

balance

What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

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How a Crisis Transformed Me

BY BOLESŁAW RAWICZ On a day in late October of 2005, I was taken to Vancouver General Hospital to be treated for pneumonia. That evening, as I was being moved to the operating room to be intubated, my breathing capacity had deteriorated to the point that I felt I was about to suffocate.

The next morning, I awoke in the intensive care unit feeling very drowsy. I spent the next few days in a fairly private section of the intensive care unit (ICU), drifting in and out of sleep, until being moved to another section. I'd had a tracheostomy, which was a decision I'd been dreading, but there was finally little choice. And, the trach relieved my reliance on a mask for breathing.

At first, I disliked being in the much more open section of the ICU. But, after getting used to more activity and contact with people, I began to prefer it. Most of the nurses and respiratory therapists were younger than me or around my age.

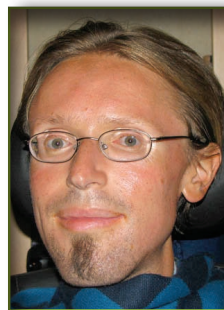
I realized that I needed to spend more social time with people near my age—something I'd done too little of for several years before that

moment. Not being able to speak—my trach had not yet been set up for that—I was becoming increasingly frustrated and impatient.

The day I was finally able to talk, I talked so much I was exhausted. I vowed to myself that I would be more social and outgoing when my hospital stay ended.

Those few weeks, that began with a crisis, were a highly transformational experience for me. Four years later, after writing poetry for some time, I wrote "a voice regained" which was inspired by these events.


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 Email and web links in the PDF version of BALANCE are live. You can jump to listed sites or send emails.

BCITS is moving to a new home! Please see page 6 for details.

balance

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Crisis, continued from previous page

A voice regained

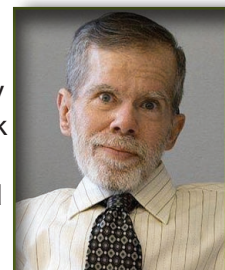
Your voice long silent,
 forgotten its existence,
 within you the angel, the purpose
 of its wings a memory distant,
 like a prisoner still imprisoned
 in a cell that's opened,
 to fly it would not even attempt it.

You'd hidden from the world,
 hiding within your self
 as demons clouded your soul,
 afraid of the pain of falling
 again into unrequited love,
 in the depths of your darkness
 your way had been lost,
 until came the crisis
 of the loss of your breath,
 unable to inspire,
 feeling nearer to death,
 that brought you inspiration,
 a stronger desire to live.

The need for healing had brought
 you to unavoidable contact with
 many,
 a place where your angel
 imprisoned
 saw other angels flying,
 some of whom that were trying
 and some on the wing high above,
 and here you were finally seeing
 the human connection you'd
 forgotten
 that you needed and had missed,
 and in the midst of the healing
 your voice had to be silenced
 for days that infinite seemed,
 and in this waiting
 had strengthened your yearning
 to awaken your voice,
 then the moment had come
 when to speak you were able,
 your voice you were regaining,
 your angel on its way ascending,
 your voice was on a journey
 to grow in its strength. ●

The Power of TIL Aids

Every once in a while, I'm asked what my disability is. I'm always quick to reply, "I'm a lawyer—don't hold it against me!"



Running a busy law practice is only part of what I do. Over the years, I've been involved in politics, elected twice to Vancouver City Council, and involved in many community boards, including Vancouver Credit Union and HandyDART, as well as community projects.

Every once in a while, I'm asked what my disability is. I'm always quick to reply, "I'm a lawyer—don't hold it against me!"

None of this would have been possible without a number of adaptive aids from Technology for Independent Living (TIL). TIL's Executive Director, Simon Cox, installed my first environmental control—a Touch Operated Selector Control. It allowed me to turn on and off many different appliances, including my telephone. Today, I have special phones set up throughout the house—each with a feather switch. But my feather switch operated e-book reader is by far the most enjoyable. TIL did an incredible job. They opened up my Sony e-reader and wired it with three feather switches, so that I can fully operate it, including next page, on/off and flipping back pages. This lets me read to my sweetie!

