

# Keeping The Beat

Heart Beats Children's Society of Calgary

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

## The Berlin Heart

Medium to Long-Term Support for Children in Heart Failure

Whether a child is experiencing a reversible form of heart failure or is waiting for a transplant, the Berlin Heart is a device that can help children survive for many months.

The Berlin Heart has many advantages over Extracorporeal Membrane Oxygenation (ECMO) devices. The ECMO takes over the functioning of the heart and the lungs of a patient, but with this device the blood must be thinned and patients must be kept sedated. The ECMO is a short-term solution, typically for 14 days or less.

On the Berlin Heart, patients can be awake and breathe without assistance. Typically there are also fewer coagulation problems. But most importantly, patients can live for several months on a Berlin Heart, allowing a heart to recover or for a suitable donor heart to be found.

The device itself is built in Germany and consists of four tubes that are implanted within the body and a computerized pneumatic pump which sits outside the chest. The tubes are attached to the right atrium, pulmonary artery, left ventricle and aorta. The right atrium delivers blood to a pump within the Berlin Heart. The Berlin Heart then mimics the pulsing action of the heart to push the blood to the pulmonary artery. The blood goes to the lungs to become oxygenated. The oxygenated blood returns to the left ventricle where it is sent outside the body to the Berlin Heart. The Berlin Heart pumps the blood back to the aorta and the oxygenated blood is delivered to the rest of the body.

The pediatric Berlin Heart can be adjusted for different pumping volumes and can support children from 2 kg to 90 kg.

The Stollery Children's Hospital, in Edmonton, expects to implant four to six Berlin Hearts every year - but this figure may rise due to a persistent shortage in donor hearts.♥

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# Calgary Child Sets Record for Longest Time on Berlin Heart in Canada

*Korey Werry, a member of our Heart Beats' community, was put on a Berlin Heart when he was 3 years old while he waited for a heart transplant. He was the second child to be put on a Berlin Heart at the Stollery Children's Hospital. We asked his parents, Linda and Barry Werry, to share with us Korey's experience with the Berlin Heart.*

## **What was the nature of Korey's heart defect(s) when he was born?**

Korey was born with multiple heart problems. His primary diagnosis was Double Outlet Right Ventricle. In addition he had Transposition of the Great Arteries, an Atrial Septal Defect (ASD), a Ventricular Septal Defect (VSD), extreme Mitral Valve Stenosis and a Coarctation of the Aorta. He also had Wolff-Parkinson-White Syndrome (WPW).

## **What procedures did Korey have done prior to his heart transplant?**

- Pulmonary artery banding and widening of ASD 13 days after birth in May 2003.
- Glenn procedure with a Damus in September 2003.
- Coarctation repair in November 2003.
- Catheter ablation to try and correct the WPW in February 2006.
- Fontan procedure in July 2006. Three days later the Fontan was reversed.
- Emergency Brain surgery to correct a subdural hematoma in August 2006. Korey had lost the use of the right side of his body, and his ability to speak.



Werry family photo. Centre front, Korey held by his mother Linda, with father, Barry to the left of Linda. Centre back, Teagan, tickling Korey, Kaden and Kai is on the far right.

## **Why did Korey need a heart transplant?**

Three days after Korey had the Fontan procedure it had to be reversed because his pulmonary arteries were not large enough to sustain the blood flow and, as a result, the Fontan shunt developed clots. He was put on ECMO in the hope that his heart would recover. After seven days on

ECMO it was obvious that his heart was not going to recover and on July 28, 2006 he was put on the list for a heart transplant.

## **Why was Korey put on the Berlin Heart?**

After ten days on ECMO, Korey's health began to deteriorate. His kidneys were beginning to fail and his skin was breaking down. It seemed that we were not going to get a new heart in time to save Korey. The doctors at the Stollery Hospital recommended we put Korey on the Berlin Heart to give us some time to wait for a heart to become available.

## **What were you told about the Berlin Heart?**

We were told Korey would be the second pediatric patient at the Stollery Hospital to receive the Berlin Heart and that they were using it in Europe with great success. We were hopeful that it would be a success for us. We were running out of time and it gave us such hope. It felt like our prayers had been answered.

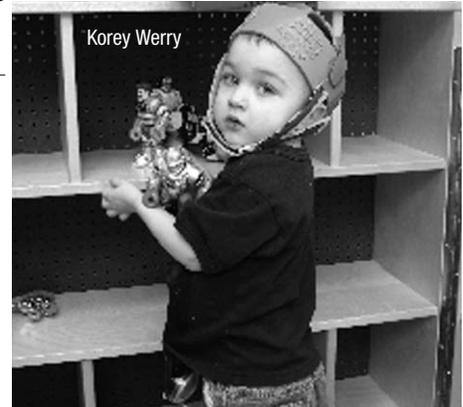
On July 31, 2006, Korey underwent surgery to implant the Berlin Heart. The surgery was done by Dr. Holger Buchholz. They removed the ECMO pump and implanted the Berlin Heart. The pumping chamber was sewn into his heart - it was attached to his descending aorta and his right ventricle - with the pumping chamber resting on his stomach, attached to a large Icus which controlled the pressure. The pump had to be monitored to ensure that clots did not form.

