Spring 2015
Healing for the Whole Family
Nature, Nurture & Everything in Between
Noteworthy News & Gifts
Local foundations step up to the Knight Cancer Challenge

Oregon and southwest Washington’s leading private foundations are responding enthusiastically to Phil and Penny Knight’s $1 billion, all-or-nothing challenge to defeat cancer as we know it. The following are the five largest local foundation grants and gifts to date.

The Collins Foundation awarded a historic $1 million grant to the Knight Cancer Challenge to help OHSU expand its imaging capacity. One of the initial projects is the purchase of advanced imaging and confocal microscopy equipment for the OHSU/Oregon Collaborative Life Sciences Building. Our world-class imaging center is crucial to our quest to understand how cancer develops — and what stops it. The Collins Medical Trust has provided three grants for cancer research since the beginning of the challenge, in addition to several grants to other areas of OHSU research. Additionally, Collins family members have been longtime generous supporters of OHSU.

The Ford Family Foundation has committed a total of $5 million aimed at expanding our state’s ability to deliver cancer prevention and care to rural Oregonians. The grant designates $2.5 million for a new statewide rural prevention and outreach network that connects community health care organizations to OHSU expertise. It will also help rural patients find opportunities to participate in clinical trials. To assist rural patients who must travel to OHSU for care and need temporary housing, an additional $2.5 million grant provides vital support to construct a patient and family guest housing complex.

The Meyer Memorial Trust has donated $500,000 to the OHSU Knight Cancer Institute’s Community Partnership Program. This program encompasses multiple community-led initiatives, including a grant program supporting community efforts to understand and address local cancer-related needs; avenues for enhanced collaboration between communities and OHSU cancer specialists; and the development of local expertise in securing additional funding to ensure the long-term sustainability of cancer-focused projects.

The M.J. Murdock Charitable Trust awarded two grants totaling more than $1.7 million to help OHSU purchase new gene sequencing and imaging technologies that will reveal new molecular- and cellular-level insights about how disease originates, progresses and responds to therapy. The impact of these grants will extend beyond cancer to support the needs of scientists from multiple disciplines.

The Oregon Community Foundation’s board of directors donated $1 million — the largest discretionary award in OCF’s 40-year history. “Many of OCF’s donors have been generous in their individual support of the OHSU Foundation over the years,” said President and CEO Stan Williams. “This grant signals our intention to honor those gifts by increasing their impact.”

“Local foundations recognize that the Knight Cancer Challenge is a once-in-a-lifetime opportunity to improve the health of our communities. We are grateful for their unprecedented level of support.”

— L. Keith Todd
President, OHSU Foundation
Families who must travel far from home for specialized medical care face a double crisis: the heartbreak of a life-threatening illness and the emotional, logistical and financial burden of an extended out-of-town stay.

OHSU is building a new five-story housing complex on Portland’s South Waterfront to provide families in crisis with an oasis of healing and stability.

John Faletagoai was 15 and fighting aplastic anemia in an Anchorage hospital when his doctors realized they lacked the expertise to save his life. With no time even to pack a suitcase, John and his mother, Hana, boarded a Life Flight Network helicopter to OHSU Doernbecher Children’s Hospital that afternoon. Arriving in an unfamiliar city, Hana was relieved to learn there was a vacancy for her at Ronald McDonald West House Waterfront. Here she could rest after long days at the hospital with John and be with other parents going through the same ordeal.

Hana is one of hundreds who arrive at OHSU from Alaska, Idaho, northern California, rural Oregon and elsewhere to help their loved one recover and thrive under the care of Doernbecher or OHSU experts. Many of them will struggle to find a place to stay that can accommodate their family — and their budget. Approximately 45 percent of OHSU’s hospitalized adult patients and 49 percent of pediatric patients reside in rural Oregon or neighboring states.

“Excellent medical care is only one aspect of healing a child — you have to consider the whole family. When a child is seriously ill for a long time, everything is put under strain — the marriage, the job, the other siblings. We do everything we can to ease that pressure, so the family can focus on healing. Family housing is the backbone of our ability to support the whole family.”

— Dana Bruner, M.D., physician-in-chief, OHSU Doernbecher Children’s Hospital

Patients travel to Portland for specialized services that other regional hospitals don’t offer:
• advanced cancer care
• access to Phase I clinical trials
• adult and pediatric bone marrow transplants
• pediatric epilepsy surgery
• advanced fetal therapy
• pediatric brain tumor surgery

John is recovering from a bone marrow transplant (his brother was his donor). He attends school online and hopes to get back to his judo practice very soon.

