Connection
Seattle Children's | November 2022

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WHAT’S NEXT

On June 2, I had the extraordinary honor of stepping into the role of senior vice president and chief development officer of Seattle Children’s Foundation and Guild Association. As many of you know, I follow Doug Picha, who built a strong record of accomplishments in his 41 years of serving Seattle Children’s mission.

I also joined the organization just after this community raised a historic $1.4 billion completing It Starts With Yes: The Campaign for Seattle Children’s. You’ll read a few stories in this publication about some of the advancements made possible because of your contributions.

So, naturally, as I have been spending the past few months getting to know our donor community, the question I get asked most is “What’s next?”

For Seattle Children’s, it has been the same answer for 115 years: We will not stop until every child has the hope, care and cures they need to live the healthiest and most fulfilling life possible.

Indeed, upholding our founding promise to provide care for all children, regardless of a family’s ability to pay, is more relevant now than ever before. I’m amazed by the amount of uncompensated care that we provide thanks to philanthropic support. In fact, the latest data shows that we provided uncompensated care and undercompensated care to more than 194,000 families last year. That’s double what we were able to provide a decade ago.

Your generosity is helping so many children and families, including patients like Harper and the Hurtado siblings, whose inspiring stories you’ll read in the coming pages. The treatments that have changed these children’s lives are made possible by all the incredible members of the Seattle Children’s community: our expert doctors, nurses, medical staff, researchers, and donors and volunteers like you.

This spring and summer, we celebrated the opening of the Forest B building at the hospital campus and Odessa Brown’s Children Clinic at Othello Square. In the coming year, we will also open a new space on Sand Point Way for autism, mental and behavioral health care and research, where brain health experts will work side by side to foster new ideas and accelerate the pace of progress for kids.

We also launched an exciting new postdoctoral scholars’ program, Invent at Seattle Children’s, which invests in training early career scientists historically underrepresented in biotech in the development of therapeutics for childhood conditions, which you can read about on pg. 10.

I am excited for this new chapter and humbled to serve children and families in such a meaningful way. I look forward to our journey together as we continue to imagine the future of philanthropy at Seattle Children’s and discover remarkable answers to the question “What’s next?”

Sincerely,

Dondi Cupp
Senior Vice President and Chief Development Officer
Seattle Children’s Foundation and Guild Association
Two years ago, Meagan Chittim stood in a hospital room at Seattle Children’s cradling her 1-year-old daughter, Harper, against her chest. Her fiancé, Josh, huddled close to them and kissed the thinning hair on top of their baby’s head.

A feeding tube was routed through Harper’s nose and her eyes were brimming with tears. Exhausted, she snuggled into her mom’s arms as a photographer took their picture.

Meagan and Josh feared those would be the last photos taken of their baby girl.

“It was a roller coaster.”

Six months before, Harper became seriously ill. After multiple visits to their pediatrician in Yakima, Meagan took her to an emergency room where blood tests revealed Harper had leukemia.

“It was shocking,” Meagan says. “Thirty minutes later we were on an emergency flight to Seattle Children’s.”

The family didn’t return home for nearly two years.

The type of leukemia Harper had — acute lymphoblastic leukemia (ALL) — is typically harder to treat and has lower survival rates when it occurs in infants who are less than a year old.

Harper’s case was exceptionally challenging. She didn’t respond to standard chemotherapy, and her care team, part of Seattle Children’s High-Risk Leukemia Program, believed a stem cell transplant would give Harper the best chance of surviving, but they had to eliminate the majority of her ALL cells first.

Drs. Kasey Leger and Brittany Lee, Harper’s primary oncologists, started her on a novel immunotherapy medication called blinatumomab, which effectively destroyed many of her ALL cells. Two weeks later, the team discovered that some of Harper’s ALL cells still remained, so the team gave Harper blinatumomab again, which finally suppressed her cancer enough for her to have a stem cell transplant just before her first birthday.