Thanks to Simon Cox and all the great folks at TIL.

Tim Louis | www.timlouislaw.com ●

Introducing The Willow



Recently, BCITS gratefully received funding through a donation from the BC Rehab Society to design an environmental control system that could be used universally, in any extended care facility.

The first step of the design was to find out which functions the environmental control would need to work efficiently in an extended care environment. Because BCITS' TIL program works within extended care facilities helping clients with their everyday control needs, our team had a good understanding of what was needed.

The second step was to find the right person to design and test the device, so we recruited the best in the business: former TIL technician and engineering professional, Joanne Bengert.

Joanne worked diligently to design and program the device, with much approval from the TIL team. Testing went very smoothly and only minor tweaks were needed before the device was ready for use.

The Willow is a software application that can be loaded onto any netbook, laptop or desktop computer. Once the software is installed and an infra-red transmitter/receiver is installed (USB), a TIL technician designs the layout and programs the software to support all environmental controls needed by a particular user.

Finally, the technician uses the Willow's "learning" ability to duplicate and store all original remote functions within the Willow software. The application is easy to manipulate and customize for the dynamic needs of different users.

The Willow uses various scanning methods and the scan speed is customizable. To activate the scanning, the user can use any switch necessary, whether it's a buddy switch, microlight switch or a sip-and-puff switch. It also has a dynamic display, so with every selection that is made, the screen changes or gives feedback to ensure the user that the system is working as expected.

Again, the design of the device has been a great success thanks to the extraordinary efforts by Joanne Bengert and the financial support of the BC Rehab Society.

We look forward to setting up the device with users in the near future.

AGM Notice

The Annual General Meeting for BCITS will be held Tuesday, September 21st, 2010 at 6:30 p.m. at George Pearson Centre, Special Events Room 700 West 57th Avenue, Vancouver BC V6P 1S1. Visit www.bcits.org for details.



Gadgets

BY SIMON COX

The Pen Friend

Everything is getting smaller these days, but smaller does not mean less technical intelligence.

The Royal National Institute of Blind People in the UK sells a device called a "Pen Friend." It looks like a hand-held microphone and allows people to use their voices to label things, such as books, CDs, food packages, medicine bottles or bills that have arrived in the mail (awful thought).

You use it by sticking a small round label to the object, registering the label using the optical scanner at the Pen Friend's tip, and then recording your comment. Pointing to the label will then play back the associated comment. That means you can call the object whatever you wish.

Any other applications you can think of? It costs around \$100-200.

Go to www.rnib.org.uk and click on "Store." ●



PROP Receives Service Award



Simon Cox (centre), with Michael Gardner, President, ALS Society of Canada (left) and Ben Wendland, Past-president, ALS Society of Canada (right)

Simon Cox, Executive Director of the Provincial Respiratory Outreach Program (PROP), received an award on behalf of BCITS and clients of the program. The 2009 ALS Society of Canada's Marcel Bertrand Exceptional Support Services Program Award was presented for PROP's extraordinary efforts to help people with ALS in BC.

Since its inception in 2001, PROP has been dedicated to helping people who need assisted ventilation meet their respiratory needs without leaving their home. The program provides a range of equipment and supplies, education, peer group support and on-call respiratory therapists available 24 hours a day. PROP also invites clients of the program to participate in every aspect of the program's delivery.

Cox says the PROP program is unique and effective because it is designed for and by the people who use it.

"I think our clients appreciate the fact that they can access us directly, there's no 'middle man.' And we kind of do it all—we provide equipment, supplies, consultation, education,

support and the services of a respirologist and respiratory therapist," says Cox.

