

Children's HandPrints

CHILDREN'S HOSPITAL & RESEARCH CENTER OAKLAND

the
HARD WORK
of HAVING
CYSTIC FIBROSIS

*Children's Cystic Fibrosis Center works harder
to make life better for its patients.*

also inside
summer 2008

CHILDREN'S EXPANSION: **Modesto**

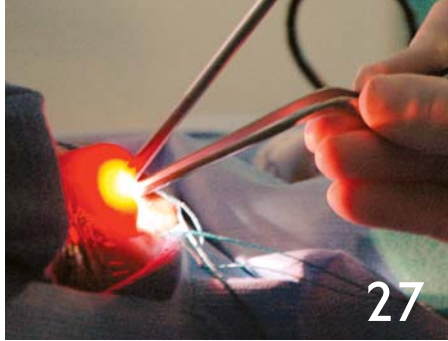
CHILDREN'S PATIENT ALUMNUS: **Christopher Cox**

PHYSICIAN FEATURE: **Bamidele Kammen, MD**

COMPREHENSIVE CARE AT CHILDREN'S: **Christopher Rodriguez**

table of contents

On the cover Korie, 5 months old, visits Children's nationally certified Cystic Fibrosis Treatment Center. See cystic fibrosis story on page 14. Photo by Gary Turchin.



14 the HARD WORK of HAVING CYSTIC FIBROSIS

Karen Hardy, MD, leads a cystic fibrosis team committed to making best practices even better.

3 LETTER FROM THE PRESIDENT AND CEO

4 THIS AND THAT

Amro's journey A little Palestinian boy comes to Children's for a new treatment for MPS VI.

Ann Petru, MD, wins Bronze Bambino Award Nobel Prize winner Dr. Albert Schweitzer inspired her to become a physician.

PACU nursing team honored Children's Post Anesthesia Care Unit is a finalist for Best Nursing Team 2008 award.

Munchausen by proxy Studying parental abusers led to a book that helps keep children safe.

Children's cafeteria gets new look Friendly Café is now even friendlier.

8 FIRST PERSON

My hero Isaac A mom, preparing for medical school, confronts her son's cancer.

12 FUNDRAISER: ST. BALDRICK'S DAY

To support pediatric cancer research, 140 heads go bald.

20 RESEARCH: CYSTIC FIBROSIS

Children's researchers make discovery that may change the way cystic fibrosis is treated Beate Illek, PhD, and Horst Fischer, PhD, look for better ways to beat back dangerous cystic fibrosis lung infections.

22 CHILDREN'S EXPANSION: MODESTO

New specialty care center opens in the Central Valley

24 CHILDREN'S PATIENT ALUMNUS

Children's cancer survivor Christopher Cox He's now pre-med and doing cancer research at Children's.

27 ADVANCED EQUIPMENT: ENDOSCOPY

Scoping it out New digital endoscopic viewing equipment helps surgeons do more minimally invasive surgical procedures.

28 PHYSICIAN FEATURE: BAMIDELE KAMMEN, MD

Seeing inside to puzzle out a diagnosis

30 COMPREHENSIVE CARE

He's no victim Injured by a gunshot, Chris Rodriguez, 10, adjusted to life in a wheelchair during a 61-day stay at Children's Hospital.

36 FOUNDATION NEWS

From Raggedy Ann to Devil Mountain Run The run's founders raised funds for Children's and created one of the Bay Area's most successful running races.

The volunteer A-Team Local Kohl's department store associates find volunteering rewarding and a great team-building experience.

When Children's Hospital is part of the family How one family supports excellent pediatric care.

Wise philanthropy: The charitable gift annuity option How it works.

letter from the president + ceo

Dear Friends,

The past year was an outstanding one for Children's Hospital. We were proud to serve more families than in the previous year—with more outpatient visits than ever and 10 percent more inpatient admissions—while maintaining high overall patient satisfaction. Last year, patient families gave us average satisfaction scores of 9 on a 1-to-10 scale.

While growing our capacity to serve more children, we also helped many low-income families, providing more than \$44 million of uncompensated care. It's all part of our mission—to serve all children regardless of their ability to pay.

What's also part of our mission is continuing to raise the bar on quality. According to the Cystic Fibrosis Foundation, we're one of the nation's best at treating cystic fibrosis.

But that wasn't good enough for our Pulmonary Medicine team, led by division chief Karen Hardy, MD. See page 14 to learn how she and her team of dedicated clinicians are helping patients do even better at managing this chronic genetic disease.

Also working hard to help patients heal quickly is our trauma center, and the teams in Surgery, Critical Care and Rehabilitation Medicine. One recent trauma patient, Chris Rodriguez, traveled his 61-day healing path at Children's under the news media spotlight. To learn more about how we helped Chris, see page 30.

Finally, we are also making sure surgical clinicians have the latest high-tech equipment. We put new, state-of-the-art anesthesia machines in every operating room and are installing new digital imaging equipment (see page 27) to help physicians perform more minimally invasive surgery.

To all those supporting Children's Hospital—especially our generous donors—thank you.



Frank Tiedemann

*President and Chief Executive Officer
Children's Hospital & Research Center Oakland*



Children's HandPrints

A CHILDREN'S HOSPITAL & RESEARCH CENTER OAKLAND PUBLICATION

Children's HandPrints is a publication of Children's Hospital & Research Center Oakland, 747 52nd Street, Oakland, CA 94609; 510-428-3000.

Written, designed and produced by:
Communications Dept.
Children's Hospital & Research Center Oakland

Frank Tiedemann
President and Chief Executive Officer

Mary L. Dean
Senior Vice President and Chief Strategic Development Officer

Tina Amey
Office Assistant

Debbie Dare
Manger, Graphic Design Services

Susan Foxall
Director, Physician Marketing

Tom Levy
Senior Writer

Michele Repine
Web Content Manager

Venita Robinson
Director, Media and Community Relations

Erika Sandstrom
Senior Graphic Designer

Gary Turchin
Director, Community Relations, and Senior Writer

Diana Yee
Media Relations Specialist

Board of Directors

Harold Davis, *Chairman*

Jeffrey Cheung, *Vice Chair*

Arthur D'Harlingue, MD

Arnold Grisham

James Keefe, *Treasurer*

Watson M. Laetsch, PhD

Michael LeNoir, MD

Barbara May, *Secretary*

Melba Muscarolas

Karen Stout

Barbara Staggers, MD

Frank Tiedemann

Gene Upshaw

Harold (Tim) C. Warner, PhD

Story requests, comments or suggestions for Children's HandPrints may be emailed to comm@mail.cho.org or sent to 747 52nd St., Oakland, CA 94609.



AMRO: Amro and his dad, Yaser, have a playful moment during their weekly visit to Children’s Day Hospital for Naglazyme treatment.

NEW DEVELOPMENT

Amro’s journey

A little Palestinian boy comes to Children’s for a new treatment for MPS VI.

Amro, 2, played with his dad on a bed in Children’s Hospital & Research Center Oakland’s Day Hospital. An intravenous line dripped Naglazyme, the first drug ever developed for Maroteux-Lamy syndrome (MPS) VI, into his veins. He started on weekly doses of Naglazyme at 8 months old, making him the first baby in the United States ever to go on the drug.

Naglazyme had its only U.S. clinical trial at Children’s a few years ago. In 2005, the Federal Drug Administration approved Naglazyme for use in kids ages 5 and up. Now Children’s is the only site in the U.S. and one of only three in the world doing an earlier-intervention trial.

Patients with MPS VI lack an enzyme

that breaks down a complex sugar (glycosaminoglycan). Without the enzyme, the sugar remains in cells, accumulates in connective tissue and causes severe damage. It particularly affects the skeleton, heart valves, spleen, liver and cornea. MPS VI patients tend toward very short stature.

The new clinical trial is designed to start treating MPS VI as early as possible. The condition is so rare—only about 1,100 people in the developing world suffer from it—that the drug developer, Novato, Calif.-based BioMarin Pharmaceuticals, had to reach out across the world to find a patient young enough and available for the trial. Amro was living in Hebron when doctors at Hadassah Hospital referred him to Children’s

researchers. BioMarin brought Amro and his dad to Oakland, where they are living during the study.

“If we can start MPS VI babies on the drug early in their lives,” said Children’s hematologist Paul Harmatz, MD, the study’s principal investigator, “we have a greater chance of preventing bone and growth abnormalities, mobility problems, airway constriction—and can offer children with MPS VI a better quality of life.” ★

STAFF RECOGNITION

Ann Petru, MD, wins Bronze Bambino Award

Ann Petru, MD, medical director of the Infectious Diseases department and the Pediatric AIDS/HIV program at Children’s Hospital & Research Center Oakland, won the 52nd annual Bronze Bambino award. The winner of the Bambino—a lifetime achievement award for service to Children’s Hospital Oakland—is chosen by a vote of Medical Staff peers.



PETRU: Ann Petru, MD, 52nd Bronze Bambino winner, examined a longtime patient in an Infectious Diseases examination room during one of his regular follow-up appointments.

Dr. Petru was inspired to study medicine by reading about Nobel Peace Prize winner Albert Schweitzer, MD, when she was a child. His work made her “want to make a difference in someone’s life, especially someone no one else cared about.”

Dr. Petru was born and spent her early years in England, where her Czech parents settled after World War II. Her mother, a Holocaust survivor, now 84, spent four years in the Terezin concentration camp, north of Prague. Her father fought with Czech soldiers as part of the French and then the British armies against Hitler and the Germans.

Her parents met in Czechoslovakia after the war, but in 1948, when the Iron Curtain descended, they fled, eventually settling in England, where the three Petru children were born.

From there they moved to Canada. When Dr. Petru was 7, the family settled in California, where she later went to medical school at the University of California, San Francisco.

In 1978, Dr. Petru came to Children’s Hospital Oakland to do her pediatric residency. She stayed on, first as a chief resident, and later to do a fellowship in Pediatric Infectious Diseases with Parvin Azimi, MD. During her fellowship, Dr. Petru provided care for one of the first pediatric HIV/AIDS cases in the Bay Area.

“(Dr. Azimi) was my inspiration,” said Dr. Petru. “It was the great challenge of using your head to puzzle out infectious diseases. It was hard, but always very rewarding.”

Voted an East Bay Best Doctor in 2007 and 2008, Dr. Petru is a serious photographer, master swimmer, avid reader, a crossword puzzle enthusiast and the mother of two grown children, Emily and Stephen. ★



PACU NURSES: Some of the 42 RNs who make up Children’s PACU nursing team share the honor of being finalists for a Best Nursing Team 2008 award.

AWARD PACU nursing team honored

Children’s Post Anesthesia Care Unit was a finalist for a Best Nursing Team 2008 Award.

