



Keeping the Beat

Summer 2008

Offering information, resources and emotional support to families dealing with congenital heart disease.

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Heart Beats' Families Celebrate Congenital Heart Defect Awareness Week with Bowling at the Calgary Winter Club

On Saturday, February 9, 2008, ten families gathered at the Calgary Winter Club for bowling and pizza for Heart Beats' Annual Family Event. The Event was held during Congenital Heart Defect Awareness Week, February 7-14, 2008, which communities around the world recognize to raise public awareness of and support for children born with congenital heart defects.

It was an enjoyable afternoon of bowling and mingling with other CHD families. We had bowlers as young as two years old. The "Crazy Bowl" game had us bowling between our legs and from a sitting position. And "Bingo Bowl" worked well for those of us who have trouble getting strikes! It was noted by some bowlers that doing well at Wii Bowling does not necessarily translate to bowling well with real balls and pins! After working up an appetite, we enjoyed pizza and sundaes and the opportunity to visit with one another.

For those who were unable to join us this year, mark your calendars for next year's family event which will again be held during Congenital Heart Defect Awareness Week, February 7-14, 2009. Preparations are already being made for it and we hope you will plan to join us.



Fun was had by all at this year's family event.



Heart Beats sent out a series of news releases during Congenital Heart Defect Awareness Week to raise awareness in Calgary about children born with CHDs . The following are two of the releases which share the experiences of two families in our Heart Beats community.

Does a Child Grow In a Mother's Heart?

Calgary, AB (February 8, 2008)
– 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 parents' hearts. 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 family doctor sent them to the Maternal Fetal Centre in Calgary for a fetal echocardiogram.

At the Maternal Fetal Centre, 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 had only 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 the Maternal Fetal Centre feeling very confused and upset, fearing that termination would be our only option. Our world turned dark. Not only we were 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.

"Dr. Patton thoroughly explained our baby's heart defect, he drew diagrams of a normal heart, our baby's heart, explained our options, the risks involved, talked to us about quality of life for us and our baby, limitations for our child with a congenital heart defect and the future for our baby as best he could without knowing what the health status of our baby at birth would be."



Russ, Lynn & Joshua Nakoneshny

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.

Where Do Broken Hearts Go?

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 two 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-stage surgery.

Joshua's first surgery was performed when he was 11 days old and his second surgery when he was 6 ½ months old, with no complications. "Joshua is now 14 months old and doing great, he is a happy, otherwise healthy, little boy who hits all of his milestones and 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.

Calgary, AB (February 9, 2008) – On March 21, 2004 the lives of Tracey and John Contrada changed forever. This was the day that their daughter, Ava Contrada, was born. This was also the day that Tracey and John began their search to find out where broken hearts go.

In the days following her birth, the Contradas learned that little Ava had Congenital Heart Disease (CHD). Congenital Heart Disease is a general term that is used to describe many types of heart malformations. Ava's heart is unique in many ways. She was born with Left Ventricular Noncompaction which means the left ventricle of the heart has difficulty creating the muscular squeeze needed to send oxygenated blood to the body. She also had several Ventricular Septal Defects (VSDs) which are also known as "holes in the heart". These holes in the wall or septum of the heart

permit oxygenated and non-oxygenated blood to mix, decreasing the amount of oxygenated blood that gets to the body. In addition to her heart malformations, Ava also had a number of blood clots, kidney reflux, acid reflux and intermittent exotropia (an outward turn of the eye).

So where do broken hearts go? First, to the Cardiology Clinic at the Alberta Children's Hospital. This clinic logs over 4,600 clinic visits each year by children aged zero to 18 years. Care is provided by five pediatric cardiologists and a complement of highly trained staff. "We have been given incredible support from Dr. Dicke, Patty Knox, and Kelly Webber at the ACH Cardiology Clinic," says Tracey. There is also the community of family and friends, with Tracey and John having a far-reaching circle.

