What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

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November 2011

#### **MEET OUR STAFF**

### Ella: A Bio-Med Dog

In our July 2011 BALANCE, we ran an article titled "Rumor Brings Independence to Langley Woman's Life." It was about Zosia Ettenberg's Service Dog, Rumor, from Pacific Assistance Dogs Society (PADS). Zosia is a long-time client of ours and a Board member of BCITS.

The article explained how PADS trains service dogs that help people with disabilities live more independent lives. While we were working on the article, a BCITS staff member was also in the process of applying for a Hearing Dog from PADS!

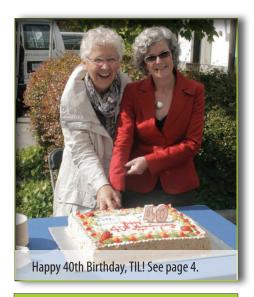


Roger Desmarais is a Bio-Medical Technologist who's been working for PROP and TIL since the summer of 2006. He and his twin brother were both born Deaf and communicate through American Sign Language. Roger is very involved with the Deaf Community at large and has been the President of BC Cultural Society of the Deaf for four years (www. bccsd.ca).

Roger went through the PADS application process and completed a training week with his Service Dog, Ella, in August. They passed their final exams together and are now finishing the probation period.

Ella is a two-and-a-half-year-old yellow Labrador. She was born in sunny California and selected by PADS, based on her eagerness to learn and perform tasks. She was raised for two years in Calgary, Alberta by a volunteer puppy raiser.

Ella helps Roger in the workplace by alerting him when Bipap and vent alarms are going off. Roger will no longer need to rely on co-workers to confirm if a unit's alarm is working. Roger really appreciates the increased independence Ella has granted him. And, we are all enjoying Ella's presence around the office. Our new Lab in the lab!



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## 2011 BCITS Client Satisfaction Survey

BY SEKA JOVANOVIC

Our 2011 Client Satisfaction Survey Report summarizes the responses gathered from the questionnaires sent to our clients in May 2011. It reveals very positive results!

The survey was completed by clients from all five Health Regions in BC. Over 940 clients received the survey and 253 responded.

A very high percentage of respondents gave us a rating of "good" or "satisfied" for:

- · access to BCITS services
- BCITS staff availability and understanding,
- services delivery, supplies and equipment, and
- ongoing education and support to ensure clients' comfort and independence.

However, clients' positive feedback does not mean our work is finished. One of the most important values we offer to our clients is a willingness to listen. The wide range of comments and suggestions clients gave us will be used to refine and improve our services. Our clients are telling us that there are areas of our services that need improvement and further attention. Here are answers to some client questions.

More information on what programs and services are available from BCITS BCITS is the home of two main programs:

- the Provincial Respiratory Outreach Program (PROP) which provides equipment and supports for people with disabilities who require home ventilation in BC.
- the Technology for Independent Living Program (TIL) which provides technology and supports for people with high level disabilities who require assistive environmental control systems in order to live independently in their homes.

### What does the client participation model mean to BCITS clients?

BCITS is committed to enabling people with severe disabilities, who need assistive technology, respira-

tory services and supports, to meet their needs while living in the community. We're guided by the people we serve all around the province and informed by the best knowledge and information possible from professionals and community organizations.

The participation model transforms service delivery by anchoring every component of the process to individual goals.

### Emergency planning with RTs or BioMeds

If you need help designing your emergency plan and putting it into effect, don't hesitate to contact us.

## More frequent visits or phone call follow-ups

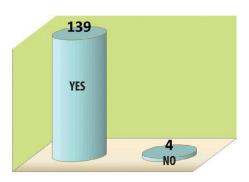
BCITS staff will make sure they follow up with clients on a consistent basis, especially with new clients after initial set up. This may be done via a phone call or a personal visit. If you need help, please call us.

## Enhance access to adaptive technology for computers

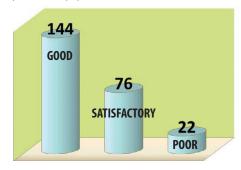
This is not a service BCITS provides, but we may be able to suggest programs that do offer this support. For example, you may be a potential candidate for the Equipment and Assistive Technology Initiative. For more information, call 1-877-333-7554 or email EATI@bcpsn.org.

