

Hasbro Children's Hospital

Caring for Kids

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2022

'LIFE-CHANGING' CLEFT LIP AND PALATE CARE: ONE FAMILY'S STORY

Courtney King was surprised when, in June 2020, she went into labor five weeks before her due date. She was even more surprised when she learned that her son, Bobby, was born with cleft lip and palate.

The birth defect had not appeared on any of Bobby's prenatal ultrasounds. "Even my obstetrician was shocked," Courtney recalls.

Following an evaluation, Bobby was transferred to the Neonatal Intensive Care Unit (NICU) at nearby Women & Infants Hospital, where he received care from a specialized team that included Hasbro Children's Hospital doctors.

From his earliest days, Bobby struggled with challenges due to the cleft lip and palate. He failed his hearing test as a result of fluid buildup in his ears, and he had difficulty feeding and gaining weight.

After five days in the NICU, Bobby was referred to the Cleft and Craniofacial Center at Hasbro Children's, which is home to a multidisciplinary team of specialists that includes plastic and reconstructive surgeons, otolaryngologists, audiologists, dentists, and speech-language pathologists.

Through the center's genetic testing, Courtney learned that Bobby has a rare genetic condition called Van der Woude syndrome, which caused him to develop cleft lip and palate.

There, Courtney met Chief of Pediatric Plastic Surgery Albert Woo, MD, FACS, a plastic and reconstructive surgeon with more than a decade of experience treating patients with craniofacial anomalies and cleft deformities.

Dr. Woo assured her that he and his colleagues would be able to correct Bobby's cleft lip and palate, and alleviate his medical issues. He often says to parents, "Your child's life is not over. It may be a shock, but with the appropriate care, they will have every opportunity to thrive and live a normal life."



Bobby

However, without appropriate care, children can experience many medical and social difficulties. Those challenges include difficulty swallowing, growth delay, hearing problems, breathing issues, speech impediment, and ostracization.

"Cleft care is life-changing," Dr. Woo says.

That October, when Bobby was four-months old, Dr. Woo successfully performed the baby's first surgery—a cleft lip repair to fix the opening in his upper lip and optimize the symmetry of his nose.

Before the surgery, Bobby had an orthopedic treatment called Nasoalveolar Molding (NAM), which reshapes the gum, lip, and nostrils by using dental molds and tape. The procedure was instrumental to his positive outcome, and Hasbro Children's is one of the few institutions in New England that provides the service. "It's something we're very proud to offer," Dr. Woo says.

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Bobby before surgery

The following June, in 2021, Bobby underwent a second surgery to repair his cleft palate. During the procedure, Dr. Woo performed an innovative surgical technique he developed, which has been proven to improve long-term speech outcomes for patients. The surgery was more complicated than initially expected, as Dr. Woo discovered that Bobby was missing bone in his palate.

After one night in the Pediatric Intensive Care Unit post-surgery, Bobby was quickly back to himself, his mother says,

and was discharged. But just two days later, Bobby caught a cold from his older sister. With his mouth still swollen from the surgery—affecting his ability to breathe through his nose—he was again admitted to the hospital.

“Thanks to the excellent care and medications, Bobby’s breathing improved quickly and we were able to go home after just a single day,” Courtney says.

Today, Bobby is thriving and living like a typical one-and-a-half-year-old. His hearing has normalized; he has started to talk; and he no longer has trouble eating. “He’s an endless eater—I can’t keep up,” Courtney says with a laugh.

As he grows, Bobby will likely need another surgery or two—a bone grafting procedure when he is between 7 and 10 years-old, and possibly a nose revision when he is a young adult. In the meantime, if Courtney has any concerns, she knows she can count on the team at the Cleft and Craniofacial Center, which she describes as “wonderful.”

“I can’t say enough about all they have done for Bobby,” she says. “As a mother, you kind of just do what you have to do. And thanks to everyone at Hasbro Children’s Hospital, we got through it.”

A YOUNG SURVIVOR’S MEANINGFUL GIFT

As eight-year-old Saoirse Purnell was celebrating five years of cancer remission, she turned to art as a way to convey her gratitude to the Hasbro Children’s Hospital physician who saved her life. Recently, and with the help of her mother, Marcella, she presented a painting of butterflies to Francois Luks, MD, the hospital’s Pediatric Surgeon-in-Chief. “I hope it makes him happy because he took good care of me when I was sick,” Saoirse says.

Saoirse, along with many children who have undergone cancer treatment, associates butterflies with chemotherapy ports. When accessed, the port’s needle attachment opens like wings.

In late 2015, when Saoirse was just two-and-a-half, Dr. Luks performed emergency surgery to remove one of her kidneys and an adrenal gland after a Wilms tumor on her kidney had burst. Looking back, Marcella says she cannot fully describe the shock and despair she felt when her daughter was diagnosed with stage 3-4 cancer and rushed into the operating room. After the surgery, Saoirse required several months of chemotherapy and radiation treatment.

Today, Saoirse’s doctors say it’s unlikely the cancer will return. “Our visit to give the painting to Dr. Luks was magical,” Marcella says. “I walked through the door with a giddy eight-year-old child. After seeing her so close to death, it’s amazing to see her as a healthy and happy girl. We are just so grateful for all the doctors and the nurses at Hasbro Children’s for giving my daughter a second chance at life.”



