



Keeping the Beat

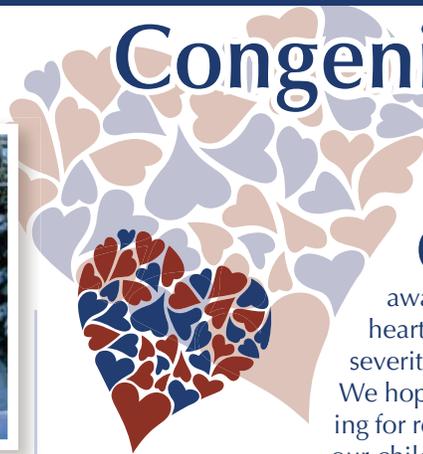
Winter 2013

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

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Congenital Heart Defect Awareness Week

February 7-14, 2013

Congenital Heart Defect Awareness Week is an annual, worldwide campaign to increase public awareness of Congenital Heart Defects and childhood heart disease. The goal is to educate the public about the severity of this disease and its lifelong impact on its survivors. We hope that increased awareness will lead to additional funding for research, support and improved access to quality care for our children and adults.

This year, Calgary Mayor Naheed Nenshi has declared February 7-14 to be Congenital Heart Defect Awareness Week. You too can promote awareness by creating a dialogue with friends and family and providing information to your child's school. Use social media to spread the word about CHD and encourage your friends to participate in a Heart Beats fundraising event, such as the annual Family Fun Run in October.

Did You Know... ?

Did you know that approximately 1 in 100 Canadian babies are born with a congenital heart defect, and that it is the leading cause of birth-defect related deaths worldwide?

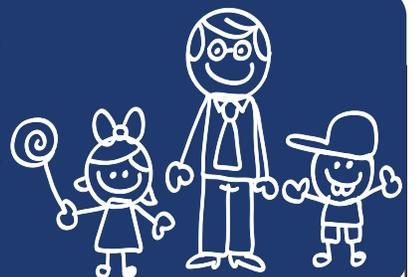
Heart Beats Christmas Party

On December 1st, 2012, Heart Beats held their Annual Christmas Party at Cardel Theatre in southeast Calgary. Nineteen families were in attendance for this festive event that featured lunch, crafts, Christmas carols and a showing of the movie "Arthur's Christmas". The highlight of the day was a special visit from Santa and one of his Elves who distributed gifts to all children in attendance. We thank Cardel Homes, the wonderful volunteers and, most of all, the special families who attended this event.



Calling all Dads!

Are you the father of a child with congenital heart disease? Would you be interested in meeting with other dads in an informal setting to socialize and share experiences? If so, please contact us at info@heartbeats.ca along with your suggestions of what kind of activity you would enjoy (food, pool, golf, etc). One of our "heart dads", Ferrell Beleshko, has volunteered to organize an outing. We look forward to hearing from you soon!



Keeping the Beat by e-mail

Never miss an issue! Subscribe to our newsletter today by sending an email to info@heartbeats.ca advising us of your name and e-mail address, and you will receive our electronic version of "Keeping the Beat". Your email subscription will enable us to reduce printing and postage costs, so that we may use these funds to assist heart families in other ways. Alternatively, you may download a full-colour version of Keeping the Beat from our website at www.heartbeats.ca.

Note: E-mail addresses will be used only to distribute Keeping the Beat newsletter and notices of Heart Beats events; e-mail addresses will not be given to any third party.



Upcoming Events

Annual Family Event

To kick off Congenital Heart Defect Awareness Week, Heart Beats will be hosting a bowling party at the Calgary Winter Club. This event is suitable for the entire family and will include pizza and beverages for everyone in attendance. We look forward to seeing you there!

Date/Time: Sat., Feb.9, 2013 from 3-6 pm

Location: Calgary Winter Club, 4611 - 14th Street NW, Calgary, Alberta

RSVP: We ask that you RSVP with the exact number of attendees no later than February 1st since a final count is required by the venue. Please confirm by email to info@heartbeats.ca or by calling Jen Beleshko at 403-246-7091.

Heart to Heart

Heart to Heart is an opportunity for parents to come together in an informal and relaxed setting to visit and chat about parenting kids with CHD. Whether your "heart child" is an infant, a teenager, or somewhere in between, we welcome you to join in and share your knowledge and experience with others. Those with children at home are welcome to bring them along. For our weekend dates, we enjoy having the whole family attend. Upcoming Heart to Heart dates are:

January:

Tuesday, January 15th at 10 am at the home of Lynn Nakoneshny, 187 Willowmere Close in Chestermere.

February:

In lieu of Heart to Heart in February, Heart Beats will be hosting its Annual Family event.

March:

Friday, March 15th at 10 am at the home of Cindy Castillo 83 Auburn Glen Heights SE, Calgary.

April:

Sunday, April 7th from 2-4pm. The Aris family will be hosting an Easter Egg Hunt at their home located at 281130 Township Road 230, just east of the city limits (contact Lynn Nakoneshny at 403.698.6171 if you need directions).

If you would like more information about Heart to Heart or if you are available to host, please contact Lynn Nakoneshny by e-mail at info@heartbeats.ca or by phone at 403-698-6171.

Heart Beats Annual General Meeting

Date/Time: Wednesday, March 6th, 2013, at 7 pm.

Location: Home of Sylvia Falk, 121 Hawkdale Circle NW, Calgary, Alberta

Details: The Annual General Meeting ("AGM") is open to anyone who is interested in learning more about Heart Beats. Please feel free to join us.



Your Support in Action

Donations made to Heart Beats Children's Society of Calgary are used to provide information, resources and support to families living with congenital heart defects. The following is just a few ways your donations have helped:

- Financial assistance to families traveling to Edmonton for their child's heart surgery through our "Helping Hand Fund";
- Supplemental equipment for the Alberta Children's Hospital Cardiology Clinic;
- "Heart & Soul: Your Guide to Living with Heart Disease" information DVDs (distributed through the Cardiology Clinic);
- Items of encouragement for children undergoing extended hospitalization;

We appreciate and acknowledge the donations received from the following individuals and organizations from September through December 2012:

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| Ingrid, E Alisch Dany Allard Alta West Capital Corp. Shawn Ambrose Andrea Anderson Beverly B. Anderson Kathleen Anderson Melanie Anderson Linda Angelo Pamela Aramburu Kathleen R Armstrong Trica Arsenaault Garth Ayres | Robi & Teresa Contrada Tracey Contrada-Phillips Gregory B Cornell Alayne Crompton Caleb Cossette Carolyn J. Crofts Maureen G Crozier | Marlene Gray Nathan Greener Deborah Guebert Monica Gurbuz | Carol Kurbis Ryan Kurbis Trisha Kurbis | Victoria Nikitina Ronald Norman Carla Novello | Stephanie Smith Michelle Southern Louise E. Sprague Ingrid Stammer Clare R. Stamp Garry Stamp Gordon F Stamp Laurie Stamp Arlene Staples Tim C Steeck Cathy Steele Sylvia Sten Jackeline Stewart Shannon Strumecki Edeltraut Stuerle Lynn M Sufiron Tracy Suhre Robyn Sullivan |
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If you wish to contribute to the support of families of children with congenital heart defects, you may mail your donation to:

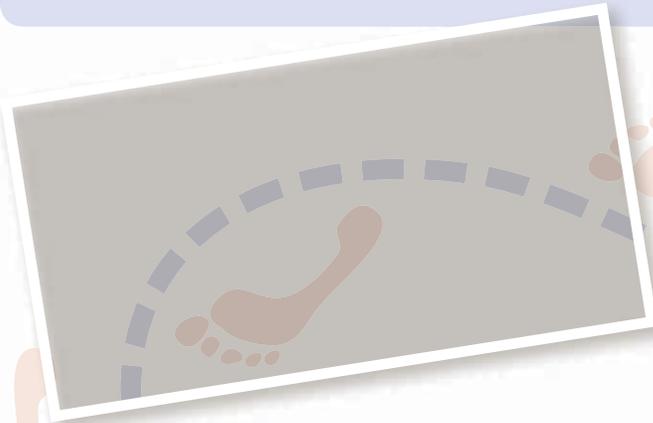
Heart Beats Children's Society of Calgary, Box 30233, Chinook Postal Outlet, Calgary, AB T2H 2V9

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.)

