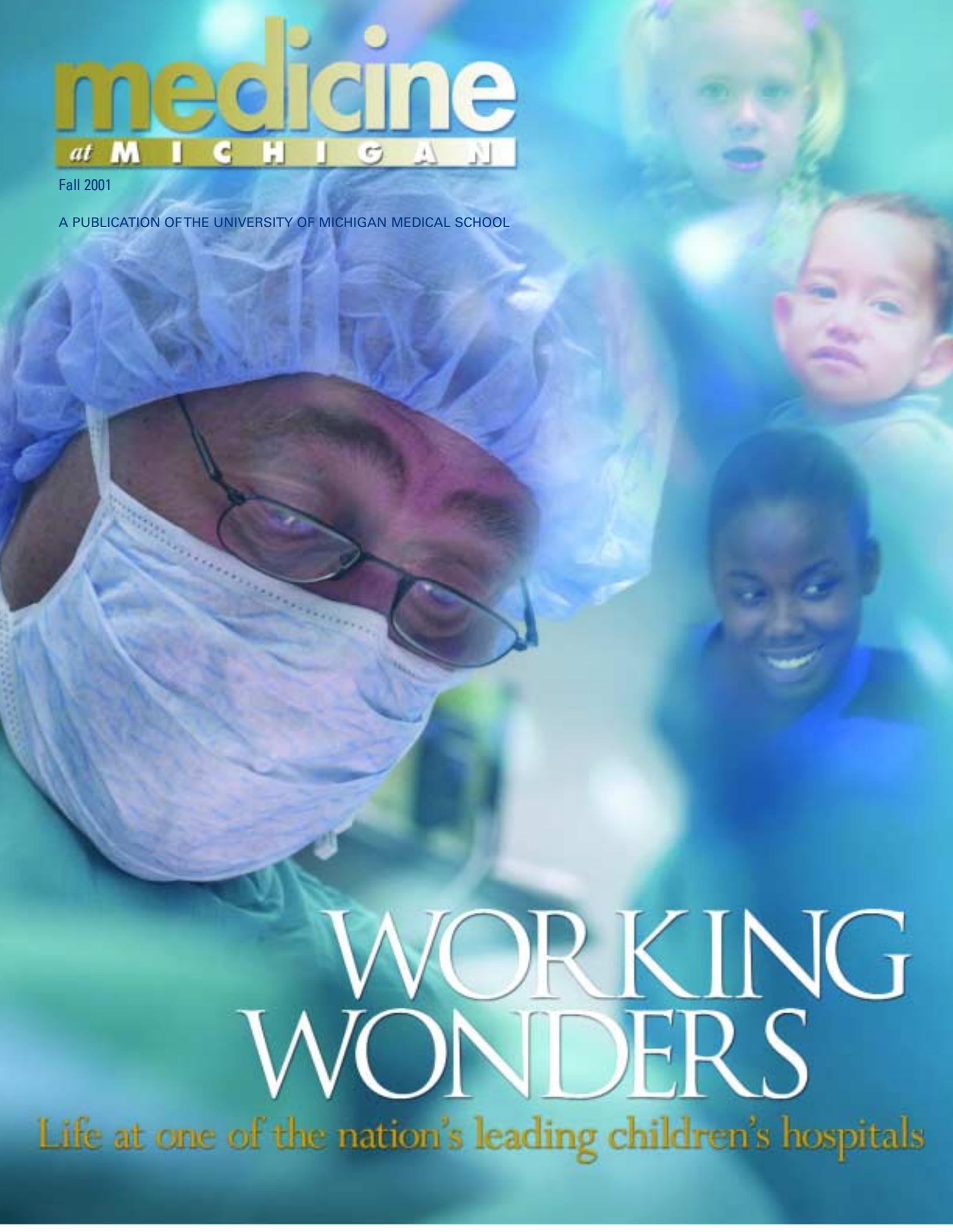


medicine

at M I C H I G A N

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WORKING WONDERS

Life at one of the nation's leading children's hospitals



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Photo: Harriette Hartigan



by Whitley Hill with Bill Clayton

miracles at Mott

From hallway hockey to stunning surgeries,
exceptional science and compassionate care add up to
some of the best children's medicine in the country. >



Visit the University of Michigan C.S. Mott Children's Hospital and you may be surprised to come face to face near the entrance with Georges Seurat's *A Sunday on La Grande Jatte*: a sunlit park, a river, children playing.

Oh, it's not the original; that's hanging in the Art Institute of Chicago. But in many ways, this wall-sized reproduction is far more valuable than the real thing. That's because it was painted by 125 young U-M Mott patients, their siblings and parents, on a pre-shrunk hospital bed sheet that was folded into sections and passed from bed to bed. The painters ranged from a 32-month-old leukemia patient to a young woman awaiting a heart transplant.

Look closely. Thousands of tiny dots cover the surface with brilliant reds, blues, yellows and greens. Thousands of moments when a child was thinking about color, form and accomplishment instead of pain and procedures, when a parent or sibling was thinking about trips to the park instead of trips to the doctor.

