Peace of Mind
Brain & Behavior Center Offers a Lifetime of Better Outcomes
Dear Friends,

Our brains are complicated and amazing organs that allow us to function at the most basic level, yet are also involved in our most complex actions and thoughts. When something goes wrong within our brain, in the case of injuries, genetic conditions, or cancers, there may be a dramatic change in our quality of life.

In this issue of Lucile Packard Children’s News, you’ll visit our Brain and Behavior Center, where restoring health for a child with a brain injury or disorder means restoring their childhood. The center’s teams blend deep expertise with a compassionate, inclusive approach to help children reach their fullest potential. You’ll also meet a few of the children who have a new lease on life because of care they received here.

Whether a child is diagnosed with autism, a brain tumor, or a concussion, they benefit from the work of leading clinicians and researchers at our hospital and the Stanford University School of Medicine. This work wouldn’t be possible without your support. Your gifts ensure that no child is turned away due to financial circumstances, and that researchers can make discoveries that change the face of treatments and cures.

Thanks to your continued partnership, children treated here today will have a chance to grow up and become the physicians, caregivers, and researchers of tomorrow. And that’s something to think about.

Sincerely yours,

David Alexander, MD
President and Chief Executive Officer

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Front cover: Morgan and Peyton Fisher. Photo by Toni Gauthier.
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Peyton Fisher loves her brother Morgan, wants to be a princess, and decorates her cupcakes with excessive chocolate and marshmallows. In most ways, she is a typical 3-year-old. But for a while, she also had a slight limp — a poignant reminder that just a few months ago, something had gone terribly wrong.

Full Circle
Brain and Behavior Center Puts Children Back on Track to Healthy Futures
It seemed like just a stomach bug at first. For five days in September 2013, Peyton woke up with nausea but then seemed to get better as the day progressed. When she started to look unsteady on her feet, her parents, Jenna and Colin Fisher, brought her to their local emergency room.

A CT scan showed that Peyton had a tumor four centimeters wide — the size of an egg — in the back of her head. The growth was preventing Peyton’s spinal fluid from draining and was putting pressure on her cerebellum. Without immediate attention, the tumor could grow and cause blindness, stroke, or worse.

Her mother immediately started calling around to find the best place to take her daughter for care.

“Everyone I spoke to said to bring her to Packard,” Jenna recalls. Within two hours, the family was speeding by ambulance to Lucile Packard Children’s Hospital Stanford for Peyton’s emergency brain surgery.

“This was a kid who was never sick,” says Jenna. “It all happened so quickly, we were in shock.”

**Emphasizing Quality of Life**

Peyton’s family was quickly put at ease. At our hospital, multidisciplinary teams of specialists care for children and adolescents in one of the most advanced surgical facilities in the country. Their medical expertise is partnered with a compassionate approach that focuses on the emotional and psychological aspects of care and the child’s quality of life after treatment.

Peyton was placed in the capable hands of the country’s most dedicated specialists who worked together for seamless delivery of care. Michael S. B. Edwards, MD, chief of pediatric neurosurgery, flew in from his regular clinical outreach rounds in Nevada as soon as his new patient was prepped for her procedure. Throughout the surgery, a nurse gave the worried parents a progress report every 30 minutes.

After eight hours in the operating room, Peyton’s tumor was completely removed by what Jenna calls “a team of the most amazing surgeons ever.” Several days later, another dedicated neurosurgeon, Samuel Cheshier, MD, came into the hospital on a Saturday holiday to happily report that the tumor’s pathology was benign. After 12 days in the hospital, Peyton returned home.

“It wasn’t only that I felt that Peyton was in the most competent hands humanly possible,” Jenna says. “Beyond their technical expertise and excellence, everyone was so empathetic and understanding about how we felt, and they made a point to include us in all decisions about Peyton’s care. They kept us involved every step of the way and were incredibly communicative. I felt like they put themselves in our shoes and genuinely cared about our entire family as human beings.”
“Beyond their technical expertise and excellence, everyone was so empathetic and understanding about how we felt, and they made a point to include us in all decisions about Peyton’s care.”

— Jenna Fisher, Peyton’s mother
“My friends understand and accept me as I am, even with the seizures. But I want to share information so other people know what it’s like.”

Aria Chimalamarri
A Continuum of Care

For 17-year-old Aria Chimalamarri, surgery is only one of the many types of care our teams have provided to improve her quality of life. Since the age of 5, Aria has experienced numerous seizures, large and small, from a tumor that started small and then came back with a vengeance. Her first surgery was in 2003 at the age of 7, while she and her family were living in India. The tumor quickly grew back, however, and in 2004 Aria underwent a second surgery.

“The seizures were unnerving,” says her mother, Devi Chimalamarri. “She would stop walking or see butterflies that weren’t there. Some would last a few seconds; others would have her thrashing on the ground. They were completely unpredictable — there was something new every time.”

After the second surgery in India, Devi started asking around for advice, unwilling to submit her young daughter to unnecessary surgeries or the long-term side effects of radiation therapy. Once she started talking to experts at Lucile Packard Children’s Hospital Stanford, she was relieved at what she heard — the tumor was less advanced than other specialists had estimated, and Aria would not need another surgery right away. Encouraged by shrinkage in the tumor after two rounds of chemotherapy in India, the Chimalamarri family packed up and moved to San Jose to be close to the specialty care Aria needed at Stanford.

That was eight years ago. Since then, Aria has undergone two more surgeries, a regimen of radiation therapy, and chemotherapy at our hospital. She is now under supervision for seizure management and tumor monitoring.

Despite getting more than her fair share of hospital time, Aria strives to celebrate all aspects of who she is, from her vegan philosophy to her small gold nose ring, which her neurosurgeon was so careful to protect during her last procedure.

“We’ve been through so much, but in retrospect I would still move here. It’s not just the incredible medical treatment Aria gets at Packard Children’s — it’s the whole team. I know we are in good hands. They are always reaching out and including Aria in making decisions,” Devi says.

Holistic Approach to Well-Being

While Aria’s close friends understand what happens to her during a seizure, there are still many misconceptions about epilepsy.

