

# imagine

CHILDRENS HOSPITAL LOS ANGELES

summer 2007





### our mission

To make a world of difference in the lives of children, adolescents and their families by integrating medical care, education and research to provide the highest quality care and service to our diverse community.

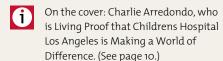
### our history

Founded in 1901, Childrens Hospital Los Angeles has been treating the most seriously ill and injured children in Los Angeles and beyond for more than a century, and it is acknowledged throughout the United States and around the world for its leadership in pediatric and adolescent health. Childrens Hospital is one of America's premier teaching hospitals, through its 75-year association with the Keck School of Medicine of the University of Southern California. The Saban Research Institute of Childrens Hospital Los Angeles is a national leader in pediatric research.

Since 1990, *U.S. News & World Report's* panel of board-certified pediatricians has named Childrens Hospital Los Angeles one of the top pediatric facilities in the nation.



The stories in this issue spotlight the work of The Vision Center at Childrens Hospital Los Angeles.



### welcome



Alyce and Michael Dalany Founding Benefactors The Vision Center at Childrens Hospital Los Angeles

 $S_{\rm o}$  much of how we perceive the world, how we learn and interact, comes to us through our eyes. Imagine a newborn baby at risk of blindness from a retinal disorder, an infant facing the loss of vision from a rare eye cancer or any school-age child struggling to read despite an undiagnosed vision problem.

Then imagine a solution to each of these heartbreaking scenarios.

We are proud to introduce The Vision Center at Childrens Hospital Los Angeles, an international center for children with complex eye diseases. The Vision Center is the only program of its kind in the world with expertise and programs in virtually every pediatric ophthalmology subspecialty.

Working in six distinct institutes, its physician-scientists are helping children to see every day through the latest medical and surgical treatments, as well as cutting-edge research that will change the lives of families across the globe. We believe every child should see the colors of a sunset. With your support for The Vision Center Endowment Fund, you can help make this dream possible for more children. Please join us. •

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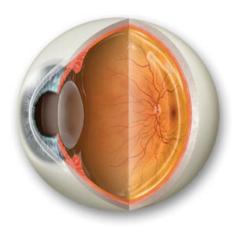
matthew low age 5

As we work to heal the bodies of our patients, we heal their spirits in an atmosphere of compassion and respect.

# imaginehealing

# seeing is **believing**

ARMED WITH PASSION & WORLD-CLASS EXPERTISE, THE VISION **CENTER AT CHILDRENS** HOSPITAL LOS ANGELES HAS A CLEAR MISSION: TO HELP CHILDREN SEE.



Every 60 seconds, somewhere across the globe, a child goes blind. Yet, according to the World Health Organization, half of all childhood blindness could be avoided by early treatment.

In the United States alone, vision impairment affects one in four school-age children and one in 20 preschoolers — making vision disorders the fourth most common disability in this country and the most prevalent handicapping condition in childhood, according to the National Eye Institute.

With 70 to 80 percent of what children learn processed through the visual system, educators say that any vision impairment can be life-altering.

Against this backdrop of challenge and need, The Vision Center at Childrens Hospital Los Angeles provides hope and answers for the children and families affected by complex and blinding vision disorders.

As one of the world's largest, most respected facilities devoted to pediatric eye care, The Vision Center handles about 12,000 patient visits each year through its six forwardlooking institutes: the Retina

Institute, the Cornea Institute, the Eye Birth Defects Institute, the Vision Development Institute, the Eye Technology Institute and the Orbit and Eye Movement Institute.

The Childrens Hospital Los Angeles Board of Trustees has designated The Vision Center as a Center of Excellence in recognition of its preeminence. "This bold new initiative will enable us to continue to develop and disseminate innovative strategies for preventing and treating blindness and other visual disorders in children," says Richard D. Cordova, president and chief executive officer of Childrens Hospital, and a member of The Vision Center Advisory Board.

"The physician-scientists in The Vision Center are at the frontier of new treatment approaches and surgical techniques, as well as cutting-edge research," says Henri R. Ford, MD, vice president and chief of surgery at Childrens Hospital, and a member of The Vision Center Advisory Board. "As a Center of Excellence, we will be able to reach out and help more children worldwide with the important and innovative work of The Vision Center."

### Wonders of the eye



The visual system is the least mature system at birth. Much of the first weeks and months of life is spent learning to see.



The human eye has many millions of cells in its 14 individual subsystems, such as the retina, iris, cornea and optic nerve. The retina alone has 10 million cells.



Mark S. Borchert, MD, with Zachary Katzbeck, who has ONH

Its expertise extends across virtually every pediatric ophthalmologic subspecialty. In fact, pioneering research in the Retina Institute has resulted in new treatment protocols that have altered the course of retinoblastoma, a cancer of the eye. The Vision Center also boasts the nation's leading pediatric corneal transplant program; enhanced surgical expertise in retinopathy of prematurity (ROP), a potentially blinding disorder; the largest clinical study in optic nerve hypoplasia (ONH), the leading cause of vision loss in children; and comprehensive treatment for strabismus, amblyopia and refractive errors - today's most prevalent vision disorders in preschool children.

"No one else in the United States offers such comprehensive care," says Mark S. Borchert, MD, director of The Vision Center. "Most important, we recognize the global implications of a vision disorder on a child's complete development, and we have the skill and compassion to care for these children and their families."