Step back and look again. The painting is the perfect image to greet people as they come through the doors of this hospital. Like Mott itself, it's the result of hundreds of people working together to make something beautiful, powerful and positive.

In 1901, Love Palmer, widow of Alonzo B. Palmer, gave the University \$20,000 to build a children's ward on Catherine Street, one of the first in the nation. The 75-bed Palmer Ward was completed in 1903 but for years had to share space with other patients. Then, in 1921, departing Medical School Dean Victor Vaughan established pediatrics as an independent department, strengthening the focus on children. Children's health-care at U-M took a giant step in 1964 when Flint industrialist and philanthropist Charles Stewart Mott gave the University \$6.5 million for the construction of a separate children's hospital on the medical campus. In 1969, U-M Mott Children's Hospital opened its doors.

One wonders if Palmer, Vaughan and Mott could have imagined their efforts would one day become a place where hearts are transplanted, cancers cured, organs rebuilt, and where kids play "hallway hockey" outside rooms filled with art projects. Could they have imagined a hospital so advanced and so special that it draws families from all over the world to a small midwestern city? Could they have imagined a bed-sheet Seurat?

Perhaps they could have. Since the beginning, pediatric care at Michigan has included a special focus on the well-being of the entire child. Seeing children as deeply feeling and creative individuals, whole in their own right and not just small adults with symptoms, has defined care at U-M. It's that kind of forward-thinking — the



Tyler White with Child Life specialist Lisa Engbrecht

blending of compassionate care and hard science—that has made the practice of children's medicine at Michigan as important and successful as it is today.

When, earlier this year, *Child* magazine produced a ranking of the best children's hospitals in America, the University of Michigan C.S. Mott Children's Hospital appeared ninth among 178 children's hospitals. Mott chief administrator Patricia Warner, who's headed the hospital for seven years, was thrilled with the news.

Gilbert Omenn, M.D., Ph.D., U-M executive vice president for medical affairs and chief executive officer of the Health System, was also pleased with the recognition, noting the wide-ranging teamwork that had made the award possible. "This ranking belongs to the faculty, staff and volunteers whose work has made Mott a top-notch hospital for children from Michigan and around the country," he said at the time. Medical School Dean Allen S. Lichter, M.D., pointed out that U-M Mott "is one of only two comprehensive children's hospitals in the state and, as such, has the special responsibility to be available to care for complex problems that children all over Michigan encounter. We do the job very well, and we're pleased that others recognize us for that expertise."

But Tyler White isn't thinking about rankings. The six-year-old Belleville boy is playing Go Fish with his buddy Rachel Standifer (a Child Life specialist) in the U-M Comprehensive Cancer Center, his I.V. standing next to him. He shyly lifts his shirt to show a visitor his Broviac, the tube through which he is receiving a blood transfusion for his leukemia, which was diagnosed just after Christmas of last year.

The Cancer Center's Pediatric Infusion Area is a cheerful place with a high, vaulted ceiling and curved windows. Sunlight pours down upon play stations covered with games and toys. While Mott is a separate hospital, the boundaries blur: Mott's pediatric oncology services are part of the Cancer Center — it's all about taking care of sick children. Many of the kids who come to the U-M Cancer Center for outpatient chemotherapy and transfusions have spent time at Mott recently. Some will again.

Seeing children as deeply feeling and creative individuals, whole in their own right and not just small adults with symptoms, has defined care at Mott.

Tyler leaves his game and goes over to see a friend who has just arrived. The boys stare at each other shyly. Nikki, a cool preteen with flashy light blue fingernails and a killer smile, pulls her I.V. pole into a cozy alcove and sits down at a computer. She's exploring StarBright, a computer network created by film director Steven Spielberg for kids in hospitals. Once she's registered online, she can cruise hundreds of approved Web sites and chat with kids from across the country — or even on the next floor at Mott. A tiny camera even allows for video conferencing. "I'll be here at least four more hours," she says, rolling her eyes, then turns back to the monitor.

Around the center of the room are satellite stations where people of all ages are receiving transfusions or chemotherapy. Some knit, read, chat or watch TV.

For nearly 80 years, the U-M Mott Child and Family Life Department has devoted its resources to easing and normalizing the hospital experience for children through the use of activity rooms, bedside play, schooling for young patients, art and music exploration, emotional support, visits by friendly dogs and much more. In fact, Mott's exemplary Child Life program — the first in the country when it began in 1922 — was one of the prime reasons for the Hospital's sterling *Child* magazine rating.

Lisa Engbrecht is a Child Life specialist stationed in the Cancer Center. With her curly red hair, gentle voice and ready smile, she could put anyone at ease. That's her job. She gestures around the room. "You don't see children with illnesses; you see children who are doing children's activities and just happen to be getting treatment at the same time. Often, when it's time to go, kids don't want to leave."

Tyler's mom Heather stops doing an Internet search for sports equipment to talk about what the Child Life program has meant to her family during a difficult time.



