

# balance

What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

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## Making the Transition from the At-Home program to Adult Service by Jo Dunaway

Jennifer Gudewill was seated in a large lift-assisted chair at Motion Specialities while waiting for her wheelchair to get some fine-tuning. She has had the chair since July and they were still getting some bugs out. Jennifer is almost 19 years old and there have been a lot of wheelchair changes and adjustments throughout her childhood.

Jennifer was 18 months old, living in Saudi Arabia with her father who was working as a consultant, when it became apparent that something was not right. Chronic Relapsing Demyelinating Polyneuropathy is rare, especially in children, so diagnosis is difficult. It is also a degenerative disease: as a baby, Jennifer walked with the aid of a walker, but over the years her mobility deteriorated with each illness and infection.

Before 1999 she operated her wheelchair with a joystick and used the trackball on her computer. But in 1999, when a health crisis kept her in Children's Hospital for six months, she lost the use of her hands and arms, and her ability to breathe on her own and to swallow. She now uses a ventilator and is tube fed.

While we wait for her wheelchair, we look through Jennifer's art portfolio. She uses graphic design software to

create pictures ranging from vibrant splashes of bright colour to meticulously drawn details of sunflowers and tree leaves. This year a picture designed as a surprise Christmas gift for her parents launched a series of art cards which Jennifer now sells at her school and church. She donates part of the proceeds to her youth group at Peace Portal Alliance Church and part to the Food Bank. She plans to enrol in an entrepreneur course to enhance her marketing skills.

Jennifer's chair is wheeled into the room and she is lifted into it. When her computer is remounted, she brings up her communication keyboard on the screen so we can talk.

A head mouse on top of the computer picks up signals from a silver reflective dot on Jennifer's forehead that she "points" to select letters or short frequently-used words and phrases and then clicks on by lifting her right shoulder. Another "clicker" mounted on her left shoulder controls her wheelchair.

She spells out what her computer means to her: "Freedom." She can do schoolwork, communicate with family, chat with friends, create art, work on her blog, and surf the web. She changes to the basic keyboard




that she uses for email and updating her blog, and then opens her Corel design program and quickly sketches a row of mountains and

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 Email and web links in the PDF version of *BALANCE* are live. You can click on them to email the person or visit websites.

## balance

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Making the Transition, continued from page 1

dresses their tops with snow. A hill in the foreground sprouts some green trees. Her latest acquisition is a digital camera which will mount on the top of her computer so that she can take photographs.

Jennifer will be graduating from high school next year and at a time when her future should be opening up into a larger world, paradoxically the assistance so essential to both her daily living and her ability to make plans is diminishing.

Until she was 18, Jennifer's equipment needs and nursing support were met by the At-Home program through Children's Hospital. However, this funding is now being phased out and will be gone when she turns 19 this year.

### Jennifer's mother Felicia is worried about the reduction in support funding that will happen when Jennifer becomes 19.

During this transitional year, she has begun working with PROP and TIL. PROP assists her with her ventilation needs—she uses a particular ventilator with an alarm that she can trigger with her chin if she needs assistance—and TIL is involved in equipment adaptations and environmental controls. For example, Jennifer can control her home TV, DVD/VCR, radio and lights. She also has a special bed, manufactured in Abbotsford, that rotates her 15 degrees every half-hour to help with breathing and prevent bedsores, as well as a lift and sling so that she can be moved by one person.

Jennifer's mother Felicia is worried about the reduction in support funding that will happen when

Jennifer becomes 19. "There will be much less funding for care support, so there will be a big drop in quality. We've had a mixture of RNs and LPNs and, because Jen is complicated with a trach and a vent, there is special training involved. Now, we've been told the support will be composed of a lot more non-nurse caregivers. This is a big concern."

Another concern is the news that CAYA (Communication Assistance for Youth and Adults) will no longer be funded by the Ministry of Housing and Social Development. The program provides specialized support services and assistive technology for adults with severe communication disabilities and was created as a project of SET-BC (Special Education Technology British Columbia) which provides support services for K to 12 students.

"It's upsetting," says Felicia, "that just when the needs of these young people increase as they leave high school and try to prepare to make their way in the world all the assistance disappears."