We would like to extend a sincere thank you to all our clients who answered our survey questions. You have participated in an important part of our process and provided us with the vital information we need to serve you better.

Do you feel that BCITS employees are prepared to help you and understand your needs?



To what degree, do you feel that you have the necessary knowledge or information to manage your own equipment and care?



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### Ask the BioMed

Power Sources for the LegendAir Ventilator

BY ROGER DESMARAIS Because batteries are so critical to home ventilation, we would like to take the opportunity to educate our clients about ventilator battery operation.

There are three possible power sources that can power the Legend-Air ventilator and it will use them in the following order of preference:

- Power Outlets which provide AC (Alternate Circuit) power from our wall outlets.
- 2. External Batteries are battery sources outside the ventilator unit, such as the batteries of your power wheelchair or another type of portable battery source. Those batteries provide DC (Direct Circuit) power.
- **3. Internal Batteries,** particularly in the Legendair and PB560 ventilators, are used when the above power sources are not available. These also provide DC power.

PROP has performed wheelchair wiring for many of our clients and, as a result, many of our PROP clients are able to enjoy more freedom. As long as your wheelchair's batteries are in good condition, it can support both the power wheelchair and connected ventilator for many hours.

It is very important to understand that when using the wheelchair wiring set-up, your ventilator should be running using the wheelchair's batteries, instead of its own internal batteries! Make a habit to check this often, especially when you are going out.

The display screen shows which kind of power source is being used. When you see a bright green LED, like the picture below, indicating that "Direct Current" is active, this means the LegendAir is using DC power (as expected).



However, in the picture below, the display screen shows the internal battery is being used, instead of the wheelchair batteries.



You wouldn't want to visit a friend or be at an important meeting when your vent runs of power–and neither do we!

If you or your caregiver do not see the "Direct Current" green LED light, check your cable for any loose connections. If after checking the connections, the vent is still not being powered by the wheelchair batteries, please contact PROP. •

# MEET OUR CLIENTS Small Things, Big Changes

My name is Suzette Lewis and I have been living with Primary Progressive Multiple Sclerosis for sixteen years. My condition mostly affects my arms and legs, and I am now quadriplegic.

Earlier this year, I was introduced to BCITS. At first, a very quiet, sweet man named Jerzy came out and adapted my living space to enable me to function easier. I explained that I was not the tiniest bit technical and he told me that he would come back anytime I needed his assistance. And he kept his word!

Next, came a wonderful gentleman named Simon Cox. He said, "We can make your remote on your bed work better." And, he did.

Then, Simon said, "You need an automatic door." I said, "Is that possible? Do they exist?"

At the time, I didn't have the freedom to come and go independently. It could take an hour to get in and out of my door because of my non-functioning hands.

Then on a sunny, July day, BCITS installed my automatic door. It was life-changing! Now I spend my days coming and going, back and forth, back and forth through my automatic door. It takes my breath away!

Thank you so much for the generosity and kindness of the BCITS team!

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orty years is a long time for an assistive technology program to exist in British Columbia.

But, TIL has a proud history of providing technologies to people with disabilities to assist with independent living and we celebrated that history on September 17th at the new offices of the BC Association for Individualized Technology and Supports (BCITS).

In 1971, a woman in Richmond received the first environmental control system in Canada from TIL (then a program of the Kinsmen Foundation). She had severe rheumatoid arthritis, was unable to leave her home and was often left alone when her husband left for work for the day. With the environmental control system, she was able to make phone calls, unlock her door, operate lighting and watch TV.

Since that time, TIL has grown to over 500 clients throughout BC.



The birthday celebration was emceed by Mark Madrega, Global TV and CKNW meteorologist.

It was attended by many clients in the lower mainland area along with supporters from the community, the Deputy Mayor of Vancouver Kerry Jang and Michelle Coleman bringing birthday greetings from Minister Rich Coleman. The Colemans have always supported the program and marched door to door in the 80's to raise money for equipment for people with disabilities.