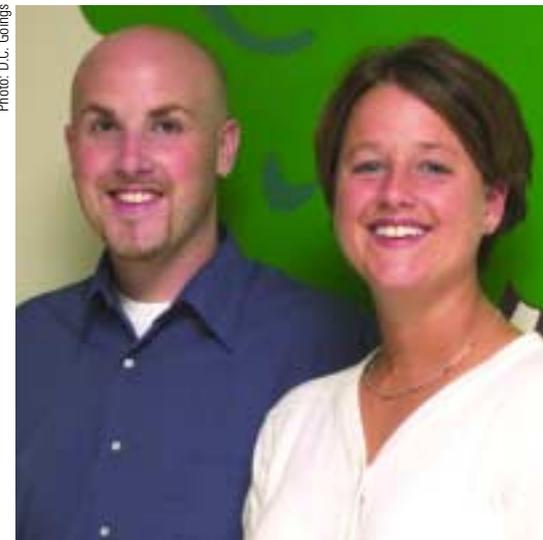
Artist Adrienne Rudolph

"There've been times when he hasn't been able to go anyplace but here," she says. "His immune system was so weak, even a common cold would be dangerous. So every Friday he would come here for treatment, play with friends, whatever he wanted to do. When Lisa was gone (for a pregnancy-related medical leave) he was worried that she got what he had. He was real glad when she came back. I mean, when they said 'playroom,' I never expected this — people who actually sit down and play with him! He likes consistency; that's the way we raised him. He likes to come here and have the same few people take care of him. They make him feel comfortable, and they do way more than what is needed."

She recalls Tyler's first visits to Mott. "There were dolls with I.V. lines and he could flush out the lines, draw blood, and understand what is happening to him. They explain in words a six-year-old can understand." A Child Life staff member is planning to visit Tyler's school in the fall, to help his classmates understand about Tyler's leukemia.

Back in Mott, the 7th floor activity room up in hematology/oncology is a busy, cheerful place. Two girls sit at a table drawing while a boombox blasts the "Wide Open Spaces" of the Dixie Chicks. There's a guitar, keyboard, paint table, computers, and a friendly guy named Devyn Baker who, with his shaved head, small hoop earrings and jeans looks more rock star than recreational therapist. There's a story behind the head.

"I did it because a girl on the floor was losing her hair. I had a bet with some boys that if they could beat ➤



Child Life specialists Devyn Baker and Theresa Foster



“I had a bet with some boys that if they could beat me at hallway hockey, they could shave my head. They lost. I made sure of it!

Then a girl on the floor started losing her hair and asked me if I would go bald with her. So for her 21st birthday, we shaved our heads.”

—Devyn Baker

me at hallway hockey, they could shave my head. They lost. I made sure of it!” he laughs. “I was not going to shave my head. Then the girl — she was 20 at this time — started losing her hair and asked if I would go bald with her. So for her 21st birthday we shaved our heads. The little guys I had the bet with lathered me up to shave, but I wouldn’t trust them with the razor.”

Baker’s philosophical when it comes to the paradox inherent in his work: celebrating life, creating fun for kids, but also dealing with loss when a patient dies. “The staff really pulls together when there’s a loss,” he says. “I also eat a lot of Little Debbie snacks.”

When he’s not in the activity room, Baker, like the rest of the Child Life specialists, brings the room to children’s bedsides when they’re too sick — or sometimes too scared, or simply unwilling — to leave their rooms.

Child Life even sponsors an in-house music consultant, renowned Michigan composer and performer (and R.N.) Dianne Baker (no relation to Devyn), who visits kids with her guitar and gets them singing, even writing their own songs.

Adrienne Rudolph, Mott’s artist-in-residence (and the force behind the Seurat collaboration) keeps the ideas coming. When she’s not devising projects to do with patients, she’s creating art for them. Walk any hallway in the hospital and the doors to patient rooms are decorated with upbeat, painted posters depicting the young people inside. She’s also officially responsible for all recreational head-painting for patients who’ve lost their hair (maize and blue for one young Wolverine fan). Casts, too, make convenient and appreciated canvases; she’s even painted on the tiny casts of premature babies. Rudolph’s work can also be seen in a 7th-floor treatment room — not exactly a favored destination for most kids. What could be a bleak and scary environment is softened with a wall-sized mural of a bucolic meadow filled with 33 different animals that children can focus on. Distraction is an often-used word at Mott.

“It’s almost primary; children are easily distracted and art captivates them,” Rudolph says. “It’s wonderful in the treatment room. We turn the art into a game.”

Rudolph, a former painter, began as a volunteer at Mott nine years ago. She’s now a full-time activities therapist who is daily amazed by the power of art to ease children through difficult times.

“A lot of pain is anticipation and anxiety. If you can distract a child and relieve that anxiety, the actual pain becomes secondary — the child is not expecting it, he’s not traumatized. Whereas a poke might capture his attention 100 percent, if it’s off in the background, he might just say ‘ouch’ and that’s the end of it.”

