



## Living with Half a Heart

My husband Justin and I were married in October 2011. Very soon after i became pregnant. We were overjoyed to be expecting our first child. Unfortunately, at our 8 week ultrasound there was no heartbeat. No matter when it is, losing a child...a life is an emotional trial. When the doctors cleared Justin and I to try for another baby we were blessed with another pregnancy in the early summer of 2012. On the day of our 20 week ultrasound we were deciding to find out if we were having a boy or a girl, not knowing the decisions we were going to be making very soon were much heavier. While the ultrasound tech went through all the checks, she seemed to have a hard time with an image. She excused herself to get the doctor. As he was searching for something he stopped to talk to us. "There is something wrong with the baby's heart". Immediately tears started to flow. All I could think is that we are going to lose this baby too.

The doctor assisted in getting us an appointment at The Children's Hospital of Philadelphia the next day at the Fetal Diagnosis Center. After a long Echocardiogram of the baby's heart we met with the team and they confirmed that our baby would be born with a severe single ventricle heart defect called Hypoplastic Left Heart Syndrome. Bella would be born without the left side of her heart. They told us the decision was ours but that there is hope. They have a plan for babies born with HLHS. She could have a series of 3 open heart surgeries to repair her heart defect. My husband and I went in knowing there were no promises, but we had to try for her. We had to give her a chance. CHOP gave us the hope we needed to move forward.

Everyday we look at our beautiful 6 year old daughter and feel overwhelmed. We are amazing blessed to have her and we want her to have every chance to live a long, happy life. Our nonprofit, Beats for Bella, has been working hard for 6 years to bring awareness to the prevalence of Congenital Heart Defects. 40,000 babies are born every year with a Congenital Heart Defect. CHD is the #1 birth defect in the world. Bella is one of the 1,000 babies born annually with HLHS. We have been working to contribute to research projects at The Children's Hospital of Philadelphia, The Mayo Clinic HLHS Program and Dr. Rodefeld's Fontan Blood Pump. The support of our family, friends and community is tremendous. They truly believe in our work and our cause. We have found a new sense of obligation, digging into WHY we do what we do. Everyday with Bella is a blessing, but that does not change the fact that if research and treatments do not advance her heart will fail. Bella's heart will fail someday if we do not do everything in our power to support the institutions and doctors who are conducting the groundbreaking treatments and research to save her life.

Through this journey we have seen sweet babies leave their families too soon. This world fills us with so much joy and breaks our hearts in the same day. Beats for Bella has a responsibility to do our part, not just for Bella, but for Xavier, Lily, Ganyyn, Blake, Danny, Gabe , Abbey and Hayden. These are only a few of the special children who have touched our lives. Their families celebrate and grieve just like ours. We have had to grieve a life we will never have, a life of "normalcy" that will never exist for Bella and our family. We made the decision to not just walk this road, but to brave the storms and make the largest impact we can...to empower and give hope to new families just beginning this journey.

# Beats for Bella

Bella was born with a severe Congenital Heart Defect called Hypoplastic Left Heart Syndrome on March 18, 2013 in the Special Delivery Unit at The Children's Hospital of Philadelphia. HLHS is a single ventricle heart defect in which the left side of the heart does not form. This type of heart defect is fatal if untreated and requires three open heart surgeries to repair the defect, typically by the age of 3. Bella had her third and final planned open heart surgery to complete her repair on April 4, 2016. While her repair is complete her life with a Congenital Heart Defect will never end. She needs continued cardiac care.

At Beats for Bella we work very hard to spread awareness for Congenital Heart Defects. Annually 40,000 babies are born with a Congenital Heart Defect (that is 1 in 110 babies!). Of those 40,000, 960 are born with Hypoplastic Left Heart Syndrome like our daughter Bella. Considering its prevalence CHD research is significantly underfunded. We hold a variety of fundraisers throughout the year as well as constant social media awareness projects to help spread the word about what Bella and so many other children fighting a Congenital Heart Defect go through.