## **How long was Korey on the Berlin Heart?**

Korey was on the Berlin Heart for 173 days. When the pump was removed he had set the record for Canada for the longest time on a Berlin Heart.

Korey is the longest surviving Hypoplastic heart patient on a Berlin Heart in the world. Korey was more difficult than a regular Berlin Heart patient. For all of his pre-transplant life he was Hypoplastic so his oxygen saturations stayed in the 60 - 80 range. As a Berlin Heart patient, they only gave him one pumping chamber instead of the normal two, so he was kept as Hypoplastic on the Berlin Heart. This caused some extra difficulties for the Berlin Heart. The blood of a Hypoplastic does not have the same clotting properties of a "normal" person, so getting the mix of anticoagulants in the blood is more complex.

With too much anticoagulant, you get a bleed, which Korey did. It almost killed



him. The Neurosurgeon only gave him a 50 - 50 chance of surviving the brain surgery, and this was exacerbated by the fact that Korey was full of anticoagulants. You don't want to go into brain surgery full of anticoagulants, but with Korey there was no other choice.

With not enough anticoagulants, clots form in the Berlin Heart, break off and cause strokes. The main pumping chamber does develop clots over time and needs constant observation to recognize when this is happening. When it happens, the system design allows swapping out of the pumping chambers (in about 30 seconds) to keep the patient alive. Korey went through five pumping chambers.

## **What was it like for Korey to have the Berlin Heart?**

For the first two months Korey was still very sick. After his brain haemorrhage Korey had to re-learn how to walk and talk. We were lucky because the Berlin Heart allowed him to get up and move around. Korey seemed to adapt to having this large machine attached to him. He was able to go to physiotherapy and get his daily exercise to keep him strong. He played at the "beach" almost everyday, which helped to keep his spirits up.

## **What was it like for you to have Korey on the Berlin Heart?**

When Korey went on the Berlin Heart we felt such a sense of relief. It gave us time to wait for a transplant, to find a perfect match for him. After his brain haemorrhage his condition did eventually stabilize and he was able to have a quality of life. He could spend his days doing what three year olds do. He got so strong on the Berlin Heart, it helped to increase the odds that he would survive the transplant surgery. The Berlin Heart helped to save his life.

We had many stressful days with bleeds and clots. Any flu or cold he caught seemed to really knock him down and

# Berlin Heart - cont'd from page 2

alter his blood chemistry, once again increasing the risk of bleeds and clots.

He also had several Supraventricular Tachycardia (SVTs), a result of the WPW syndrome. He was at a decreased risk of them causing brain damage because of the Berlin Heart and they were treated with medication.

## When did Corey have the heart transplant?

After 177 days on the transplant list our prayers were once again answered and on January 20, 2007 Corey received his new heart.

## What procedures has Corey had since the heart transplant?

Corey had a Catheter procedure to fix some collaterals he developed as a Hypoplast. Corey had some of his arteries and veins connected directly together to keep him alive when he was a Hypoplast - his own body grew these as an adaptation. In particular his Right Internal Mammalian Artery (RIMA) was directly connected to his Right Pulmonary Vascular Bed via a couple hundred little tiny vessels. With his old heart this was a good thing as it kept him alive, but this was causing his new right ventricle to have to pump directly against his new left ventricle. This was very hard on the main heart valve on the right side, the tricuspid valve. It couldn't close properly, and Corey was having trouble keeping his blood

oxygenated. To correct this problem Corey had a catheter procedure to block off his RIMA with stainless steel coils to stop blood from flowing into it. This worked and about 20 days after the transplant they were finally able to take him off the ventilator and he could breath on his own.

In March 2007 Corey's skull was put back together. After the brain surgery they did not completely assemble his skull. They put about 25% of his skull in a freezer and waited for the transplant. So Corey's skull was open from the day of brain surgery until March of this year. This was in case he developed another bleed, rather than crushing his brain and damaging it, his head would just balloon up from accumulating blood. This is good for a few reasons, you can tell he has another bleed, it protects the brain from the bleed, and getting back in to fix it is relatively quick and easy. The downside, and it's a big one, is that there are only a couple layers of skull protecting his brain from the outside world. Everyone really had to watch what we did with his head, him included. Even after putting his skull back together it still has large openings in it, which the neurosurgeons will correct after he grows more and gets closer to his adult size.

## What is life like now for Corey following the transplant?

Corey is doing very well with his new

heart. He is strong, healthy and enjoying life. To look at him you would never know he was ever sick except for the never ending scars.

He has to take a lot of meds to ensure that his body does not reject the new heart and that it stays healthy. He really dislikes the taste of some of them, but he understands that they are a necessity and he is resigned to the fact that they are part of life. Some of the medication suppresses his immune system so we have to be extra careful to insure he gets exposed to as few illnesses as possible.