(continued on page 4)



John, Tracey & Ava Contrada

“Unfortunately,” says Tracey, “while family and friends try to be empathetic, they cannot truly understand what you go through as parents of a child with CHD. Connecting with families in the Heart Beats community has provided us with a much-needed cushion of support!” 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) including support groups such as Heart to Heart, targeted to parents and their children, and Off Beats, which is designed to support tweens and teens in a peer setting.

“The Heart to Heart group has been fantastic! The support offered and advice given has enabled us to understand and effectively deal with Ava’s challenges — especially around feeding,” explains Tracey. After her birth, Ava left the hospital with a feeding tube — as well as 11 different medications and two daily shots of Enoxaparin (a blood thinner which is used to help break up blood clots). It took nine months before Ava’s progress was sufficient to remove the feeding tube and stop the Enoxaparin shots. Today, all of her VSDs have closed and only one tiny blood

clot remains. Ava remains on medications to help the left side of her heart squeeze.

“And,” Tracey adds, “each month we look forward to connecting with our newfound friends at Heart to Heart. Our first year with our daughter was profoundly impacted by Heart Beats and we are so grateful!” In addition to her involvement in Heart to Heart, Tracey has since become involved in the Heart Beats’ executive allowing her to provide even more support to other families in need.

Ava turned four years old on March 21, 2008. To say John and Tracey are grateful for Ava’s life is an understatement. “To be able to celebrate Ava’s fourth birthday is such a privilege!” says Tracey. “We feel Ava has been blessed by so many gifts over her short lifespan, especially the support from the Alberta Children’s Hospital, our family and friends, and Heart Beats.”

Your Support in Action

Donations made to Heart Beats Children’s Society of Calgary are used to provide information, resources and support to families dealing with congenital heart defects. Your donations have provided:

- Financial assistance to families having difficulties meeting expenses relating to their child’s heart defect.
- Items of encouragement for children experiencing extended hospitalization.
- “Heart & Soul: Your Guide to Living with Heart Disease” information binders (distributed through the Cardiology Clinic).
- Toys and supplemental equipment for the Alberta Children’s Hospital Cardiology Clinic

We appreciate and acknowledge the donations received from the following individuals and organizations from January to May 2008:

- Raelene Brummond, in honour of Ava Contrada
- Remo Cardone, in honour of Ava Contrada
- Jasmin Craig & Michelle Robertson, in honour of Ava Contrada
- John Croft through the United Way of Calgary, Donor Choice program*
- Peggy Gardner, in honour of Joshua Nakoneshny
- Donna & Michael Gerlinsky, in memory of Brittany Gerlinsky
- Dr. Robert Kinniburgh and staff of North Calgary Orthodontics
- Catherine & David Mahood
- Natalia Malnar
- Gail MacKean
- Donald Nakoneshny, in honour of Joshua Nakoneshny
- Karen Perl-Pollard
- The Watson Family Foundation at The Calgary Foundation
- Isabelle Wiebe’s Grade 1 classmates: Matthew, Justin, Michaela, Jordan B., Jake, Tyler, Janessa, Max, Lydia, Sam, Rachel, Isaiah, Ellen and Jordan I and Jillian.

If you wish to contribute to the support of families of children with congenital heart defects, you may mail your donation to:

Heart Beats Children’s Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

You may also donate online at www.heartbeats.ca where you can make secure donations by credit card to **Heart Beats** through CanadaHelps.org.

*(If you donate to Heart Beats through the United Way, please let us know so we can acknowledge you as the United Way does not provide us with the names of the donors.)

Heart to Heart

Heart to Heart is open to all parents of children born with congenital heart defects (CHD). Whether your “heart child” is an infant, a teenager, or somewhere in between, we welcome you. We meet once a month to visit and chat about parenting children with CHD. Those with children at home are welcome to bring them along. For our weekend dates, school-aged children are welcome as well. We vary our meeting days, times and locations from month to month to try to include as many parents and families as possible.