But hospitals are more than just environments to be humanized with color and compassion. At the core of this place is leading-edge medicine and fascinating research, and it’s distraction of a different kind that is the metier of Steven Buchman, M.D. He’s currently in the process of performing distraction osteogenesis — a jaw-lengthening procedure — on two-year-old Savanna Falls, a blindingly blonde little girl born with Pierre Robin Sequence, named for a French physician who first reported the combination of small lower jaw, cleft palate and tongue displacement in 1923. Savanna’s parents, American missionaries living in a remote Venezuelan village, initially had no idea something was wrong. Said Savanna’s mom, Cassandra Falls, “The night after she was born we were sitting down to dinner and I had her cradled in my arms — you know, the way you hold a baby — and she turned blue. I flipped her up and she was fine... the next morning we saw blood-stained mucous coming out of her nose and mouth. Within 24 hours of her birth we were on a plane to Caracas.”

Doctors at the hospital there diagnosed PRS. Children born with the syndrome have a lower jaw that is either small in size (micrognathia) or set back from the upper jaw (retrognathia). As a result, the tongue tends to be displaced back towards the throat, where it can obstruct the airway (glossoptosis). Most infants, but not all, will also have a cleft palate. These babies struggle terrifically to breathe and eat but with surgery can grow to live completely normal lives.

A church member arranged for a Life Flight to transport the family to Philadelphia, where Savanna received a feeding tube and the family took time to



Savanna Falls with her mom, Cassandra

regroup and find the best place to settle. When the Fallses were offered teaching positions at a Bible college in Jackson, they jumped at the chance. “Our plastic surgeon told us, ‘If you take the job in Jackson, you can go to Mott Hospital and work with Dr. Buchman.’ So really, we picked our jobs based on Mott and the availability of good service for our child.”

Distraction osteogenesis of the jaw is a procedure in which the jawbone is broken, then a series of pins and rods is surgically implanted into the separated bones. A screw mechanism allows the bones to be slowly separated — a tiny bit every day — until new bone is formed between the edges and the jaw is lengthened to its correct size. Little Savanna seems quite unconcerned by the metal posts and screws that surround her jaw which, for now, juts forward from her face. Quite intentionally, Buchman has overcorrected the chin; when the framework is removed, a bit of retraction is to be expected. Savanna is also expected to “grow into” her new chin rather than be subjected to subsequent surgeries. When the process is completed, he will perform another surgery to close her palate.

Says Cassandra Falls, “Dr. Buchman knows his stuff. You don’t get to work at Mott because you have a diploma and just show up! What’s neat is the teamwork that it takes to get this surgery to come together. There are six different teams: ear, nose and throat, a speech pathologist, the gastroenterologist people, the plastics team with Dr. Buchman, sleep study people — that’s

neurology — respiratory people when she’s in the hospital...and Katherine Kelly, the orthodontist and dentist — she’s one of the most personable people I’ve ever met. I was talking to her and I got a little teary and she did too. It’s all about people with all of them.”

The team approach is central to medical care at Mott. Because children are growing and developing, their systems are continuously changing — and they differ from adult systems. Or, as Karin Muraszko, M.D., chief of Pediatric Neurosurgery, puts it: “Kids aren’t small adults.” Such medical issues as blood loss, fluid management and anesthesia are more complicated in children, she says. The variance between children and adults is something that physicians and nurses have to keep in mind every time they listen to a heartbeat, palpate an abdomen or prescribe a medication.

Janet Gilsdorf, M.D., professor of pediatrics and communicable diseases in the Medical School, expands on Muraszko’s observations. “Since young children can’t use language to communicate, we need to rely on non-verbal cues from our patients and on parents’ observations,” she says. “Children are physiologically, emotionally, anatomically and socially different from adults, so we as pediatricians learn these differences and incorporate them into our assessment and management techniques.”

James Ferrara, M.D., professor of medicine and pediatrics and director of the U-M Cancer Center’s Bone Marrow Transplant Program, adds that children “get sicker more quickly. Often there isn’t a lot of time to make decisions, and if you don’t get the best treatment for cancer the first time, you may not get a second chance at a cure.” Ferrara notes that children who are bone marrow transplant patients “are among the sickest anywhere. It takes a critical mass of multidisciplinary talent and expertise — doctors, nurses, play therapists, pharmacists, dieticians, radiologists, clinical laboratories — to bring a child through this harrowing process safely.



Steven Buchman

“When I was born, children’s cancers were almost universally lethal. With new therapies, including bone marrow transplant, we can now cure almost 75 percent of our young patients. That’s one huge leap for humankind in a single lifetime, but it’s that last 25 percent that keeps driving us.” Ferrara, who left a tenured ►

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—James Ferrara

Photo: Lin Goings



Karin Muraszko

Photo: D.C. Goings



Janet Gilsdorf

Photo: Marcia Ledford



James Ferrara

Photo: Paul Thacker



Valerie Castle

position at Harvard to come to U-M, did so because “I think this is the place where I can help do this work the best.”

Valerie Castle, M.D., professor and associate chair of Pediatrics and Communicable Diseases, says, “Whenever I tell people I’m a pediatric oncologist, the first thing they say is ‘Oh, how can you do that? It must be a terribly difficult job.’ Actually, it’s probably the best job in the world.” For acute lymphoblastic leukemia, for example, Castle cites survival rates of near zero in the 1930s and 1940s, rising to over 85 percent today. Looking back on her “relatively short career,” Castle takes heart and hope in the major strides that have been made. At U-M, Castle says, scientists forge unique collaborations across disciplines, “and we’re seeing our patients in the same place we’re doing our research,” allowing for effective translation to bedside treatment of childhood cancers.