## How has your family coped with all this?

The past year we all felt numb. As we look at the last school year it feels like it didn't even happen. It is as if time stood still for us as we waited for a new heart for Corey.

This experience has helped to bring us closer both to each other and to God. It has given us a new appreciation for life and how delicate and special each and everyone of us is.

## Is there anything else you would like to share about all this?

We are grateful for the wonderful care Corey received. It helped to save his life and we are so thankful to still have him with us. And we thank God for giving us such a blessed child. ❤️

## One Year Later:

*Berlin Heart Bridges Patient Back to Health*

*Capital Health's first pediatric Berlin Heart recipient weaned from device*

*Originally released on August 28, 2007. News Release reprinted with permission from Capital Health.*

**M**elissa Mills, a 15-year-old patient at Capital Health's Stollery Children's Hospital is the first pediatric Berlin Heart recipient in Canada to be weaned from the device not because a donor heart was found, but because her own heart recovered.

"We thought the miracle was that the Berlin Heart would give us time to find the perfect donor heart for Melissa," said her mother, Sharon Mills. "We are overwhelmed that instead, the Berlin Heart gave her own heart time to rest and repair itself."

Following a sudden illness last August, Melissa, from Camrose, Alberta was transferred to the Stollery in such grave

condition that her parents were told to prepare for the possibility she might not survive. Melissa required a heart transplant urgently, and continued to deteriorate while waiting for a suitable donor. Doctors at the Stollery elected to implant a Berlin Heart, the first mechanical heart designed specifically for children, hoping to give Melissa time to recover while she continued to wait for a heart.

Within a few months, Melissa's overall condition had improved dramatically, and her heart muscle had regained much of its strength. After 146 days on the Berlin Heart, Melissa underwent surgery to have the device removed.

"We are just beginning to understand all the applications for the Berlin Heart," said Dr. Ivan Rebeyka, Clinical Leader of the Berlin Heart program, Head of Pediatric

Cardiac Surgery for Capital Health, and Associate Clinical Professor, Surgery and Pediatrics, University of Alberta. "We are thrilled with Melissa's outcome and excited by what this means for future patients."

Last fall, the Stollery Children's Hospital became North America's first training and support centre for the world's first mechanical heart designed for children. To date, five patients have received Berlin Hearts at the Stollery Children's Hospital.

Under the agreement, Stollery physicians provide training and advice to other children's hospitals that use or plan to use the Berlin Heart across Canada and the Western United States. "The Berlin Heart program will complement the full range of services available at the Mazankowski Alberta Heart Institute when it opens in 2008," said Dr. Rebeyka. ❤️

# Cardiology Clinic News

## Pediatric Pacemaker Clinics Now at Alberta Children's Hospital

On September 12, 2007, the first pacemaker clinic was held at the Alberta Children's Hospital. The clinic was coordinated by a nurse from the Foothills Hospital Pacemaker Clinic and Dr. Harder from the Cardiology Clinic. This first clinic provided four children with their routine check-up and adjustments.

This collaboration between the Foothills Hospital Pacemaker Clinic and the Alberta Children's Hospital Cardiology Clinic will provide more efficient, collaborative and child-centred care. Bookings will be coordinated through the clerks at the Cardiology Clinic, with information provided by the Pacemaker Clinic regarding who requires a check-up. Attempts will be made to coordinate with other appointments at the Cardiology Clinic if required.

Clinics are expected to be on a monthly or bi-monthly basis. Any questions regarding the Pacemaker Clinic should be directed to the Foothills Hospital Pacemaker Clinic at 944-1248.

## New Echo Machines Expected in Early 2008

New echo machines are being tested at the Echocardiograph Lab. Technicians expect to order new machines by the end of October and receive delivery of them in early 2008. Why are new machines required? The echo machines that are currently in the lab are eight to 10 years old and technology has changed a great deal. The new machines being tested have more powerful software which leads to brighter, clearer and more precise images.

What will this mean for patient experience? The new machines will look

a bit more sleek, but they will also be able to provide more precise measurements. Precise measurements provide more information for creating a care plan for young patients.

Unfortunately, the new echo machines have not developed the anti-wiggle technology that some digital cameras now employ. Therefore the anti-wiggle distraction function still resides with parents.

The echo lab technicians provide two key tips on preparing your child for an echo:

1. Ensure your child is dressed in chest accessible clothing to make things easier for everyone (no onesies, overalls or dresses).
2. Remember you are welcome to bring your child's favourite DVD for the visit as an old favourite may make them feel more relaxed and comfortable. ♥



## Heart to Heart

**H**ear 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.

Both parents and children benefit from getting together with others who have gone through, or are going through, similar experiences. One mom recently commented on how encouraging it is to see an older child who has been through the surgeries that her infant son is facing. Another mom said that interacting with other children with CHD helps her elementary school aged son feel better and less self-conscious about his own condition.