Heart to Heart in June will be on Wednesday, June 18th at 10:00 am at the home of Lynn Nakoneshny at 187 Willowmere Close in Chestermere

Heart to Heart in July will be on Tuesday, July 8th at 10:00 am at Lake Midnapore. If you are able to attend, please contact Patty Wiebe at 256-7423 or pattyw@heartbeats.ca as she must provide your name to Lake Midnapore staff so you can be admitted.

Heart to Heart in August will be on Sunday, August 17th at 1:30 pm at Lake Midnapore. We welcome the entire family! If you are able to attend, again please contact Patty Wiebe at 256-7423 or pattyw@heartbeats.ca as she must provide your name to Lake Midnapore staff so you can be admitted.

Heart to Heart in September will be on Tuesday, September 16th at 10:00 am at the home of Lynn Nakoneshny at 187 Willowmere Close in Chestermere

We invite you to join us to meet other parents, to ask questions about caring for and raising children with CHD, and to share your knowledge and experience with others.

For more information, feel free to contact Patty Wiebe by e-mail at pattyw@heartbeats.ca or by phone at 256-7423.

An Opportunity for Families in the Medicine Hat Area to Connect

Colleen Finnerty, mother of eight-year old Brendan who was born with an Atrial Septal Defect and Supra-valvular Pulmonary Stenosis, wants to meet other families of children born with congenital heart defects. Colleen and Brendan live in Medicine Hat. They are interested in connecting with others in the area to share experiences, information, encouragement, and support. If you live in the Medicine Hat area and are interested in meeting other families of children with CHD, contact Colleen by e-mail at colleenfinnerty@hotmail.com.

Off Beats

Off Beats is a fun, activity-based group for youth aged 12-17, offering peer-to-peer support and friendship. We meet monthly during the school year.

Coordinator Laura Thurber-Larsen reports that in January, Off Beats had “an AMAZING night” at the Saddledome. “We had supper, received gifts, had personal visits from Flames President and CEO Ken King and Flames players Adrian Aucoin and David Moss, then watched the game from seats in the lower bowl just behind the goalie.” In February, Off Beats celebrated Congenital Heart Defect Awareness Week with heart-shaped pizzas and a night at the movies. In May, we met at Firescape to tap into our “creative side”.

Our final get-together before summer will be at the beginning of June. Even if you have not attended any other Off Beats meeting, you are welcome to join us in June.

For more information, contact Laura Thurber-Larsen at 955-7888 or Laura.Thurber-Larsen@CalgaryHealthRegion.ca.



Off Beats with Calgary Flames players Adrian Aucoin and David Moss

Community Updates

Congratulations Karen!

Heart Beats' Communications Director Karen Perl-Pollard and her husband Ron celebrate the arrival of their daughter Veronika, born on March 10, 2008. Mathias (born with Tetralogy of Fallot, ASD and PDA) immediately took to the role of big brother. Karen shares, "On our first day home with Veronika, Mathias did not want to hold her at first. I set her on the floor and went about getting supper ready. Then, he went over to her and gently wrapped her in the blanket and tried to pick her up. We told him he couldn't pick her up, but asked him if he wanted to hold her. He held her on the couch for about 45 minutes – kissing all the parts of her body. He had to take her feet out of her sleeper and count her toes, his toes and all our family toes."

He also took Veronika to Show and Tell at preschool. There he told the kids that he likes to kiss his baby sister and that he is very good at helping. He sometimes rubs her tummy if she is crying. When she is happy he sings her lullabies or plays peek-a-boo.



Mathias with his baby sister Veronika



Karen, Ron, Mathias & Veronika Pollard

Kirsten Chisholm

Kirsten is a very busy and mischievous little two-and-a-half year-old now. She enjoys picking on her four-and-a-half year old brother, Nolan, and running away, laughing hysterically! Medically, she is doing fabulously. No further GTube feeds, no CPAP, and her immune system seems to be functioning very well by itself now. Just as we had hoped two years ago, she is eating, walking, running, breathing, laughing, and playing with and like all other kids we see. She is using sign language to communicate with us. She will start school in September, four days a week. Right now she is participating in an early preschool intervention program and LOVES playing with the other kids without Mom around! She will be starting swimming lessons and gymnastics this summer after her third visit with grandparents and family in Nova Scotia. She is at a point now that we weren't sure we would ever see and that is reason to believe in miracles. She and her big brother bring us smiles every day!