The celebration included an award to the Kinsmen Foundation of BC (accepted by John Meneghello, President of the Kinsmen Board) for their foresight in developing the program in the 1970's.

TIL presented the first BCITS alumni awards to three TIL clients who have contributed over many years to the community and the program.

The recipients of the awards were JoAnn Brekaas from Summerland, and Jeanette Andersen and Terry LeBlanc from the lower mainland.





## From Alumni Award Winner Jeanette Andersen

I lived at George Pearson Centre until 1992. Around 1975, the Kinsmen Foundation and Simon Cox gave the residents with TVs an adapted device that allowed us to turn our TV on/off and change channels.

At that time, this was very innovative—a little bit of independence!

In 1975, I got a job working with the Provincial Consumer and Corporate Affairs Department monitoring the media for deceptive and misleading advertising. I was writing by holding a pen in my mouth and my job required that I be very accurate. I called Simon Cox at TIL and asked him if there was a device I could use

Thanks to everyone who helped to make this a very Happy Birthday for us!



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to record and play back deceptive ads at my leisure and with greater accuracy. Simon came up with a device that I was able to operate with one finger and two very sensitive switches. I was able to work for over ten years because of that device.

Eventually, I was able to do 70 different functions with my one usable finger and these two switches.

When I'm in my motorized wheel-chair, I use a "sip and puff" switch which is equally amazing. I'm able to open my apartment door and the outside doors of my Co-op, access the elevator and select a floor, open and close the blinds, and do all the functions on my TV, Stereo, CD player and computer. Besides giving me a great deal of independence, it also means that I don't have to call on my caregivers to do these things for me.

TIL has also enabled me to use my cell phone with a "sip and puff" switch. I can chat easily with friends and family, and have a back-up phone in case of an emergency. Because I'm vented 24-7, I feel safer knowing I can contact someone if my chair gets stuck or my ventilator acts up.

TIL has made, and continues to make, a very positive difference in my life. •



#### **DEAR FRIENDS:**

Through the work you do and the services you've developed, you are empowering people through technology.

Whether you're helping people who cannot speak to communicate with others, or equipping people with physical disabilities with special tools for their homes, you are making a real difference in people's lives every day.

Thank you and congratulations to all of you on this milestone.

SINCERELY,
THE HONOURABLE
HARRY BLOY



### You Can Support Us!

id 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. Thank you!

NAME

**ADDRESS** 

CITY

PROVINCE AND POSTAL CODE

PHONE

**EMAIL** 

Please return this form to: BCITS, #103-366 E. Kent Ave S.,

Vancouver, BC V5X 4N6

We will be pleased to send you a tax receipt for donations of \$10 or more.

Thank you for your support!

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### The Importance of Membership

BY CHRISTINE GORDON When you first connected with PROP or TIL you received a letter inviting you to become a member, by returning a signed copy of the letter by mail to BCITS. Some of you returned this letter and became a member, but many more PROP and TIL clients did not.

Perhaps you forgot or did not have a postage stamp handy or put the letter at the bottom of your to do pile, where it slipped into obscurity.

Whatever the individual circumstances that led you to not becoming a member, I urge you to consider how important membership is to BCITS.

 As a non-profit charitable society, BCITS is governed by its members. If you are not a member, you cannot participate at Annual General Meetings, be nominated

for the Board of Directors or elect the members of the Board. This is equivalent to not voting in a general election! Good governance is always dependent upon full participation. Just like your citizenship responsibility, you have a responsibility to make BCITS a democratic, effective organization. If you are not a member, you can't fulfill this responsibility.

- BCITS was developed as a consumer-driven organization because consumers like you told us they wanted PROP and TIL to be person-centered in all of the supports and services we offer. If the people who use PROP and TIL do not become members, then we run the risk of losing that vision.
- When BCITS applies for grants to finance its work-our programs and services that support you-po-

Members are vitally important to our organization. You can play an important role in BCITS by becoming a member.

tential funders look at the number of members as one important piece of evidence that BCITS is a member-driven, democratic organization. If funders do not see a good roster of members, they may not provide the funding we need meet the needs of our clients.

