

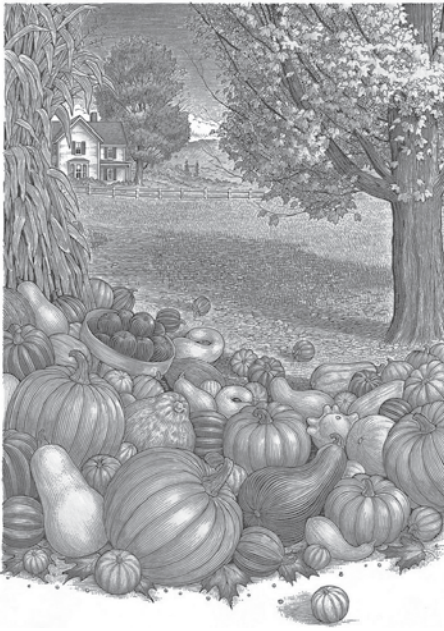


Keeping the Beat

Fall 2008

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

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THREE AMAZING KIDS!

by Cindy Castillo

When my husband and I found out that our daughter Alexa would be born with a heart defect, one of the most difficult issues we faced was the uncertainty of not knowing what her future would be like. Would she be able to function as a “normal” child? One doctor told us, “Well, she won’t be an Olympic athlete.” I remember feeling disappointed about that, and later realized how silly that feeling was, as how many people actually become Olympic athletes anyway?

The second time Alexa’s future athletic abilities were questioned was by a cardiologist in Edmonton. When we asked him what activities she would be able to do, he said, “Well, she won’t be a marathon runner. But how many people actually run marathons?” I quietly told him that at that time my husband had already run five and I had completed two half-marathons. Okay, so now it was getting a little closer to home.

We have never really known what to expect from Alexa. I think “heart parents” often don’t know how to treat our “heart children”. Should we be overprotective and not let our children push themselves athletically? Should we, as I read in one article, expect them to be more academic than athletic and thus push them in that direction?

Dr Harder of the Alberta Children’s Hospital says she tries to reassure parents that a child will rest when he or she needs to, before his or her heart is in trouble. She tells parents that the child will be able to do most of life’s activities and will be able to participate in most sports. Some heart defects do require some limitations and she says the children should stay away from sports like basketball or soccer that require too much running. She says, “A heart that does not have normal anatomy needs exercise just like one with normal anatomy”.

I am honored to introduce you to three amazing kids who have broken all stereotypes about children with congenital heart defects. These three can be an example to us all. They give us hope for the future and show us that having a heart different from everyone else’s doesn’t mean they can’t enjoy the rewards of physical activity.

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THREE AMAZING KIDS!

(continued on page 2)

LUCAS

Lucas, or “Lucky Luke” as he is known to his family, is seven years old. He loves swimming, rock climbing, and hiking, and he loves to ski.

When Luke was just ten weeks old he was diagnosed with coarctation of the aorta, aortic stenosis and a bicuspid valve. He was immediately flown to Edmonton where he had two surgeries within nineteen hours. His mother, Anne, says that Dr. Harder was honest about Lucas’s diagnosis and that she and her husband “entered a very dark tunnel, fell off our chairs and were very very down”. As far as Lucas’s athletic future was concerned, Dr Harder told them that he would not be very limited but that there were certain sports such as scuba diving and weightlifting that he should stay away from. But those limitations didn’t bother this family of avid skiers.

The first year of Lucas’s life was worrisome for his parents. Anne says that if any little thing didn’t seem right with Lucas, she rushed him to the Children’s Hospital. But, despite their fears, Luke was always included in family ski trips. His first ski experience was actually in utero, and after he was born he either rode on his Mom’s back while she skied or he rode behind her in a trailer. The first time he was on skis himself was at just eighteen months when he skied between Anne’s legs.

From age three to five, Lucas took regular morning classes at Norquay and at Canada Olympic Park. He continued that until he was five and then he joined his big sister Charlotte in the Nancy Green ski league at Norquay. He’s also starting his third season as a Bow Valley Quickie this December.

At Norquay he trains every Sunday from 10:00 until 3:00. The afternoon part of the day is dedicated to “racing” on a designated run at Norquay. Sometimes the kids even race against their parents, and naturally the kids always win.

Last year, downhill skiing didn’t seem enough for Lucas. He was interested in biathlon skiing but he was too young, so he joined in a cross-country skiing program called the Jackrabbits, a program for 4- to 12-year-olds. Dr Harder really encouraged Lucas to get involved and he ended up loving it. Now he spends Monday nights from 6:30 to 8:30 cross-country skiing at Canada Olympic Place, and almost every winter day-off from school in Kananaskis or on a nearby ski hill.

