



Andrea Celebrating her Birthday

### 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 Andrea Sager.

I was born in Calgary, Alberta on September 10th, 1976 with the heart defect called tetralogy of Fallot. My parents didn't know when I was born that I would have a heart defect, and at 3 months old I was taken from Calgary to the Sick Kids Hospital in Toronto by airplane. I had a shunt done for my heart by Dr. Bill Williams. I saw Dr. Harder in Calgary as my cardiologist and when I was 5 years old I had my first open heart surgery. I had open heart surgery again when I was 7 years old.

Later, we lived in Ontario and I saw Dr. Robert Freedom. When I was 15 and 17 years old I had heart surgery again, all done by Dr. Bill Williams. I also had a stent put in when I was 15 years old at Sick Kids Hospital.

Since moving to Ontario with my parents. I've been through a lot of heart tests and I now go to the Peter Munk Centre at the Toronto General Hospital. I see Dr. Benson, and so far my heart has been great. I have not had to have surgery since I was 17 years old. I live my life every day to the fullest - I like to go for walks, do yoga, and I am on the board of directors for Community Living. For a job I work as a receptionist. I have great support from my friends and family who are always there for me. I have also made some great heart friends.

In my spare time I like to listen to music, sing, watch DVDs and TV, and I also like to spend time with friends and family. I also like to read and make hand-made holiday cards.

As a child I went to Brownies and Girl Guides, ballet, and gymnastics. I have a brother who has always been very supportive of me, along with and my mom and dad. When I was in grade 1, I had to go to Special Ed because it was discovered that I was mildly mentally delayed. These days I live with a roommate.

I think that heart awareness is important because it helps parents and kids face the heart defect more easily, knowing what to expect. I would like to talk to parents and kids about heart defects. I also like to talk to Facebook friends who have heart defects, and help them.

#### 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](mailto:jenb@heartbeats.ca)

### Family Testimonials

A big thank you to everyone who submitted testimonials! These letters will be essential in sharing the impact on and difficulties experienced physically, emotionally, and financially by families travelling for their child's surgery. If there are families who didn't send in a testimonial but would still like to please don't hesitate to contact us. [www.westernchildrensheartnetwork.ca](http://www.westernchildrensheartnetwork.ca)

### Website:

The following items have been added to our website:

The Stollery Children's Hospital Pre-Admission Clinic (PAC) video is now available in the Public Knowledge Base page, under Resources.

An informational video about Long QT Syndrome created by BC Children's Hospital has been uploaded to the Public Knowledge Base page, under Resources.

Family Stories: If you have family stories you would like to share on our website, or if you have an update to your story that is posted on the website, please forward your story or updates to: [wchn@albertahealthservices.ca](mailto:wchn@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: [wchn@albertahealthservices.ca](mailto:wchn@albertahealthservices.ca).

### Family Satisfaction Survey

The WCCHN will be completing regular Family Satisfaction Surveys, effective December 2012. These surveys will be distributed on a quarterly basis to families who have had procedures completed within the Network.

