Parents of children with autism often grapple with a bewildering array of questions and choices: “Did I do something to cause the disorder? Could it be genetic? What is it like to be a child with autism?”

About 300 family members, caregivers and teachers of children with autism recently gathered on the Stanford campus to get answers from the people on the other front line of the war against the difficult disorder: researchers. Organizers of the first-ever conference, Recent Advances in Autism Treatment and Research, hope that this type of summit will become an annual event.

“We really want to engage family members and caregivers of children with autism,” said Carl Feinstein, MD, the Endowed Director of Psychiatry at Lucile Packard Children’s Hospital. “We want to share with the parents what we have learned and learn from the parents what they know.”

Such openness was appreciated by many participants, who don’t usually get such access to ongoing research.

“I got so much out of it,” said Eileen Avila, the mother of Patrick, a 14-year-old boy with autism. “A lot has happened in autism research since Patrick was diagnosed, and I found the basic science very interesting. It really highlighted how few evidence-based studies have been conducted in the field, and I think it made me a lot more cautious about what I might try with Patrick.”

SEE AUTISM ON PAGE 7
An inside look
New center to offer advanced imaging services

State-of-the-art technology is paired with a patient-centric focus at Stanford Medicine Imaging, a new facility in Palo Alto.

The outpatient center, which opened in June, will focus on serving patients and referring physicians from throughout the Bay Area with prompt, responsive and informative feedback on imaging studies. The 10,000-square-foot building will feature the latest computed tomography (CT) and magnetic resonance imaging (MRI) equipment, with subspecialty imaging expertise provided by Stanford radiologists.

“We are devoted to advancing the power of imaging to detect disease at the earliest possible phase and to using these powerful new technologies to help provide optimal care to our community,” said Gary Glazer, MD, chair of the Department of Radiology. The center’s leading-edge technologies, together with frequent equipment upgrades, will also allow physicians, physicists and engineers to carry out research directed toward advancing medical imaging, he added.

The center’s CT and MRI technologies include clinical capabilities for imaging the body, musculoskeletal structures, coronary arteries and nervous system.

Hand-held computers help promote exercise

Today’s younger generation may reckon that “neer the twain shall meet” where technology and their elders are concerned. However, ongoing research by Abby King, PhD, professor of health research and policy and of medicine at the Stanford Prevention Research Center, appears to be gradually dispelling that notion.

In a recent study, King showed that specially programmed personal digital assistants, or PDAs, can prod middle-aged and older Americans—the most sedentary segment of the U.S. population—into increasing their physical activity levels.

Developing approaches to help people increase their exercise frequency, while taking into account an individual’s schedule and environment, is particularly important, she said.

“Portable computer devices are useful because they can be carried around throughout the day,” King said. “Such devices represent one kind of strategy for being able to provide individuals with the help and support they need, in a convenient, real-time context.”

Study participants were randomly assigned to an eight-week program in which they received either a Dell Axim X5 PDA or traditional handouts related to physical activity.

The PDA was fitted with a program that asked, “What barriers did you face in doing your physical activity routine? The device automatically beeped in the afternoon and in the evening if participants ignored it the first time, it beeped again at 30-minute intervals.

The researchers found that while participants assigned to the PDA group devoted approximately five hours each week to exercise, those in the control group spent only about two hours on physical activities—in other words, the PDA users were more than twice as active.

In a companion study to be published later this year, King and her colleagues also evaluated the usefulness of PDAs in modifying dietary behavior. Results indicate that similar “probing” and feedback by a computer program can nudge participants toward changing their eating habits.
When did the notion of a “healing environment” become part of health care planning?
In the early 20th century, the creation of sanitariums for tuberculosis patients first introduced the idea that physical environments, where patients could benefit from fresh air and even sleeping porches, would enhance healing. Starting with the age of antibiotics, however, emphasis on the environment went by the wayside and the focus shifted to rapidly advancing medical treatments.

How has our understanding of the role that design plays in promoting healing changed?
Over the past two decades of my career, there has been an absolute revolution. What used to be considered wishful thinking is now fundamental to our understanding of how to design new health care facilities. We are returning to a more balanced view, informed by our knowledge of how social, psychological and environmental aspects of a patient’s experience actually impact physiology.

Is there proof that the physical environment influences healing?
Yes, and the concept is known as “evidence-based design.” There is strong scientific evidence, for example, supporting the advantages of single-patient rooms, which have been shown not only to provide better infection control but impact a wide range of issues, from improved comfort and privacy for patients and families to reduced medical errors related to transferring patients between rooms during hospitalization.

