One Friday in February 2009, little Ramsey Farrar was running a fever and complaining of abdominal pain. His parents gave him Tylenol and monitored him closely, but by Sunday the 2-year old was feeling worse.

Over the next few days, Ramsey’s family made several trips to the emergency room. By Tuesday, Ramsey was much sicker and tests revealed “serious concerns,” recalls his father, Joe Farrar. The Farrars, who live in Vancouver, Wash., were sent to Randall Children’s Hospital at Legacy Emanuel in Portland where they heard “the worst thing you can ever imagine,” Farrar says. Their darling bouncy toddler had leukemia.

Survival rates on the rise
Ramsey is one of about 12,000 kids diagnosed with cancer every year in the United States and, although pediatric cancer is rare, it’s still the leading cause of death by disease for kids 15 and younger, according to statistics from the National Cancer Institute.

The good news is, more and more children are beating it.

“In the 1980s, about 60 percent of kids (diagnosed with cancer) survived five years, with 40 percent dying within five years,” says Dr. Linda Stork, MD, head of the Division of Pediatric Hematology/Oncology at OHSU Doernbecher Children’s Hospital. “Now the survival rate is around 80 percent for all types of childhood cancer and only 20 percent are dying within five years, so we’ve cut the death rate in half.”

Ramsey’s cancer – dubbed ALL for acute lymphoblastic leukemia – has one of the most encouraging prognoses.

“They know the most about this cancer,” Farrar says. “In the 1950s, there was a 3 percent survival rate for ALL. Now there is a 90 percent five-year survival rate.”

Various types of leukemia (cancer of the blood cells) account for about one-third of all childhood cancers, according to the National Cancer Institute. Brain tumors and lymphomas (cancer of the lymph node system) are the other two most common types of cancer in children. According to local pediatric cancer experts, there might be a few more cases of melanoma (a type of skin cancer) beginning to show up, but the main types of childhood cancer have remained the same for decades.

There are no known causes for these childhood cancers. “That is something that is important for parents to hear, that there just isn’t an explanation for it,” says Dr. Janice Olson, MD, medical director of the Children’s Cancer and Blood Disorders program at Randall Children’s Hospital at Legacy Emanuel. “A cell makes a mistake and once in a great while that one mistake develops into cancer.”

A rough road for the whole family
“It was like an out-of-body experience,” says Tigard mom Renie Webb of her then 9-year-old daughter, Lilly, being diagnosed with Ewing’s sarcoma two years ago. A solid tumor cancer, Ewing’s had wrapped around Lilly’s spine. To treat the cancer, Lilly had to endure two surgeries and start an aggressive course of chemotherapy three to five days every other week.

“She lost every hair on her body. She lost weight,” Webb reports. Weakened, Lilly also required transfusions. Then, halfway through the chemo Lilly had six weeks of radiation. The chemo gave her painful sores in her mouth and she couldn’t eat.

Webb stayed with Lilly every night she was in the hospital. Lilly’s dad and six siblings – now ranging in age from 6 to 21 – “managed,” says Webb, “but it wasn’t easy.” Her eldest sister took a semester off from college in California to help with Lilly and her siblings, and Webb says she will feel guilty forever about missing another daughter’s high school graduation.

Ramsey’s family faced unimaginable challenges, too. “It was brutal,” says Farrar, recalling how doctors shoved a tube into tiny Ramsey’s hip to take samples of his bone marrow for testing. Then came the chemotherapy.
“The first seven days they hit him hard with chemo,” Farrar continues. “He vomited. He didn’t want anything to do with doctors.”

His appetite dulled by the powerful drugs, Ramsey had to have a feeding tube for about eight weeks.

“The doctors said to let him eat anything,” Farrar says, “so we literally let him drink ranch dressing. That’s all he wanted.”

