

What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

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Meet David Thomas

BY JO DUNAWAY "I've always liked computers," says David Thomas. Even before the Internet and email were ubiquitous, David, a high school student in Port Alberni, set up and ran a Bulletin Board for three years.

His interest in the capability of computers for gathering and sharing information, as well as for creative applications, continued after he moved to Vancouver in search of independence, and more education and employment opportunities.

"There wasn't much future for me in Port Alberni and I wanted to live on my own. So I came to Vancouver," says David. "What I really wanted to get into was computer animation, but the course was \$15,000 a year! And there wasn't any government help available, so that was out."

In 2007, with the help of a grant, David took a one-year course at Vancouver City College and earned an Information Technology Specialist Certificate. His practicum was with Uniserve, an Internet service provider. He worked as a quality assurance tester on the company's award-winning Kinzin.com, a social networking site that created a private by-invitation-only social network for families and close friends.

When several former Kinzin staff started a new company named

Ayogo, David was hired on. Ayogo is a company that develops casual games that span social networks and mobile platforms to help companies engage with their customers in fun ways. David works a five-day week for Ayogo–"more if we have a project going"–out of his bright, airy apartment with a view of Coal Harbour.

"I'm doing quality assurance and software development. It's interesting work. I really got lucky where I did my practicum!

"I'm doing quality assurance and software development. It's interesting work. I really got lucky where I did my practicum! Usually people from my course end up doing tech support for customers somewhere like Shaw or Telus. It was just luck that I went to Uniserve where I turned out to be a good fit for what was happening right then."

David has Spinal Muscular Atrophy which severely limits the use of his hands, so TIL has set up environmental controls for the door, lights, TV, stereo, telephone and other items in

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his apartment. The computers and other technology he uses in his work have also been adapted for him.

As busy as he is, David is looking ahead. He wants to take a three-year software development program at the UBC Robson Square campus.

"It's in the evenings so I can fit it in," says David."I applied, but there weren't enough people enrolled so the course was cancelled. I'm hoping it will get rescheduled."

David also has a few projects of his own on the go. He wants to create a website to help people with disabilities do research about adaptive devices.

Also in the plans is a website for designing websites (David has a Webpage Design Certificate from VCC) and an ambitious project to develop content management software that could be customized to gather information on a continuous basis according to the needs of each individual client.

Peer Show and Tell

It's hard to believe a whole year has passed since we last got together for Peer's annual Show and Tell. This popular event provides a wonderful opportunity for clients, caregivers, family and friends to hear about the latest in ventilator technology and to chat and swap stories.

A Respiratory Therapist and Biomedical Engineer will be on hand to demonstrate new equipment and answer your questions. After the Show and Tell, a delicious light supper will be served in the garden.

2009 Show and Tell

Wednesday, September 2, 2:00 PM George Pearson Centre 780 West 57th Ave. (Lots of free accessible parking) Room number to be confirmed



Please RSVP at 1-866-326-1245 or email at info@bcits.org

Our Program

E BUN

Opening remarks by Simon Cox

RT & Bio-Med presentations: The latest respiratory news

A talk by Karen Martin on Emergency Preparedness for People with Disabilities

TIL: Feel free to ask questions, raise concerns and make suggestions

Door prizes and supper (catered by Pacific Café)

We hope to see you there!

Welcome Sebastian!

Some clients have been asking about the latest addition to the BCITS family so I thought I would take a few moments out of my new life as

"mom" to introduce you to my new little one. Sebastian Oscar Bengert Lundgren (yup, it is a mouthful) was born on December 15th, 2008. The past few months have been a whirlwind of diapers and baby clothes, but Sebastian is all the things you would expect him to be: happy, healthy, beautiful and exhausting. At TIL, I've designed some pretty cool things, but Sebastian is easily the best thing I've ever made. It is a pleasure to watch him figure out the world. ~ Joanne Bengert



Wayne's World

Wayne Pogue • BioMedical Technologist

Q&A Ask the BioMed

Why is my GEWA remote blinking and alarming every 30 seconds, even when I'm not using it?

This is one way of telling that your GEWA is running low on batteries. Another indicator of low batteries is that the GEWA doesn't control any, or some, of the devices that have been programmed into it.

Changing the batteries is a simple procedure that doesn't need to be done by a TIL technician. All you need is 4 AAA batteries and a phillips screwdriver.

