Pediatric Health

Enhancing Your Child’s Development

One family battles against a deadly disease

Cystic fibrosis
Working to find a cure

Newborn screening
Identify early warning signs

Empowering children
Fighting obesity
All parents want the best for their children, and pediatricians share the same goal.

Growing up healthy

The American Academy of Pediatrics (AAP) was founded in 1930 to address the unique developmental and health needs of children. Today the AAP advocates for the health and well-being of children everywhere, whether they’re coping with a bully at school, struggling with obesity or lacking affordable health insurance.

Children today face serious challenges, including a poverty rate not seen in 15 years. Children who don’t have adequate nutrition, shelter and medical care will not have the best start in life. That makes health care reform all the more important. The new law will enable millions of children to get the health care they need, including children with pre-existing conditions and young adults up to age 26 who have not yet obtained health insurance on their own. Insurance plans will be required to fully cover well-child visits to the doctor—including all of the immunizations recommended by the CDC.

These changes will make a difference in the lives of children and families. The AAP, with its 60,000 member pediatricians, wants all children to have access to high-quality, affordable health care provided through a medical home. As health reform continues to roll out in the coming years, the AAP will continue to advocate so that children and families remain at the forefront.

Families play an important role too

Families play an important role too. Over the past 20 years, the number of children who are obese has doubled. That’s why the AAP has partnered with First Lady Michelle Obama in her Let’s Move! campaign to encourage families to make healthier choices. Families can strive to reach these goals:

- **Five** fruits and vegetables a day
- **Two** hours or less of screen time per day
- **One** hour of physical activity a day
- **Zero** sugary drinks

**Parents set the example**

By choosing healthy foods and exercising every day, parents can be effective role models for their children.

Because we know parents will have questions about their children’s health, the AAP has launched a consumer website, HealthyChildren.org, that offers trustworthy, up-to-date advice backed by pediatricians. Parents can learn about medical conditions, read about the latest scientific research or find a local pediatrician. I know that by working together, pediatricians and parents can give all children the greatest chance of success in life.

O. Marion Burton, MD, FAAP
President, American Academy of Pediatrics

“Children who don’t have adequate nutrition, shelter and medical care will not have the best start in life.”

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**TIP**

A HEALTHY DIET

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Is the new recommendation of universal influenza vaccination achievable in a nation of 300 million people? Does it matter if it is not?

The universal recommendation is based on the idea that all persons over six months in age can benefit from getting the flu vaccine. The fact that healthy adults were hardest hit by 2009 H1N1 virus prompted the CDC to broaden the “at risk” group to everyone over six-months old. Vaccinating all Americans is not set as a goal since it is not realistic. Approximately half that number of vaccine doses will be available, and that is considered a realistic goal. The important thing about this new “universal” recommendation is that the flu is serious and that vaccination is your best protection.

Can herd immunization—the immunization of substantial parts of the population but not everyone—lead to the control or eradication of contagious diseases?

There’s no simple answer to that question because much depends on the nature of the particular disease. A single vaccine has provided long-term protection against some diseases—polio and smallpox are two examples. The situation with the flu is different as we are constantly combating new strains that require development of new vaccines, often on an annual basis. Even with diseases that are no longer problems in the United States, it’s important to remember that infection is still only a plane ride away. There was an outbreak of measles in California, apparently started by a visitor from Europe, as recently as 2008.

With one in three American children classified as overweight or obese, it should come as no surprise that childhood obesity is a major public health concern.

And while there is no single explanation for the epidemic, out of control portion sizes, decreased activity, increased television and gadget time, and poor nutrition all contribute.

The role of food marketing

In addition to general bad nutrition and sedentary lifestyle, food and beverage marketing to children also plays a role in childhood obesity.

Research shows that American kids are consumers in their own right with a powerful ability to influence their parents’ purchasing decisions. But they are also powerfully influenced by the more than $1.6 billion the food industry spends marketing products directly to them. Marketing techniques utilizing favorite cartoon characters and games are very successful—and typically associated with unhealthy products.

Additional research suggests that food marketing to young people increases their desire for and consumption of advertised foods as well as their calorie intake. As a result, their diets and overall health are directly affected.

