

ONWARD



FALL 2017 /// A publication for friends and supporters of Oregon Health & Science University

THE
UNSTOPPABLE
LAURA
SCHROEDER



/// Cover: Doernbecher patient Laura Schroeder wearing traditional Klamath Tribes powwow regalia.

Contents

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- 4 **Unstoppable:**
*The impossible story of
Laura Schroeder*
- 14 **Only at Doernbecher**
- 16 **Progress Report**
- 18 **Donor Spotlight:**
George & Janet Boldt

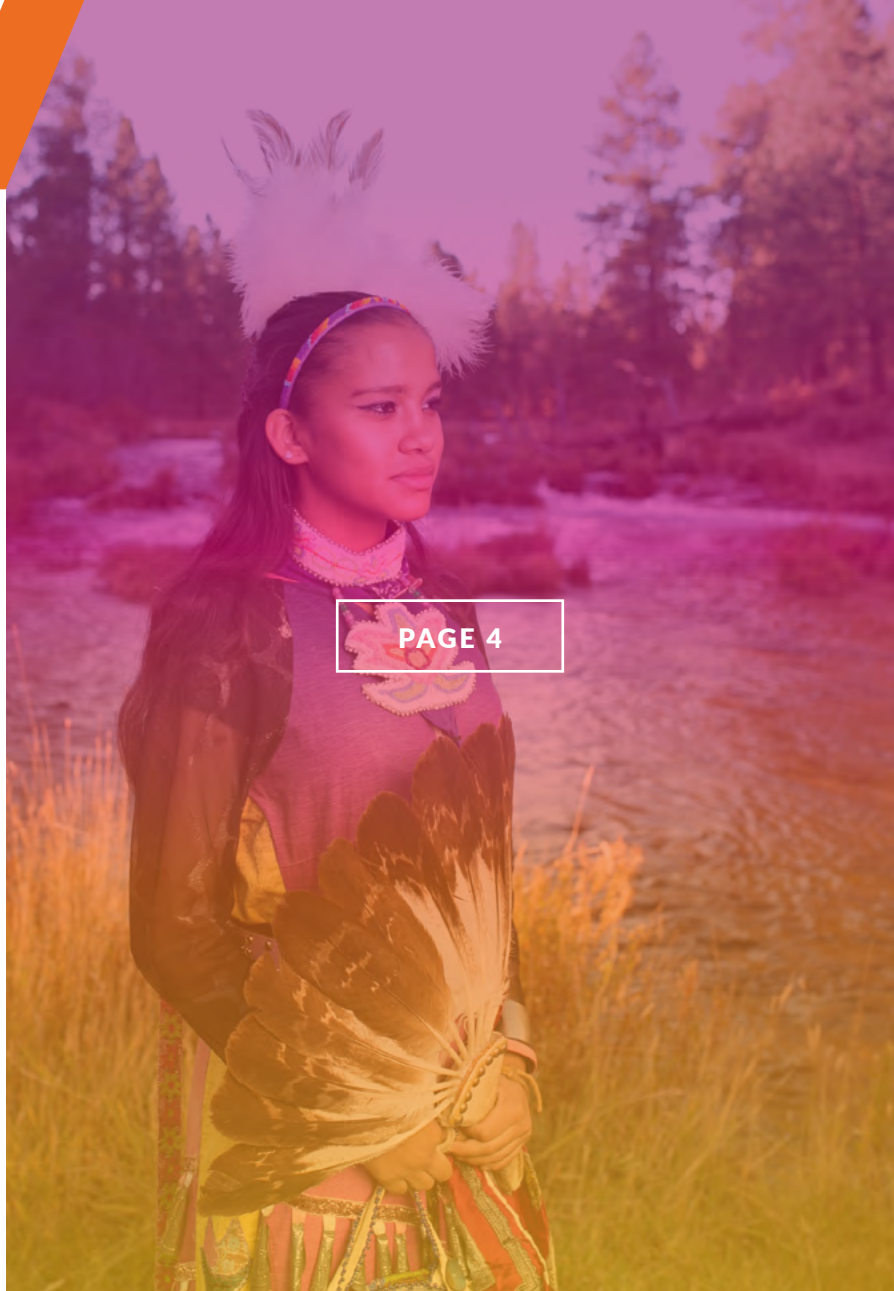
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ONWARD