As founding benefactors, Alyce and Michael Dalany have been instrumental in providing key funding for The Vision Center, formerly known as the Division of Ophthalmology within the hospital's Department of Surgery. The Dalanys are members of The Vision Center Advisory Board, which has set a goal to raise \$100 million over the next 10 years to fund an endowment supporting the faculty, research and programs.

"The endowment is crucial to enabling us to discover new treatments that will help more children see," says Dr. Borchert, an associate professor of clinical ophthalmology and neurology at the Keck School of Medicine of the University of Southern California (USC).

He stresses that children need to be treated at a place like The Vision Center, with its team of pediatric ophthalmological specialists, because pediatric vision disorders often are different from those seen in adults.

For example, retinal diseases affecting children can be more aggressive and deadly than in adults. Glaucoma (increased intraocular pressure) often manifests subtler symptoms in children, making it more difficult to diagnose. (The Vision Center has received the support of the Pearle Vision Foundation for a research and training project to improve early detection of eye diseases in young children.)

Other visual disorders — including ONH — are part of an interwoven knot of problems, such as endocrine and brain disorders, that require a cross-disciplinary medical approach.

Vision Center physicians routinely collaborate with the hospital's specialists from other disciplines. Its faculty members are associated with the Doheny Eye Institute and the Keck School of Medicine, both at USC.

"Because we are dedicated entirely to the care of infants and children, we are able to collaborate to ensure optimal outcomes," notes Dr. Ford, professor of surgery and vice chair



The human eye is so sensitive it enables the brain to distinguish between images only one ten-thousandth of an inch apart.



Our eyes process 36,000 bits of information hourly. More than 80 percent of everything we learn is a result of visual processing.

for clinical affairs in the Department of Surgery at the Keck School of Medicine. "Everyone is attuned to the physiological stresses taking place in a child and the interventions needed."

Childrens Hospital's support system for families plays a role. "We work hard to ensure that each child gets the services he or she needs in terms of mobility, physical therapy and education," notes Dr. Borchert. "We care for the whole child."

Here's a closer look at the components of The Vision Center, each of which is headed by a board-certified pediatric ophthalmologist:

### The Retina Institute

The Retina Institute combines the latest treatments for blinding retinal disorders with molecular research and education. Its physicians treat infants with ROP, the second leading cause of blindness in infants, and it is the nation's foremost program for treatment of retinoblastoma. Also treated are such conditions as retinal detachment, hereditary retinal degenerations and Coats' Disease, which is the abnormal development of blood vessels behind the retina.

### The Cornea Institute

The Cornea Institute performs the largest number of pediatric cornea and cataract surgeries in the United States, including laser-assisted in situ keratomileusis (LASIK) under general anesthesia. It is one of a few programs worldwide with expertise in corneal transplants for infants. Childrens Hospital Los Angeles was the first hospital in the country to implant an artificial cornea in a pediatric patient.

### The Eye Birth Defects Institute

Childrens Hospital is the leading research center for ONH and other eve birth defects. ONH occurs when a child's optic nerves fail to develop fully during early pregnancy, resulting in reduced vision or blindness. Children with ONH have abnormal nerve connections in several areas of the brain, which often result in abnormal growth, hormone deficiencies, seizures, cognitive deficits and learning disabilities.

### The Vision Development Institute

Of particular interest are binocularity, depth perception and sensory integration — functions that largely develop in the first year of life and ultimately impact learning and social development. The Neurophysiology of Vision Program is studying connections between the developing brain and vision, how eyesight changes during infancy and which interventions are most effective at each stage.

### The Eye Technology Institute

Unique within ophthalmology programs, the Eye Technology Institute is developing better diagnostic

and treatment tools for conditions impacting sight. Raman spectroscopy (the use of light to study matter) is measuring glucose levels in the eye, which could help people with diabetes, addressing the second leading cause of blindness in the United States. Other technologies use the eye to measure chemotherapy levels in the brain and abnormal metabolic products in the retina that may lead to macular degeneration.

### The Orbit and **Eye Movement Institute**

The Orbit and Eye Movement Institute offers comprehensive treatment and research into strabismus. among other programs. In this disorder, one eye cannot focus with the other because of an imbalance of the eve muscles. As a result, the brain cannot use the information from the two eyes together normally. The result can be loss of vision or even blindness. Early intervention is critical and typically effective. When necessary, minimally invasive surgical techniques are employed. •

To help more children see by supporting the work of The Vision Center, please contact David D. Watts, associate vice president of Major and Planned Gifts at 323-361-1752 or dwatts@chla.usc.edu.



The six external muscles that move the eyes are the strongest muscles in the human body for the job they have to do.



Our eyes utilize 65 percent of the brain's nerve pathways and can set in motion hundreds of muscles and organs — instantly.

# the human eye

### Cornea

The clear "front window" of the eye that transmits and focuses light into the eye

#### Iris

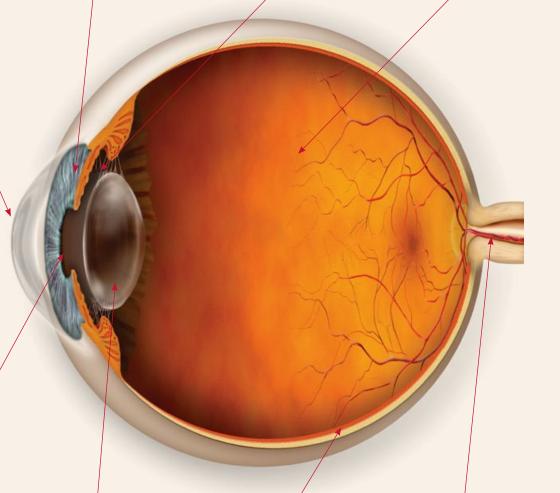
The circular, colored curtain of the eye, which opens and closes to regulate the amount of light entering the eye