3rd Annual Family Fun Run

On a beautiful fall day in October, over 450 people walked and ran on behalf of children with heart defects. The run was the most successful yet, raising over \$35,000 (net), funds that will go a long way to supporting the children in our community. This event would not have been possible without the many sponsors and volunteers. We look forward to an even bigger and better event in October of 2013!



Team Kevin

Our beautiful son, Kevin Roger Moore, was born on May 11, 1988. He weighed 9 pounds 15 ounces, a perfect, blue eyed brother for big sister Keri. Our world fell apart when we learned he had congenital heart defects, specifically, VSD, ASD, pulmonary stenosis and transposition of the arteries. Kevin had his first BT shunt at 3 weeks of age and another shunt at 1 year. He was two and a half when he went to Toronto for the Fontan procedure. Kevin lived a full and very active life - he loved playing his guitar, music, computer games, tobogganing, street hockey to name just a few. He was a world traveler and was able to step foot in 6 of the 7 continents. Kevin passed away on August 27, 2008. He was loved by many as was evident at the Heart Beats Run. We had over 50 family and friends join "Team Kevin" and are looking forward to making this an annual event. – Bev Moore

Heart Beats thanks the following sponsors for their generous contributions:

Boston Pizza – Beddington
CheeCha Potato Chips
Edmonton Trail Auto Body Ltd., in memory of Renee Flyershop
Home Loans Canada, Sylvia Falk
JPIX Photography
Manitoba Harvest
SIGIT
The Running Room

We also thank the running teams who organized their friends, families and workmates to come out and run on behalf of their children. On these pages are some of the teams that participated this year.



Bentlee's Beats

On October 13th we had the pleasure of participating in the Heart Beats Family Fun Run. We walked and ran for our daughter, Bentlee Maria Leidl, who was born on May 12th, 2011. Bentlee was born with a single ventricle heart as well as transposition of the great arteries, double inlet left ventricle, absent left SV valve and pulmonary stenosis. Our Bentlee has a very complicated heart defect but she is an absolute blessing to her parents, her big brother, and all of our friends and family. Our team was called Bentlee's Beats. Bentlee is a vibrant, energetic and very mischievous little girl who, despite her heart defect, continues to defy the odds and makes us proud every single day of her life. Bentlee's grandparents, great grandparents, cousins, friends, her big brother Jaxton, her parents Chelsey and Jamie, as well as many colleagues from our respective places of employment all wore pink Bentlee's Beats t-shirts and either ran or walked to raise money for Heart Beat's Children's Society of Calgary. Bentlee's Beats was thirty people strong; all giving of their time to help out not only our beautiful Bentlee, but all the wonderful children who are supported through Heart Beats.

The day was truly wonderful for all and Bentlee's Beats even walked away with some best times in several age categories -- it was the icing on the cake of a very inspiring day. We are so proud of our little Bentlee and we cannot wait for next year when we return with an even bigger team of Bentlee's Beats so we can raise even more money for all the children who need the love and support of Heart Beats.

Currently, Bentlee is on 24 hour oxygen, has a feeding tube for weight gain and various medications. She had her first open heart surgery called the Glenn in September of 2011 as well as two heart catheterizations and an AV Fistula surgery on her right arm. Currently we are awaiting a date for her heart cath and next major open heart surgery, the Fontan.



Team Hope Holly Lincoln

On November 18, 2011 we went as a family for our 18 week ultrasound. We were excited to find out if our daughter, Sadie, would be getting a little brother or sister. We expected to leave that office elated. Instead we left with deep pain and fear for our daughter. She had a problem with her heart and we were advised to abort her. We decided to give her a strong name as she fought for her life and named her Hope. Hope was born on April 4, 2012 with Hypoplastic Left Heart Syndrome. She underwent her first open heart surgery at the Stollery Children's Hospital on April 18th. She had gotten sepsis and needed to wait longer for the surgery than we had expected.

During this time we lived at the Ronald McDonald House in Edmonton. I grew very close to two other pregnant mothers that were waiting to deliver babies with heart defects as well. We were all from Calgary and spent many hours getting to know each other as we waited to deliver. We shared our fears and our joys as we walked through this difficult journey together. Holly and Lincoln were born on the same day, one week after Hope.

Hope recovered well from her first surgery (the Norwood) and was back in Calgary at Alberta Children's Hospital just 10 days later. We were there for 72 hours before being airlifted back to Edmonton. Hope had a clot in her SVC and they told us not to expect her to survive the night. Since that day, Hope has had three major life threatening clots, numerous procedures, a dangerous surgery and terrible prognosis from doctors. We truly believe that every breath she takes and every beat of her heart is a miracle. We prayed before she was born that she would be a beautiful woman with confidence. She is truly beautiful and we continue to pray that she will be proud of all she's overcome and encourage others with her story.

During a routine cardiology visit, I saw a flyer for the run with Heart Beats. I called my husband to tell him that I would sign him up. He asked why I wasn't going to sign myself up. Out of sheer pride, I agreed to do the one thing I truly hate...run! When I shared with friends and family that I had decided to run, many people signed up to run alongside us. I wanted to run for Hope and Holly and in memory of Lincoln. He passed away 2 months after he was born. Over 60 people ended up on team Hope Holly Lincoln and were ready to race together. My husband and I were disappointed to miss the race, we couldn't leave Hope in Edmonton, but still wanted to be apart of it. The two of us ran the race together in the neighbourhoods surrounding the hospital. We didn't have a cheering squad or the company of the crowd, but we had Hope, Holly and Lincoln on our hearts.

Feel free to journey with us: www.mendingheartsandbendingknees.blogspot.com



Holly

Holly Ottenhof was born with Hypoplastic Left Heart Syndrome on April 11, 2012: a week after Hope Koslowski, and the same day as Lincoln Roen and his twin brother, Kade. Us moms (myself, Amy & Sharla) had met at Ronald McDonald House while waiting to have our heart babies. Holly was the last to arrive, but the first to get her surgery. Despite a rocky start (her Norwood was performed under emergency conditions), she came home at 6 weeks old. However, her function was severely diminished by 3 months old, and when they couldn't find a structural reason for it, she was listed for transplant on July 27. We were totally shocked to receive a call on August 27, merely a month later, saying a match had been found for Holly. She has been a different baby since then - full of beans, PINK, and so lively. Every day, we can't believe just how lucky we've been when it comes to Holly!



Offbeats

Offbeats kicked off the school year playing Bingo at Alberta Children's Hospital. Everyone seemed to win at least one game and the prize cart was almost empty by the end of the night. We also enjoyed ice cream sundaes, which seems to be a regular occurrence with Offbeats!

*"Twas the night before Halloween
And all through the hospital
Not a creature was stirring, not even a doc.
When all of a sudden great laughter was heard.....who makes such a racket?
Well the Offbeats Group of course! "*

Well, it doesn't rhyme but the group did make a racket and some very scary pumpkins during our October meeting. In November, the group went to Build-A-Bear to make a wish on a heart and then have the bears given to cardiac kids in hospital over Christmas. Upcoming activities for the rest of the year include Laser Quest, painting pottery, heart shaped pizzas...who knows what this group will be doing next!