Nursing is a team sport, and Children’s is proud of its great nursing teams. One of our most experienced nursing teams, the Post Anesthesia Care Unit (PACU) was selected as a finalist for *Advance for Nurses* magazine’s Best Nursing Team 2008 Award.

The PACU team—42 RNs strong—was honored for its adaptability in the ever-changing, unpredictable world of post-anesthesia nursing.

Children’s PACU is one of the most demanding and sought-after assignments in our nursing corps. PACU nurses work in several locations and must handle a wide-range of complex procedures.

“We’re the front line for patient safety in surgery,” said Mary Frazier, RN, MS, assistant director, PACU nursing unit. PACU nurses are responsible for patient identification, correct site and surgery identification, as well as for registering and preparing patients for surgery, and then seeing them through post-anesthesia recovery. ★

COLLABORATION

Munchausen by proxy

Studying parental abusers led to a book that helps keep children safe.

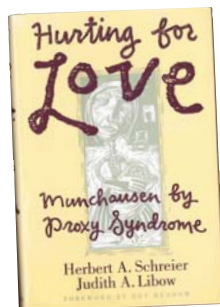
Studying abusive parents is not pleasant. But two clinicians at Children’s Hospital & Research Center Oakland have learned how to better protect children from parental abusers by working with and learning more about parents with Munchausen syndrome by proxy.

What they learned also put one of them—Judith Libow, PhD—on a plane to Los Angeles for an appearance on Dr. Phil’s television show.

Munchausen syndrome is named after an 18th-century German baron who became famous after a book detailing fantastical tales he had told about himself was published. People with the disorder consciously do things to make themselves sick or appear to be sick, so they’ll get attention from healthcare clinicians.

The “proxy” part comes when a disturbed parent does something to make her child ill, instead of herself. Parents with the disorder may bring their child to a hospital, getting the attention they’re seeking through their child’s illness—by proxy.

In the early 1990s, Dr. Libow and her colleague in Children’s Psychiatry department, Herb Schreier, MD, found themselves dealing with a few cases of abusive parents like this. Usually mothers, they exaggerated or induced illness in their



children to get attention from clinicians.

Drs. Libow and Schreier were shaken, but also intrigued. They studied the medical literature, finding little on psychological aspects of the disorder. In researching and writing a book about these parents, and working with cases that came their way, they became de facto experts on the subject.

In 1993 they published a book about what they’d discovered—*Hurting for Love: Munchausen by Proxy Syndrome*. Their work, and the book, received notable attention.

They appeared on TV: segments on “Dateline” and “20/20,” and a piece on the Discovery Channel. They also lectured at conferences across the United States and internationally—in Scotland, England, Sweden, Denmark, Germany, Albania, Turkey, China and Japan. They were even called to appear as experts in court cases.

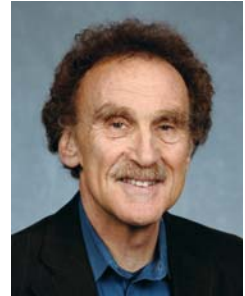
Then, late last year, Dr. Libow was asked to appear as a guest expert on a “Dr. Phil” show that aired in October 2007. For the August taping, she carefully packed a favorite off-white suit and got on a late evening flight to Los Angeles. Dr. Libow arrived, rode in a limousine to the Hollywood Renaissance Hotel, and barely had time to admire the room before falling asleep.

At 6 a.m. the next morning, Dr. Libow got another limo ride, this time with a chatty Russian driver. Before the driver dropped her off at Dr. Phil’s studio, her tour included famous Hollywood sites such as the Paramount studio and a set where some of *Spiderman 3* was filmed.

In the “Dr. Phil” studio, she



Judith Libow, PhD



Herbert Schreier, MD

discovered that white and off-white clothing are unsuitable for television. But she also learned that Hollywood TV wardrobe people can do anything. Multiple outfits in her size were found, and one was selected. Dr. Libow, who dislikes using make up, also had her hair and make up done—TV style.

The case Dr. Phil presented was nasty. A mother diagnosed with Munchausen syndrome by proxy was interviewed by phone from the jail cell where she was being held. Her adult daughter and other family members appeared in the studio. There were also a pediatrician, a police detective and Dr. Libow.

After Dr. Libow had her 30 seconds of fame, discussing some fine points of the disorder, and the show was over, there was a debriefing in the green room. A psychologist made sure family members were OK.

Dr. Libow rode in another limo to the airport and took her flight home. “It was a once-in-a-lifetime experience; I figured it would be fun to do,” she said.

But Dr. Libow is clear that her real reward for the work is not the fame. “It’s rewarding to see that through our work, (Dr. Schreier and I) can protect children from the abuse of trusted adults like parents with Munchausen by proxy.” ★

REMODEL Children's cafeteria gets new look

Friendly Café is now even friendlier.

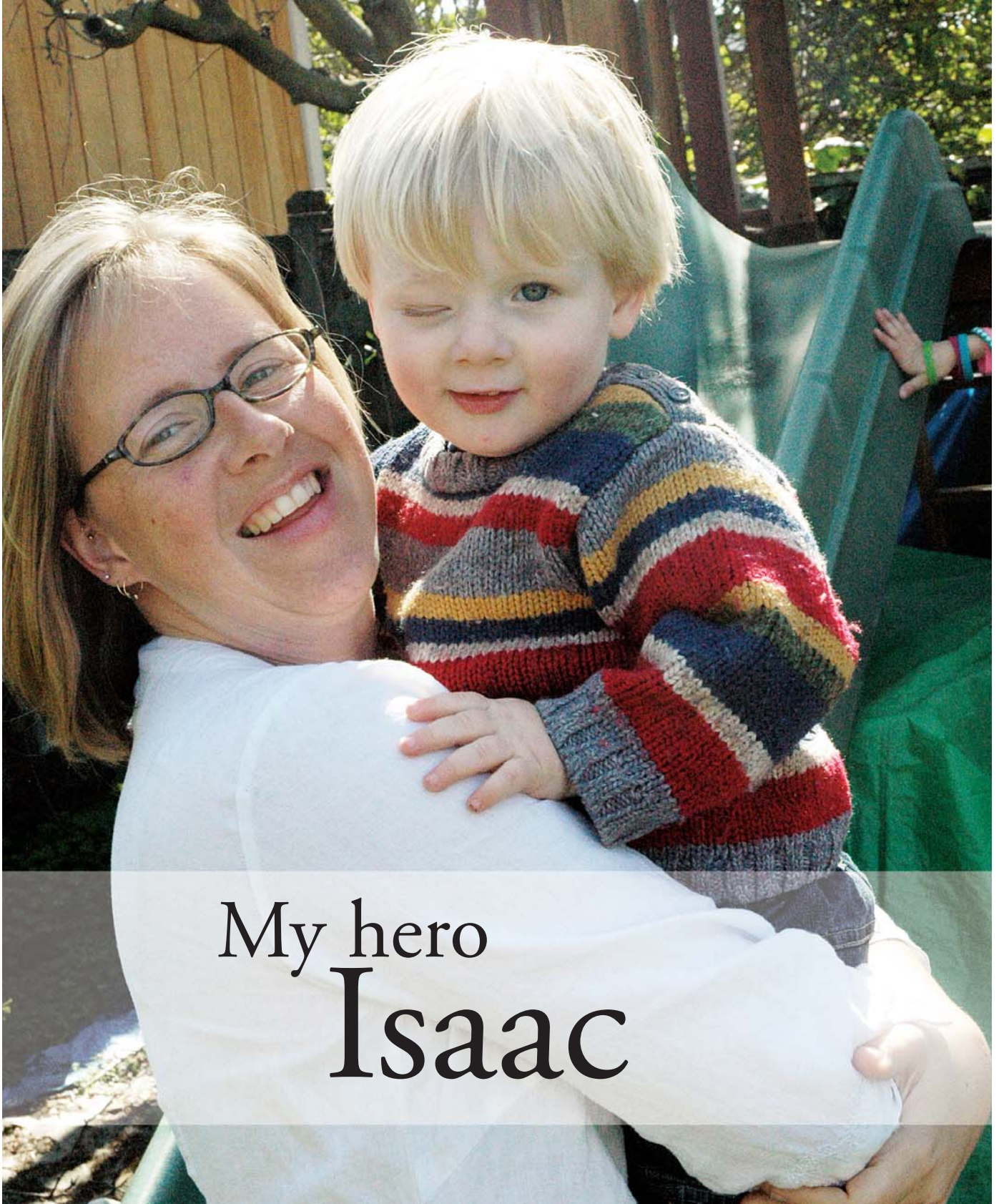
Construction crews working nights have turned Children's Hospital & Research Center Oakland's Friendly Café into a beautiful new bistro. The elegant remodel includes new tile, carpets, tables and chairs, light sconces, a designer color scheme, and even a lounge area with comfy sofas and chairs, making the Friendly Café friendlier than ever. A spacious new salad bar allows more room for patrons to build healthful salads.

"We made it better for families and better for staff," said Lawrence Headley, manager, Food Services. The new décor highlights the focus on better nutrition that Food Services has been cooking up all year—less sugar, fat and calories; no hydrogenated oils; and more healthy choices. ★

CAFETERIA REDESIGN:

(top) The Friendly Café's new look. (center) Chef Jaime Salazar prepares a nutritious jambalaya lunch. (bottom right) Executive chef Gil Lazaro places a fresh, hot pizza out for hungry diners. (bottom left) New nutrition labels help Children's staffers and visitors make healthy choices.





My hero
Isaac

written BY LISA BARACKER
 photographed BY GARY TURCHIN

I was studying for my Medical College Admission Test (MCAT) when we found out that my son Isaac, 14 months young, had cancer. There was a large tumor behind his right eye that was found in an MRI just after Christmas 2006.

I came home after the MRI with a CD of the images and popped it into the computer. My sister and I looked at every slice of that MRI. We were both science majors in college and graduate school, so it was immediately clear that there was a large mass behind Isaac's eye. I thought 'Gosh! There is a hematoma there, or a tumor. No, that's not blood; it's a solid mass!'

When my husband Gabe got home, I showed him the MRI, and I explained what I knew about the anatomy of the brain—what was normal-looking and what was obviously not normal. I was in a state of shock like I had never been before.

Later, while in the car, we got a call from our pediatrician, David Kittams, MD. Dr. Kittams started to tell me what was wrong with Isaac. "Cancer, a tumor..." I repeated it to Gabe. Gabe pulled the car over and started to cry, which made me cry. I snapped out of it and frantically wrote down everything Dr. Kittams was telling me: the diagnosis, the names of all the specialists that would now be involved and the appointments that were scheduled for next Tuesday. It all happened so fast, which I guess is what made it so scary.

