

2020 Silent Auction Results

The 2020 Virtual Silent Auction was a huge success! The event raised **\$7,030** for the Ella Marie Fund. "We are so excited to be able to host the event in person again this year and we hope to see you there!"

To register, visit: EllasTriviaNight.com

— The Mertens Family



2021 Ella's Book Bash Results

♥ Total value of books donated:

\$1,501 (145 Books)

♥ Total proceeds and other gifts donated:

\$915

♥ Total gifts made online directly to Ella's Fund:

\$1,030

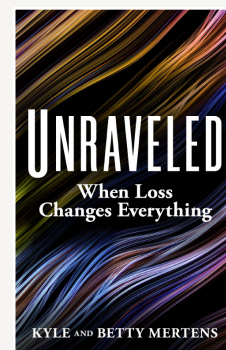
♥ Grand total raised as a result of the Book Bash:

\$3,446



More great news!

Ella's legacy continues to expand as Kyle and Betty are launching a book to support others who are grieving an unimaginable loss. The official launch of "Unraveled" is scheduled for April 2022.



Great News

Ella Marie Trivia Night



Dear Friends,

On behalf of our patients, families and staff, thank you for supporting Ella's Trivia Night! 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 Trivia Night.

With Gratitude,

Tanya L. Waskiewicz

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Chief Development Officer, St. Louis Children's Hospital



Mark Your Calendar

Ella's Trivia Night
Saturday, April 2, 2022

Doors open at 6 p.m.

Trivia begins at 7 p.m.

IBEW Electrician's Local Hall 1
5850 Elizabeth Avenue
St. Louis, MO 63110

St. Louis Children's Hospital 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 foreign countries**.

We are ranked among **the nation's top children's hospitals** by U.S. News & World Report.

We are recognized as a Magnet[®] hospital in **nursing excellence** by ANCC*

*American Nurses Credentialing Center





Ella Marie

Every parent hopes their child will grow up to change the world. Ella did.

Ella was born on April 4, 2016, and Kyle and Betty were overjoyed to welcome their first child into the world. In her first 12 months, Ella flourished, hitting all her developmental milestones and keeping her new parents on their toes. She seemed to be a perfectly healthy and happy baby.

Around her first birthday, Ella began having what appeared to be cold-like symptoms. Unfortunately, her illness was far more serious; the Mertens were shocked to learn their daughter was in heart failure. After a brief hospital stay, she started to show signs of improvement. However, shortly after her discharge, Ella's condition took a dramatic turn and she passed away suddenly on May 15, 2017.

How could this happen to a baby who had previously seemed so healthy? It wasn't until six weeks later that results from a genetic test revealed Ella had 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 and to create a positive from this tragedy, the Mertens established the Ella Marie Endowment Fund at St. Louis Children's Hospital, supporting pediatric cardiology research. "Not every parent is able to clearly see their child's impact on this earth," Betty says, "but we know that Ella was a true hero and her light will live on forever."

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."



A Brighter Future for Children with Genetic Heart Defects



Dr. Lavine's research, which is partially funded by the Ella Marie Endowment, has the ultimate goal of learning why heart failure develops and how to best treat it individually based on each person's unique genetics.

Dr. Lavine recognized gaps in knowledge that were ripe for research. "Rather than lumping all patients with heart failure together and treating them the same, we will take a more personalized approach to why that person has heart failure in the first place. This precision therapy is the future of treatment."

Dr. Lavine says more than 40 percent of patients with dilated cardiomyopathy have identifiable genetic mutations that affect how the heart muscle contracts. Each mutation ultimately points to a specific, individual reason for heart failure. "Kids have the biggest need to identify diagnostic and therapeutic approaches to treat the cause of their heart failure," Dr. Lavine says.

Because standard heart failure medications for adults aren't effective in children, he and his research team are collaborating to identify drugs that will target those mutations for heart failure in pediatric patients. "We want to develop a therapy that is specific to the patient's individual mutation," he says. "That will mean so much to families like the Mertens."

Ella's Gift to Change the Future

Since the Ella Marie Endowment Fund at St. Louis Children's Hospital was established, generous friends and family members have raised more than \$50,000 through trivia nights and other gifts. Philanthropic support for this groundbreaking research has been essential to its progress. Dr. Lavine says, "Unlike federal support, philanthropy provides us intellectual freedom and allows us to open up what we do to be more inclusive of a broader group of patients and focus more on discovery."

If you are interested in making a gift, visit our online fundraising page, bit.ly/ellamariefund.