It is with heavy hearts that we say goodbye to Laura Thurber-Larsen, who will be leaving the Alberta Children's Hospital in December for a new position closer to her home in Okotoks. Laura has been with Offbeats for the past eight years and she has grown very fond of all the wonderful kids in the group. Thank you for everything you have done for Offbeats, Laura - you will be greatly missed and we wish you all the best in your new job!

Offbeats is a fun, activity-based group for youth aged 10-17 who are seen at the Cardiology Clinic. The group offers kids and teens a chance to come together and enjoy fun activities throughout the school year. For more information, please contact Norma Becker, RN at Norma.Becker@albertahealthservices.ca or at 403-955-7316.



Offbeats at Build A Bear in November

Kids Up Front

Heart Beats is pleased to be partnered with Kids Up Front Calgary, an organization that collects and distributes event tickets to children's charities. So far over 20 "heart families" have enjoyed free tickets to hockey and football games, concerts, movies and live theatre. Don't miss out on these and other great offers. If your heart child is under 18 years of age, you can sign up to receive email offers to these exciting events. Please contact Jen Beleshko at jenb@heartbeats.ca for more information.



One little ticket, one big lift.



Staying in touch with other heart families and joining in fascinating conversations has never been easier! Our Facebook group is growing, so stay in the loop by searching Heart Beats from your Facebook page or click on the link at our website to become a part of this expanding group.

Plan Now to Attend a Summer Camp

Did you know that there are summer camps available that are specifically tailored for children and teens with CHD? If your child is between the ages of 7 and 17 and has a heart condition, they qualify to attend one of these amazing camps!

Located in Mission, B.C., Zajac Ranch hosts hundreds of children per year with serious and chronic illnesses and disabilities who might not otherwise have a chance to enjoy a summer camp experience. While this camp is not exclusive to heart kids, it does include one week in the summer that is only for children and teens with CHD. Activities include swimming, fishing, canoeing, kayaking, volleyball, archery, rope courses, climbing wall, baseball, basketball, bocce ball, horseback riding and much more. There is a fee for this camp of approximately \$545 in addition to travel expenses. For more information visit their website at www.zajacranch.com.

Camp del Corazon is held at Catalina Island Camps located at Howland's Landing, a private cove on beautiful Catalina Island, California. All of the activities are led by trained Activity Counsellors and supervised by onsite nurses and physicians. Activities include hiking, adventure games, court games, boom ball, arts & crafts and a variety of beachfront activities. Older campers also have the option of snorkelling and participating in powerboat fun, including tubing. Trained lifeguards oversee each activity in addition to one or two counsellors at all times. The only cost for campers is for their transportation to and from the camp. To register or for more information, please visit their website at www.campdelcorazon.org

Heart Beats is pleased to sponsor any child seen at the ACH Cardiology Clinic who wishes to attend one of these camps (offer is for one stay per child at the camp of their choice). A reimbursement of the enrolment fee (Zajac Ranch) or return airfare (Camp del Corazon) will be provided to the parent who signs up their child for one of these camps. For more information, please contact us at info@heartbeats.ca or speak with one of the nurses at the Cardiology Clinic.

Eric Menu attended Zajac Ranch this past summer, and although he was nervous to attend at first, he ended up enjoying it very much.

"I am fourteen years old, and visited Zajac Ranch in August of 2012 for five days. We did all kinds of things, like horseback riding, archery, climbing wall, and we even climbed up a telephone pole and walked across another one. The food there was awesome. They even had a Superheroes theme day. I made some friends that I really liked hanging out with. I would definitely recommend Zajac Ranch – it's great!"

If you would like to speak with Erik and his mom, Nikki, they would be more than happy to answer any questions from potential campers. Please email your name and phone number to info@heartbeats.ca and we can put you in touch with the family.



Step By Step, Hand In Hand

Growing Up With Congenital Heart Disease

Conference review by Jen Beleshko

I had the opportunity to attend this conference at the BC Children's Hospital on the weekend of September 22 & 23, 2012. The conference was dedicated to "the parents and families of children growing up with heart disease, for their wisdom, courage and resilience". There were concurrent sessions including a "Youth Only" group that discussed heart knowledge, lifestyle issues (drugs and alcohol), and reaching one's own potential. This is a brief overview of some of the sessions I attended based on my personal notes.

The program began with a lively discussion from **Dr. Sanjiv Gandhi**, Chief of Pediatric Cardiovascular and Thoracic Surgery at BC Children's Hospital. Dr. Gandhi discussed how modern advances in cardiac surgery have vastly improved in recent years and continue to do so. The mortality level in even the most complex cases continues to improve. At the hospital, the average post-op stay is now 4-5 days and the use of blood products is down by 50%. The challenge now is improving the quality of life for these patients to near normal levels.

Dr. Gandhi also provided an interesting history lesson into the early years of cardiac surgery, including an important Canadian connection. Born in Ontario, Dr. William Mustard joined the surgical staff of SickKids Hospital (Toronto) in 1947. He devoted his time to improving surgical treatment for children with congenital conditions. In 1963, he devised an ingenious and effective operation to obtain total correction of transposition of the great vessels. This procedure is now referred to throughout the surgical world as the 'Mustard Procedure'. He also developed the first heart-lung machine, which permitted cardiac surgeons to open the heart of living patients and operate on it. The heart-lung machine, developed in 1951, revolutionized heart surgery for all time.

Dr. Martin Hoskings, Paediatric Cardiologist, followed up with his presentation of catheter interventions. He discussed various devices such as coils, balloons, and stents and how catheterization has gone from being purely diagnostic to a viable alternative for some surgical interventions. Technology has greatly improved over the past ten years and continues to do so. One example is a transcatheter "Melody" valve—a heart valve attached to a stent that functions as an artificial pulmonary valve. Another advancement is a bio-absorbable stent that does its job and then degrades using the same compound that dissolvable sutures are made of.

An interesting discussion entitled **The Perils of Activity and Inactivity in Congenital Heart Disease** was given by Dr. Kevin Harris, Dr. Elizabeth Sherwin and Astrid de Souza. It reviewed the benefits of exercise in children and youth with CHD and discussed the current exercise recommendations and restrictions. Most children, including those with heart defects, are not exercising enough.

Preschoolers should be active for three hours every day through normal play and should not be inactive for more than 60 minutes at a time. This means limiting TV time. Older kids and teens are encouraged to exercise a minimum of one hour per day. Make exercise a normal part of family routine - repetition is the key to learning. Encourage children to find activities and sports that they can enjoy and excel in. For example, steer them toward golf over hockey - it can be devastating to an older child to be told he or she can no longer play their favorite sport. Speak with your child's cardiologist about what sports your child can safely enjoy throughout their youth and beyond.

Reference was made to the Bethesda guidelines (36th Bethesda Conference: Eligibility Recommendations for Competitive Athletes With Cardiovascular Abnormalities) to find out what sports are recommended for each particular type of CHD. For example, a patient with an uncomplicated ASD may have no exercise restrictions, whereas a patient with the Fontan circulation may be limited to low intensity sports only. Children with arrhythmias have an increased risk of sudden death and need to self-limit. It was recommended to check with your child's cardiologist about what sport classification your child falls into.