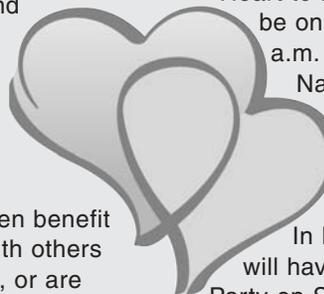
We vary our meeting days, times and locations from month to month to try to include as many parents and families as possible.

Heart to Heart in November will be on Tuesday, Nov. 20 at 10 a.m. at the home of Lynn Nakoneshny at 187 Willowmere Close in Chestermere.

In December we will have a Christmas Party on Sunday, Dec. 9 at 2 p.m. at the home of Patty Wiebe at 43 Midvalley Crescent SE. If you are able to attend the Christmas Party, please RSVP to Patty before November 30 by e-mail [pattyw@heartbeats.ca](mailto:pattyw@heartbeats.ca) or phone 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 at [pattyw@heartbeats.ca](mailto:pattyw@heartbeats.ca) or 256-7423. ♥



Parents Nikki Ballendine and Claudette Chisholm chat while also keeping an eye on children Emily, Landen and Kirsten at July's Heart to Heart at Midnapore Lake

## Off Beats

Off Beats is a fun, activity-based group for youth aged 12-17, offering peer-to-peer support and friendship.

We have already kicked off this year with great food, updates from the summer and discussions of what we would like to do this year. Some of the ideas discussed include Theatre Calgary, time donated to stuff shoe boxes for Christmas, Shakers Amusement Park, a Flames game, Paul Brandt concert, heart shape pizza night, in-house movie, bowling and the list goes on.

Great ideas including some new ones!! As tradition goes, our October meeting will include large balls and 10 pins, yes it is bowling time. Bowling is at Frank Sisson's Silver Dollar Bowling, October 9, 2007 from 7-9 p.m. Kelly is a bit competitive and is hoping for a dynamic team and she needs all the help she can get!!

Kelly and Laura are very excited and look forward to another great year with Off Beats. We look forward to seeing familiar faces and really hope to see some new faces join us.

We thank Heart Beats for their continued financial support so we can do all the things we do!!

We invite all youth between the ages of 12 and 17, living with congenital heart defects, to join us. For more information, please call Kelly Webber at 955-7316 or Laura Thurber-Larsen at 955-7888.♥

## 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. Friends and loved ones can then visit your CarePage to be kept up-to-date and to provide you with emotional support.

CarePages let patients and families:

- Update everyone at the same time without repeated phone calls or emails
- 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, password protected and comply with all patient privacy regulations.

Until December 31, 2007, CarePages will donate to Heart Beats \$25 per active CarePage created through Heart Beats' CarePage website at [www.carepages.com/heartbeats](http://www.carepages.com/heartbeats).

Should you require help in setting up a CarePage, please contact [support@carepages.com](mailto:support@carepages.com) or call 1-888-852-5521, Monday through Friday from 8 a.m. to 6 p.m., Central time.

To create or access CarePages, visit [www.carepages.com/heartbeats](http://www.carepages.com/heartbeats) or visit [www.heartbeats.ca](http://www.heartbeats.ca) and click on the CarePages icon.♥

## Long View Systems Supports Heart Beats

By Tracey Contrada

For many reasons I am blessed. My employer, Long View Systems, held its annual client appreciation golf tournament on July 9, 2007 at the Glencoe Golf and Country Club. Again, Heart Beats was selected as one of the recipients of our fundraising efforts. My daughter, Ava, was diagnosed with congenital heart disease at birth, and Heart Beats has been instrumental in supporting my family over the past 3 years.

In conjunction with Long View, one of our key partners, Network Appliance Inc. stepped up and offered to help us raise money for our great cause. Cordell Caldwell, Channel Account Manager for Network Appliance, was so enthusiastic when discussions commenced around why Long View supported Heart Beats, that he gave up his spot at the tournament and dedicated his day to fundraise on our behalf. With Cordell's determination, his efforts netted a significant sum for Heart Beats! Don Bialik, CEO of Long View Systems, generously matched the amount raised.

So why am I blessed? I have wonderful people that I get to work with every single day - co-workers, partners and clients that truly support me, my family and what I believe in. I don't think you can ask for much more in a career, and for that I am thankful.

We wish to acknowledge the following people who generously donated to Heart Beats through the Long View Systems Annual Client Appreciation Golf Tournament:

Keith Aasen	Rick Farmer	Mike Moore
Garnet Amundson	Blaine Feniak	Ian Munro
Bill Arnett	Wade Fisher	Scott Nelson
Jason Auck	Peter Forte	Client Neusitzer
Ted Aumentado	Marc Galeski	Al Oanza
Dave Ball	Tim Gillespie	Donald Oart
Dean Baloy	Justin Gobeil	Brian Peters
Robin Bell	Keith Grae	Darrell Popowich
Andrew Bentley	Simon Graham	Derek Preston
Gary Bianchini	Gray Graves	Peter Przybylski
Greg Bolin	Eddie Hacala	David Quinn
Jim Bowman	Darryle Hawkings	Richard Roskey
Cordell Caldwell	Regan Hold	Gregg Shoemaker
Gary Cameron	Lane Irvine	Cindy Sibel
Hal Carmichael	Ken Jans	Orvil Smith
Mark Clark	Bob Kehler	Cathy Swanberg
Bob Clifford	Scott Klassen	Ed Teron
Jamie Coley	Dwight Lemky	Greg Theron
Greg Convery	Lee Lodge	Patti Thuell
Tracey Contrada	Kent MacDonald	Christine Vander
Ray Crockett	Gordon MacLean	Glenn Ward
Stephanie Curry	Joanne Major	Jake Warken
John Deausy	Doug Martin	Nick Wieler
Doug Dunwoody	Garrett Mazurenko	Gary Witiw
Robert Duval	Mike McCrae	Dave Yates
David Engel	Shaun Moar	Brad Zingle

- Tracey Contrada is the mother of Ava (3) who was born with Left Ventricular Non Compaction.♥

# Talk with the Docs - Dr. Frank Dicke

So often we only know the Cardiologist your child visits at the Cardiology clinic, but each of the Cardiologists has his own area of expertise that contributes to the overall care provided to all patients of the Cardiology Clinic.

We look forward to introducing you to each of the Cardiologists at the Cardiology Clinic. In this issue we feature Dr. Frank Dicke who has been a Cardiologist for seven years and with the Alberta Children's Hospital for the past five years.

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

I would be the tallest of the cardiologists with the least amount of hair on my head. I am generally fairly quiet and unassuming and I like to run a punctual clinic as I believe everybody's time is valuable.

## What is your favourite thing about working at ACH?

I love working with the kids and the working environment here is also very upbeat with a superb staff in the clinic.

## You have been doing some interventional cardiac catheterization work. Can you explain to me what this is?

Interventional cardiac catheterization involves using catheters to do something previously done by the surgeon. This allows a quick recovery and avoids the need for surgically opening a chest or the need for bypass. Examples are closing atrial septal defects (ASDs), patent ductus arteriosus (PDA), opening up valves or arteries, creating or closing communications in the heart and most recently, pulmonary valve replacement. The procedures are suitable for most children greater than 5 kg.

## How has interventional cardiac catheterization changed the patient experience?

Kids can now go home the next day with no scar on the chest. Previously they would have to be in hospital up to 2 weeks and would have the discomfort of a surgical wound as well as the scar to go with it.

## Are there even more innovations in this field to come? What can we expect to see in the next 5 years?

Valve replacement is likely to become more

routine in the next few years. Biodegradable devices are at the cutting edge of current research and hybrid procedures involving a combination of surgery and interventional catheterization to reduce risk will become more common.

## What are Melody valves and what are their applications?

Melody valves are valves obtained from the jugular vein of a cow and are sewn to the inside of a metal tube called a stent. They can be compressed to fit inside of a catheter and then expanded in the position of the pulmonary valve in patients.

## How are they different from other valves?

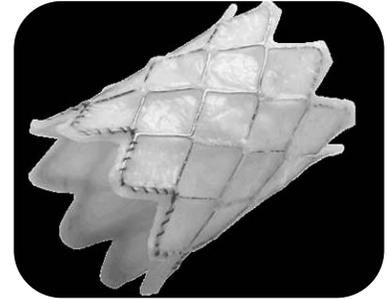
They can be inserted with a catheter and do not require opening the chest or cardiopulmonary by-pass. The children can go home the next day.

## What types of children/conditions are suitable for the melody valves?

For now, only children over 20 kg who have a conduit or artificial pulmonary valve in place such as with pulmonary atresia or Tetralogy of Fallot are candidates. This is likely to expand over the next few years to include others.

## In terms of working with the valves - what can we see in the next 5 years?

Likely an increased use in other types of heart disease and eventually a replacement aortic valve. ♥



Melody Heart Valve is constructed of a jugular vein of a cow sewed into a metal stent



Melody Heart Valves can be inserted with a catheter and do not require open heart surgery

## Your Support in Action

Your donations to the Heart Beats Children's Society of Calgary provide information, resources and support to families dealing with congenital heart defects. Your donations have provided:

- Heart and Soul: Your Guide to Living With Heart Disease information binders to families (distributed through the Cardiology Clinic).
- Financial assistance to families having difficulties meeting expenses related to their child's heart defect.
- 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 June through September 2007:

The Imperato family  
FirstEnergy Capital Corp.  
Long View Systems Corporation  
Mercer Valve Co., Ltd.

We also want to recognize Unified Valve Ltd. for its donation directly to the Cardiology Clinic, which also benefits heart families.

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

Donations can also be received online at [www.heartbeats.ca](http://www.heartbeats.ca) where you can make secure donations by credit card.

# Your Questions Answered

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**Q: My son has Tetralogy of Fallot which has been repaired. As a result of his repair, he now has a pacemaker and is 100% ventricularly paced. We are planning a vacation to Mexico and had read that pacemakers can be affected by the metal detectors at the airports. Are there any special precautions we should take in relation to Air Travel with a heart condition?**

A: Depending on a child's cardiac problem, air travel is not necessarily a problem. But it is good to ask questions and be informed before you embark on your trip.