Jennifer does have plans for the future which include college-level courses. And she intends to continue her art, and to explore writing. A recent trip to California and an Alaskan Cruise have whetted her appetite for travel. She is hoping to join her church's young adult group on a trip to San Francisco in the Spring. For these adventures, she transfers her ventilator and computer to a lighter-weight manual chair.

But first she is going to the Olympics! Jennifer is a big fan of figure skating and her family won tickets in the lottery for both the pairs and the ice dance. Jennifer will be there cheering on her favourites. ●

## TIL Survey Results

BY WAYNE POGUE  
BIOMEDICAL TECHNOLOGIST

Well, we've received your feedback from our 2009 annual TIL survey and, although you've told us we are doing a fairly good job, we understand there are some things we need to work on.

We have a great appreciation for your needs and wants, so we'll be taking the feedback from 107 of your responses and working on improving TIL.

Some of your more widespread suggestions included the following topics.

We received a few suggestions to increase our presence throughout the province by having technicians in the interior and on the island. We don't have the capacity to add more techs at the moment, but we do make frequent trips to the island, interior and the north. If you would like to be added to our "trip list," please let us know.

Many of you would like us to become more involved in computer access supports. It has never been within our mandate to provide these supports, but we know how important they are. One of the members of the Personal Supports Network (see the article on page 4) is the Neil Squire Society. They are experts in this area and have assisted people with computer access needs for many years. We recommend you contact them.

Some of you would like more access to troubleshooting manuals



for equipment, since we cannot always do on-site visits to people's homes faster than a couple of days. We are currently trying to include a manual for each piece of equipment that we set up with you.

If we didn't give you a manual during your set up, if you've misplaced your manuals or if you need help troubleshooting your device, please call us at 604-326-0175. We can either help you through the troubleshooting process or mail/email you a manual for your devices.

Our future plans (when time permits) also include having some troubleshooting guides/manuals/videos on our website so that you have access to them 24/7.

Again, we really appreciate your feedback to our annual TIL survey and will be working diligently to address some of your TIL concerns. If you have any questions, comments or suggestions about future TIL surveys, please don't hesitate to contact us.



Suppose you want to charge up a number of electronic devices at once, like your cell phone, iPod and your camera.

Most of us have to charge them up one at a time or have a tangle of wires and chargers to keep all our gadgets ready to go.

There is a neat new gadget called a Power Mat. You can charge up to three devices by simply placing them on the mat, without plugging them in separately into their own chargers.

I haven't been able to check one out yet personally, but they are sold at London Drugs and other electronics stores. The Mat itself is around \$100 and you may need other options to get it to work for you and that may cost you more.

You can see a video guided tour at [www.powermat.com](http://www.powermat.com). Please let us know what you think of the Mat if you purchase one. ●





# BC Personal Supports Network

## Equipment and Assistive Technology Initiative

Do you have a disability and are looking for work or for volunteering opportunities? And, do you need some kind of assistive devices to realize this goal? You may be eligible for a new program that will provide equipment and training.

**The BC Personal Supports Network** (PSN) consists of a number of groups and organizations, across the province, who have come together to improve access to personal supports, beginning with equipment and assistive devices.

The Network uses the **Participation Model for Personal Supports** as their operating framework. The Participation Model is a person-centered, functional approach which begins with a person's goals and offers assistance with navigating all of the stages of acquiring and using personal supports in order to reach this goal.

For example, if you are looking for an assistive device that may help you with the tasks you need to accomplish, the way things usually work is: you will contact an organization and they will tell you the equipment they have. The Participation Model, and the Personal Supports Network, starts with your goal of being employed and then finds out who has the equipment and how to help you get it. If the PSN cannot find the supports for you, it will register that as an unmet need. This will help us to understand the programs or supports that we need to develop in the future to serve people with disabilities in BC.

In partnership with the Ministry of Housing and Social Development, the BC Personal Supports Network is responsible for delivering a brand new project called the **Equipment and Assistive Technology Initiative (EATI)**.

EATI provides a source of funding for assessment, trialing, acquisition and/or training with equipment and assistive devices for people with disabilities who have employment or volunteerism goals. This funding has been provided to the province through the federal/provincial Labour Market Agreement which transferred funds to British Columbia in order to increase the participation in the workforce, enhance the quality of skills development and training, facilitate workforce mobility, and provide the information necessary to make informed labour market choices.