The team had done everything they could to get Harper healthy enough for a stem cell transplant, hopeful that it would be the treatment to finally cure her. Tragically, Harper’s leukemia was back less than a month later.

“When leukemia comes back so soon after transplant, patients have very few treatment options, if any,” says Dr. Corinne Summers, Harper’s stem cell transplant specialist. “Many patients will not survive long term.”

Harper’s parents were terrified they were going to lose her. “Her bone marrow was packed with leukemia,” Josh remembers. “You could tell the life was slipping out of her and she just looked like it was going to be the end.”

They struggled to decide if they should continue treatment. “How do you know when enough is enough?” Meagan says. “When do you say, ‘We can’t do this to her anymore?’ Harper couldn’t tell us how she was feeling, so it was all our decision.”

This unfortunate outcome, called lineage switch, occurs in less than 5% of infant ALL cases.

“It was a roller coaster,” Josh says. “She didn’t do anything they expected her to do. It felt like every day we had to come up with a new plan.”

Drs. Leger and Lee gave Harper a different kind of chemotherapy that destroyed the new AML cells. Some of her ALL cells still remained, so the team gave Harper blinatumomab again, which finally suppressed her cancer enough for her to have a stem cell transplant just before her first birthday.

NO STONE UNTURNED: How Harper’s Unrelenting Care Team Saved Her Life

By Alice Thavis and Rose Ibarra
Meagan and Josh worked closely with the care team to decide what to do next. “Those conversations were emotional for all of us,” says Dr. Lee. “Thankfully, we had a close, trusting relationship with their family and were able to give recommendations that reflected what they wanted for their daughter and what they felt was most important.”

After much consideration, Meagan and Josh decided Harper was strong enough to continue treatment. Drs. Leger and Lee filed a compassionate use request with the Food and Drug Administration to give Harper an investigational chemotherapy drug called venetoclax. Their request was approved but the treatment didn’t work.

Collaborating with the family, the team decided to try an unprecedented approach — giving Harper an investigational chemotherapy drug called blinatumomab one more time. There was no evidence suggesting the medication would work so soon after a bone marrow transplant and with such a high burden of leukemia, but within a week Harper was in remission today.

“Harper had a very unique disease in that her leukemia manifested as both ALL and AML,” says Dr. Leger. “Thankfully, we have team members with deep expertise in each of those diseases. Having internationally recognized chemotherapy, transplant and immunotherapy specialists on our team allowed us to be creative with her care when she needed to go beyond the standard pathways.”

Risk of relapse

Today, Harper is a joyful, boisterous 3-year-old who loves experimenting with musical toys and splashing around in her kiddie pool.

Because of the treatments Harper received at such a young age and the extended time she spent in the hospital, she is behind on some developmental milestones like speaking and walking. Still, Meagan and Josh say she’s catching up.

“She’s starting to bloom and take off and it’s so nice to see,” Meagan says. “At the same time, we can’t get too comfortable. We know how relentless her disease is and that it could come back one day.”

Harper’s family encourages community members to support cancer research at Children’s so new treatments can be developed for Harper and other kids like her.
Choosing Liver Transplant

One family’s journey in selecting Seattle Children’s liver transplant program

With outcomes among the best in the nation, Seattle Children’s pediatric liver transplant program has completed over 330 transplants since 1990 and is the only such program in the Pacific Northwest.

Even with such a high success rate, the decision to go forward with liver transplants for their four children was not taken lightly by Justino and Eugenia Hurtado.

All four of the Hurtado children have maple syrup urine disease (MSUD) — a rare genetic metabolic disorder in which the body is unable to break down certain parts of proteins due to an enzyme deficiency. For years the children were on a strict formula and diet because many foods could lead to a buildup of toxic substances that can result in organ and brain damage.

Justino describes how the smallest change in their diet can disrupt the children's health, saying, "If they eat something, like for example, a candy, the defenses they fall down completely, and we notice that they are tired and sleepy. We know when they’re not feeling well.”

All the Hurtado children have had to be admitted to Seattle Children’s over the years because of MSUD.