“It’s hard because there’s a lot I can’t do independently,” says Aria, who participates in a monthly support group with other teens. “My friends understand and accept me as I am, even with the seizures. But I want to share information so other people know what it’s like.”

To ease the experience for Aria during her middle school years, specialists from the Hospital Educational Advocacy Liaisons program went to her school to help her classmates and teachers understand her condition. This year, as a high school senior, Aria attended our on-site Hospital School to avoid having to attend classes in a wheelchair. She also participates in clinics for acupuncture and to learn biofeedback techniques to help manage pain.
“These kids are not treated in isolation,” says Paul Fisher, MD, the Beirne Family Professor of Pediatric Neuro-Oncology and chief of child neurology. “We take a holistic approach to their well-being and connect them to all the resources we have available.”

Aria continues to have regular MRI scans to track any possible recurrence of her tumor and receives ongoing care from specialists in our growing epilepsy clinic, which features the latest tools for diagnosing and treating young patients.

**Environment of Expertise**

In recent years, new faculty members have been added to increase the breadth and depth of care for more children like Aria and Peyton.

“We already have a great team in place, but now we are building out to expand our expertise and resources,” says Fisher. “We have brought in recruits who have been specially selected to be great clinicians, strong researchers, and national leaders in their respective fields.”

One of these experts is Brenda Porter, MD, associate professor of neurology, who joined the faculty last year to enhance care for children with seizure disorders.

“Epilepsy is not one diagnosis, but many,” says Porter. “There are lots of therapeutic options, but the challenge is to diagnose the disorder correctly and then to identify the best therapy. Our advantage here is that we are in the heart of an academic medical center where the science is the best in the world. It makes it easier for research to translate into clinical care.”

In addition, our specialists are developing and refining innovations like implantable devices, precise imaging technologies, laser surgery, and targeted medication, all designed to be less invasive and improve outcomes for young patients with neurological disorders. With increased scientific insights into human genetics, Porter predicts there will one day be novel treatments that are customized based on the genetic makeup of each patient’s individual disease.

Packard Children’s is also one of only 10 hospitals in the country participating in the Pediatric Brain Tumor Consortium, which is focused on developing new therapies for brain tumors while improving support services and follow-up care.

“There is an environment here that encourages the exchange of expertise, which is the groundwork of a multidisciplinary center of excellence in pediatric neuroscience,” says Gerald Grant, MD, FACS, associate professor of neurosurgery, another recent addition to the team. “Different disciplines can bridge between our children’s hospital and the adult hospital, and together we can design strategies to help kids not only survive, but to survive well.”
“We have to love the kid more than we hate the disease,” Grant adds. “We need to be aggressive, but cannot push the limit and risk permanent neurological injury that could negatively impact the child’s quality of life.”

Today, Peyton has only six small circles where her hair is still growing in — the marks of the state-of-the-art minimally invasive surgery she received to remove her tumor. She took her first trip to Disneyland in April and enjoys playing with Lucile, the American Girl doll she named in honor of our hospital’s founder.

“We have to love the kid more than we hate the disease. We need to be aggressive, but cannot push the limit and risk permanent neurological injury that could negatively impact the child’s quality of life.”

— Gerald Grant, MD, FACS

For the next 10 years, Peyton’s family will continue to visit the hospital on a regular basis for her MRIs and checkups. “Peyton loves to go to the hospital, and we feel very much a part of the community there,” says her father, Colin.

“I remain so impressed with everyone we come in contact with there, including valets, janitors, physical therapists, the medical staff, and more,” says Jenna, who, with her husband, was inspired to make a philanthropic gift supporting our brain tumor research and child life programs. “Their dedication, passion, and excellence in what they do motivate me to push myself harder in whatever contribution I can make to the world. I have so much appreciation and admiration for everyone at Packard Children’s.”

This June, Aria will walk across the stage to receive her high school diploma. While she still has ongoing seizures, those steps mark an especially important transition for her — one that promises a bright future where she can draw, take voice lessons, play with her dog Charlie, and start college in the fall.

“I envision a future for her free of seizures,” her mother says. “But for now we are focused on managing her symptoms and being adaptable. No one wants to be in a hospital, but there’s no other place I would bring her.”

Sustaining Excellence in Pediatric Neurosurgery

The Stanford University School of Medicine would like to establish an endowed professorship in honor of Michael S. B. Edwards, MD, to recognize his legacy in pediatric neurosurgery at our hospital, and enable Stanford to build on his accomplishments for future generations of children and families.

Regarded as one of the top pediatric neurosurgeons in the United States, Edwards is chief of the division of pediatric neurosurgery and director of the Center for Children’s Brain Tumors at Lucile Packard Children’s Hospital Stanford. He specializes in the advanced microsurgical treatment of all forms of benign and malignant central nervous system tumors.

Under Edwards’ leadership, our pediatric neurosurgery program has earned a national reputation for delivering the highest standard of family-focused care. In the most recent U.S. News & World Report, our hospital was recognized as one of the best neurology and neurosurgery programs in the country.

This professorship would be held by an outstanding surgeon who would lead training and research to advance the health of children diagnosed with brain and spinal cord tumors and other neurological disorders. A group of generous donors, including Jeffrey Chambers and Andrea Okamura, and The Schow Foundation, has already stepped forward with gifts toward the required endowment of $4 million. With $1.5 million remaining to be raised, this is a unique opportunity to join with other key supporters to provide instrumental funding for a critical area of pediatric medicine.

To learn more, please call (650) 498-7641 or email leanne.newman@lpfch.org.
The developing brain is a particularly complex organ, an interconnected network of cells that controls everything we experience, do, or say. If this intricate system goes awry — from disease, infection, injury, or genetics — the results can be devastating. When it happens in childhood, the entire future of a child can be put at risk.

For children facing disorders that affect their brain development, function, or behavior, Lucile Packard Children’s Hospital Stanford offers an advanced level of care unavailable at most other hospitals. In our Brain and Behavior Center, multidisciplinary teams blend deep expertise and groundbreaking research with a personalized, family-centered approach.