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“I’m one of six kids, but it’s just me and my mom right now. Dad’s staying home in Anchorage to keep the household together.”
Not enough of a good thing

OHSU is able to offer housing to some patients, but not all. In 2014, Doernbecher housed approximately 580 families for 5,899 nights at West House Waterfront. Located on the sixth floor of the Marriott Residence Inn, the facility is operated in partnership with Ronald McDonald House Charities of Oregon and Southwest Washington. In 2014, the West House had to turn away families nearly 700 times due to lack of space.

“The Knight Cancer Institute works with a patient navigator from the American Cancer Society to help patients and their families/caregivers find short-term housing. The Knight depends on hotels donating or discounting rooms to ACS. Teisha’s Place, a private home in North Portland, is another resource for bone marrow transplant patients and families. (See page 9.)

"Some of our bone marrow transplant patients spend four to six weeks in the hospital and then must stay in Portland with a full-time caregiver for three months to receive specialized follow-up care. We do all we can to find housing for these patients and their caregivers. We have to get really creative sometimes. " — Susan Hedlund, M.S.W., L.C.S.W., manager, Patient and Family Support Services, OHSU Knight Cancer Institute

In 2014, the West House Waterfront had to turn away families nearly 700 times due to lack of space.

No one plans for this

A diagnosis of cancer is devastating enough without having to uproot your whole life. Providing a place to stay for the patient and their family and/or caregiver is one more way OHSU can support them in their journey.” — Anne Raish, M.H.A., R.N., vice president for oncology services, OHSU Knight Cancer Institute

Building a solution

OHSU has recently unveiled a family housing plan that’s every bit as world-class as the care we provide here. To meet the growing need at Doernbecher, an anticipated increase in patients at the Knight Cancer Institute and a financial necessity for even the most financially secure families, but it is especially difficult if one or more members of a family must give up a job to be with a hospitalized loved one. A 2012 survey found that six out of 10 families of children with cancer reported spending between $1,000 and $5,000 on non-medical expenses like transportation and housing on top of thousands of dollars in out-of-pocket medical costs for cancer care.

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Architectural plans are still evolving, but OHSU currently intends to offer 80 guest beds in 68 units. One of the house’s five floors will be devoted to common gathering spaces. Two guest room floors will be reserved for families of pediatric patients and the remaining two floors will be open to families or caregivers of adult patients. The house will significantly expand OHSU’s capacity to accommodate families.

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“In 2014, the West House Waterfront had to turn away families nearly 700 times due to lack of space.

“I work here, I thought I understood what this was like, but I really didn’t get it until my son needed a bone marrow transplant when he was 18 months old. It was devastating. Parents are pulled in so many different directions. Any help we can offer to parents is critical to healing our patients.” — Sarah Power, L.C.S.W., social worker manager, Doernbecher Children’s Hospital

OHSU’s new Patient and Family Guest House will:

• Provide an affordable housing option for out-of-town patients and families by offering sliding-scale rates.
• Enable families visiting OHSU and OHSU Doernbecher for extended stays to participate in clinical trials.
• Promote social interaction and support.
• Create clinical benefits for patients — studies show a positive benefit from family involvement in complex care.
• Allow patients from out-of-town to participate in clinical trials.

“Having a space away from your home for extended stays offers families an opportunity to spend more quality time with their loved ones and lessen the stress associated with having to uproot your whole life. Providing a place to stay for the patient and their family and/or caregiver is one more way OHSU can support them in their journey.” — Anne Raish, M.H.A., R.N., vice president for oncology services, OHSU Knight Cancer Institute

With your help, we can create an oasis of peace and healing for patients and families facing the stress of a medical emergency. Email ohsufinfo@ohsu.edu to make a gift today.

To learn more about building a Patient and Family Guest House, join OHSU leadership, faculty, staff and distinguished guests at our Building a Solution — An Evening of的 Philanthropy event on Friday, April 1, 2016 at the Oregon Convention Center. In recognition of your generosity, we are pleased to offer three levels of support:

• $50,000 - $99,999: Founding Partner
• $100,000 - $999,000: Founding Sponsor
• $1 million and above: Founding Benefactor

For more information, visit ohsu.org/PHH.
Brylee is in treatment for acute myeloid leukemia. She and her parents Rob and Monica traveled to OHSU from Boise, Idaho. “Monica and I take turns sleeping at the hospital and at West House. Brylee's four-year-old brother Zayden is staying with his aunt in Boise until day 100 of chemo. We're lucky: Monica was able to arrange a virtual workplace with her employer for the next six months while Brylee is in recovery,” said Rob.