Gabe and I called a family meeting to talk to everyone. My mom was in town, as were his parents. We met at my sister's house and got my dad on the phone. We told everyone what Dr. Kittams had told

us just a few hours earlier. "Isaac has cancer; there is a large tumor behind his right eye."

Repeating it to the family made it real. Gabe began to cry again and so did some of the other family members. I guess I was already done crying. Our family had a hundred questions, which I made into a long list.

We all celebrated New Year's Eve together in what I remember being the saddest New Year's Eve in the history of my life.

On Jan. 2, 2007, we went to see the team of Children's Hospital & Research Center Oakland doctors that would be taking care of our little man: pediatric ophthalmologist Selim Koseoglu, MD; oncologist Carolyn Hastings, MD; and neurosurgeon Peter Sun, MD. Meeting all of them in one day was quite overwhelming, but they took all the time that we needed to answer our questions.

First we spoke with Dr. Sun about the tumor's location and the MRI results. Then Dr. Koseoglu came to visit Isaac to assess the vision in Isaac's right eye. Dr. K looked Isaac over very thoroughly, checking every little detail. When he covered Isaac's left eye so that Isaac had to use the right eye, Isaac fought him desperately. It was like Isaac couldn't see anything out of the right eye at all. It became apparent that Isaac was not going to make it out of this thing with his vision intact, at least not on the right side.

The last doctor called in was Dr. Hastings. With Dr. Hastings we discussed the tumor in depth. Isaac was diagnosed with an optic nerve glioma—a pretty rare tumor—and while the news seemed surreal, we had to keep to our questions and

find out exactly what to do.

As we understood things, there were three treatment options: 1) Do surgery immediately to remove the tumor and the optic nerve; no vision for Isaac on the right side. 2) Start chemotherapy immediately to reduce the size of the tumor so that surgery could be more successful. 3) Hope that the chemo would get rid of Isaac's tumor—there was an infinitesimally small chance of this—so there would be no need for surgery.

Radiation was not an option because Isaac was too young, and it would severely impact his brain development.

Drs. Sun and Hastings both agreed option 2 was best: Let chemotherapy do some work on the tumor so that Dr. Sun could take it out in the cleanest way possible.

Gabe and I did get some second opinions—enough to learn that Dr. Hastings and Dr. Sun were going to give Isaac exactly the kind of care that he needed, right here at Children's Hospital and close to home.

I changed jobs to be closer to home and family, and pressed on with my MCAT studies while our baby boy started on a different kind of journey. On Jan. 12, 2007, Isaac got his Mediport implanted, so medication could go directly into his blood stream. He was immediately started on chemotherapy.

Isaac's first rounds of chemotherapy were quite difficult. He was nauseous and vomiting all the time and constipated to top it all off. We didn't know what to do. It felt like he was dying. He was so tired that he slept all through the days, and he wouldn't eat. He didn't even want a bottle of milk. We took many trips to the emer-



Isaac was released from the hospital on April Fools Day 2007.

Only six days before, his head had been cut open, his brain moved out of the way and his tumor removed from behind his eye, and now he was home and running around like a crazy little man again!

FLYING HIGH: (above) Isaac is flying high again, on the back of his mom, Lisa, with dad, Gabe (left), and sister, Jordan (right), joining the fun. (below right) Isaac and his dad, a year earlier, with matching mohawk haircuts.

gency room. They gave him fluids and ran tests to see what was wrong. Once, they took an x-ray to make sure his digestive system was OK. Turns out that he was so constipated he couldn't eat, but he was also immuno-compromised, so they couldn't really do anything but tell us to wait it out.

Our lives began to rotate around Isaac's chemo and MRI follow-up schedule. There were appointments every single week. There was a blood draw every single week, too.

Four weeks into chemotherapy, Isaac had his second MRI. Not much had

changed. The tumor was still growing, but only a millimeter or so, so we were safe to continue chemotherapy as planned. Dr. Hastings thought that the tumor might be responding, and the only way to know was to finish round 1 before making any decisions about surgery. They told us that once the tumors start responding, they usually continue to do so.

Gabe and I decided to finish the chemotherapy. When we left that appointment, we made another decision: If Isaac's tumor didn't stop growing by the next MRI, he would have the surgery. No more waiting around when we had a brilliant

neurosurgeon like Dr. Sun on our team. We made a pact.

By the end of round 1 of chemo, Isaac's MRI number 3 confirmed that the tumor was still growing, though ever-so-slightly. It was March 23, and we were sitting with Dr. Sun and Dr. Hastings in the same office where we had initially talked about the whole treatment plan. Now we were where we hoped we'd never be. We made plans for Isaac's surgery.

I postponed my MCAT exam from April 7 to May 25 because there was no way that I was going to be able to study with Isaac in the hospital. We had a plan,

so all we had to do was have a fun weekend and relax so that we'd be ready for Isaac's surgery Tuesday morning.

On Monday morning we went to Isaac's pre-op appointment, and on Monday afternoon I was laid off from my job. I remember thinking: Why me? Why now? My company knew that Isaac was having brain surgery, so why did I get laid off? Better yet, why did they hire me in January in the first place?

This was probably the moment when I realized how much things were going to change for our family.

Isaac went on to have a very good surgery. I stayed with him in the hospital every day, only taking a break at night to go home and get a good night's rest so that I could get up and be with him again.

He was asleep for more than 24 hours in the ICU, and when he woke up, the first thing that he wanted was a bottle. I got to hold him and feed him again.

He was so tired and cranky. They had to brace his arms to keep him from grabbing at his eyes; both were swollen shut.

The right eye was the worst of the two: It was sewn together to keep the eye in, and it was black and blue. It looked like our baby had been beaten up in a boxing match. After day 2 in the ICU, Isaac started to open his eye, and they released him to the recovery ward that evening.

Isaac was released from the hospital on April Fool's Day 2007. He was ready to go home and doing great.

This was the most amazing thing to us. Only six days before, his head had been cut open, his brain moved out of the way and his tumor removed from behind his eye, and now he was home and run-

ning around like a crazy little man again!

His scar was huge, but it was also like a badge of courage. You can't even see it now because it's under all his blond hair.

We had another period of waiting while the tumor board convened to look at Isaac's pathology reports. The oncologists at Children's Hospital Oakland conferred with Jonathan Finley, MD, at Children's Hospital Los Angeles and decided that Isaac needed to continue chemotherapy for a year to make sure that the tumor would not grow back. They decided it was prudent to do whatever it took to protect the vision he still had in his left eye.

This news meant there was still a long road ahead of us, but the worst was over. Isaac no longer had a tumor in his optic nerve. He no longer looked like his eye was popping out of his little head. Gabe and I were very happy.

These past 16-plus months have been very difficult, but we are blessed that Dr. Sun was able to get Isaac's tumor out, that

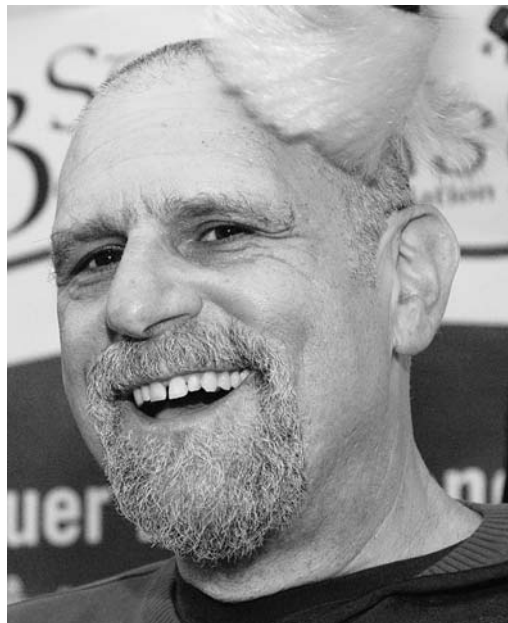
Bryant Toth, MD—Children's craniofacial surgeon—was able to put Isaac back together again; and that Dr. Hastings and Joseph Torkildson, MD—a Children's neuro-oncologist—have been able to keep Isaac cancer-free since then, all without Isaac ever having to have radiation.

Isaac is developing right on track for his age, and he is so brave. This year Isaac has had seven MRIs, three surgeries, 50-plus chemotherapy treatments, and hundreds of needle sticks for lab work. He's been to the ER several times and was admitted once after Christmas.

He's been through more in his first two years of life than I have been through in 30 years of living, and he is my hero.

Lisa Baracker did take her MCATs, twice. While waiting for her scores, she volunteered to organize Children's Hospital's St. Baldrick's Day event (see page 12). About 140 people shaved their heads in solidarity with kids with cancer. Lisa was one of them.





Fundraiser : st. baldrick's day

March 17 was St. Baldrick's Day at Children's Hospital & Research Center Oakland. Hundreds of people gathered in the Outpatient Center to be part of this hair-raising fundraiser. More than 140 people shaved their heads to show solidarity with kids with cancer and to raise funds for pediatric cancer research. Children's Hospital's team lost the most hair and raised the most money.

Doctors, nurses, staffers from all departments, families, neighbors, friends and classmates jumped in with both feet, and all their locks.

Women and girls with long, beautiful hair—now bald! Men with hair down their backs—bald! Big Santa beards—gone! Sideburns—gone! Leftover '60's hairdos—gone! '80s spikes—gone! Dreads—gone! Purple dye—gone! Ponytails—gone!

It was a festival of letting go, and of honoring kids.

It was a you-had-to-be-there experience, but if you weren't, you can still make donations at www.StBaldricks.org.

SHAVEES: (right) Brave Elora got her locks shaved in honor of Ariel, her twin sister, who is battling cancer. Her mom, Crystal Gariano-Biller, is a Children's Hospital staffer.

(left) A few of the precious St. Baldrick's Day moments. More than 140 people let go of their locks, raising more than \$130,000 for childhood cancer research.

written + photographed
BY GARY TURCHIN



the HARD WORK *of* CYSTIC FIBROSIS



HAVING

written + photographed
BY GARY TURCHIN



A DAY AT THE CYSTIC FIBROSIS CLINIC: (left) Isabel in her mom, Kendal's, arms during an appointment at Children's nationally certified cystic fibrosis treatment center. (center) Isabel kept her feathery friend close while lying on the exam table. Above Dr. Hardy's pointing finger is a feeding tube to help bolster Isabel's nutrition. Keeping CF kids in the average growth range is essential for good CF care. (right) Dr. Hardy listened to Isabel's lungs. Keeping the airways clear is part of the hard work of managing CF.



ELIDA: (top left) Elida got a hug from D.J. Kaley, RN, during a visit to Children's CF clinic. (top right) Elida doing airway clearance treatments during a stay at Children's Hospital. (above) Elida maintains a positive attitude through all her CF struggles.

If you think being 15 is tough, try being 15 and having cystic fibrosis (CF).

