




Duke Children's

stories

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This year the Duke Children's Classic—an event that has raised \$14 million for Duke Children's Hospital & Health Center—will end a remarkable 35-year run.

This event has generated major financial support that has translated directly into better service to our patients and important advances in children's health care. But after more than three decades, we decided it was time to look to new ideas and new ways to support our mission.

As we move forward, we are very excited about the successes of other fundraising events like the MIX 101.5 Radiothon and the Teddy Bear Ball.

Our volunteers are among our greatest assets. Your help made the Classic successful and will help us continue to provide the best care and remain a leader in pediatric research.

We thank you... and hope to see you on the golf course!

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Samuel L. Katz, MD

VACCINES AND AUTISM
Q&A with Dr. Katz

Some parents fear vaccinations because of Internet and media stories linking them to autism. *Duke Children's Stories* recently asked Samuel L. Katz, MD, co-creator of the measles vaccine and chairman emeritus of pediatrics at Duke, about the truth behind the rumors.

Q. What causes autism?

We don't yet know the cause of autism. I think we will find there is not a single cause, but a number of contributing factors, including genetic predisposition.

Q. How did vaccinations become linked with autism?

Autism began being linked with vaccines because of a single, flawed study in the United Kingdom in the late 1990s involving 11 or 12 children. The conclusion of this research has been proven totally false.

Q. Are there scientific studies that link vaccines to autism?

No. Scientific investigations have failed to demonstrate vaccines as a cause of autism.

Q. Are any vaccines singled out?

In the United Kingdom, the measles, mumps, and rubella (MMR) vaccine is implicated by parents as a cause of autism, in part because of the temporal relationship of the two. That is, the first MMR vaccine is administered around 12 to 15 months of age, a typical age for the diagnosis of autism—although there is no evidence to suggest any other connection. In this country, that theory was quickly dropped, and what persists is the idea that vaccines containing the preservative thimerosal cause autism. However, thimerosal was removed from vaccines for children (except some influenza and virus vaccines) in 2001, and the cases of autism continue to increase instead of decrease.

Q. Why has the number of diagnoses of autism increased?

The definition of autism in recent years has broadened to include a whole host of learning disabilities and psychiatric disorders that, in the past, were not labeled autism.

Q. Why do the misconceptions about autism persist?

There is an abundance of misleading and scientifically unreliable information on the Web and in the media from alleged authorities and even celebrities. However, the Academies of Pediatrics and General Practice, the Centers for Disease Control, the Institute of Medicine, and the World Health Organization have all agreed that vaccines do not cause autism.

Q. What are the risks when parents refuse vaccinations?

There have been outbreaks of preventable diseases among unvaccinated children in this country—very recently in San Diego and Hawaii. All of the cases of measles we've had in this country in the past 16 years have been due to importations from countries abroad where measles still exists. The disease then spread into clusters of unvaccinated children. Diseases are just a jet plane ride away, and children who are not vaccinated are at risk. ●



Check out our newly redesigned Web site dukechildrens.org



Big packs on little backs

Like little sherpas, each day schoolchildren dutifully tote their backpacks, stuffed with books and papers and a student's daily necessities.

But these overstuffed packs may play a role in childhood back pain. According to Duke pediatric rheumatologist Laura Schanberg, MD, "In our practice, the use of backpacks is a frequent cause of thoracic back pain, particularly in adolescent girls."

Egla Rabinovich, MD, also a pediatric rheumatologist at Duke, says that while the relationship between backpacks and back pain in children is debated, parents and pediatricians should take steps to address potential problems.

She recommends encouraging children to carry only the supplies they absolutely need, and to use both shoulder straps. Some schools are helping by supplying kids with two copies of each book—one for school and one for home.

"Unfortunately, it is uncool to have a wheeled backpack, but they would solve so many problems," says Rabinovich. "These packs can be 40 pounds and more."

In addition to backpacks, poor posture and even stress are common causes of back pain in children. "You know the knots you get in your back when you're stressed? Kids get that, too," Rabinovich says. Fortunately, she adds, such back pain is benign and can be alleviated by addressing the source of the problem.