Les Hart, a PROP client living with ALS in Surrey, BC, commends the program for providing him with the training and services to live a more comfortable life at home. "Before I had the tracheostomy, PROP met with me and my family and laid out the plan, showed us the equipment I would be using and then trained us on the home care. They put our minds at ease and cleared up the unknown in layman's terms, not satisfied until we were satisfied," says Hart.

The Marcel Bertrand Award is given to an individual or group of health care providers in recognition of an exceptional service designed to enhance the quality of life for people with ALS and their families.

ALS, more commonly known as Lou Gehrig's disease, is a rapidly progressive and fatal neuromuscular disease that causes the degeneration of nerve cells in the brain and spinal cord. As the nerve cells die, people with ALS lose control of their muscles which makes breathing, eating and even smiling almost impossible. Eighty per cent of those diagnosed will die within two to five years.

The ALS Society of Canada is the only national voluntary health organization dedicated solely to the fight against ALS and support for people living with ALS. The Society funds research toward a cure, supports our provincial partners in the provision of care and provides information to build awareness about the disease. ●

Fundraising Golf Tournament

It's the time of year to get out and golf at the 11th Annual Rodney Stanes Golf Tournament at the Mount Brenton golf course in Chemainus.

Each year, the funds raised by generous donors like you, enable us to make a donation toward research for a cure to spinal cord injury. Last year's event raised over \$7,500.

Currently, the Spinal Cord Society is funding research projects in Edmonton, as well as Australia, New Zealand, Portugal and Beijing.

Entry Fee

\$125 per golfer (tax deductible)

Donations

Tee Sponsorships and Green Sponsorships (\$125)

Refreshments

A "Juice and Cheese Party" for golfers and the general public

Food

Breakfast and lunch (included)

Entry forms

Registration by September 1

Referrals

If you know an individual or company that would support this event, please contact Chris.

100% of all profits to research

Contact Chris Loscerbo at chris.loscerbo@telus.net or 250-246-9971.

Getting to Know Your Service Technician

As a direct result of your feedback in our most recent client survey, we have restructured our biomedical engineering department to service your TIL and PROP needs more efficiently.

Our biomedical engineering department has been redesigned to combine TIL and PROP services to improve service for all clients. By combining the two programs, our Biomedical Technicians will be able to address all your needs (TIL and/or PROP) with one visit. This restructuring also means that you will likely be visited by the same technician for most of your requests, so our technicians can become very familiar with your particular setup and your needs—and that will improve efficiency, too.

For our Island, Interior and Northern Health clients, we hope that this means we will be visiting your regions more frequently

which is something you have been asking for over the years. By combining the services, there will be more work for the area's technician, allowing them to visit your areas more often.

The province has been divided into 4 service areas. We would like to introduce you to your service technicians.

Stephen, the ultimate family man, will be visiting most clients south of the mighty Fraser River. This area includes Surrey, White Rock, Langley, Abbotsford, Chilliwack, Hope and, when needed, he will fly his way up to the Northern Health region to serve your needs.

Wayne, the department's sports nut, will be hitting the highway to service all needs in the Okanagan and Kootenay regions. Also, when he's not baking in the Okanagan sun, he will be servicing

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ing all equipment north of the Fraser (Burnaby, New Westminster, Coquitlam, Maple Ridge and Mission).