THE OHSU FOUNDATION MAGAZINE
FALL 2017

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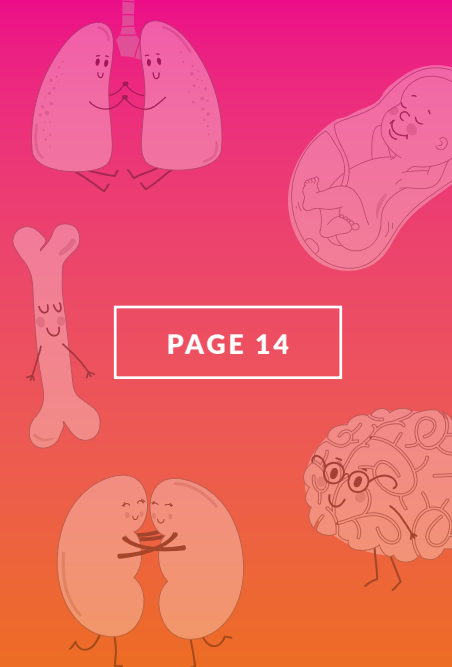
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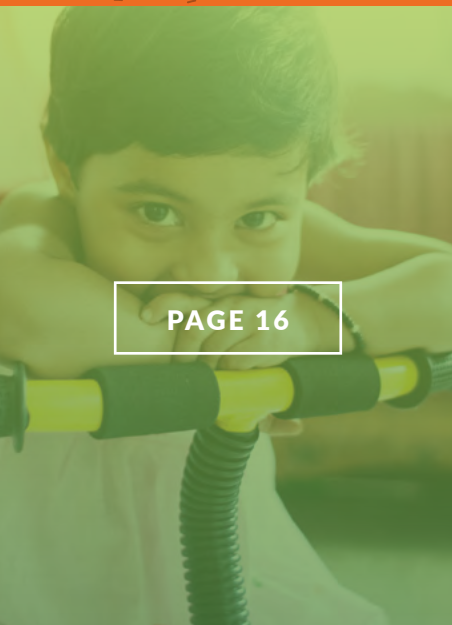
PAGE 4



PAGE 18



PAGE 14



PAGE 16



Welcome to **ONWARD**

As we near the end of a tumultuous 2017, it's tempting to focus on the many calamities that have befallen our nation and planet this year. Floods. Fires. Earthquakes. Hurricanes. Hateful demonstrations. Mass shootings. I invite you to read this edition of *ONWARD* magazine for a dose of optimism.

Take the subject of our cover story, for example — Laura Schroeder. At 17, Laura has undergone nine major surgeries to repair her malformed kidneys and other congenital anomalies. She and her family have been traveling from Chiloquin, Ore., to OHSU Doernbecher Children's Hospital every two months or so for appointments for Laura's entire life, not counting those times when she has been in the hospital. And yet Laura is on track to graduate from high school on time and dreams of becoming a physician. Her experiences make her want to give back, not back down.

This edition's donor spotlight shines on Janet and George Boldt of Wilsonville, who insist that they are getting the better end of the bargain when they donate to OHSU. Who are we to disagree? You will also find inspiration in our progress report, which encapsulates some of this year's proudest achievements.

You have played a crucial role in these achievements, and I am grateful for your continued encouragement. Our vast and varied donor community is an ongoing source of pride. Thank you for all that you do to justify my optimism.

Joseph E. Robertson, Jr., M.D., M.B.A.
President, OHSU

UNSTOPPABLE



THE **IMPOSSIBLE** STORY OF LAURA SCHROEDER

Laura came into the world as a question mark.
How had she made it this far?

/// From Left:

The Schroeder siblings Adaline, Hannah, Laura, Orville and
Scarlett near their home in Chiloquin, Ore.



Laura's parents, Nanny and Ron Schroeder of Chiloquin, Ore., had been in suspense for several months. It was painful. "I'll never forget it," said Nanny. "We went to Medford for an ultrasound when I was seven months pregnant and the doctor said, 'We can't see any kidneys. But your baby is making amniotic fluid and surviving, somehow.'"