In rare cases, childhood back pain could be caused by more serious conditions including arthritis, cancer, congenital spine deformity, tumors, and infectious diskitis.

When should a parent be concerned that the problem may not just be mechanical? According to Rabinovich, parents should talk to their pediatrician when back pain is accompanied by weight loss, fever, looking pale, and having pain even when at rest. ●

Consider a clinical trial

Why are children's clinical trials important? Daniel Benjamin MD, MPH, PhD, a specialist in clinical trial research at Duke, says, "It was only 100 years ago that nearly one out of every six children born in the United States died prior to their fifth birthday. Infant and early childhood mortality in the United States is now uncommon. It is from prior research studies conducted in children that we have reduced early childhood mortality to a relatively rare event."

Current children's clinical trials at Duke include studies on anxiety disorder, brain development, compulsive hair pulling, healthy family lifestyles, and others. To search clinical trials offered, go to dukehealth.org/clinicaltrials. ●



Children with a fatal genetic disorder receive transplants—and a friend for life

Early in her career as a pediatrician at Duke, Louise Markert, MD, believed her training and research had rendered her an expert when it came to treating certain



Louise Markert, MD

childhood diseases. But to her surprise it was a child's parent who forever changed her approach to patient care.

Markert recalls visiting with the child's parents every day and telling them their child was sick and might die. "Finally one day the mother said to me 'Louise, you should play with my baby. Show me that you care for my baby, and then you can talk to me about this.'"

Today Markert primarily treats children with a fatal genetic disorder called complete DiGeorge Syndrome, and not only does she play with them while in the hospital, her relationships with the children and their parents last long after the children are discharged.

She stays in touch with each family through phone calls, letters, and e-mail. She even makes an effort to take part in special events such as kindergarten graduations and award ceremonies, no matter the distance. "I never let go," she says. "I tell them they're stuck with me for life, and we're holding hands wherever they are in the United States or somewhere else."

Children born with complete DiGeorge Syndrome have no thymus, a gland important in the development of T cells. The thymus teaches T cells to fight infection while not attacking the body's own tissues. Without treatment the children usually die from infection.

Building upon programs that had already been established at Duke by Rebecca Buckley, MD, in immunodeficiency diseases and Barton Haynes, MD, on human thymus tissue, Markert found a novel way to prepare thymus tissue—normally discarded during pediatric heart surgery—for transplantation. The pediatric general surgery team at Duke then transplants the tissue into children with DiGeorge Syndrome.

Of the 48 children who have received the transplant since 1993, including three this year, 33 are alive and doing well. The first patient who successfully received the transplant is now in the eighth grade.

Because Duke currently is the only medical center where thymus transplantation is performed, children come from all over the world seeking treatment.

"Some have never traveled before," Markert says. "You can envision how scared they are." So Markert does her best to make the families feel comfortable. While Markert and her team dress in masks, gowns, and gloves when entering the child's room, the parents do not.

"I think development is so important in the first year, and how can you develop if you can't touch your parents or if you can't see their faces? There is some risk in allowing that to happen, but I really want the parents to be able to love their children and touch their children."

Even though the thymus transplantation has proven successful for many DiGeorge patients, the procedure is still experimental. But Markert and her team continue their research in the hopes that the transplant will be funded more easily by Medicaid and insurance companies. Currently the approval process is a lengthy one.

Markert and her team are collaborating with Great Ormond Street Hospital in London to teach the procedure to doctors there. In addition to treating DiGeorge, one of their goals is to find new treatments for other autoimmune diseases such as lupus. On the home front, Markert says numerous people all across Duke have done their part to help save these children's lives—from the staff in the microbiology lab to the families of the children who have donated their thymus glands. "They all do it happily for a child they'll never see," she says. ●



Update: Nevaeh Jones

Nevaeh Jones's story first appeared in the fall 2004 issue of this newsletter. Nevaeh and her family relocated to Durham from Alabama in order for Nevaeh to receive a life-saving thymus transplant at Duke Children's. Nevaeh was the twelfth child to be given a thymus transplant.