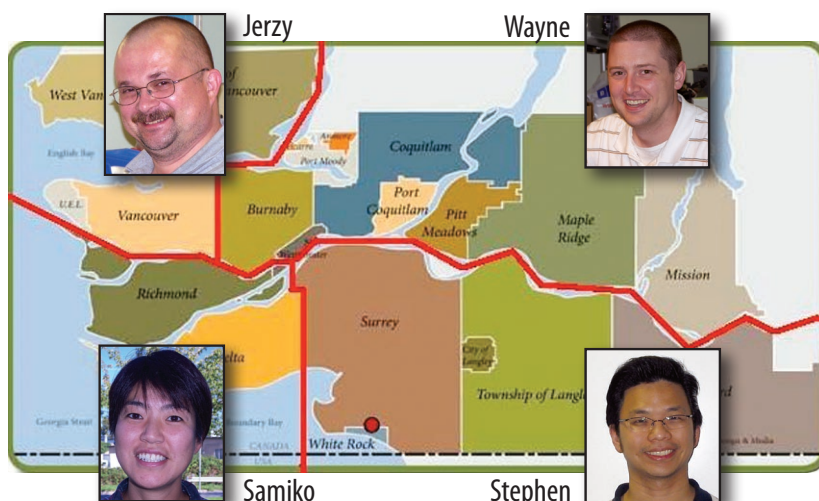
Jerzy, the expert in both programs (and "football" [soccer]), will be at your beck and call in Vancouver, North and West Vancouver, Squamish, Whistler, Pemberton and the beautiful Sunshine Coast.

Samiko, who will repair your equipment and make you smile, will be spreading her positive attitude while visiting you in Richmond and Delta, as well as ferrying to see you on Vancouver Island and the Gulf Islands.

If you are a client of our PROP program, we will be attempting to exchange your ventilators and BiPaps in person. Because we will be coming to your region more often to do this, we will be able to ensure your new equipment is working properly, save on shipping costs, and ensure all your other PROP and TIL equipment is working efficiently for you.

We look forward to getting to know you and your set up better, and we look forward to hearing what you have to say about our new service structure.

Sincerely, Your BMET team! ●



PICK UP YOUR FREE ENERGY SAVING KIT

If you live in a lower-income household, you're probably eligible to get our free Energy Saving Kit. It's packed full of products and info that anyone can use to make a home more comfortable, more affordable, and a little easier on the planet.

BC Coalition of People with Disabilities (BCCPD) will be giving out free Energy Saving Kits on-site starting June 15, 2010.

Call us at **604 872 1278** or visit bccpd.bc.ca to find out more.



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We're Moving!

As BCITS continues to grow and expand services for our growing client base, we've run out of space at our current location. Fortunately for us, we won't be stepping on each other's toes, treads or paws much longer! We're moving to a larger location, only a few minutes away. Our new address as of **August 1, 2010** will be:

#103 - 366 East Kent Avenue South, Vancouver BC V5X 4N6

We are still across the train tracks with the Fraser River serving as our backdrop. Instead of being between Oak and Cambie Streets, we are now right by Main Street. We have been preparing for the move to ensure that our clients' needs are met during the transition to our new home.

You can reach us at the same phone numbers and email addresses.

Please remember when returning equipment by post after August 1st to use the new address.

Our Thanks to MHSD

Dr. Moira Stilwell, Minister of Advanced Education and Labour Market Development, presents a \$100,000 cheque to Ken Kramer, BCITS Board Member and Simon Cox, Executive Director of BCITS. The grant originates from Direct Access to Gaming through the Ministry of Housing and Social Development. The funds are used to purchase much-needed equipment for people with disabilities through the Technology for Independent Living (TIL) Program.





Meet the VersaCom

The VersaCom is an augmentative communication device developed as a student project at British Columbia Institute of Technology (BCIT).

Intended for people living with ALS or others who cannot use a direct-access keyboard, it uses a row-column scanning interface controlled by a single-switch input. Users are set up with an easily-activated switch (such as the buddy switch, microlight switch or a sip-and-puff switch) and compose messages on the LCD screen by clicking when their desired character is backlit by the scan.

Messages can be saved and recalled to memory, and played out as text-to-speech. Natural-sounding messages (in the user's own voice, if voice-banked snippets are available) can also be stored on a SD memory card and played back by the VersaCom. The user has control of scanning speed and display brightness, and the volume can be adjusted.