“Whether we are caring for a child with autism, epilepsy, cancer, or an eating disorder, we put all our resources together to offer a lifetime of better outcomes,” says Paul Fisher, MD, director of the Brain and Behavior Center and chief of the division of child neurology.

The impact of childhood brain and nervous system disorders, as well as the side effects of treatment, can range from emotional and learning problems to physical impairments — issues that can carry through childhood and adolescence and into adult life.

Therefore, in addition to lifesaving medical treatment, the center offers nurturing support that continues long after a child leaves the hospital, in order to ease their recovery and a return to a healthier, happy childhood.

With a full complement of resources and support services including physical therapists, mental health experts, genetic counselors, and child life specialists, our hospital cares for all aspects of a child’s needs.

“It’s an approach designed to improve both survival and quality of life,” says Fisher.

Streamlining Research

The Brain and Behavior Center also takes a “big picture” approach to research — with physician-scientists working across different disciplines to better understand the nervous system and how the brain operates, changes, and breaks down. Thanks to close alignment with the Stanford University School of Medicine, interactions between researchers and clinicians are streamlined — laying the foundation for innovative therapies.

For example, the center’s growing epilepsy program is exploring new ideas about how to reduce the side effects of medications and improve treatment.
options. Ongoing studies may lead to new devices that predict the onset of seizures and prevent them.

Research is also pointing to the development of new drugs and specialized therapies for children with learning and behavioral disorders, as well as better tools for earlier diagnosis.

“With advances in research and technology, we now have more accurate diagnostic tools and more options for interventions,” says Fisher. “By working as a team, we are able to reach the right diagnosis and treatment quickly, and bring peace of mind to the families in our care.”

Center Highlights

Our faculty has tripled since 2008, and we now have the largest neurology program in the western United States.

We are one of only 10 hospitals to participate in the National Cancer Institute’s selective Pediatric Brain Tumor Consortium.

Our Neuro NICU, one of just a few around the country, brings expertise in new diagnostics and treatment for newborns with acute brain injury and neurological disorders.

Our Comprehensive Eating Disorders Program is at the forefront of treating these conditions and leading research to understand their neuropsychological underpinnings.

The Best Care Available

In the Brain and Behavior Center, our teams work across numerous specialties to provide a continuum of care for children with disorders affecting their brain development, function, and behavior. We work closely with families to deliver the best care available for children with a wide range of conditions including:

- Attention and Behavioral Disorders
- Autism
- Brain and Spine Tumors
- Cerebral Palsy and Spina Bifida
- Developmental Delay
- Eating Disorders
- Epilepsy and Seizures
- Headaches
- Learning Disabilities
- Movement Disorders
- Multiple Sclerosis
- Neonatal Conditions
- Neurogenetic Disorders
- Neurometabolic Disorders
- Neuromuscular Disorders
- Sleep Disorders
- Stroke
- White Matter Diseases
The next time you play Angry Birds, consider this — the same type of sensors that capture movements on your phone are also playing a role in biomedical research to make sports safer for children.

For the past three years, investigators at the Stanford University School of Medicine and Lucile Packard Children’s Hospital Stanford have been using these sensors in new ways to understand and measure what happens when athletes experience collisions that lead to brain injury.

“We’re now defining concussions more broadly as a blow to the head with some neurological effect such as headache, dizziness, or nausea — not just loss of consciousness.”

— Paul Fisher, MD

Though abundant media attention has been given to concussions in adult players in the National Football League, children — both boys and girls — are also being widely affected by milder, repetitive injuries. In terms of numbers, there are millions of children nationwide playing recreational sports, compared to only a couple thousand players in the NFL. Many young athletes are now playing harder and faster with frequent incidental contact in a variety of sports, such as basketball, soccer, and lacrosse.
“The problem of concussions is more pervasive than we previously thought,” says Paul Fisher, MD, chief of child neurology. “We’re now defining concussions more broadly as a blow to the head with some neurological effect such as headache, dizziness, or nausea — not just loss of consciousness.”

Ava James, 13, recently came to Fisher’s clinic after suffering nausea, dizziness, and headaches following a hit to her head during soccer practice. She is part of a growing trend — approximately half a million children nationwide visit the emergency room each year for sports-related concussions. Many others are not seen in the emergency room and under-report their symptoms. The concussion rate for girls has risen 21 percent annually over 11 years, a greater increase than the concussion rate for boys at 14 percent annually.

The Science of Impacts

Though concussions are a growing concern, very little is actually known about how different types of impact actually cause injuries to the brain. When players take a hard hit, the injuries and their effects are sometimes not felt or seen immediately afterwards. With different symptoms in different individuals, concussions are hard to diagnose, often undetectable on CT scans and largely dependent on players’ self-reports — if they’re honest.

In order to predict and prevent concussions, Stanford researcher David Camarillo, PhD, assistant professor of bioengineering, is developing an innovative approach that may be a game-changer in sports concussion research.

Using accelerometers and gyroscopes, the same types of sensors found in smartphones, Camarillo’s lab is gathering data about brain trauma as it occurs. Through a remarkable partnership with Stanford Athletics, most players on the Stanford football team wear mouthguards outfitted with sensors that record and measure the physics of every hit to the head during practices and games. In addition, by using ultra-high-definition, slow-motion cameras, Camarillo and his team are also closely observing and videotaping collisions — yielding footage that shows, down to each painful millisecond, how the impact of a hit ripples through players’ bodies.

“This story is still in the early stages,” Camarillo says, “but we’ve already seen some startling data.”

For reference, 1 G is the standard measure for the linear acceleration of gravity. In a car crash, the acceleration might reach 50 or 100 Gs. In some of the hardest hits in football, Camarillo and his team have observed linear acceleration of up to 150 Gs. This does not even account
for angular acceleration, the rotation of a player’s head and neck after a hit. The Stanford study is one of the first to measure angular acceleration as an important factor that may also contribute to brain injuries.

“Our ultimate goal is to discover the mechanism of concussion so that we can develop better preventive measures, particularly for young athletes.”

