started young, can have a huge impact. Children with autism can improve their skills a great deal. In fact, you may see little difference between them and any other kid. ♦

Red Flags

- Lack of showing or sharing interest or enjoyment
- Engaging in unusual repetitive movements or behaviors
- Lack of response to their name being called
- An odd quality of voice (monotone or singsong, for instance)
- Absence of imitation
- A variety of odd verbal sounds

SOURCE: Adrian Sandler, M.D.

To Learn More

- Autism Society of America: www.autism-society.org
- The National Institute of Child Health and Human Development: www.nichd.nih.gov/autism

FAMILY ADVISORY COUNCIL



Making a Difference

Whether it's the first or the fifth time, being admitted to a children's hospital can be an overwhelming and emotional experience for families. Families are taken from the comfort of their home and are thrust into an unfamiliar world filled with strangers, intimidating medical terminology, and frightening equipment—all while caring for a sick child. Recognizing that these family members have a unique perspective on the hospital experience, the **Penn State Children's Hospital Family Advisory Council (FAC)** was established in 2002 to enhance how the hospital responds to the needs of patients and their families. Jointly supported by the Pennsylvania Department of Health's Family Consultant Program and the Children's Miracle Network, the FAC is a dedicated network of family members and Children's Hospital staff who promote comprehensive and compassionate health care through a family-centered approach.

"As a family member of FAC, having this opportunity to share concerns with the Children's Hospital staff and working together on solutions has allowed me to see how truly dedicated the hospital is to providing the best in family-centered care," says **Eileen Austin, FAC secretary** and parent. "Our children are in good hands!"

Since September 2002, the FAC has focused on the spiritual and emotional needs of children and their families. The

council has already built an impressive list of accomplishments, including:

- The creation of a part-time pediatric chaplain position exclusively for the Children's Hospital.
- A family prayer book that is now available in the Children's Hospital so family members can add the name of their child without leaving the seventh floor.
- Informational handouts that are provided to families of admitted patients listing the hospital's support services, along with a directory of local churches and service times.

Striving to increase staff education about the family experience, the FAC recently developed the Family Faculty Program. In this lecture series, family members share their child's hospitalization story while providing examples of what was done well and what could have been done better during their child's treatment. Other ongoing projects of the FAC include educating families about the roles of staff members and providing beepers so family members can comfortably leave a child's bedside.

A. Craig Hillemeier, M.D., medical director and chairman, Children's Hospital, says, "The group has helped us tremendously over the past two years with identifying key areas to focus our attention on, and we couldn't be more grateful for their support and commitment to making Children's Hospital a better place for everyone." ♦



To Learn More

Parents and caregivers who are interested in joining the council may contact Patti Agosti, FAC chairperson, at (717) 531-7671.





The Family Advisory Council was established to enhance how the hospital responds to the needs of patients and their families.



Children's Hospital Establishes Advisory Council of Teens

The Advisory Council of Teens (ACT) was created by the Child Life department in Spring 2004. Currently, there are eight ACT members ranging in age from 14 to 27 who are current or previous patients at Penn State Children's Hospital. The purpose of this council is to strengthen the services of the Children's Hospital by providing recommendations from a pediatric patient's perspective. Due to the uniqueness of each individual's experience and diagnosis, each ACT member contributes significantly to the council.

The ACT members have provided numerous ideas and suggestions, some of which have been implemented. One of their biggest projects was purchasing and painting mailboxes, which are now posted outside of the pediatric rooms

down the south and west hallways on the seventh floor. These mailboxes not only will be used for general mail, but also for special announcements from the Child Life department, as well as providing another means of communication between patients and families.

The council has also created "communication boards" to help staff and families locate each patient. Using dry erase boards, the members thought of the most common places a patient would go during the day and wrote them in permanent marker on the board. They then made magnets out of clay with the intent that the patient and/or family member moves

the magnet to the appropriate location prior to leaving the room.

Other accomplishments of ACT include: Creating a logo, "Been there, done that ... now let's make a difference!" created by Kohl Cleckner, which was printed on members' T-shirts; holding a rolling bake sale to raise money for the council; creating an ACT web site for other hospitals to use; posting a bulletin board outside of the teen lounge to inform families and staff of what the council is doing; and many other projects that the council works on monthly.

This group serves as the pediatric "voice." These teens volunteer their time to help make the stay of patients and their families less stressful and more enjoyable. ♦



What Is Tuberous Sclerosis Complex?

by Cindy Richards, outreach & awareness coordinator, Tuberous Sclerosis Alliance

Tuberous sclerosis complex (TSC) is a genetic condition commonly characterized by seizures and tumor growth in vital organs such as the brain, heart, kidney, lungs, and skin. This disorder affects some children and adults severely while others are so mildly affected that it often goes undiagnosed.

TSC is not one of “the big diseases” that you typically hear about. About 1 million people worldwide have TSC, and about 50,000 in the United States. Families and loved ones often scramble for answers and information.

The Tuberous Sclerosis (TS) Alliance just celebrated its anniversary of 30 years. This nonprofit organization is dedicated to research, education, and support of families affected by this disease.

In researching issues of families with children affected by TSC and personal experience of our family, the most frustrating may be getting a diagnosis. I am the grandmother of a 3-year-old girl affected by TSC. Ashlin developed an “ash leaf white spot” on her calf when she was 3-months-old. My daughter was told it

was a birthmark; however, it was not present at birth. Ashlin began having seizures at the age of 5 months; at times they were almost unnoticeable (focal seizures), and then they progressed to extreme episodes. My daughter was told by her pediatrician not to be alarmed and to schedule her for an electroencephalogram (EEG) as soon as possible.