– *Claudette Chisholm, mother of Kirsten who has Tetralogy of Fallot with an absent pulmonary valve which was repaired at 3 months old and will need further replacements as she grows.*



Kirsten with her brother Nolan

We want to hear

what is happening with your CHD child and family! Whether it is an update on their treatment, or a special accomplishment in school, music or sports, please let us know so we can share it with the rest of the Heart Beats community. Send your update to info@heartbeats.ca.

Alexa's Story

Six-and-a-half months ago I met the strongest person I have ever known. Her name is Alexa and she is my beautiful baby daughter.

When I was just over seven months pregnant, we found out that Alexa had a severe heart condition called Critical Aortic Stenosis. The aorta in her left ventricle was too small. Doctors said it was unlikely that they would be able to fix it and predicted she would have to undergo single ventricle repair which would entail three open-heart surgeries.

Alexa was born in Edmonton on October 14, 2007. As soon as she was born she was given a breathing tube and whisked away to the Stollery Children's Hospital. That same day she had her first heart catheter procedure done to try and balloon open her aorta. We waited two long weeks for results and were then told that the aorta still wasn't open enough and that her mitral valve was leaking. They decided to try the balloon again. We waited another two weeks. Alexa fought hard. She pulled at her tubes and woke up whenever she had the strength. She squeezed our fingers and learned to smile. At the end of those two weeks doctors told us there was nothing more they could do to save the left ventricle. The mitral valve leakage was too severe and the aorta was still too narrow. She would have to go through the single ventricle repair.

On November 15 Alexa underwent the Norwood procedure, the first of a three-stage repair. She did well after the Norwood and on December 3 she was flown to the Alberta

Children's Hospital in Calgary. For the next month she stayed in the hospital and we stayed by her every day. Her growth was very slow and she struggled to get weaned off morphine and Ativan. Every time they went down on the doses she went into terrible withdrawal. We watched her struggle to grow and struggle to be drug-free. But despite all of that she still smiled at us and at the nurses and snuggled into our arms when we held her. Finally, after a few day passes she was officially discharged on January 7.

The next two months were more difficult than we could ever have imagined. She was being tube-fed and we struggled with the feeding device. We were exhausted from continually getting up in the night to feed her and give her medication. For reasons still unknown she began to throw up at every feed. It became so severe that at the beginning of February she was hospitalized for three days because of dehydration. We finally got her hydrated and the vomiting stopped. As time passed she began to be more and more lethargic. She was too tired to drink much from a bottle and simple things like having a bath left her exhausted. She was sleeping 18 to 20 hours a day. We started to notice a change in her color as well and she began to look a bit more blue around the mouth and eyes. When her SATs slowly crept down to 68 she was put on oxygen. We then had to deal with hauling around oxygen tanks everywhere. We knew that her second surgery, the Glenn, was much-needed. After going to Edmonton once and having the surgery cancelled, she finally had her



Alexa Castillo with her mom Cindy, dad Jorge and sister Sophia.

surgery on March 10. A lot of people had told us that after the second surgery we would see big improvements. We really hoped that was true but at the same time couldn't imagine it.

We were amazed at how well the second surgery went. The surgery took place on Monday afternoon and she was discharged home on Friday of that same week!! It has now been almost two months since her surgery and we are astounded at how well she is doing. On April 9 she pulled out her feeding tube and I decided not to put it back in. She has been drinking all the milk she needs from a bottle and eating all kinds of new foods. She is alert and active and eager to join her sister in life's adventures. She is gaining weight rapidly and quickly catching up to her age group in physical activity. She laughs out loud and is seldom sad. When I look at her I learn what it is to appreciate life. She knows how

to laugh and be happy even when life is hard.