David Camarillo, PhD

In addition, incidents that may previously have been counted as just one hit are actually two successive collisions. A player experiences an initial impact during a tackle, but the brain receives trauma again when the head collides with the ground — resulting in a double hit that generates more than one concussive impact.

By taking measurements on both non-injury events and injury events, Camarillo aims to narrow in and define the thresholds for injury. “Our ultimate goal,” he says, “is to discover the mechanism of concussion so that we can develop better preventive measures, particularly for young athletes who would be at risk of brain damage and impaired cognitive development.”

Though the research may take five or 10 more years, the data collected from Stanford football players may also help to determine the “doses” of impact that children and adolescents are experiencing in recreational activity. With a grant from the David and Lucile Packard Foundation, the project is now expanding to include testing other types of wearable head sensors that could be more widely used in women’s sports, where mouthguards are not required equipment. This basic research and pilot studies in Stanford women’s lacrosse and soccer players may help researchers better understand the different effects of head injuries in girls’ sports.

Gerald Grant, MD, FACS, associate professor of neurosurgery, is a new arrival at Lucile Packard Children’s Hospital Stanford, but has quickly embraced the opportunity to advance sports concussion research here. A veteran of the U.S. Air Force and a pediatric neurosurgeon, Grant has treated patients ranging from soldiers with blast concussive injuries in Iraq, to an increasing number of girls with soccer concussions in clinic.

Grant notes that more and more research is showing that head injuries may have a cumulative effect. “It’s not just a severe blow,” he says, “but a series of repetitive, milder blows that can actually result in significant damage over time.”

“Considering that the average college soccer player heads the ball hundreds or thousands of times a season, we have to better understand and speak up about these issues,” Grant adds. Since his arrival at Stanford last fall, Grant has joined with Camarillo, Fisher, and others to move the research forward, leveraging the university’s tremendous wealth of expertise.

“We have incredible athletes and scholars at Stanford — we’re like the Greek city-state of Sparta,” notes Fisher with a smile. Joking aside, there is indeed a unique confluence of elite athleticism and deep intellectual curiosity here, even in the players and
coaches who willingly and actively participate in the research. In addition, the opportunity to collaborate across disciplines such as engineering, biodesign, and medicine at Stanford University makes advances more readily achievable.

For worried parents, pediatricians Fisher and Grant are quick to point out that the positive effects of children participating in sports — such as improved physical health, body image, and self-esteem — far outweigh the risks of head injury. After two weeks of rest, 13-year-old soccer player Ava was ready to return to normal activity, though it took five months for her headaches to subside. While the researchers continue to work toward more definitive metrics to predict and prevent head injuries, they encourage coaches, players, and parents all to become more educated about concussions, including the importance of following rules and using proper safety equipment, giving young athletes adequate time to heal both physically and mentally, and returning to the classroom before returning to the playing field.

These custom-designed mouthguards, outfitted with accelerometers and gyroscopes, are worn by Stanford football players to record and measure the physics of hits to the head during practices and games.
A diagnosis of childhood autism can be shattering news for many parents. But when doctors at Lucile Packard Children’s Hospital Stanford confirmed that 6-year-old Lucas had autism, his mother, Valorie, felt a sense of relief.

For years, Valorie had been deeply concerned about Lucas’ behavior, from his poor communication skills and frequent tantrums, to his unusual fixations and hypersensitivity to smells.

“Lucas needed to have certain things done in a certain way,” Valorie recalls. “He preferred his toast cut into rectangles. However, sometimes this would change, so I would often get it ‘wrong.’”
Lucas rarely made eye contact with people, had serious speech problems, and even had difficulty holding a pencil. At age 4, he underwent a series of psychological tests that suggested he had an autism spectrum disorder. After two years of inconclusive results, Lucas’ pediatrician referred him to Lucile Packard Children’s Hospital Stanford for an evaluation.

It didn’t take long for Stanford pediatrician Brian Tang, MD, and clinical psychologist Barbara Bentley, PsyD, MS Ed, to diagnose Lucas.

“They could see right away that he was on the autism spectrum,” Valorie says. “For me and Lucas’ father, the diagnosis was a huge relief. It finally gave us a direction to go in to give our son the help he needs.”

For Valorie and other parents of newly diagnosed children, the roadmap for treatment is far from simple.

“When you see a doctor for high cholesterol, you get one drug and you’re told to follow a diet,” says Antonio Hardan, MD, director of the Autism and Developmental Disabilities Clinic. “But when you have a child diagnosed with autism, you may need to work with 10 different services, including occupational therapy, speech therapy, child psychiatry, developmental pediatrics, neurology, and medical genetics.”

Over the last few years, the Stanford Autism Center has become a campus-wide effort to coordinate and facilitate clinical activities, research investigations, and supportive services for patients and families facing autism. “Our goal is to have all these services accessible to our patients and available in a coordinated way to their families,” Hardan adds.

Helping a Growing Community

Despite better coordination of services, a dramatic rise in children diagnosed with autism has made it increasingly difficult for families to get the help they need in a timely manner.

“The large number of new patients is overwhelming our clinical services,” says Hardan, who is also a professor of psychiatry and behavioral sciences at Stanford. He points to recent statistics showing that about 1 in 68 American children — including 1 in 42 boys — has been identified with autism spectrum disorder.

“We get families coming in from throughout California, but we don’t have enough staff or resources here to support all of them,” adds psychologist Jennifer Phillips, PhD, co-director of the Autism and Developmental Disabilities Clinic. “Sometimes we have to tell parents that it will be a year before we can see their child.”

Even children diagnosed with autism have a long wait for follow-up services and treatments. To address that challenge, our hospital and the Children’s Health Council — with support from generous donors — recently established the Early Support
Program for Autism, or ESPA, to provide support services to parents at no cost following a diagnosis.

“The idea for ESPA came when we realized that it takes several weeks for kids newly diagnosed to get into treatment,” Hardan explains. “During that time, the parents are dealing with a lot of emotions. We felt something should be done for them while they wait to connect with the right providers.”