### **Aqueous humor**

A clear, watery fluid circulating in the chamber of the eye between the cornea and the lens

### Vitreous body

A transparent jelly-like substance, which provides a cushioned support for the rest of the eye and a clear unobstructed path for light to travel to the retina



### Pupil

The dark aperture or opening in the center of the iris which gets bigger or smaller, depending on the light coming in

### Lens

A transparent structure behind the iris that changes shape to focus light rays onto the retina in the back of the eye

### Retina

The inner layer of the eye, which contains millions of light receptors called rods and cones

### Optic nerve

The nerve that connects the eye to the brain and carries the impulses formed by the retina to the visual cortex

"As you make progress, there are always new questions.

MARK S. BORCHERT, MD



# long-distance **View**

Not yet four years old, Ryan Chapman is a boy who loves speed — from rollercoaster rides to scooters to the swing in his backyard.

His parents, Courtney and Joe Chapman, call him a "thrill seeker." His mother says, "We encourage him because that's how he'll learn." Their enthusiasm is impressive since Ryan's vision is limited to light perception. Born with optic nerve hypoplasia (ONH), he is essentially blind.

Like all children with ONH, Ryan lacks welldeveloped optic nerves, the pathways between the light rays outside the eye and areas in the brain that turn them into images. A disease of the hypothalamus in the base of the brain, ONH is today's leading cause of vision loss and blindness in children.

Some ONH babies have abnormalities in brain structure and brain function. Often they also have hormone deficiencies because the pituitary gland, which initiates hormone production, rests at the base of the brain. Such neurological peculiarities can lead to multiple symptoms, including delayed speech, motor skill problems, growth retardation, autistic behavior and seizures.

Unfortunately, doctors can't predict all the symptoms at the time of diagnosis. Living with that uncertainty can take its toll on a family. "After Ryan was born, the doctors told us about the ONH," Mr. Chapman recalls. "They explained that he needed daily injections of



The vitreous humor, the clear gel in the vitreous body of the eye, makes up about 80 percent of the eye's total volume.



The macula, near the center of the retina, is 100 times more sensitive to detail than the peripheral retina and is used for seeing fine detail.





Ryan Chapman swings into action with his dad, Joe Chapman.

growth hormone. Later they did more tests and told us he was blind. Honestly, it seemed like one thing after another."

With help from extended family, the Chapmans pursued every possible community resource. Their efforts produced two years of physical and occupational therapy for Ryan. Last fall, they discovered a nursery school program for visually impaired children near their Covina home. To wake Ryan each morning, they simply have to ask if he wants to go to school. He bounds out of bed and races to get dressed.

Their commitment also led them to Mark S. Borchert, MD, director of The Vision Center and its Eye Birth Defects Institute at Childrens Hospital Los Angeles. "From the start, the medical team was incredibly experienced and informative," says Mrs. Chapman. "There's never a question they aren't able and willing to answer."

Still, notes Dr. Borchert, nobody knows enough about ONH. "We know it's a congenital disorder occurring with ever greater frequency. But we don't know why."

Seeking answers, Dr. Borchert, an associate professor of clinical ophthalmology and neurology at the Keck School of Medicine of the University of Southern California, has been researching ONH for more than a decade. He's uncovering clues about genetic and geographic influences. "As you make progress, there are always new questions," he says.

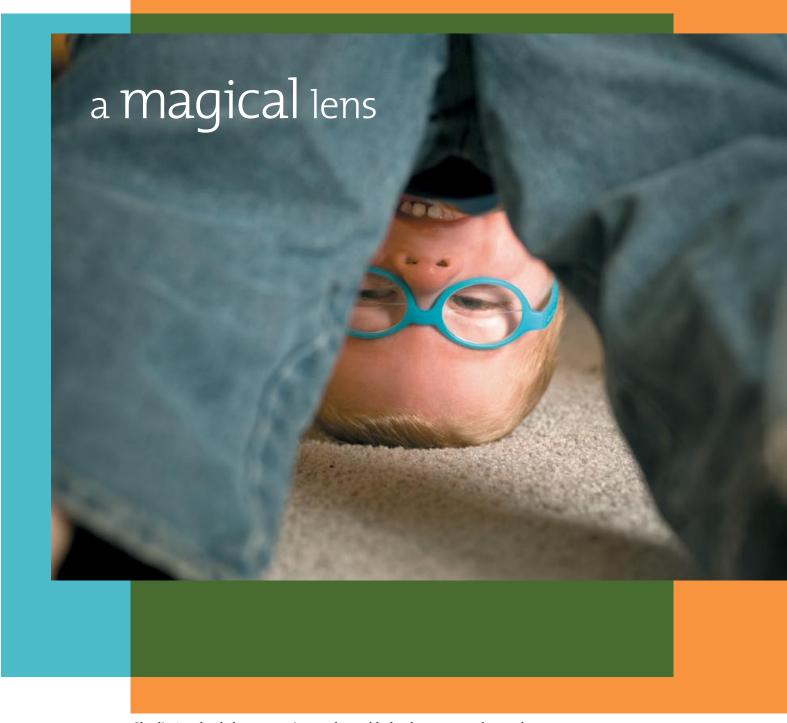
The Chapmans understand this long-term view. "We're not sprinting, we're running long distance," says Mrs. Chapman. "Ryan has shown us he will do everything, at his own pace. We believe in him, so we live on Ryan Time." •



The retina, the light-sensing structure of the eye, contains 100 million rods and 7 million cones, which handle vision in low light and color, respectively.