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|----------------------------------|------------------------------|--|---|--|
| Increasing Static Component ↑ | III. High (>50% MVC) | Bobsledding/Luge*†, Field events (throwing), Gymnastics*†, Martial arts*, Sailing, Sport climbing, Water skiing*†, Weight lifting*†, Windsurfing*† | Body building*†, Downhill skiing*†, Skateboarding*†, Snowboarding*†, Wrestling* | Boxing*, Canoeing/Kayaking, Cycling*†, Decathlon, Rowing, Speed-skating*†, Triathlon*† |
| | II. Moderate (20-50% MVC) | Archery, Auto racing*†, Diving*†, Equestrian*†, Motorcycling*† | American football*, Field events (jumping), Figure skating*, Rodeoing*†, Rugby*, Running (sprint), Surfing*†, Synchronized swimming*† | Basketball*, Ice hockey*, Cross-country skiing (skating technique), Lacrosse*, Running (middle distance), Swimming, Team handball |
| | I. Low (<20% MVC) | Billiards, Bowling, Cricket, Curling, Golf, Rifle | Baseball/Softball*, Fencing, Table tennis, Volleyball | Badminton, Cross-country skiing (classic technique), Field hockey*, Orienteering, Race walking, Racquetball/Squash, Running (long distance), Soccer*, Tennis |
| | | A. Low (<40% Max O ₂) | B. Moderate (40-70% Max O ₂) | C. High (>70% Max O ₂) |
| | | Increasing Dynamic Component → | | |

The session concluded with an inspiring speech from Jordan Marcia, a very fit young man who had a heart transplant at age 4. He began taking his health seriously in grade 9 turning to a heart healthy diet and running track. He also hit the gym regularly and focused on both aerobic and anaerobic exercise using very light weights for long reps. His fitness has earned him a gold medal in track at the Beijing Transplant Games and he ran the torch at the Vancouver Olympics.

Mary Paone is the Nursing Lead/Coordinator for Transition at BC Children's Hospital. She gave a wonderful presentation about young adults **transitioning from paediatrics to adult care**. She refers to this group as "half-baked cakes" because on the outside they look ready or "done" but on the inside they are still immature or "raw". Brain development catches up to adults at around age 24. The Children's Hospital often feels like home - having to suddenly switch to adult facility can feel like "falling off a cliff". 50% of young adults don't go to their first appointment, and 35% of those who go to their first appointment, don't go back for their second appointment. Many don't want to go because they don't feel sick...and eventually end up in the ER. Learning self-advocacy means knowing what their condition is, what it means for their body, what surgeries they've had. Promote independence by teaching them to make and keep an appointment and fill their own prescription. The need for educational and vocational planning (choosing a career that they can actually do for the rest of their lives) was also stressed.

Step By Step, Hand In Hand Growing Up With Congenital Heart Disease (Continued)

Perhaps the highlight of the entire conference for me was “**Youth Empowering Youth - Hearts of Gold Teen Panel**”. As the mother of a five year old, it’s always so interesting to see teens and grown-ups talk about their heart journeys. Seeing this panel of beautiful and well-spoken youth talking about the ups and downs of CHD brought me to tears. The program began with a movie they made about their lives. At the end of the movie, the panel took questions from the audience. They discussed self-image (scars), athletics (gym class is a struggle for many), school, and what they want from their parents, which is to be treated normally. It was both touching and humorous, with lots of kidding around and giggles.



Hearts of Gold youth group

Pam Husband is the president of the **Canadian SADS Foundation**, a charitable organization dedicated to supporting families affected by genetic cardiac rhythm disorders. SADS refers to a variety of cardiac disorders which are often genetic and can be responsible for sudden death in young, apparently healthy people. Pam became interested in promoting awareness after her son unexpectedly died at the age of 16 after being misdiagnosed with epilepsy. Soon after, her daughter was diagnosed with long QT syndrome, a genetic arrhythmia disorder, and is now being treated and lives a healthy life. Pam stressed the need for parents to be vigilant in getting the right diagnosis for their child if they exhibit warning signs, like fainting during physical activity or during emotional excitement. A simple genetic test could save a life. For more information, visit www.sads.ca.

Dr. Penny Sneddon is a Psychologist whose primary area of practice includes assessment and treatment focused on pain and anxiety management. She is responsible for clinical consultation, assessment and treatment to inpatients and outpatients with a variety of pediatric medical conditions including cardiac patients. Her research interests include the impact of and adjustment to serious illness on the child and family. Dr. Sneddon’s presentation, entitled **Fostering Effective Coping Skills and Resilience in Your Child with Chronic Illness** was a very revealing glimpse into how our cardiac kids feel about their medical condition and what role we play as parents in helping them to adjust.

Dr. Sneddon stressed how important it is for parents to teach kids coping skills at a young age. How we cope with stress will determine how they cope with it. Prepare your children for medical visits and procedures. Prepare yourself first by asking as many questions as possible so you know what to expect. Knowledge allows us to accurately convey information to them in an age-appropriate way. Coping strategies during visits can include breathing exercises, distractions, problem-solving. Give them choices because they often have no control, i.e. ask what arm they want for blood pressure, etc.

Communication is key. Older kids don’t want their parents to worry so they suppress how they feel. Have those difficult conversations with them and help them to express their feelings. Feelings change over time so keep checking in with them. Provide as much normalcy in their lives as possible. Give them responsibilities. Do physical activities with them or set a family game night. Routine, boundaries and discipline make them feel safe.

Parental self-care is vital. Often this is put on the back-burner but it’s very important to take care of oneself. How well we cope will impact them so we need to be role-models. It’s okay to ask for help if we are concerned about our own feelings of depression or anxiety or those of our child.

Some book recommendations were given:

- Helping Your Child Cope With Medical Experiences (available online: http://childrenshospital.org/az/Site1705/Documents/parent_guide2.pdf)
- Extreme Parenting: Parenting Your Child with a Chronic Illness - by Sharon Dempsey
- Freeing Your Child from Anxiety: Powerful, Practical Solutions to Overcome Your Child’s Fears, Worries, and Phobias - by Tamar Ellsas Chansky

Bindy Sweett gave the next presentation entitled “**Moving Forward: Steps Big and Small**” about coping with transitions. When we think about the big transitions our children will have to make in their lives, such as leaving home and entering the workforce, it may seem overwhelming. Big changes are challenging because it’s going into the unknown. It requires adjustment and adaptation. Children cope with smaller transitions on a day to day basis, such as going to school, going between divorced parents homes, etc. Our ability to adapt to transitions is affected by our temperament, ability, experience and support.

Chronically ill children are especially vulnerable to transitions. Many changes occur on surgical days: going from admitting, to being wheeled into surgery, waking up in the PICU, moving onto the ward, etc. There is a lot expected of them (hold still so we can give you a needle, swallow this medication) and the frequent interruptions are hard. It is all very overwhelming for a child who is already feeling sick and unwell. Kids have trouble communicating their feelings and generally do so through play. Many teens in the audience fondly recalled Bindy giving them a doll to give needles to or put band-aids on while they were recuperating from their surgeries.

Coping means going beyond your limits. Your ability to cope with change will directly impact how our child copes. Understanding a child’s “style” or temperament can help to predict how they will cope. Acknowledge their feelings – don’t just say “everything will be fine”. They feel vulnerable and need you to be a partner to them.

Simon Keith concluded the conference with his keynote presentation entitled “**Moments of Truth**”, a stirring account of his incredible heart journey and his determination to follow his dream. Growing up in Victoria, Simon was quickly becoming a world class soccer player, playing at the University of Victoria soccer team. Suddenly, at 19 years of age he received the devastating diagnosis of myocarditis. Two years later, he deteriorated to the point where he needed a heart transplant. The surgery was performed in England where he received the heart of a 17 year old boy who, ironically, died while playing soccer.

Keith resumed his soccer training just weeks after the transplant. He refused to let go of his dream and was determined to return to “his normal” as quickly as possible. He moved to Las Vegas in 1987 where he played soccer for the University of Nevada Rebels with his older brother Adam. He has the distinction of being the first athlete ever to have played professional sports after having undergone a heart transplant.