Valorie agrees. “We felt overwhelmed at first,” she says. “Fortunately, Dr. Tang referred us to ESPA right away. The support they’ve given us has been amazing.”

About 175 families have received services from ESPA since the program began in July 2013. The clinical care coordinator, Christina Ardel, is usually the first contact from ESPA who provides information about resources to families. She also refers them to the parent coach and trainer, Gina Baldi, who became the main contact for Valorie.

“Gina makes everything so much easier,” Valorie says, “like scheduling evening appointments for me, which I really appreciate. She’s helped me deal with the school district and my insurance company, and she’s given me all kinds of useful advice, like where to find online chat rooms with local parents. Just today, she sent an email with helpful apps for my phone.”

Valorie has also enrolled in several ESPA-run classes designed to help parents handle the lifelong challenges of autism. “I would never have been able to participate in ESPA if the services weren’t available for free,” she adds.

Less than a year after he was diagnosed at our hospital, Lucas is showing signs of improvement. His tantrums are more under control, and he has learned to hold a pencil and draw. He’s even engaged other kids in conversation. “As a parent I can’t express how much I appreciate everything ESPA and Packard Children’s have done,” Valorie says. “Even a little progress is good, and thanks to early intervention, his prognosis is likely to improve.”

Numerous studies of young patients with autism have already confirmed the value of early childhood interventions. One method widely used at Stanford is pivotal response training, a technique that teaches parents creative ways to build a child’s language and social skills at home.

“In pivotal response training, the parent learns how to set up behavioral expectations naturally,” Phillips says. “Instead of letting the child take a snack from the

Endowed Directorship Named for Feinstein

arl Feinstein, MD, professor emeritus of psychiatry and behavioral sciences at the Stanford University School of Medicine, was the first holder of the Endowed Directorship of Child and Adolescent Psychiatry at Lucile Packard Children’s Hospital. Last summer, he stepped down from the position, which will now be named in his honor.

Feinstein has devoted his career to the mental health needs of children with medical illness, including improving the scientific understanding and treatment of autism spectrum disorders and neurodevelopmental disorders. Over the past 15 years, he has overseen the creation of the Stanford Autism Center at Lucile Packard Children’s Hospital and helped launch Stanford’s annual Autism Spectrum Disorders Update.

The success of the Stanford Autism Center has been made possible largely by the support of generous donors including the Eucalyptus Foundation, the Taube Foundation, and the Koret Foundation.

In admiration of Feinstein’s legacy and instrumental role in advancing treatment for children and adolescents with mental and developmental disorders, anonymous donors stepped forward to endow the directorship and requested that it be named in Feinstein’s honor. The Carl Feinstein Directorship of Child and Adolescent Psychiatry at Lucile Packard Children’s Hospital will ensure ongoing support for the hospital’s research and patient care in the area of childhood mental health.

“While providing expert evidence-based care is my primary objective, every patient is different and the care I provide is as personalized as possible,” Feinstein says. As director of child psychiatry, he championed the practice of psychotherapy for children and adolescents and has been particularly active in training the next generation of child psychiatrists in psychotherapy.

Feinstein continues to lead the Stanford Autism Center. His research has contributed to a better understanding of the clinical features of autism, particularly the social deficits that are its defining feature.
The Journey Ahead | Autism

cupboard, he’s taught to ask for what he wants and to make eye contact when he asks for it. By using a kid’s natural motivation for things they want, you can get them to socialize more and to use more language.”

Phillips and Hardan, in collaboration with their colleague Grace Gengoux, PhD, are now leading a clinical trial to evaluate what happens when parents of children age 5 and under with autism use the pivotal response technique in their home for six months in combination with in-home therapy provided by a trained clinician. “Based on our earlier research, we expect promising results with the ‘higher dose’ of six months compared to the standard regimen of three months,” Hardan says.

He and his Stanford colleagues, including Karen Parker, PhD, assistant professor (research) of psychiatry, are also conducting placebo-controlled clinical trials to determine if children ages 6 to 12 with autism respond to treatments of oxytocin or vasopressin — two hormones that play an important role in social recognition and bonding.

The majority of participants in these and other clinical trials are drawn from a large pool of children, adolescents, and young adults who visit the Stanford Autism Center, which receives more than 3,500 patient visits each year. Lucas is one of many patients whose parents have agreed to participate in this research.

Preparing for Adulthood

For TJ and Cheryl Scimone, innovative research offers the most promising pathway to a successful treatment for their son, Alex. Diagnosed with autism at age 3, Alex is now 15 years old, stands 6’2” tall, and weighs 190 pounds.

“I play a lot of games and I draw cartoons,” he says quietly. “When I grow up, I want to either build an arcade or work at my father’s company.”

Despite his seemingly calm demeanor, Alex is prone to sudden outbursts of violence. “He’s huge, and if he has a meltdown, it can be pretty scary,” says Cheryl.

As Alex approached adolescence, he became increasingly aggressive. “He was very explosive. The smallest thing would set him off,” Cheryl says.

“A toothpaste cap not put on properly or the wrong facial expression could cause a debilitating tantrum that would last the whole day,” TJ recalls.

“He really wasn’t having much quality of life with all of the screaming and hair-pulling,” Cheryl adds. “We wound up at Stanford about four years ago because of the need for medication. I’m glad we found Dr. Hardan. I like the way he works with Alex. He’s very friendly and calm.”

Over the years, Hardan has prescribed different medications to help stabilize Alex’s violent mood swings and to complement the behavioral interventions that are being implemented. “He’s gotten better,” TJ says. “It’s still a challenge, but it’s not as bad as it used to be.”

What worries TJ most is what will happen when Alex becomes an adult, and his parents are no longer able to care for him. “What’s the prognosis for Alex?” TJ wonders. “We don’t know, but he’ll need a lot of care for a very long time.”

Having a large staff capable of helping patients like Alex transition to adult care is one of the many challenges facing the Stanford Autism Center, says Carl Feinstein, MD, professor emeritus of psychiatry and behavioral sciences.

“Right now, we’re sort of a virtual autism center,” Feinstein says. “We need a unified place where the clinicians are all together so parents can have one-stop shopping and coordinated care.”

