

## Benefit for young girl in need of a heart transplant Saturday

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The Salem Eagles club will host a Chili Benefit supper for the “Prayers for Anna” Heart Transplant fund. The menu included chili with cheese for a \$5 donation. There will be a 50/50 raffle and Karaoke will follow the benefit.

The event will be Saturday beginning at 6:30 p.m. at the Eagles club, which is located at 2310 Quarry Road in Salem.

Please visit facebook page, “Prayers for Anna” for more information.

All proceeds will benefit the Kaelin family and Children’s Cardiomyopathy Foundation.

When Anna Kaelin was 2 she was found to have a heart murmur at a routine pediatrician visit.

This was caused by her mitral valve being prolapsed (floppy) which allowed some of the blood flow backwards from the bottom chamber to the upper chamber of her heart.

This is a fairly popular issue and her mom, Keisha Kaelin, said it (the condition) didn’t seem to be causing any sort of complications.

In July of 2012 Anna was also diagnosed with a growth hormone deficiency for which she takes daily injections. During the work up for this, she was found to have a bone deformity in the base of her skull called a Chiari I malformation.

She underwent a successful surgery in March 2013 to correct this.

With that procedure in the review mirror, her mom thought, “this has to be the last thing, right?”

That wasn’t the case.

In June 2013, Anna developed tetany in her hands and feet. Her magnesium and calcium were dangerously low. She was diagnosed with Gitelman’s Syndrome, a salt-wasting disorder of the kidneys. This means she takes supplements three times a day to replace the magnesium, potassium, and calcium that her body dumps.

While she was hospitalized, her cardiac function decreased. Her ejection fraction decreased to 30% (normal is 50-60 percent). Then the family received another diagnosis of dilated cardiomyopathy (DCM).

She was asymptomatic with the condition but was put on medications to keep her heart function from worsening.

Fast forward to Feb 16, 2014 and Anna had complained of belly pain off and on for about a week.

She had a dry cough as well, according to her mother Keisha Kaelin.

“Early that morning, she told me she was ‘out of breath’” Kaelin said. “When we arrived at the emergency room, we found that Anna was in heart failure. Her ejection function had decreased to 10-15%. She had fluid in her lungs from her heart not being strong enough to pump correctly. Her heart rate was very high in the 170’s. My baby girl was much sicker than she looked.”

Kaelin said the hours that followed were very scary.

Anna was taken to the cardiac catheterization lab on Feb 17 and had an area inside her heart ablated (small areas of cells burned/cauterized). This allowed her heart to beat at an appropriate rate (110-120). She was placed on the ventilator for the procedure and left on for at least 24 hours so her heart could rest.

“The hope is that her heart will recover it’s pump function (ejection fraction) now that the rate is not so fast,” Kaelin said, “But this is going to be a long road.”

On March 7, Anna went into cardiac arrest a second time.

Hospital staff performed CPR and did several shocks and medication to get Anna’s heart restarted and in the normal rhythm.

She was also placed back on the ventilator.

Kaelin said after this event it was decided to go ahead and place her on ECMO. She is now in the cardiac cath lab. They are going to create a hole between the top two chambers of the heart to offload the left ventricle.

Since then Anna has been transferred to St. Louis.

She had open heart surgery on March 12 where they repaired the hole that was created in the top 2 chambers of her heart. She had a device implanted called a Berlin Heart, which is a biventricular assist device. Anna has four tubes that are connected to her heart and to two pumps outside of her body that will perform the function of the ventricles (pumping chambers of the heart). This takes the place of the ECMO circuit that she is on now. The purpose of it is to preserve the circulation to the “end organs” such as kidneys, liver, brain. She has also be placed on the heart transplant waiting list as a Status 1A (highest priority). Her echo has shown that the pumping function of her heart has gotten worse and the team feels there is little chance that it will improve.

The Berlin Heart gives Anna the opportunity to be weaned from the ventilator and participate in rehab.

Her mom said the goal is for her to be as healthy and strong as possible when she receives her new heart.

The heart transplant, of course, comes with risks. The surgery itself has a 12-15% chance of

death. Because of the nature of the device, she has to be on blood thinners. This of course, can lead to severe bleeding, including in the brain. The time she has spent on ECMO also increases the risk for bleeding during surgery. She also has a 25% risk of developing a clot that will cause a stroke.

“As scary as those numbers sound, the alternative (doing nothing) is much worse. This will be a rough surgery and the next few days are going to be long days,” Kaelin said. “There is no way for us to know amount of time that we will wait for Anna’s new heart. Because of her size, the wait will likely be longer. The average wait for this age/size is 3 months. We will not be able to leave the hospital until several weeks after her transplant. Although she will be in the highest priority category, matching a heart is complicated. There are many factors that play into finding her new heart.”

Everyone is encouraged to visit, ‘like’ and share the “Prayers for Anna” facebook page, and tell everyone about the Saturday’s benefit at the Eagles Club.