The PSN is looking for people to be part of EATI. In order to be eligible for EATI funding, you must be:

- A person with a disability who has an employment or volunteer goal
- 18 years of age or older
- A BC Resident

- Unemployed or employed with low skills (for example, low English literacy, incomplete high school) and looking to upgrade
- Ineligible for Employment Insurance (EI)
- Have not received an EI benefit in the past 3 years
- Have not received an EI maternity or parental benefit in the past 5 years
- Able to demonstrate a need for Assistive Technology
- Unable to access funding through other programs
- Part-time students who are available for work may be eligible for EATI. Also, older citizens available for work or volunteering (i.e., those over 65) are eligible.

## How to apply for EATI

If you are a person with a disability and you think that you might be eligible for EATI funding, there are two ways that you can proceed:

**1** Connect with one of the BC Provincial Personal Supports Network member organizations listed in this article and they will help to navigate you through the EATI process.

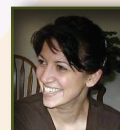
**2** If there is no PSN member organization available to you, then contact the BC Personal Supports Network's EATI navigators below and one of them will help you to navigate the EATI process.



### Meet Our Super Navigators!

They are based in different locations around the province.

Super Navigators Josh Vander Vies (left) and Vicki Kwong, and Network Coordinator Paul Gauthier (right)



Super Navigator  
Wendy Cox



Super Navigator  
Albert Ruel

## PSN Network Members

Western Institute for the Deaf and  
Hard of Hearing  
<http://www.widhh.com/>  
Voice: (604) 736-7391  
TTY (TDD): (604) 736-2527  
Fax: (604) 736-4381

BC Coalition of People with  
Disabilities  
<http://www.bccpd.bc.ca/>  
Voice: 604-872-1278  
TTY: 604-875-8835  
Fax: 604-875-9227

Neil Squire Society  
<http://www.neilsquire.ca/>  
Voice: 604-473-9363  
Fax: 604-473-9364

Richmond Centre for Disability  
<http://www.rcdrichmond.org/>  
Voice: 604-232-2404  
TTY: 604-232-2479  
Fax: 604-232-2415

Prince George Personal Supports  
Centre  
Voice: 250 563-2008  
Fax: 250 563-2058  
Victoria Personal Supports Centre  
<http://www.drcvictoria.com/>  
Voice: 250-595-0044 ext. 100

British Columbia Association for  
Individualized Technology  
and Supports  
<http://www.bcits.org/>  
Voice: 604-326-0175  
Fax: 604-326-0176

The Seeing Causus  
(for those with vision loss)  
Linda Bartram (Chair)  
[lindabartram@telus.net](mailto:lindabartram@telus.net)  
Voice: 250-498-2434

## Contact a Super Navigator

Toll free hotline: 877-333-7554  
Fax: 604-326-0176  
Email: [EATI@bcits.org](mailto:EATI@bcits.org)  
Postal mail: EATI  
9007 Shaughnessy St.  
Vancouver, BC  
V6P 6R9 ●

# Recycle your cell phones

Donate your old cell phone handset to help our environment and raise funds for the Children's Medical Equipment Recycling and Loan Service.



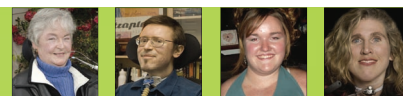
CONTACT: PATRICIA BARRETT

TEL: 604-709-6685

1-800-565-8000



## 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 any applicable membership fees to BCITS - The Home Of PROP and TIL, 9007 Shaughnessy Street, Vancouver BC V6P 6R9.



## PROP Survey Results BY GILLIAN HARNEY RRT

We would like to thank all of you that responded to our PROP client satisfaction survey. Here are some of your overall concerns and what we can do to address them.

### Challenge

Power outages seem to be a recurring concern for quite a few of you, especially the clients that use a bilevel unit that does not have a battery back up.

### Solution

For those of you that do not have any external battery back up for your unit, please call us and our biomedics will be able to help you find the type of battery back up unit most appropriate for your equipment (the length of time that it will run your equipment and the compatible voltage/wattage).