— Carl Feinstein, MD
“What’s the prognosis for Alex? We don’t know, but he’ll need a lot of care for a very long time.”

—TJ Scimone, Alex’s father
The Journey Ahead | Autism

Transformational Giving

Private philanthropic support has played an integral role in expanding clinical care and research efforts through the Stanford Autism Center. The Early Support Program for Autism (ESPA, see page 18) was established by a grant from the John and Marcia Goldman Foundation. Other generous donors including the Simons Foundation, Oxnard Foundation, and Nancy and Bruce Mosbacher have also made key investments that have significantly expanded our hospital’s ability to care for and understand the needs of children with autism.

While much has been achieved, there are still many unmet needs as the number of children being diagnosed with autism continues to increase. Support for the following would ensure continued advances in care for future generations of children and families.

Endowed Chairs $4 million
An endowed chair, the highest honor that can be awarded to a faculty member, would enable our hospital and School of Medicine to recruit and retain leading physician-scientists who will teach and mentor the next generation of care providers.

Endowed Fellowships & Faculty Scholar Awards $2 million
Fellowships and faculty scholar awards provide advanced training and research support for talented young physicians poised to become the next generation of leaders.

Research Support
Expendable support for research personnel, equipment, and infrastructure will enable our faculty to make exciting breakthroughs to improve care for children with autism. Endowed research funds can be established with gifts of $100,000 or more.

For more information about giving opportunities, please call (650) 498-7641 or email leanne.newman@lpfch.org.

“After meeting Dr. Hardan, we thought it would be a good idea to give the money directly to his department,” TJ explains. “He’s been doing this a long time. You can tell just by talking to him that he’s passionate and cares so much.”

For Hardan, it’s the parents’ commitment to their children that fuels his enthusiasm. “They do their best to make things better just so their kid can go to a baseball game or a movie,” he says. “It’s very humbling when you see what they do every day. It puts things in perspective.”

In April, Slice co-sponsored Stanford’s seventh annual Autism Spectrum Disorders Symposium, a day-long conference focusing on the latest research on brain imaging, oxytocin treatment, and related topics. About 300 parents, educators, and health care providers heard talks by Feinstein, Hardan, Phillips, and other autism experts from Stanford and elsewhere.

“The day may come when researchers finally figure out what causes autism spectrum disorders,” says Cheryl Scimone. “We have quite a few friends whose children have autism, and everybody is just scratching their head, wondering why did this happen? We don’t know yet. Maybe someday we’ll have an answer.”

Adds Hardan, “We want to have a great autism and developmental disabilities center at Stanford that will make us proud. We’ve made some progress, but we need more support and help to make it happen.”

Alex Scimone has made significant progress with our care.
Home Videos Could Be a Powerful Tool for Diagnosing Autism

By Erin Digitale

Short home videos may become a powerful tool for diagnosing autism, according to a study by Dennis Wall, PhD, associate professor of pediatrics in systems medicine at the Stanford University School of Medicine.

On average, children with autism are diagnosed at age 4, though their parents often suspect it for years before diagnosis. Long wait times and the lengthy tests required often cause diagnoses to be delayed beyond the ages of 2 or 3, the windows of time in which early interventions are most effective.

In Wall’s study, research assistants with only brief training were able to accurately score autistic-type behaviors in home videos of children in natural settings. Since short videos can be shared over the Internet and evaluated quickly, using them to aid diagnosis could reduce families’ need to travel long distances or wait — in many cases for over a year — for a medical evaluation.

For the study, Wall’s team found 100 videos on YouTube that showed kids from 1 to 15 years old at play. Forty-five of the videos had been tagged by their creators with “autism,” “ASD,” “Asperger’s,” or “hand-flapping/stimming;” these were classified by the researchers as showing children with autism. The remaining 55 videos did not have such tags and were classified as not depicting autism spectrum disorder.

Then, a group of undergraduate students was trained to score the behavior of the children in the videos. The rating scale they used was based on the Autism Diagnostic Observation Schedule, which is widely considered the gold standard for diagnosing autism. For example, the raters tracked whether children showed eye contact and picked up on social cues from others in the video, whether they played with toys appropriately, and whether they engaged in repetitive behaviors.

The researchers found that the students accurately classified children in the videos 97 percent of the time.

Supplementing Current Methods

The finding raises several interesting possibilities for future clinical applications. Although video-based evaluations are unlikely to completely replace standard diagnostic methods in which a trained clinician spends several hours evaluating a child, they could augment standard approaches.

“For instance, we could use this system for clinical triage, as a way to channel traffic so that children can get the kind of attention they need as early as possible,” Wall notes. Children who clearly have autism might be diagnosed primarily with videos and quickly started on therapy, freeing clinicians to spend more time evaluating children whose diagnosis is less clear-cut.

In addition, video evaluations could be used to track a child’s development and improve the watchful-waiting period prior to diagnosis, Wall says. Autism cannot usually be diagnosed prior to 2 years of age; some children who will never develop autism have early oddities in their social and language skills that resolve by age 2. However, if parents suspect that their 18-month-old has autism, a video evaluation at that age could provide a baseline for “informed watchful waiting” and later assessments at 24 or 36 months. Similarly, scored home videos could provide a simple way to track progress after children begin receiving behavioral therapy.

“Our goal is to bridge the gap between families in need and the services they require,” Wall says.

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Sandborg Receives National Award of Distinction

The American College of Rheumatology has honored Christy Sandborg, MD, pediatric rheumatologist at Lucile Packard Children’s Hospital Stanford, professor of pediatrics, and associate chair of pediatrics at the Stanford School of Medicine, with a Distinguished Service Award, one of the College’s Awards of Distinction.

The prestigious award was bestowed at the organization’s annual meeting late last year. Sandborg was an early pioneer in efforts to develop a clinical research infrastructure for pediatric rheumatology in the U.S., and was one of the founding members of the Childhood Arthritis and Rheumatology Research Alliance in 2002.