For the next 30 days, Ramsey’s tiny body was assaulted with more chemotherapy, but after that, Farrar says, “he was in remission. There were no detectible leukemia cells.” Ramsey finished his maintenance therapy just this spring. They expect to remove the port in his chest (used to facilitate chemo treatments and other medical procedures) in early October.

“He has battled cancer more than half his life,” Farrar says.

It’s not just the cancer parents worry about, though. With immune systems suppressed, they worry constantly about infections – and for good reason. A temperature of 100.4 and a simple ingrown toenail both put Ramsey back in the hospital. Parents constantly weigh the benefits of letting their kids have normal childhoods with the risk of picking up chicken pox at church or a cold at a birthday party.

**New treatments offer new hope**

Research has led to better treatments for cancer in people of all ages, and pediatric cancers are no exception. Doctors now have access to an array of much improved medicines and are increasingly able to target what is most likely to work for each individual child.

“About a decade ago, research showed us ways to target the cancer cell with less toxins,” says Dr. Suman Malempati, MD, head of the Developmental Therapeutics Program and assistant professor of pediatrics (hematology/oncology) at OHSU Doernbecher. Although this approach is groundbreaking, there are many hurdles.

“Not every cancer has a clean target, with one specific abnormality (in a cell),” Malempati says. In addition, he adds, “ Childhood cancers are
heterogeneous. They don’t all have the same ‘switch,’ even with the same cancer (in different kids). A lot of new drugs are coming out and being tested.”

Research and clinical trials are more difficult with children than with adults. For one thing, pediatric cancer is so rare, there are fewer patients to try out new therapies. That’s why clinical research and patient care are so integrated, Malempati says.

Still, there are scores of clinical trials for pediatric cancer going on around the world.

Ramsey Farrar participated in a study comparing European and American protocols for treating ALL. Lilly’s tumor was donated for research and her health will be followed for life.

“We thought it was the least you can do,” says Webb.

One example of promising new research can be seen in recent developments in the treatment of neuroblastoma, a cancer of the nervous system usually starting in the adrenal glands. Until two or three years ago, the survival rate for children with advanced neuroblastoma was only about 35 percent, according to Stork, but new research and trials of a drug called Chimeric Antibody 14.18, which targets a protein on the surface of the neuroblastoma cells, has brought the survival rate to 60 percent. This targeted medicine is a type of monoclonal antibody, which selectively targets the “bad” cancer cells.

Malempati currently is heading a study looking at combining chemotherapy drugs with monoclonal antibodies for children with rhabdomyosarcoma that has metastasized or spread in the body. This is a rare cancer of the muscles that attach to bones, with only about 350 cases diagnosed annually.

Hope for Kids with Cancer continued from page 11

heterogeneous. They don’t all have the same ‘switch,’ even with the same cancer (in different kids). A lot of new drugs are coming out and being tested.”

Research and clinical trials are more difficult with children than with adults. For one thing, pediatric cancer is so rare, there are fewer patients to try out new therapies. That’s why clinical research and patient care are so integrated, Malempati says.

Still, there are scores of clinical trials for pediatric cancer going on around the world.

Ramsey Farrar participated in a study comparing European and American protocols for treating ALL. Lilly’s tumor was donated for research and her health will be followed for life.

“We thought it was the least you can do,” says Webb.

One example of promising new research can be seen in recent developments in the treatment of neuroblastoma, a cancer of the nervous system usually starting in the adrenal glands. Until two or three years ago, the survival rate for children with advanced neuroblastoma was only about 35 percent, according to Stork, but new research and trials of a drug called Chimeric Antibody 14.18, which targets a protein on the surface of the neuroblastoma cells, has brought the survival rate to 60 percent. This targeted medicine is a type of monoclonal antibody, which selectively targets the “bad” cancer cells.

Malempati currently is heading a study looking at combining chemotherapy drugs with monoclonal antibodies for children with rhabdomyosarcoma that has metastasized or spread in the body. This is a rare cancer of the muscles that attach to bones, with only about 350 cases diagnosed annually.