Maritza, 24, says that her parents would take her and her siblings to the hospital if they got sick. They went to avoid getting a fever and to ensure that the toxins in their blood would go down. They had to remain at the hospital until their levels were back to normal.

It can be difficult for children with MSUD to avoid foods that will cause a reaction. Imagine being invited to a birthday party but not being allowed to join your friends in eating a slice of cake.

Dr. Evelyn Hsu, division head of gastroenterology and hepatology, says that the decision to have a liver transplant for patients who have a metabolic disease can be difficult because the disease can be managed.

The discussion about a liver transplant can be very scary for patients and their families. There are risks of rejection, complications in surgery, and then needing to be on 10 different medications for possibly up to one year post transplant.

That is how Justino and Eugenia felt. They were scared about the risks.

Dr. Hsu often counsels her patients that they're "kind of trading one disease condition for another." This is because of the medications that patients must take for the rest of their lives. But the benefits often outweigh the risks.

After learning about a successful liver transplant with another MSUD patient at Seattle Children’s, Justino and Eugenia decided to place their children on the transplant list in 2020.

Since then, two of the Hurtado children have received their transplants: Marysol, 10, was the first, and Fernando, 17, was next. Both had successful surgeries and are enjoying expanding their diets and trying previously off-limits foods. Goldfish crackers and ice cream have become favorites.

Maritza has said that Marysol is saving trying some foods until after Maritza has her transplant so they can try them together.

It isn't just the freedom in their diets that has changed. Marysol and Fernando both have more energy. Their sister Maritza even noted, "Fernando’s doing exercise. He’s walking. He never gets tired.”

The Hurtados are thankful for the care they have received at Seattle Children’s, including help with managing the children’s MSUD and the entire transplant journey.

100% One-year patient survival rate for both kidney and liver transplants (Over 5% higher than the national average)

56% Of our liver transplants are done using advanced techniques that allow more children to get their transplants sooner

330+ Transplants since program inception
Groundbreaking ‘Invent’ Program Builds Diversity in Research

By Alice Thavis

Last summer, as kids were wrapping up the school year and the weather was warming, Seattle Children’s Research Institute was launching a first-of-its-kind program. The institute is bringing underrepresented scientists into the research field to help cure the most debilitating childhood diseases — and it’s all happening through a new model that pulls together diverse talent, innovative thinking and unprecedented funding support.

In the past 10 years, Seattle Children’s has launched a portfolio of clinical trials for leukemia, lymphoma, brain tumors and solid tumors — and cancer is just the start. Thanks to the ability to translate laboratory discoveries into real-world treatments at our own Good Manufacturing Practices (GMP) facility — also known as the Cure Factory™ — the sky is the limit. Genetic and cellular therapies hold the promise of cures for a host of other diseases that affect children, including sickle cell disease, autoimmune diseases and more.

Why therapeutics and why now?

All children deserve the best shot at a long and healthy life, yet they face diseases that often don’t have the medicine and treatments needed for a cure. Adult treatments can sometimes be modified for pediatric use, but Seattle Children’s is taking a stronger approach.

Researchers are committed to developing cellular, protein and gene therapies for pediatric diseases, with the knowledge that children are more than “mini-adults” and need treatments that are fully customized for their age and developmental stage.

Dr. Alison Williams and Eric Nealy are working toward more diverse representation in research to achieve better health outcomes for all patients.

Seattle Children’s has put together a robust plan to support the scientists. They’ll have access to extensive education, mentorship, biotech infrastructure and financial resources. Scholars will receive guidance from mentors in their research field to create cellular, gene or protein therapeutics that ultimately advance to clinical trials for children, all while preparing for careers in the biotech industry or academia.

More than 80% of recruiting efforts focused on building a diverse community of scholars

Drs. Alison Williams and Jim Olson are part of the team that launched Invent at Seattle Children’s to bring diverse research talent to the field of therapeutics.