## Impacting our Heart Community

### Research Support

**The Children's Hospital of Philadelphia Research for The Underlying Causes of Congenital Heart Defects**

**The Mayo Clinic Todd and Karen Wanek Family Program for HLHS**

**The Mayo Clinic Todd and Karen Wanek Family Program for HLHS in support of post Fontan Monitoring**

**Dr. Rodefeld Fontan Blood Pump Device Research and Application**

### Outreach Support

**Mended Little Hearts Philadelphia Chapter**

**Hayden's Heart Sponsorship for Angel Mom Retreat**

**Support of local heart families in need financially**

**Beats for Bella has a growing team supporting the Philly Spin In at The Children's Hospital of Philadelphia  
(*benefitting the Cardiac Center at CHOP*)**

**BE  
THE CHANGE  
THAT YOU  
WISH TO SEE  
IN THE WORLD.**

MAHATMA GHANDI



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[www.beatsforbella.org](http://www.beatsforbella.org)

Dear Sir or Madam,

**Beats for Bella presents...**

*Bella of the Ball Gala on March 20, 2020 at Normandy Farm Hotel in Blue Bell, PA*

The money raised from this event will support ongoing research for Congenital Heart Defects. 40,000 babies are born every year with a Congenital Heart Defect and continued research is essential as many are still losing their battle too soon. Congenital Heart Defects remain the #1 birth defect in the United States.

Considering the research being conducted at hospitals around the country we are very close to major breakthroughs in treatment for children and adults living with Congenital Heart Disease.

We invite you to be a part of this evening and our initiative to impact the world of congenital heart research. Whether you join us or support our cause through donations your generosity will help Beats for Bella make a difference.

Since the formation of Beats for Bella as a 501(c)3 in 2014 we have made donations in excess of \$220,000. This includes the \$101,000 raised at the innagural Bella of the Ball in 2019. 100% of the money raised through Beats for Bella is donated to Congenital Heart Defect Research and support of our CHD Community. Our organization is committed to finding a CURE for CHD, but we need your help. Over the past 4 years Beats for Bella has sought out research platforms where we can make the largest impact. Our goal over the next 5 years is to continue contributing to research that will save the lives of children and adults living with Congenital Heart Disease. The future of our daughter Bella and so many others depends on it.

Please fill out the enclosed form(s) and help Beats for Bella do our part in finding a CURE for Congenital Heart Disease. Please mail the completed form(s) and your donation to Beats for Bella at 23 Copper Beech Drive, Lafayette Hill, PA 19444.

Donations can also be made through our website at [www.beatsforbella.org](http://www.beatsforbella.org).

If you have any further questions please contact Erin at [info@beatsforbella.com](mailto:info@beatsforbella.com).

Sincerely,

*Erin C Borkowski*

Erin C. Borkowski  
Co-founder and President





## Corporate Sponsorship Levels

### Event Sponsors - \$10,000.00

- \*Company name tied to all event materials (Separately recognized as Event Sponsor)
- \*Company recognition on Beats for Bella Website and Social Media
- \*10 Complimentary tickets
- \*Company name on all marketing materials and prominently displayed on signage at event
- \*Custom Banner
- \*Full page color ad in program book (inside front cover)

### Diamond Sponsors - \$5,000.00

- \*Company name on all marketing materials and signage at event
- \*Company recognition on Beats for Bella Website and Social Media
- \*5 Complimentary tickets
- \*Full page color ad in program book

### Platinum Sponsors - \$2,500.00

- \*Company name on signage at event
- \*Company recognition on Beats for Bella Website and Social Media
- \*3 Complimentary tickets
- \*Company name on Beats for Bella website
- \*Half page ad in program book

### Gold Sponsors - \$1,000.00

- \*Company recognition on Beats for Bella Website and Social Media
- \*2 Complimentary tickets
- \*Half page ad in program book