Hope for Kids with Cancer continued from page 11
Help Eliminate Learning Problems

HELP has successfully treated over 3000 children and adults with ADD, ADHD, Dyslexia, Aspergers and other learning problems WITHOUT DRUGS. We don’t ask the world to accommodate you. “We Change the Way You Learn!”

HELP, INC
Not for Profit on the MaryHurst University Campus
326 Davignon Hall
503-635-3389 • www.helpadd.com

The Vancouver Clinic OB/GYN
WELCOMING NEW PROVIDERS

Services Include
• Well Women Care
• Family Planning
• Obstetrical Care
• Menopause Support
• Maternal Fetal Medicine

(360) 882-2778
www.tvc.org

Cynthia McNally, MD
Jacob Calvert, MD

Where bright smiles begin!

Voted “Top Dentists” in pediatric dentistry for FIVE consecutive years by Portland Monthly Magazine.

Ben Kang DMD, MS, PC
Board Certified Pediatric Dentist
Located behind Regal Cinema in Bridgeport Village
503.992.6189
www.BrightLittleSmiles.com
It is still too early to know if this drug combination will make a difference,” Malempati says, “but it is promising.” The study should be completed in December 2014.

Another key to the improved survival rates for pediatric cancer patients is the ability to identify kids who need more intensive therapy and those who can be treated effectively with less, Olson says.

“Part of the success is better combinations of chemotherapy and stronger supportive care,” Stork adds. “We have better antibiotics so we can push the chemo harder, for example, and the side effects of chemotherapy can be better treated.”

While children with cancer still have surgery and are blasted with chemotherapy and radiation, they’re also benefiting from these breakthroughs in newer targeted therapies and immunotherapy which often have fewer side effects. Many involve only a daily pill, making it easier for kids to lead more normal lives without being tethered to a chemotherapy schedule and infusion center.

“The treatments are still hard,” Olson says, “but they are doable.”

Learn More:

Groups Providing Fun & Respite for Families Battling Cancer:

Candlelighters For Children With Cancer: This group provides support, education and advocacy for kids with childhood cancer and their families in Oregon and southwest Washington. Activities include fun monthly outings for families and quarterly educational programs for parents. 503-235-5722. 4kidswithcancer.org.

Children’s Cancer Association (CCA): This national group, which is based in Portland, runs programs for seriously ill children in hospitals and at home. CCA has music programs, a cabin families can use for a getaway, a chemo pal volunteer program and more. 503-244-3141. joyrx.org.

Children’s Healing Art Project (CHAP): This local group brings teaching artists into hospitals to work with young patients one-on-one and in groups to experience the healing power of creating art. CHAP’s work is not limited to children with cancer. 503-243-5294. chap.name.

Read more about programs like these in Focusing on Fun on page 18.

National Research and Advocacy Groups:

The National Children’s Cancer Society: This group aims to improve the quality of life for children with cancer and their families worldwide. They provide financial, emotional and educational resources, and their website provides links to camps, wish foundations, support groups, medical/insurance information, clinical trials and more. 314-241-1600. thenccs.org.

Children’s Oncology Group (COG): This global pediatric cancer research organization is supported by the National Cancer Institute. COG member hospitals treat more than 90 percent of children with cancer in the United States. COG also provides information and support to families.

— Teresa Carson
Because kids get sick at all hours.

A fever that spikes at 2 a.m.
Weekend bumps and bruises.
A sudden, itchy rash.

Do you need to go to the Emergency Room? Let MD 4KIDS, Doernbecher’s mobile app, help you decide.

Your pediatrician’s office might be closed, but MD 4Kids is always open. Enter your child’s symptoms and get immediate advice. Doernbecher Children’s Hospital: Because every child deserves the best.