We will look at doing an article on this in a future *BALANCE* edition.

### Challenge

You want updates on new equipment, more information on use of equipment, cleaning procedures and care of your equipment, as well as troubleshooting of equipment

### Solution

PROP is going to create video clips to show you how to care for and clean your equipment. We'll also have videos of our trach/vent training course that will be available any time you want to review them. This is going to take some time, but will be started this year and we'll keep you updated in *BALANCE*.

We'll write other articles for *BALANCE* about new equipment or supplies as the PROP team reviews them.



### Challenge

More Registered Respiratory Therapist (RRT) visits or phone calls on a consistent basis, as well as prompt follow up when assistance is requested. Distance from RT's is an issue in some locations.

### Solution

The PROP RT's are going to make sure that they follow up with their clients on a consistent basis, especially for a new client after the initial set up. This may be done with a phone call or a visit.

We'll contact all of our clients to make sure they are comfortable with their equipment and address any questions or problems they may have in a timely manner.

Once again, thank you to all of you that participated in this survey and we urge you to call us if you have any questions, concerns or need a visit from the PROP RT's. ●

You can contact the PROP Respiratory Therapists by calling 1-866-326-1245.

## Anthony Chan

### Receives Alumni Award for Excellence in Teaching and Research

For over 15 years, BCITS Board Member Anthony Chan has been teaching generations of BC's Biomedical Engineering Technologists. In that time, he has also continued to innovate and advance the state of practice. Through collaboration with other health programs, Anthony is able to provide his students with a well-rounded approach to health engineering education. He is held in high regard by his peers for his extensive involvement in professional activities and his original research.

In the last 5 years, Anthony has also published two textbooks on medical device technology. He received recognition for his irreplaceable contribution to the industry when he was awarded the Outstanding Canadian Biomedical Engineer Award in 2007 from the Canadian Medical and Biological Engineering Society.

Anthony's students say he is very thorough, providing them with real-world examples that teach them to use critical thinking and deepen their understanding.



## Bits & Pieces

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 [info@bcits.org](mailto:info@bcits.org) or by calling 1-866-326-1245.

### Your email address

Please send us your up to 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. ●

## My Experience with Setting Up Day-time Ventilation

**BY LUKE MELCHIOR** In the summer of 2005, I received a Legendair™ ventilator from PROP. This amazingly portable machine not only boasts an 11-hour internal battery (long enough so that I don't have to wire it into my wheelchair battery), but it also weighs less than 10 pounds and fits into a convenient backpack that attaches to my wheelchair.

The Legendair came at a time when I had been using my night-time ventilator (ResMed's VPAP®III ST) for an additional four hours during the day while I was in my wheelchair. The VPAP needed to be plugged into a wall outlet in order for it to operate and this greatly impeded my mobility.

Another drawback of using my nighttime ventilator during the day was having to wear a nasal interface. The interface irritated my skin and also made it awkward for me to talk on the phone, see my computer screen and eat without aspirating.

Needless to say, when my Legendair arrived, I was determined to find a better interface to use with it. Luckily for me, my respiratory technician heeded my wish and set me up with an angled mouthpiece for mouthpiece ventilation. While this system managed to solve the issues I described earlier, the bracket used to hold the mouthpiece in front of my mouth created its own set of challenges. The bracket, which clamped onto the side of my wheelchair, was bulky and difficult to adjust. Because it was attached to my wheelchair, I would only be able to use the Legendair when I was sitting in the wheelchair.

Despite its limitations, that particular bracket was the only mouthpiece



interface the technician could offer me at the time. I was not happy with this state of affairs so I decided to invent a new bracket. With the help of a different technician, I created a chestplate fitted with Snap-Loc bendable tubing to hold my ventilator hose and mouthpiece in place. Now the mouthpiece and hose are attached to me instead of to my wheelchair, and the hose could be easily readjusted with little to no effort.

The incredible battery life and light weight of the Legendair combined with a chestplate interface and mouthpiece allowed me to achieve complete portability for my daytime ventilation. Now I can breathe with ease whenever I have to travel by airplane or in a manual wheelchair. ●

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