Their local doctor advised Ron and Nanny to give birth at OHSU Doernbecher Children's Hospital. They would be five hours from home, but surrounded by the region's top kidney specialists and pediatric surgeons. Nanny's parents made the trip from Chiloquin, too. "My mom was right there at my hip the whole time. I don't know what I would have done without her," said Nanny.

"I'll never forget it. We went to Medford for an ultrasound when I was seven months pregnant and the doctor said, 'We can't see any kidneys. But your baby is making amniotic fluid and surviving, somehow.'"

NANNY SCHROEDER

Laura was born early the morning of May 31, 2000 with one poorly formed or hypoplastic kidney as well as several other congenital abnormalities. She had been getting along with one partial kidney but would not survive without immediate intervention. One week after her birth, Laura underwent her first surgery.

Steven Skoog, M.D., then Doernbecher's chief of pediatric urology, performed the surgery along

with now-retired surgeon Marv Harrison, M.D. Dr. Skoog remembers baby Laura well. "We knew she had complex congenital anomalies, but we couldn't figure it out from imaging alone. We had to do exploratory surgery."

After the surgery, Dr. Skoog sat down with the young parents. "He took us aside and said, 'Your daughter has very complicated anomalies and we're not quite sure what to do, but we're going to confer with some other people and figure it out,'" said Nanny. "That made me feel good – he was willing to admit he didn't have a clear answer, and he was going to keep trying until they got it right. We knew he was going to be straight and honest about our daughter."

They ended up staying in Portland for a month after Laura was born, to make sure she received the best care possible. Nanny and Ron were 19 and 21, just starting their adult lives. Ron took a temporary leave from his job at Crater Lake National Park. Nanny had been in school, but put it on hold.

Thus began a 17-year journey that's included nine surgeries, many hospital stays, several medical teams, and countless procedures, appointments and trips from Chiloquin to Doernbecher. What's remained constant is that, through baffling and sometimes life-threatening medical challenges, Doernbecher has been there with expert and compassionate care. And the family has stayed strong.

Ron put it this way: "Laura's already been through more than most people go through in a lifetime. She's a fighter and she just keeps going."

An underappreciated organ

Laura's single, partially formed kidney was her biggest health challenge. As Doernbecher kidney specialist David Rozansky, M.D., Ph.D., pointed out, "The kidney is an underappreciated organ. >>>>

/// From Left: Ron, Nanny and baby Adaline attend Laura's check-up with Doernbecher pediatric kidney transplant coordinator Debra Wachsmuth, R.N. Debra has been tracking Laura's progress for 16 years.



Doernbecher kidney specialist David Rozansky, M.D., has been caring for Laura since she was a year old.

“The change she went through after the transplant was phenomenal. She grew more than four inches and gained 20 pounds in a year. The best part was knowing that she was going to be around a lot longer than anyone thought.”

RON SCHROEDER

It's not just for filtering waste products and balancing water and salts. It's also crucial for bone health, general growth and preventing anemia.”

Dr. Rozansky, along with kidney transplant coordinator Debbie Wachsmuth, R.N., started coordinating Laura's care when she was about 1. Starting in her first year, Laura underwent two surgeries in order to maintain partial kidney function and to repair other internal anatomical issues.

When she was 9 years old, Laura also started seeing Dr. Amira Al-Uzri, director of Doernbecher's kidney transplant program.

It was around that time that the team decided she would need a kidney transplant in order to keep growing and thriving and to avoid the need for dialysis.

Laura was lucky. Her father, Ron, was an ideal kidney donor. In 2009, Laura received one of her dad's kidneys. Dr. John Barry performed the surgery. The difference was obvious almost right away. “It was an amazing feeling,” said Ron. “The

change she went through after the transplant was phenomenal. She grew more than four inches and gained 20 pounds in a year. The best part was knowing that she was going to be around a lot longer than anyone thought.”

Laura is grateful. “I have always had a strong bond with my dad. I know he is there for me when I need him.”

Between 10 and 15 children receive kidney transplants at Doernbecher every year. They travel from as far as Idaho and southern Oregon, as Doernbecher is the only hospital in the region with the expertise to perform kidney transplant surgery.

