



Calgary Family's Journey of the Heart

Approximately two weeks after fertilization, a child's heart begins growing in its mother's womb. By the 24th day, the heart is beating, although it does not look like an adult heart. By eight to nine weeks of gestation, the heart is fully developed. This important process happens before many women even know they are pregnant.

What happens when something goes wrong with this process? An abnormal heart structure can develop, resulting in Congenital Heart Disease (CHD). Most heart defects do not affect a baby's development in utero because blood circulation within the womb is much different than circulation once a baby is born. A heart defect may be detected during the standard 18-week ultrasound, or it may go undetected until after birth.

But a child does not just grow inside its mother's womb, it also grows inside its parent's heart. This is clearly illustrated by the story of Lynn and Russ Nakoneshny.

Lynn and Russ Nakoneshny learned of their child's heart defect shortly after their 18-week ultrasound. Lynn recalls, "At our routine 18-week ultrasound the ultrasound technician was not able to get a good view of the four chambers in our baby's heart." Erring on the side of caution, the Nakoneshny's were sent by their family doctor for a fetal echocardiogram at the Maternal Fetal Centre in Calgary.

Lynn had two hours of diagnostic imaging including an ultrasound and fetal echocardiogram. After the images were analyzed, the Nakoneshny's had a consultation with a perinatologist. "We were advised that our son would be born with a life-threatening heart defect. At this time the perinatologist was not able to tell us a lot about this heart defect or what it was, only that it was serious and termination of the pregnancy should be considered," said Lynn. If the Nakoneshny's were to choose this option, termination would have to be done within the week following, as they only had until 23 weeks gestation for medical reasons.

Russ and Lynn wanted more information on what their child's heart defect was, what caused it and what all their options would be. The perinatologist referred Russ and Lynn to a pediatric cardiologist at the Alberta Children's Hospital.

"We left feeling very confused and upset, fearing that termination would be our only option. Our world turned dark. Not only we were we advised that our baby would be born with a life-threatening congenital heart defect but also the fact that we may have to make one of the most heartbreaking decisions of our lives... to end our child's life," said Lynn. "This day we were introduced to the world of CHD."

That same afternoon, the Nakoneshny's received a call from Dr. Patton, a pediatric cardiologist at the Alberta Children's Hospital. "After a two-hour visit with Dr. Patton and the nurse clinician, Patty Knox, our once dark world had light again," explains Lynn.

Russ and Lynn's son had a congenital heart defect known as Critical Aortic Stenosis. This is a condition in which the heart's aortic valve does not form normally and does not allow sufficient flow to move blood through the aorta to the rest of the body. This was causing the left ventricle in their son's heart to become dilated, thick and not able to pump efficiently. Eventually the left side of the heart, being muscle, would become overdeveloped and unable to pump well enough to sustain life. Each day, the left side of their child's heart was working harder to try to pump blood through the aortic valve. Lynn and Russ were also told to prepare for the worst case, that their baby's condition could develop into a more serious heart defect known as Hypoplastic Left Heart Syndrome.

There are generally three options for children born with Hypoplastic Left Heart Syndrome:

- 1) A three-stage surgical procedure. The surgeries are typically performed at birth, six months and three years to re-engineer the heart to allow the child to live as normal a life as possible. The first of the three surgeries, the Norwood procedure, carries a 70-80% survival rate. It will never fully cure the defect, but it buys time should a transplant be required later in life. Adult hearts are more readily available than infant hearts. In addition, medical advances in the area of Congenital Heart Disease continue to develop with possible new options for treatment in the future.
- 2) A heart transplant if a heart becomes available within a reasonable amount of time; or
- 3) Compassionate care - do nothing and the baby would die within days or weeks of birth.

"We hoped for the best but prepared ourselves for the worst case," explains Lynn. During the remainder of her pregnancy Lynn was followed very closely with fetal echocardiograms and ultrasounds every 2 weeks to ensure that all was going well for her baby in utero. If anything out of the normal arose it could be seen right away and be dealt with.

On December 8, 2006, four hours after Joshua Nakoneshny was born, he had his first echocardiogram, with a diagnosis of Hypoplastic Left Heart Syndrome. Lynn and Russ chose the three staged surgery.

Joshua's first surgery was performed at 11 days old and his second surgery at 6 ½ months old, with no complications. "Joshua is now 2 years old and doing great, he is a happy, otherwise healthy, little boy who enjoys life to the fullest. He is the light of our lives and we are so glad that we made the decisions we did for him," say Lynn and Russ Nakoneshny.

Does a child grow in a mother's heart? Yes. Lynn and Russ had Joshua growing in their hearts long before he made his first appearance in this world.

February 7-14 is Congenital Heart Defect Awareness week in Calgary. An estimated 180,000 Canadians have Congenital Heart Disease (CHD) of which, approximately 8,000 reside in the Calgary area. How can you help during this week? Visit the Heart Beats' Website (www.heartbeats.ca) to learn more about Congenital Heart Disease. You may send an e-card to let others know that you care about children with this condition. You may also donate to Heart Beats to help provide financial assistance to families having difficulties meeting expenses related to their child's heart defect.

The Heart Beats Children's Society of Calgary (www.heartbeats.ca) is a grassroots, registered charitable organization offering information, resources and emotional support to families dealing with Congenital Heart Disease (CHD). Since 1987, our group of parents, caregivers and professionals have provided practical and compassionate service to children and families impacted by Congenital Heart Disease (CHD).

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For further information, interviews or photos please contact:

Karen Perl-Pollard
Heart Beats
Communications Manager
Phone: (403) 270-7335
E-mail: karenperl_pollard@hotmail.com
Website: www.heartbeats.ca

Patty Wiebe
Heart Beats
Chairperson
Phone: (403) 256-7423
E-mail: pattyw@heartbeats.ca
Website: www.heartbeats.ca