The optic nerve in the brain is about one-anda-half inches in length, and contains approximately 1.2 million nerve fibers.



Charlie Arredondo has a new view on the world, thanks to a corneal transplant.

THE CORNEA INSTITUTE OF THE VISION CENTER SAVES THE EYESIGHT OF NEWBORNS AND INFANTS WITH ITS EXPERTISE IN CORNEAL TRANSPLANTS AND OTHER SOPHISTICATED TREATMENTS.

> It is the human body's most sensitive tissue. A five-layered sandwich of living cells, the cornea is an extremely complex and vulnerable part of the eye. For Jonathan Song, MD, director of the Cornea Institute in The Vision Center at Childrens Hospital Los Angeles, this area of the eye — dense with nerve fibers and collagen tissue — is infinitely fascinating.

> Under his leadership, the Cornea Institute performs the largest number of pediatric cornea and cataract surgeries in the United States each year — 25 to 30 cornea transplants and 70 to 80 surgeries.

> "The cornea is such a small part of the body, but it can do such amazing things," says Dr. Song, an assistant professor of clinical ophthalmology and pediatrics at the Keck School of Medicine of the University of Southern California. "It is the most powerful optical system."

For proper vision, this transparent, dome-shaped covering of the pupil must be smooth and clear. Scarring caused by eye trauma or congenital disorders can cause the cornea to cloud up, eventually eclipsing eyesight. For children, addressing the problem as soon as possible is critical. During the first four months of life, the eye's ability to absorb light assists in development of the brain's visual pathways.

Childrens Hospital is one of the few facilities in the United States with expertise in corneal transplants for infants, allowing newborns the gift of sight during the brief window of opportunity available. "When you are born, the connections between the brain and the eye aren't permanent," explains Dr. Song. "During the first few months of life, it is very important to clear the way for light to

### The cornea at work

Similar to the lens of a camera, the cornea provides two-thirds of the eye's focusing power. Its five layers must be free of any cloudy or opaque areas to allow proper vision. Each serves a unique function:

1st layer: Blocks the passage of dust, water and bacteria.

**2nd layer:** Protects the cornea from injury.

3rd layer: Consisting mostly of water, it gives the cornea its strength, elasticity and form.

4th layer: Serves as a protective barrier against infection and injuries.

5th layer: The innermost layer, it pumps excess fluid out of the middle layer of the cornea.

come through so children develop these connections. By age eight, whatever connections you have are what you keep for the rest of your life."

Seventy percent of the Cornea Institute's young patients are under the age of eight. Three-year-old Charlie Arredondo exemplifies the critical importance of early intervention. When Charlie was born, routine exams failed to indicate any vision problems. His mother, Emily

Arredondo, noticed that her son's pupils seemed unusually dilated — "almost like a koala bear's eyes," she recalls.

By the time he turned three months, Charlie was diagnosed with glaucoma (optic nerve damage) caused by a congenital collagen disorder. Unsatisfied with the grim prognosis and initial treatment at a local medical facility, the Arredondos, who live in Burbank, found Dr. Song, a leading expert in pediatric vision disorders.

"Before we came to Childrens Hospital, we didn't know what was happening,

and we were told to prepare ourselves for the worst," recalls Charlie's father, Joseph Arredondo. "Dr. Song answered so many of our questions. He put us at ease right away and gave us hope."

To save Charlie's eyesight, Dr. Song surgically removed both of the infant's natural lenses, which were not attached properly, allowing for clearing of the central vision. Three months later, at eight months of age, Charlie underwent a

successful cornea transplant to replace the damaged, opaque tissue on his left eye with a healthy donated cornea.

Surgery on newborns and infants is a special challenge, different from operating on adults or even older children because a newborn's eye tissues are soft and delicate. In the painstaking surgery, Dr. Song first had to remove the center of Charlie's damaged cornea, then sew the donated cornea into place with 16 sutures using thread finer than a human hair.

Charlie's world opened up immediately. It expanded even more when he began wearing eyeglasses at age 10 months. "One hour after he had his glasses on, Charlie started crawling," recalls his mother. "He just wanted to see where he was going." Charlie, who loves to swim at his grandpar-

> ents' house and play with his cars and trucks, soon will begin preschool.

With its sophisticated diagnostic tools and therapies, the Cornea Institute treats 1,200 children annually for a full spectrum of conditions involving the cornea, including unequal refractive power, acquired and congenital corneal scars, cataracts and glaucoma. Patients receive rigorous follow-up care to minimize the chance of rejection, as well as longterm treatment to enhance visual development into adulthood.

An active research program is refractive techniques to treat unequal refractive power and corneal scarring in children. Three years ago,

exploring the use of adult corneal and

Childrens Hospital became the first place in the nation to implant an artificial cornea in a pediatric patient. Children have a 30 percent higher rate of rejection following a donor transplant, making artificial corneas a viable alternative. The Cornea Institute is developing an innovative laser ultrasound to better identify the defective area in the cornea, potentially allowing for a partial transplant.

For Dr. Song, the most rewarding aspect of his work is giving children like Charlie a chance at a normal life.

"At Childrens Hospital, we have the best technologies and expertise," he says, "but more important, we have people who are truly committed to working together for a single cause. Everyone is thinking about how to advance the treatment of children." •



Jonathan Song, MD, with Ilse de Luna

'this truly is a global issue.'