For legal reasons, Lucas’s coaches must be aware of his heart condition. The first year was a concern for them as they had never had a student with a congenital heart defect, but they soon saw that it was not a problem and did not affect his athletic abilities in any way at all. In fact, Anne says, after a full family day of skiing, his sisters fall asleep in

the car and Lucas is either talking non-stop or singing loudly.

Way to go “Lucky Luke”! What a wonderful example for us all!

ISABELLE

Seven years ago, Isabelle was born with critical aortic stenosis with Hypoplastic Left Heart Syndrome and endocardial fibroelastosis. She has had three open-heart surgeries: the Norwood Procedure at eleven days old, a Bilateral Glenn Shunt at six months old, and a Fontan at four years old.

Doctors told Isabelle’s parents that her physical activity would be restricted because of her heart defect. They said that her maximum cardiac output would be about 60% of that of a person with a healthy heart, which is the equivalent of the average “couch potato”. They also were told that Isabelle wouldn’t be an Olympic athlete but that she could be active.

Isabelle’s family is another family active in sports and Isabelle always takes part. She rides a bike, skis, and swims. She even drove a quad with her dad last summer. She has taken swimming, skating, and skiing lessons. Not bad for “the average couch potato”!



Lucas on the slopes of Mt. Norquay.



Isabelle (left) competed in the Kids of Steel Triathlon with her sister Janelle, and cousins Gabrielle and Stephanie.



Alysha plays competitive tennis.

Patty, Isabelle's mom, says that she does not stop Isabelle from doing anything athletic, but she does often ask Isabelle if she's okay, if she's too tired, or if she needs any help. Most of the time, Isabelle says no.

Two years ago Isabelle's dad Colin started participating in triathlons. Older sister Janelle soon followed suit and completed her first triathlon last summer. Their enthusiasm for the sport caught on and this year Patty started doing triathlons as well. Isabelle wasn't one to be left out of the family fun and amazingly this year she did a kids' marathon and not one but two kids' triathlons!

Isabelle completed the Tinbits Triathlon in Vulcan in June, which included the usual triathlon events of swimming, biking, and running. She competed in the eight and under category.

She also participated in the Timbits Kids' Marathon in Calgary in July. The kids are to run 41 kilometers before the race day, and then run the final 1.2 km on race day to complete the distance of a full marathon. Isabelle did a kilometer a day for 41 days, and she ran the last stretch on the day of the Calgary Marathon with the other 450 participants between the ages of two and fourteen.

The third event Isabelle completed was the Lake Chaparral Kids of Steel Triathlon in August. Isabelle swam 50 meters in Lake Chaparral, then rode her bike for 1.5 km, and ran for half a kilometer. Kids can choose to have a parent accompany them so Colin stayed with her the entire time, but Isabelle did not really need any assistance.

Patty says, "Isabelle didn't set any records, but the fact that she was able to compete in those events with her peers with her heart condition makes her a winner in our eyes." And ours too! What Isabelle has accomplished is truly astounding!

ALYSHA

Alysha is eleven years old and was born with Hypoplastic Left Heart Syndrome. She is a very active girl and takes weekly gymnastics, fitness, and yoga classes; she golfs, bowls, plays badminton, skis, ice skates, swims, dives, knee boards, and rides her bikes. On top of all of that, Alysha is an excellent tennis player. An unbelievable amount of activity for a girl with a single-ventricle heart!

Alysha's parents were always aware that Alysha would not compare physically to children with healthy hearts, but it was again Dr Harder who reassured them. She said they should let Alysha determine what she was capable of handling and that Alysha herself would learn to listen to her body and know when to rest.

Five years ago Alysha joined a tennis program at the Calgary Winter Club. She began training for an hour every week and two years ago increased her training time to four hours a week. She has been fine with that and stops and rests whenever she needs to. For example, at the beginning of every training session, Alysha and her teammates have to run laps, and sometimes Alysha stops and catches her breath before she runs again. Alysha's mom, Jeannine, makes coaches aware of Alysha's limitations and assures them that Alysha will rest when she needs to.

In the Spring of 2007 Alysha was named the Calgary Winter Club U10 Club Champion. She had to compete against both boys and girls in her age group at this annual event, and she came out on top!