There are two primary concerns - the ability of a child to tolerate the decreased oxygen levels during the flight and any precautions regarding the

pacemaker. Commercial planes are pressurized, but if the flight exceeds one hour it will be pressurized to 8,000 feet above sea level. People with good health can easily tolerate this. People with compromised cardiovascular systems may encounter circulation problems. Since your son has been repaired and can participate in all levels of activity, there is no concern about his ability to tolerate the oxygen levels within the plane.

Pacemakers do not prohibit patients from traveling, nor do they interfere with aviation navigation equipment. Passing through the metal detector at airports will not damage a pacemaker, but the metal in it may sound the alarm. It is best to avoid the wand metal detectors if possible.

You may also want to follow these recommendations:

- Travel with a letter indicating your child's health status.
- If on medication, carry enough in your carry-on.
- Keep a list of medications and dosages in case they are lost.
- Ask your doctor regarding adjusting medication times if you are crossing time zones.
- Ask your doctor if it would be appropriate to carry a copy of your child's most recent electrocardiogram.

This information is just a guideline and it is recommended that you consult with your cardiologist before travelling by air. ♥



## Parent Resources

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This section of the newsletter is for 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 - so let's share these ideas with each other! For the next issue of *Keeping the Beat* please submit your tips on dealing with medications. You may submit these to the Newsletter Coordinator at karenp@heartbeats.ca

we arrived home I searched everywhere for resources on congenital heart defects. I ordered this book through Chapters Online and have found it to be a very good resource.

The book starts off with a forward by Sylvester Stallone and Jennifer Flavin-Stallone. This introduction was reassuring - I was not alone and, in fact, I was in the company of stars! Living in Hollywood or Calgary, the journey congenital heart disease takes you on is a humbling one.

This book takes a more personal approach, providing both support and guidance. Each chapter is packed with personal stories and advice of other families who are going through the same journey.

The book goes through diagnosis, technical explanations of common defects, finding support, day-to-day living, surgery, the hospital stay, life after surgery and perspectives on approaching adulthood. There are even helpful tips in each chapter including

tips for echos and EKGs and for giving medications. (Two of the biggest challenges for us while our son was a baby.)

In the question and answer section, it was like the authors were reading my mind as I found almost every question that I had asked in the previous weeks. Examples include: Why does an enlarged liver sometimes signal a heart problem? How can new parents tell if their baby has difficulty eating or shortness of breath? Can my son be circumcised?

This is a book that I will continue to refer to as my son grows. It is like having a support group right on your bookshelf - that is available 24 hours a day. I would definitely recommend it to others.

- Karen Perl-Pollard is the mother of Mathias (3) who was born with Tetralogy of Fallot, Atrial Septal Defect (ASD) and patent ductus arteriosus (PDA).♥

## Book Review

**The Parent's Guide to Children's Congenital Heart Defects - What They Are, How To Treat Them, How To Cope With Them** by Gerri Freid Kramer and Shari Maurer Copyright 2001

My son was diagnosed with Tetralogy of Fallot a few days after he was born. We stayed in hospital for a week and when

# Special Tribute to Noah Maurette

*Noah Maurette was born with Hypoplastic Left Heart Syndrome. He went through the Norwood Surgery, the Glenn Surgery and the Fontan Surgery, and was an active and delightful boy completing grade one. Tragically, on June 20th, 2007 - his 7th birthday - Noah was hit by a vehicle that backed out of a parking spot in a reckless manner. Noah died of his injuries a few hours later.*

*At the Prayers and Tributes service Noah's mom, Michele Maurette, gave a moving and inspiring tribute. The following is an excerpt from that tribute.*

As I look across this room, I am once again overcome by the outpouring of love and support our family has received. It has been truly remarkable and a testament to how many lives one little boy has touched . . .

The kids always ask me what my favourite days of the year are. I have seven - the day Andrew and I were married, Noah's birthday, Jacob's birthday, our birthdays and the two solstices. I love the winter solstice for it is the coming of the light, and the summer solstice for being the longest day of the year - the celebration of light. I always find it bittersweet, however, as the days grow shorter from here on. How appropriate that Noah should die on the solstice - the day after his birthday.

Over the last six days, I have been listening to the many wonderful stories going around our house and I found that there were several common themes to Noah's life: He had the need for speed, a deep love for his family and friends, a passion for strange food, a great sense of humour, and a raw determination that I have seen in no other.

Before I begin, let me take you back to June 20, 2000 . . .

Noah was born on a beautiful summer day - much like last Wednesday. He came into this world at three minutes to midnight and shortly thereafter was sent to the special care nursery at the Peter Lougheed hospital. They said he was

breathing a little fast, might need some oxygen and they wanted to watch him overnight. By the next afternoon he was ready to leave the SCN and join me in my room. Prior to leaving the unit, Dr. Ackerman pulled Andrew and I aside and said, "I have some bad news." "What - what news?" we asked. "Your baby has a hip click and you will have to double diaper him for about three months," said the doctor. "Well, how are we going to do this?" I thought.