Hewlett-Packard Supports New Fellowship in Clinical Informatics

Thanks to a generous grant from Hewlett-Packard, the Stanford University School of Medicine will welcome Veena Goel, MD, and Lance Downing, MD, as the inaugural HP Fellows in Clinical Informatics. Throughout the program, the fellows will learn from world-class medical professionals and benefit from an extraordinary partnership between the medical and high-tech communities. Their rotations will include sites at the Stanford University Medical Center, and regional health care partners Sutter Health and Kaiser Permanente, as well as on-site work at HP Labs.

In preparation for the fellows, four Lucile Packard Children’s Hospital physicians, Christopher Longhurst, MD, Natalie Pageler, MD, Jonathan Palma, MD, and Jin Hahn, MD, were among the first to receive the inaugural board certification in Clinical Informatics. In addition, the hospital applied for accreditation in the Clinical Informatics (Pediatrics) subspecialty with the Accreditation Council for Graduate Medical Education. If approved, our hospital will be one of the first in the nation with this distinction.

Fisher Named Associate Editor of Journal of Pediatrics

Paul Fisher, MD, chief of pediatric neurology, has been named an associate editor for The Journal of Pediatrics. He has been an editorial board member for the Journal since 2006, and has also served as an editorial board member for The Journal of Clinical Oncology and The Journal of Neuro-Oncology.

Fisher is also the Beirne Family Professor of Pediatric Neuro-Oncology at the Stanford University School of Medicine.
Stanford Teams Delivers Care in Philippines Following Typhoon Haiyan

In the wake of Typhoon Haiyan in November, a team of doctors and nurses from Stanford Hospital and Lucile Packard Children’s Hospital delivered much needed emergency care and medical supplies to victims in the Philippines.

The team of 10 volunteers from the Stanford Emergency Medicine Program for Emergency Response, including emergency medical technicians and mental health specialists, went to work within hours of landing, treating patients in crowded, temporary clinics. The team saw several hundred patients a day, taking just brief breaks to eat, sleep, and record some of the images of communities struggling to recover together.

New Interventional Radiology Chief

Pediatrician-radiologist Glen Seidel, MD, has been appointed chief of the new pediatric interventional radiology program at Stanford Children’s Health and Lucile Packard Children’s Hospital Stanford.

Seidel is known as a national leader in the field. He served as chief of a highly successful pediatric interventional radiology service at Texas Children’s Hospital from 2001 to 2007, and then he returned home to Minneapolis, where he led the University of Minnesota’s pediatric interventional radiology program prior to coming to Stanford.

Kennedy Shares Expertise on Adolescent Health

William Kennedy, MD, an associate professor of urology at Lucile Packard Children’s Hospital Stanford, provided a Master Lecture during a meeting of the International Society of Men’s Health at the annual Men’s Health World Congress in Washington, D.C.

During his remarks, Kennedy discussed the care of boys as they make the transition from adolescence to young adult life. Also during the conference, he was named an editor for the newly established Children and Adolescent Section of the Journal of Men’s Health.
American College of Clinical Engineering Honors Prasad with National Award

Purna Prasad, PhD, director of clinical technology and biomedical engineering at Lucile Packard Children’s Hospital Stanford and Stanford Hospital & Clinics was honored with the American College of Clinical Engineering’s Professional Achievement in Management Award earlier this year, and will also be recognized in Philadelphia during the Association for Advancement in Medical Instrumentation 2014 convention this summer.

Larger South Bay Specialty Clinic to Open in Campbell

In response to high demand for specialty clinics in the South Bay, Stanford Children’s Health and Lucile Packard Children’s Hospital Stanford announced that the Los Gatos-based South Bay Specialty Clinic will eventually move from its current location to a building in Campbell. In doing so, the hospital is expanding its capability for patients to access world-class care and world-class pediatricians.

Now children can receive care from urologists, neurologists, pulmonologists and more — without having to travel to Palo Alto for each specialty. Care not centered on a trip to the hospital is part of a growing national movement to add more value for families. That’s one of the reasons Stanford Children’s Health and Lucile Packard Children’s Hospital Stanford have six multi-specialty pediatric specialty centers in the Bay Area: in San Francisco with partner California Pacific Medical Center; in Walnut Creek with John Muir Health; and in Emeryville, Palo Alto, Los Gatos and Capitola, where a new and expanded Santa Cruz-area location began seeing patients earlier this year.

Book Launch Addresses Needs of Children with Serious Illness

To support children with serious illness, Sheri Sobrato Brisson, a donor and a cancer survivor, has co-authored *Digging Deep, A Journal For Young People Facing Health Challenges*. The book provides children with a safe outlet for self-expression with the goal of improved communication with everyone around them.

In conjunction with the book’s launch in May, a panel gathered to discuss how to support seriously ill children and their families, and the role journaling can play as the children sort through their feelings and thoughts. Moderated by Paul Fisher, MD, chief of pediatric neurology at Lucile Packard Children’s Hospital, the panel featured Stanford faculty Barbara Sourkes, PhD, director of pediatric palliative care; Hans Steiner, MD, professor emeritus of psychiatry and behavioral sciences; and Michael Amylon, MD, professor emeritus of pediatric hematology-oncology.

**DIGGING DEEP**

* A Journal For Young People Facing Health Challenges

By Paul Fisher, MD

Designed by Pony Studio

Published by Bitty Publications, Inc.
Sourkes Recognized by Palliative Medicine Group

Barbara Sourkes, PhD, director of palliative care, has been awarded the prestigious 2014 American Academy of Hospice and Palliative Medicine Humanities Award. The award, presented by the premier academic program in palliative medicine, recognized Sourkes for her work to advance the relationship between the humanities and palliative care, and for her authorship of books that exemplify how the arts can serve as an important tool in the care of seriously ill children.

Sourkes is the John A. Kriewall and Elizabeth A. Haehl Director of Pediatric Palliative Care at our hospital and also professor at the School of Medicine. A member of our staff for the past 12 years, Sourkes has played an integral role in the development of our hospital’s palliative care program which works with families and primary care teams to ensure our patients achieve the best quality of life possible.