Over the past year she has entered many tournaments in Alberta and has played against Alberta's top tennis players. This July she participated in the Alberta Outdoor Provincial Tournament in Red Deer.

At the beginning of September, Alysha was invited to participate in a selection camp for Alberta's High Performance Provincial team.

This is where all of the best child tennis players come together for a full weekend of training and seminars. The kids participate in various physical testing, and some will be chosen to be part of the provincial team. Alysha's family talked a lot about whether or not Alysha should be a part of this weekend; they knew it would be particularly strenuous. Alysha convinced her family that she would be okay. She was determined not to let this opportunity pass her by and successfully completed the weekend. She was tested on her technical ability and also attended seminars on nutrition and mental toughness.

Alysha's mom Jeannine says, "Whether she makes the High Performance team or not, whether she wins or loses her tennis matches, Alysha will always be a winner in life!" Well said! Alysha is a stellar example of what can be accomplished despite having a heart defect.

Cindy Castillo is the mother of two daughters. Her youngest, Alexa, was born with hypoplastic left heart syndrome.

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.**

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:

- FirstEnergy Capital Corp.
- Long View Systems Corporation
- Lucas and Charlotte Neander
- Ms. Zaganelli's class from St. Benedict School

The following people made donations to Heart Beats in memory of Kevin Moore: (see story on page 11)

Janice Alberts
P. Amirault
Sylvia Arneson
Layne and Donna Baker
Pierre Berger
The Brookwells
Rob and Teresa Brown
Canyon Meadows Golf & Country Club
Paddy and Bryan Cowan
Monica Croft
Victor and Joanna Curtis
Jim, Kathy, and Zachary Delday
Bob and Irene Duncanson
Edna Duncanson
Reinhard and Janis Dyck
Lorna Forst
Gee Vee Holdings Inc.
Philippe Giguere
Annette, Tom, and Allison Gillis
Ameen and Jocelyn Hamdon
Betty and Herbert Hassall
Bernard and Brenda Hemsing
Dennis and Gay Hemsing
Robert and Ruth Hemsing
Rod and Nadine Hudson
Mark and Dianne Kaun
Colleen Kozy
Bryan Kump
Mercedes Landals
Paul Langlois

Bill and Irene Lester
Leroy and Bonny Lester
Anne, Steve, Kenna and Julie Lockwood
Darlene and Frank Lotz
Karen Manley
Gail Markovich
Jean and Herb Matthews
Karin and Harald Matthiessen
Lillian McConnell
Ken & Jenna McCullough
Judy McKnight
Grant Meadows
Les and Lavene Morin
Buff and Jean Murrell and family
Herman and Sheila Oldeheuveel
Robin Purnell
Phyllis and Ronald Quarrie
Sidney and Karen Quibell
Kenneth & Judy Roper
Kyle Sandahl
Marie, Allan, Curtis and Amy Sinton
Tom Smillie
Don and Sharon Snell
Rachele Toovey
Ulevog Financial Corporation
Irene Wheeler
We also thank our shy but generous Anonymous donor.

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.)

Young Donors Support Heart Beats

For Easter 2008, six-year-old Lucas Neander and his seven-year-old sister, Charlotte, gave up chocolate and juice for Lent. For every day they successfully avoided chocolate and juice, their parents gave them each 25¢ per item. The kids were so disciplined they never gave in and each received 50¢ a day, which they deposited into a clear glass jug on the kitchen counter. After 40 days they each had \$20. As in previous years, they were allowed to keep half the money and give the other half to a charity of their choice. In 2007, they gave their Lent savings to the Alberta Children's Hospital; in 2008, they chose to give it to Heart Beats Children's Society of Calgary.

When Lucas was ten weeks old he was diagnosed with coarctation of the aorta, aortic stenosis and a bicuspid valve. He was immediately flown to Edmonton and underwent two surgeries within 19 hours. He is now seven, full of energy and ideas for building!

Thank you Lucas and Charlotte for your donation to Heart Beats!



Lucas and Charlotte with younger sister Clara.

Heart to Heart

Heart to Heart is a social group 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, we enjoy having the whole family attend. 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 October will be on Monday, October 6th at 10 AM at the home of Patty Wiebe, 47 Midvalley Crescent SE.

Heart to Heart in November will be on Tuesday, November 4th at 10 AM at the home of Lynn Nakoneshny, 187 Willowmere Close in Chestermere.