Reagan, Brantley and Marshall Koumentis: 2 months

The Koumentis triplets weighed little more than 2 pounds each when they were born at OHSU Hospital. They spent 63 days in the neonatal intensive care unit. Because Marshall still has health problems, his parents Bre and Cameron Koumentis of Salem will continue to stay at West House while he goes in for surgery and ongoing care. “Bre has been at the hospital every day we’ve been here, and it’s really helped a lot staying so close by. The nurses said her closeness to the babies has helped them thrive,” said Cameron.

Teisha Helgerson, 1969 – 2011

Teisha was an accomplished musician and real estate agent who lived in North Portland. She received a bone marrow transplant in 2007 at OHSU to treat her chronic lymphocytic leukemia. The leukemia returned and she died in 2011. After Teisha’s death her mother, Deb Helgerson, opened Teisha’s home to other families going through the bone marrow transplant process. Deb offers the house (called Teisha’s Place) for free, and works with a local church to raise funds to cover utilities. “When Teisha was diagnosed we considered the possibility of going for treatment out of state. The idea of leaving my job, relocating to a city I didn’t know, finding housing — it was overwhelming. It’s beyond my imagination how people do it,” said Deb. “It is a gift to be able to share Teisha’s home as a way to support and nurture the healing spirit in our guests.”

Sylvia Rea Buzzard: 2 months

Sylvia travelled to Portland with her mother Brittany shortly after being born in Anchorage. At Doernbecher they learned she has campomelic dysplasia, a severe disorder that affects development of the skeleton, reproductive system and other parts of the body. “I had to quit my job and leave my other two children with family members in Anchorage. When we Skype, my oldest boy always asks when I’m going to come home,” said Brittany.
What makes some kids more likely than others to develop ADHD, autism or dyslexia? How can we identify and protect kids at risk for these and other brain disorders? Is it possible to treat these conditions? Together they are expanding what we know and how we treat a wide range of developmental brain disorders.

Expanding on the traditional “nature-vs.-nurture” debate, OHSU neuroscientists are taking an all-of-the-above approach to these questions. Together they are expanding what we know and how we treat a wide range of developmental brain disorders.

“OHSU is special because we have the capacity to go after these questions from many different directions. We are not limited by finding one kind of answer—we are working with several leading angles in order to help families faster.” — Joel Nigg, Ph.D., professor of psychiatry and behavioral neuroscience

Are there different kinds of ADHD? Joel Nigg, Ph.D., along with Damien Fair, Ph.D., and Sarah Karalunas, Ph.D., are creating subphenotypes—categories of children who have different forms (subphenotypes) of ADHD and, therefore, may respond differently to treatments. As we have learned in cancer and other diseases, correctly classifying a patient’s specific disease type helps ensure safe, effective treatment. Since 2018, Dr. Nigg’s team has recruited close to 700 families from greater Portland area to help his team better understand ADHD and its physiological and temperamental typologies.

What can we learn from looking at brain structure? Researchers are looking to detect and describe ADHD in young children in increasingly clear ways. Using advanced magnetic resonance imaging, Dr. Fair and others have learned that the brains of people with ADHD look very different than typical brains. The teams are beginning to develop ways to classify different types of ADHD.

Where does it all begin? As recently as the 1970s, it was widely assumed that autism was caused by “refrigerator mothers,” moms who didn’t show enough affection. Parents were also told that their parenting style was causing their children ADHD. Science has come a long way since then. Now we understand that such conditions are linked to a mixture of genetic and subtle environmental factors that are potentially set in motion even before birth. Knowing that there is no single answer that will apply to all children with these conditions, OHSU scientists are looking at the fundamental question from a variety of directions.

Are autism and ADHD genetic? The question of whether autism and ADHD run in families is one of the world’s leading experts in epigenetics, Dr. Nigg, research also has shown that even low levels of lead may contribute to ADHD risk, possibly due to some children’s increased genetic sensitivity to the substance.

