

St. Louis Children's at a Glance

At St. Louis Children's Hospital, we serve kids through more than **275,000** patient visits each year.

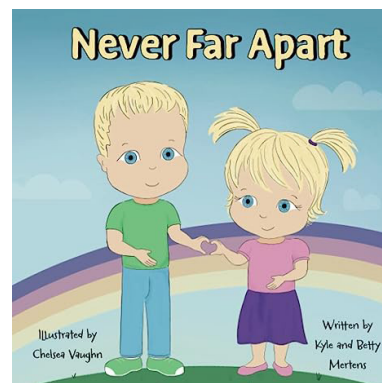
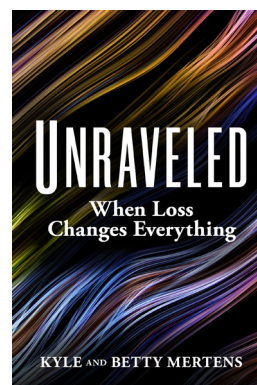
We treat children from all **50 states** and more than **80 countries.**

We have been ranked in the **top 25** of all children's hospitals nationwide for the 15th consecutive year.

We are recognized as a Magnet® hospital in **nursing excellence** by the American Nurses Credentialing Center (ANCC).

More Great News

Betty and Kyle Mertens were inspired by Ella's legacy to write two books. "Unraveled" is a resource for grieving people and those supporting them and is accompanied by a guided journal to aid the grief process. Released in 2023, "Never Far Apart" is an uplifting children's book designed to help children and grown-ups alike who are missing loved ones.



To purchase "Unraveled" and "Never Far Apart," scan the QR code.

Great News

Dear Friends,

On behalf of our patients, families and staff, thank you for supporting Ella's Umbrella! Through your continued support of Ella and the Mertens family, you are supporting researchers at St. Louis Children's Hospital as they strive to change the future for children affected by congenital heart disease.

With substantial support from committed donors like you, we are making transformative advancements in pediatric healthcare. Most importantly, the breakthroughs enabled through generous donor dollars are providing answers for children and families living with congenital heart disease and fueling hope that earlier, more accurate diagnoses will lead to improved outcomes. Please accept our sincere thanks for helping us fulfill our mission to *do what's right for kids* by supporting Ella's Umbrella.



With Gratitude,

Tanya L. Waskiewicz

Tanya L. Waskiewicz
Chief Development Officer
St. Louis Children's Hospital



Ella's Umbrella donated **\$17,000** from Ella's Trivia Night 2023 to support pediatric heart research at St. Louis Children's Hospital. To date, more than **\$100,000** has been donated to the Ella Marie Endowment Fund.

Save the Date!

Ella's Trivia Night is scheduled for Saturday, April 6, 2024.



St. Louis Children's Hospital Foundation
1001 Highlands Plaza Drive West, Suite 160
St. Louis, MO 63110
314.286.0988 or 888.559.9699
StLouisChildrens.org/Giving

Making *Strides* in Monitoring Neurological Impact of Extracorporeal Membrane Oxygenation in Babies and Children

Extracorporeal membrane oxygenation (ECMO) is a lifesaving intervention for babies and children who are non-responsive to other interventions. Blood is pumped outside the body to a heart-lung machine that removes carbon dioxide and sends oxygen-filled blood back to tissues in the body. ECMO is used in critical care situations and allows the heart and lungs to heal. Many children with congenital heart disease (CHD) must undergo ECMO during their course of treatment. The pediatric ECMO program at Washington University in St. Louis is one of the highest volume programs internationally, with more than 30% of ECMO runs involving infants with CHD.

Currently, neurological monitoring for patients on ECMO is limited to short-term EEG or advanced imaging with CT that requires patient transport and therefore adds inherent risk to the assessment. Washington University physicians Adam Eggebrecht, PhD, and Ahmed Said, MD, PhD, are studying the use of continual bedside assessment with high-density diffuse optical tomography (HD-DOT), which may provide direct access to real-time measures of brain health and may alert the care team to potential changes in the child's physiological status.

In the first year of this project, they spent significant efforts updating the custom HD-DOT clinical console and imaging cap that patients wear to ensure feasibility in this group of uniquely sensitive patients. They have expanded the options to include small, medium and large sizes that can comfortably monitor infants with head circumferences as small as 30 cm and as large as 44 cm. This allows for the caps to better conform to the variable head shapes with each size range.

Additionally, they updated the optical fiber tips to be flatter and softer to provide greater comfort for prolonged monitoring sessions. They also updated the real-time data analyses on our system to provide additional information on both data quality and spatial maps of cerebral oxygenation to our imaging team at the bedside.

They piloted the new console in rooms within the cardiac intensive care unit to assess logistical feasibility with both beds and bassinets along with the charge nurses to ensure the system will not disrupt care and not be a concern for the families. They have trained teams on recruitment and data collection and are now collecting data on patients.

“With your support, doctors are finding more effective and comfortable ways to monitor the brain activity of kids who need ECMO.”

Betty Mertens

This project is extremely important to improving child health because establishing a new direct and semi-continuous tool for brain monitoring that can be used concurrently with ECMO offers tremendous promise to track and even minimize or prevent injury.

“With your support, doctors are finding more effective and comfortable ways to monitor the brain activity of kids who need ECMO,” Ella's mother, Betty says.

Ella's Story

Every parent hopes their child will change the world. Ella did, and her legacy continues to grow.

Ella was born on April 4, 2016. In her first 12 months, Ella flourished, hitting all her developmental milestones. It wasn't until around her first birthday that there was any sign of an issue. What started as cold-like symptoms quickly escalated to a heart failure diagnosis.

After a brief hospital stay, Ella started to show signs of improvement. The doctors were optimistic about a full recovery. Shortly after her discharge, Ella's condition took a dramatic turn. On the morning of May 15, 2017, her lips started turning blue at daycare. She was rushed to the nearest emergency room, but before she could be airlifted to St. Louis Children's Hospital, her heart stopped beating.

Everyone was completely baffled. It wasn't until six weeks later that the results from a genetic test revealed a rare heart mutation that led to dilated cardiomyopathy (DCM). In DCM, the heart's main pumping chamber becomes enlarged and weak, making the heart unable to pump enough blood to the rest of the body.

Out of a desire to keep other families from experiencing the same heartbreak, the Mertens established the Ella Marie Endowment Fund at St. Louis Children's Hospital, supporting pediatric cardiology research. To date, they have raised



more than \$100,000. In 2022, the family officially launched a non-profit in her name. The vision of Ella's Umbrella is to continue her legacy by providing knowledge, resources and tools that will help save children's lives and bring hope and healing to their families.

Making Personalized Progress in Heart Disease

With her passing, Ella made her own gift. Her heart tissue was donated for research now underway by Kory Lavine, MD, PhD, a cardiologist and researcher at the Children's Discovery Institute, a partnership of St. Louis Children's Hospital and Washington University.

“Ella's tissue donation is huge,” Dr. Lavine says. “By studying tissue, we can see the heart muscle and learn why the person develops heart failure and why it progresses. There is no other way to actually study the disease so thoroughly. The mutation Ella had has been a significant part of our research project.”