Today, Keith is married and has three children. Since retiring from professional soccer, he travels across the country as a speaker captivating audiences with his motivating story. He keeps up his fitness by breaking a sweat every day. In 2011, he founded the Simon Keith Foundation which promotes organ donation. In 2012, Simon published his story entitled “**Heart for The Game**” - Heart Beats will be reviewing this book in our next issue of “Keeping the Beat”.



COLE

Our third son, Cole, was born via c-section in September of 2000. During my 24th week of pregnancy I had a regular doctor visit, and was sent on to a specialist as the baby's heart was beating irregular. At that appointment, the heartbeat was fine, but the doctor noticed an enlarged right atrium. Total Anomalous Pulmonary Venous Return (TAPVR), was eventually diagnosed. Every three days, I went for an ultrasound to watch for hydrops (extra fluid in the tissues) which would indicate that my baby would be going into heart failure. His heart beat dropped to 50 beats/min, and later he was diagnosed with having heart block, too.

Knowing he would need surgery, we planned to have him delivered by c-section up in Edmonton (we lived in Calgary). Those weeks were an emotional rollercoaster and I relied on a good friend to share my fears of what might occur. He was born one pound bigger than what the ultrasound indicated, which was a huge difference to help sustain a bit of weight for a future heart surgery as he withered his weight away waiting for a proper diagnosis, fighting infection, etc. When he was born, his heartbeat was only 35 beats/min. He was pink and not blue. Two days old, he received his pacemaker. He remained in Edmonton for five days then was taken by plane back to Calgary. Many hours, tests, prayers and blessings were given on his behalf. I do know it was through my faith, my family and friends' faith, the skills of the doctors and of the Lord that Cole did amazingly well with the obstacles that he faced. I have witnessed the Lord's hand in many ways. All three cardiologists (Harder, Patton, and Giuffre) worked as a team to figure out his diagnosis. Dr. Harder was a huge advocate for us, as we were overwhelmed and stressed, in preparing us for days ahead. Cole's diagnosis was changed to Partial Anomalous Pulmonary Venous Return, and his open heart surgery was performed by Dr. Rebeyka back in Edmonton at 6 weeks of age.

Sometimes, when you live in the hospital for so long, you start to think that this is "normal" and forget to realize that you are only seeing a small portion of this new reality. My burden was heavy; I had 2 other children at home that needed me too. Every milestone Cole faced created another hurdle to overcome. That burden was lifted through my faith in God. I felt I would be relieved once he had his open heart surgery, I could get off this rollercoaster ride. After open heart surgery, he arrived with only 7 iv's compared to the expected 8-15 and that was a welcoming sight, but not when there was hemorrhaging. Several strokes occurred during the operation, and he had continuous seizures -- it wasn't the journey I expected to be on. Returning to Calgary, Dr. Harder gave us hope and knew little brains can adapt, especially if it's the Lord will. Cole was on anti-seizure medication for only three months, and has never had a seizure since -- even the neurologist couldn't believe it.

I've also learned with him, that if it's rare, Cole will have it! Heart block, having more than one spleen, a good chance of having a mal-rotated bowel! He had preventive surgery for this at age 9 months. 16 months after he was born, I had another baby. It took me a long time to feel okay with this, especially after having such an emotional year, but all did go well! She came along with Cole to his speech and physiotherapy appointments.

Today Cole is a healthy 12 year-old. He has gone through several pacemakers, with one even being recalled. He is a wonderful, sweet young man who always has a smile on his face. He is full of compassion and is in great health! He is a huge sports fan, and is limited with contact sports as he relies on his pacemaker 99% of the time, but excels in running and badminton. I haven't been an active member of Heart Beats because he seems so healthy, but I am here for anyone as a listening ear! I am truly grateful for those that watch over him in so many ways, and for the expertise of the doctors, nurses, surgeons, and therapists. We have truly been blessed because of having Cole in our lives. Saying "Thank you" just isn't enough!

-Christina Parker (mother) Calgary, Alberta.

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 jenb@heartbeats.ca



Cole, with our good family friend Sharon Coleman, who is 23 years post her heart transplant, as well as having a pacemaker, too.

Annual Golf Tournament Raises Over \$250,000 For Alberta Children's Hospital

By Tony Migliarese

Three and a half years ago, one of our twin daughters was born with a congenital heart defect. After a number of surgeries including her most recent at the Stollery Children's in Edmonton, she developed complications and, as a result, ended up spending several weeks in the Alberta Children's Hospital. It was then that my wife, Traci, and I discovered and truly began to appreciate the kind of facility it is. We experienced firsthand the quality and professionalism of the doctors, nurses and support staff. Their commitment and dedication to the patients was simply outstanding. They were compassionate and took a personal interest in getting to know my wife, myself and our daughter which made us feel completely at home.

As a result, we felt compelled to give something back, and with the help of Haywood Securities (the company I work for), founded an annual golf fundraiser. I am pleased to report that after our third consecutive sold out event, we have raised over \$250,000 in total for the Hospital, with the majority of the proceeds having been directed to the cardiology department, specifically to purchase leading edge technologies, such as the Ventripoint 3-D diagnostic system and a new Metabolic cart.

We are excited to report that this year we raised \$94,000 for the Alberta Children's Hospital. This will allow us to purchase a metabolic cart for the cardiology department, which we're very happy to see.



CHD & Me Talking With Adults With CHD

A concern that “heart parents” often have is how our children will do in the future. Will they be able to lead productive adult lives? Will their heart defects prevent them from doing activities or jobs that they want to do? In this edition, we feature the story of Matthew Moreira

“A Modified Life”

I was born on November 2nd 1984, with brown eyes, brown hair, and powerful lungs. Born into an already big Portuguese family I was the new talk of the town. I was given a clean bill of health and was sent home with my very beautiful, but very new first time mother. Four weeks went by when I suddenly began to show weird symptoms no one had ever seen before. I would scream and cry out of the blue, heavy breathing was becoming more and more usual, and feeding was becoming a hassle. After trying to figure it out – blaming it on itchy clothes, etc., my mother took me to the family doctor and that is when my life would change forever.

My mother recalls that I was breathing heavily and rapidly, moaning and groaning along with crying and screaming that could be heard for miles, it seemed. The family doctor immediately said “Get your son to Sick Kids Hospital ASAP”. Once there, I was rushed into a room and was surrounded by nurses and doctors. Within the hour the doctors told my parents that I had a rare heart abnormality called tricuspid atresia. As the doctor explained further, my parents couldn’t help but wonder if I would even live past that night. The doctor told my parents that I needed emergency surgery immediately. After my parents agreed, I had a 9-hour surgery performed by Dr. Williams and Dr. Coles. I had survived my first of three surgeries and was doing just fine. The doctors’ informed my parents that, to their amazement, during surgery they found a small hole where my fourth chamber should have been. This hole had kept me alive up until that point. The doctors then made an adjustment to this hole. I spent my first Christmas in the ICU, where my mother spent endless hours by my side while my father went to work, worrying constantly about his first-born son. A few days had passed after my first surgery when an echo revealed that the pulmonary banding was too tight and the hole they had widened was too large. Later that night I was back in surgery and by morning I was back in ICU. For the next nine months I lived at Sick Kids. My mother would pretty much become a nurse by the time those hard nine months were over. Finally I was sent home, finally I could start to live my life, and all the way to age 3 I did. I went on many outings that every child goes on: Toronto’s Centre Island, birthday parties, and always causing trouble and giving my parents a few early gray hairs. At a routine checkup the doctors informed my parents that it was now time for what they called a “modified Fontan” surgery.



