



# EXCOR® Pediatric

Ventricular Assist Device | Parent Booklet



## WHAT IS EXCOR® PEDIATRIC?

The Berlin Heart EXCOR® Pediatric is a mechanical cardiac support system for critically ill pediatric patients suffering from severe heart failure that is intended for use as a bridge to heart transplantation. When a child's heart is so weak from heart failure that it can no longer pump enough blood to meet the body's needs, a pediatric heart surgeon places the EXCOR® Pediatric device on the heart to help pump the blood while they wait for a heart transplant.

EXCOR® Pediatric has been used on hundreds of pediatric patients all over the world, from newborns to teenagers.



*Model of EXCOR® Pediatric attached to both ventricles*



*The system allows most normal activity*

## HOW DOES IT WORK?

A normal heart has two main pumping chambers, called ventricles, that pump blood throughout the body. In severe heart failure, the heart can no longer deliver enough blood to keep the body and its organs healthy.

The surgeon places the EXCOR® Pediatric on your child's heart during an operation. Because either or both of the ventricles may need help, the surgeon may place an EXCOR® Pediatric pump to assist the left ventricle, the right ventricle, or both ventricles.

The type of support your child receives will be determined by the condition of their heart. The doctors taking care of your child will make that decision. Your child's physician will explain the procedure in more detail. Once the operation is complete, your child will return to the intensive care unit and will be given medications to keep them asleep and comfortable. When your child is ready, they will receive less medication to keep them asleep. Once your child is awake, it may be possible for them to begin eating. Many times a physical, occupational, and/or a music therapist will begin working with your child to help increase their strength, and will encourage your child to begin his or her normal activities. Many of our patients have been able to get out of bed, to go for short trips around the hospital, and are able to play with other children. Many school-aged patients have scheduled school work time. Being active helps your child return to a healthy state, which may decrease the recovery time following their heart transplant.



*Blood pump sizes vary based on patient size*

## BAILEY'S STORY



The joyful, happy voice that sings on Bailey Hunsberger's voicemail defies the expectations that most people have of a heart failure patient. But this is only one of the many unexpected surprises in Bailey's story. She was born with aortic stenosis. On the third day of her life, Bailey had her first open heart surgery. She spent her first month at the Riley Hospital for Children in Indianapolis, Indiana, with her parents and her Cardiologist, Robert Darragh, MD, by her side. Team Bailey remained together during another open heart surgery when she was three years old, and faced the crisis of heart failure when Bailey was only twelve.

In December of 2004, Bailey began to have classic heart failure symptoms, with worsening shortness of breath, edema and fatigue. Her congenital heart defect included scar tissue inside her left ventricle that prevented it from growing to accommodate her growing body. Dr. Darragh prepared Bailey and her family for the range of possibilities, including the need for using the Berlin Heart, either as a bridge to transplant if needed, or to let her heart recover while she was treated with medications and eventual heart valve replacement surgery. Bailey says, "Dr. Darragh always tells me what is going on. Riley and he have been with me my whole life, helping me through everything. They are the best."

In fact, Bailey did require a left ventricular assist device. She spent just over five months supported by the EXCOR® Pediatric Ventricular Assist device, known as the Berlin Heart. "I didn't fully realize how sick I was then until I saw documentary years later," explains Bailey. "When I first saw images of me with one-third of my body weight as fluid, I had to leave the room."

Cardiologists around the world turn to Berlin Heart to treat patients suffering from life-threatening heart failure. More than a hundred pediatric heart centers around the world use EXCOR® Pediatric as a bridge to cardiac transplant or to allow cardiac recovery.

Robert Kroschwitz, VP of Clinical Affairs for Berlin Heart, remembers Bailey's case well. "Dr. Darragh called me to discuss Bailey's need. She met the criteria for compassionate use of EXCOR® Pediatric and we rushed to fly a device from our Berlin headquarters to Riley Hospital for Children." "Riley's surgical team, lead by pediatric cardiothoracic surgeon Mark Turrentine, MD, implanted

EXCOR® Pediatric in January 2005. Within a few weeks, Bailey's family and nurses surprised her with a slumber party, where they watched movies and giggled the night away. Bailey recalls how the staff at Riley transformed her hospital room into her home. Bailey was able to walk around the hospital pushing the EXCOR® Pediatric console, which she calls "the cart".

Dr. Turrentine came by several times a day to check on Bailey. She laughs at the memory of her telling him about accidentally running over a connector hose with the cart. "He thought I said *car*, and totally flipped out, thinking a real car ran over it while I was walking outside." Bailey speaks fondly of her care team and the Berlin Heart clinical affairs team who have been supporting her for her "whole life."

After five and a half months, Bailey's heart had recovered enough to allow removal of the Berlin Heart without the need for heart transplant. She survived this dramatic course of heart failure but was left weak and thin, with little muscle tone. Bailey spent the rest of the summer dedicated to a program of physical therapy and good nutrition to regain her strength in preparation for entering eighth grade.

Bailey, Class of 2010, managed the girls softball team in her senior year as she prepared for college. "I am going to Indiana University in the fall and will major in Biology," Bailey explained. "I do have to take a lot of medications for my heart, but I am doing great. I have always wanted to jog and have not been allowed to until now. Dr. Darragh told me that as long as I stop if I don't feel good, I can start jogging."

But Bailey is only positive in her outlook. "When I first heard I might have to get a Berlin Heart, I told my Mom that I would probably have to get one for a little while but I would be okay." Then, Bailey predicted, "I would be able to share my experience and help a lot of people." Most would expect that someone who had spent so much of her life in a hospital would seek a career in a non-medical field, to avoid those memories. However, because of her positive personal story and her interest in life sciences, Bailey will fulfill her prediction of helping other people. The cheerful voice on her voicemail tells you that.



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