In December we will have a Christmas party on Sunday, December 7th at 1:30 PM at the home of Patty Wiebe, 47 Midvalley Crescent SE. If you are able to attend, RSVP to Patty before November 30th by e-mail pattyw@heartbeats.ca, or by phone at 403-256-7423.

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 403-256-7423.

Another New Cardiologist Joins the ACH Cardiology Clinic

Dr. Robin Clegg joined the Cardiology Clinic in August, 2008. Dr. Clegg brings to the Cardiology Clinic her expertise in heart-rhythm disorders. For more information about Dr.Clegg, read “Talk with the Docs” on page 6 .

Cardiology Clinic Wants More of Your Stories for the 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, 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 to Alberta Children’s Hospital, Pediatric Cardiology, 2888 Shaganappi Trail NW, Calgary, AB T3B 6A8. Thank you to those who have already submitted photos, but we have room for many more!!

Offbeats

Offbeats 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.

We are excited about starting up again after the summer break. Norma Becker, cardiology nurse, will not be with us this year as she is taking parental leave. In her place we are happy to have Kelly Webber return to Offbeats from her parental leave last year. Activities for the coming year will include our old favourites such as bowling, a Calgary Flames hockey game, and heart-month pizza at Boston Pizza. We also hope to include some new activities such as art projects (which might even get displayed in the hospital), music play, volunteering for Operation Christmas Child, and whatever else the group would like to do this year.

We encourage any patients of the Cardiology Clinic aged 12 to 17 to join us!

For more information, contact Laura Thurber-Larsen at 403-955-7888 or Laura.Thurber-Larsen@CalgaryHealthRegion.ca.

Talk with the Docs – *Dr. Robin Clegg*

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 past issues of Keeping the Beat we have featured Dr. Frank Dicke, Dr. David Patton and Dr. Deborah Fruitman. In this issue, we feature Dr. Robin Clegg.

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

August 2008.

Where did you train before you came to our Cardiology Clinic?

I grew up in Winnipeg and attended the University of Manitoba for my undergrad degree, BSc, Honours Genetics and also my medical doctor degree. I then did a three year Pediatric Residency at the Alberta Children's Hospital, University of Calgary. I was the Chief Resident in 2003. After that I did a three year Fellowship in Pediatric Cardiology at the Hospital for Sick Children, University of Toronto followed by a two-year Fellowship in Pediatric Electrophysiology. The electrophysiology fellowship was split between the Hospital for Sick Children, University of Toronto and Boston Children's Hospital, Harvard University.

What made you decide to come to Calgary?

I knew that the Department of Pediatrics at ACH is excellent, there is a strong team of Pediatric Cardiologists and there was an identified need for a specialist in heart rhythm disorders. In addition, there is a strong adult Electrophysiology group. With good support from both the pediatric and adult groups, there was a great opportunity to developing a strong pediatric and adult congenital heart disease electrophysiology / heart rhythm disorder service.

Calgary is also a great city – fresh air (recall I just moved from Toronto and Boston), lots of green space, conducive to an active lifestyle, and great for raising a young family.

How do you like the city so far?

It is lovely. We are living in a great community and have met friendly neighbors with young families. We (my family) have been participating in lots of outdoor activities, especially with the nice weather we have had this September. It has been easy to settle in. Although, I do miss apple picking in September, which was a tradition in Toronto.

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

I am the other short, young, pregnant cardiologist (Dr. Fruitman is also short, young and pregnant – we are both due in the early new year). Seriously, I am petite, walk and talk too fast, and am always sniffing out interesting ECGs.

When you are not working, what do you like to do? Do you have any particular hobbies or interests that you enjoy?

I feel like the dust is just settling. My daughter and husband have organized extracurricular activities for the fall and winter. However, for me, most of my activities are on hold with the new job and pregnancy. I look forward to getting back into snowboarding and skiing (avid boarder), running – I love road races (just 5K to 15K, I haven't found the time to train for longer events) and yoga. I love to read and am looking for a new good book. My favorite book is still "A fine Balance" by Rohinton Mystery. I love to bake (cookies, muffins, breads, pies, etc), but can't cook!

You are an electrophysiologist- a specialist in disorders of heart rhythm and the cardiac conduction system. Can you tell us about this?