Elida is 15. She's also a patient at the Cystic Fibrosis Center at Children's Hospital & Research Center Oakland. She typically rises at 5:30 a.m. to take her CF medications—she can reel off a dozen prescriptions by name; have breakfast—she must take digestive enzymes at every meal to break down her food; and do airway clearance treatments (ACTs). Then she catches a 7:30 a.m. bus to school with her classmates.

To clear her airways, Elida dons a vest that uses air pressure to massage her lungs. While wearing the vest, she breathes aerosols that deliver Albuterol, a bronchial dilator; Tobramycin, an antibiotic; and a hypertonic saline solution to replace her salts. She also inhales DNase, a medicine that breaks up the mucus so the vest can move it. She spends about 20 minutes in the vest—not including set up and clean up.

"It's like watching TV to me," Elida said of the time-consuming effort.

Like many teens, Elida enjoys playing soccer. She was good enough to make her high school varsity team.

"To make girls' varsity soccer, that's something," she said.

But to Elida, soccer is more than a game. It's part of her CF treatment. "When I move and play around, I cough it (the mucus) up. It helps in making everything stay clear," she said.

When Elida comes home from school, she repeats her airway treatments. On bad days, she repeats them four times. When things get particularly challenging, she comes in to Children's Hospital for what she calls "a tune-up." Usually that means a couple of weeks as an inpatient receiving

antibiotics intravenously and getting frequent airway clearance treatments.

What is cystic fibrosis?

Elida inherited the recessive gene that causes cystic fibrosis from both her parents. The gene helps make a protein, the cystic fibrosis transmembrane regulator protein, or CFTR. CFTR regulates the movement of salt across certain body membranes, including membranes in the lungs (see research sidebar, page 20). If patients have abnormal CFTR, they get sick.

CF symptoms vary widely because more than 1,500 CF gene mutations have been found. The connection between the mutations and symptoms is not always clear.

"We'll cure it before we understand it," is how D.J. Kaley, RN, Children's cystic fibrosis case manager and nurse with 32 years of CF experience, puts it.

In most CF cases, thick, sticky mucus clogs the lungs. Besides causing breathing difficulties, the mucus can lead to life-threatening lung infections. Because 90 percent of CF mortalities are pulmonary-related, airway treatments are life-savers.

The mucus also forms in and obstructs the pancreas, preventing its enzymes from helping the body digest food. Without nutritional support and digestive enzymes, many CF kids quickly become emaciated. Monitoring height and weight is essential CF care.

"There's a huge correlation between nutrition and outcomes," said Karen Hardy, MD, the no-nonsense medical director of Children's Pulmonary Medicine division and Children's CF center. "If we get them over the fiftieth percentile of BMI (body-mass index), they have the best survival rate."

High-performance center

Elida has been coming to Children's CF center for care since she was 3.

"Children's is a big part of my life," Elida said. "It's like a big, whole family."

Children's CF team works hard to give Elida, and all their patients, the kind of care they'd give their own families. National Cystic Fibrosis Foundation statistics bear out their good—no, great—efforts.

In 2005 and 2006, Children's CF center's lung function test scores—a benchmark for good CF care—ranked the highest and second highest in the state, respectively, compared to other CF centers. Nationally, the program ranks in the top dozen CF programs. Nutritional scores at Children's CF center are also well above the national average, and rising.

Children's success is hard-earned. A coordinated effort by Children's team of pediatric specialists—including respiratory therapists, pulmonologists, nurses, dieticians, a social worker and research coordinator—is required for comprehensive CF care. But it's the patients and families themselves that must do the hard work of monitoring their food intake and performing their ACTs correctly every day of the year.

"That's where the rubber meets the road," is how Dr. Hardy puts it.

It's also the great challenge in CF care.

"How many people tell you to exercise and eat well?" Dr. Hardy asked. "We all have things we should do. CF kids have all those, plus CF requirements. If they falter, they can get sick, and it can be life-threatening."

Developing a better game plan

Dr. Hardy appreciates her team's nationally ranked test scores. But she's also



KORIE: (above) Pulmonary technician Cheryl Johnson, RRT, taught little Korie's dad, Korey, how to do his daughter's airway clearance treatments. Cheryl showed him how to hold the small blue palm cup and then watched as (right) Korey tapped Korie's chest with it.

Thump. Thump. Thump.

Korey turned Korie over and tapped her on the back.

Thump. Thump. Thump.

Korie accepted the procedure—which helps loosen the mucus that binds the lungs of CF patients—with little fuss. It's already part of the 5-month-old's life, and of her parents' daily routine.

Korie's CF was diagnosed at 2 weeks, thanks to California's newborn screening program, which launched in July 2007. Even today, CF can go undiagnosed, or misdiagnosed as asthma, for many years.



a tough coach, the kind that squeezes every ounce of potential out of her team. The quality of life of all her patients, including Elida's, is at stake.

So Dr. Hardy applied for, and her team was accepted in, a sort of cystic fibrosis care-team training meeting, sponsored by the national CF Foundation. It was called the 2007 Quality Assurance Learning and Leadership Collaborative V program (LLC5). The CF Foundation is a leader in quality-improvement initiatives, like the LLC program series, that bring better care to its patients.

During the year-long LLC5 intensive—filled with hands-on, active learning experiences—Dr. Hardy and three colleagues—D.J.; Manisha Newaskar, MD; and research coordinator Anamaria Robles—joined 15 CF clinic teams from around the country. The teams met in person twice, and participated in frequent conference calls and Web-based seminars. They also received twice-monthly coaching calls from renowned CF experts.

LLC5 training was system-focused: How can you create a more efficient, quantifiable, interdisciplinary game plan that delivers better CF care?

New system

With the LLC5 experience guiding them, Children's CF team developed a new game plan. Their goal—ball in the net, score!—was to get patients 100-percent compliant with their treatment plans. They called it their "global aim," or what they wanted all their patients to do, all the time, no matter where they were.

"That global aim is to have patients really understand their treatment plan, whether they are well or sick," Dr. Hardy described. "We want them to know exactly what to do, every day, and not just to

know, but to have the skill to do it, and then to actually do it. We need to somehow get them to actually do things."

They established four teams, with one LLC5-trained coach leading each group, to answer crucial CF questions: Do patients know what they need to do? Do they know why? Do they have the skills? Can they change the game plan when things get tough? Are they emotionally prepared for the CF game?

Knowledge team

"Do families understand the disease?" Dr. Hardy wondered. "Do they know why we're asking them to do things?" If families don't, she suggested, they might not manage CF consistently.

To find out what patients and families knew, the knowledge team created questions assessing nutrition, pulmonary and general CF knowledge. They now ask these as part of regular appointments. The scores are tracked in patients' medical records, and re-education is made part of the treatment plan, as needed.

Measuring skills

Knowledge is one thing, but do patients and families know how to perform their treatments? And if they do have the skills, are they using them every day?

"If I teach you how to do an airway clearance and you get 100 percent on demonstrating that skill to me, but you never do it, the efficacy is zero," Dr. Hardy explained. "You haven't done anything. Or maybe you are diligent: You do the skill every single day, but you are doing it incorrectly. You're still not going to get anywhere."

The skills team developed something new: an efficacy score that is the product of a skills demonstration and how many

times a patient actually performs the skills.

Thanks to the skills group, at Children's CF clinic, the question is no longer, "How many times did you do your airway clearance treatments this month?" It's, "How many times did you do them *correctly* this month? Oh, and by the way, *show* us how you did it so we know you know. And if you don't know, let's teach you again."

Triage

Intervening early when a CF kid is sick is essential.

"We don't want people to linger along and wait two months to see us," Dr. Hardy noted. "By then, their lungs might be damaged."

Thanks to the triage team's work, when a patient calls in sick, whoever answers the call uses a standardized questionnaire. Everyone asks the same questions. This results in an "exacerbation score" that determines appropriate treatments.

"If you score a certain number or higher, you have to come in for treatment," Dr. Hardy explained. "We systemized care so we can do a better job."

Mental health

Lastly, the mental health team brought something new—attention to emotional well-being—to CF care best practices.

"More and more research on chronic illness in children points to how depression affects families and the patient," Dr. Hardy acknowledged. "Depression in the parent means they won't do what you tell them to do. They may be unable to get the treatment done for the child. If the child is depressed, they won't want to do treatments."

The mental health task force—led by



BEATE ILLEK, PHD, AND HORST FISCHER, PHD
Children’s researchers make discovery
that may change the way cystic fibrosis
is treated

written + photographed
BY GARY TURCHIN

Everyone’s respiratory system secretes mucus. Normally this mucus layer is a freely moving defensive barrier protecting the lungs. But in children with cystic fibrosis (CF), the mucus stops moving: It thickens, hardens and makes breathing difficult.

Exterior lung cells have hair-like cilia that undulate rhythmically through a two-layer liquid environment. In healthy lungs, the cilia keep the mucus, and an underlying liquid layer it floats on, moving through the respiratory tract.

But to keep that liquid layer refreshed takes chloride ions (salty water) continually moving into the tract through the membranes of exterior lung cells. A particular protein regulates their movement. But CF kids make a malformed version of the protein; it won’t let salty water move from the cell to the liquid environment outside.

As a result, the watery layer outside lung cells dries up and the mucus thickens. That stops the cilia from keeping liquid and mucus moving. Besides making it difficult to breathe, the thick mucus also makes lungs more susceptible to infection.

But no one understood why CF kids get these infections until two scientists at Children’s Hospital’s research institute—Horst Fischer, PhD, and Beate Illek, PhD—took a hard look.

A normal immune system easily fights off the infection caused by pseudomonas bacteria. But in CF kids, the bacteria can be dangerous.

“What we wondered for the last 10 year is why these kids got bacterial infections,” asked Dr. Fischer. “Why can’t CF kids kill that bug?”

Wonder no more.

When Drs. Fischer and Illek studied the relationship between the defective protein (also called a chloride channel) and pseudomonas infections, they found something unexpected: Lungs have an innate defense mechanism no one knew about.

In healthy lungs, the previously undiscovered defense mechanism, since named DUOX, easily fights off pseudomonas. But in CF kids, DUOX doesn't work.

If the DUOX in the lungs of CF kids could be turned back on, it would fight those infections.

But what turns DUOX off?

Drs. Fischer and Illek already understood that the protein regulating salty water movement also regulates bicarbonate movement. Bicarbonate helps keep the respiratory tract's pH level, a measure of acidity or alkalinity, in the right range.

Because CF kids' lungs have trouble moving the salty water out of cells, Drs. Fischer and Illek reasoned they might also have trouble regulating the pH of the surrounding fluid.

They were right. They looked at CF kids' lungs and found they were too acidic for DUOX to work. "It can't produce its antibacterial function anymore. It's just sitting there, not doing anything," described Horst.

