

No More Pretending

by Mike Brown

My name is Michael Brown and I was born in 1969 with a condition called hemi facial microsomia. I was born with only one ear on my left side and, to the best of my knowledge I did not have the ability to hear from my right side. For 35 years I believed that I was only able to hear from my left side. Because of chance circumstances through people in my work community, I became aware of a facility called iRSM.

In the summer of 2005 I was introduced to iRSM. After some specific hearing tests I found out that I had close to full hearing on my right side and was given several options that would give me full hearing for the first time in my life. The facility in Edmonton looked at my needs, and along with doctors in Calgary as well as Edmonton, I chose to go with the procedure that would allow me to use a bone anchored hearing aid (BAHA™).

After my surgery and almost four months of healing, I had attached my hearing aid for the first time. The experience of the BAHA was profound. I cried tears of joy. I had always understood the idea of stereo hearing but until I attached my hearing aid, my world of hearing was only half. The hearing aid has changed my life.

I remember going to see my first movie with my hearing aid. It was a truly exhilarating experience. The hearing aid has increased my confidence with conversations in crowded rooms. I found it possible for the first time to not worry about where my position was in the room to hear a conversation. I didn't find myself having to fake my way through a conversation pretending I heard what other people were saying. I didn't have to laugh when everyone else did because I missed the joke. I was unaware of how many concessions I had made in my life because of my hearing impairment. My hear-



ing aid has removed those concessions. Now I miss nothing. I have always been an outgoing person. My hearing impairment could have caused me to be an introvert and to close my life up to the rest of the world but that wasn't me. My hearing aid has extended my outgoing nature, my confidence and my belief that I can accomplish anything.

iRSM has been nothing short of amazing. When I first arrived I felt quite vain about my needs. I could hear from my left side just fine. They help so many people there that have worse problems than mine. But iRSM always made me feel that my desire to be a fully hearing person was no less important than any other patient. In many respects I feel that I am part of a completely different extended family. I have felt so comfortable with the people and the facility that I now volunteer my time to speak to new people who may become patients. My experience and positive story reinforces the quality of work, the professionalism and the expertise that iRSM brings to this medical field.

And, yes, my life would have gone on had this treatment not been available to me but I would not be in the position that I am today. I am thrilled to share my story, to scream from the mountain tops about the changes and growth that I have seen in myself, and my ability to completely enjoy my world. I no longer have to pretend that I hear what's going on around me. I thank iRSM for what they have done for me.

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In this Issue

This issue of Headlines presents inspiring and informative stories from iRSM's patients, families and caregivers.

Our next Headlines issue will be published in June 2011.

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I'M A SURVIVOR

by Jerome Youngchief

I am 58 years old, father of one daughter and three sons. I live in Kehewin Cree Nation. In 2005 I was going back to see my family doctor every month for an eye infection. I was prescribed antibiotics and ointments but none of this worked. Finally, I asked for a second opinion and was sent to a specialist in Edmonton, who ordered a CT scan.

On November 10, 2006 I went to see the next specialist who did a biopsy. Two days later they told me I had a tumour and I had to wait one more week to find out it was cancer. When I got the news one of my sons was with me, I looked over at him and tears were running down his face. I was very surprised at the news; I felt sad and hurt.

Four days later, I was in surgery to remove the tumour, at that time they also removed my ear and used skin from my stomach to cover the area where my ear had been. I was in the hospital for two months.

In February 2007, they sent me to the cross cancer for radiation. The radiation happened four times per week for two months. The radiation left me with painful burns and I almost quit. My brother was with me and I told him how I was feeling; he gathered two more of my brothers and they got together and convinced me to continue with the treatment. I finished the radiation in March 2007.

The radiation affected the hearing in my good ear, so in June I went to be fitted with a hearing aid. It took some getting use to and finally I was fitted with one that worked for me.

In November 2007 the cross cancer told me the treatments and surgery were successful and I was cancer free.



In November 2007 the Cross Cancer told me the treatments and surgery were successful and I was cancer free. My uncle was with me and shared in the good news.

In April 2009 we started the journey at iRSM to reconstruct my ear. I started with photos and a plan. The next step was hyperbaric treatment. This treatment was 6 weeks long. I would go into a capsule for four hours a day. I was able to watch movies and sleep during the treatments. The worst part was staying in Edmonton away from my community.

On July 13, 2009 I had one more surgery. They put six implants where my ear will be attached as well as one for my bone conduction hearing device processor to connect to. This was a short surgery and I only had to stay for one day.

The next surgery was in February 2010 where they attached the external pins to those implants.