“This work is very rewarding,” said Wachsmuth. “I get to know these kids over several years. I've seen Laura go from being a very shy little girl to being someone who can communicate and who accepts who she is. Laura may get down for a little while, but she always gets right back up.”

The kidney kids

For kids who are contending with serious medical issues, it can be hard to make friends. They're in and out of school, and many activities are simply out of reach. The fortunate ones, like Laura, have opportunities to meet other kids going through the same thing. Laura met Prissy Hampton and Anthony Roletto three years ago at Kidney Camp, an annual outdoor camp held in Turner, Ore., put on by the nonprofit Northwest Kidney Kids. The organization was founded by Randall Jenkins, M.D., holder of the new Y.B. Talwalkar Professorship in Pediatric Nephrology. The late Doernbecher social worker Suzanne Billings, M.S.W., was also deeply involved in the organization, as is Dr. Rozansky, who now serves as interim president. Laura has been going to Kidney Camp for nine years.

Prissy and Anthony both had kidney transplants at Doernbecher. Laura feels comfortable with them because, “They understand my situation. >>>>



Amira Al-Uzri, M.D., director of Doernbecher's kidney transplant program, has been working with Laura since she was 9.



/// From Left: Anthony Roletto, Prissy Hampton and Laura know their way around Doernbecher.

“This work is very rewarding. I get to know these kids over several years. Laura may get down for a little while, but she always gets right back up.”

DEBBIE WACHSMUTH, R.N.

I don't have to explain every single detail. And I can talk to them about anything that's happening, and I know I won't get judged. I wish I could see them more.”

Prissy, 19, lives in Portland and wants to become a special education teacher. Anthony, 16, attends Glencoe High School. In 2011, he was selected to design a pair of custom Nike shoes for Doernbecher Freestyle. The tight-knit group stays in touch through social media and phone calls.

Complications

Each of Laura's nine surgeries has improved her quality of life. But they come with a cost. Surgeries increase the risk of adhesions, fibrous tissue that can cause organs in the abdominal cavity to stick together. In the winter of 2015, Laura was hospitalized at Doernbecher for 45 days with a life-threatening bowel obstruction, caused by abdominal adhesions. Ron and Nanny stayed at Ronald McDonald West House Waterfront. They left siblings Hannah, Orville and Scarlett with grandparents so the children could stay in school.

As the days went by, and with Christmas approaching, Nanny, Ron and Laura were missing home and the younger kids. “We decided, it's time to go get those kids,” said Ron. It was the right decision. “When her sisters and brother came into her hospital room, she really perked up,” said Ron.


The Hospital School Program at Doernbecher has been crucial in helping Laura and her siblings stay on track academically. During Laura's last hospital stay, Hannah, Orville and Scarlett went to school at the hospital every day. Their teachers from Chiloquin coordinated with hospital teachers to keep them up to date on lessons and homework.

This is our normal

Nanny says being part of a tight-knit community and family has helped her through the hard



Laura checks in with Steven Skoog, M.D., who performed the first of Laura's many surgeries.



From Left: Adaline, Hannah, Laura, Scarlett and Orville Schroeder hanging out on the family trampoline.

times. She remembers a few years back when she was upset because Laura was having problems. Nanny noticed that her father was managing to stay calm. “I asked him, ‘Why aren’t you upset? Don’t you care?’” said Nanny. “He said, ‘Of course I care, but you have to realize, this is your life. Your normal is always going to be different than everyone else’s. You still have to keep living and being happy.’”

Laura has not let her medical challenges stop her from doing what she loves. She’s been playing softball since she was 5 (Ron is a coach). Along with siblings Hannah and Orville, she holds a seat on the Klamath Tribes Youth Council. And just this last summer she was made the 2017 Klamath Tribes Restoration Powwow Queen, which requires her to make public appearances and participate in tribal affairs.

There’s no doubt that Doernbecher has saved Laura’s life, more than once. But her caregivers are quick to point out that Laura’s determination and strong family support have been equally important to her survival. >>>>

TEAM LAURA

Ron and Nanny Schroeder

Parents

Steven Skoog, M.D., F.A.A.P., F.A.C.S.