I remember the day of the surgery, and walking into the pre-surgery rooms that looked like a huge indoor playground with paintings on the walls of animals and cartoon characters. Nurses dressed up as clowns as they made balloons and handed out toys. I, along with many other congenital patients, was rather comfortable! This a congenital patient’s life from day one: hospitals, doctors, nurses, appointments, ECG’s, echo’s, stress tests, Holter monitors - it all becomes the norm to the point where, heck, you could probably perform all the test yourself and even make your own diagnosis!

A congenital heart disease child’s life is a different life. From day one our cardiologist reminds us time and time again how we must live our lives. They tell us we cannot do this and cannot do that, how they rather us go to a salad bar instead of McDonalds, how we should drink water and not

Coca Cola. A brisk walk is better than playing a game of football, and when playing any sport to take many breaks. Well I say that is all great advice, and it is great that we were reminded on a regular basis. But, I say that every patient should at least try everything once. I always joined school sports, played street hockey, rode my bike, skate boarded (not very well mind you), went on school trips. As I got older I got into cars, went out with friends, and did pretty much anything they could do. The only thing I never tried was a cigarette. I tried alcohol in my early 20’s and realized that I wasn’t really missing that much.

Sadly not every congenital patient has the same opportunities as me; some do not even see their 20th birthday, or even their 2nd. There have been many amazing advancements in the congenital heart disease world that are making our life spans decades longer, but some do not have the chance to make it to those stages and even some of those who do really struggle.

I am now 28 years old. I had my last heart surgery at the age of 3, but the past few years have been rough. At 25 I developed Warm Auto Immune Hemolytic Anemia (WAIHA) which has resulted in having my spleen removed, and just this June I spent four weeks in Toronto General Hospital fighting off two blood clots in my right atrium and a few others in my lungs due to a heavy relapse that sent my CBC from 153 to 77 in two weeks. I have been on prednisone and Imuran for about a year and at the moment I am receiving Rituximab infusion in hopes that this will cure my relapsing WAIHA. In February 2011, I had brain surgery from a brain abscess that was again most likely caused by my heart disease. Since the surgery I have developed epilepsy and have a seizure every two to four months. I can no longer work due to all these complications. I take about 20 pills in total every day, one of which is Metoprolol to control my arrhythmias. I have even changed my diet; I am finally picking salad over fries and water over Coke. There is even talk of future heart surgery as my cardiologist tells me that my right atrium is 8cm and that this may become a bigger issue as time goes on. But, a positive mind is a positive body, and anything is possible. I am living proof. No matter how dark the path may look I am confident I will get passed all this. I have faith in God and myself that one day I will look back at this and smile and thank God for being blessed for everything I have experienced and accomplished in my life, and that I can move forward knowing that heart disease to me is not a death sentence but a “modified” way of life. With encouragement from family, friends, other congenital patients, and most importantly my mother, I will continue to push through everything that is sent my way.

I would like to remind everyone that a congenital disease is a disease that not only affects the child but the entire family. Everyone is affected since day one of the child’s life in dealing with the disease, but they are often forgotten in all the chaos. So please remember the child’s family. Finally, to my fellow “Cardiac Kids” young and old, always remember your mother! There is no greater love in the world than a mother’s love for her children and for all they experience with us - the ups and downs, the tears and the smiles. So remember, honour your appointments, take your medication, and live a healthy, happy fulfilled life.



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, teens and adults 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 jenb@heartbeats.ca



Talk with the Docs

Dr. Steven Greenway

So often we know only the cardiologist our child visits at the Cardiology Clinic, but each of the cardiologists has an area of expertise which contributes to the overall care they provide to patients at the Cardiology Clinic. In past issues of "Keeping the Beat", we have featured Dr. Frank Dicke, Dr. David Patton, Dr. Deborah Fruitman, Dr. Robin Clegg, Dr. Joyce Harder, Dr. Kimberley Myers and Dr. Michael Giuffre. In this issue, we are pleased to introduce Dr. Steven Greenway.

You are new to Calgary. Where are you from, and what do you think of our city so far?

Hi! Thanks for the opportunity to introduce myself to your readers. I was born and raised in Winnipeg and remember driving out to Calgary in the summer when I was a kid to visit Banff with my family. A lot has changed since then! Most recently I have lived in Boston and Toronto so living within sight of the mountains is a welcome change of scenery. My family and I are settling in and we all like Calgary very much. We are still discovering all the things that Calgary offers and are enjoying the active atmosphere of Calgary.

How long have you been practicing pediatric cardiology?

I am brand new! I finished my four-year fellowship in June 2012 and started work in September. Fortunately I am well supported here with an experienced group of expert colleagues available for help and advice.

What made you decide to go into pediatric cardiology?

I was very interested in Cardiology in medical school but really liked the environment of a children's hospital. When I discovered that you could do both then I knew that was the career path for me.

What is the biggest challenge and the biggest reward about being a pediatric cardiologist?

Cardiology is probably the most sub-divided specialty in medicine so being knowledgeable and staying up-to-date in all areas is very challenging (if not impossible). Being part of a group of Cardiologists with diverse interests, like we have in Calgary, is very helpful.

I think congenital heart disease is not well known or understood by most people (doctors and the public both!). Dealing with uncertainty (will the hole close? how long will the ventricle function?) and the absence of evidence guiding our practice is also very challenging and can be frustrating. Watching what kids and families go through is humbling and being able to help is very rewarding.

What role will you play at the Cardiology Clinic? Will you focus on or specialize in a certain group of patients?

I have been appointed as a Clinician-Investigator so 50% of my time will involve patient care and the remaining 50% will be spent doing laboratory research. I am interested in the genetics of congenital heart disease so I will be searching for the DNA mutations in children that caused their heart malformation. Trying to make the advances in genomics relevant to the clinic will also be a major focus. My clinical areas of interest are in heart failure and heart transplantation. I will be helping look after the heart transplant patients and hopefully will develop a clinic to support children with decreased heart function.

Thanks to recent advancements in research and technology, children with even complex hearts can reach adulthood. Are there any new advancements on the horizon that you feel will improve the quality of life for heart kids?

Implantable heart pumps (ventricular assist devices or VADs) that support heart function are being widely and successfully used in adults. These pumps are mostly still too large for children but smaller devices are being developed. These pumps may support children whose heart is failing either as a replacement or as a support until a heart can be found for transplantation and allow them to be at home instead of staying in hospital. However, adapting these pumps for children with a single ventricle will be challenging.

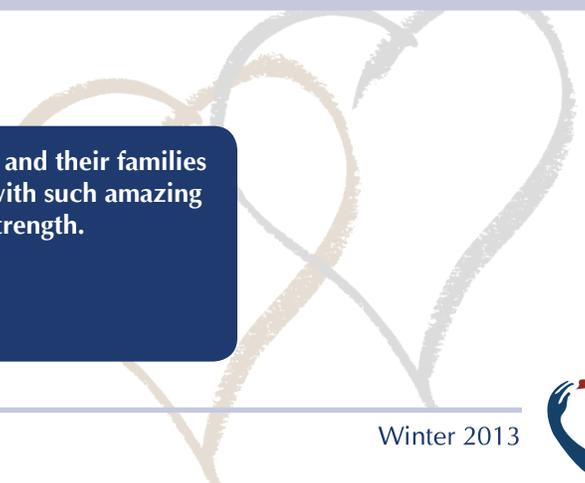
I hope that genetics will be of use in the clinic. New technology ("next-generation sequencing") is allowing the rapid (and relatively cheap) reading of a person's entire genome. What to do with all this information is still not clear. Predicting an individual's response to medication ("personalized medicine") would be helpful and may help avoid serious side effects. Using next-generation sequencing to develop "biomarkers" that could signal developing problems would also be useful (for example, telling us when or why a Fontan is "failing"). Genetics may someday tell us why a child was born with a heart malformation and may even be able to predict future problems.

