



Keeping The Beat

Heart Beats - Children's Society of Calgary

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

Congenital Heart Day on the Evening News

We always celebrate Valentine's Day with a special heart in mind, we families of kids with special hearts.

This year in Calgary, on February 14, about 45 children and their families responded to the Heart Beats invitation and gathered in the City Municipal Building for the reading of the mayor's proclamation declaring Congenital Heart Day.

CFCN and A-Channel news crews, as well as a Calgary Herald photographer joined us.

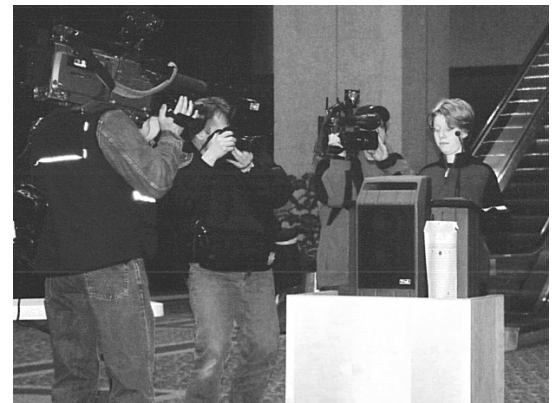
"The aim of Congenital Heart Day is to raise awareness about congenital

heart defects and the impact that they have on children and their families," stated Mayor Bronconnier's proclamation, as read by 16-year-old Jared Harrill.

Jared, who was born with a major ventricular septal defect, transposition of the arteries and pulmonary stenosis, was interviewed with his parents some 13 years ago by CFCN's health watch reporter, Karen Owen, upon returning from surgery at the Mayo Clinic in Rochester, Minnesota. Reading this year's proclamation,

and being featured on the CFCN evening news was, for Jared and his family, a triumphant moment.

(Continued on page 2)



News crews filming the reading of the Mayor's Proclamation on Congenital Heart Day

Contest Easily Won With Words of Wisdom

Congratulations Jared Harrill, for submitting your best and worst advice in response to last month's Keeping The Beat contest — and winning a pair of movie passes!

This insight from Henry Ford, "Is my most favourite quote," says Jared, "And it's better than any advice I've been given."

Henry's inspiring words: "If it seems that everything is against you, remember this, planes take off against the wind."

Jared says the worst advice he's ever been given is to just conform to everyone else.

"I don't agree ... we all have individuality and suppressing it is disrespect-

ing yourself."

Sixteen-year-old Jared's favourite classes are drama, science and technology. We're sure with his passion, wit and wisdom, he'll go far! Henry Ford would be proud of you, Jared! Enjoy the movie!

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Congenital Heart Day on the Evening News

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"It was kind of like coming full circle," says Ian Harrill, Jared's dad. "All those years ago, at just three years of age, Jared was already a gregarious, intelligent little man chatting with a TV reporter with remarkable awareness about what he had just been through."

As Jared's nonchalant attitude toward the reading of the Mayor's proclamation shows, he still takes what life offers in stride.

"My mom and dad and my uncle all think this is a big deal, but for me, it's really no biggie," says Jared, with a wry twinkle in his eye.

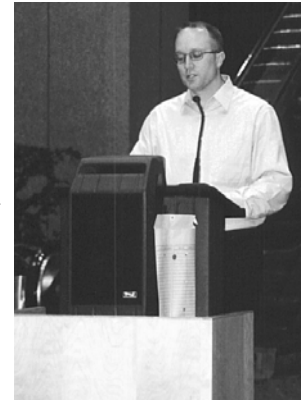
Following the reading of the procla-

mation, Colin Wiebe shared a short speech about congenital heart defects, highlighting a few interesting statistics. (For instance, did you know there are about 10,000 children, teenagers and adults living with congenital heart defects in Calgary?)

"As a parent of a child with congenital heart disease, I am very excited that Mayor Bronconnier has proclaimed today "Congenital Heart Day" in Calgary," said Colin, father of two and a half year old Isabelle, who lives with hypoplastic left heart syndrome.

There are those among us who can remember a time when families of children born with congenital heart defects were given little more than a

compassionate shoulder and a quiet place to mourn the passing of their babies. That we today celebrate "heart month" by declaring February 14 Congenital Heart Day with our children in our midst, is a miracle of science, medicine, family and faith.