### alyce and michael dalany



Alyce and Michael Dalany

The unexpected call in the middle of the night woke Alyce and Michael Dalany. Friends living in Switzerland were distraught — their Portuguese twin grandnephews had been born with retinopathy of prematurity, which occurs when abnormal blood vessels and scar tissue grow over the retina.

The friends knew the Dalanys were involved with the Doheny Eye Institute at the University of Southern California, Mr. Dalany on its board of directors and Mrs. Dalany in the Luminaires Juniors support group. In 2002, the couple started the Van Wyck-Dalany Childrens Retina Center at the Doheny Eye Institute.

The Dalanys dove into action. Within 36 hours, including time to obtain passports, the twins were at Childrens Hospital Los Angeles — and the Dalanys were on their way to an even deeper involvement to advance the frontiers of pediatric eye care.

Impressed with the expertise they witnessed at Childrens Hospital, the Dalanys immediately began talking to hospital leaders about how they could impact clinical care and research for children with blinding eye disorders.

Today, the Dalanys are founding benefactors of The Vision Center at

Childrens Hospital and members of its Advisory Board, helping to guide its future. "It's exciting for us to participate with people who are so excellent and dedicated to their profession," says Mr. Dalany.

They are providing funding to support eight new staff positions, additional equipment and other important initiatives. They choose not to have their names on The Vision Center, as often is customary for philanthropic partners.

"The name has universal appeal. It says, 'This is The Vision Center, available to all children," explains Mrs. Dalany.

"Our satisfaction comes in knowing we are making a real difference right now," adds Mr. Dalany.

Together, they are bringing their considerable marketing and management experience to the task. Mrs. Dalany worked as an interior designer in the United States and Europe before taking over the family business, Van Wyck Products Company, founded by her father in 1955 to promote his invention, Easy Wash. The company later was sold.

After beginning his career in aerospace, Mr. Dalany launched his finan-

cial and labor relations consulting firm at the age of 30. After retiring ("too early," he says), he has been involved in many ventures.

Now, The Vision Center is at the top of their agenda. Mrs. Dalany assisted with the design of its logo and is collaborating on its Web site. Mr. Dalany is offering input on financial controls and reporting procedures toward the Advisory Board's goal to raise a \$100 million endowment over the next decade. In addition, the Dalanys plan to host fund-raising events in the Santa Barbara area, where they live much of the year.

Of the twin boys they helped three years ago, one now sees perfectly. The other, whose retinas were detached at birth, perceives shapes and shadows.

For the Dalanys, their original quest has broadened to encompass all children who need The Vision Center. "The knowledge that these physician-scientists develop from their patients and their research can be translated worldwide," notes Mrs. Dalany.

"A child's blindness affects the entire family," says Mr. Dalany. "This truly is a global issue." •

candace pearson

# firstsight

PHYSICIANS AT THE RETINA INSTITUTE OF THE VISION CENTER ARE GIVING BABIES AND CHILDREN WITH SERIOUS EYE DISEASES THE CHANCE FOR A BRIGHTER FUTURE.

> When Madison Adam was born at 26 weeks gestation weighing one pound, 10 ounces — doctors didn't know if she would survive. After spending nearly three months in a hospital near her family's home in Paramount late last year, she was well enough to go home. Then another problem surfaced: retinopathy of prematurity (ROP).

> The second leading cause of blindness in infants, ROP results from premature birth, which interrupts the normal development of blood vessels in the retina, the light-sensitive part of the eye

### Pioneering program

Founded and led by A. Linn Murphree, MD, the Retinoblastoma Program in the Retina Institute of The Vision Center has been the site of significant discoveries.



### 1987

Dr. Murphree's team discovered the gene responsible for the development of retinoblastoma. It was the first human cancer gene to be discovered.

A. Linn Murphree, MD

essential for vision. Abnormal blood vessels can begin to grow in the wrong direction and lead to lifelong blindness. Until 1979, ROP was untreatable.

Fortunately, Madison was referred to Thomas C. Lee, MD, director of the Retina Institute in The Vision Center at Childrens Hospital Los Angeles. Dr. Lee treated Madison's retina with a laser, stopping the abnormal growth of vessels. Madison now appears to have good vision, to the relief of her parents, Sylvia and Jason Adam.

"She didn't even have a scar," says Mrs. Adam. "She looks at me, sees objects and smiles. She's a miracle."

Saving the sight of babies with ROP is only part of the Retina Institute's mission. "As good as our current therapies are, some kids still fail to respond to treatment," says

Dr. Lee, who is an associate professor of clinical ophthalmology at the Keck School of Medicine of the University of Southern California. "Our goal is to provide extraordinary care for today's patients and find new treatments for tomorrow's."

As the major referral center for retinal disorders in the western United States, the Retina Institute also treats retinal trauma and detachment, hereditary retinal degenerations and retinoblastoma (Rb), a rare cancer of the eye that affects infants and children under the age of five.

The Retinoblastoma Program is the only one of its kind world-wide in a pediatric hospital. Nearly one-fifth of all cases nationwide are treated at Childrens Hospital, and the current international treatment standards were developed here. (The program has the support of such donors as The Karl Kirchgessner Foundation, which funds psychosocial support for children with Rb and their families, as well as care coordination for children with optic nerve hypoplasia.)

Although Rb is curable if detected early, two-thirds of patients with the advanced form of the disease need to have at least one eye

### 1990s

The team designed a new treatment protocol for retinoblastoma, now used worldwide. Before, treatment involved radiation to the eye, which caused facial deformity and increased the risk for developing radiation-induced cancer. The current protocol involves chemotherapy followed by laser treatment.