2013 Top Children’s Hospital Award

The Leapfrog Group, a national organization aimed at improving the safety, quality, and affordability of health care, named Lucile Packard Children’s Hospital Stanford to its annual list of Top Hospitals. Packard Children’s is the only children’s hospital in Northern California to receive the prestigious award.

“This is a wonderful honor that we share with our entire staff and medical staff at Lucile Packard Children’s Hospital and Stanford Medicine,” said Christopher G. Dawes, president and chief executive officer. “We thank The Leapfrog Group for recognizing our network-wide commitment to quality and patient safety.”

Paul Sharek, MD, MPH, chief clinical patient safety officer, said the award acknowledges the hospital’s continued excellence and international thought leadership in reducing medical and health system errors. “The Leapfrog award is a highly respected recognition that our quality of care and patient safety outcomes continue to be among the nation’s best,” Sharek said.

Lucile Packard Children’s Hospital was selected as a Top Children’s Hospital out of a record number of 1,324 hospitals participating in The Leapfrog Group’s annual survey. The selection is based on measurements of a hospital’s performance on patient safety and quality, focusing on critical areas of hospital care in place to prevent errors.

Asthma Care Service Earns Top Recognition from The Joint Commission

Lucile Packard Children’s Hospital Stanford was named a Top Performer on Key Quality Measures® by The Joint Commission, the leading accreditor of health care organizations in America. Our hospital was recognized for exemplary performance in using evidence-based clinical processes that are shown to improve care for certain conditions. In this case, the hospital’s Top Performer honor was the result of achievements and measures in children’s asthma care.
McKenna Claire Foundation Fights Pediatric Brain Cancer

The McKenna Claire Foundation, which strives to increase awareness, community involvement, and research for pediatric brain cancer, has donated a cumulative total of $480,000 to the efforts of Michelle Monje, MD, PhD, assistant professor of neurology and neurological sciences.

The foundation’s namesake, McKenna Claire Wetzel, suffered from diffuse intrinsic pontine glioma (DIPG), an inoperable form of brain cancer that has a near-100-percent mortality rate. The McKenna Claire Foundation funds cutting-edge research efforts at the Monje Lab at Stanford University, a leading research facility for DIPG and home to the cell line developed when the Wetzels donated McKenna’s brain tissue after her passing.

“With the McKenna Claire Foundation’s funding and support, we continue to grow McKenna’s (and other) donated tumor cell lines, sharing these invaluable resources with dozens of scientists internationally, which is stimulating a swell of DIPG research activity,” says Monje.

Butte Receives Highest Honor for Pediatric Research

Atul Butte, MD, PhD, associate professor of systems medicine in pediatrics and of genetics, will be one of two recipients of the 2014 E. Mead Johnson Award for Pediatric Research from the Society for Pediatric Research. The award, the highest honor given for pediatric research, was presented in Vancouver, Canada in May. It recognizes Butte’s contributions to biomedical informatics, including his use of public-access data to discover new diagnostics, therapeutics and insights into disease. Butte is the fifth Stanford scientist to receive the award.

American College of Obstetrics and Gynecology Honors Druzin

Maternal-fetal medicine pioneer Maurice Druzin, MD, was honored with the American College of Obstetrics and Gynecology Council of District Chairs Service Recognition Award during the organization’s annual meeting this spring in Chicago. The teacher, clinician, and researcher, often called “the father of Stanford obstetrics,” is the author of more than 100 publications and has been a leader in the California Maternal Care Collaborative’s Preeclampsia Quality Improvement Collaborative.
Ambassadors for Lucile Packard Children’s Hospital

In May, members of the Ambassadors for Lucile Packard Children’s Hospital and their guests gathered at the 7th annual Lunch & Learn event benefiting our patients and their families. This year’s luncheon featured guest speaker Condoleezza Rice, PhD, interviewed by her friend and loyal hospital donor, Susan Ford Dorsey. The pair discussed Rice’s childhood, her former role as Secretary of State, and her connection to Stanford University. During her time as Stanford’s provost, Rice oversaw the Stanford School of Medicine.

“I was able to see the extraordinary work of the doctors and researchers at the School of Medicine, and I know they couldn’t do what they do without philanthropy,” Rice said.

Over the past two years, Ambassadors members have contributed approximately $2 million to the hospital. Each year, members raise support for both the Children’s Fund and a special member-selected Fund-a-Need opportunity. This year, they voted to fundraise for a medical patient room in the hospital expansion. The benefits of this private and spacious room include family-centered care and infection control. Fold-out double beds and private bathrooms with showers will help parents remain close to their children throughout their inpatient stay.

While the Lunch & Learn is the largest event hosted by the Ambassadors, the group works year-round to provide meaningful opportunities for members and their children to support our hospital, as well as interact with and learn from world-class physicians. From the annual Pumpkin Patch and Project Elf events to small-group “Coffee Talks” with hospital experts, the Ambassadors tirelessly champion one of our community’s most valuable assets: Lucile Packard Children’s Hospital Stanford.

In addition, the Ambassadors volunteer their time to host child-centered activities in the Forever Young Zone and support events such as the Winter Carnival and the Hospital Prom. Many events are designed to encourage Ambassadors members to engage their own children to support the children in the hospital, so they can start to learn about service and philanthropy at a young age. Volunteers, tall and small, are able to see the impact of their gifts firsthand, while bringing extra cheer to patients and families.

When asked why she is proud to be an Ambassador, co-president Suzanne Crandall explains, “As an Ambassador, I’m supporting countless children that I’ve never met, and will never meet. To me, that is the definition of true philanthropy.”

Become an Ambassador

The Ambassadors strive to engage the community in supporting Lucile Packard Children’s Hospital Stanford through education, philanthropy, and volunteerism. Visit ambassadorslpch.org to learn more.
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Lucile Packard Children’s Hospital Stanford

5k, 10k & kids’ fun run
Sunday, June 22 • Stanford

Join us for a fun-filled morning benefiting patients and families at Lucile Packard Children’s Hospital Stanford. Register today at SummerScamper.org.

Run for healthier happy lives.

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