Saoirse

Q&A WITH DR. MICHAEL KOSTER, DIRECTOR OF THE DIVISION OF PEDIATRIC INFECTIOUS DISEASES AT HASBRO CHILDREN'S HOSPITAL

What role does the Division of Pediatric Infectious Diseases serve in the hospital?

We typically consult on patients who have been admitted throughout the hospital for a myriad of complex infectious diseases. We spend a lot of time diving into patients' charts to determine how they got where they are, what's ultimately wrong, and how to get them better. The range of kids we serve have severe infections such as sepsis, a bloodstream infection, to less severe infections such as osteomyelitis, a bone infection. At our outpatient clinic, we also treat patients with a wide range of illness, including pediatric HIV and tuberculosis.



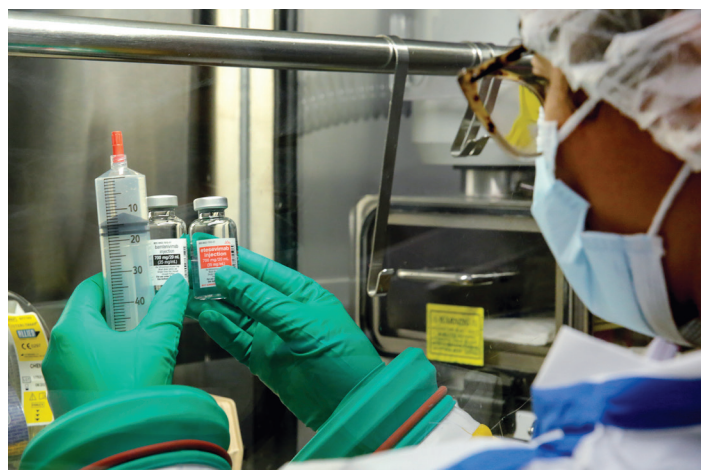
Dr. Michael Koster

How has the COVID-19 pandemic affected your work?

From an infection control standpoint, we had to put mitigation processes in place to minimize the risk of infection spread within the hospital and among families. This was challenging, in that you cannot eliminate visitors in pediatrics – there has to be a parent or guardian present. At the beginning of the pandemic, we began to see children with multisystem inflammatory syndrome (MIS-C) and helped develop guidelines on how to manage and treat it. One thing we are especially proud of is that, prior to the emergence of the Omicron variant, we were the only children's hospital in New England providing monoclonal antibodies to kids under the age of 12 through a research trial that began in May 2021. This positioned us as leaders within our geographical area.

COVID-19 vaccines for children are a hot topic right now—what advice do you have for parents who are hesitant to vaccinate their kids?

Speaking to your pediatrician is always a good place to start. I tell my patients' parents that this vaccine will protect your child. It is effective. It is safe. And I didn't hesitate to give it to my eight-year-old. We know that one in 10,000 kids who have had documented COVID-19 have died from the virus. That may be a low percentage, but it is measurable, and it is real. COVID poses a threat to kids. You're gambling if you choose to forgo vaccination.



Has the pediatric medical community learned anything surprising about kids during the pandemic?

Kids have shown amazing resiliency and adaptation to things like wearing masks and using hand sanitizer, and we must applaud them for that. This winter season and going forward, we hope that the measures we are taking against COVID will also help prevent the spread of other viruses such as influenza, respiratory syncytial virus (RSV), and the common cold.

RENOVATIONS NEARING THE FINISH LINE!



Hasbro 4 Inpatient Workstation



Mezzanine Level



Pediatric Intensive Care Unit Workstation

Two years ago, as part of the \$35 million *Every Child, Every Day* campaign, sweeping renovations began at Hasbro Children's to transform the region's leading pediatric hospital and position it as a premier care provider well into the future. Today, most phases of the extensive work have concluded or are reaching their final stages, and all projects are expected to be completed by spring 2022. "The finish line is definitely in sight, and we are all very excited about that," says Tracey Wallace, Vice President of Pediatric Services. "The structural changes being made to our physical space reflect how health care has evolved over the years and incorporate what we know about the importance of creating family-centered healing environments to ensure optimal outcomes."

Improving the hospital experience for patients and families and helping staff achieve their mission of *Delivering health with care* was at the heart of every design and construction decision. For patients and families, more comfortable furniture, new areas for quiet conversation or to consult with doctors, improved wayfinding signage, enhanced color schemes and plentiful art, and entirely reimagined outdoor space for respite and activities are just some of the welcomed

additions. Smarter room layouts, which enable staff quicker, easier access to the technology, equipment, and supplies they need, is but one example of the improvements on the provider side.

The recently completed renovation of the upper and lower lobbies has been particularly exciting. The areas are now brighter, with semi-private sitting stations and large conference room added. An eye-catching art sculpture designed by award-winning artist Peter Diepenbrock has also been installed.

Tracey emphasizes that many individuals and organizations have helped make the renovations possible. Chief among them, she says, are Dimeo Construction—the hospital's exceptional builder partner. The builders have been mindful to minimize any disruption to patient care.

Of course, none of this would be possible without Hasbro Children's generous donor community.

"Without philanthropic support we would simply not be able to do this work," Tracey says. "We are fortunate and grateful to have such committed, caring people on our side."

Caring for Kids, a publication of the Rhode Island Hospital Foundation, is published for the friends and supporters of Hasbro Children's Hospital. For more information, please contact the Development Office at 401-444-0394.

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