Alexa: my daughter, my fighter, my hero!

Cindy Castillo

Share Your Story

We invite you to share your experience with congenital heart disease with us. We want to hear from parents, and from children and teenagers who themselves have a CHD. Your story may provide the encouragement and support someone else needs! For assistance in preparing your story, or to submit your story, contact the Newsletter Coordinator at karenp@heartbeats.ca

Talk with the Docs – *Dr. Deborah Fruitman*

So often we only know the Cardiologist our child visits at the Cardiology Clinic, but each of the Cardiologists has their own area of expertise that contributes to the overall care provided to patients at the Cardiology Clinic. We want to introduce you to each of the Cardiologists at the Cardiology Clinic. In our Fall 2007 issue we featured Dr. Frank Dicke and in the Winter 2008 issue we featured Dr. David Patton. In this issue, we feature Dr. Deborah Fruitman.

When did you begin at the Alberta Children's Hospital Cardiology Clinic?

I began working at ACH on February 1, 2008.

Where did you study and practice medicine before you came to our Cardiology Clinic?

I went to medical school in Halifax, Nova Scotia, at Dalhousie University. I then went to Toronto, Ontario for my paediatrics residency as well as my paediatric cardiology training at The Hospital for Sick Children.

Prior to specializing in Paediatric Cardiology did you work in other areas of medicine?

No, since finishing my general paediatric training, I have only been involved in pediatric cardiology.

What made you decide to come to Calgary?

My decision to come to Calgary was based on many factors. When I was deciding on the type of practice that would best suit me, I realized that I wanted to be in a centre where I could really build on my interests in echocardiography and fetal echocardiography, while practising general paediatric cardiology. The position here in Calgary seemed to be a very good fit for my career goals. As well, the group of people in the cardiology department as well as throughout the hospital appeared to be great to work with and provide a wonderful atmosphere, which is very important. My family and I are very active, outdoor people, and we were looking for a place where we could enjoy activities in and around the city, as well as the surrounding areas that would be good for young children. Indeed, the mountains are very attractive!

How do you like the city so far?

So far, I have really enjoyed living here in Calgary. Although the spring, as I have learned, is very snowy, we are certainly catching up on our skiing since we have been here.

For those of us who haven't met you, how would you describe yourself? How would we recognize you in clinic?

I have to laugh, as I think most people would describe me as short – I like to think of it as vertically challenged.

When you're not working what do you like to do to pass the time? Do you have any specific hobbies or interests that you enjoy?

Most of my time outside the hospital is spent with my family, enjoying them as much as I can. I enjoy being active, and outdoors whenever possible. I love playing soccer and am meeting quite a few soccer lovers here. In the past, horseback riding was a big part of my life and now that I am out west, it is a sport in which I would like to get involved again.

I understand you are particularly interested in the antenatal diagnosis and treatment of babies with congenital heart defects. Can you tell us about this?

Yes, in addition to my general cardiology training, I have done extra training in Toronto in fetal echocardiography. This is where we perform ultrasounds during pregnancy, focusing on the baby's heart. Fetal echocardiography is performed in pregnancies where there is a risk factor for congenital heart disease or when an abnormality is detected on routine screening ultrasound. A fetal echocardiogram can be performed as early as 16-18 weeks of pregnancy, but the optimal time is between 18-22 weeks. This is a way that we can image the baby's heart before the baby is born and look for the heart structure, function, or abnormal heart rhythms. It can also be helpful if there are issues in pregnancy that can have a secondary effect on the heart.

With fetal echocardiography, we are able to diagnose heart problems early in pregnancy and counsel families so they have the knowledge and support they need for management of the pregnancy. It can also assist the medical personnel involved in their prenatal care to make decisions regarding the management of particular problems and hopefully improve outcomes.

What changes or advances have there been in this area over the past 10 year?