#### 1990s

The team developed the current international classification system for retinoblastoma.

Thomas C. Lee, MD



removed. Current treatment includes chemotherapy, radiation and laser surgery. "Right now, we give chemotherapy to the whole child, when we really only need to give it to the eye," explains A. Linn Murphree, MD, head of the Retinoblastoma Program in the Retina Institute.

Researchers are looking at next-generation treatments, including a way to deliver chemotherapy into the eye via a miniature inverted "cup" placed over the eye to allow more of the drug to enter and remain there. "This new system is still in the early stages, but it potentially could reduce toxic side effects and make treatment more efficient," says Dr. Murphree.

Meanwhile, Dr. Lee is testing new targeted drug therapies for retinoblastoma in the laboratory, in the hope that they will kill the cancer cells without causing the DNA damage that occurs from chemotherapy. Doctors at the Retina Institute plan a clinical trial this year to test a more precise laser system, which potentially could treat tumors unaffected by conventional lasers.

Since 10 percent of its patients also have a family history of retinal disease, the Retina Institute recently created the first-ever prenatal diagnosis center for high-risk patients with the Institute for Maternal-Fetal Health at Childrens Hospital. Using high-resolution ultrasound and fetal Magnetic Resonance Imaging, specialists can detect tumors as small as one millimeter (0.039 inches) in the eyes of a fetus. If a tumor is found, doctors may deliver a baby a few weeks early and start treatment.

Dr. Murphree, professor of ophthalmology and pediatrics at the Keck School of Medicine, has been active in promoting more aggressive routine screening for retinoblastoma, along with genetic testing and the study of proteomics, an emerging method for early cancer detection. (See story on page 18.)

These physician-scientists are hard at work improving treatments for ROP, too. Today's laser treatment succeeds in 90 percent of cases in giving children good vision — even 20/20. That rate drops to 70 percent for babies born between 24 and 26 weeks. The Retina Institute is testing an ROP-related laser device, and this fall will participate in a national clinical trial for Avastin, a drug that targets abnormal blood vessels in babies who fail laser therapy.

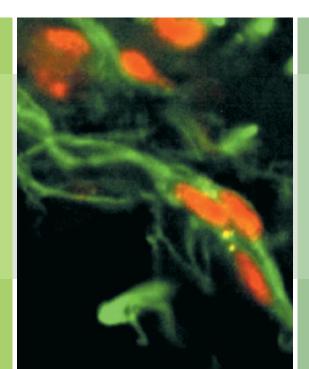
Six-month-old Madison Adam is now a healthy, happy baby. Her three-year-old sister, Jocelyn, delights in pretending to be Dr. Lee.

"Jocelyn was really concerned about Madison's eyes," Mrs. Adam says. "We told her, 'You don't have to worry anymore. Your sister's going to be okay." •

### Today

Childrens Hospital recently became the first in the nation to offer gene testing for all retinoblastoma patients, and the first to offer a prenatal diagnosis center for the disease.

Retinal stem cells





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We must care for children everywhere through research to find cures, develop new treatments and prevent disease.

# imaginediscovery



## visibledifference

THE DAHL FAMILY HAS TURNED A PERSONAL EXPERIENCE WITH RETINO-BLASTOMA INTO A OUEST FOR FAR-REACHING ANSWERS TO CANCER.

What worried the Dahl family's pediatrician was not what he saw in the newborn's eyes — it was what he didn't see.

Two-week-old Rory Anne Dahl's well-baby checkup had gone routinely until Grady Huckaby, MD, looked into her right eye and encountered no red reflection, only white. At that moment, Rory Anne's young life, and her family's world, turned upside down.

Joni and Eric Dahl's third baby had been born with bilateral retinoblastoma (Rb). Her vision was blocked by masses of cancerous tumors in both eyes. "She was, essentially, blind," says Mrs. Dahl.

The day his daughter was diagnosed, Mr. Dahl began researching Rb online. What he found alarmed him. About 250 children in North America are diagnosed with Rb each year, almost all under the age of three. Because the cancer can spread to the optic nerve, brain and spinal cord, eyes with advanced tumors may even have to be removed.

There were glimmers of hope. Rory Anne had been diagnosed far younger than the average 12 to 18 months. And one physician's name kept appearing on Mr. Dahl's computer screen: A. Linn Murphree, MD, head of the Retinoblastoma Program in the Retina Institute of The Vision Center at Childrens Hospital Los Angeles, and originator of many of today's standard treatments for Rb. Mr. Dahl e-mailed Dr. Murphree, a professor of ophthalmology and pediatrics at the Keck School of Medicine of the University of Southern California. He arranged to see Rory Anne that afternoon.

At only five weeks of age, Rory Anne began treatment at Childrens Hospital. In the first six months, she underwent six rounds of full-body chemotherapy, direct treatment of the tumors in her right eye, four blood transfusions and growth hormones to boost her immune system.

Because young children's eyes must be absolutely still for examination and treatment, she had 50

procedures under anesthesia by age three-and-a-half.

At that point, Rory Anne graduated to office exams, which she handles awake. "She was a star from the first exam," says her mom.

The demanding regimen and emotional stress took a toll on the entire family. While their parents were at the hospital, Rory's siblings — Carly, then nine, and Evan, six stayed with their grandparents. "We were back together at night," says Mr. Dahl, "but life revolved around Rory's treatment at home, too."