Jean Robillard, M.D., a French-Canadian originally from Montreal, heads the Department of Pediatrics and Communicable Diseases which oversees the complement of extraordinary pediatric medicine and pioneering research that converges in U-M Mott Children’s Hospital. He loves talking about the great researchers and clinicians with whom he works.

“One of our major research programs is being conducted by Samir Hanash, a professor in the Division of Hematology and Oncology,” Robillard says. “He is looking at determining the different genes and proteins

involved in cancer — sequencing proteins, finding genes, then finding therapies; this is very exciting work.

“Another group, Delia Vasquez, John Barks, Faye Silverstein, and Sheila Gahagan, are involved with the development of the brain — the normal brain and the effect of stress during the perinatal period on brain development. That same group is looking at brain injury in newborns. Barks and Vasquez have a tremendous amount of funding and what they do is starting to be applicable to patient care. It’s very important and very timely.

“We’ve just recruited a physician from Germany, Dr. Friedhelm Hildebrandt. He’s a renal geneticist and has made tremendous discoveries in multiple renal diseases. He’s coming to join a fantastic team and concentrate on his work on the genetics of renal disease.

“Gary Freed is another major recruit in this department — a pediatrician who is doing his research in health services. He is looking at the distribution of care, studying the implementation of vaccines, evaluating state programs, looking at the economic aspects of these programs. He came here with one research associate and now has a program with over \$10 million in funding and 25 people working for him. His program in health services focusing on children is very unique in many respects, and it’s become one of the major programs in the country.”

Robillard himself left Canada to finish his residency and complete a research fellowship at UCLA. His

mentor there, Fred G. Smith Jr., decided to accept a chair at the University of Iowa; Robillard moved with him and stayed 20 years. Then Michigan called and “I got in love with the place — the excellence of the Medical School, the ability to collaborate. There are no departmental barriers. What is most important is the quality of the people — from the top on down. With this type of philosophy, I was ready to change careers and be more of an administrator, to get a chance to influence academic pediatrics using this position,” a position he has held for five years.

“The University is a leader in a multitude of spheres. When you look at the ratings of schools — business, engineering, social work, nursing, medicine — this is unbelievable! To have this much excellence across-the-board!”

Robillard speaks of his own attraction to the field of pediatric medicine: “One day you may take care of a baby at 30 weeks gestation, and the same day you work with a young adult 20 years old. The huge range of physiology, that’s what attracted me — the whole aspect of development in terms of emotion, physiology, learning. You don’t see that in adults so much. In pediatrics, the diseases we see are often reflected later in adults. In a way, it is the fetal origin of adult disease. You have a chance as a pediatrician to influence health later in life — if you do good things!”

As an academic administrator, Robillard says, “The challenge is really to find the best people, especially in pediatrics where there is a huge demand for the best faculty and the best scientists. There are very few people available. Because of this, we are looking at the entire world when we try to recruit the best people. That’s why we were able to recruit Hildebrandt, one of the best renal geneticists in the world.”

For Patricia Warner, keeping the University of Michigan up there with the best of the children’s hospitals in the nation associated with major academic research centers is her first goal. “There are other wonderful children’s hospitals,” she notes, “like Children’s Hospital in Detroit. But the breadth of our research and the leading-edge clinical care that immediately results from that research is our great strength.

Photo: Martin Vloet



Patricia Warner

“The first extracorporeal membrane oxygenation (ECMO) with children was offered here, for instance. And we were the first to be able to give a child ECMO while being transported here by air. Also, our birth center is geographically and programmatically very integrated with our Neonatal Intensive Care Unit. That’s important because when you have a high-risk delivery, the babies often have to go into the NICU. In a freestanding hospital, the baby has to be transported away from its mother.”

Warner also believes that the atmosphere of creative caring fostered by the Child Life program is a powerful plus. “Child Life offers those services that truly support the children and families, to maintain as close as possible a child’s developmental environment. Developmental play, education, pet therapy, preparing children for operations through play therapy...and we celebrate every holiday that can be dreamed up!”

Why does she think people choose to come here? “We really are the state resource for special services. We also serve a lot of out-of-state needs. People come here because we have absolutely comprehensive services. Not only physicians but nurses, respiratory therapists, physical therapists, pharmacists — all have training in pediatrics. And remember, children aren’t usually hospitalized unless what they have is very unusual, or they are very ill. People want to come where the most research exists.