Professor of Urology

John Barry, M.D.

Professor of Urology

Debbie Wachsmuth, R.N., B.S.N.

Pediatric Transplant Coordinator

David Rozansky, M.D., Ph.D.

Professor of Pediatrics, Division of Nephrology

Amira Al-Uzri, M.D., M.C.R.

Professor of Pediatrics, Division of Nephrology

Elizabeth Fialkowski, M.D.

Assistant Professor of Surgery, Division of Pediatric Surgery

David M. Lee, M.D.

Associate Professor of Obstetrics and Gynecology

Hannah, 15, Orville, 12, Scarlett, 6 and Adaline, 8 mos.

Siblings



Nanny, Laura and
Ron in Chiloquin.

out. They do it with humility and no fanfare.”

Growing up Doernbecher

At 17, Laura is now on the cusp of adulthood. This is a challenging time for most kids, but even more so for kids with chronic medical conditions. With that in mind, Dr. Rozansky has been teaching Laura about her medications since she was 11, with the hope that the better she understands how they work, the more likely it is she will take responsibility for her health when she’s no longer under her parents’ watchful eye.

“I am continually amazed at Laura’s positive attitude,” said Dr. Al-Uzri. “They are a very tight family. That is one of the big factors that keeps her going.”

Dr. Rozansky echoes the sentiment.

“Doernbecher has been important, but I would give equal credit to Laura’s family,” he said.

“They have been supportive and very determined to learn about her condition and figure things

Laura has always enjoyed this part of her health care. “I started taking notes at my appointments, and Dr. Rozansky would quiz me,” she said.

That process also got Laura interested in pursuing a career in medicine. Even though she has missed many days of school, Laura is poised to graduate on time from high school, aspires to attend Portland State University next year and ultimately dreams of attending medical school at OHSU.

“The older I get, the more I understand my situation and realize I can help other people going through the same thing.”

LAURA SCHROEDER

Laura explains, “The older I get, the more I understand my situation and realize I can help other people going through the same thing.” Despite all of the difficult hours, days and months she has spent at Doernbecher, she dreams of working there as a doctor.

“I want to be a doctor at Doernbecher because it’s an excellent hospital. And I’ve grown up here. If I were a doctor at Doernbecher, I could show kids that they can do whatever they put their minds to.” ■



Laura and Scarlett
dressed in traditional
powwow regalia.



Laura attends a meeting
of the Klamath Tribes
Youth Council.

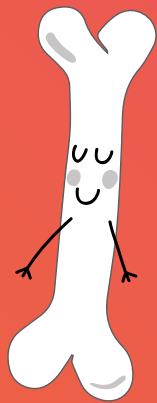
ONLY @ DOERNBECHER

Doernbecher Children's Hospital plays a vital role in the region, offering care and expertise not available at most local hospitals. Thanks to generous philanthropic support from donors like you, Doernbecher is able to continually expand the range of services available to kids, accelerate new cures for hard-to-treat children's diseases and train an exceptional new generation of pediatric specialists.

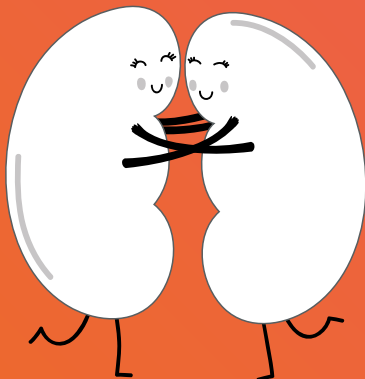


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children.



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program
between
San Francisco
and Seattle.



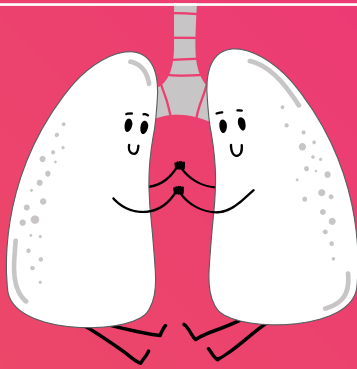
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kidney
transplant
service.