Colin Wiebe at Calgary's Municipal Building celebrating Congenital Heart Day

Heart Defects In Children: What Every Parent Should Know ... a Book Review

Heart Defects in Children:
What Every Parent Should Know

By Cheryl Wild, R.N., B.S.N.

Chronimed Publishing (1999)

155 pages

Available at Chapters/Indigo stores, and online

by Olana Thomson

There have been many CHD books written for doctors, nurses, and medical specialists. In Heart Defects in Children, registered nurse and mother of five Cheryl Wild has created a simple guidebook for parents, filled with information presented in a clear, non-sense manner.

Aside from listing defects, she also supplies useful points about how the heart forms in utero, common tests

and procedures, as well as a handy glossary of CHD-related medications.

There are many illustrations which allow parents to really understand their child's defect. One part of the book even supplies "draw-on" hearts so that parents can personalize what their child's heart looks like before

and after repair.

Perhaps most valuable and insightful are the chapters which address questions you can ask your pediatric cardiologist and surgeon. The author divides the surgery questions into time frames, taking into account things

parents need to know before and immediately after surgery, as well as follow-up information required when the child is discharged from the hospital.

As Wild explains, these moments are harrowing ones for parents, and having a list of questions laid out beforehand will ensure that families receive all the medical advice they require.

Heart Defects in Children is an easy, straight-forward read. Parents will appreciate the practical, easy-to-access information. Wild says, "This book is for the children."

Olana is mom to six-month-old Tyra and three-year-old Adam who was diagnosed with a sinus venosus ASD at 6 months old, and who will require



Parenting Children with Hypoplastic Left Heart Syndrome

by Patty Wiebe

Of particular interest to me at the Growing Up With Heart Disease Conference in Vancouver last September was a session featuring a discussion on parenting children with hypoplastic left heart syndrome (HLHS).

Researcher Gwen Rempel, currently completing her doctorate in nursing at the UofA, hosted this session which featured her research "describing how fathers and mothers parent in the face of multiple life threatening surgeries and an uncertain future for the child who has HLHS," says Rempel.

During the course of interviews with parents of nine children living with HLHS, and who have undergone the Norwood surgical approach, Rempel identified a core parenting concept which she came to identify as "safeguarding survival."

"Safeguarding survival," Rempel explains, "is a concept which describes a parental attitude that, 'once our child has survived the Norwood, we're leaving nothing else to chance.'"

To explain, the left side of the heart of children with HLHS is non-functioning, so it is unable to pump oxygenated blood to the rest of the body. Until recently, HLHS — which occurs once in about 6,000 births — was considered fatal. In 1988, mortality was about 64 per cent. By 2001, HLHS mortality had decreased to about 33 per cent, although, at the UofA's Stollery Children's Hospital, the mortality rate for children undergoing the Norwood procedure is only 18 per cent.

The Norwood approach to HLHS involves a series of three surgeries — commonly known as the Norwood, Glenn and Fontan — collectively designed to create a different pathway for oxygenated blood to be circu-

lated.

Rempel explains that safeguarding survival becomes an all consuming task for parents who, on the one hand, are confident they have made the best choice on behalf of their children.

On this hand, parents are confident in the technological advances inherent in the Norwood approach.

"However," Rempel continues, "On the other hand, despite all the posi-

tive information about the Norwood, parents are constantly reminded that their child lives with a life-threatening condition and that there remains the chance for complications, or even death."

It is a fine line to walk for parents of children with HLHS: We are cautiously optimistic as we celebrate our children's progress while we remain vigilant in caring for and monitoring the unique needs of our heart "babies". Since we are really in a first generation of successfully maintaining the life of children born with HLHS, it takes a determined effort to safeguard our own parental emotional survival by focusing on the positives, keeping the rest "on the back burner".

Rempel's research identifies feeding and weight gain as a major challenge for the parents in her study who all had to initially feed their children through nasogastric or gastric tubes. "The second greatest challenge for parents of children with HLHS is

what I call 'germ warfare'" explains Rempel.

Many parents of children living with potentially threatening heart defects typically describe living a "bubbled life", avoiding crowds, worrying about older children bringing germs home, constant hand washing and, essentially, "cocooning" themselves and their children.

"Parents of children with life threatening heart disease need a comprehensive program of support, over time," advises Rempel, "So they do not become overwhelmed safeguarding survival on their own."