On April 28, 2010 I received and learned more about the bone conduction hearing aid (BAHA™) that will allow me to hear with two ears. Proceeding with the fabrication of my prosthetic ear will probably begin near the end of this year. Once I have received my prosthesis I will have a summer ear and a winter ear. iRSM will clip on a bar over the implants and look like a regular ear. They will also trim the excess skin that covers all of that technology.

I hope that when this is all done I can get back to my usual activities including Pow Wow dancing and Hoop dancing.

MICROPHONE

We want to hear your story

We invite you to share your stories with others who may be just starting on their journey through care at iRSM, or who may be looking to hear from someone in a similar stage of treatment.

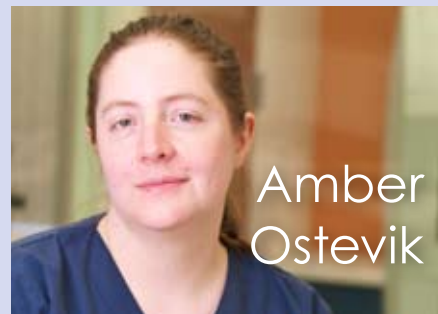
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RED CARPET



I came to iRSM after finishing my graduate studies in Audiology at Dalhousie University in Halifax, Nova Scotia. I grew up in Saskatchewan and completed an undergraduate degree in engineering at the University of Saskatchewan. Coming to iRSM and Edmonton was an unexpected surprise as I expected to enter into the private sector after graduation. I currently work in the Bone Conduction Amplification Lab (BCAL) with Dr. Bill Hodgetts and provide audiological support for a Neurotologist, Dr. Allan Ho.

The experiences and opportunities I have had since I began my employment in May 2009 have been incredible considering I am at the beginning of my career. I am grateful for the support of my colleagues and patients, both of whom I continue to learn from.

I hope to begin a PhD program through the University of Alberta within a year's time. If you have any hearing-related questions, please feel free to contact me at aostevik@gmail.com.

Have a wonderful New Year and holiday season.



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You Have Got To Hear the News!

by Sherry Shonbeck

Can you please repeat that?... Don't speak so softly!... Turn up the television!

Wow... where did that emergency vehicle come from!!

Hi, my name is Sherry and 10 years ago I spent a lot of my time repeating those very sentences. It was frustrating for me and even more frustrating for those around me. My job as an office assistant was becoming more and more difficult—if I couldn't hear, I couldn't take meeting minutes or answer the phone. A visit to a health care professional, regarding another issue, led to a startling discovery regarding my sudden hearing loss. An emergency visit to an ENT (ears, nose & throat) specialist, followed by a series of CAT scans, x-rays and MRIs, revealed what had been causing the hearing loss. A "cholesteatoma" was discovered in the middle area of my right ear. A cholesteatoma is a benign growth of skin in an abnormal location such as the middle ear. The fact that the growth was benign was fantastic news—what followed for over the next 8 years was not.



My son, Christopher always checking on the progress of "Mom's Frankenstein bolt". Each checkup appointment felt like going to the spa—iRSM staff were so attentive and caring.

The first surgery resulted in some life altering news—the cholesteatoma had formed around the bone structure in the middle ear—when the cholesteatoma was removed—so was my ability to hear. That left me with a 100% hearing loss in the right ear.

I felt I had been robbed of something most individuals take for granted. Common everyday events such as driving in traffic became hazardous (where was that siren coming from?), having a conversation in a public place (talking in a restaurant had become next to impossible!), my employment became jeopardized (with my inability to accurately take dictation or follow along in meetings). Even watching television was futile with most family members wincing at the loud volume. Continuous infections and a series of 4 more operations proved to be ineffective and provided no relief. At one point I developed such a severe ear infection in both ears that my world was void of any sound for almost 8 weeks!!

I missed major milestone events—straining to hear those first cries during the birth of my son. Missing the "I dos" at my daughter's wedding. Embarrassed at missed instructions and introductions. The thought by some that I should be thankful for at least having some hearing was of little comfort. In 2008 a retirement meant my file was passed to another ENT specialist—Dr. Richard Liu. He seemed personable enough, but little did I know at the time how he would in fact change my life.

The light on my desk phone lit up with an incoming call. The voice on the other end began to explain how Dr. Liu felt I would be a good candidate for a Bone Anchored Hearing Aid (BAHA™) and would I be interested in coming into iRSM (formerly COMPRU) to learn more about a BAHA?—well they didn't have to ask me twice! I rushed home, bursting with excitement to tell my family of the news. I literally counted down the days to that appointment—like a child waiting for Christmas to arrive! The staff at iRSM were fantastic—answering every question, explaining the procedure. Next came the education class—I was in awe and filled with gratitude. Again the light on



my desk phone lit up—the now familiar voice had a question to ask me—I was afraid to answer—in case somehow the opportunity would slip away from me. The voice asked... what color I would like my processor to be!! I sighed a sigh of relief—Imagine I had an opportunity to hear again and decide in what color that sound would come to me! That was music to my ears.