Have patients and families influenced medical and architectural planners?
Their influence has been transformational. It began in the 1970s and ‘80s when women began asking for (or should I say demanding) a more humane labor, delivery and recovery experience with a more homelike atmosphere. Children’s hospitals led the way in recognizing the importance of involving families and introduced innovations such as rooming in and family-centered care. These innovations have now expanded to include all areas of care for all types of patients.

How are these concepts influencing the design of the new Stanford Hospital and the expansion of Lucile Packard Children’s Hospital?
Single-patient rooms are the new standard, and the potential for rooming in by family members will be available in every room. Our goal is to create hospital rooms that are as much like the home environment as possible. Today that means providing the same kind of information, communication and entertainment technology that people have in their homes. We are designing family-friendly, comfortable rooms that will also allow families at the hospitals to communicate with friends and relatives.

What role does the outdoor environment play and how is that a special consideration here?
This is a truly extraordinary physical environment, with weather, views and sunlight that simply are not present elsewhere. It offers us the opportunity to bring these unique outdoor experiences inside and to make healing gardens, contemplative outdoor spaces and breathtaking views integral to what our patients, visitors, caregivers and staff will experience.

To describe a setting as being “like a hospital” generally means cold, sterile and institutional. How is that changing and why?
Health care is learning from other sectors in which the design of environments is very important. For example, the hospitality industry has taught us that people form their impressions of...
Create a long-term plan for cancer survivors

As an oncologist and a cancer survivor, I appreciate the fog of a new cancer diagnosis as well as the need to coordinate care for survivors at risk for a wide range of late complications of treatment.

By Sandra Horning, MD
Professor of Medicine (Oncology and Blood and Marrow Transplantation)

Few years ago, one of my patients published a book encouraging people diagnosed with cancer to be aggressive information-seekers and to play an active role in their treatment decisions. In “The Patient from Hell,” MacArthur scholar and climate scientist Stephen Schneider used his cancer treatment experience “to argue for needed reforms in a medical system that … is not optimally serving patients.”

While only a small percentage of people surviving cancer will publish books on the topic, most of them—along with many of my colleagues in oncology—agree with Schneider’s assertion that the way we care for people with cancer can be improved.

Growing concern
Nearly 12 million Americans are cancer survivors, and the number of people living with a cancer diagnosis as part of their health history will continue climbing, as the population of citizens age 65 and older grows. More than 1.5 million people will be diagnosed each year, roughly 10 percent of them Californians.

This rapidly growing population commands attention for the distinctive medical and psychosocial needs associated with cancer survivorship. Cancer changes a person’s health care needs forever, even after primary treatment has ended.

In fact, people who have been treated for cancer frequently report that the most unsettling part of their experience was when treatment ended and they were left with the uncertainty of “What next?” Their fears about recurrence, how often to be tested, insurability, employability, sexuality and many other short- and long-term issues need to be addressed.

After treatment ends
Those who have not been touched by cancer have difficulty fathoming the extent to which this diagnosis changes a person’s life. Many have heard of the fatigue and other adverse effects caused by cancer therapy, but few are aware of the long-term and late effects of treatment.

Late effects most often occur years after treatment and can include a host of conditions resulting from damage to the heart, lungs, bones, joints, bone marrow, nervous system and more. Some survivors are at higher risk for serious infection, infertility, thyroid dysfunction, hearing loss, premature osteoporosis, anxiety, depression and second cancers.

In a report commissioned by the independent and respected Institute of Medicine, a panel of ex-
Health warnings on hard plastic

Bisphenol A—a chemical used to make hardened plastics—has been the subject of many recent news stories. Canada has banned baby bottles containing bisphenol A, and the U.S. National Toxicology Program has concluded that there is “some concern” that fetuses, infants and children may be harmed by small amounts of bisphenol A. In the early 1990s, researchers at the School of Medicine were the first to identify and call attention to the possible impact of bisphenol A on human health. Alan Greene, MD, an attending pediatrician at Lucile Packard Children’s Hospital, answers some common questions about this substance.

What is bisphenol A and what does it do?
Bisphenol A, or BPA, is a synthetic, estrogen-like substance that is found in polycarbonate plastic and epoxy resins. Polycarbonate plastic is hard and clear, and is used in many reusable food and beverage containers, and epoxy resins are used to line metal cans.