Rempel's study confirms what we parents of children with

CHD already knew: The challenge of raising a child with CHD is an empowering experience that changes us in positive and meaningful ways.

"The parents in my study were grateful to have the opportunity of facing such difficulty and to be changed by it. They delight in their children, they marvel at their progress and they are adamant that there is something "special" about their child's personality."

Indeed.

Patty and her husband Colin live in Calgary with their daughters, Janelle and Isabelle, who lives with HLHS.

Parents of children with life threatening heart disease need a comprehensive program of support

Opportunities to Serve Your Heart Beats Community: Annual General Meeting in March

The current executive of Heart Beats invites you to attend our Annual General Meeting, on March 31 at 7:00 pm. Anyone interested in the business of what makes the Heart Beats – Children's Society of Calgary such a vital link in the community of families with children born with congenital heart defects is encouraged, and most welcome to attend! The meeting will be held at Patty Knox's home, at 159 Shawnessy Drive SW. For more information, or directions, call Jeannine Oliphant at 289-4329.

If you have been considering volunteer opportunities with Heart Beats, the AGM will be a great place to learn more. Briefly, the following positions comprise the executive team, and, within each portfolio are a variety of ways you can volunteer your support, with your time, energy, ideas or finances. If you can't make a meeting, but are interested in learning more about Heart Beats, please contact us, using any of the contact options on the back page of this newsletter.

Executive and Board of Directors Roles and Responsibilities	
<p>CHAIRPERSON</p> <ul style="list-style-type: none"> • Oversees operations of society • Organizes and prepares agenda for executive meetings <p>SECRETARY</p> <ul style="list-style-type: none"> • Records and distributes minutes of the meetings <p>TREASURER</p> <ul style="list-style-type: none"> • Balances monthly statements • Ensures cheque requisitions and receipts are in order • Sends out tax receipts • Completes yearly taxes <p>ACH FAMILY LIAISON COUNCIL REP</p> <ul style="list-style-type: none"> • Attends monthly meetings • Liaises with ACH in a consulting capacity regarding the hospital care needs of CHD children and their families <p>FUNDRAISER CO-ORDINATOR</p> <ul style="list-style-type: none"> • Oversees fundraising events 	<p>NEWSLETTER EDITOR</p> <ul style="list-style-type: none"> • Produces Keeping The Beat six times per year • Recruits contributors and facilitates writing assignments <p>WEBSITE MANAGER</p> <ul style="list-style-type: none"> • Monitors and maintains the website <p>LIBRARIAN</p> <ul style="list-style-type: none"> • Oversees and maintains the collection of books, videos and articles in the library located at the ACH Cardiology Clinic • Provides information for the newsletter, ie. Book reviews, missing borrowed items, etc. <p>BOARD OF DIRECTORS</p> <ul style="list-style-type: none"> • Remains informed of and adheres to the Bylaws of Society • Remains informed of and generates new business, activities and policies



Our Sixteen Year Milestone

by Sherry and Ian Harrill

We feel a real heartfelt need to thank everyone at Heart Beats for the almost 16 years of our association with this wonderful group!



Our son Jared will be 16 years old on March 7, 2004. This is a major milestone for us. It is one

we wouldn't have been able to celebrate with so much joy without the involvement of the people associated with Heart Beats and the Cardiology Clinic at the Alberta Children's Hospital.

Like other parents of kids with heart complications, we were aware of issues from the moment he was born. Initially we were overwhelmed. We weren't knowledgeable about the issues and without information we were beset with fear. We recall today a feeling of helplessness. It was very formidable and impossible to explain to any of our friends. This was very

frustrating to us and we really felt alone.

We later discovered that Jared had multiple defects. Given his young age, and the limited amount of information available at the time, it was very difficult for anyone to give us a reasonable expectation for the future. This only added to our fear, uncertainty and doubt. It was around this time that we were referred to a fledgling organization call Heart Beats.

We didn't know much about this group and, to be honest, we were a

(Continued on page 6)

Heart Beats: What's In It For Me?