The **ONLY** children's
hospital in Oregon to earn top
ranking by *U.S. News and World
Report*. This year marks the
eighth year in a row that the
magazine ranked Doernbecher
among the nation's top
children's hospitals.

The **#1**
referral center for
cleft palates and
craniofacial problems
in Oregon.



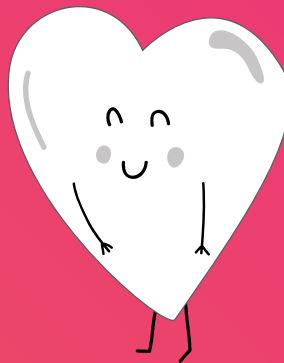
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Doernbecher transport
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MOVING ONWARD

/// THE CAMPAIGN FOR OHSU

Philanthropy is driving our momentum in multiple areas, helping OHSU continually redefine what's possible in research, education and health care. The *ONWARD* campaign has raised a total of \$1.545 billion toward its \$2 billion goal since its launch in 2013. The following are highlights of what your dollars helped make possible in 2017.

Total as of October 2017.

A notable groundbreaking

OHSU leadership joined Oregon Gov. Kate Brown and others to break ground on the OHSU Knight Cancer Institute research building. The seven-floor, 320,000-square-foot building will house top scientists and physicians working together to end cancer as we know it. The Oregon Legislature played a large role in the construction of the research building by authorizing \$200 million in state funding in 2014.

Gene repair breakthrough

OHSU's Shoukhrat Mitalipov, Ph.D., electrified the international scientific community by publishing research showing that it's possible to repair a heart disease-causing gene in a human embryo, and prevent that disease from being passed down to future generations. The findings, which appeared in the scientific journal *Nature*, inspired front-page coverage in *The New York Times* and thousands of headlines around the globe.

Life-saving heart surgery performed at Doernbecher

A team of OHSU pediatricians, cardiac surgeons and others repaired a rare and life-threatening congenital heart defect in 4-month-old Fatemeh Reshad. Baby Fatemeh and her family traveled from Iran to OHSU for the life-saving surgery, and their story captivated a global audience.

25 years of vision at Casey Eye Institute

The Casey Eye Institute celebrated its 25th anniversary this past year. Casey is a global leader in research, with innovations such as non-invasive optical angiography and gene therapy. The Casey Vision Screening Van travels statewide, providing eye exams at no cost to low-income, uninsured and underinsured Oregonians.

Exciting new recruits

OHSU and OHSU Doernbecher Children's Hospital hired more top scientists and health care leaders this past year. Here are just a few:

David Bangsberg, M.D., M.P.H., founding dean of the OHSU-PSU School of Public Health. Dr. Bangsberg is building the first urban school of public health in Oregon, a collaborative project that leverages the strengths of OHSU and Portland State University.

Yoon-Jae Cho, M.D., chief of the Division of Pediatric Neurology, Ericksen Family Endowed Professor for Research and scientific director of the Pediatric Brain Tumor Program. Dr. Cho seeks to understand the most lethal pediatric brain tumors and identify more precise treatments.

Bita Moghaddam, Ph.D., chair of the Department of Behavioral Neuroscience, Ruth G. Matarazzo Professor of Behavioral Neuroscience. Dr. Moghaddam has a long track record of translating research into new treatments.

Mike Heller, Ph.D., distinguished scientist in the OHSU Knight Cancer Institute Cancer Early

Detection Advanced Research (CEDAR) Center. As a bioengineering and nanoengineering expert, Dr. Heller will lead the CEDAR Center's efforts to use technology to detect lethal cancers much earlier.

Gordon B. Mills, M.D., Ph.D., director of precision oncology for the OHSU Knight Cancer Institute. Mills is one of the most highly cited medical scientists in the world, and brings a breadth of research and leadership experience to OHSU. His research focuses on the genomics and genetics of breast and ovarian cancers.

Bob Macauley, M.D., F.A.A.P., medical director of the Bridges Palliative Care Program and the inaugural holder of the Cambia Health Foundation Endowed Chair in Pediatric Palliative Care at Doernbecher Children's Hospital. The interdisciplinary Bridges team provides comprehensive care to children who face long-term, life-threatening conditions.