"A cold could have killed her," reflects Liz Simmonds, Nevaeh's mother. "Before the transplant we had to wear gowns and masks and keep her away from everyone."

Today, Nevaeh is in first grade and visits Duke Children's once a month for blood tests. Other than that she is the same as any first grader— with a bright, innocent smile and enough charm to light up a room.





Radiothon raises over \$1 million

What does it take to raise \$1,175,759 in three days? It takes a dedicated radio station, amazing stories of the care received at Duke Children's, and people like Chad Ray of Olde Heritage Builders in Zebulon who pulled off the road to call in a pledge.

For the second year in a row, Chad had called in his pledge of \$1,000 to help the kids at Duke during the MIX 101.5 Radiothon. But he kept listening and felt that he needed to do more. Then came the Foresters Double Power Hour—when Foresters, a financial services organization and this year's Duke Children's Radiothon phone bank sponsor, offered a challenge to match pledges dollar for dollar up to \$60,000.

That was just the push that Chad needed. According to his mother, Chad reflected that his company had had a good year and he wanted to give more. Chad called back and pledged an additional \$14,000 to bring his donation to \$15,000 for this year's Radiothon. What an incredible gift!

Chad's gift—along with hundreds of other donations from \$25 to thousands of dollars—were combined with the Foresters match to set an all-time record hour for day two of the MIX 101.5 Radiothon. Magic was in the air and the momentum—and the Radiothon total—kept building. We salute Olde Heritage Builders, Foresters, and more than 4,000 donors who helped us surpass the goal of raising \$1,000,000. Together we can continue to make miracles happen for the patients at Duke Children's Hospital & Health Center. ●



Hyundai fellowship supports pediatric cancer programs

Since 2002 Hyundai Motor America and its Southern Region Dealers Association have donated more than \$700,000 to pediatric cancer programs and research at Duke Children's Hospital & Health Center.

This year, Duke Children's was one of only three pediatric cancer programs in the United States to be chosen to receive an additional \$100,000 fellowship grant to support pediatric cancer research by a junior faculty member whose career commitment is to better understand and develop new treatments for pediatric cancer.

Duke Children's selected Corinne Linardic, MD, PhD, a faculty member whose research is focused on understanding pediatric rhabdomyosarcoma, the most common muscle tumor in children. Linardic is doing exciting work that is providing new insights into how these difficult-to-treat tumors form, with the goal of developing new therapies.

In times of relatively limited support from the National Institutes of Health (NIH), support from private foundations like Hyundai is crucial for junior investigators. In addition, the Hyundai Scholars Program can propel a junior investigator to successfully obtain NIH support.

The goal of the Hyundai Scholars Program is ultimately to support six junior faculty investigators across the country for several years each, as well as approximately 20 pediatric oncology fellow trainees across the United States, in an effort to commit them to pediatric cancer research. The awards will be made on a competitive basis.

Dan Wechsler, MD, chief of pediatric hematology-oncology, has been asked to be a founding member of the Medical Advisory Board for the Hyundai Scholars Program (along with David Poplack, MD, of Texas Children's and Leonard Sender, MD, of University of California, Irvine) to help plan the program for both junior faculty and fellow awards, and to participate in evaluating applications. ●



Call them crazy, but they care

Not only do the legendary Cameron Crazies have tremendous spirit and energy, it turns out they have a whole lot of heart. A new organization has emerged on the Duke University campus called Crazies Who Care, founded by Duke University students Anders Campbell, Leah Fisher, and Sterling Cross.

"It has taken a lot of work, and we're not finished working, but Crazies Who Care has come a long way from a simple idea to becoming a 'new tradition of giving' in the Duke Basketball culture," says Campbell.

Crazies Who Care raises money for the Emily Krzyzewski Family Life Center and Duke Children's Hospital & Health Center—two organizations that are critically important to the Durham community.