“Even though I’ve worked here many years, I still feel very privileged to do my best to support the care team that does such a great job, not only with medical sophistication, but also with family-centered care. All our staff nurses, the allied health people, really work as a team. I feel challenged and excited to be able to support that.” ➤

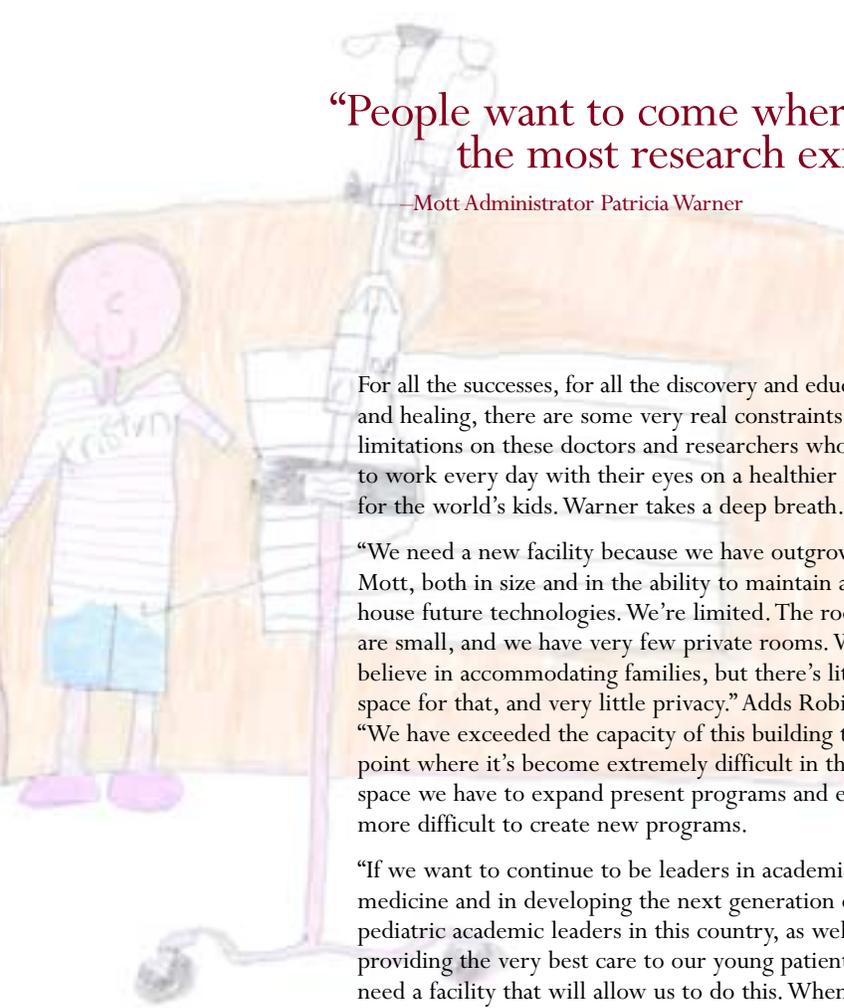
Photo: Bill Wood



Jean Robillard

“People want to come where the most research exists.”

—Mott Administrator Patricia Warner



For all the successes, for all the discovery and education and healing, there are some very real constraints and limitations on these doctors and researchers who come to work every day with their eyes on a healthier future for the world's kids. Warner takes a deep breath.

“We need a new facility because we have outgrown Mott, both in size and in the ability to maintain and house future technologies. We're limited. The rooms are small, and we have very few private rooms. We believe in accommodating families, but there's little space for that, and very little privacy.” Adds Robillard, “We have exceeded the capacity of this building to the point where it's become extremely difficult in the space we have to expand present programs and even more difficult to create new programs.

“If we want to continue to be leaders in academic medicine and in developing the next generation of pediatric academic leaders in this country, as well as in providing the very best care to our young patients, we need a facility that will allow us to do this. When you have a great research and clinical facility, then you can attract the best fellows, residents, faculty and researchers. In the last five years, we have seen at least eight medical centers that have built new children's hospitals or have tremendously improved existing ones, including UCLA, the University of Chicago, and the University of Pittsburgh.”

On a cool day in August, just a few days after the break of a two-week-long heat spell, Jesus David Andrade Ysea is doing well, sitting up in bed, busy looking as cute as a happy 22-month-old can look. His mother and father, both physicians in Venezuela, are hovering over him, reading books, stroking his leg. At the entrance of a visitor, Jesus looks a bit apprehensive and holds out his arms to his father who soothes him with kisses and soft words.

Just five days earlier, Jesus had an esophagus created for him by Arnold Coran, M.D., Mott's head of Pediatric Surgery. And in a few days more, little Jesus will begin to learn how to eat. Television's *The Learning Channel* took a great interest in the case; a camera crew taped the operation and spent hours interviewing Jesus's family and Coran for an upcoming segment on rare surgeries.

Photo: D.C. Goings



Jesus Andrade Ysea with his mother, Lizmar Ysea

It's all in a day's work for the Boston-born Coran who sits in a hospital library, unfazed by lights, microphones and cameras. “Jesus was born with an absence of his esophagus, called esophageal atresia,” says Coran. “It's an anomaly that occurs in about one in 2,000 live births. He had a very rare variant of that anomaly: a pure atresia. The distance between the ends of the esophagus was extreme — there was a little tissue in the neck and a tiny bit in the abdomen. His father contacted me by email when the baby was 16 months of age. There was nobody in South America who wanted to tackle it.”