Although there is no conclusive proof that ingesting small amounts of BPA can adversely affect human health, studies have implicated low levels of BPA exposure in aggression, hyperactivity, breast cancer and early puberty in lab animals.

How widespread is this problem?
BPA is estimated to be in more than 90 percent of baby bottles and in the liners of many cans of powdered and liquid formula. In fact, about 90 percent of people over the age of 6 have detectable levels of BPA in their urine.

Many major manufacturers and retailers are now starting to phase out its use. For example, Playtex and Nalgene have announced plans to drop the use of BPA-containing plastics and resins in their products, and major retailers like Wal-Mart are pulling these products from their shelves.

Should parents be worried? What can they do to reduce BPA exposure?
I think it’s more important to be educated than to be worried. In lab animals, BPA exposure slightly increases the risk of aggression, hyperactivity, cancer and early puberty—it doesn’t guarantee it will happen.

However, if it’s practical to replace BPA-containing bottles, that’s great. If not, then I’d avoid using worn bottles, which may be more likely to leak BPA, or heating breast milk or formula in them. I would also choose powdered over liquid canned formula. If liquid formula is used, the concentrated version is preferable to the ready-to-feed liquid. Finally, parents can look for formula cans that contain as little metal as possible.

Most of the concerns about BPA exposure seem focused on very young children. What about older children and adults?
Studies have indicated that protecting fetuses, infants and very young children should far-and-away be our biggest concern. A preliminary study in pregnant lab animals suggested that supplementation with folate reduced or eliminated the adverse health effects of BPA exposure in the offspring. In addition to providing our bodies with healthful micronutrients and vitamins, we can also exercise and eat right at every stage of life.

How can I identify BPA-containing containers, and what’s the most environmentally responsible way to dispose of them?
BPA-containing polycarbonate containers are often labeled on the bottom with recycling number 7. However, group 7 is a miscellaneous group that includes some really cool, environmentally friendly, potato- or rice-based materials. Call the manufacturer if you want to be certain.

You can recycle polycarbonate bottles or containers. Although BPA-containing polycarbonates are likely to be phased out of use for foods and beverages, the material still has many other useful applications in industrial safety equipment, park benches, etc.

More information on the scientific debate around the potential human health effects of bisphenol A can be found at the Web sites for the National Institute of Environmental Health Sciences (www.niehs.nih.gov) and the National Toxicology Program (ntp.niehs.nih.gov).

Sandra Hornig, MD, is a professor of medicine (oncology and blood and marrow transplantation) and cancer specialist at Stanford University Medical Center. This article was first published in February 2008 in the San Jose Mercury News.

Pediatrician Alan Greene, MD, takes a balanced approach to cutting back on plastic made with bisphenol A.
Reunion brings out stories of survival

Ricky Bunch was a 16-year-old high school junior in December 2002—a lucky kid with a brand-new truck. With great enthusiasm, he took it out for a drive. Sixteen hours later, desperate friends and family found Bunch trapped, unconscious, hypothermic, with a brain injury, one leg nearly crushed, a lung collapsed. He’d missed a curve and the truck plunged 30 feet off a cliff, landing upside-down in Calabazas Creek.

Bunch was rushed to Stanford Hospital & Clinics’ Trauma Center, a place dedicated to extensive medical rescues. Treatment is focused and intense—a marvel of skill and expert teamwork—and then patients transition out for continuing recovery.

This spring, the fourth Trauma Survivor Reunion was all that its chief, David Spain, MD, had hoped for: an afternoon when doctors, nurses and medics could see the results of their work and patients could come back to say thanks and share their experience.

Bunch has come to every reunion to join others who inevitably talk of their immense appreciation of life and the commonality of experience. Their stories are chronicles of bewilderingly sudden and serious injuries. “We have that connection,” Bunch said.

A year ago, Mae Briskin, 83, crossed a street in Mountain View and was hit by a car, her pelvis fractured, her face hitting the pavement first. She’s a writer, winner of a PEN/American West Award for short stories. For her, the reunion was more than a chance to say thank you. “I’m interested in the other people,” she said. “What happened to them? How are they?”

Thomas Pavelko, 59, also celebrated a year of survival since the day a driver ran a red light in Sunnyvale and hit him on his motorcycle. His pelvis cracked; both legs broke, one so badly that it was days before he knew he’d keep it. Pavelko remembers hearing one of the ambulance crew say they’d be taking him to Stanford—and he began to relax. “It doesn’t get any better than that,” he said. Throughout his care in the trauma program, Pavelko, an executive at Lockheed Missiles & Space, noticed the “high, high degree of competence, not only of the doctors, but of the medical support staff, too.”

