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## IN THIS EDITION,

Donna Gibbings writes about her recent trip to California. It's a great article and we hope more of you will write and tell us about what you've been up to. Or, perhaps you have a question or a User Tip? Let us know, we'd love to hear from you.

## Roadtrippin' With Your Vent

by Donna Gibbings

When I decided to undergo my tracheotomy and go on a ventilator, it was like getting a new lease on life. No longer did I have to struggle for every breath and feel constrained by the limited capabilities of my own lungs.

While there is so much more open to me, there are some areas that can seem off limits because of my new mechanical companion. Suctioning, physiotherapy, basic care and maintenance add so many more daily rituals and complications that many activities simply seem too daunting.

For me, travelling was something that seemed impossible. There was a further complication. In addition to being on a vent, I'm unable to sit in any other wheelchair than my own. This makes the prospect of air travel a little mind boggling. I was almost ready to resolve myself to the fact that I was stuck in one place forever!

Almost. During an especially dreary Vancouver winter, I'd had enough. I announced to anyone who would listen that I was going to California in the spring, even if I had to wheel down the I-5 by myself. Luckily, I didn't have to do anything that drastic. My cousin and her family live in southern California and offered to let us stay with them, eliminating the



Donna, her brother Neil (right) and Colorado Avalanche Joe Sakic.

expense of hotels and making an affordable trip a reality.

After investigating the challenges of flying with a motorized wheelchair and ventilator, my Mom and I decided that we would drive the 2,118 kilometres to Newport Beach with the help of a close friend. My trip south made me somewhat of an expert on travelling with a vent. In the interests of promoting a better, more enriching lifestyle for ventilator users, here are some helpful tips on roadtrippin with a vent.

### 1. Planning: The Key to Avoiding Trouble

We did a fair amount of planning before we hit the highway. I learned that the most important thing was packing supplies. Know exactly how many days you'll be away and how many catheters, saline instillers, dressing trays, etc. you will need, plus extras in case of emergencies. Place all supplies in clear plastic containers to

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**Stock the van with candy and new tunes on the iPod. These are as crucial as travel insurance when your driver gets lost in the wilds of Oregon.**



*Donna and friend Brenna at Disneyland*

keep everything sorted, portable and accessible.

### **2. Double Up on the Equipment**

Take two vents, two suction machines, and extra parts for the in-line humidifier. In case of any technical mishaps, you always need a back-up.

### **3. Dress for Success**

Clothes are equally important: take an outfit for every occasion! Well, okay, maybe that's just me.

### **4. Cover the Legalities**

Before leaving, get a letter from the good people at PROP, identifying your vents and suction machines. This will come in handy in preventing customs officers from ripping through your stuff for drugs or diamonds. Also, buy extended traveller's insurance.

### **5. Be Familiar with Your Destinations' Medical Supply Stores**

You may need a lift while you're there. Rent one and have it delivered to your destination before you get there. This will prevent you from having to spend your visit in the carport. It's easy to check for any medical supply stores at your final destination before you leave that will rent any equipment you may need.

Finally, it's time to leave. Stock the van with candy and new tunes on the iPod. These are as crucial as travel insurance when your driver gets lost in the wilds of Oregon. All the fun is getting there!

We sailed through the border and drove a total of 24 hours in three and-a-half days, complication free! Along the way, we stayed at the Holiday Inn Express, each time checking in with no reservation. Of course, it's best to ask for disability designated

rooms and it's good to know where you're stopping for the night so you can make reservations. The staff was exceedingly accommodating and everything was 100% accessible. Even the parking spaces were ideal, with specially marked spots for vans with side-loading lifts.

I was very impressed by the special consideration I saw everywhere—even in the smallest towns—for wheelchair users. People were very friendly. I was even given a stuffed pig in Corning, California, by the fine people of the Butte Community Bank!

Once in California at my family's home, it was a dream vacation. We settled into a new routine with no complications. We had successfully avoided any travelling pitfalls because of our careful planning. We went shopping, attended four Stanley Cup play-off games, hung out at the beach, did Disneyland and a studio tour. Some Disneyland rides are accessible for motorized chairs (and vents!): a great surprise and treat. All of it was fantastic and very accommodating for me, my equipment and entourage.