Thankfully, the hospital's care included Nancy Mansfield, PhD, a counselor and patient advocate on the retinoblastoma team. An assistant professor of clinical ophthalmology at the Keck School of Medicine, Dr. Mansfield is executive director of the Institute for Families, a Los Angeles nonprofit that provides support for families of children with visual impairments and other anomalies. "She was with us through every surgery, and we could call her day or night," remembers Mrs. Dahl.



Opposite: Rory Anne, Carly and Evan Dahl. This page: Joni and Eric Dahl watch a spirited soccer match.

Today, aggressive, cutting-edge treatment has preserved much of the sight in Rory Anne's left eye and some peripheral vision in her right. "She'll never fly a plane or play pro ball," notes her mother, "but not much is going to stop her."

While the family's journey has gotten easier, it never will be over: children with Rb are at greater risk of secondary cancers throughout their lives. That has spurred the Dahls to launch The Rory Anne Proteomics Fund at Childrens Hospital Los Angeles.

Proteomics is the study of proteins in a cell, tissue or organism. The fund will support a landmark investigation into specific protein patterns as early detectors of childhood cancers, in association with Retinoblastoma International (RBI). In May 2006, Representative Adam Schiff (D-CA) spearheaded a bill providing \$750,000 for this research.

"Proteomics has the potential to help with early detection of many cancers," says Mr. Dahl. "In the long run, everyone will benefit."

The Dahls have served on the RBI board and sit on the board of the Institute for Families. The Rory Annie Bananie Bunch, a team of family and friends, participates in the American Cancer Society's Irvine Relay for Life. Carly, who heads her own relay team, was named one of "35 Everyday Heroes" by the City of Irvine for her work with Team Kids on behalf of pediatric cancer research.

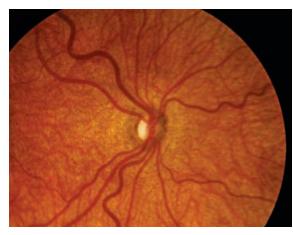
All three Dahl children are involved in Team Kids, whose programs have inspired about 4,000 Irvine students to raise and donate more than \$11,000 for The Rory Anne Proteomics Fund. To date, the Dahl family has raised more than \$340,000 for proteomics research at Childrens Hospital.

Lately, fund raising for Rory Anne has taken a back seat to a new experience: normal childhood. Yet, she understands its importance. Recently, when cancer was mentioned on TV, the four-year-old reacted. "Do you know what that word means?" asked her mom.

"Money!" Rory Anne answered triumphantly. •

### innovative research in The Vision Center

### full exposure



An eye with optic nerve hypoplasia

For the physician-scientists in The Vision Center at Childrens Hospital Los Angeles, a child's eyes are like fingertips of the brain, remarkable extensions of the mind's sensory network.

These ambitious researchers are pursuing investigations into a full range of eye diseases affecting children — and creating new knowledge about our visual system.

A case in point: Kristina Tarczy-Hornoch, MD, DPhil, director of the Vision Development Institute in The Vision Center, is working toward a basic understanding of the child's developing brain and how it learns to see. Teaming up with Vincent Chen, PhD, in Childrens Hospital's Department of Radiology, she is employing functional Magnetic Resonance Imaging (fMRI) to identify precisely where visual activities occur in the brains of children, adolescents and adults with signs of visual suppression.

The latest in neuro-imaging technology, fMRI generates high-resolution scans in which specific regions in the brain light up when various mental processes take place.

The study's focus is on eye crossing, often a result of farsightedness and a frequent precursor to serious vision deficit. When adults develop the disorder, their brains permanently produce double vision. "When it happens very early, the brain learns to completely suppress images entering through one eye or the other," says Dr. Tarczy-Hornoch, an assistant professor of clinical ophthalmology at the Keck School of Medicine of the University of Southern California.

Potentially, investigations like this may lead to therapies for youngsters whose eyes and brain aren't in sync. "A child's brain is so potentially modifiable," says Dr. Tarczy-Hornoch, "we believe there must be ways to make this adaptability work for the child's vision instead of against it."

Also trying to uncover the secrets of early visual disorders is Mark S. Borchert, MD, director of The Vision Center and its Eye Birth Defects Institute. For the past decade, he has been conducting the largest clinical research study into optic nerve hypoplasia (ONH), which has its roots during pregnancy and is the leading cause of vision loss in youngsters. His study targets the patterns of ONH occurrence and the roles that environment and genetics play.

As director of the Eye Technology Institute, Dr. Borchert is using the eye

as a window into the body. He has partnered with James L. Lambert, PhD, from the Jet Propulsion Laboratory at the California Institute of Technology, a specialist in next-generation bioinstrumentation for medical research. Together, they have found that by measuring the concentration of certain substances in the watery fluid of the eye, they can infer the levels of those substances in the body.

Researchers currently are testing a measurement device that potentially could replace a needle-stick for people with diabetes, as well as compute chemotherapy levels. A separate device under study calculates intracranial pressure noninvasively by scanning the optic nerve. An increase in pressure from tumors or other neurological conditions can be fatal.