They make donating as easy as possible. When the Crazies go in for a game at Cameron Indoor Stadium, they make a donation by simply swiping their Duke card. "I have been shocked by the amount of support we have received in our first year, especially from the freshmen," says Campbell. "For them, swiping for Crazies Who Care is just part of going to the games."

"I wanted to start Crazies Who Care because it's such a simple idea that has enormous potential to do good in the Durham community, both today and in the future, as our idea becomes a part of the tradition of Duke Basketball," says Fisher.

Crazies Who Care has also raised money selling t-shirts and holding small student events such as having students pay to guess how many pancakes it takes to make a stack as tall as Duke center Brian Zoubek. (It takes 302 pancakes.) ●



continued from the cover

Duke Children's patient to play in last Classic

For 35 years the Duke Children's Classic has brought together volunteers, loyal sponsors, celebrities, mascots and more, all committed to the same cause—helping the patients and families at Duke Children's Hospital & Health Center, patients like Matthew Cooper.

It is pretty remarkable that 15-year-old Duke Children's patient Matthew Cooper played in last year's Duke Children's Classic celebrity golf tournament, but it is even more remarkable knowing that Matthew is blind.

Matthew has been playing golf ever since he was a "little kid." He has also been battling cancer. Matthew lost his vision as a result of an inoperable tumor. He was diagnosed with a brain tumor at the age of three in his home state of California. Nine hours of neurosurgery removed 60 percent of the tumor, which was wrapped around his optic nerves. After five chemotherapy treatments the tumor continued to grow. Doctors recommended whole brain radiation—an option the Cooper family did not want to take. Their Internet search on brain tumor treatment centers identified Duke as the place of hope for Matthew. Henry Friedman, MD, met with the Coopers and suggested a new chemotherapy treatment for Matthew.

Travel to appointments was challenging. For each visit the Coopers endured a five-hour drive to the nearest airport in San Francisco, and then a cross-country flight to the East Coast. But the care Matthew received at Duke Children's was worth the effort. In July 2005, after seven years of commuting coast-to-coast for care, the Coopers moved to Durham. Duke Children's offered Matthew more treatment options than hospitals closer to his home. As an added bonus, Matthew had more opportunities to hone his golf skills in the Durham area. In March 2006, Matthew started taking golf lessons with a private instructor. Matthew said of the Duke Children's Classic, "By playing in the tournament, I got to talk to people and tell them that Duke is amazing."

Matthew is amazing. He is fully mainstreamed into high school. He is one of the top students even while completing his schoolwork in Braille. He runs the sound for the school plays through a Braille computer, and he is currently looking into Michigan Institute of Technology, Stanford, or Johns Hopkins to pursue his avid interest in engineering and math.

Join us in celebrating patients like Matthew and 35 years of Duke Children's Classic success. The Classic began as a Sunday morning golf game discussion between then-pediatrics chair Sam Katz and pediatric neurologist John Griffith about the department's challenges. The pair was looking for ways to attract private funds and Griffith, an athlete and avid golfer, suggested a golf tournament. Thirty-five years and \$14 million later Duke Children's will celebrate its final Duke Children's Classic. We hope you will join us at Duke University Golf Club for free family fun on May 31 and June 1. 📍



Photo by Keith Papke

“At Duke Children's there is always a backup plan. There is always another option. There is always hope.”

— Matthew Cooper, 15

The Classic through the years



Fall 1973

Doctors Sam Katz and John Griffith search for a way to raise money for a department in need. Planning begins for the inaugural Duke Children's Classic to benefit the Department of Pediatrics.

September 8, 1974

The first Duke Children's Classic, hosted by singer Perry Como, takes to the links for the kids at Duke Children's Hospital and nets \$5,284.



1980

A tennis tournament is added to the lineup of Duke Children's Classic weekend events. Tennis star Stan Smith chairs this portion of the Classic.



1985

A running festival is added and chaired by LeRoy Walker, PhD, of the U.S. Olympic Committee.



Make new stories with us

For more information on these or other Duke Children's events, visit dukechildrens.org or e-mail dukekids@notes.duke.edu.