My specialty area is heart rhythm disorders in childhood (fetal life to young adulthood) and in heart rhythm disorders in adults with congenital heart disease. The scope of my practice, in addition to general pediatric cardiology, includes, but is not limited to the following:

- assessment and management of
 1. tachyarrhythmia (too fast or racing heart rhythms)
 2. bradycardia (too slow)
 3. syncope (fainting)
 4. electrical cardiomyopathies (inherited disease of heart muscle and electrical conduction system e.g. Long QT syndrome, arrhythmogenic right ventricular cardiomyopathy)
 5. children who have had a relative (sibling or a parent) die suddenly, presumably due to a sudden cardiac event (looking for inherited rhythm disorders, cardiomyopathies)
- interventional electrophysiology:
 1. ablation – a cardiac catheterization procedure to treat heart rhythm disorders
 2. pacemakers and implantable cardiac defibrillators (ICD): management of pediatric patients with devices – they have unique needs compared to adult patients with devices

What changes or advances have there been in the study and treatment of arrhythmias over the past 10 years?

There have been huge advances!

Ablation techniques and technology have advanced in leaps and bounds – especially in children. This has resulted in dramatically improved success rates and a huge decrease in complication rates. Now this is a very safe and successful treatment for heart rhythm disorders in children, for example, it is the recommended treatment for disorders such as Wolff-Parkinson-White and for rhythm disorders in patients with congenital heart disease.

With respect to devices (pacemakers and ICDs), smaller and smaller devices are being created – more appropriate for pediatric size – without compromising functionality. Increasingly, the issue of device battery longevity is being addressed.

Genetic based diagnosis and screening for inherited electrical diseases is rapidly advancing, greatly improving our ability to diagnose and tailor appropriate treatment for these life-threatening diseases. It has also made a huge difference in being able to rule out disease in relatives of a patient known to have the disease, which has a huge impact for the families!

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

There is safe, curative therapy for the common heart rhythm disorders in children.

Device therapy is more “pediatric appropriate”, allowing us to tailor our therapies to the lifestyle of kids (instead of having the kids modify their lifestyle to the device).

Improved management of heart rhythm disorder in older children and adults with congenital heart disease has had a major positive impact on lifestyle and quality of life as often rhythm disorders result in frequent ER / hospital visits and a decline in ability to do activities of daily living. We are getting better and more knowledgeable

at treating these arrhythmias allowing people to live symptom-free and recurrence free. This management includes the novel use of medications, ablation techniques, as well as novel pacemaker and ICD programming.

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

There will continue to be improvements in the technology: ablation – continue to improve success rates; devices – continue to get smaller, longer battery life

Major changes will continue to be in genetics of inherited electrical myopathies, which will lead to more rapid and sensitive diagnostic tools and improved, targeted therapy.

The management of adults with Congenital Heart disease will always be evolving.

As the pediatric care of these patients improves and the surgical therapies evolve, the substrate for heart rhythm disorders will change too. This will continue to be a demanding field requiring collaboration across North America with centres with heart rhythm specialists in Adult Congenital Heart Disease

I understand that in addition to seeing patients at the ACH Cardiology Clinic you also spend time at the adult cardiology clinic at the Peter Lougheed Centre. What do you do there?

I am a Heart Rhythm specialist for patients with Adult Congenital Heart Disease. Children with congenital heart disease, especially complex heart lesions (ie. single ventricle / Fontan, repaired Tetralogy of Fallot), have a very high rate of developing heart rhythm disorder in adulthood. As you know, they are a very unique group of people with special cardiac anatomy and physiology and therefore present

with a unique set of heart rhythm disorder requiring a specialized approach to diagnosis and management. In depth knowledge of both congenital heart disease and rhythm disorders is an asset in working with them. I work as part of the Adult Congenital Heart Disease team at the PLC diagnosing and managing (including ablation procedures) these special heart rhythms.

How does your work at the PLC assist your treatment of children with CHD?

Transitioning to the adult health care system from the Pediatric Cardiology service is often a difficult one for patients and families. I have a unique position in working at both clinics. In addition to being a familiar face from the Children’s hospital at PLC, I look forward to taking an active role in helping make this transition a smooth process.

2009 Family Celebration of Congenital Heart Defect Awareness Week

Plans are being finalized for our annual family event during Congenital Heart Defect Awareness Week, February 7-14, 2009. We look forward to celebrating with you. Stay tuned for more details in the next issue of “Keeping the Beat”.



Share Your Story

Noah's Success Story

Noah William Holmes was born on January 15, 2002. Surprisingly, we were told by our family doctor that Noah, our brand-new baby boy, had a heart murmur. We were concerned as there was a history of heart problems in our family. So we asked to see a specialist and were soon referred to Dr Frank Dicke at Children's Hospital.