Ultrasound technology itself has advanced in so many ways over the past 10 years. This, along with introduction of screening of the fetal heart on routine prenatal ultrasounds, have improved the rate of detection of congenital heart disease during pregnancy. Over the past decade, there has been an interest in learning not only how to more accurately diagnose heart problems, but increase our knowledge about how they progress during the pregnancy and how to best manage these babies after they are born.

What impact has this had on the treatment of children with CHD?

The impact of these screening programs continues to be evaluated. Early diagnosis allows a variety of treatment options to be considered. It can also prepare both the families and the medical team involved for what to watch for throughout the pregnancy, involve other specialists and further testing if needed, as well as decide on the best management and

setting for delivery. Fetuses with heart problems that require an intervention shortly after deliver may benefit from closer care and the planning of delivery and management. In some cases, such as abnormal heart rhythms, treatment during pregnancy has improved the outcome throughout the pregnancy .

What can we expect to see in this area in the next 5 years?

There are still some limitations to ultrasound during pregnancy and I believe that the technology will continue to advance and improve our accuracy of antenatal diagnosis of congenital heart disease. We still do not understand many things about what causes heart problems and how they change throughout pregnancy. Currently, we are able to treat abnormal heart rhythms during pregnancy, and consequently, the possibility of other interventions during pregnancy are being investigated, with the hope of improving the outcome of pregnancies with heart disease. There is a great deal of interest and investigation into the genetics, embryology, and natural course of congenital heart disease that will help to increase our knowledge, management, and hopefully improve the outcomes of our patients.

An area of echocardiography which is also growing rapidly is three-dimensional imaging. Many centres are investigating the new technology and improving it so we will be able to image the fetal heart in 3D. There are still many limitations

as I mentioned, but the ability to image the heart as a three-dimensional structure will be very exciting and allow us to gain knowledge into congenital heart disease, not only in pregnancy, but at all ages.

As the machines and technology advance, and our knowledge expands, there are many possibilities that may improve the outcome of fetuses with congenital heart disease. As the screening ultrasounds improve, our detection rate of congenital heart disease in pregnancy will also improve.

I understand that in addition to seeing patients at the ACH Cardiology Clinic, you also spend time at the Maternal Fetal Medical Clinic at the Foothills Hospital. What do you do there?

I spend my Wednesdays at the Maternal Fetal Medicine Clinic (MFM) which is attached to the Foothills Medical Center. This is where the fetal echocardiograms are performed when there is suspected congenital heart disease and I am available for consultation and counselling.

In collaboration with the radiologists, perinatologists, and geneticists, I consult and read the fetal echocardiograms which have suspected heart problems. Once the diagnosis is established, I would meet with the families after their ultrasound and counsel them about the diagnosis and what the prognosis and treatment options would be depending on the type of heart problem found. We follow women throughout their pregnancy and provide the supports and close monitoring needed as well as arranging the appropriate management around delivery and newborn care so families are as informed and prepared as they can be.

How does your presence there assist families who receive a diagnosis that their baby has a CHD?

Having a diagnosis of congenital heart disease can be stressful and difficult no matter if it is during pregnancy or after. I feel that my presence there allows the families to gain as much knowledge as possible and ask questions in order to help them with the management of the pregnancy. There is a great team in the MFM clinic, which includes the radiologists who read the ultrasounds, the perinatologists, geneticists, genetic counsellors, sonographers, and nurses, who are all available to support families with a prenatal diagnosis and arrange any further testing or counselling which may help with the management. I follow our families with prenatal diagnoses of heart disease throughout the pregnancy and help to arrange the plans around delivery to optimize the care of the baby.

Ready or Not: Parenting Adolescents with CONGENITAL HEART DISEASE

- ☛ Is your teenager 13-17 years of age?
- ☛ Has your teenager had more than one heart operation?

If yes, we would like to talk with you!

Dr. Gwen Rempel, Faculty of Nursing, University of Alberta, is conducting a study with parents and adolescents to learn more about parenting teens (13-17 years) with CHD. She would love to talk to moms, dads and teens (interviewing each one on his or her own on two occasions) and needs to have at least one willing parent along with their teen from each participating family.