Unprecedented study for childhood brain development

The National Institutes of Health tapped OHSU to be one of 21 research sites for a groundbreaking study on cognitive development in the adolescent brain. The OHSU site is co-led by Bonnie Nagel, Ph.D., associate professor of psychiatry and behavioral neuroscience, OHSU School of Medicine.

New investments to advance vaccine research


An OHSU team led by Louis Picker, M.D., is developing a unique vaccine technology that could stop HIV, tuberculosis, malaria and other infectious diseases. This first-of-its-kind vaccine technology platform has been acquired by Vir Biotechnology, a biotech start-up backed by investors such as the Bill & Melinda Gates Foundation.

Read the complete progress report here:

OnwardOHSU.org/ProgressReport2017

DONOR SPOTLIGHT /// George and Janet Boldt



 George and Janet Boldt like to insist that they are the main beneficiaries of their philanthropy. “Doernbecher Children’s Hospital is one of our favorite charities. We’re learning so much and meeting so many interesting people who are doing worthwhile things. We’re definitely getting more back than we’re giving,” said George.

George and Janet founded and ran a steel import business (George B. Boldt, Inc., based in Wilsonville) for 45 years. Now retired, they are ready to give back. “We ran a successful business for years and have been blessed beyond any

measure we could have dreamed of. Now we are at the point where we’re ready to redistribute those blessings. We can’t think of a better recipient than Doernbecher,” said George. “We are doing what we are supposed to be doing: helping less fortunate children.”

The Boldts have been married for 49 years, running their business as a team and now making philanthropic decisions together. They first became Doernbecher supporters in 2008, after Janet saw a presentation at a Christmas gathering. Janet said, “A doctor from Doernbecher was there and it really touched my heart.”

“It’s a chance to help children who may not otherwise receive help. And, as it happens, it’s kind of fun!”

GEORGE BOLDT

The Boldts are longtime members of the Frank Doernbecher Guild and have included Doernbecher in their estate plan. More recently, after learning about OHSU’s plan to build a new guest house for out-of-town families, they were inspired to make a gift that could be used right away. They liked the fact that the guest house, the Gary & Christine Rood Family Pavilion, served both the logistical and emotional needs of families. And, like Gary and Christine Rood, they were inspired to invest in something that met such a crucial, immediate need.

“Families come from all over for care at Doernbecher and OHSU. They should be able to visit their loved one as often as possible. We believe it’s going to be fully booked the day it opens,” said George.

Janet is a passionate gardener. Their home in Wilsonville is surrounded by ancient fir trees and Janet’s beautifully tended perennial beds. So it’s fitting that they chose to make a gift designated for creating a special rooftop healing garden at the Rood Pavilion.

“I love being in the garden,” said Janet, “so the idea was very appealing.”

The George and Janet Boldt Healing Garden will offer an oasis of peace and beauty for out-of-town patients, families and caregivers.

When asked why they support Doernbecher, George said, “It’s a chance to help children who may not otherwise receive help. And, as it happens, it’s kind of fun!” ■

Here because of YOU

For more than 90 years, OHSU Doernbecher Children’s Hospital has provided the best, most comprehensive pediatric health care services in the region—saving countless kids’ lives. Your support makes that possible.

Please visit our website to read more inspiring stories about Doernbecher kids.

COMEBACK KID

Kya recovered from traumatic injuries after being crushed by a log.



Find out more about Kya at
OnwardOHSU.org/Kids

ONWARD /// THE CAMPAIGN FOR OHSU



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MACEY IS ON HER WAY. THANKS TO PEOPLE LIKE YOU.

Meet Macey. When she was 5, her parents got the call no family expects. Brain cancer. The news could have been devastating, but they knew she had an amazing team behind her. And after nine hours of surgery at OHSU Doernbecher Children's Hospital, there was hope.

At Doernbecher, the leading edge is everywhere, thanks to generosity from people like you.

For Macey, that meant two of the country's best pediatric brain surgeons. For kids across the Northwest, it means new discoveries, breakthrough treatments and more smiles.

Please make a gift today. So that whenever the call comes, Doernbecher's lifesaving care will be there.



Macey at Doernbecher. Today, she's a thriving 9-year-old. Your generosity makes all the difference.



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