Stanford’s Trauma Program is certified by the American College of Surgeons as a Level-1 trauma center for adults and children, the only such center between San Francisco and San Jose. The trauma team treats approximately 2,000 people annually, the majority from Santa Clara and San Mateo counties. m

LEARN MORE ABOUT HEALTH

Space may be limited. Please call to register in advance.

Offered by Lucile Packard Children’s Hospital

Mama Yoga
Join prenatal and postpartum mothers in a yoga class designed to enhance strength, flexibility and tranquility.

**Date:** Saturdays, Aug. 2–23, at 9:30 am

**Location:** Willow Room, Oak Creek Apartments, 1600 Sand Hill Road, Palo Alto

To register, call 650-723-4600.

Pediatric Weight Control
Families learn healthy eating and exercise habits for life.

To register, call 650-725-4424.

Heart to Heart: A Seminar on Growing Up
Two-part discussions for pre-teens and their parents on issues of growing up.

**For Boys:** Fridays, Sept. 12 and 19, at 6:30 pm

**For Girls:** Tuesdays, Sept. 23 and 30, at 6:30 pm

To register, call 650-723-4600.

Car Seat Fitting
Have a certified technician ensure that your child’s car seat or booster is safely installed. The service, aided by Kohl’s, is free and available Monday-Saturday.

To make an appointment, call 650-736-2981.

Pivotal Response Training for Autism
Child psychiatrist Mendy Boettcher, PhD, explains techniques to improve an autistic child’s language and social skills during family interactions.

**Date:** Wednesday, Sept. 24 at 7 pm

**Location:** Packard Hospital Auditorium

To register, call 650-723-3783.

For more information and updates on the Medical Center Renewal Project, visit the project Web site, www.stanfordpackard.org.
Teen students get a sneak preview of medical school

It can be challenging to get into medical school, but it was no problem for a group of local students earlier this year. More than 150 teenagers, including many from East Palo Alto, Palo Alto and Redwood City, flocked to Stanford’s campus to play medical student for the day.

They came for Med School 101, an all-day experience designed to expose students to the world of medical research and to get them thinking about possible careers in medicine and science. Participants had the opportunity to perform virtual CPR, touch animal hearts and view embryonic stem cells that had given rise to heart cells beating in a lab dish.

A particularly popular course was led by Sean Mackey, MD, PhD, an associate professor of anesthesia, who introduced the students to “real-time brain control” that showed how chronic pain sufferers are able to reduce pain levels by using mental strategies and by studying their own brain images.

“It’s really cool, those images he showed and his ideas about controlling pain,” said Scott Kidd, a sophomore at Summit Preparatory High School in Redwood City, who says he has definite plans for medical school.

Other students flocked to a session on surgery at the Goodman Simulation Center, where they were allowed to “perform” a laparoscopic procedure on one of the simulators there. “It’s like a video game,” said Jessica Reyes of Sequoia High School in Redwood City, as she maneuvered her laparoscope like a joystick.

The students also got acquainted with “Mr. Jones,” one of the mannequins that surgical interns practice on at Stanford before heading into the operating room. Awed whispers could be heard as the mannequin responded, in a very real fashion, to various manipulations.

Students weren’t the only ones to get something out of the experience. “It is a joy to see the excitement on the students’ faces when you explain a difficult topic and they really get it,” said Mackey, who also presented at last year’s event. “I remember what high school was like, and I know that a single event can make a big difference in the direction you choose for your life.”

Sherry Wren, MD, a professor of surgery who gave a talk on her volunteer work in Africa, felt the same way. Though she had never lectured to high schoolers before, she said she took time out of her busy schedule to inspire a few students. “Wouldn’t it be great if someone in the audience thought, ’I want to do what that woman does,’ and became a Stanford surgeon?” she said.

High school students perform surgery on mannequins at the Goodman Simulation Center during Med School 101, a special event to spur interest in medical careers.

Did you know?
Our eyes are always the same size from birth, but our nose and ears never stop growing.

**FROM AUTISM ON PAGE I**

Feinstein, a professor of psychiatry and behavioral sciences in Stanford’s School of Medicine, co-directs the Stanford Autism Working Group—a collaboration of physicians and researchers at Packard Children’s Hospital and Stanford School of Medicine dedicated to discovering the neurological and biological basis of autism.