“Think of recruiting efforts focused on building a diverse community of scholars as the traditional application process in order to bring the most promising applicants forward,” says Dr. Jim Olson, program director. “We want to create an on-ramp to the biotech sector for people who have traditionally not had that opportunity.” The reason is simple and compelling: More diverse representation in biotech contributes to better health outcomes for all patients.

Diverse talent for diverse ideas

To develop therapeutic treatments that are as strong and innovative as the diseases they fight, Seattle Children’s is building the team of the future. We need the next generation of scientists to step forward and discover new, effective and nontoxic therapies for kids. The recently established Invent at Seattle Children’s Postdoctoral Scholars Program takes a huge leap in that direction.

The Invent program brings together talented young scientists historically underrepresented or excluded in the research field who are ready to tackle the difficult challenge of curing pediatric diseases. Because some admission processes in academia and healthcare contribute to systemic racism, Seattle Children’s has upended the
Success through mentorship, training, resources

Dr. Alison Williams is a research scientist in Olson’s lab who is focused on developing therapeutics for all children with brain cancer. Her sister is a cancer survivor, and after completing her doctorate, Williams switched fields from chemistry to cancer research. “I wanted to do research that directly helps people,” she says. She found it challenging to find a position in cancer research until she joined Olson’s lab.

His mentorship was truly life-changing and has allowed me to continue my career as a scientist today,” Williams says.

With that model in mind, Williams is taking responsibility for recruiting the Invent at Seattle Children’s biotech mentors.

Donors partner to launch program

Invent at Seattle Children’s represents a $45 million investment in diverse scientists who are early in their careers and want to design cures for kids. Washington Research Foundation made a $12.5 million award to support the launch of the program — the largest single-program grant in its 40-year history. This critical funding, combined with additional funds from Seattle Children’s and its donors, will support 10 scholars per year or 50 total over the next five years.

“Many organizations have important diversity, equity and inclusion goals,” says Olson. “Few commit $45 million, with plans to raise an additional $30 million, to meet those goals.” Olson hopes the example set by Seattle Children’s and Washington Research Foundation is one that other institutions will follow.

The potential for the 50 postdocs to ultimately find their own biotech companies and advance pediatric research is tantalizing. With a proven track record of launching hundreds of clinical trials and 14 biotech companies, Seattle Children’s is positioned to make tremendous long-term contributions to care and cures for kids through the Invent program — and donors are excited about the possibilities.

“There’s a very strong entrepreneurial spirit here — and a strong donor community,” says Olson. The combination of the two will provide the essential underpinnings of the Invent program. Already, generous donors have stepped forward to provide $2.3 million in gifts to support the program and help meet the $10 million fundraising commitment.

In this and countless other initiatives, philanthropy is fully present and its donors, will support 10 scholars per year or 50 total over the next five years. Funding the program.”

Meet the Inaugural Scholar

Exciting news! Dr. David Johnson was the very first scholar selected for the Invent program and moved from New York City to start his postdoc in August. He says he applied because of the unique structure of the program, which he sees as a bridge to the next stage of his career, and also because of the thoughtful approach and high-caliber leadership of Invent at Seattle Children’s.

Johnson is excited to be part of the ground floor. “With the right support and backing, I think this will revolutionize the way principal investigators and trainees think about their career trajectories after their PhDs — it is one of a kind,” he says. “To be at the inception of the Invent program will be an ongoing gift for both the scholars and the donors who are funding the program.”

“Thank you.
To many children, professional athletes are real-life superheroes, which makes it even more special that Cliff Avril, Seattle Seahawks Superbowl champion, serves on Seattle Children’s Foundation Board of Trustees.

“I was inspired to join the Seattle Children’s Foundation Board after supporting Odessa Brown Children’s Clinic (OBCC) the last few years,” Avril says.

In 2014, Avril and his wife, Tia, formed the Cliff Avril Family Foundation. Equipped with the mission to encourage active lifestyles among today’s youth in an effort to decrease diabetes, Avril became very hands-on in creating change.