When it came time for the visit, we were shocked to find out that Noah had a hole in his heart, an Atrial Septal Defect (ASD). Noah was only 13 months at the time. We visited Dr Dicke the following year and found out that the hole was not closing and probably would not close due to its size and location. There was a possibility of two scenarios to close the hole, open-heart surgery or a plug inserted through a catheter to cover the hole. As new parents, we had a gruelling decision to make.



Noah loved the beach at Akiskinook in Windermere, BC.

By the time Noah was two, additional tests were completed to find out the exact size and location of the hole. We decided to have the Amplazer Septal Occluder option but were concerned about its limited history (at that time only 10,000 had been used worldwide) even though the success rate was stellar. Dr Dicke assured us that this solution would remedy the problem with the least amount of pain and recovery time for Noah.

On July 20th, 2005, the Holmes family, including his parents Chris and Jackie, both sets of grandparents and Noah's little 13-month-old brother Jonah, drove to Edmonton to support Noah during his procedure, which was performed by Dr Coe and Dr Dicke. The procedure took almost 4 hours and Noah came out of it very smoothly. He only stayed overnight in the hospital and ran down a hill the next day at a rest stop on the drive home.

Our high-pain-threshold little trooper recovered quickly and just over three years after the procedure, Noah's hole has grown over and the enlarged portion of his heart is now a normal size. All Noah wanted was for Dr Dicke to tell him was that his heart was normal, and he did! This made the whole family extremely happy and thankful to be so lucky to have such medical expertise available to us.

Noah is now 6-and-a-half and is in grade one at St. Joan of Arc school. He is extremely active and a great reader; he loves to swim, ride his bike, fish, rock climb, and play with Lego.

Jacklynn Holmes



Veronica and her brother Taylor.

Veronica Arnett

Our relationship with the Alberta Children's Hospital and Dr. Michael Giuffre began six years ago when our daughter, Veronica, was clinically diagnosed with Marfan Syndrome by our pediatrician in Calgary. The primary danger of this condition is the potential for an aortic rupture. Even though we had had top specialists from many fields attending Veronica since birth for various other problems relating to Marfan's, no one was able to clinically diagnose her problem until she was in grade four. It is a condition that can run in tall families and her dad is 6'4" so no one seemed to be looking in the right places.

Two years after the clinical diagnosis, Veronica's blood work was sent to the United States where they have the facilities to genetically prove the malfunctions in the gene. To our surprise, the technology at the time could not, in fact, confirm this difficult case, despite her having had all the clinical symptoms and related heart abnormalities associated with Marfan's. As her brother, Taylor, also shows a lot of clinical symptoms of Marfan Syndrome, he has been watched by the

same Calgary doctor team. When Taylor was diagnosed with Type 1 Diabetes at age 13, his beta blockers interfered with detection of low blood sugars and he had to stop that preventative medication. We sought alternative medications that would be compatible with insulin. In addition, the whole family had blood work sent to Sweden for the latest and most advanced genetic testing. There are no local laboratories that have comparable diagnostic capabilities for fibrillin mutations.

Summer 2008, as our 6'1" lovely Veronica was approaching her 16th birthday, we were blessed with the bittersweet scientific proof that she definitely has the genetic mutation of Marfan Syndrome, but that her 6'2" brother with diabetes did not! Too bad we did not know this sooner—he might have chosen to play hockey.

Community Updates

When we read the request for stories of Calgary families involved with Heart Beats, it was a prompt to share the good news for any other families in the community who do not know of all the genetic testing improvements of this year. There are still no local laboratories with comparable capabilities, but testing is available.

We have appreciated the direction and efficiency of the cardiology clinic so much over the years and regret that we will have to meet a new team when our daughter is 18—only 2 more years!

Mrs. Nora Arnett

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

Kel Sorenson

We don't know if any other original Heart Beats kids has had a child yet, but we are thrilled to report that ours has!! This is a photo of our Kel with his 20-month-old daughter Lily (she looks just like her Daddy!). Kel is 24 years old now and was born with TAPVD (Total Anomalous Pulmonary Venous Drainage). He had two repairs at Toronto's Hospital for Sick Children in 1984 and 1985, before he was a year old. His repairs were new techniques back then—they really worked, and he seems to get better with age!!

Very proud Grandma – Maureen Sorensen



Kel with his 20-month old daughter Lily.