Drs. Fischer and Illek are now looking for ways to get the pH back to normal by neutralizing the acidic environment found in CF kids' lungs.

The team has just gotten some help with that research. They recently landed a four-year, \$1-million National Institutes of Health grant to look for ways to turn DUOX back on in CF kids.

If they find a way, it might do more than help CF kids; it might also be a way to help kids with asthma and other respiratory disorders. That could bring a sigh of relief to many afflicted patients, young and old.

social worker Cleo Rice-Hodges, MSW, LCSW—adapted some depression measurements to use in the CF clinic. Cleo has begun measuring depression in patients and parents as part of standard CF care at Children's. When appropriate, Cleo tries to get families the emotional support they need.

"Sometimes mothers burst out crying," Cleo reported. "No one ever asks about me," one mother said. "The focus is always on my child."

Outcomes

The CF team has been using the new procedures for a year now. The assessment tools are starting to yield data.

Children's patients scored 71 percent (a product of skill and performance) on their ACTs, reported Anamaria. The national average for ACT adherence (performance alone) is 40 percent. Children's is beating the average by a mile. But there's still a ways to go to reach 100 percent efficacy.

The triage questionnaire indicates about 70 percent of patients who call in sick are beginning sick-treatment plans within two days of starting to cough. This is a pretty good result, but the goal is one day, and 100-percent compliance. It's a target that wasn't clear before.

Children's CF clinicians plan to present three abstracts based on their new approach at the Cystic Fibrosis Foundation national convention in October 2008. The other 116 CF centers around the country will be watching. So might a few non-CF services at Children's. Quality of care issues are universal.

Elida's spirit remains strong

Shin splints took Elida off the soccer field this season. She's rehabbing at Children's Sports Medicine Center for Young Athletes. But her spirit isn't dampened.

"The way I see it, I have CF; CF doesn't have me," Elida said. "It's hard to explain, but (CF) is like a gift from God. He knows why He gave it to me; I'm very positive about it. I don't mind being different from other people. I'm me.

"For me, it's really great having CF, because having CF is like an adventure. If I didn't have CF, I never would have met all the great people I've met, or been to all the great places I've been. I never would have had all these experiences that really prepare me for the grown-up world.

"A lot of people tell me, 'Wow, you are so mature, so well educated and everything.' And I think it's because of all I've been through.

"When I go to school, I see all these kids and they don't really care about life. They just say 'Oh, whatever. I don't really care. I'm going to do whatever I want.'

"It's because they're blind; they don't see what's out there in the world.

"For a kid with CF, you don't know when you are going to go. You don't know how much time you have, so the time you do have—you just have to enjoy it, try to make the best of it."

To learn more about cystic fibrosis, visit the Cystic Fibrosis Foundation's Web site at www.cff.org.

Our amazing network of care grows

written BY GARY TURCHIN

photographed
BY DEBBIE DARE



MODESTO AND ITS STANISLAUS COUNTY NEIGHBORS CAN SEEM LIGHT-YEARS FROM OAKLAND. The geography is more expansive, and the economic engine more agricultural. But Modesto's families have the same needs as East Bay families: world-class medical care for their kids.

Starting in July, Children's Hospital Oakland is bringing its renowned pediatric expertise to Modesto when it opens its newest specialty care center at 4016 Dale Road.

Subspecialists from a number of Children's services will open clinics over the coming months. The site features a 1,000 square-foot sports rehabilitation facility where physical therapists at Children's Sports Medicine Center for Young Athletes can help rehabbing young athletes get back in the game quickly and safely.

Technologists from Diagnostic Imaging and the Clinical Laboratory will also be on site.

Modesto is Children's fifth specialty care center, part of its network of care that includes centers in Larkspur, Pleasanton, Brentwood and Walnut Creek.

NEW BUILDING: The new Children's Specialty Care Center in Modesto.



expansion : modesto



CHILDREN'S HOSPITAL
& RESEARCH CENTER OAKLAND

NETWORK of CARE

We're in your neighborhood!

OAKLAND LOCATIONS

Hospital

747 52nd St.
510-428-3000

Outpatient Center

744 52nd St.

5220 Claremont Ave.

Developmental and
Behavioral Pediatrics
Clinic Pharmacy
Encore Medical Clinic
Neonatal Follow-Up Clinic
Primary Care Clinic

5275 Claremont Ave.

Center for the Vulnerable
Child
Cytogenetic Lab
Eye Clinic
International Adoption
Clinic
Medical Genetics
Speech and Language
Center

**Nicholas C. Petris
Ambulatory Care Center**
5400 Telegraph Ave.
Adolescent Medicine/
Teen Clinic

Psychiatry

770 53rd St.

**Parent Infant Program
Early Childhood Mental
Health Program**
638 3rd St.

**Children's Hospital
Autism Intervention
(CHAI)**
645 4th St.

**Children's Hospital
Oakland Pediatric Unit
at Alta Bates Summit
Medical Center**
Providence Pavilion
Building, 5th Floor
3100 Summit St.

SPECIALTY CARE CENTERS

**Specialty Care Center
Brentwood**
1181 Central Blvd.,
Suite B
Brentwood, Calif.

**Specialty Care Center
Larkspur**
1100 Larkspur
Landing Circle,
Suite 150
Larkspur, Calif.

**Specialty Care Center
Modesto**
4016 Dale Rd.
Modesto, Calif.

**Specialty Care Center
Pleasanton**
5820 Stoneridge Mall
Rd., Suite 210
Pleasanton, Calif.

**Specialty Care Center
Walnut Creek #1**
106 La Casa Via,
Suite 220
Walnut Creek, Calif.

Walnut Creek #2
108 La Casa Via,
Suite 104
Walnut Creek, Calif.

*New expanded services in
early 2009*

**Specialty Care Center
Walnut Creek
Shadelands**
2401 Shadelands Dr.
Walnut Creek, Calif.

Larkspur
Specialty
Care Center



Summit
Unit

Walnut Creek
Specialty Care
Center

Pleasanton
Specialty Care Center

Brentwood
Specialty Care
Center



NEW!
Modesto
Specialty Care
Center

Children's cancer survivor now pre-med and doing cancer research

written BY LISABETH KIRK and TOM LEVY
photographed BY TOM LEVY



Sacramento pre-med student Christopher Cox has already logged more time in a hematology/oncology unit than most attending physicians. But he's not your typical pre-med student; he's a leukemia survivor, successfully treated as a child at Children's Hospital & Research Center Oakland.

Chris has beaten cancer once; now he's trying to beat it again, as a budding cancer researcher working with noted Children's physician/scientist Julie Saba, MD, PhD.

"When he was about 10 years old, Chris was diagnosed with leukemia, and he was treated here at Children's Hospital by our own James Feusner, MD," said Dr. Saba. She was Chris' mentor last summer, and she hopes to work with him again this summer. "It was Dr. Feusner who got Chris connected with the research program."

Before the Sacramento State University junior in pre-med became a 2007 Summer Research Program participant, Chris had survived cancer, gotten a BS in business, and, with some friends, had started a home remodeling company.

During college, Chris and a close friend worked in the flooring department at a Lowe's home improvement store. They decided they didn't want to be employees after graduating, so they started their own home remodeling business in the Sacramento area.

They were soon getting more work than they could handle. "We were working morning, noon and night," recalled Chris. They got more ambitious, got general contractor licenses, became Custom Cuts Home Remodeling, and began buying homes to fix up and flip.

But in less than a year, the housing market slowed. Chris and his partners found themselves selling the three homes

they'd fixed up for about what it had cost them in materials. They made nothing.

When winter came and work slowed down, Chris had an accident that broke his arm. Eight weeks of recuperation with his arm in a cast gave him time to think. "I'm not happy—this is not what I want," he recalled thinking.

His brother advised Chris to revisit Okizu, the Northern California cancer summer camp where he'd spent time during his bout with leukemia. There Chris discovered that working with the children at Okizu did something for him that remodeling houses didn't. "It was amazing," said Chris. "I rediscovered my connection with the families and the patients. As soon as you mention you're a survivor, the floodgates open."

He started thinking about a career in medicine. But Chris didn't think he could go back to school or be smart enough to hack it, even if he did. Talks with an engineer friend, who *had* returned to school to successfully study medicine, snapped another piece of the puzzle into place for him.

"It just clicked," said Chris. "If he can do it, I can do it. If you eat, sleep and breathe something, you can make it work." So in 2006, he enrolled at Sac State as a pre-med student. Chris did well, but realized he wanted research experience too.

"I had no clue what research was about," said Chris, "but I thought it would be a good idea to get research experience before going to med school, and if I was going to do research, I wanted to do it in the cancer field."

Through his former oncologist at Children's, Dr. Feusner, Chris was lucky enough to find a fitting mentor in Dr. Saba. For 10 years she's been doing pioneering research on how sphingolipids,

molecules associated with cell membranes, may play a role in suppressing cancer. She was happy to introduce Chris to the world of laboratory research.

But first, she told him, "you need to learn the Western Blot." Scientists studying molecular biology, biochemistry and immunogenetics use the blot to identify proteins.

Chris took her advice to heart. He convinced three Sac State professors to let him sit in on portions of their classes, and Chris learned what he needed to know.

"The Children's Hospital Oakland research program is amazing," said Chris. "It gives you a perspective on lab work that you can't get in a class." His Children's Hospital research mentor was also impressed—with him.