### Silver Sponsors - \$500.00

- \*Company recognition on Beats for Bella Website and Social Media
- \*1 Complimentary ticket
- \*Half page ad in program book

### Giving Heart Sponsors - \$250.00

- \*Company recognition on Beats for Bella Website and Social Media
- \*Company name listed in program book

### Sweet Heart Sponsors - \$100.00

- \*Company name listed in program book

Please fill in the requested information below:

Level of Sponsorship: \_\_\_\_\_  
Company Name: \_\_\_\_\_  
Company Contact: \_\_\_\_\_  
Contact Email: \_\_\_\_\_  
Company Address: \_\_\_\_\_  
Company Website: \_\_\_\_\_

Please email your high resolution company logo to [info@beatsforbella.com](mailto:info@beatsforbella.com).

Please make checks Payable to Beats for Bella Inc. and mail to:

23 Copper Beech Drive Lafayette Hill, PA 19444

(Sponsorships can also be paid through the Bella of the Ball page at [www.beatsforbella.org](http://www.beatsforbella.org))

Thank you from the bottom of our hearts for your support of our cause!

Sincerely,

*Erin C Borkowski*

Erin and Justin Borkowski

Beats for Bella EIN for Tax Deductions – 47-1176982

# *The Fontan Blood Pump*

## The NEED

For people born with a single ventricle heart (like Bella Borkowski), options are scarce. They must either undergo a palliative series of open heart surgeries, ending with the Fontan, or receive a heart transplant. As the first Fontan patients reach adulthood, emerging data suggests that all Fontans will eventually fail. It is no longer a matter of if, but when. There are several complex and individualized factors that determine when and how failure will present, but once it does, the only option becomes a heart transplant and that is not an option for all Fontan patients. While heart transplants are lifesaving, they come with their own risks and another timeline for eventual failure. In 2000, while at Stanford University, Dr. Mark Rodefeld began rethinking the way Fontan patients should be treated. Guided by the belief that there must be a better approach toward stronger outcomes for single ventricle heart patients, he began his research. He sought to develop a treatment option for Fontan patients that would extend the life of the Fontan repair and put off, or eliminate, the need for a heart transplant.

## The PROGRESS

In 2013, after years of research, Dr. Mark Rodefeld reached out to NASA for assistance in developing a conical motor for the Fontan Blood Pump. Unfortunately, the prototype built over the course of 3 years with NASA underperformed, not reaching the necessary speed or accounting for the viscosity of blood. With this information and some residual funds, Dr. Rodefeld assembled a team and got to work on the next prototype, which met the requirements for full functionality. He has received research grants from the National Institute of Health and The Children's Heart Foundation, however, prototyping is extremely costly. It will take another estimated \$300,000 to complete the build, and once finished, this prototype will be at near FDA-level sophistication. With the current regulations in place for testing and approval of prototypes – a working Fontan Blood Pump could be ready in 5 years.

In June 2018, the prototype confirmed full feasibility. Now it is a matter of fine tuning and moving forward. The next step is to apply for an NIH grant to fund optimization, clot resistance and studies.

In March of 2019 The Fontan Blood Pump Initiative reached a fundraising milestone of \$500,000. This allowed Dr. Rodefeld to clear some hurdles. The first, the completion of the prototype and the second the feasibility study. Armed with this new information Dr. Rodefeld reapplied for a new grant from the NIH. This would be a multi-year, multi-million-dollar funding. The new grant proposal scored in the top 20% of all submissions this round. The largest concern is the investment needed. Now more than ever we need to share our story and create awareness for what this device would mean for Bella and our family. Should we see signs of heart failure in Bella as she gets older this device would save her life.

For more information visit: [www.fontanbloodpump.com](http://www.fontanbloodpump.com)

Watch Dr. Rodefeld's video on the need for the Fontan Blood Pump at <https://vimeo.com/190027599>