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The Current

Sunday, February 11, 2007

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Guest Commentary: Valentines day brings love, and awareness

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Issue date: 2/11/07 Section: Opinions

Valentine's Day, 1995, will linger in my memory for a long, long time. The four month old baby who squirmed in my womb had a heart defect, and my neonatologist said that her odds of survival were slim.

However, he encouraged me to seek a second opinion. That is how I found myself spending Valentine's Day with Dr. Angela Sharkey, pediatric cardiologist at St. Louis Children's Hospital, as she waived her magic wand over my stomach, bringing ghostly images of a tiny body and tiny heart into focus.

"The neonatologist told me there is no aorta," I said in a sad voice. "Oh, I can usually find one," she said, and she did, although it was small and not functional.

My baby had no left ventricle. "Why do we hear more about hypoplastic left heart syndrome than hypoplastic right heart syndrome?" I asked her. "The people on the left are more outspoken," she joked, her eyes never leaving the screen. I needed that humor, and I needed good news!

On Valentine's Day 1995 I learned that my daughter had a fighting chance at life, even with only a single, weaker ventricle (the right side). A holiday that celebrates romantic love evolved to have a secondary meaning for me, as a holiday of hope.

When the Congenital Heart Information Network (affectionately known to its members as "CHIN", www.tchin.org) decided to commemorate Valentine's Day as "Congenital Heart Defect Awareness Day," it echoed the silent celebration I held in my heart every February 14.

Eleven years later, my daughter is a veteran of three open heart surgeries, all performed before she was four years old. When people meet my sprightly daughter for the first time, they can't tell she has been through so much. It's the same for a growing number of children and adolescents who are surviving open heart surgeries at a young age and are emerging into adulthood, pioneers in a new medical world.

As the first generation to grow up with congenital heart defects (CHD), they are presenting new challenges to a medical profession used to battling clogged arteries and strokes.

As an academic advisor, I have worked with many of these young pioneers. It is for my daughter's sake and theirs that I spread the word every Valentine's Day about Congenital Heart Defect Awareness Week. This year its runs from February 7 through 14.

The students who have CHD, and the young people I know through our local family support group "Heart to Heart," have issues that adult cardiologists have never encountered before.

The oldest survivors with my daughter's condition are only in their mid-twenties. How long can their weaker right ventricles continue to do the job of the left ventricle? How long will the complex repairs that many of these young people have hold up? Can women

with single ventricles have successful pregnancies? It's my hope that the awareness we raise each February 14 will result in additional research into the causes and cures for congenital heart defects.

I want my daughter and my college students with CHD to have an opportunity to make a difference.

The internet allows adults who have congenital heart defects to give each other support, information and opportunities to advocate for themselves.

Information on these resources is available at: <http://tchin.org/adults/index.htm>

The issues that concern them aren't always medical. I asked a cardiologist who works with this group what he found to be their biggest challenge. I expected the answer to be fatigue, or arthymias.

He said, "Health insurance."

It shouldn't have surprised me. I remember a student with CHD who told me he had to take an overload of courses to graduate by a certain date - when his parent's health insurance would no longer cover him.

So I wish all who read this column a "Happy Valentine's Day!" For those of you with congenital heart defects, know that there are resources available to you, and you are most certainly not alone. As for me, there are still lingering memories of that cold February day in 1995 when I discovered that there is hope for even babies with the most complicated heart conditions. Like my daughter.

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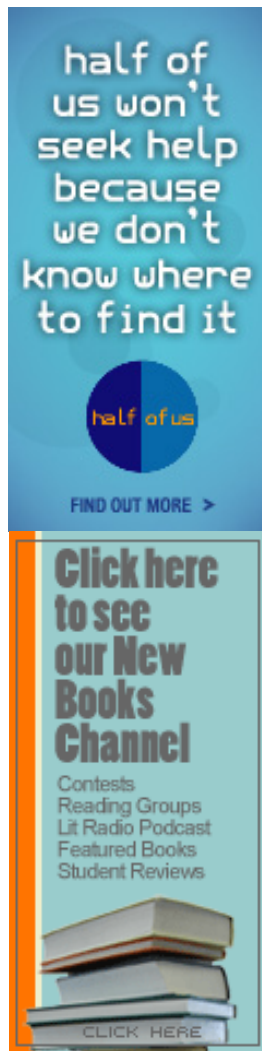
- Yes, I got exactly what I wanted
- Pretty much, it's the thought that counts
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