Available on iTunes and Android Market.
Doctors, families focus on the future

Both Webb, whose daughter was treated at OHSU Doernbecher Children’s Hospital, and Farrar, whose son was treated at Randall Children’s Hospital at Legacy Emanuel, praise the doctors, nurses and others who work with pediatric cancer patients. (Doernbecher and Randall are the only members of the international research organization Children’s Oncology Group in Oregon and southwest Washington. All other medical facilities in the region refer pediatric cancer patients to these two hospitals.)

“They give you hope,” Webb says of the pediatric oncology staff who worked with her family. “They make you feel normal. They talk to you in future terms. They say, ‘When you are 15’ and ‘When you are 18,’ and you think, well they think she’s going to be 18!”

“They are real heroes,” Farrar agrees.

Although childhood cancer is still a devastating diagnosis with a long and difficult journey, doctors, patients and their families resolutely focus on the positive.

“We have lots of happy, happy stories,” Olson says. “Parents have more emotional scars than the kids. Kids are very in the moment. They do have discomfort, but they are resilient. Almost all of these kids come through it just fine.”

Lilly diligently completed her homework throughout her treatment, finished this past school year with straight “A”s and is currently happily attending sixth grade.

Ramsey Farrar, now 6 years old and healthy, loves to play games on Wii and jump on the backyard trampoline.

Ramsey’s dad sums up the family’s feelings simply, saying, “We are so happy he is going to kindergarten and will be a normal boy.”

Teresa Carson is managing editor of Metro Parent, a freelance writer and a mom.
Focusing on Fun

There’s nothing fun about cancer, but local hospitals and nonprofit groups work hard to ease the rough circumstances for children with cancer and their families. Both Randall Children’s Hospital at Legacy Emanuel and OHSU Doernbecher Children’s Hospital – the only two hospitals who treat pediatric cancer patients in Oregon and southwest Washington – have social workers on staff to guide families through financial, emotional and logistical needs. (Treating childhood leukemia can cost $250,000 to $500,000 or more!) They also have child-life experts on staff to add a bit of fun and distraction for children who are hospitalized.

“It takes a village (to treat a child with cancer),” says Dr. Linda Stork, head of the Division of Pediatric Hematology/Oncology at OHSU Doernbecher Children’s Hospital.

“We had one (volunteer) family that made it their mission to stock a drawer with new pajamas,” says Dr. Janice Olson, director of the Children’s Cancer and Blood Disorders program at Randall Children’s Hospital at Legacy Emanuel. “When you have diarrhea and vomiting, it is nice to have new jammies.”

Young cancer patients – and their siblings – can’t help but lose some of their childhoods to cancer.

“The kids have a long journey with their treatments,” says Shelly Charles, director of programs for the Children’s Cancer Association (CCA), a nonprofit dedicated to bringing joy to children and families battling serious illness. “They are off the soccer fields, not in math club. They lose the fun and joy and social connections, but they’re still just kids.”

Volunteers and nonprofits strive to add back some of the memory-making childhood fun these kids might otherwise be missing. CCA has a beach cabin families can use at no cost, and Candlelighters For Children With Cancer sponsors fun monthly events for families, such as outings to Oaks Park, fishing days and Halloween and holiday parties. CCA also has an in-hospital music program called Music Rx.

As a toddler battling acute lymphoblastic leukemia, Ramsey Farrar of Vancouver, Wash., had a volunteer Chemo Pal provided by CCA. (A Chemo Pal is an adult friend who hangs out with a young patient as he or she undergoes tests and treatments.)

“She was at every one of Ramsey’s appointments,” says Ramsey’s dad, Joe Farrar. “She brought a bag of toys and they played. She has become part of our family.”

Various “wish” groups send families to Disneyland and other vacation destinations, and now that Tigard fashion plate and budding actress Lilly Webb has finished her treatments for Ewing’s sarcoma, the Make-A-Wish Foundation is sending the 11-year-old to New York to watch a taping of her favorite television show, What Not to Wear.

— Teresa Carson