Over the past few years, he has made a tremendous impact on Seattle Children’s patients and families. Avril mentors young boys through OBCC as part of his “Cliff’s Crew.” When the pandemic began, he partnered with Safeway to give OBCC families gift cards for groceries. After the opening of OBCC Othello in South Seattle, Avril and former Seahawks teammates organized a day of service at the clinic where they stocked up the community marketplace with diapers, wipes, hygiene items and shoes. He also recently launched Champions of Change alongside fellow Seahawks champions Doug Baldwin and Michael Bennett. In June, the group hosted their first Celebrity Basketball Game, benefiting OBCC and other local nonprofits.

“I would encourage others to actually take a visit and see firsthand the work that the Seattle Children’s organization is doing for our community,” Avril says. “There’s nothing like stepping into a clinic, such as OBCC, and witnessing the impact of the care being provided.”

The Odessa Brown Children’s Clinic mission means that families facing some of the hardest moments of their lives can be hopeful that the staff and team at Seattle Children’s will do whatever is possible to ensure they provide the best care,” Avril says.
What does philanthropy mean to you?

The power of philanthropy unleashes human potential in ways that transform and save lives. Philanthropy is about serving other people. It means you care and you want to make a difference. You give your time and you volunteer. And yes, it does mean you give money, but you can give at any level. Everyone can be a philanthropist.

What are you most looking forward to at Seattle Children’s?

Without a doubt it’s meeting the people, learning about the research programs, connecting with donors and volunteers, learning more about our history and becoming a champion for our mission.

Why Seattle Children’s?

The role Seattle Children’s plays in the community is just so important. I’m a parent, and I don’t think there’s anything more upsetting than the sound of your child’s voice in distress. I want to help our team at Seattle Children’s make sure that every child in our community has access to great care.

You can give families hope for the future.

A gift made through your will or by adding us as the beneficiary of an account is an easy and impactful way for you to leave a legacy for future generations of kids at Seattle Children’s. Making a gift is simple — you don’t have to rewrite your will. To learn more, contact Lilah Helton at 206-987-2153 or legacy@seattlechildrens.org.
We are grateful for the many fun, creative and thoughtful ways community members support Seattle Children’s. Thank you for all you do to help us provide hope, care and cures.

**ON THE SCENE**

**Friends of Costco Guild**

Members held their 23rd annual Children’s Golf Classic in August and raised a record $12.4 million for uncompensated care! The program at T-Mobile Park in Seattle featured the Viernes family, who shared their son Tiago’s brave journey battling neuroblastoma, and concluded with a memorable concert by Seattle folk-rock artist Brandi Carlile. The next morning, 1,300 golfers hit the links for Seattle Children’s at nine courses around Puget Sound.

**ACE Hardware**

From August 5 to 7, local participating Ace Hardware stores raised funds for Seattle Children’s through the annual Miracle Bucket campaign. For a $5 donation, customers received 20% off almost everything that fit in their bucket and 100% of donations benefited Seattle Children’s Greatest Needs Fund, allowing children the opportunity to lead healthy, fulfilling lives, while also fostering the builders and creators of tomorrow.

**Safeway Albertsons’ Immuno Heroes Campaign**

Associates at Safeway and Albertsons stores showed off their superhero skills in July to raise funds for pediatric cancer immunotherapy research. Customer donations at the check stand and vendor sponsorships, including the Safeway Celebrity Invitational golf tournament at the end of June, totaled $1,302,297.

**Marriott Root Beer Float Day**

On August 6, participating Marriott hotels hosted a Root Beer Float Day fundraiser for associates and guests. This day holds a special place for Marriott, Children’s Miracle Network Hospitals’ longest standing partner, as J. Willard and Alice S. Marriott launched their 9-seat A&W Root Beer stand in Washington, D.C. to cool off from the summer heat, years ago. To honor this history and legacy, Marriott properties hosted Root Beer float socials to benefit Seattle Children’s.