After a side trip to Las Vegas, we headed home. This time, we had a stop at the border, but only because I had spent too much money (Oops!).

It was a great trip, not only because of all the things I got to do and the time I spent with my family, but because now I know I can travel. The world isn't shut off from me any more and the feeling you get when you are out there experiencing life is indescribable.

With some planning, a little help and lots of determination you can go anywhere. I'm already planning another expedition for next spring! □

MEET THE STAFF

# Kirsty Dickinson

As BCITS's Manager of Client Services, Kirsty is an invaluable member of the PROP/TIL team. In fact, we couldn't do without her. She oversees client intake and work order distribution. This means she knows exactly who needs what, when and where it has to go. She prioritizes requests and makes sure everyone gets what they need, when they need it.

As often happens, Kirsty came to work at BCITS through happenstance. "I trained as a physiotherapist, but left work to raise my children. I did a course at VCC on non-profit management and was volunteering for the City of Vancouver Accessible Dwellings project when I met Simon Cox about 9 years ago. I wanted to get back into the workforce and asked Simon if he knew of any openings. The next thing I knew I was working for TIL at the Kinsmen office at Oak and Broadway."

TIL, Kirsty and Simon have moved a few times since then. "We moved to Boundary and East 1<sup>st</sup> with the Kinsmen and then to the BC

Paralegic Association which gave us a great opportunity to build up our services. PROP joined us and we moved to where we are now on Shaughnessy Street."

Kirsty's job has changed over the years from the days when it was just her and Simon working together. At one time, she used to do shipping and receiving and pretty much everything else. "We now have 4 office staff, 4 biomedes and 2 RTs. But I still like to jump in and do things, it's what makes the job so interesting."

Kirsty is excited about working for BCITS and sees it as a great opportunity to move forward. The creation of the new association is a big move, but it's important to remember that small things are important too. Kirsty relates a story about when Simon designed a device that enabled a man with ALS to operate his TV. His wife phoned to say that this small modification had made a world of difference to her husband. "You don't have to make a big difference to make a big difference," Kirsty says. □



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# all about us

PROP is funded by the Ministry of Health through Vancouver Coastal Health.

**We need  
your help!**

We have a very long list of clients waiting to have an overnight oximetry test. You can help us shorten everybody's waiting time by performing your test as soon as you receive the oximeter and returning it promptly to PROP.

Thank you for helping us to serve you better.

#### EVENTS

## PROP Show and Tell

*On July 21<sup>st</sup> PROP clients, family members and staff gathered for the annual PROP Show and Tell at the George Pearson Centre. Participants heard about the latest equipment and shared their ideas and experiences.*

Daniel LeBlanc talked about the Diaphragm Pacing System he had implanted earlier this year in Cleveland, USA. The surgery was a great success, "it has changed my life," said Dan. "I'm super healthy now because of it." Dan said the first thing he noticed was that he could smell. "I have not used a ventilator since March, before that I was using my ventilator 24 hours a day."

Dan explained that there have been 27 implants done in North America. His was number 19. The first implants were for people with spinal cord injuries, but they are now being provided to people with other conditions, including ALS. Dan used a ventilator for 18 months before his implant: the procedure may not work as well for people who have used a ventilator for longer. Implants are only available in the United States; however, Dan said there are tentative plans underway for a Vancouver site for the procedure.

**Daniel LeBlanc talked about the Diaphragm Pacing System he had implanted earlier this year in Cleveland, USA.**

After the Show and Tell, participants adjourned to the beautiful gardens for dinner. The weather was beautiful and we all enjoyed chatting and eating the wonderful food organized by Heather and Jeanette.

Thank you everyone who came. See you next year! □

### UserTips

Here are 2 User Tips by Bob Gordon for users of in-line suction catheters.

1. Once daily while the in-line is inactive, extend your catheter out of the shield, start the suction machine, and draw saline through the catheter to remove secretions stuck inside. It may be necessary to also remove secretions from the exterior of the catheter tip.
2. Pump the valve a few times after each use to clear secretions that may be stuck within the valve mechanism. □



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