Mathias Pollard

Mathias Pollard had his pacemaker replaced on August 19th at the Stollery Children's Hospital in Edmonton. Mathias received his first pacemaker on March 8, 2006. Because he is bigger, he is now able to have an adult pacemaker. The battery on this pacemaker is expected to last 4.5-5 years, which is twice as long as the battery on the pediatric pacemaker he had. Mathias started Spanish Bilingual Junior Kindergarten this year.

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

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.

Canadian study to test value of heart-lung machine during cardiac surgery

The Canadian Press

It's a question that divides cardiac surgeons — is it better and safer to perform bypass surgery with the patient on a heart-lung machine that stands in for the heart, or to do it on a pulsing organ still pumping blood to the body?

For a number of years, a debate has raged about whether so-called on-pump or off-pump surgery produces better results and whether the latter reduces the risk of complications such as cognitive losses known in cardiology circles as “pump head.”

Over the next seven years, a Canadian-financed and -led study will try to answer the questions, studying what happens when 4,700 patients from 16 countries are randomly assigned to either the traditional on-pump or the newer off-pump technique.

“You have the believers [in the off-pump approach] and the non-believers,” said Dr. Andre Lamy, a cardiac surgeon at McMaster University in Hamilton who is leading the study along with renowned McMaster cardiologist Dr. Salim Yusuf.

“So with this study, we're trying to figure out if the technique is really safe and on top of that, if there's any benefits for the patients for stroke and pump head and so on.”

For the record, Lamy suspects off-pump will turn out to be superior, at least for older, sicker patients.

But no large randomized trial comparing the two techniques has been done, despite the fact the off-pump method has been in use for at least a decade. Without the

reliable evidence such a trial would generate, “I don't know the answer. I truly don't,” he said.

Canadian Institutes of Health Research to fund study

The trial — the largest to date to compare the two approaches — is being funded through a \$6.5-million grant from the Canadian Institutes of Health Research.

A cardiac anesthesiologist from Duke University in Durham, N.C., welcomed the news, saying the trial is “absolutely needed.”

“We tried to do it in the United States, but the NIH [National Institutes of Health] never gave us the funding that we needed,” said Dr. Mark Newman, chair of the department of anesthesiology at Duke.

“So I think it's great that the Canadians are going to be able to do it. Because ... everybody has their opinion and each surgeon believes something different, based on his own practice. So I think you won't really know until you have a good randomized trial.”

The study is designed to compare the safety profiles over the short- and long-term of the two techniques, measuring things like whether one or the other has lower rates of death, post-surgery neuro-cognitive losses, stroke, blood transfusions and quality-of-life concerns.

A key question will be whether, as hoped, off-pump surgery leads to fewer complaints of the memory loss and cognitive impairment that have come to be known as pump head or bypass brain.

It's a commonly seen but not commonly warned-about phenomenon: People who are placed on a heart-lung machine during their surgery can wake up foggy-brained and confused. While the cause is not clear, a theory is that people who undergo the surgery while on the machine may produce tiny clots that travel to the brain and cause mini-strokes.

A study by Newman and colleagues from Duke published in the *New England Journal of Medicine* in 2001 showed slightly more than 50 per cent of bypass patients suffered cognitive decline at the time of discharge from hospital. Followup five years later showed 42 per cent still sustained cognitive losses.

The Canadian trial — which will go by the name the Coronary trial — will enrol middle- to high-risk patients. It will follow patients for an average of five years after surgery, will look to see if there are higher rates of repeat bypass surgery or more procedures to insert artery-opening stents in the off-pump group.

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Kevin Moore

Kevin Moore and his parents, Gary and Bev, were very involved in the early years of Heart Beats and have been a part of the Heart Beats' community for many years. We share their sadness at the passing of Kevin on August 27, 2008 at the age of 20 years. While Kevin's life was too short for those who shared it with him, he made the most of his 20 years, experiencing more than many who live to old age. His life is an inspiring example of how to live fully and meaningfully, and a testimony to his family who encouraged and enabled him to live it that way.

Kevin was born in Brooks, Alberta on May 11, 1988 and later that year, the family moved to Calgary. Kevin began his life with a complex congenital heart condition – Atrial Septal Defect, Ventricular Septal Defect, and pulmonary stenosis – and as an infant underwent two BT Shunt procedures in Edmonton. At the age of two he underwent a Fontan open heart surgery in Toronto and since then had led a full and active life.