The big day arrived... the staff were great and the surgery a resounding success. My son, Christopher always checking on the progress of "Mom's Frankenstein bolt". Each checkup appointment felt like going to the spa—iRSM staff were so attentive and caring... the 3 months flew by... finally the BIG appointment... the day the processor was attached and I instantly stepped back an entire decade... I could HEAR... from both ears... in stereo!!—it was truly a moment to remember.

I left the iRSM office and stood outside in the parking lot for quite some time—listening to nearby traffic, the late summer birds, tires crunching on the ground, people talking and babies crying! WOW!! I was truly able to once again "hear" the news!!!!

I recently reached my 1 year milestone with my BAHA and what a year it has been. Having been asked "Why bother with the surgery?" (since I still had one functioning ear) my answer—Why would I Not? My son, Christopher now 7, has loved the opportunity to try out the Share the Experience device, which has allowed him to hear how his Mom and other BAHA recipients actually hear (bone conduction sound versus air conduction). My teenage daughter, Victoria and I have enjoyed the opportunity to have many "car conversations" and "ipod symphonies". Thanks to my supportive husband, Mike (who now truly understands about "selective hearing"), and thanks to the leading edge care provided by Dr. Liu and the specialized team at iRSM. Thanks to all.

Sherry can be contacted via iRSM at irms@albertahealthservices.ca

SPOTLIGHT ON iRSM

This spotlight features highlights from iRSM

Design Research Society (DRS) Conference

Ben King and Heather Logan presented a paper at the Design Research Society (DRS) conference proceedings in Montreal, Quebec on July 7, 2010. Title: 'Transformative Design: From Consultant to Clinician'.

Rotary Club Presentations

Ben King presented to Rotary Club of Edmonton Mayfield August 18, 2010.

Myka Osinchuk presented to the West Edmonton Rotary Club on September 27, 2010.

Caritas Hospitals Foundation Lottery

Tuesday, Sept 7, 2010: Dr. Gordon Wilkes was interviewed on a Global TV segment featuring Caritas Hospitals Foundation Lottery support for iRSM.

Digital Technology in Reconstruction of the Head and Neck

Dr Wolfaardt was an invited lecturer to the Canadian Military, Western Detachment, Dental Services: Digital Technology in Reconstruction of the Head and Neck. November 17, 2010.

TEC Venture

Diana Shaw was featured for her on-going role as a business plan screener in the TEC Venture Prize two page advertisement that ran in the Edmonton Journal (pages A10-A11) and Calgary Herald on October 14, 2010: "Fascinated by Ideas".

SDA and MADE exhibit: 'Out of the Bag'

Ben King, Heide Heine and Heather Logan had work featured in the SDA (Student Design Association) and MADE (Media, Art, Design, Exposed in Edmonton) exhibit 'Out of the Bag'. The show featured a diverse range of alumni and student work in Industrial Design, Medical Design, Furniture, Product Design, Graphic Design, Typography, Photography and Architecture. The exhibit was on display at Enterprise Square from October 18-23, 2010.

Bone Conduction Amplification Webinar

iRSM presented a web-based information session to increase awareness of implantable bone conduction amplification and improving candidate selection for bone anchored hearing solutions. November 30, 2010.

Telus World of Science

Diana Shaw, Bill Hodgetts, Jana Rieger & Heather Logan presented at Telus World of Science on November 26, 2010. Aimed at Grade 8 & 10 students, the "Human Body" IMAX film was shown followed by our presentation titled "Real People, Real Science: Project 'Spare Part Human'". There was a morning and an afternoon presentation, with approximately 270 students per session.

Cool Companies Article

iRSM was featured in the article "Research & Development Support for Alberta's Medical Devices & Technologies" by Claudia Sammer, in the first edition of "Cool Companies: Alberta's Medical Devices & Technologies." First edition Canada, 2010.

Research Funding

The Governments of Canada and Alberta announced an investment in iRSM on November 10, 2010.

Western Economic Diversification and Alberta Advanced Education and Technology, through the Western Economic Partnership Agreement (WEPA) have provided funding for the development of improved technologies for implantable hearing devices and an innovative neurosurgical device. www.wd.gc.ca/eng/77_12448.asp



HEADLINES TEAM

Headlines is a newsletter created for iRSM patients, their families and friends. It is dedicated to improving life for all iRSM partners.



Heide



Nicole



Sarah



Leanne



Anna



Diana



Richelle