For more information about this study, please contact:

Sandy MacPhail RN MN
Project Coordinator

Phone (780) 492-9047

E-Mail sandra.macphail@nurs.ualberta.ca



Cardiology Clinic *News*

Change of Division Head of Cardiology

After twenty years as Division Head of the Cardiology Department at the Alberta Children's Hospital, Dr. Joyce Harder has decided it is time for a change and she has stepped away from that position. Her patients and their parents will be delighted to know that Dr. Harder will continue to see and treat patients, but she has turned over the administrative duties to Dr. Frank Dicke, who is now Acting Division Head of the Cardiology Department.

New Cardiologist Joins the ACH Cardiology Clinic

Dr. Deborah Fruitman joined the Cardiology Team on February 1, 2008. Dr. Fruitman is at the Cardiology Clinic four days a week, and on Wednesdays she does fetal echocardiograms and prenatal counseling at the Maternal Fetal Medicine Clinic at the Foothills Hospital. To learn more about Dr. Fruitman, read "Talk with the Docs" on page 8.

Cardiology Clinic Wants Your Stories to Create Bulletin Board of Encouragement

When expectant or new parents learn that their child has a heart defect, their initial response is often dismay, uncertainty, even fear of what this means for their child. These families need a positive view of the possibilities for their child's life after treatment. We are asking you to help provide that view. Patty Knox at the ACH Cardiology Clinic has volunteered to provide a window for that view, in the form of a bulletin board in the clinic. We are looking for photos of your child being active and successful in his or her world. We want to see your heart child in action! Please submit a photo which you think would give hope to families walking into the clinic for the first time. Perhaps your son looked particularly sunny in his soccer uniform, and your daughter beamed when her dance-recital photo was taken—or vice versa! Include the following information: child's first name, age, the name of the heart defect repaired, and a sentence or two to describe their favourite activities now. Please send them to: Nurse Clinician Patty Knox by regular mail at Alberta Children's Hospital, Pediatric Cardiology, 2888 Shaganappi Trail NW, Calgary, AB T3B 6A8. Thank you!

Website Review

The Western Canadian Children's Heart Network ("WCCHN")

www.westernchildrensheartnetwork.ca

WCCHN is a network of pediatric cardiac care providers for the four western provinces. It was created in 2004 to share clinical knowledge and expertise to improve care for children with heart disease, and to provide support for these children and families. One of the initiatives was a collaborative effort by families and professionals to provide an overarching website.

The website provides excellent information on each of the hospital sites including a list of services and staff. There is an excellent section on vocabulary, as well as general information about preparing your child for surgery, general care questions, definitions of care providers and a Q and A section. There are also links to family-friendly websites, resource books, and family support newsletters from Calgary, Edmonton, Vancouver, and Winnipeg. The family stories are especially heartwarming and encouraging.

Overall, the website is easy to navigate, bright, and cheerful. The fact it is a western Canadian organization makes it relevant. Stories and photos from heart families are always welcome and can be sent to diana.locher@capitalhealth.ca.

reviewed by Heidi Smethurst

Heidi Smethurst is a mother of four. Her third child, Ryan (9), was born with Transposition of the Greater Arteries and a Ventricular Septal Defect.

Parent Resources

In this section of the newsletter we invite you to share your expertise. As a parent of a child with heart disease, you have learned a lot! Share with us the books, websites and other resources you have found valuable on your journey. Whether your child is a baby, teen or somewhere in-between, we all have things that have made our days a little easier—let's share these ideas with each other!

Advice from Our Parent Expert: You! Preparing for Surgery

Being prepared for how bad he would look afterwards helped, although it still didn't lessen the shock factor. Also, knowing it was our time to rest and recover and that it was okay to let the nurses look after him for the days after the surgery was good as well. That "permission" was great for recovering from the c-section and getting some rest before the next round—weaning off the pain meds.

– Lana Warren, mother of Nathan (2) who was born with Transposition of the Greater Arteries.