Every year, we extend the invitation to renew, or acquire, a Heart Beats membership, for a \$15 fee. Since we've recently decided to offer Keeping The Beat direct to your home, by mail, for free, to everyone who would let us know they would like to receive it, we thought it would be interesting to ask the question, "Why buy a Heart Beats membership anyway, since I can stay informed and connected, through the newsletter, at no charge?" Response was overwhelming. Here is just some of the feedback you offered:

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I was really reluctant to join, initially, as I was very leery about anything that seemed like a "support group". After much encouragement from our pediatrician, the cardiology clinic nurse and then another parent who was quite involved with Heart Beats, I started coming to meetings. I was so grateful for all the support we received through my son's first heart surgery that I really wanted to give something back to other families. It is personally gratifying to help make families' journeys a little less rocky, by:

- steering them in the right direction for accurate information
- helping them connect with experienced families for helpful tips
- providing emotional support
- providing practical support to families experiencing financial hardship
- advocating at a systems level for services that meet our kids' (and families) needs

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What's in it for me is the opportunity to work with a great group of people who all have a common goal: helping make this somewhat treacherous journey a little easier for ourselves, and for others ... while having a lot of fun along the way. Even if you don't have a lot of time to give, being a member of Heart Beats and supporting the organization through your annual membership — and, if you can afford it, a small donation — can go a long way to helping many families. Knowing I am helping families with heart kids just like mine, makes me feel just great! I think \$15 is a small price to pay for the payoff of feeling great!

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I joined Heart Beats to meet other families of children with CHD. While we have a wonderfully supportive network of family and friends, it is also helpful to meet people who have been through similar experiences with their child and who can share an understanding of what we have been through, and continue going through. All my expectations have been met in that I have very much enjoyed the other parents I have come to know and been supported by. Also, I feel that it will be helpful for my daughter to know other children with CHD so that, as she grows up and becomes more aware of her condition, she will not feel alone and will have other children who can relate to her experiences.

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I think being a member of Heart Beats connects families who all struggle with "busyness" and may not make it to meetings, but still feel supported by knowing they are connected at some level with other families who know exactly what it means to care for a child with a heart defect. Now that my heart child is 15, we are involved in many teen pursuits and do not have the same ability to get together with our fellow Heart Beats families as we once did ... but we still enjoy hearing about them and staying in touch. We remain grateful for the revolving roster of volunteers who keep Heart Beats alive year after year. Thanks for your work!

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I have been personally touched by the generosity of this group by seeing how grateful are the families who have been cared for, in tangible ways, by the support of Heart Beats. The money you raise through memberships, fundraising and donations has, for years, supported heart families with the day to day stresses unique to families dealing with CHD. At Christmas the gift certificates and hampers of food and toys you discreetly offer to families in need are so very gratefully received. Throughout the year, you come to the rescue with such things as:

- buying washer and dryer sets for needy families so they do not have to take their sick babies out to the laundromat
- renting breast pumps
- paying medical supply bills

And, without your help, Off Beats would not be what it is today — and that is a dynamic, remarkable group of peers who are truly empowered through seemingly ordinary activities under extraordinary circumstances.

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Our Sixteen Year Milestone

(Continued from page 4)

little hesitant to bare our private issues and emotions to a group of people that we hadn't met. Nevertheless, we decided to give it a try. We soon realized that what we were missing was information AND the opportunity to discuss the issues we faced with a group of people that had "been there" and who had real experience. Heart Beats became a real godsend to us and we've never experienced a similar level of compassion, deep understanding and useful assistance from any other group.

We met a wonderful group of parents through Heart Beats, attended a myriad of social events (Christmas Parties, Teddy Bear Picnics ...) and participated on various committees. An important aspect of the deep value of this relationship was the continuing connection we felt with a growing community of parents who share similar issues.

Keeping The Beat has kept us in the fold throughout all of these years. We know producing a newsletter is a demanding task that takes significant discipline and tenacity to maintain.

Oops! How Embarrassing!

In the last issue of Keeping The Beat, in the article titled *Social Work Works for Families Under Stress*, I made a glaring error! (With my two munchkins nattering at my feet while I keypunched at warp speed trying to publish the January/February issue sometime actually in January or February, apparently I myself was under a bit of stress!)

I am embarrassed to admit, I wrote, "Until a baby is born, the baby relies on the mother's circulation system for its own. The heart of an unborn baby may only beat three or four

We deeply appreciate the efforts of the many people who keep Keeping The Beat publishing regularly.