Food industry response

Though food and beverage industry advertising is not regulated, many companies are beginning to respond to criticisms about child-targeted advertising.

“Because the most influential companies in our industry now apply nutrition standards to child-directed marketing, two-thirds of food and beverage ads now seen during children’s programming features healthy products and active lifestyles,” says Lisa Guillermin Gable of the Healthy Weight Commitment Foundation, a food and beverage industry coalition formed with the goal of reducing obesity by 2015.

Gable also says the food industry is committed to doing its part to improve the quality of its products. “In recent years, we have changed the way we develop and market more than 20,000 products, reducing fat, sugar, salt and calories without sacrificing the convenience and taste consumers demand.”

Fighting obesity and empowering children

The good news is that eliminating childhood obesity is a goal many are fighting for, and there are an abundance of initiatives like Michelle Obama’s national “Let’s Move” campaign and the locally based Consortium to Lower Obesity in Chicago Children that are focused on solving the problem. By drawing attention to food and beverage industry practices and engaging everyone from parents and schools to community organizations and government, the hope is children will get the tools they need to make better choices and live healthier lives.

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Newborn screening gives parents and doctors early warning that an infant may have a serious medical problem so treatment can be started and serious problems such as intellectual disorders, and even death, can be prevented.

When Connor Osowski of Texas was born in 2000, expanded newborn screening wasn’t required and doctors didn’t know why he vomited and his muscles weren’t developing properly. It wasn’t until Connor was a year old that tests confirmed he had a rare genetic disorder, propionic academia. Connor still must take medications, eat special food and makes frequent trips to the hospital emergency room. Many of Connor’s problems might have been prevented if he had been diagnosed at birth.

“We’re grateful for every day,” said Connor’s mother, Lillian, who worked with the March of Dimes to expand Texas’ newborn screening.

“ar I got a phone call from a lady whose daughter was diagnosed with the same disorder. It’s a wonderful thing, even though my son may not have benefited from being diagnosed at birth, at least she was.”

Required screenings
Today, thanks to years of intensive advocacy efforts by March of Dimes volunteers, all 50 states and the District of Columbia require that every baby be screened for 26 or more of the identifiable and treatable, serious genetic, metabolic or functional disorders recommended by the Secretary of Health and Human Services.

Regardless of how many tests a state requires, parents and health professionals should know about the benefits and availability of newborn screening. Where screening is limited, parents should check with their doctor or health department for a list of private providers that offer expanded screening.

Except for hearing, screening tests are done by testing a few drops of blood from a newborn’s heel, taken in the hospital 24 to 48 hours after birth. If a result is positive, it does not mean the infant has a disorder. The baby is referred for additional testing and, if the diagnosis is confirmed, given treatment as soon as possible.

Visit www.marchofdimes.com for more information about newborn screening.
Courage, hope and activism

Mary and Lou DeFalco were ecstatic to learn they were expecting their first baby.

But different emotions took over when routine testing showed they were both carriers of the Cystic Fibrosis (CF) gene, and their child had a one in four chance of having the disease.

“A bit of shock, confusion and heartache took over,” said Mary. “But we chose not to do any further testing and instead put our energy into having a healthy pregnancy and educating ourselves.”

Action mode
The DeFalco’s soon learned that CF is a life-threatening disease that causes mucus to build up and clog bodily organs, which can impede proper digestion, make breathing difficult and eventually lead to lung damage. When their son Michael was born, it became apparent that he wasn’t growing properly, and a test confirmed he had CF. When Mary became pregnant again, a prenatal test revealed their second son, Dylan, would also have the disease.

“Though we grieved a bit with each diagnosis, our natural tendency is to take action,” said Mary. “We believe we create our own destiny, and today we have two rough and tumble little toddlers who love to play.”

A day in the life
CF is a labor-intensive disease, and the DeFalco’s take an aggressive approach to their boys’ care. Mary is a devoted caregiver, administering three breathing treatments and 25 pills to each child daily. And while the boys’ health is always top of mind, she said the family also lives for the moment. “Everyone has their own normal, and this is ours. Our kids are just kids—Dylan is hysterical and Michael goes to preschool and loves soccer. They have a lot to deal with, but their bravery is remarkable.”