Since Jesus's birth, his mother and father have kept him alive with a feeding tube and by scrupulously caring for the pump that continually suctioned his saliva, which he was unable to swallow. Coran and his team performed the surgery to connect the ends of Jesus's esophagus on the morning of August 10. “On his first day in the ICU, he was quite stable,” Coran says. “This (operation) can do damage to the vocal cords, but there was no problem.” Jesus's stay in intensive care was prolonged by two days only because of a shortage of beds on the regular floor.

And so now, two weeks before the family is scheduled to return home, there's a new hurdle to cross. Often, a child with a condition necessitating long-term feeding via tube, develops an aversion to food. Indeed, Jesus's father says, in soft and halting English, that he and his wife have never eaten in front of their son. In the time that remains before the family's departure, Mott pediatric occupational therapists will slowly begin to introduce the boy to the joys of juice and rice and cookies.

A dangerously sick child, a trip halfway around the world, major surgery on a tiny and treasured boy. What has this been like for these young parents? “We had faith that the surgery would be OK,” says Heberto Andrade. “It was a surprise when we arrived. This hospital, the people here make you feel like home. They have been doing great work. I want to give thanks to the people here. We were afraid, but now we are so happy. He’s playing, he’s laughing, he’s a strong boy.” Such triumphs keep Coran going at a pace he couldn’t have imagined when he was younger. “I love to go to work,” he says. “I’m going to be 64 next April and I’m as excited about what I do here as I was 29 years ago.”

“At Thanksgiving,” Heather White recalls, “Tyler started complaining of his knee hurting and the doctor couldn’t see anything, but there was fluid there. Then a couple of weeks later his shoulder was hurting and you could see the swelling; it looked pretty weird. We took him back and they said ‘If he develops a fever take him to the ER, don’t call, just go.’ On December 28 he ran a fever. They ran some tests and at 2:00 in the morning came in and said, ‘Well, it’s either a tumor or leukemia.’ We were half-asleep — what do you do? What do you say? You just stand there dumbfounded. They said ‘You need to be at Mott Children’s Hospital in the morning. Go home and get some sleep.’ As if we could sleep...”

And thus began a certain kind of nightmare for the White family of Belleville: stay-at-home mom Heather; ➤

Photo: Martin Vloet



Photo: Paul Thacker



Arnold Coran

Pediatric surgeon Arnold Coran has done more than 60 operations in which he’s used a child’s stomach to create an esophagus. But Jesus Andrade presented a challenge that Coran hadn’t seen before: a fistula connected the tiny bit of esophagus that the child did have to his trachea.

“It’s an extremely rare variation,” Coran says. “It was fortunate that we discovered it before the actual surgery.” It meant that, during the nearly five-hour surgery, the connection created by the fistula had to be cut before a tunnel could be created in the baby’s chest via incision in the lower neck and abdomen to bring the stomach through, with good blood supply, to successfully complete the esophageal connection. The toddler, enjoying solid food for the first time in his life, and his parents were able to fly back to Caracas just three weeks later.

“Whenever I tell people I’m a pediatric oncologist, the first thing they say is ‘Oh, how can you do that? It must be a terribly difficult job.’ Actually, it’s probably the best job in the world.” —Valerie Castle



attorney Thomas; and kids Amanda, 12, Zachary, 9, and Tyler, 6. The months since that winter night have been a whirling blur of hospital stays, invasive procedures, a crash course in cancer, and a whole lot of hope.

At Mott early the next morning, the Whites met Jim Williams, M.D., clinical assistant professor of pediatrics and communicable diseases, and an immediate bond was formed. After an examination of Tyler’s bone marrow, Williams visited the family, now joined by grandparents and friends, to discuss the diagnosis: acute lymphoblastic leukemia.

Recalls Heather White, “I remember he said, ‘If you have to get leukemia, this is the one to get.’ With chemo alone, there’s almost a 90 percent cure rate. And my older son Zachary wanted to know everything. Dr. Williams explained things in a way he could understand. We were relieved—just knowing the problem helped. It didn’t make it go away, but we knew what we were fighting. He was in the hospital for five days. His first clinic visit (for chemotherapy) was on January 5. They don’t waste time. It’s six months of intense treatment, then three years of maintenance.”

From the beginning, the relationship between doctor and patient has been a lifeline in more than the expected ways. Says Heather White, “The man is fabulous. I haven’t seen a kid in that clinic who doesn’t like him. Tyler runs to him and jumps in his arms. He thinks Dr. Williams is the greatest thing in the world. He takes his job very seriously. He finds the positive, even if it’s very small, and he gets down on a kid’s level. He can talk to a six-year-old and make a six-year-old understand. Ty loves him. He’ll go off with him and couldn’t care less if I’m in the room. Anyone else, forget it — I have to be there.”

Tyler White has also forged a special friendship with his nurse, Marcia Louisell-McFawn. He doesn’t like any of the poking, but if she’s there, it’s easier. And for

Photo: Bill Wood



Jim Williams and Tyler White

spinal taps, his buddy, nurse Laura Siggins, has to be on hand. Tyler and Laura share a passion: country singer Reba McEntyre. “He loves Reba,” smiles Heather. “He calls her ‘his woman.’ When he has hair it’s the same color as hers.” And when the Whites went to a McEntyre concert last summer, Laura went along too. Tyler’s nurses also attended Friend Day at the Whites’ church.