What a hassle - but we were up for the challenge. Little did we know that 30 hours later we would be boarding a plane for Edmonton to be with our son - who was about to embark on the first of three life saving surgeries. Oh to have a hip click now!

Noah had a congenital heart defect called Hypoplastic Left Heart Syndrome. Ten years prior I had learned about it in school and at that time these children were left in the care of their parents to die. So two days after Noah's birth, I was confused as to why we were being sent to Edmonton. Dr. Giuffre and the cardiologists in Edmonton assured us, however, that surgery was indeed an option - the decision was made for us.

By all rights, Noah should never have survived. When the duct that normally closes in the heart shortly after birth closed, there was only a trickle of blood leaving Noah's heart. His brain barely had any blood flow for 15 minutes and he was the colour of concrete. At one point in Edmonton we were told that he had little to no brain wave activity and the possibility of surgery seemed bleak. We prayed and prayed and prayed. I pulled in all my favours from the "Big Guy" that week. Noah survived and we went home the day after the tornado hit Pine Lake. Then just prior to his second surgery - six months later - Noah crashed again while having a test done on his heart. Once again God saw fit to leave the little man in our care for awhile longer.

I will not dwell on his heart anymore as it played a minuscule part in defining who he was. The turning point for my



Pictured from left to right are Jacob in front of Michele, Andrew, and Noah

husband and I was one day when Dr. Giuffre said to us, "You have two choices - you can keep him in a glass box - or you can let him go." From that point on we were determined to give him the most normal life possible and let him take the lead as to what he could and could not do. There was always a sense of urgency though and the need to celebrate the little things.

We named him Noah. I originally wanted Zechariah, but Andrew thought it was too biblical. I should point out that our second child is named Jacob. I discovered today that Noah means "at rest and peaceful." How ironic as, contrary to what Noah's doctors said, he was anything but restful. We often joked that we were thankful for his heart defect as we could not imagine how he could be anymore energetic. His boundless energy first showed through in his need to hurl himself down steep inclines. I know that most of you cannot imagine where he gets that from! When he was 14 months old we would take him to a hill outside our condo complex and send him hurling from the top on a little orange and yellow car with handles. Andrew would do the pushing and I would catch him at the bottom. I loved to be the catcher as I got to see the sheer joy on his face. From there he graduated to sledding at the green park and riding the jumps on his bike at the jumps park . . .

Noah also tried to impart his love for speed and steeps on to Jacob. One day while I was in the kitchen I was beginning to wonder why the house was so quiet. The silence broke with, "Are you ready Jacob?" Hmmm, this cannot

be good. I went looking for them and found that Noah had Jacob perched at the top of the stairs in a laundry basket. I will leave the rest to your imagination. At least he thought enough to put a helmet on his brother first.

How Noah loved you Jacob. He could hardly wait until you were born. He missed you when you were apart, always asked for a treat for his brother too when he got to go to the treasure chest at the doctor's, and had the best built in buddy he could ever want. This love of family extended far beyond Andrew, Jacob and I to his cousins, aunts and uncles and grandparents . . .

(He had a) wonderful sense of humour. He was always telling a joke or making some rude noise that only 6-year-old boys can make. He often had pet names for his cousins and friends that usually involved odour and bodily functions. He and Jacob would sit in his room and kill themselves laughing over a new name they had come up with . . .

Andrew's favourite was Noah's ability to make noise with his armpit and a sweaty hand. I came to the school to pick him up one day, and as his teacher walked by he made the loudest armpit fart I have ever heard. Sra Moir rolled her eyes and in a voice full of exasperation said, "He has been doing that ALL day." Yes and he continued to do that ALL night. I don't think we have ever seen someone who could armpit fart, whistle, snap his fingers and wiggle his butt - all at the same time. You try - it's not easy.

The things I will miss most though are his brilliant smile and the smacks on the butt he would deliver as he went running by . . . oh yah - and the horseradish.

That child had the strangest affinities for certain foods. He loved horseradish so much that he would phone my mom and dad to make certain there was enough in the house for him at dinner. He could eat an entire bottle to himself - 5 ounces of horseradish to each ounce of steak. As soon as he walked into someone's house, he would check the fridge for something good to eat. For Noah that meant pickles, blue cheese, pepperoni

sticks and medium rare steak. If those weren't available he would ask for sour soothers and freezies which, after eating, he would stick out his tongue and ask, "What colour is my tongue? What colour is my tongue?" Because of his heart and Andrew's genes, his metabolism was on overdrive. When he was young his doctors told us to feed him fat, let him eat cakes and pastries, high fat milk, meats and cheese . . . I thought to myself, "Put weight on him - now I know how to do that." Hahaha . . . how can you compete when your son's favourite food is broccoli? He was the only child I knew who would pick a carrot over chocolate cake.