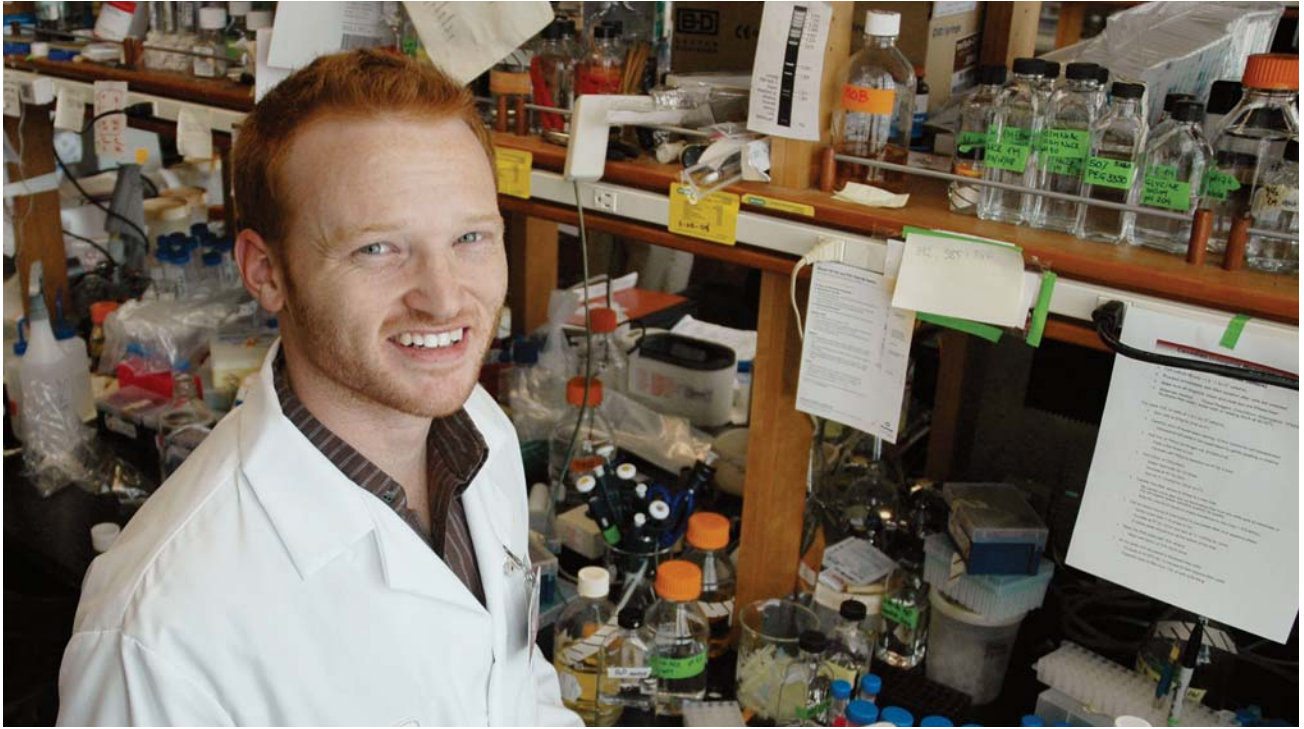
"It was very motivational to have someone who actually survived cancer come into the lab and share with our researchers the urgency and importance of what we do," said Dr. Saba. "We're all working at the signaling and cellular levels, and here we have someone who is walking around as the result of people's research efforts from years ago."

Chris inspired the researchers, and the researchers did the same for him.

"I had no idea there was a connection between clinical work and research work, and that there are oncologists who are often doing both at the same time," said Chris. Now he's found his passion. "Research is amazing: It opens up more new doors every time you find some new results."

In Chris' case, the results have been exciting. He and Dr. Saba have been working with a sphingolipid similar to one with cancer-fighting abilities that's found in the fruit fly.

Dr. Saba hopes to soon publish the results of the research, including projects



Cox worked on. Meanwhile, they're looking forward to Children's Hospital's 2008 Summer Research Program, when Chris resumes training with Dr. Saba.

Thanks to Dr. Feusner—and now Dr. Saba—Chris' Children's Hospital connections are helping him follow his heart. "The most exciting part of all of this is knowing that at some point, when I finally become a doctor, I'll have the opportunity to do research and further the field," said Chris. "I'll get to examine ideas that I get from treating patients and create better treatments as a result."

The Summer Research Program at Children's Hospital's research institute, now in its 18th year, pairs students with staff scientists. They help students design and do their own experiments. For more information, visit www.chori.org and look for "Summer Research Program" under the "Education & Training" link.

Financial aid for childhood cancer survivors

Chris has also landed some financial aid, from another organization inspired by young cancer survivors. Working Against Cancer, a national organization that helps young cancer survivors lead productive, fulfilled lives, has awarded Chris one of five highly competitive scholarships to help him achieve his academic and career goals.

"The essential idea behind the scholarship is to help cancer survivors do something to benefit others fighting cancer," said Chris.

For more information, visit www.workingagainstcancer.org.

Camp Okizu

Camp Okizu is a summer camp and peer support program for Northern Californian children with cancer and their families.

Since 1982, more than 3,000 children with cancer have spent summers at Okizu. Okizu (oak-eye-zoo) is a Sioux word meaning "unity, to come together, to heal from a hurt, to make whole." The camp program is free.

Summer campers are referred through a collaboration of area medical centers, including Children's Hospital & Research Center Oakland.

The first annual Okizu Cup golf tournament will be held Friday, Sept. 19, in Fairfield, Calif., to benefit the summer camp. The Paradise Valley Golf Course will host the tournament. For more information or to sign up, call Sarah Uldricks, event coordinator, at 415-382-1503, or send an email to sarah@okizu.org.

For more information about Okizu, visit www.okizu.org.

Scoping it out: Surgeons can now do more minimally invasive surgery

written + photographed
BY TOM LEVY

Putting advanced surgical equipment into the hands of surgeons at Children's Hospital & Research Center Oakland is a top priority. That's why Children's recently signed a \$1-million contract with endoscopic specialist Karl Storz, a leading manufacturer of precision surgical instruments.

"I'm pretty excited about the changes going on in the operating room," said Frederick Rosen, MD, an otolaryngology specialist at Children's Hospital since 2006. "The biggest positive is going to be that we'll have more access to more endoscopy units."

Dr. Rosen, whose interests include airway and sinus surgery, referred to imaging units and equipment useful to ear, nose and throat specialists like himself. The same equipment is also widely used to perform minimally invasive surgery, including arthroscopy procedures by orthopedics subspecialists.

"(The new contract) will enable more surgeons to work endoscopically simultaneously," said Dr. Rosen. "That's just what we need because so much of what surgeons are doing now is minimally invasive surgery." Minimally invasive surgery is performed through a very small incision; the surgeon uses a scope for viewing and for performing some surgical procedures.

Ann Altaffer, MSN/OB, RN, CNAA, BC, Surgical Services' director, shares surgeons' enthusiasm. "The conversion to Storz is a huge, wonderful opportunity to move our minimally invasive surgery equipment from analog to digital



LIVE SURGERY: Frederick Rosen, MD, an otolaryngological specialist, performed a functional endoscopic sinus surgery with the new high-definition endoscopic viewing system. (left) Dr. Rosen handles the scope, while operating room technologist, Chiaka Obi, ORT, flushes a patient's sinus with saline solution.

technology," said Ann.

But Storz is only part of Surgical Services' \$3.2-million 2008 investment. The rest will pay for replacing anesthesia machines, cardiac monitors and future construction costs.

Fourteen state-of-the-art, pediatric-specific anesthesia machines are now in place. And Anesthesiology division chief

Maurine Heard, MD, is pleased. "It improves our care," said Dr. Heard. "We also have computers in every operating room for order entry, which also improves outcomes. We sort of heralded that; most children's hospitals didn't have them when we started putting them in years ago."

Dr. Kammen was chosen to be highlighted in the “People in Science” career section in the Grade 2 edition of a Houghton Mifflin science textbook in 2005.

“Here at Children’s Hospital, the focus is on the child.
The subspecialists that I work with here are exceptional.
This is where I would bring my child.
I wouldn’t think twice about it.”



Seeing inside to puzzle out a diagnosis

BAMIDELE KAMMEN, MD, WAS 5 WHEN SHE AND HER PHYSICIAN PARENTS MOVED FROM NIGERIA TO NEW YORK STATE, where she grew up in White Plains. With two doctors in her life, it's no wonder she pursued medicine herself. In 2000, she came to Children's Hospital & Research Center Oakland, where she specializes in diagnostic imaging.

Dr. Kammen was always attracted to the sciences; after she graduated from high school she attended Harvard University, where she received her SB degree in Engineering Sciences. She decided on a medical career and attended Harvard Medical School. During that time she also conducted an additional two years of research, in electrophysiology, as a Howard Hughes Medical Research Fellow.

Solving puzzles, which had originally drawn her to engineering, eventually drew her to pediatric diagnostic imaging, which she finds challenging and fun. Dr. Kammen did her internship at Robert Wood Johnson University Hospital in New Brunswick, NJ, and a radiology residency at the Hospital of the University of Pennsylvania.

She also found time for a special trip back to Nigeria, to be married in Ifaki, her grandmother's hometown. In addition to a celebration and a time for her American husband to get acquainted with Nigerian relatives, it was a chance to use her near fluency in Yoruba, one of the country's major languages.

Back in the States, Dr. Kammen headed west for her fellowship when her husband, Dan, accepted a professorship in the Energy and Resources Group at the University of California, Berkeley.

Dr. Kammen did a fellowship in Pediatric Radiology at the University of California, San

Francisco, and then joined Children's Hospital Oakland.

Pediatrics appealed to Dr. Kammen all along. For her, that appeal has found its highest expression at Children's Hospital. "Here at Children's Hospital, the focus is on the child," said Dr. Kammen. "The subspecialists that I work with here are exceptional. This is where I would bring my child. I wouldn't think twice about it."

She enjoys working with the latest equipment and the emphasis that her group takes to modify imaging protocols for children. "Fluoroscopy at Children's is state-of-the-art, a pulsed fluoro machine," said Dr. Kammen. "That allows us to minimize the patient's exposure to radiation. We also have a state-of-the-art 16-detector CT scanner, and we obtain excellent images using the smallest doses possible."

Dr. Kammen enjoys spending free time with her husband and two daughters. Not long ago, she took her 10-year-old to Nigeria to meet family and experience the culture.

She also loves to get up early in the morning to run, swim or bike, and she recently participated in her first triathlon.


Imaging services will be available at the new Children's Specialty Care Center Modesto.



He's no victim

Injured by a gunshot, Chris Rodriguez, 10, adjusted to life in a wheelchair during a 61-day stay at Children's Hospital Oakland.

written + photographed
BY TOM LEVY



Feature : comprehensive care

Feature : comprehensive care

ON JAN. 10, A BULLET FIRED BY A GAS STATION ROBBER CROSSED PLEASANT VALLEY AVE. IN OAKLAND, tore through the wall of the Harmony Road Music School and hit Christopher Tajai Rodriguez in his left side. He was playing the piano during a music lesson.

The bullet didn't kill the 10-year-old, but it damaged his spleen and kidney. It also narrowly missed fatally severing his aorta. Then it cut his spinal cord, paralyzing him below the waist.

The bullet changed Chris' life, but it did not make him a victim.

Chris and his family say they have no hatred for the gunman. "We're not here to hate," said his father, Richard Rodriguez. "We just want to heal and move on."

Instead, they're focusing on his "new normal." For Chris, that includes video games, school, playing piano and drums, a pet Bearded Dragon lizard named Curious, a sleepover with friends and a recent trip to the movies with other friends to see *Drillbit Taylor*.

To get there, Chris spent 61 days healing at Children's Hospital & Research Center Oakland.

Every day, Chris was helped by teams from across Children's Hospital—the Emergency Department, Surgery, the Pediatric Intensive Care Unit, the inpatient Rehabilitation Medicine unit, Psychiatry, Clinical Social Services, and physical and occupational therapists in Children's Rehabilitation Medicine unit.