Mostly, Tyler comes to the Cancer Center for outpatient chemotherapy on Friday mornings, but when fevers cause him to be admitted to Mott he takes up residence on the 7th floor and, when he feels up to it, plays hallway hockey with Devyn Baker, gets visits from friendly dogs, or gets propelled at breakneck speed around the hospital in a stroller that’s gussied-up to look like a car. One nurse rigged up his I.V. on the back of a tricycle so he could ride around on his own, untethered. Says his mother, “They should get horns; I don’t know how many people he’s run over.”

At the other end of childhood is 22-year-old LaTasha Tigner. As Tyler White and his buddies tackle puzzles and popcorn out in the playroom, she’s snuggled into a chair-bed, under a blanket. “I’m waiting for my blood,” she smiles sleepily.

The 10 Best Children's Hospitals

University of Michigan's C.S. Mott Children's Hospital

- Recognized internationally for its success in performing heart transplants and in treating congenital heart conditions and rare heart syndromes
- Developed ECMO, a system that provides temporary heart and lung assistance for children
- Improved ventilators that help premature babies breathe easier
- Assists children in preparing for surgery by running through a "pretend" version of the procedure
- Boasts a top-notch pediatric trauma center, one of 13 nationwide recognized by the American College of Surgeons
- Specializes in treating birth defects of the face and skull
- Staff board-certified in pediatrics: 100%



Photo: Bill Wood



LaTesha Tigner

Battling sickle cell anemia, LaTesha has been coming to Mott for a long, long time. "I had a major stroke when I was six," she says. "It paralyzed my whole body for three to four months."

With time and treatment, LaTesha is getting around just fine now, despite arthritis in her knees and a susceptibility to migraines. A recent graduate of Ypsilanti High School, she's planning to be a pediatrician. She, too, is a Williams fan.

"I just love Dr. Williams. He's my favorite doctor. He knows what I go through. I just love him..."

And U-M Mott Hospital and her treatment here? She lies back and smiles. "It's a part of life..."

It is a part of life, too, for the hundreds of dedicated U-M Mott men and women who, like each of the countless dots of brilliant color in the Seurat tapestry, work their individual wonders every day in an incredible collective effort to make sick children from Michigan and beyond well again — or maybe even for the very first time. 

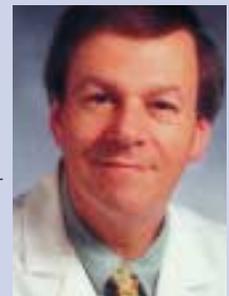
Physicians at the Congenital Heart Center at C.S. Mott Children's Hospital are among the country's most experienced, having treated about 20,000 children since 1978. And every year, they increase their caseload. In 1999, they performed 850 major heart surgeries, 700 cardiac catheterizations, and 600 open-heart procedures. "Despite the high volume, we treat every patient as an individual," says Patricia A. Warner, associate hospital director. "Teams of specialists, including surgeons, cardiologists, nurses, pharmacists, and dieticians, put their heads together to ensure the best results for each patient."

Besides a comprehensive cardiac care center, C.S. Mott has also built a well-respected transplant program, including kidney, heart, heart-lung, pancreas, liver, bone marrow, and cornea grafting. While waiting for a heart transplant last year, 9-year-old Julia Strecher went into cardiac arrest six times. "The doctors assured me that they would do their best not to let Julia die before she got a heart transplant," says her father, Vic. "They kept their word."

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Progress for Premies

When native New Yorker Steven M. Donn, M.D., began his fellowship in neonatology at the University of Michigan Medical Center in Ann Arbor, he began to notice that something was not quite right with the ventilators widely used for premature babies. "They weren't in synchrony with the baby's own breathing," explains Dr. Donn, 51, director of neonatal and perinatal medicine at C.S. Mott Children's Hospital. "They would drive oxygen into the baby's lungs when the infant might be exhaling." The result: Babies were more likely to suffer a ruptured lung and even brain damage.



But it wasn't until 1990 that the technology became available to detect minute changes in air flow and react lightning-fast—within 35 milliseconds—so the baby and the ventilator were working in unison. "When I heard about the new technology, I jumped all over it," says Dr. Donn, who had wanted to be a physician since he was a toddler. In the next several years, he led a series of clinical trials that showed babies treated with the new ventilators could breathe on their own six days earlier than those given the older types. The risk of complications was reduced, too.

One of Dr. Donn's first patients on the ventilator, now a 10-year-old basketball player, visited him last summer. "He was born under 24 weeks and weighed just a tad over a pound. No one thought he'd survive. But he did so well on the new ventilator that I extended the clinical trial so I wouldn't have to switch him to the older model," he recalls.

In the late 1990s, patient-triggered ventilators became the standard of care for infants. Dr. Donn is now studying other ways to combat brain damage and improve lung function in premies.