Cardiology Clinic News

Everyone in the Cardiology Clinic would like to wish all of our Heart kids and their families a Happy and Healthy New Year. It is a blessing and a privilege to work with such amazing kids, to be part of their journey and to be inspired by their courage and strength.

All the Best in the Coming Year,

Cardiology Staff



The Transplant Connection

By Kelly Webber, Nurse Clinician at the Cardiology Clinic / Alberta Children's Hospital

2nd Annual Family Heart Transplant Camp

On September 28-30, 2012, the 2nd Annual Family Heart Transplant Camp was held at Camp Evergreen near Sundre, Alberta. It was a great weekend with beautiful weather and many fun activities. 17 families from the Western provinces attended, with five families from Calgary. Some of the sessions that were held for parents covered infection precautions and transplant, and a presentation by three adult transplant mentors who came to share their experience. Bernadette, CNS at the Stollery Transplant Program, and I held a session for the kids on "how well do you know your transplant". This included a quiz, scavenger hunt and learning a song which they performed for everyone the next day (see below for the words to the song). But the weekend was more about having fun with old friends and making connections and new friends. Families and staff participated in various activities such as horseback riding, canoeing, archery, and a climbing wall. The final highlight was a game of soccer for everyone and of course, the famous mini Olympics for the kids in which Calgary competes against Edmonton. Unfortunately, although a valiant effort was given, we were unable to defend our title and we lost the cup to Edmonton. In the end, the feedback was very positive and everyone is looking forward to next year.



The following is the song the kids learned at camp to help them remember the key points in staying healthy and taking care of their heart. It is sung to the tune "If You're Happy And You Know It".

*If you wanna stop infection, wash your hands.
If you wanna stop infection, wash your hands.
If you wanna stop infection, then you need some protection!
If you wanna stop infection, wash your hands.
If you wanna stop rejection, take your meds.
If you wanna stop rejection, take your meds.
If you wanna stop rejection, then follow this direction!
If you wanna stop rejection, take your meds.
If you wanna protect your kidneys, drink your water.
If you wanna protect your kidneys, drink your water.
If you wanna protect your kidneys, and not go to Sydney
If you wanna protect your kidneys, drink your water.*



The Lara's Story About Camp

In September, our family spent an amazing weekend together in the great outdoors at the second annual Family Heart Transplant Camp. It was a truly amazing place for our son to meet and interact with other children who have had heart transplants. He was able to enjoy all of the challenges and rewards of summer camp as well as develop new friendships and learn more about his heart transplant. It was also an opportunity for us, as parents, to learn more about heart transplants and how to deal with some of the day-to-day challenges. Some of the highlights of the weekend for us were listening to the talk by the young adults who had heart transplants and the soccer game.

The young adults had some great advice for the parents. We also appreciated hearing about some of the challenges they've faced. Even with the challenges, they all had very positive outlooks on life and were encouraging to listen to.

Some of the camp activities we participated in included horseback riding, wall climbing, canoeing, archery and, of course, the 'marathon' soccer game. This was the second year in a row for our family to attend the camp and we can't wait to go back next year!

- Lee and Dan Lara

Quote from Ryder: *"I had lots of fun at the camp and can't wait to go back next year. My favorite part was the horseback riding!"*



A Note from Kerri Paine

We are extremely grateful to have been able to attend the 2012 Transplant Camp. It was wonderful to be able to bond with both the transplant medical staff as well as other transplant families. Our children thoroughly enjoyed all of the activities and still talk about the many "first experiences" that the camp offered. Having such demanding medical requirements, many camps are not an option for our son; as such, this provided our transplant child with the opportunity to experience this very important, normal child milestone. I also personally relished the time that we had to meet and speak with adult heart transplant recipients; it was an experience that I will continually draw on for guidance as my child matures.

A Heartfelt Thanks to the Adult Mentors

One of the greatest highlights of camp for families and for staff was to hear what life is like after transplant from the perspective of three graduates from the pediatric transplant world to the adult world. Vittorio, Oloff, and Jonathan were transplanted in their early to late teens and are now all in their twenties. They are kind, funny, thoughtful young men who are enjoying some of the same experiences others in their twenties are, such as working, going to university, dating and having fun with family and friends. They spoke of the challenges they have faced and how they have managed life after transplant. Not only did they lead one of the sessions but they spent the whole weekend joining in on the camp activities and took the time to get to know the families and the youth who have had heart transplants. Their perspective about life after transplant was very insightful and it was a pleasure to have them join in on the camp.



Winter Party

We are in the process of organizing a party this winter for all the transplant families – be sure to watch your mailbox for the invitation!

WCCHN UPDATE

On September 22, 2012, the Family Advisory Committee (FAC) held an in-person meeting in conjunction with the Growing Up With Heart Disease Conference in Vancouver, BC. The group welcomed Kerri Paine to the FAC, as the second representative from the Children's Heart Society group in Edmonton. Cindy Castillo from Heart Beats Children's Society of Calgary has agreed to be the FAC representative on the WCCHN Steering Committee.

WCCHN Family Advisory Committee (FAC)

The pre-operative tool has been finalized, and is now available on the WCCHN website (www.westernchildrensheartnetwork.ca) under Public Knowledge Base, Resources page under Checklists. A "Traveling with your Child" checklist has been created by this committee, and is also available on the WCCHN website under Public Knowledge Base, Resources page under Checklists. It includes helpful information required for traveling, regarding documents, contacts, medications, pacemakers, and heart transplants.

The following major enhancements have been made to the WCCHN website:

- PACE WEST (Pediatric & Congenital Electrophysiologists of Western Canada) resources for families have been uploaded under Family Support.
- Managers have been added to each centre's staff page.
- Additional transplant resources listed.

If you have family stories you would like to share on our website, or if you have an update to your story that is already posted on the website, please forward your story or updates to: wcchn@albertahealthservices.ca. Be sure to include your child's name, diagnosis, and a picture(s) along with your story.

We welcome your comments and suggestions for our website! Please send us an e-mail with your feedback: wcchn@albertahealthservices.ca.



We welcome the following new Cardiologists and Surgeons at the WCCHN Centres:

- **BC Children's Hospital, Vancouver:**
Dr. Paul Brooks, Head of Echo and Fetal Echo
Dr. Kevin Harris, Specialty in Interventional Cardiology and Research
Dr. Elizabeth "Libby" Sherwin, Special Interest in Electrophysiology
- **Stollery Children's Hospital, Edmonton:**
Dr. Mohammed Al Aklabi, Junior Staff Surgeon
- **Alberta Children's Hospital, Calgary:**
Dr. Steven Greenway, Heart Transplantation & Heart Failure and Research
- **Royal University Hospital, Saskatoon:**
Dr. Charissa Pockett
- **Health Sciences Centre – Winnipeg:**
Dr. Daryl Schantz, Cardiac MRI's

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—so let's share these ideas with each other!

Website Review

The Somerville Foundation - www.thesf.org.uk

By Jen Beleshko

While this website is a great resource for parents, it is really meant for teens and young adults with congenital heart disease. The Somerville Foundation is based out of England and provides practical and emotional support to people with CHD, empowering them to take control of their lives and manage their own heart condition. It contains personal stories, videos and downloadable material such as a medical passport. It also discusses lifestyle concerns and transitioning to adult care, all written in a very dignified way that encourages independence. Perhaps the most unique offerings on this site are two very cool comic books designed specifically for teens (although I enjoyed them very much!) I would recommend parents and teens to check out this website as it could be the basis for many interesting conversations.