Minutes after the shooting, Chris was rushed to Children's Emergency Room, the busiest all-pediatric emergency department in Northern California. After he was stabilized and assessed, he was wheeled upstairs for emergency surgery. Veteran surgeon James Betts, MD, helped two colleagues—Olajire Idowu, MD, and Thomas Hui, MD—repair the damage, including removing Chris' appendix.

"He's a remarkable kid," said Dr. Betts. "He's older than his years."

After surgery, Chris spent a week in the Pediatric Intensive Care Unit. He and his parents had to come to grips with his damaged body. Fortunately, they had help from Children's pediatric professionals. "From the ICU to Rehab, the nurses, the whole medical and hospital staff, are friendly and really like children," said Jennifer Rodriguez, his mother.

Chris and his family also had support from their community at Crocker Highland Elementary School. Parents and students sold cupcakes, cookies and Rice Krispies treats, and received donations from all over the Bay Area. They raised \$30,000.

"I don't think we would have made it without (the Crocker community)," said Richard.

Others organized benefit concerts, including one at the Harmony Road Music School, one by the Oakland Youth Chorus and another at jazz icon Yoshi's.

Putting on the benefits took teamwork; so did the care Chris received at Children's Hospital. "(Caring for Chris) involved a whole lot of care from different points of the hospital," said Jacob A. Neufeld, MD, MPH, Rehabilitation Medicine division director. "There's a whole team that gets together to care for him. And everybody has to work together."

When Chris' wounds healed sufficiently, he left intensive care for Children's fourth floor and a bed in Northern California's largest pediatric inpatient rehabilitation unit. Here Chris began the work

of strengthening his new-normal body. Chris worked with physical and occupational therapy clinicians to develop his inpatient care plan.

Then nurses like Guy Miller, RN, helped Chris stay on his plan. The ex-Army corpsman takes a no-nonsense approach with his patients. He knows there's only so much time to help a recovering kid get better before their progress stabilizes.

"I know what I'm doing is the best thing for the kid," said Guy. "If he can work hard, it's the best thing for him. If he has a day he doesn't want to work hard, that could be another day he's stuck in the hospital. Because as soon as you get him in and start therapy and work with him, you only have a certain timeline before you hit that plateau."

Guy saw Chris react to his leg pain. It may be called "phantom pain," because the spinal cord has been cut, but damaged and irritated nerves can continue sending pain messages to the brain for months.

Guy's approach worked. Chris responded and worked hard on his rehabilitation exercises with Children's physical therapists. Over time, Chris and Guy bonded.

Fishing helped bring them together. When Guy offered to teach another patient how to cast, Chris asked to join them outside for the demo. Before leaving Children's, Chris even asked Guy to take him fishing.

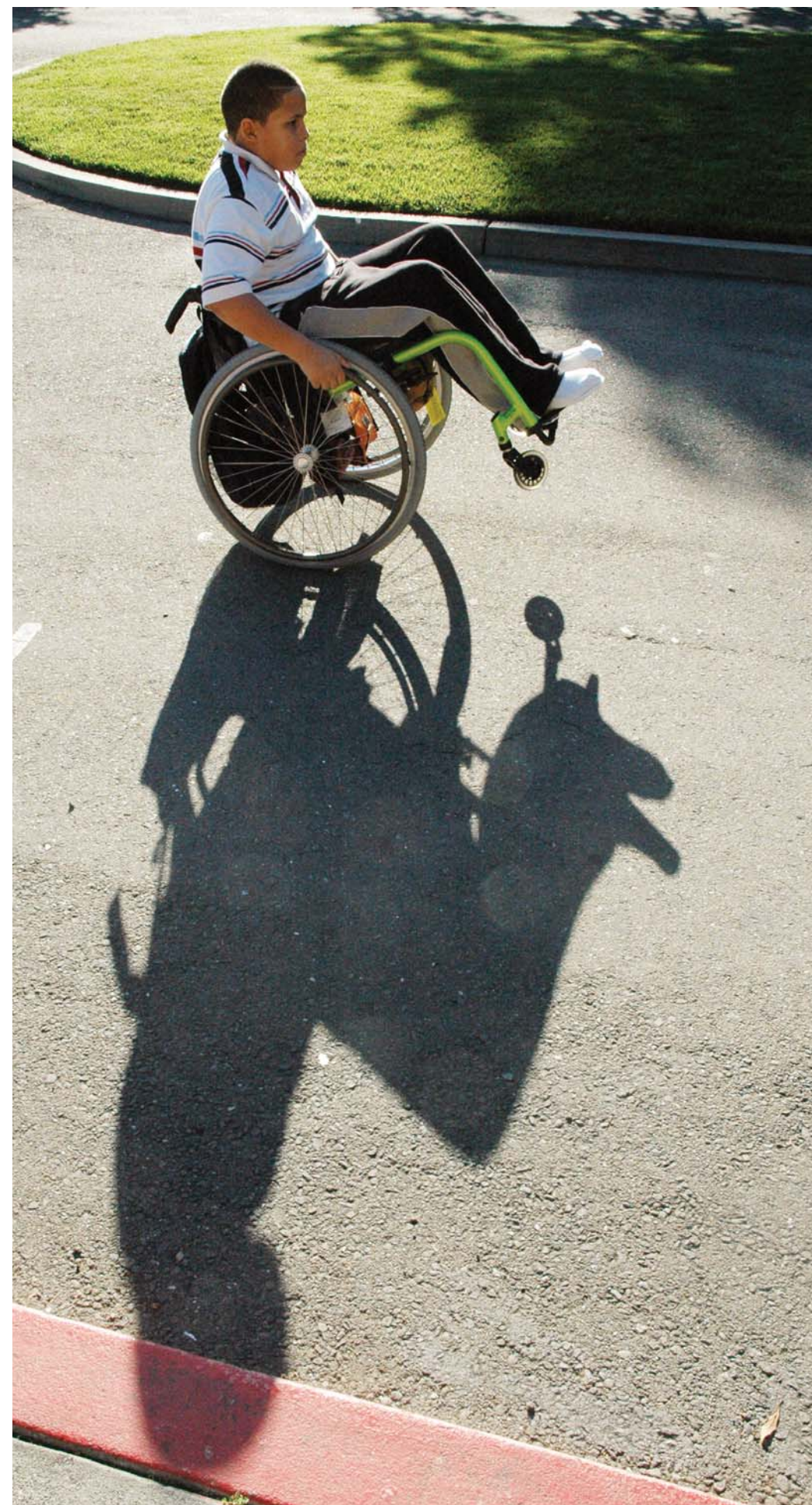
Chris also got more traditional psychological help from a Children's psychotherapist. He helped Chris come to terms with



THE FIRST DAYS: Richard Rodriguez comforted his son, Chris, during the week Chris spent in the Pediatric Intensive Care Unit at Children's. Here Chris healed from his wounds and the emergency surgery that repaired them.

THE REHAB DAYS: (below left) Chris did push-ups on a blue Bosu Ball, aiding core strengthening of his abdominal and upper body muscles. Guiding his efforts were senior physical therapist Shawn Norris, PT, at left, and occupational therapist Renee Graham, OT. (below right) Chris practiced getting from street to sidewalk with coaching from Shawn.





his feelings and the new life he faced as a wheelchair user. Clinical social services professionals also offered help to the family.

As he quickly got stronger, Chris graduated to his own wheelchair, equipped with sparkle wheels, and worked hard with Children's physical and occupational therapists. While continuing to live on the fourth floor, Chris began spending more time on the second-floor rehabilitation unit.

Here he worked intensively, learning how to get in and out of his wheelchair, from the floor and from other furniture. Strengthening his upper body was a top priority; so was helping his parents come to grips with his new needs. "We want to treat Taj (Chris), but part of treating Taj is teaching his parents," said senior physical therapist Shawn Norris, PT. "In the end, they did everything they had to do."

Feature : comprehensive care

WHEELING HOME: (left to right): Chris popped a wheelie, showing his wheelchair prowess, during an outdoor practice session with a physical therapist at Children's Hospital Oakland. Back at home, Chris raised his arms in victory after beating his mom in Wii bowling. Posing in front of Chris' piano, Chris and his parents enjoy their new, wheelchair-accessible home in Oakland.



Before he was injured, Chris played center on his elementary school's YMCA basketball team and was learning to skateboard. Those athletic skills may have helped him ease more quickly into the wheelchair world.

"His wheelchair skills when he left here exceeded many other kids'," said Shawn. "He just didn't seem to have a fear about it and wanted to challenge himself. Oftentimes those more advanced skills are the ones you learn out in the community or from peers (in wheelchairs)."

The family is grateful to Children's Hospital for helping them on their way. "The whole medical and hospital staff were friendly, and everyone was very sensitive and caring," said Richard. "They have the ingredients you need: the people, their attitude, their love of their jobs, their love of children. They carry

that love of kids throughout their work."

Chris and his family continue healing in their new home, a wheelchair-accessible house in a quiet Oakland Hills neighborhood.

It's spacious: One front room holds a piano and Chris' electronic drum kit. In a family room, Chris is learning to master a Wii video game system played on a large-screen television. During an April visit, he easily beat his mother and a visitor at video bowling and baseball.

Challenges lie ahead for Chris, but those who got to know him at Children's Hospital are optimistic. "I think Taj went home excited to be there, not here anymore, and open to the challenge," said Shawn.

Dr. Neufeld is positive too. "I expect that he'll finish high school, I expect him to go to college. I expect him to work," he said. "I expect him to be able to learn

to take care of himself. He can travel the world if he wants to and even play wheelchair basketball and other sports."

Chris will forever carry, in muscle tissue near his spinal cord, the .40-caliber bullet that took away his ability to walk. But that angry nodule didn't take away his spirit—his ability to adapt, to grow, to explore, and to live. Christopher Tajai Rodriguez is no victim.

For information about how to help the Rodriguez family, visit their Web site at <http://christopherrodriguez.blogspot.com>. To learn more about Rehabilitation Medicine at Children's, visit the department's Web pages at www.childrenshospitaloakland.org.

donate online at www.chofoundation.org

From Raggedy Ann to Devil Mountain Run

THEY RAISED FUNDS FOR CHILDREN'S AND CREATED ONE OF THE BAY AREA'S MOST SUCCESSFUL RUNNING RACES

written + photographed
BY AUDREY CHIANG

"Every year we made Raggedy Ann dolls for the holiday bazaar," said Nancy Lewis, co-founder of Children's Hospital Oakland's Devil Mountain Run. "Then we thought, 'Why not try something new?'"

Nancy became involved with Children's Hospital as a grateful parent and joined the Branches, a longtime Children's auxiliary, in the late 1960s.

"We all raised our kids doing Rowan Branch projects," Nancy recalled. "The fundraisers were great, but we were asking the same people to the same functions again and again. How could we get the word out about Children's Hospital to new people? It was 1978 when the idea for a run hit me."