May 31-June 1

35th Annual Duke Children's Classic
 Washington Duke Inn & Golf Club
 and Duke University Golf Club
 Durham, NC
 Comedian Jeff Foxworthy and dozens of other celebrities return to Durham to play a couple of rounds of golf for all the right reasons. Bring your family out for this fun-filled weekend of celebrities, mascots and more. Join us in celebrating 35 years of Classic success and \$14 million raised for Duke Children's!



Jeff Foxworthy keeps 'em laughing on the green at the Duke Children's Classic.

July 11-12

Jim Valvano Kids Klassic
 Washington Duke Inn & Golf Club
 and Duke University Golf Club
 Durham, NC
 If you'd like to help kids with cancer, this event will suit you to a tee! Join us for the 23rd annual Kids Klassic, where funds raised benefit our pediatric cancer programs. Jimmy V said "Never give up," and we live by that inspiration.

September 12-14

Circle of Caring at Pinehurst
 Benefiting Duke Children's Hospital & Health Center
 Pinehurst Resort
 Pinehurst, NC
 An exclusive weekend of golf and social events for donors of Duke Children's at the beautiful Pinehurst Resort. Guests will stay at the luxurious Carolina Hotel and will play two of the nation's most prestigious golf courses, including the legendary Pinehurst No. 2.



October 4

Cape Fear Mini Grand Prix
 UNC Wilmington Campus
 Wilmington, NC
 Custom-painted miniature racecars zoom around a specially designed track competing for the coveted checkered flag. The Mini Grand Prix has all the feel of a real NASCAR race with pit crews, racecars, news media, a midway of games and food, and die-hard fans. You will not want to miss the action in Wilmington.



1996

The Duke Children's Classic has a banner year, raising \$1 million.

1997

Comedian Jeff Foxworthy visits Duke Children's in search of a charity to support. A drop-in visit becomes five hours visiting with patients and families. Duke Children's won his heart, and he has been chairing the Classic ever since.



1998

Dream Round (taking place on Monday after the Classic) features Arnold Palmer, Lee Trevino, Fred Couples and Michelle McGann.



2006

Duke's Coach K honors Jeff and Gregg Foxworthy for 10 years of chairing the Classic.





Partners in Safety

Duke Children's Hospital & Health Center has become the lead agency for Safe Kids Durham County, a coalition focused on reducing the number of injuries and deaths in our community by educating children and families about the importance of injury prevention in our everyday lives. Safe Kids programs focus on safety in and around cars; fire and burn prevention; and bike, pedestrian, water, and firearm safety. For more information about Safe Kids contact Theresa Cromling, RN, Safe Kids Durham County Coordinator, at theresa.cromling@duke.edu.

MAKE IT A SAFE SUMMER!

WHEEL SAFELY

- Always wear a properly fitted helmet that fits snugly and does not rock back and forth. It should be centered on the top of the head and always buckled
- Ride a bike that is not too big and is in good working order
- If your child is under 10, make sure that he cycles, skates, or rides a scooter only on sidewalks, paths or designated areas
- Wear bright clothing
- Teach your children traffic rules

RIDE SAFELY

- Secure all children younger than 13 in the back seat for every ride in the car
- Children should never be left alone in the car. The interior of a car gets hot very quickly in

the summer and babies and young children will get overheated rapidly

SWIM SAFELY

- Always keep your eyes on your children when they are playing in or near water. Have a designated "water watcher"
- Install fencing around all sides of your pool or spa. The fencing should be at least five feet high with a self closing, self latching gate
- Always wear a life jacket when riding on a boat or taking part in water sports
- Children should learn to swim after age 4
- Never swim alone

- Never dive into water that is less than nine feet deep
- Only a trained individual should enter the water to help someone who is in trouble. Reach, throw, row, but do not go