How can early experiences change our genes in a way that affects brain development? — Eric Fombonne, M.D., professor of psychiatry and director of autism research, Institute for Development & Disability

“We have the ability to look at multiple factors that affect the developing brain, and to translate what we learn into new provincial interventions that can help children now and over their lifetime.” — Eric Fombonne, M.D., professor of psychiatry and director of autism research, Institute for Development & Disability

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“OHSU is home to some of the world’s leading experts in epigenetics, an emerging field of research that looks at how early life experiences — such as stress, nutrition and exposure to toxic chemicals — alter gene expression in ways that lead to disease. Beth Willett, M.D., and Dr. Nigg’s research will help identify clearer paths to prevention and treatment.

Are autism and ADHD genetic? Brian J. O’Roak, Ph.D., has pinpointed 27 genes that, if mutated, contribute to a child’s development of these disorders. The teams are beginning to develop ways to classify different types of ADHD.

What role does nutrition play? Dr. Nigg, Elmore Sullivan, Ph.D., and their colleagues have shown that children with ADHD need to have balanced levels of omega-3 fatty acids, and that some children’s ADHD symptoms improve when they get more omega-3 fatty acids in their diet. Dr. Fair, Sullivan and Nigg are now using animal studies to zero in on the connection between omega-3 fatty acids and ADHD in the brain.

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### Knight Cancer Challenge

Several recent gifts have brought OHSU closer to our goal of raising $500 million for cancer research.

- The McCoys also committed $50,000 to help bring a full-time facility dog to Doernbecher. Hope, a highly trained English Cream Golden Retriever, is already on the job providing affection and comfort to Doernbecher patients and their families.

- The Harry A. Merlo Foundation has made a $1 million gift to support the Knight Cancer Challenge. The family is working to establish a pediatric oncology professorship.

- Kate and Craig McCoy made a $1.5 million endowment, to support the Harold Schnitzer Knight Cancer Institute and the Department of Cell, Developmental & Cancer Biology in the OHSU School of Medicine. Schedin, who was recently recruited from the University of Colorado Denver, studies the impact of pregnancy on breast cancer in young women.

- John and Joanne Lilley have made a significant gift of $250,000 to help protect cancer patients from a serious side-effect of chemotherapy.

- Several funders contributed, including CareOregon, the Oregon Community Foundation. OHSU received a $140,000 grant to support community dentistry from the NIH to continue this important research.

- A gift of $500,000 from Fred Thompson will complete the work of the Knight Cancer Institute and the Department of Cell, Developmental & Cancer Biology in the OHSU School of Medicine. Schedin, who was recently recruited from the University of Colorado Denver, studies the impact of pregnancy on breast cancer in young women.

- A $100,000 grant from The Kay Yow Cancer Fund visits Pepper Schedin, Ph.D., in her lab.

- A grant of $4.15 million donation through their estate. The gift will support patient care at Casey and research that will improve treatment options for patients everywhere.

- The Neufelds visited Dr. McBride and graduate student Brett Dufour and told them of their personal experience with the disease. The story inspired Dufour to focus his studies on the disorder cognitive and emotional impacts. The gift allowed him to collect promising initial data that in turn qualified him to receive a $100,000 grant from the NIH to continue this important research.

- Members of the DeStefano family made a generous donation to the Knight Cancer Challenge in honor of Mark’s late parents. The Maddens are longtime supporters of the Doernbecher and the Doernbecher Freestyle program.

- Doernbecher Children’s Hospital Foundation board member Kate McCoy and her husband, Craig, pledged $1 million to Doernbecher in support of the Knight Cancer Challenge. The family is working to establish a pediatric oncology professorship.

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- The foundation’s gift will support the Knight Cancer Institute’s endowment and reflects its commitment to ending cancer as we know it.

- A gift of $500,000 from Fred Thompson will complete the endowment of The Fred and Joan Thompson Endowed Professorship in glaucoma care and research.

- OHSU Center for Regenerative Medicine is finding new ways to rebuild heart muscle in those who have experienced congenital heart failure after chemotherapy treatment. Hans Jörg Vatheuer, founder of the Vatheuer Family Foundation, suffered from various heart conditions that greatly impacted his quality of life in his later years. The foundation made a gift of $510,000, and a prior gift of $113,000, to support the research of Konstantin Gobert, M.D., and his team at the OHSU Center for Regenerative Medicine in their work on cardiac muscle regeneration. This research promises to help protect cancer patients from a serious side-effect of chemotherapy.