An idea ahead of its time

Back then, road racing was not as big as it is today. The fitness craze had not yet hit. Nationally, marathons were just taking off, and the Bay to Breakers in San Francisco was just starting to get big.

Fellow Rowan Branch member Jacquie Graham was attracted to the idea of a race in Danville as a fundraiser for Children's Hospital. Nancy described their partnership: "I was the enthusiastic runner, and Jacquie was the excellent fundraiser. We



RUNNERS: Devil Mountain Run founders Jacquie Graham, Nancy Lewis and Mary Ann Snodgrass are pictured on the cover of a special insert to the May 2, 1979, edition of *The Valley Pioneer*. (right) Nancy Lewis and her longtime friend and fellow Rowan Branch member, Cheryl Morris, look over photo albums of the first few races.

went in with two different approaches, and together it was like magic."

Organizing a road race is no small task. The first challenge was to get buy-in from the city of Danville and its local businesses. Nancy found herself serving as a public spokesperson for Children's Hospital, raising awareness in this San Ramon Valley city about how a hospital in downtown Oakland serves children throughout the Bay Area and beyond.

"We started with one real estate guy, he made a phone call to the next developer, and so on and so on," explained Nancy. "Soon, we had the bankroll to launch the event. Next, we had to get runners out to Danville."

Nancy's running partner at the time, KNBR radio personality Mike Cleary, was also key to the run's successful launch. He agreed to emcee the event, wrote articles for the local papers, posed in publicity photos, and got the attention of local sports journalists.

In its first year, the Devil Mountain Run attracted 2,000 runners. It also helped the Rowan Branch achieve its goals: raise awareness of Children's Hospital in the local community, secure significant support from individuals and businesses, and reach a broader range and larger number of people than any cocktail party ever could.

At its peak, the run attracted nearly

10,000 runners from around the Bay Area and from as far away as Massachusetts.

Dave Rhody, a longtime runner and race organizer, remembers the race's high-profile reputation. "I signed up for the Devil Mountain Run in 1982; I was an elite runner at that time. There was no question it was a cut above efforts by other volunteer groups." Dave later started his own company producing races, and, at the invitation of the Branches, has managed the run since 1997.

An annual tradition

Now in its 31st year, the Devil Mountain Run is the oldest running event in the East Bay and has raised more than \$2 million for Children's Hospital.

This year's run, with software company Workday as its title sponsor, followed the tradition set by the Rowan Branch three decades ago. The run was on Sunday, May 4, and the course was flat and fast and ran through downtown Danville. Runners, walkers, adults, children of all ages, and adults pushing children in strollers all enjoyed the family-focused event. Before the race, warm-up exercises were led by Children's Sports Medicine department staffers.

The run's next generation of racers participated in the Kid's Fun Run, sponsored by Links for Life Foundation, before they headed over to the bouncy house and face-painting booth. The post-race party also included free refreshments, lots of giveaways and live music.

"I loved working on the Devil Mountain Run," Nancy said. "It's the best job I've ever had."

And what a tremendous job—building the Devil Mountain Run into a hugely successful running and fundraising event which has helped support Children's Hospital for more than 30 years.

And it's still running strong.



The Volunteer A-Team

LOCAL KOHL'S DEPARTMENT STORE ASSOCIATES FIND VOLUNTEERING REWARDING AND A GREAT TEAM-BUILDING EXPERIENCE

written + photographed BY LYNN SAGRAMOSO

When something needs to be done, you send your best. That's the motto of the Kohl's Cares for Kids volunteer program, which focuses on supporting local programs that make a positive impact on the youngest members of our community.

"Children's Hospital is one of the key beneficiaries of the Kohl's Cares for Kids program," explained Wendy Robertson, Kohl's Department Store District 63 captain and Brentwood store manager. "The hospital's mission benefits children's health, and we love supporting that important work."

Kohl's has generously supported Children's Hospital's injury prevention program through direct donations from the profits of in-store sales of special plush toys and children's books. "Our A-Team volunteer program is an additional way for our associates to connect to Children's personally," said Wendy. "It is very rewarding and a fantastic way to do an off-site team building event."

A team of 20 Kohl's associates volunteered to help staff the phone bank for the Children's Hospital

Radiothon for Kids fundraising event this past April.

"We've volunteered at this event for three years now, and it is very moving to hear the patient stories and know that we help make Children's special," shared Wendy. "I'm a two-time survivor of cancer, so I can really relate to what these families go through and how important hope is for the future."

Kohl's also sent employees from each of the district's stores to volunteer at the 2008 Workday Devil Mountain Run, another fundraising event which benefits Children's. In addition to these important volunteer hours, Kohl's also directly donates \$500 for every five associates volunteering three hours to Children's—over and above their corporate support.

"We are proud to help," Wendy said enthusiastically. "I can think of nothing better for employee team building than doing something together to enrich our community. It is really satisfying—and fun—to get involved."

written

BY LYNN SAGRAMOSO

FAMILY: Event organizers work year-round to ensure the success of Chase the Blues, a Piedmont fundraiser for Children's. (left to right) Jan Kessler, event chair; Brynne Staley, honorary co-chair; and Kate Montgomery, honorary co-chair. Photo by Tim Kaihatsu.



When Children's Hospital is part of the family

HOW ONE FAMILY SUPPORTS EXCELLENT PEDIATRIC CARE

"I grew up with Children's Hospital," said Jan Kessler. "It has always been a big part of my life, and I don't want that to change."

Jan's father, Seymour J. "Sy" Harris, MD, was a highly respected and dedicated pediatrician at Children's. "My father served a leadership role at the hospital, and he was very proud of the important work being done there," Jan said. "When I was 16, I volunteered as a candy-striper, playing games with patients, or reading to them. My sisters and I all firmly believe in the mission of the hospital."

When Jan became a parent, she learned firsthand how crucial Children's mission is. "When our infant daughter faced surgery and hospitalization, we really understood how important it is to have the expert, compassionate care Children's provides—not only inside the hospital, but also the extensive services that go out to the community," Jan said.

When Dr. Harris passed away, his family set up an endowed teaching professorship to continue the tradition of compassionate care that he exemplified

throughout his career. "We wanted to make a lasting contribution to the hospital in my father's honor," Jan explained. "Compassion isn't part of the usual medical school curriculum, but it is so important when working with children and their concerned parents."

Not only have Jan and her husband Randy given generously, they have been active in raising awareness and money to support Children's. "I am always on my soapbox, telling people how lucky we are to have this hospital, and how much it needs and deserves our support," Jan

admitted. The couple recently hosted a house party for fellow Children's Circle of Care donors, which is a national program recognizing philanthropic leaders who give at least \$10,000 annually to pediatric care.

For the past two years, Jan has also served as chair of the Chase the Blues committee, a volunteer group that organizes a very successful annual dance party and live music fundraising event in support of Children's. "Chase the Blues is such a fun, celebratory event," Jan said. "This year we will be raising money for Children's Neurology department. It is so rewarding to know that our efforts will directly enhance a child's life and health."

You and your family can support Children's too. To find out how, visit us at www.chofoundation.org.



ALL IN THE FAMILY: Randy, Drew, Jan and Gina Kessler gathered for a snapshot. Photo courtesy of the Kessler Family.

Wise philanthropy: the charitable gift annuity option

HOW IT WORKS

What is a charitable gift annuity, and how will it help me give wisely?

A charitable gift annuity allows you to make a substantial gift to Children's Hospital and receive guaranteed fixed annual payments (they can never go down) for the rest of your life. See the chart below for age-based rates.

In addition to secure payments, the benefits of a charitable gift annuity include:

- A significant charitable income-tax deduction
- Partially tax-free payments
- Flexibility to fund your annuity with cash, mutual funds, stocks or real estate
- Payments may be made to couples, with payments continuing at the same level to the survivor
- Assurance that your annuity payments are backed by the assets of Children's Hospital & Research Center Foundation
- Satisfaction of assisting generations of children to come, with no probate fees or estate taxes.

If you would like to explore whether a tax-advantaged, charitable gift annuity is right for you, contact Ron Streitz at 510-428-3814, or visit our Web site, www.chofoundation.org/plannedgiving. Let us help you explore your options, free of charge or obligation. See how a charitable gift annuity can provide benefits to you and your chosen philanthropy.

Charitable gift annuity sample rates

Single Person		Married Couple	
Age	Rate	Age	Rate
70	6.1%	70/70	5.6%
75	6.7%	75/75	6.0%
80	7.6%	80/80	6.6%
85	8.9%	85/85	7.4%

Rates effective July 1, 2008.

THOMAS J. KROETCH

Thomas J. Kroetch and Children's Hospital & Research Center Oakland go back a long way. In the 1970s, as a member of the Children's Hospital Foundation Board of Trustees, Tom helped raise funds for what was then the hospital's "new" wing.

Tom's support of excellence in pediatric care at Children's Hospital will continue on into the future, thanks to several charitable gift annuities he's established. They benefit the hospital, make him a member of Children's Circle of Care and provide Tom with lifetime annual income payments.

"Throughout the years, I've been very impressed with the level of dedication, skill and selflessness found at Children's," said Tom. "The loving, compassionate treatment and the high degree of technical skill of the doctors and nurses are amazing!"

Thank you, Tom, for helping make sure Children's Hospital will always be there for every Northern California child needing the specialized care only be found in a hospital that's just for kids.





CHILDREN'S HOSPITAL
& RESEARCH CENTER OAKLAND

NETWORK of CARE

We're in your neighborhood!

Larkspur
Specialty
Care Center



CHILDREN'S HOSPITAL
& RESEARCH CENTER OAKLAND

Summit
Unit

Walnut Creek
Specialty Care
Center

Brentwood
Specialty Care
Center

Pleasanton
Specialty Care Center

Main campus in Oakland

747 52nd St., 510-428-3000

Plus 7 other Oakland locations!

CHILDREN'S SPECIALTY CARE CENTERS

Brentwood

1181 Central Blvd., Suite B, 888-530-3034

Larkspur

1100 Larkspur Landing Circle, 866-854-0550

Modesto

4016 Dale Road, 209-543-3200

Pleasanton

5820 Stoneridge Mall Rd., 925-463-8970

Walnut Creek

106 La Casa Via, Suite 220, 925-939-8687

108 La Casa Via, Suite 104, 925-952-3849

www.childrenshospitaloakland.org

NEW!

Modesto
Specialty Care
Center

Children's Hospital & Research Center Oakland
747 52nd Street
Oakland, CA 94609-1809

Non-Profit Org.
U.S. Postage
PAID
Oakland, CA
Permit No. 3



CHILDREN'S HOSPITAL
& RESEARCH CENTER OAKLAND

www.childrenshospitaloakland.org