Kevin graduated from Lord Beaverbrook High School in 2006 and enrolled in the Travel and Tourism program at SAIT where he was about to begin his second year of studies. He worked at the Canyon Meadows Golf Course for the past year and developed a love for the game of golf. Kevin enjoyed trying different sports and activities and always accepted challenges without complaining or feeling sorry for himself. He had a passion for street hockey and the cul-de-sac in front of his house was regularly filled with a variety of buddies participating in a game of shinny. Kevin's musical skills began with two years of piano lessons before moving on to guitar. He became self-taught with the help of the Internet, as well as numerous basement jams with his friends.

Travel was always a passion of Kevin's, and he was able to set foot on all major continents. Family trips throughout the years took Kevin to Disney World, Disneyland, Texas, Costa Rica, Mexico, Cuba, Dominican Republic, Brazil (including Foz du Iguassu Falls), France, Hong Kong, and Thailand. A trip with his dad to South Africa for a game safari fulfilled his quest to see the "African Big Five" after years glued to watching the Discovery Channel. After graduating from high school, Kevin planned, saved, then went to Australia to "live the dream", spending six months meeting new friends and having new adventures.

He had a great sense of humour and was always able to make sure that we did not take life too seriously. He had a unique ability to develop friendships regardless of age, gender, or status. Wherever Kevin went and whatever he did, he was always able to make an impression with his casual manner and his ability to toss out an unexpected one-liner joke.



Kevin, his sister Keri, and his parents Bev and Gary.

Kevin became ill on a family trip to Panama. He was transferred by air ambulance back to Canada where he fought a courageous battle at the University of Alberta Hospital.

Our heartfelt condolences go out to his parents, Gary and Bev, and his sister, Keri.

Kevin's spirit, laughter and joy of life will never be forgotten. He was a special gift.

We would like to extend our sincere gratitude to our friends at Heart Beats for the beautiful flower arrangement and amazing emotional support during this very difficult time. Over the past 20 years Heart Beats has filled a void that only parents of children with medical conditions can understand, and the realities and fear we live with. We cherish our wonderful memories of Kevin and know that he lived each day with love and laughter. He was a ray of sunshine....

Bev, Gary and Keri Moore

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! How have you helped your heart child to gain weight?

This question takes me back a few years ... now, I make Daniel (almost 20) exercise and nag him about good choices in food. My how things change...

When he was little though, I added butter to his oatmeal to make each bite count and we had his milk higher strength (formula) so it was higher calorie as well. I used PediaSure before surgeries to bulk him up a little and I also added a little butter to his applesauce and berries (melted of course). I was liberal with the cheese and gravies too. Now I need to avoid all those things because none of us around here is getting any smaller!

Sylvia Falk, mother of Daniel (20 years old) who was born with Pulmonary Stenosis and a single ventricle.

When we got our little warrior, Owen, back to Foothills Hospital post-op the nurses added 5ml Isomil to my expressed breast milk, which seemed to help. Getting transferred to the Alberta Children's Hospital second floor was a blessing because it enabled me to room in with Owen and breastfeed our sweet heart baby back to health around the clock—our discharge from there all depended on his weight gain. . . . When we first arrived at the Children's Owen was not gaining the daily amount he should, but within two days of our rooming in together he gained well over the recommended daily amount and we were discharged. So my advice to other heart parents would be to breastfeed if you can, and if you do take in lots of healthy calories yourself, or express and supplement if you need to. Keep your baby warm but not overheated so they don't burn extra calories staying warm, and last but not least, hold and love your baby as much as you can.

Michelle Dominique-Aris, mother of Owen (6 months old) who was born with a coarctation in the left side of his heart and a bicuspid.

Minigos (yogourt cheese cups) were always a delight to Alysha and definitely an easy way to get calories in her!

Jeannine Oliphant, mother of Alysha (11 years old) who was born with Hypoplastic Left Heart Syndrome

One of the best sources of extra calories for us was avocado. I actually froze it into ice cube trays and then mixed one cube in with Mathias' baby food. Another favourite (and still is to this day) is Minigo, although it is higher in sugar than I like....

Karen Perl-Pollard, mother of Mathias (3 years old) who was born with Tetralogy of Fallot, ASD, Patent Ductus and Pacemaker for acquired heart block.

When I express breast milk, I pump four bottles to make sure to get the extra-fatty hind milk. I put the bottles in the fridge to allow the fat to separate. When it's time to feed Anika, I skim the fat off the first two bottles and I give her the extra-rich hind milk along with the separated fat from the fore milk. Then I throw away the fore milk. She's gaining well and we've been able to take the extra oils out of Anika's diet.

Tina Brandt, mother of five-month-old Anika, who was born with Hypoplastic Right Heart Syndrome

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