“Parents are really powerful advocates for their kids,” said child psychiatrist Antonio Hardan, MD, who directs the autism and developmental disabilities clinic at Packard Children’s. “But it is very important for them to be informed about the risks and benefits of any intervention.”

Hardan, an assistant professor of psychiatry and behavioral sciences at the medical school, reviewed the safety and effectiveness of traditional and innovative medications to treat some symptoms of autism and Asperger syndrome. He was joined by a dozen other researchers and physicians from Stanford and Packard Children’s.

“Stanford and Packard Children’s have a very broad scientific community devoted to autism research,” said child psychiatrist Joachim Hallmayer, MD, an associate professor of psychiatry and behavioral sciences at the medical school, who is studying pairs of twins to determine if there is a genetic link to autism.

Other conference topics included the medical management of autism, the basic science of autism, neurological problems associated with the disorders and how a child with autism perceives the world.

“Much of this research owes its existence to the family members of these children,” said Hallmayer. “There are some very strong parent groups that have been driving these types of investigations for years now. They push for resources, for services and for public awareness of autism and associated disorders.”

“We’re really frustrated and really motivated,” agreed another mother, who did not want to be identified. “Unlike many other more acute disorders, autism is a lifelong challenge for the entire family. The parent acts as case manager, therapist and health care provider for his or her child. We need to be informed about what’s effective and what’s not.”

Although current interventions have been somewhat helpful in treating the secondary behavioral issues, such as aggression and hyperactivity, that frequently accompany the disorder, they have been less successful at addressing the core problems of language delays, social interaction deficits and restrictive or obsessive interests.

“It’s good to feel that progress is being made,” said Avila. “Of course I’d love to see a cure, but in the meantime you want to be treating the symptoms. If you give these children what they need, you will be astonished by the results.”

The conference was organized by the Autism Working Group, aided by the Lucile Packard Foundation for Children’s Health.
**First Person**

Bob Upham moved to the Peninsula from the East Coast two years ago for a position at Yahoo!, where he is the director of business development for Yahoo! Geo and Maps. He is on the board of the Yahoo! Employee Foundation, chairs its fundraising committee and serves on the Yahoo! for Good grants committee. Upham has been a volunteer at Stanford Hospital & Clinics for the past year and a half and is currently a lead volunteer in the Emergency Department.

### Why I volunteer at Stanford

After many years in philanthropy, I decided two years ago to begin a new kind of giving: hands-on. I wanted to do something that would make a difference on an individual level. I chose Stanford Hospital & Clinics because of its excellent reputation. Now I volunteer two evenings a week in the Emergency Department, doing whatever I can to free the nurses, doctors and staff so they can concentrate on patient care.

During the day I have a demanding job at Yahoo!, but in the evenings I clean beds, move gurneys, make sure patients have warm blankets or a glass of water. A lot of people are alone and in pain, or are scared or lonely. I have the time to talk to them and to try to make them feel more comfortable.

When you contribute money, you can’t always see quick results. As a volunteer, you are personally involved and the satisfaction is immediate. Volunteering re-energizes me, even when I’ve had a long day at work. Though I often work late and travel a good deal, I still find time to volunteer. It has improved my quality of life—it balances everything else. I look back on the years I was serving on boards, attending galas or writing checks, and I realize now that I could have been doing this all along as well.

Some people think they don’t have the time. Others might be afraid to serve. Before I came to Stanford, it never would have occurred to me to volunteer cleaning beds. But this kind of service is in all of us. We just don’t recognize it.

For me, the most powerful transformation was that moment when, without even thinking about it, I moved from volunteering to make myself feel good to volunteering because I’m needed. And I know that I’m needed.

Volunteering at Stanford Hospital—in the Emergency Department, gift shop, Cancer Center, spiritual care, Health Library or in one of the clinics—provides the same palpable benefits. I feel lucky to be a volunteer here. It is an honor and a privilege to be a part of the Stanford Hospital team.

### Become a volunteer

Volunteers play a critical role in the hospitals’ mission to deliver high-quality patient care and make a tremendous difference in the lives of patients, families, caregivers and staff.

- For information about volunteer opportunities at Stanford Hospital & Clinics, please call 650-723-7424 or visit www.stanfordhospital.com/employment/volunteering.
- To volunteer at Lucile Packard Children’s Hospital, please call 650-497-8696 or visit www.lpch.org/jobsVolunteering/Volunteering/index.html.
- The Hospital Auxiliary has a junior program for teens between the ages of 14 and 18. Call the auxiliary office at 650-723-6636 for information.