To change the batteries, unscrew the Phillips screw(s) in the back of the device, remove the battery cover, replace the batteries and reinstall the battery cover. Now all you need to do is press the program button (inset button) on the GEWA with a toothpick to bring your program back. If you have a red & black GEWA, the program button is found in a small-round hole on the right side of the device. If you have a silver & black GEWA, the button can be found in a small-round hole in the very center at the bottom end of the device (right beside your switch input).

Your Gewa is now ready to use!

Does TIL do cellphone access? If so, do you recommend any specific cellphone?

Absolutely! TIL recognizes the importance of portable communication, especially for our clients. TIL offers adapted Bluetooth (wireless) headsets that can be accessed with any type of switch.

We don't recommend any specific cellphones, but the cellphone **must** have voice dialing and Bluetooth capabilities.

Once you have bought a cellphone, TIL will setup the Bluetooth headset, mount a switch, teach you how to access your phone and show you how to use voice dialing.

Testing 1, 2, 3...

Because of the nature of our services, making sure equipment functions properly upon arrival in our clients' homes is of utmost importance. Unfortunately, we cannot always personally deliver equipment and make sure it is setup and working properly. That's where we need your help. By following three easy steps, you can ensure that your new equipment is working before you send the old equipment back to BCITS. And, you'll also be sure your new equipment will work when you really need it! Here are three steps to testing new equipment:

1 Unpack new equipment and make sure you have all instructions, manuals and accessories, such as power cords.

2 Setup new equipment and match it's settings to your old equipment's settings. **3** Try the new equipment; make sure it works properly!

If there are missing accessories or you need help setting up call:

For PROP equipment: 1-866-326-1245.

For TIL equipment: 604-326-0175.

If the new equipment was sent to you by BCITS to replace equipment in need of service, it is very important that you return the old equipment promptly–even if it starts working again. The prompt return of old equipment is very important for two reasons: first, there may be an intermittent problem that can be very dangerous if not checked and, second, we may have another client that would benefit from the equipment once it is serviced.

Returning equipment to BCITS is as simple as receiving and testing your new equipment:

1 Make sure you include all accessories, such as power cords, so that once it is serviced the unit can go directly to another client without waiting for new accessories to be ordered.

2 Use the box and packing materials in which the new equipment arrived to pack the equipment that needs to be returned.

3 Follow the instructions, supplied with the new equipment, to return your old equipment to BCITS.

If you have any questions regarding shipping and receiving of BCITS equipment, please call us at TIL: 604-326-0175 or PROP 1-866-326-1245.

balance

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Barcelona Conference

by Gillian Harney



I'd like to update our clients on a conference I just attended in Barcelona, Spain. This conference, on home ventilation, is held every 4 years in Europe. Some of you may recall that the last one was held in Lyon, France.

There were speakers from all over Europe and North America, and some very interesting topics were discussed from new methods of ventilation (either invasive or noninvasive), to updates in technology of equipment and supplies, to telemedicine and how to better communicate with our clients.

As usual, Europe has the advantage of having newer ventilators and bilevel units that we do not have access to here.

However, there is a light at the end of the tunnel if we can find a distributor willing to obtain some of these units and have them approved by Health Canada for use here at home.

On the positive side, it was clear that we have a wonderful health care system compared to some of the European/North American countries where there is no funding, or very limited funding, for ventilators/bilevels or associated supplies.

These countries also do not have anything that even resembles PROP and TIL for their clients that require invasive or non- invasive ventilation and assistive devices.

Although Barcelona is a beautiful city, I am always happy to return to Canada and all of you, and it makes me appreciate the benefits that we have in this great country.

Gillian Harney is a Registered Respiratory Therapist with PROP.

On the Web

The Client Cafe is a new gathering place we've created on our website. We'd like the Cafe to be a place where you can:



- read a story about one of our clients or information from a Peer. We find these stories interesting and inspiring and we hope you will too.
- share or seek information. You can send a question using a simple on-line form to one of our Peers who will be glad to help. You can ask about your equipment or about our services. Or, if you have a helpful tip on equipment you'd like to share with others, we'd love you to send it in and we'll post it on the site.

Drop into the Client Cafe at <u>www.</u> <u>bcits/clientcafe.htm</u>.