Grassroots activism
The DeFalco’s also take an aggressive approach to advocacy and fundraising. Because CF is considered rare, it receives little attention or financial support from federal agencies and large pharmaceutical companies. As a result, Mary said parents have always been a key force behind CF research and funding. “We’re in this to find a cure, and grassroots fundraising is the best way we can help make it happen.”

A reason to hope
Historically, CF treatments have focused on symptoms, but Dr. Michael Konstan, chair of pediatrics and director of the CF center at University Hospitals Rainbow Babies and Children’s Hospital and Case Western Reserve University in Cleveland Ohio, one of the leading CF care and research centers in the country, said the most promising new research focuses on treating the cause.

“The basic, life-shortening defect of CF results in abnormal transport of salt and water across cells lining the airways. A number of potentially new drug therapies in Phase 3 clinical trials are directed at restoring the normal salt and water balance, and we are very hopeful that one of these will essentially represent a cure for some patients within the next several years.”

For the Defalco’s, that moment can’t come soon enough. “When you have two kids fighting the disease, you want the miracle to happen today.”
**Question 1:** What do you think has been the most important development in pediatrics and child education in the last five years?

**Thanks to** the pneumococcal vaccine, serious infectious diseases are much less prevalent, which allows pediatricians to focus on establishing and maintaining a healthy trajectory for children, particularly in prevention of obesity and fostering a medical home for each child. We can now concentrate on all aspects of life that impact a child’s present and future health—proactively keeping kids well and healthy rather than reacting to disease.

**One of the most important developments in a child’s education is the presence of toys that encourage a child’s imagination and creativity. Toys at a young age allow children to roleplay, problem solve, and interplay with other students in real-life situations. From basic tools to language and understanding emotions, toys represent an intelligence builder. The simpler the toy, the more opportunity it gives them to create the vision in their mind and imagine, therefore encouraging their thought process to expand.**

**Question 2:** What has been your most rewarding experience working with children?

**I love hearing from parents** whose lives have changed. Whether it’s a mom whose three-hour home injection routine is now five minutes thanks to Buzzy®, or a grandmother who brings me a picture of a now-healthy child who was critically ill when I resuscitated her in the emergency department, knowing that for one person I really was able to make a difference has been so rewarding.

**My rewarding experience** has been watching children grow and mature, for them to learn to love learning. Exploring beyond the concrete in terms of broadening their awareness and independence, to see a child grow and blossom into a young highly functional integral part of society, is truly the measure of success as an educator. Teaching is a profession but has become my passion as I continue through these 35 years of working with young people and seeing them become our future.

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**Leonore A. Herzenberg, PhD**
Professor of Genetics, Stanford University

**What is N-acetylcysteine and why is it a promising cystic fibrosis therapy?**

- Certain cells in CF patients are deficient in a key nutrient called cysteine that is necessary to produce glutathione, which is vital to proper cell function. In CF, cysteine-glutathione deficiency is associated with life-threatening lung inflammation and infection. N-acetylcysteine (NAC) is a non-toxic nutritional supplement that replenishes cysteine and glutathione, potentially protecting lung function and improving quality of life.

**Why did the Herzenberg Lab begin studying NAC?**

- We were working to develop ways to measure glutathione in cells when Dr. Rabin Tirouvanziam joined our lab to investigate whether glutathione deficiency occurs in CF and, if so, whether it could be treated with NAC. He found clear evidence of this deficiency and started a series of clinical trials aimed at finding whether NAC would be beneficial. Based on promising initial results, we are now collaborating with numerous CF treatment centers in a multicenter trial.

**NAC is available over the counter—why shouldn’t CF patients just buy some and use it right away?**

- The clinical trial is determine which patients (if any) NAC will benefit. NAC sold at local retail outlets may be sold in inadequate doses or in bad formulations. The preparation and packaging at these local outlets is unregulated, which means the NAC can be oxidized and be harmful. I can’t stress enough how important this is. Taken in a bad formulation, NAC can do more harm than good. The NAC we use in our study, PharmaNAC, is supplied by a Canadian company, BioAdvantex. It is prepared and packaged according to European FDA-enforced “good manufacturing practices” and is approved by the US FDA for use in our trial.

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**Jill Smits**
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