Eventually, Jared reached an older age where he just didn't feel motivated by social events that also included the very young children. As it turned out he was not alone. Patty Knox sensed an opportunity to create a new group within the Heart Beats community; one that would be focused on the pre-teen and teenage jet set. They named it Off Beats — a fitting name for a group of highly intelligent kids that had overcome more obstacles than they should have had to at their age ... yet who were still able to often recognize their situations with ironic humor.

Looking back, it's become clear to us that this was another major milestone for Jared. You see, he's felt a little different than his peers for many years. He really couldn't put his finger on why but he knew it existed. His participation in Off Beats has allowed him to find a group of people among whom he truly feels he belongs and where he can let his hair down and enjoy. He looks forward to every

'practice' beats per minute."

As it was laughingly pointed out to me by someone totally qualified to know better, a baby whose heart only beats a few times a minute — in or out of the womb — would be in some kind of trouble!

In fact, it is a baby's respiratory system that remains relatively inactive until birth, with the pre-natal lungs generally taking only three or four 'practice breaths' per minute. A healthy fetus heart rate can range from about 120—170 beats per minute. (Of course! What exactly did I

monthly get-together ... to be with his friends who share a special heart and a special bond.

Thank you Heart Beats! Thank you Patty Knox!

Each day we are blessed to have Jared and we are equally blessed for all the kindness and support we have received from everyone associated with Heart Beats and Off Beats.

We are deeply grateful for your collective involvement in our lives.

Off Beats

Off Beats had a bowling pizza party at Frank Sissons on January 21 which was great fun. Some interesting bowling styles were observed ... such as Courtney's double handed, stop, drop and roll.

"In February, we had our own 'heart month' celebration at ACH," says Patty Knox, "With pasta from Chianti's, heart cookie decorating, and a rousing game of Cranium."

She adds, "We discovered great talent during our Cranium game which included some interesting artistic abilities and some great acting. Jared did a great imitation of President Bush!"

For more information about Off Beats, and upcoming events in March and April, contact Patty Knox, founder of Off Beats and Clinical Resource Nurse at the Alberta Children's Hospital Cardiology Clinic at 943-7316.

think that thump thump thumpthump-thump sound was in the doctor's office as she pressed the Doppler into my tummy ... ?!)

So now it's official. Do NOT rely exclusively on Keeping The Beat for sound medical advice.

your fallible editor

Cliffnotes:



Introducing Your Heart Beats Executive ...

Last year, *Keeping The Beat* ran a series of articles profiling the executive team of Heart Beats. Continuing on that note, we're proud to introduce Heidi Smethurst, who has been serving our community for about four years.

by Heidi Smethurst

Five years ago in June we were introduced to the world of "ICU, 3G, TGA, ER and DR", among a lot of other confusing and scary vocabulary. Our third son Ryan, at one month old was diagnosed with a transposition of the greater arteries (TGA) and a ventricular septal defect (VSD).

After a 12 and a half hour surgery at the BC Children's Hospital, and a month's post-op stay, we took our brave little soldier (Saving Private Ryan had just won the Oscar) along with his older brother and sister and moved to Calgary.

Filled with gratitude for our wonder-

ful team of life givers, and wanting connections with other "heart families", I contacted Heart Beats. In September 1999, I began attending the monthly meetings and, with encouragement from board members, took the position of "Alberta Children's Hospital Liaison" participating in the monthly meetings of the Family Liaison Council.

As I reflect on my time with both committees, I feel especially privileged to work with such a committed group of moms and dads. These are parents like you and I who, out of love and devotion to their children, volunteer their time to improve, change or support families impacted by the health of their children.

It has been gratifying to know that we have a voice as we strive towards a model of "family centered care." It is also gratifying to see our kids run around and enjoy the Heart Beats parties that are organized every

February, and to hear about the ongoing activities of Off Beats throughout the year.

As for Ryan, well, he now has a younger sister to 'direct'! In September, he begins kindergarten. We thank God every day for his continuing good health and we appreciate the continuing camaraderie of fellow Heart Beats families.

"Soldier on ..."

Heidi and her husband Dave live in Calgary with their children Erika, Evan, Ryan and Jill.



Erika, Ryan and Heidi, making nitrogen ice cream

Mom and Tots Group Celebrate Heart Month

On February 13, about ten heart kids and their siblings gathered with seven parents at Angie Enslow's home in Bridlewood for Valentine's Day.