Dual LCD displays make it possible for the audience to read messages while facing the user. The device is light and portable, and runs on rechargeable batteries or an AC adapter. It can be placed on a table, the user's lap or mounted on a wheelchair.

The VersaCom was designed and built by a team of four BCIT students: Brad Haws, Julie Hrvatin and Stephen Tarrant, as well as programmer Morgan Redman, under the supervision of Bruno Jaggi, P.Eng.

It won the Principal Award at the third annual Jim McEwen Excellence in Engineering Design Awards competition, sponsored by the ALS Society of BC. ●



**Visiting
Biomed
Student**

Stephen Tarrant is working with the Biomed at BCITS this summer.

He is a student at BCIT's Biomedical Engineering Technology program, and will be returning to finish second year courses in September.

When he's not soldering electronic circuits, he enjoys playing with his baby daughter Evelyn.

Yes, I Accept Your Invitation To Join BCITS

The BC Association for Individualized Technology and Supports for People with Disabilities (BCITS)
Home of Provincial Respiratory Outreach Program (PROP) & Technology for Independent Living (TIL)

Name: _____

Address: _____

City/Prov: _____ Postal Code: _____

Telephone: _____ Email: _____



Please Check One

☐ **Membership for registered BCITS clients**

Please mail completed form to BCITS (the cost of postage constitutes your membership fee)

☐ **Non-client membership fee**

Please mail completed form along with \$20.00 annual membership fee payable to BCITS.

Please mail this form along with your membership fees to our new address (as of Aug.1/10): #103 - 366 East Kent Avenue South, Vancouver BC V5X 4N6

Bits & Pieces

Help us Make Balance Great

Your feedback on **BALANCE** or questions for our RTs or BioMed Technicians are all welcome. Contact us at info@bcits.org or at 1-866-326-1245.

Show and Tell

The annual BCITS show and Tell event will be held in September this year. We will notify you by mail, about the date, time and location. Hope to see you there!

You Can Support Us

Did you know that BCITS is a charitable organization and can accept donations toward the expansion of our services and equipment? If you would like to support us, you can contribute by sending a donation to: BCITS, 103-366 E. Kent Ave S., Vancouver, BC V5X 4N6. We will be pleased to send you a tax receipt. ●

Cleaning red rubber suction catheters

BY ANDRÉ G. FONTAINE RRT

During our travels around this beautiful province, we have the opportunity to witness the many different ways that you, our clients, use your equipment and supplies, and how you clean them.

Keeping ill people away, and proper and thorough cleaning of your equipment and supplies, are integral parts of staying healthy. This month we'll review how to clean and store reusable red rubber suction catheters. When properly cleaned and stored, these catheters pose little risk of infection and can easily be used for more than 6 months.

Supplies Needed

- Mild dish soap, unscented and without the antibacterial component
- 3% hydrogen peroxide (full strength)

Do not use water and vinegar because it is no longer classified as an disinfecting agent.

1. Suction.
2. Rinse the used catheter with water. If you do it immediately after the suctioning, cleaning later will be easier.
3. When you have enough used catheters in the "dirty" container, you can wash them using hot, soapy water.
4. Rinse the freshly washed suction catheters with tap water.

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Attach each catheter to suction to remove any remaining soap, if necessary.

5. Soak the catheters in a basin filled with 3% Hydrogen Peroxide (full strength) for 30 minutes.
6. Rinse all catheters in fresh, clean water.
7. Air-dry the catheters completely before using.
8. Store all suction catheters that have been cleaned and disinfected in a clean, dry container.

Although water can be used for cleaning, it should never be used to lubricate the suction catheter before suctioning or in between suctionings. Always use either sterile saline or homemade saline for this. Depending on how often suctioning is performed, it is not unusual to have 20 catheters in use at a time. This cleaning method may add several more steps than you use now, but it offers you the greatest protection from picking up a bug and getting sick.

Next month: BiPAP masks—strategies for leaks and pressure discomfort. ●