BIPAPs and CO₂ levels

BY VALERIE SHAVER RRT, CAE, ANDRE FONTAINE, RRT

The term "BiPAP" means "two" (Bi) "pressures" (inspiratory and expiratory). The BiPAP is a step up from the CPAP machine which gives one continuous pressure.

BiPAP is used for more complex medical conditions, i.e. restrictive lung disorders, cardiac conditions, neuromuscular diseases and complex sleep disorders (obstructive and central apneas). With these conditions, a person either has difficulty taking deep breaths or stops breathing while sleeping. When this happens, not only does oxygen not get to your lungs, carbon dioxide (CO₂), or your waste gas, is not expelled. The build up of carbon dioxide can be very dangerous and can significantly impact your health.

Signs and symptoms of increased CO_2 levels are:

- Headaches upon awakening in the morning. They usually subside within a few hours because when we sit or stand our gravity increases our lung volume. Also we breathe deeper when we're awake and get rid of the CO₂ much faster.
- Changes in cognition: inability to concentrate, poor memory, confusion, not as "sharp" as usual.
- Shortness of breath while lying down.
- Increased blood pressure. High CO₂ levels in the blood make the blood more acidic which constricts blood vessels, which in turn increases blood pressure. Left untreated, this can also lead to heart failure.

Normally our bodies get rid of this excess CO₂ by either breathing faster or deeper. With different diseases, this process can become very difficult and you may need help. This is why we use the BiPAP machines.

The BiPAP machine assists your regular breathing. The two pressuresyour inspiratory and expiratory settings-assist your regular breaths and make your breathing much easier. Your PROP Registered Respiratory Therapist (RRT) will work with you to help select the proper settings to meet your body's needs and make your breathing comfortable and easy. The inspiratory setting helps you inhale and the expiratory setting makes sure you have enough pressure left in your lungs to maintain optimal oxygen levels. The larger the gap between the inspiratory and expiratory pressures, the larger the "breath" you receive. This mimics your body's natural mechanism for deep breathing. The BiPAP does not breathe for you. You initiate a breath and the BiPAP supplements your breathing. In the case of apneas, the BiPAP can be set to give you the missed breath, so you have no side effects from apnea.

The best way to think of a BiPAP is that it's helping your breathing, to make it easier for you and to conserve your energy for other tasks.



New Touch Screen Remote Control

If you want to control the world, this may be your first step. At least, this new Logitech 1100 Harmony remote control can control all of your TV and DVD functions within the same remote. All of the functions can be programmed onto the touch screen for easy access. It is capable of operating up to 200,000 devices.

One of the drawbacks is that it may require two hands to operate. I am not certain what that means until our TIL department can get our "hands" on one. We will test it for mouth-stick use and ability to customize.

The cost is also high for a remote control: around \$500.00

But if a remote control can be considered beautiful, then this one is!

Check out other Logitech remotes and other wild things at <u>www.log-</u> <u>itech.com</u>.



Bits & Pieces



We Do it Your Way

Technology is always changing and, at TIL, our approach is to customize equipment specifically for what you need. So we recommend that you tell us what it is that you are having difficulties with and we will work on a solution tailored to your needs. We take pride in finding creative, new ideas that will solve your particular issues.



Ventilator and Trach Training course

Some of you may be aware that PROP offers Ventilator and Trach Training courses. The courses are usually held on the first Monday and Tuesday of the month, from 9:00am to 5:00pm.

You need to register for the course and we take participants on a first come, first served basis. We limit the class to 10 students to allow everyone time for hands-on training.

There is no cost for the class for our clients, their family members and their care workers. Classes outside of the Lower Mainland are arranged upon request. Please contact us if you have any questions at 1-866-326-1245.



Staff update

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We would like to welcome Valerie Shaver, a Respiratory Therapist. Valerie joined BCITS in April 2009 and we are looking forward to working with her.

Yes, I Accept Your Invitation To Join

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

ddress:			
ity/Prov.			

Telephone:

Name:

Postal Code: _____

____ 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.

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Smooth Sailing

By Jo Dunaway It's late April and very soon Terry LeBlanc will be in one of his favourite places–alone in a 16-foot sailboat off Spanish Banks. Terry is a high paraplegic, but he says, "It's a level playing field out on the water." A life-long sailor, he has no problem maneuvering his craft with power-assisted steering (sip to starboard; puff to port) and often races against able-bodied sailors.