Members are vitally important to our organization. You can play an important role in BCITS just by becoming a member.

If you have not become a member yet, please do so today. Just clip and mail the membership form at the bottom of this page. Thank you! •

### Yes, I Accept Your Invitation To Join BCITS

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





Memb	ership	for re	aistere	d BCITS

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 any applicable membership fees to BCITS - The Home Of PROP and TIL, #103-366 E. Kent Ave S., Vancouver, BC V5X 4N6

Telephone: Email:

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#### **Coming Soon to our Website!**

It was unanimous among staff and clients that BCITS needed to have more information readily available for our growing client group, to help troubleshoot some basic issues that may arise within the home.

With our goal of helping our clients to live as independently as possible in the community, we have created a series of instructional videos.

These videos feature our very own RRTs Elaina Zebroff and Miranda Whiteley and will soon be available on our website <a href="www.bcits.org">www.bcits.org</a>.

The videos cover the following topics:

- What is a Bi-level?
- How to Fit your Bi-level Mask
- How to Fit your Nasal Mask and Pillows
- Cleaning Bi-level Parts
- Lung Volume Recruitment Manoeuvre or Cough Assist
- Trach Care and Cleaning the Inner Cannula
- Cleaning your Ventilator Circuit
- Cleaning the Red Rubber Suction Catheters



We hope that you find these videos easy to follow, educational, and easy to access.

If you have an idea for a future video that you feel would help the majority of our clients, please let us know.

### Are you backed up?

BY ELAINA ZEBROFF Please help PROP provide better service to you. As many of our clients are aware, and for those who are unaware, PROP cannot provide equipment or supplies after hours, weekends or holidays.

Because your respiratory equipment and supplies are important and may be essential to your health, PROP strongly suggests that clients have back up supplies on hand at all times.

All of our clients have different and unique respiratory needs, so the back up supplies you need will be different from other clients.

If you are a client using a bi-level unit, do you have a spare hose and a spare nasal or face mask to use if your current mask or hose break after hours, on a weekend or on a holiday?

If you are a client who requires a ventilator, do you have a spare circuit, trach tube and ambu bag?

If you have suction machines in your home, do you have spare suction supplies such as suction canisters,



PROP strongly suggests that clients have back up supplies on hand at all times.

lids, suction tubing and suction catheters?

We cannot stress enough how important these back up supplies can be. Because our clients have individual needs, we rely on you to inform us when you require supplies. They will be delivered to you in a timely manner.

Please do not hesitate to call if you have questions or concerns regarding the back up supplies you should have.

With the holiday season fast approaching PROP is asking you: "Are you backed up?" •

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### Keep In Touch!

We want your opinions– really! Your feedback and ideas, things you would like to see on these pages, questions for our RTs or BioMed Technicians or other staff–are all welcome.

Our goal is to make BALANCE as relevant to you as we possibly can, so please keep in touch at <a href="mailto:info@bcits.org">info@bcits.org</a> or by calling 1-866-326-1245.

Please send us your upto-date email address.
We'd like to use email
as much as possible to keep you
on top of news, equipment bulletins and other updates between
BALANCE editions.



### Vent user TIPS

BY JEANETTE ANDERSEN

- Check the ventilator pressure every time you hook up to the vent.
- Check the circuit from the vent user to the vent to make sure all the connections are tight.
- Have 2 ambu bags: one to keep on your chair, and one to leave in your bedroom.
- Always keep the ambu bag in your bedroom, in the same place—and visible—in case of an emergency.
- Check for leaks in the circuit by running your hands very slowly along the flex hose and the plastic tubing. When the air is being pushed through the circuit, this is when you will feel air escaping through a crack or puncture hole somewhere in the circuit.
- Carry a roll of duct tape with you. It is an excellent temporary fix, if there is a crack in the vent circuit or any thing else on your wheelchair (scooter, walker) that might need to be held together until you get home.

## balance

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