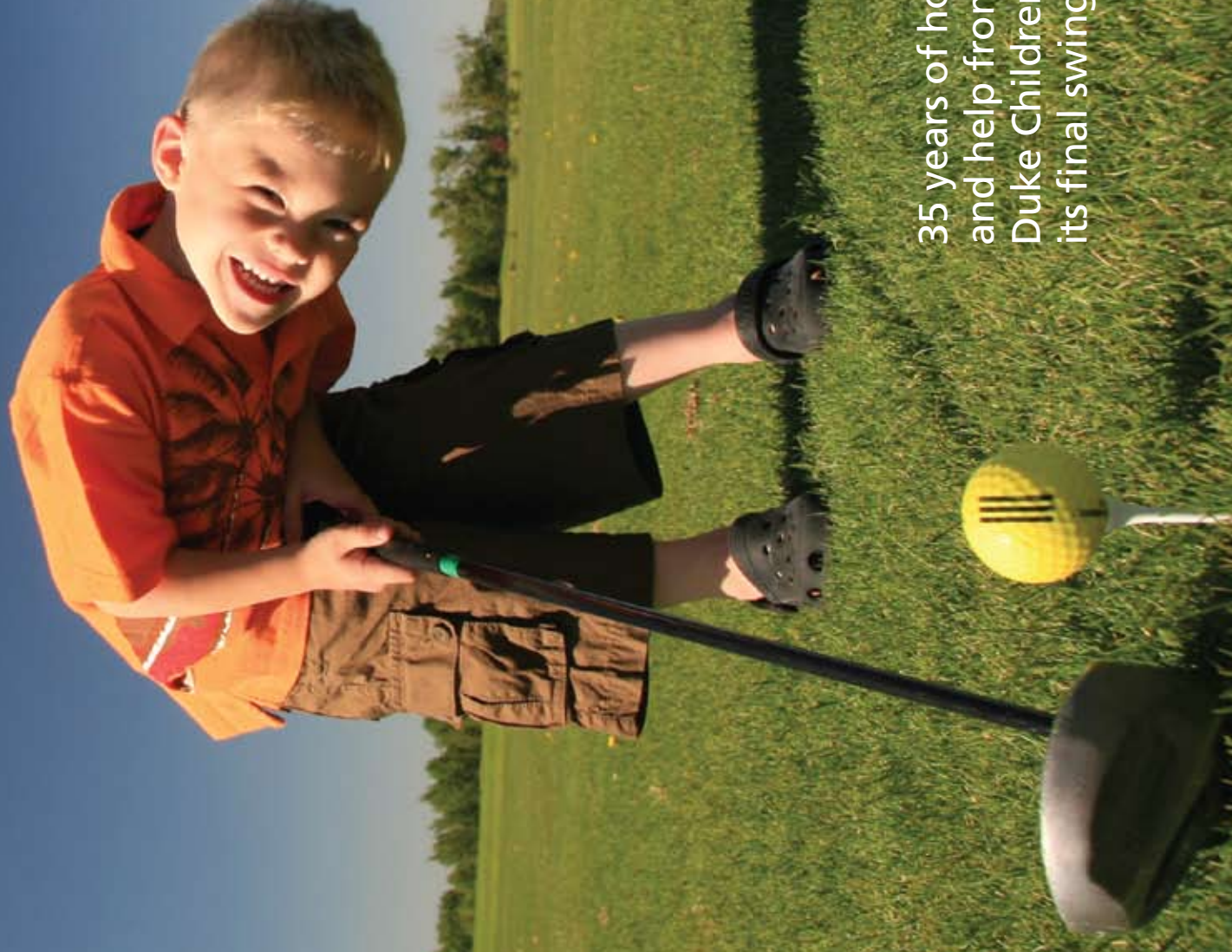
WALK SAFELY

- Teach children to cross the street at the corner
- Look left, right, and left again before crossing
- Make sure that children under 10 cross with an adult
- Wear bright colors so that you can be easily seen
- Never run into the street for a toy
- Remember that the streets are for vehicles, not children

dukechildrens.org



Stories



35 years of hope, healing,
and help from our friends:
Duke Children's Classic takes
its final swing