"We ate pizza, decorated cupcakes with cinnamon hearts and," says Isabelle and Janelle's mom, Patty Wiebe, "We munched on my personal favorite, heart shaped brownies!"

Patty will host another Mom and Tots gathering, at her home in Midnapore, at 43 Midvalley Crescent SE. Lunch will be provided. (Thanks Patty!)

"If the weather is good, we may go to the lake, where we can skate, toboggan or play on the playground equipment," says Patty, "And so I'll need to know specifically who is planning on attending."

For more information about the March gathering, and to confirm your attendance, contact Patty by phone, at 256-7423 or e-mail, pattywiebe@shaw.ca.

On April 22 at 11:00 a.m., Michele Maurette will welcome moms and tots to her home in Braeside, located at

10512 Brackenridge Rd. SW. Again, lunch will be provided, (thanks Michele!) so please RSVP to Michele at 251-2446 by April 20.

"Our Mom and Tots gatherings are open to all heart tots — and their siblings and moms," says Mom and Tots founder Angie Enslow. "Even dads are welcome!"

"Really, we are simply offering an opportunity for families with young kids to connect with other families who share a common bond of CHD," says Angie.

For more information about Mom and Tots, or if you'd like to host a future Mom and Tots gathering, phone Angie Enslow at 251-3989.



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.

Chairperson Jeannine Oliphant
Secretary Patty Wiebe
Treasurer Sylvia Falk
Nurse Liaison Patty Knox
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We Had A Blast!

On February 28, about 45 children and, well, let's just say children of all ages, gathered at the Calgary Science Centre to celebrate Heart Beats' annual family event! If you, like this writer, haven't seen the Science Centre since it was called the Planetarium ... you, like this writer, have been missing out on one of Calgary's finest attractions!

After pigging out on pizza, veggies and dip (yeah, right) and cookies, we let loose on WOWtown, the Magic School Bus and Lego Mindstorms. We made shadows that didn't follow us, dammed waterways, stirred up clouds and tornados and pedaled enough electricity to film ourselves pedaling. When I caught my breath, it looked like the kids were having fun too!

A definite highlight of the night was making ice cream in coffee mugs using cream, sugar, vanilla and chocolate ... oh, and liquid nitrogen poured right into the soup! This was a great lesson on the scientific properties of solid, liquid and gas ... while clouds of freezing cold air spilled in our laps, our creamy ingredients thickened instantly into scrumptious, very scientific ice cream. Yum!

The evening ended in the Science Centre's ginormous Discovery Dome theatre that wraps around and above you, making you feel like you're right there ... amid all those millions of wee crabs ...

Beat The Drum Slowly

an editorial by cindy bablitz

My son, ever the thoughtful paleontologist, had this to say over his dinner plate of pork chops:

"Mom, chewing bones is really hard."

Mm hm. Eat up, sweetie.

"Mom, you know what's even harder than chewing up bones? Digesting bones."

Right. Digesting bones is hard. Take another bite of supper sweetpea.

"But mom, you know what's the hardest thing of all?"

No ... and I'm not sure I like where this train of thought could be leading ... at the dinner table ...

"Patience."

And once again, my heart babe surprises me.

It was surprising to be told, after a

profoundly healthy pregnancy, that my baby had a potentially life threatening hole in his heart. It was surprising to carry him home from the hospital just five days after surgeons cut open his wee sternum. It was surprising to watch his little head sprout hair like it'd just been fertilized and his skin pink up like he'd been given a pigment transplant. And, yes, surprising to be informed by him that, even harder than digesting bones, is patience.

So it is. We safeguard the survival of our precious young people and we chart and monitor their progress and we read and learn all we can to be the best caregivers possible. We cocoon them and consume ourselves with their health and our collective well-being. And in spite of our preoccupa-

tion with yesterday and tomorrow, our children — regardless of diagnosis or prognosis — remain fully engaged in the important minutiae of this moment.

What joy! What bliss!

What a powerful gift. Nevermind what did happen or may happen or may never happen. Consider the lilies. Know what matters in this moment. The digestive nuances of pre-historic predators. The misfortune of delayed gratification.

Kids with hearts really get what we grown ups with hearts can sometimes stand to be reminded of: There is no guarantee on tomorrow's delivery. So be here now. Supper can always wait till we're done tending to the really important stuff.