I found that you should rest and take time for yourself when your child is in PICU. This is hard to do because you want to be there. But you really need your resources when your child goes to the ward. There is not one-on-one nursing care there and I really felt like I needed someone with my child all the time. My husband had to return to work at this time so grandma came up. I found you almost need two people when you are on the ward so that you can get a break to get food or go for a refreshing walk.

– Karen Perl-Pollard, mother of Mathias (3) who was born with Tetralogy of Fallot Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA) and now has a pacemaker for acquired Heart Block.

When Matthew went for his surgery at the Alberta Children's Hospital, we attended an orientation put on by the hospital.* They show the kids some of the equipment and masks and various items they might see when in for surgery. They gave the kids a surgical mask at the end and the kids seemed to like that. Also there was a parent information session which walked the parents through what to expect and the logistics of the hospital and physically where their child would be along each step of the procedure and where to wait for them, etc.

We bought the book "Franklin Goes to the Hospital" by Paulette Bourgeois to read to Matthew. We also received a kids' coloring book at the Stollery Children's Hospital specific to pacemakers and kids that is really excellent.

*The ACH has weekly orientation sessions for children age 4 to 6 and age 7 to 10. To register, call Admitting at 955-7783.

– Tracey Fedorchuk, mother of Matthew (6) who was born with a complete heart block and is 100% paced with an implanted endocardial transvenous pacemaker.

I suggest having a plan in place for how to keep your family and friends updated. We appreciate their interest and concern and encouragement, but it does take a lot of time to answer phone calls and e-mails and to repeat the same thing over and over again. We found a CarePage a great way to provide people with updates and to receive their encouragements. Our family members and friends said they appreciated it also as it allowed them to be informed without feeling they were inundating us with calls and e-mails. We set up the CarePage up before surgery to let people know about the upcoming surgery, provided updates while Isabelle was in the hospital, and also let people know how her recovery was going once she was back home.

– Patty Wiebe, mother of Isabelle (7) who was born with Hypoplastic Left Heart Syndrome.

I think the most important thing is to never, never, never show your child that you are afraid for them. You are your child's translator for the world; they look to you to understand how they should feel about what's happening. If you seem afraid, your child will be afraid. Sometimes it's impossible to not feel the fear. If you are beginning to feel overwhelmed, do your best to take a break, take a walk, talk to someone if you can, then take some deep breaths until you can return and show your child that you have confidence in the people around you, and that your little one can trust them too. The less afraid they are, the smoother their recovery will be.

– Jennifer Keane Mackinnon, mother of Kathleen (11) and Lindsay (6), who were both born with Atrial Septal Defect, AKA the "tonsillitis" of heart defects.

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Heart Beats
Supporting Children with Heart Disease

Heart Beats and CarePages Partner to Benefit Heart Families

Heart Beats is pleased to offer CarePages to the Heart Beats community. CarePages are free, private, personalized Web pages available to patients and families that help you stay in touch while dealing with a healthcare issue. The service allows you control over communication and provides an easy way for friends and loved ones to respond with messages of support. You can share updates, photos, and contact information when the time is right for you. Family and friends can visit your CarePage to keep up-to-date and provide you with emotional support.

CarePages let patients and families:

- Update everyone at the same time without repeated phone calls or e-mails
- Create a Web page that is private and not open to the general public
- Create Web pages that they can update themselves
- Receive messages of support from family and friends

CarePages are fully secure and password-protected and they comply with all patient privacy regulations.

Keeping the Beat by e-mail

In our efforts to be good stewards of the donations made to Heart Beats, and to make use of the benefits technology can provide, we invite you to receive *Keeping the Beat* by e-mail rather than "snail mail". Please send us an e-mail at info@heartbeats.ca advising us of your e-mail address, and you will receive future issues of *Keeping the Beat* by e-mail. Thank you for helping us to reduce printing and postage costs and allowing us to use these funds to assist heart families in other ways. **Note: E-mail addresses will be used only to distribute *Keeping the Beat* or notices of Heart Beats events and will not be given to any third party.**