**Auction of Washington Wines**

Thank you to all who participated in the 35th Auction of Washington Wines this past August! The event series, including Wine Country Dinners, Winemaker Picnic & Barrel Auction, Online Gala Auction and the Wine Gala, raised nearly $4 million.

**ON THE SCENE**

**Auction proceeds support Seattle Children’s uncompensated care, homelessness prevention and Tri-Cities Clinic.**

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**Friends from Marriott shared sweets on a hot day.**

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Generosity in Action

Thank you all who joined us for Generosity in Action in September! Guests heard from Drs. Mignon Loh and Michael Jensen, on the progress of cancer care, research and therapeutics at Seattle Children’s and how our teams are working tirelessly to bring cures to kids faster — with your support. The evening ended with a heartwarming outdoor lighting ceremony honoring Childhood Cancer Awareness Month.

DQ® Miracle Treat Day®

On July 28, we celebrated DQ® Miracle Treat Day®. With every Blizzard purchase, a portion of the proceeds were donated to Seattle Children’s. DQ® Miracle Treat Day® is the most satisfying way for fans to raise funds and give kids a world of opportunity by enjoying delicious Blizzard Treats.

Friends of Alyssa Burnett Center Guild benefiting the Alyssa Burnett Adult Life Center

In June, the Friends of Alyssa Burnett Center Guild hosted its first Bling & Swing dinner and golf tournament. Matthew, a student at the center, gave an inspirational keynote speech preceding a raise the paddle. Auction items included student artwork, which added to a lively spirit of community at the event. The auction and golf tournament raised more than $342,000 to support programming and ensure rich opportunities for lifelong learning for more adults in our region with autism spectrum disorder and other developmental disabilities.

Run of Hope

Congratulations to the Pediatric Brain Tumor Research Guild for hosting their 14th annual Run of Hope at Seward Park on September 25. The 3K Fun Run brought together patients, families and community members to raise funds and awareness. The event included raffle prizes, a special visit from Seattle Storm mascot Doppler and a touching poem read by a patient ambassador. Over $320,000 was raised for pediatric brain tumor research.

NextGEN Summer Mingle

Our NextGEN community met at Westward to hear from NextGEN Council Chair Ira Gerlich and Foundation Chief Development Officer Dondi Cupp about plans for the future and new possibilities in pediatric healthcare for children. Members harness their passion for kids’ health by committing to give, engage and network in support of Seattle Children’s mission. To join NextGEN or learn more, please send us an email at NextGEN@seattlechildrens.org.

Giving Tuesday 2022

Support hope, care and cures by donating on Giving Tuesday: Nov. 29.

One Big GIVE

Tune to 95.7 The Jet for Bender’s 20th annual One Big GIVE Radiothon on Dec. 15.

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You’re Invited!
Mental health care is one of the greatest unmet needs in pediatric health. That’s why Seattle Children’s is taking the lead in transforming pediatric health through Generation REACH, a multifaceted initiative based on the simple yet transformative premise that children’s health always includes mental health.

Since launching last year, we launched mental health services at our North Clinic in Everett, Washington – the first service of this type at any of our regional clinics. We aim to expand our mental health services to all our regional clinics and develop innovative and equitable approaches like our new Child and Adolescent Latino Mental Health Assessment and Treatment Clinic, which provides culturally responsive mental health care in Spanish and English.

We opened a Behavioral Health Crisis Care Clinic (BHCCC) at our hospital campus to serve youth who are struggling with suicidal thoughts and behaviors. The clinic provides an alternative pathway for kids and families who urgently need brief, intensive mental health services rather than hospitalization.

Thanks to the generous support of our community, particularly the Sundance Foundation and the Norcliffe Foundation, the Autism Center and outpatient Psychiatry and Behavioral Medicine services will move to a newly remediated combined location on Sand Point Way in Seattle in the coming months. The space is intentionally designed for youth with autism and/or behavioral health needs.

Here are just a few updates on our progress since launching last year:

More updates are available online at seattlechildrens.org/generation-reach/.
Providing hope, care and cures for all kid-kind.

Harper, living cancer-free