"We can only do this kind of research in a place like Childrens Hospital, with our collaborative spirit," says Dr. Borchert, an associate professor of clinical ophthalmology and neurology at the Keck School of Medicine. "People here welcome collaboration and exploring novel ideas in ways I haven't seen anywhere else."•

-kate vozoff

#### The Vision Center

### a history of innovation

The Vision Center at Childrens Hospital Los Angeles has furthered the understanding and treatment of pediatric eye disease with a number of noteworthy discoveries and advances over the past three decades. They include:

- · Identification of the gene that causes retinoblastoma (Rb), an eye cancer that most often occurs in children under 5 years — 1987
- · Development of all of the major state-ofthe-art strategies for treating Rb in the Retinoblastoma Program of The Retina Institute, the only program of its kind in the world based in a pediatric hospital
- Invention of the RetCam more than 20 years ago, a device now used worldwide for visualizing the back of the eye in infants and children
- · Invention of the most widely used test comparing vision in pre-verbal children (Fixation Preference Test) — 1980s
- · Advances in measuring vision in pre-verbal toddlers and infants, with recent development of a computerized version of the Forced-Choice Preferential Looking Test, which tracks eye movements with a computer and records response speed
- Direction of the largest-ever clinical research study in optic nerve hypoplasia, which is zeroing in on a greater understanding of the single leading cause of blindness and vision loss in young children
- · Exploration of functional Magnetic Resonance Imaging as a tool in the study of connections between the developing brain and vision, which may lead to early intervention strategies for sight-threatening disorders affecting young children

- Development of new tools that use the eye to measure metabolic processes in the body, including the presence of glucose, which could have major implications for diabetes treatment, as well as levels of chemotherapy, which could help determine if drug treatments are reaching the brain
- · Development of pediatric application of vision care advances developed at the University of Southern California, including the Tono-pen™, a portable device to measure pressure in the eye — 1989

Other distinctions of The Vision Center include:

- The largest contact lens program in the nation for children, even fitting babies for refractive errors, with tremendous success in achieving normal or near-normal vision
- Treatment of refractive errors with LASIK (laser-assisted) surgery for children who can't tolerate contact lenses; one of only a few places nationwide to provide this avenue of improving children's eyesight
- Excimer laser surgery for children who have potentially blinding conditions, such as corneal scars — one of only two centers in the country to do so
- · The benchmark for quality in corneal transplants, with the highest number of pediatric corneal transplants in the U.S. (25-30 a year) and the highest success rate

To play a role in the exciting advances to come at The Vision Center, please contact David D. Watts, associate vice president of Major and Planned Gifts at 323-361-1752 or dwatts@chla.usc.edu.

-candace pearson



# abby rowley [dog trainer]

Nine-year-old Abby Rowley takes her dog, Jack Sparrow, to agility training every week. She loves to dance, bounce on her trampoline and ride horses. Abby does it all, plus attending classes and church, while wearing an eye patch because she has amblyopia, which occurs when one eye doesn't develop normal sight during early childhood.

When she was two years old, her parents, Susan and Jerry Rowley, noticed that she sometimes crossed her eyes. A doctor near their Riverside County home put Abby in glasses. Over the next few years, her vision only deteriorated.

The Rowleys came to Childrens Hospital Los Angeles when Abby's older sister, Hannah, was being treated for leukemia. They met Angela Buffenn, MD, MPH, director of the Orbit and Eye Movement Institute in The Vision Center, and assistant professor of clinical ophthalmology at the Keck School of Medicine of the University of Southern California.

She began an aggressive program of occlusion therapy for Abby. With a patch over her strong left eye up to eight hours a day, Abby's weaker right eye works harder — and gets stronger. "When you're doing something you like, you don't even notice you're wearing it," says Abby, whose friends like to see her growing patch collection. Before treatment, her right eye had 20/200 vision. Now, it is 20/40. Eventually, she won't need a patch, once her brain "sets" her vision. Until then, Dr. Buffenn's goal is "the absolute best vision we can get for Abby." Abby agrees. •

### Children's Miracle Network sponsors calendar year 2006

### honor roll of friends



Stephanie age 11

Children's Miracle Network (CMN) is the alliance of premier children's hospitals dedicated to saving and improving the lives of children. Sponsors of CMN, their employees and customers help raise millions of dollars each year for more than 170 CMN-affiliated children's hospitals throughout North America, including Childrens Hospital Los Angeles.

Childrens Hospital Los Angeles has been a member of the alliance of premier pediatric hospitals since CMN's founding in 1983.

Over the past 24 years, generous sponsors have contributed more than \$2.7 billion to CMN, enabling its hospitals to treat 17 million children annually for every disease and injury imaginable. In calendar year 2006, these pledges totaled more than \$4.5 million to care for children treated at Childrens Hospital Los Angeles.

We offer our deep-felt appreciation to these sponsor organizations for their dedication, support and tireless work on behalf of children. Each sponsor, employee or volunteer who participates is a true hero. We also would like to send KBIG 104.3 a special "thank you" for giving its passion and talents

in hosting the 104.3 KBIG Tunathon each year, benefiting Childrens Hospital Los Angeles.

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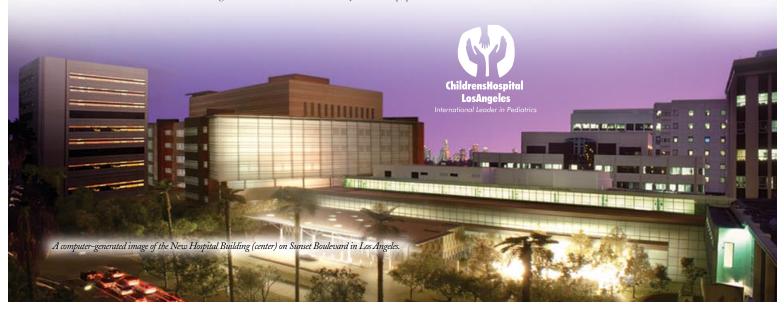






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