Outside of his love for family, sense of humour and bizarre tastes for food, the trait that embodies Noah for me was his fierce determination. When Noah got something in his mind there was no stopping him and he had that from the time he was a baby. The only trick was to find the right motivation. He loved basketball and would shoot hoops in our basement. One day Andrew asked how many he could do in a row. He said 20. Everyday after that he would go into the basement and practice until he could do 20 baskets in a row without missing. In kindergarten he wanted to learn to tie his shoes. Night after night he would sit on our stairs and practice over and over again - until three days later when he got it. The week after he decided he was going to do the monkey bars in the playground. It took him a week or two, but he did it. He was determined to skate and loved to play hockey and soccer. He has spent the last three years skateboarding - in our basement, in the yard and across at our neighbour's house on their ramp. Just last week Andrew was mowing our lawn while Noah was skating across the street. He crashed and the skateboard hit him in the shin. He was rolling on the ground - holding his leg for a minute - then got up, brushed himself off and went right back to the top of the driveway to try again. That was who Noah was. He never quit.

I will leave you with the words from his final project in school. It was originally in Spanish:

## **I AM UNIQUE**

**My name is Noah**

**I am six years old**

**My hair colour is blonde**

**My eyes are brown**

**My family is nice**

**My mom works at home**

**My mom's name is Michele**

**My dad's name is Andrew**

**My dad's eyes are brown**

**My mom and dad love me**

**I like to swim in the swimming pool**

**My favourite food is broccoli**

**My dog is brown**

**My favourite fruit is apple**

**My house is white**

**My friend is Andrew D. and Rachelle**

**My brother's name is Jacob**

**My dad is handsome**

**My mom is beautiful**

**My favourite movie is "Sponge Bob Square Pants"**

**Mrs. Tenove is pretty**

**My mom works with babies**

**My Brother is special. My Mom is**

**special. My Dad is special**

*- By Noah Maurette*

For us this poem gives us the comfort that our son really took to heart what we were trying to foster in his life: He had his own identity, a passion and a zest for life and knew he was loved and he appreciated beauty. He also liked broccoli - which is any parent's dream.

In order to make some sense out of this now - and even over the years - we wonder if we were ever meant to have Noah at all. I think at the last moment God threw us a bone and said, "OK - you can have him for a bit - but I get him back in 7 years, 1 hour and 13 minutes . . . you guys better make the best of it." And I think we did. Our house looks like 1965 in bad repair . . . but we traveled, played games, went hiking, camping, spent time with family and friends, laughed, and rarely passed a park we didn't stop for. We celebrated.

There are no regrets and we finally understand why we lived with such a sense of urgency.

So little man - enjoy your eternal solstice and dance in the light. We love you. ♥

## Friends Rally to Support the Cantius Family

Little Noah Cantius has endured more than one person should in a whole lifetime, let alone in only ten months of life. He has been through three open heart surgeries, including one heart transplant. Unfortunately, there have been further complications and Noah is in need of a second heart transplant.

Noah and his parents, Christian and Melanie, are residents of Calgary, but have spent most of the past ten months in Edmonton while Noah has been at the Stollery Children's Hospital. They will continue to be there for an uncertain length of time while they await another heart transplant. In addition to the emotional strain, they are also experiencing financial strain due to the lack of regular employment because of

Noah's hospitalization and extra living expenses while they are temporarily relocated in Edmonton. Regrettably, the government does not provide proper assistance for families in these situations.

Friends held a fundraising dance and auction at the Chestermere Recreation Centre on October 6, 2007. A trust fund has been set up and they would be grateful for further donations to support the Cantius Family.

To make a donation, make your cheque payable to "R. Paddock - in trust of Noah" (R. Paddock is Noah's grandmother) and mail it to 189 Prestwick Way SE, Calgary, AB, T2Z 3Z5. ♥

## 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 by snail mail. Please send us an e-mail at [info@heartbeats.ca](mailto: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 assisting us in this way which will reduce printing and postage costs and allow us to use these funds to assist heart families in other ways.

*Note: E-mail addresses will only be used for distribution of Keeping the Beat or notice of Heart Beats events and will not be given to any third party.*

## Congenital Heart Defect Awareness Week, February 7-14, 2008

Calgary joins other communities around the world in celebrating Congenital Heart Defect Awareness Week on February 7-14. Keep your calendar free for the weekend of February 9 and 10, 2007 to attend Heart Beats' Annual Family Event. You will receive more details in the next *Keeping the Beat*.

We also welcome volunteers to assist with additional events being planned to take place during Congenital Heart Defect Awareness Week. Please contact Patty Wiebe at [pattyw@heartbeats.ca](mailto:pattyw@heartbeats.ca) or 256-7423. ♥

## Share Your Story

We invite you to share with us your experience with congenital heart disease. We would like to hear from parents, as well as 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](mailto:karenp@heartbeats.ca) ♥



**HEART BEATS**  
Heart Beats Children's Society of Calgary  
charitable registration no. 88907 6261 RR 0001  
Providing information, resources and emotional support to families dealing with congenital heart disease.

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