About 1 million people worldwide have tuberous sclerosis complex.

When Ashlin was finally admitted to a local hospital, our family was humiliated and falsely accused of “shaken baby syndrome” by social services based on the CT of her brain. We continued to work through this; meanwhile, Ashlin was removed from her parents’ home.

We advocated for a referral to Penn State Children’s Hospital, where she was diagnosed with TSC by **Vivian Faircloth, M.D., a pediatric neurologist at Children’s Hospital**. Her CT was typical of children with TSC. Finally a treatment plan was in place, and we could move forward! We then got in touch with the TS Alliance to educate us and help us cope with this disease, and began our life journey with Ashlin.

In April 2003 when she was 20-months-old, Ashlin suffered an episode involving prolonged seizures. She was hospitalized at Children’s Hospital and when she returned home she was paralyzed on her right side. Ashlin had to relearn to walk, talk, and regain the use of her right side through therapy. She is still in therapy for speech but has recovered quite well. She would be considered moderately affected at this point; we are blessed. Tuberous sclerosis is a very unpredictable disease. Many families struggle with major medical issues involving the heart, liver, kidneys, lungs, and infantile spasms.

After this incident we decided to form a Community Alliance in our area with full support from the national TS Alliance. We encourage families of children and others affected by TSC to get involved. We are committed to educating, empowering, and supporting those affected by TSC. We are grateful to the staff at Children’s Hospital for their services, skills, and compassion. ❖



Ashlin was hospitalized at Penn State Children’s Hospital after suffering prolonged seizures when she was 20-months-old.

To Learn More

For more information, contact:

Tuberous Sclerosis Alliance
www.tsalliance.org
(800) 225-6872

Cindy Richards
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Find Safe, Fun Ways to Keep Young Kids Active

Don't let toddlers be couch potatoes ... encourage structured and free play

In a world that hypes baby yoga and baby swimming classes, can baby football be far behind? Physical activity for the very young is vital—but avoid such extremes, experts say.

“The norm now is for kids to be inactive, and your child is never too young to begin movement,” says Eric Small, M.D., who chairs the American Academy of Pediatrics committee on sports medicine and fitness. “But on the other end of the spectrum we have parents enrolling kids 1, 2, and 3-years-old in classes they are not ready for. I just treated a preschooler for knee pain from being overstretched in a yoga class.”

On the other hand, some busy parents keep kids in one place to aid child care. “We containerize kids for safe-keeping and convenience,” says Jim Pavarnik, Ph.D., president of the

North American Society for Pediatric Exercise Medicine. Some spend hours in car seats or strollers. But kids have to move to build cognitive and motor skills, and to learn that physical activity is fun.

“Giving toddlers the proper activity at this age can teach the importance of exercise and make a significant impact on preventing childhood and adolescent obesity,” says **Ronald Williams, M.D., director of the Pediatric Multidisciplinary Weight Loss Program at Penn State Children’s Hospital.**

The experts recommend:

- Toddlers should have at least thirty minutes of structured physical activity a day. Preschoolers need at least an hour.
- Toddlers need an hour or more each day in free play. That could mean

riding, pushing, pulling, and climbing safe objects, for instance.

- Toddlers and preschoolers shouldn’t be inactive for more than an hour at a time except when sleeping. Activity doesn’t have to be complex or costly. Play pat-a-cake, for instance.

Activity builds bones

One payoff for activity may be better bones. A study of 460 children (average age is 5) compared those who did 40 minutes of vigorous activity a day, like hopping, running, and jumping, with those who didn’t.

The study, printed in the journal *Medicine & Science in Sports & Exercise* in July 2004, found the active kids had:

- 9 percent more bone area and 12 percent greater bone strength in boys.
- 7 percent more bone area and 9 percent greater bone strength in girls. ♦

Children's Hospitals Provide Top Health Care to Kids

You've heard the saying countless times: Children are not small adults. Never is this more apparent than when it's your child who's sick. Children are unique, growing individuals who require special care. And nobody knows more about caring for kids than children's hospitals.

Whether your child needs to undergo a simple procedure or needs complex surgery, children's hospitals are technologically advanced, kid-friendly facilities staffed by the top pediatric specialists in the country.

The National Association of Children's Hospitals and Related Institutions (NACHRI) supports children's hospitals and their efforts to ensure that all children receive the

highest quality health care possible.

Children's hospitals devote 100 percent of their services to children. That's why they are able to provide the majority of highly specialized care for kids hospitalized with complex and rare conditions—regardless of ability to pay. In fact, children's hospitals provide 90 percent of all pediatric heart surgery and 94 percent of all pediatric transplants, and care for 84 percent of children in hospitals for advanced cancer.

While most children's hospitals are best known for serving children with these severe conditions, they also help all children grow up healthy through routine and preventive care, including vaccinations, nutritional counseling, and injury prevention education.

NACHRI helps its member hospitals continuously improve in all areas of children's health care by providing data and educational and networking opportunities that lead to new breakthroughs in pediatric health care.



For more information about children's hospitals and the services they provide, visit www.childrenshospitals.net or contact your local children's hospital. ♦



NACHRI

National Association of Children's
Hospitals and Related Institutions

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For questions
or additional copies,
please call (717) 531-8606.

pennstatechildrens.com

A. Craig Hillemeier, M.D.
Medical Director and Chairman



the four diamonds fund
Conquering Childhood Cancer



CHI-1708-05



Community Celebration

A kickoff event for the CMN Telethon June 4-5 on **WGAL-TV8**

June 4, 2005

10 a.m.–4 p.m. • Free Admission

Front lawn of Penn State Milton S. Hershey Medical Center

PENNSTATE



Children's Hospital