For Terry, and other sailors with a disability, sailing is made possible through the Disabled Sailing Association of BC, a creation of Sam Sullivan, which operates out of the Jericho Sailing Centre.

Terry was injured in 1978, diving into shallow water while on vacation in the Okanagan. He was only 24 and, after six months at the GF Strong Rehabilitation Centre, where he benefited from counseling from people like Norman Haw of the BC Paraplegic Association, he knew he didn't want to continue institutional living and moved into a group home. The Kinsmen Rehabilitation Foundation, a forerunner of BCITS, made environmental adaptations that allowed Terry to be as independent as possible in his home.

"Simon Cox set it up for me," says Terry. "Back then, Simon was out working in the field and I was one of the early recipients of the environmental controls that let me do things for myself, like answer the phone and the door, and operate the TV and radio. I remember we were talking about adapting a typewriter, so that was awhile back!" The controls have been updated many times since and expanded to an ever-growing array of technology.

In the years following his injury, Terry tried to return to his career in surveying. "By the time I had my accident, I wasn't working out in the field any more. I was doing computations from the data gathered in the field. With the use of computer technology, it wouldn't matter if I was in a wheelchair. But I couldn't find a survey company that would hire me. For a while, I taught drafting software at BCIT."

After a four-year stay in Toronto, ("No ocean. No work. And very poor services and accessibility for people with disabilities."), Terry returned to the Maritimes where he grew up. He worked as a stockbroker in Bridgewater, Nova Scotia, and acted as general contractor for the home he and his wife had built. The twostorey revolutionary house used solar power and was completely wheelchair accessible. One of Terry's favourite accessibility features was the ability to roll into the second storey by way of the berm that surrounded and insulated the back of the house.

When his marriage ended, Terry returned to Vancouver and, after a number of moves, settled in the co-op in southeast Vancouver where he presently lives independently. He has three visits a day from a home support worker who he hires through the CSIL program (Choice in Supports for Independent Living).



A life-long sailor, he has no problem maneuvering his craft with power-assisted steering (sip to starboard; puff to port) and often races against able-bodied sailors.

There is a woeful shortage of wheelchair-accessible suites like his, says Terry. "Housing is a huge issue for people with disabilities! Accessible housing is so limited that people are being forced back into Pearson Hospital because they can't find a place to live."

In addition to his involvement with his co-op, Terry also volunteers with the BC Paraplegic Association's Peer Program and serves on the Association's board of directors. He is also a member of DIGA (the Disabled Independent Gardeners Association), an organization that works to remove physical barriers for gardeners with disabilities. He helps find accessible gardening spaces in local community gardens and puts on seminars and garden talks."I like growing my own salads," says Terry."And it's an enjoyable way to spend time outdoors."

Opinions

We want your opinionsreally! 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 or by calling 1-866-326-1245.

Emergency Preparedness

The BC Coalition of People with Disabilities is continuing its work on emergency preparedness and people with disabilities. Please visit their website for the latest on these projects and resources at www. bccpd.bc.ca, under Projects.



New Cleaning Standards for Supplies

Vancouver Coastal Health recently issued new Reprocessing Standards for cleaning equipment and supplies, such as suction tubing, catheters, ventilator circuit parts, masks, suction collection bottles, humidifier chambers and hoses.

Please visit our website to see all of the new guidelines for proper care of your equipment.

Visit www.bcits.org, under PROP.

UBC Students Help with PROP On Call Service

A student project competition, designed to improve the technical support the PROP On Call service provides to our clients, was completed in April of this year. The students developed a variety of methods to improve the service, from colour coding the ventilator connectors, to the use of video phones to connect with our clients. The results look very promising and some will be implemented to increase the responsiveness of the service.

Anthony Chan, Biomedical Engineering Director from BCIT and Mike Van der Loos, Professor of Mechanical Engineering organized five teams of students through their UBC Biomedical Engineering course.

Mark Nah and Cindy Wang came in first for their presentation and Roza Bidshahri, Bernard Coguinco and Jie Yu were second. All presentations presented creative solutions to enhancing On Call Support and we thank them for their efforts.



BCITS Executive Director, Simon Cox, worked with students and reviewed their ideas to improve our On Call Service.