PARENTING A HEART CHILD

By Cindy Castillo

When my daughter, Alexa, was still in the hospital after she was born, we talked to another family whose son was older than Alexa and had a similar heart defect. They told us how when their son first left the hospital he had to be fed with a tube in his nose and that they had to change it at home. I tried not to gawk. I listened politely and thought, "Alexa will never have a tube in her nose! And ME change it! I'm not a nurse!! Thank goodness that won't be us!"

Fast forward three months and my husband and I with a nurse learning how to insert a tube into our daughter's stomach through her nose.

Of course it doesn't happen with every child - some just naturally feed as they are supposed to. But a great many children with heart defects will, to some degree, have feeding problems. It could be from medications they are on that suppress their appetites; it could be an inability to suck because they were intubated for so long; it could be some kind of aversion to swallowing; or, as was the case for Alexa, an inability to take in as much milk as they need simply because they are still too weak.

After her second open heart surgery when Alexa was around six months old, we saw a great difference in her energy levels. When she would look indifferently at a bottle and start jumping around every time I pulled out the feeding pump, I knew it was time to start being more aggressive with the bottle. When she pulled out her tube yet again, I decided to try solely bottle feeding her. I carried a bottle of her concoction (breast milk, formula and canola oil) everywhere I went and shoved it in her mouth every time she opened it. After a couple of weeks she got the hang of it and she never had to go back to tube feeding.

That was our case, but every baby is different. Some will take many more months than that to drink from a bottle and some take to it much faster. So what are the different methods of feeding a baby that won't or can't eat orally? They are:

- 1. TPN:** TPN stands for Total Parenteral Nutrition. It is a liquid that contains all of the nutrients and vitamins that a body needs and is given intravenously to people who can't have food.
- 2. NJ Tube:** A Nasojejunum Tube (jejunum is the small bowel) goes from the nose straight into the small bowel. Bolus feeds cannot be given through an NJ tube. This is usually how a child starts to feed before receiving an NG tube.
- 3. NG Tube:** A Nasogastric Tube goes from the nose into the stomach. This is the one babies go home with and their poor parents have to learn to change.
- 4. G Tube:** A Gastric Feeding Tube is a tube inserted through a small incision in the abdomen. It is used for long term feeding. It must be put into place in the OR.

My advice to parents is this: be patient with your child and try not to listen to what others think or say about the tube. Seeing a child with a feeding tube is shocking for people not used to it. I remember people continually asking things like "When are they going to take that tube out?" as if it was a choice doctors had. Use your instincts and intuition as to when your child is ready to eat orally and don't force them if they are somehow uncomfortable with it or simply can't. They will get the hang of it eventually, when they are ready (and probably not when you are!) Don't compare your child's feeding ability with other children's. Every child has their own reason for not being able to feed and each child will orally feed when he or she is ready. And finally, learn to change tubes and manage tube feeding on your own as much as you can. Your child will pull out the tube at the most inconvenient times and it is so much easier to be able to get things back to where they should be instead of waiting for a nurse to help.

Advice from Our Parent Experts – You!

What tips can you give to parents who are home with an infant being fed through a nasogastric (NG) tube or a G-tube?

My daughter, Alysha, was fed with an NG tube for a good portion of the first year of her life. She seemed to know exactly when my eyes were off of her, and became very good at removing it with those quick little hands of hers. It would stress me because I knew I had to go through the process of inserting the tube again which was something I did not enjoy, nor did she. I then came to the realization that we should take advantage of those moments, and give Alysha a break from that darn tube. She would enjoy a nice bath, we'd go for a walk, snap a few pictures for grandma and grandpa, or just have a good old play date amongst all her toys and books. I loved those moments!

Jeannine Oliphant, Mom to Alysha, age 15 years.

Jax now has a G-tube, but he had an NG tube until last November (he's 2 and a half now). I prefer the G-tube because it is low maintenance, there is no tape and no traumatic tube changes. He's just a much happier child on the G-tube. The formula, however, is terribly expensive and I just wanted my friends to know that our formula can be ordered from the home nutrition office for about 1/3 of the price (I now pay \$23 a case instead of \$77). Getting back to the tube feedings, I also like the G-tube better because he no longer looks like a sick child and no one is staring at him in public places. Since opting for the G-tube, Jax has finally started to swallow tiny bites of soft foods like bread or cheese and he loves soup so we are making baby steps.

Shannon Summers, Mom to Jax, age 2 and a half years.



Reese was admitted to the Children's hospital for the NG tube training and insertion the beginning of May 2010. Her energy plummeted, waiting for surgery, as feeding became such a struggle to get even 5ml via syringe of formula in a 24 hour period. Reese was placed on an extremely high calorie diet, but had issues with larger volumes, therefore her feeds were lower volume, but high calories. Reese was also placed on lasix for her congestive heart failure, making it even more important to measure the fluid intake carefully. This gave her nutritional requirements, but it did not give her enough water in her diet and therefore we struggled with constant constipation. Every child is different and you should discuss this with your paediatrician or cardiologist first, but Reese was placed on lax-a-day to help relieve the constipation, this helped and she was on lax-a-day recently, until June 2012. However I wanted to make sure I was doing everything possible for my daughter and I researched and read that if you prime the little tummy before a feed by 20-30 minutes, with 15-30mls of water, it would be absorbed and would not affect Reese's absorption or issue with the volume of the feed. This helped immensely and I found that it also decreased the amount of times she would vomit during her feeds, which was every feed. Reese was fed every 3 hours for 45 mins-1 hour, basically until she got rid of the tube. I received the pump in September 2011, this allowed me to really control the volume over time better and it allowed me to train grandma and grandpa to use it, so we could have a break once and awhile. I was also given a website to go to it is called www.mealtimeotions.com. From this website I ordered the DVD on feeding, a Homemade Blended Formula Handbook and special drinking cups. I talked with the support team from the Children's Hospital to get ideas and feedback. The NG tube is quite small, but I did introduce some foods via the tube, with and without the doctor's permission. I had a wonderful dietician follow Reese all along and had a great working relationship with her to help guide us in the right direction. Another small, but crucial thing to use is when taking off the tag-derm and the other tapes, we purchased adhesive remover from the pharmacist at the Children's Hospital, totally worth it. Also on Sundays (our tube changing day) we would allow Reese to have her morning feed and then we would place her in the bath and take out the tube, sometimes she didn't even notice it was gone. Knowing we would have to check for placement when we put the new tube in and it had been a few hours, she would take small amounts by mouth, so we would offer her a sippy cup and normally she would take just a bit, it was almost always enough to allow us to check for tube placement when we put in the new tube. To our amazement, March 18, 2011, daycare called and said that Reese vomited out her NG tube, and was interested in the food that the other children were eating. I told them to call me if she doesn't eat and I would come and pick her up and put the tube back in..... no phone call, she was eating and drinking. Scary yes, so exciting, as we had just cancelled her surgery for a G-tube that week, because we just had a feeling that it wasn't the right thing to do at the time for us. We were followed extremely close by doctors, the feeding team and dieticians and yes, I can say we made it. Coming to the Heart Beat meetings gave us the strength and direction. I hope our story will give some hope to others out there that it is possible and miracles do happen, we know, we have Reese in our lives and are truly blessed.

- Keremy and Scott Dry, Parents of Reese, age 2 years.

"At two weeks old, it was decided that our son would require an NG tube for nutrition in order to gain weight prior to his surgery. My husband and I learned to remove and replace the NG tube and did so every other day (or more when he would pull it out or throw it up). Meanwhile I was pushing nursing too because I didn't want him to get so used to tube feeds that he would lose the ability to suck/feed orally. It took lots of persistence but within a few weeks he was off the NG and feeding and gaining weight exclusively through oral feeds.

- Jen Beleshko, Mom to Roman, age 5 years.



It is the heart that makes a man rich. He is rich according to what he is, not according to what he has

Henry Ward Beecher



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