- John and Joanne Lilley have made a significant gift of $250,000 to help protect cancer patients from a serious side-effect of chemotherapy.

- A $100,000 grant from The Kay Yow Cancer Foundation for Cancer Research and The Kay Yow Cancer Fund will benefit the research of Peppy Schepen, Ph.D., at the Knight Cancer Institute and the Department of Cell, Developmental & Cancer Biology in the OHSU School of Medicine. Schepen, who was recently recruited from the University of Colorado Denver, studies the impact of pregnancy on breast cancer in young women.

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- Two significant gifts in this period will benefit the OHSU Casey Eye Institute. Doug and Jo Peterson made a $4.5 million donation through their estate. The gift will support patient care at Casey and research that will improve treatment options for patients everywhere.

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- The fund will bring critical resources to OHSU — and their researchers — to help change the trajectory of mental health diagnosis and treatment for young people like Eric. Eric DeStefano was a soccer player, a loving son, a devoted brother and a caring friend. At the age of 14, following a four-year battle with mental illness, he took his own life.

- The DeStefano family made a generous gift to establish the Eric DeStefano Innovation Fund in Mental Health Imaging Research. The fund will help arm the causer and early signs of mental illness to help change the trajectory of mental health diagnosis and treatment for young people like Eric. Eric DeStefano was a soccer player, a loving son, a devoted brother and a caring friend.

- “Our search for a meaningful way to honor Eric’s life led us to the groundbreaking brain imaging research being done at OHSU’s Eric’s mother, Karen, speaking on behalf of the whole family. “Here we stand as a way to honor our son and brother and to fulfill his desire to find more innovative answers and solutions for himself and millions of others affected by mental illness.”

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OHSU collaborates with PSU to expand educational and community enrichment opportunities in the region

Encouraged by the success of the OHSU/OUS Collaborative Life Sciences Building, OHSU announced that it will invest $7.5 million to develop Portland State University’s Collaborative Life Sciences Building, a new facility for educational, community and athletic events on Portland’s South Park Blocks. When completed in 2017, the pavilion will provide space for OHSU events such as commencement and athletic events on Portland’s South Park Blocks. When completed in 2017, the pavilion will provide space for OHSU events such as commencement and athletic events on Portland’s South Park Blocks.

Study identifies new genetic risk factors for autism

OHSU scientist Brian J. O’Roak, Ph.D., has published the results of a groundbreaking autism study in the journal Nature. O’Roak’s study has identified 27 genes that, if mutated, will either cause autism or contribute to its risk. The study is the most comprehensive look at the genetic make-up of families where one child is affected by autism.

The work establishes the largest number of high-confidence genetic risk factors for autism to date and provides important insights into the underlying biology of the disorder. “Ten years ago, when I began researching autism, we never would have predicted these genes and pathways would be involved,” said O’Roak, assistant professor of molecular and medical genetics in the OHSU School of Medicine and member of the Institute on Development & Disability at OHSU.

O’Roak collaborated with scientists at the University of Washington, Yale School of Medicine and Cold Spring Harbor Laboratory in New York. He recently was selected as a prestigious Alfred P. Sloan Research Fellow in neuroscience for his work.

Physician leader known for breakthrough in cancer care joins OHSU Knight Cancer Institute

Raymond Bergan, M.D., has joined OHSU as the head of the Division of Hematology and Medical Oncology in the School of Medicine and associate director of medical oncology for the OHSU Knight Cancer Institute. Bergan, who was recruited by O’Roak collaborated with scientists at the University of Washington, Yale School of Medicine and Cold Spring Harbor Laboratory in New York. He recently was selected as a prestigious Alfred P. Sloan Research Fellow in neuroscience for his work.

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The inpatient facility will include psychiatric emergency services for people undergoing an acute psychiatric crisis, as well as an inpatient facility with services for both adults and adolescents.

The center is modeled on a successful program in Alameda County, Calif., where 75 percent of the patients are successfully treated for mental illness.

Local providers come together to improve behavioral health care

In an unprecedented collaboration, Adventist Health, Kaiser Permanente, Legacy Health and OHSU plan to open the area’s first comprehensive behavioral health care center in late 2016. Called the Unity Center for Behavioral Health, the facility will include psychiatry emergency services for people undergoing an acute psychiatric crisis, as well as an inpatient facility with services for both adults and adolescents.

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