

# balance

What it's all about.

BC Association for Individualized Technology and Supports for People with Disabilities

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## Dogs Put the Wow in Bow-Wow

People who depend on ventilators to help them breathe live with many daily challenges. But one family has found a solution for their daughters that is bringing peace of mind to Mom and Dad, and much-needed freedom to the girls.

**BY DEBBIE BUNCH** In many ways, Kristen and Annalies Kocourek are just like other young women their age. The 16-and 21-year-old sisters like to hang out with friends, go to movies, shop—all the typical girl stuff.

The fact that they do it all while suffering from chronic breathing difficulties requiring intermittent, mechanical ventilation is remarkable enough, but the really remarkable thing about these two is who is at their sides every step of the way. Not a Respiratory Therapist (RT). Not even a nurse.

While therapists and nurses do, of course, figure into their care, Kristen and Annalies make their way through life with the able-bodied assistance of a golden retriever/lab mix named Brooklyn and a golden retriever called Stitches.

"They are unbelievable," say the girls, who live in a suburb of Chicago with their parents and brother Joshua. "They make life so much better and allow us to do things with our friends that we could not begin to consider doing before."

The service dog first came into the Kocoureks' lives several years ago when Kristen, who suffered from a rare medical condition called congenital central hypoventilation syndrome (CCHS), received Brooklyn to assist with her care. CCHS is a disorder of the central nervous system in which the autonomic control of breathing is absent or impaired. Kristen was diagnosed with CCHS at the age of three and placed on nocturnal ventilatory support. By the time she was in kindergarten, she was among the minority of patients who experience breathing problems during the day as well.

Sister Annalies appeared relatively healthy until puberty, but then she too began suffering from somewhat similar breathing problems while she was sleeping. However, CCHS was ruled out in her case. Further testing eventually led doctors to diagnose both girls with mitochondrial cytopathy or mitochondrial encephalomyopathy—an even rarer, multi-organ condition resulting in everything from muscle spasms,



Annalies praises Stitches for a job well done.

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### DOGS PUT THE WOW IN BOW-WOW, CONTINUED FROM PREVIOUS PAGE

seizures, respiratory problems, and hearing loss to heart problems and periodic lapses in the ability to communicate.

By the time Kristen was 12, it became clear to her parents, Tom and Joanne Kocourek, that their daughter needed something more than the dedicated care of family and home care providers to effectively meet all her needs.

"I wondered if a service dog could be trained to assist, but I wasn't sure," says Kocourek. She discussed the idea with Kristen's physician, who agreed it might work, but knew of no organization training dogs to handle Kristen's needs.

About this time [Kocourek heard about] East Coast Assistance Dogs (ECAD). She contacted ECAD and the gears were soon set in motion to train Brooklyn to meet Kristen's needs. That was in 2002.

Two years later, Annalies' condition began to worsen and Stitches became a member of the family as well.

All ECAD service dogs, says Kocourek, go through comprehensive standard service dog training. In Kristen's and Annalies' case, however, Brooklyn and Stitches also learned how to respond to the specific alarms on their medical equipment, a task facilitated by Lisa Gorsky, CRT, senior respiratory

Gorsky says the dogs react well to the apnea alarms, stimulating the girls to wake them up or, if that fails, finding an adult and summoning them to the girls' sides.

care practitioner at Walgreens Home Care.

When Kocourek approached Gorsky about the service dog idea, she made a tape of all the equipment alarms which Kocourek gave the dog trainers to use in training Brooklyn (and later Stitches) to respond.

Gorsky says the dogs react well to the apnea alarms, stimulating the girls to wake them up or, if that fails, finding an adult and summoning them to the girls' sides. Kocourek says the dogs do a great job, each responding to the girls' alarms in

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Kirsten (left), puts Brooklyn through her paces as Lisa Gorsky, CRT, looks on.



unique ways suited to each situation. Since Kristen was in a Port-a-lung, and could not self-correct an alarm situation, Brooklyn was taught to “get help” if one of the alarms sounded and to “speak” if given a specific hand signal.

Because Annalies could self-correct a problem, Stitches was taught to first place a paw on her chest in the event of an alarm. If that doesn’t awaken her, then he paws and licks her face, doing so persistently until the alarm is turned off and she rewards him with a treat or pat. If Annalies fails to respond in an appropriate amount of time, the dog will sense danger and find Kocourek or another adult.

“The dogs are with the girls everywhere they go,” says Gorsky, who notes Brooklyn was a big hit in her offices when Kristen was ready for a new ventilator. “Joanne, the girls and the nurses came into our Tinley Park branch for training on the LTV 950 ventilator. Kristen had her dog with her. The dog was very well behaved and listened to the commands... (they) seem to be very capable of meeting the needs of the girls, and from what I have heard from the nurses and Joanne, do an excellent

**Since the service dogs came into the girls’ lives, both have gained confidence in their ability to function without parents or caregivers constantly at their sides.**

job responding to the alarms and alerting the family and girls of the alarms.”

She also believes—as do the girls’ parents—that Brooklyn and Stitches are improving the girls’ quality of life. “They seem to provide a great companionship to the girls and the family. The girls seem to have a tight bond with their dogs and are quite happy and smitten with the animals.”

Since the service dogs came into the girls’ lives, both have gained confidence in their ability to function without parents or caregivers constantly at their sides.

Stitches, for example, helps stabilize Annalies’ gait, which is often compromised due to ataxia, and serves as a brace when she stumbles and needs to get back up. Brooklyn keeps a watchful eye on Kristen’s breathing and, whenever it becomes too shallow, she will bump her to remind her to breathe normally.

The girls credit the dogs with allowing them to “do things that are normal for people our ages,” such as a recent Disney cruise where they were able to leave the ship without a parent in tow, visit the spa alone and “fully participate in any activity we desired.”

And the girls look at their service dog with youthful eyes. “Did you know that a well-behaved happy serviced dog is a guy magnet?” they ask. “They love the dogs.” ●

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I really don’t pay much attention to Bluetooth headsets, but this model has something different to offer.

Incidentally, Bluetooth, for those of you who want to be technically correct, is the wireless exchange of data between devices. The name comes from a Viking king by the name of Harald. Apparently, he loved blueberries so much, his teeth were stained. I also found out that the term for people that use Bluetooth headsets is “bluetool.” (Just a little humour).

Now, back to the VoicePRO 901 headset. What does it have to offer that other headsets do not have?

The answer is “voice separation technology” for those that wish to use their phones in crowded rooms. Another feature is its ability to charge in a few hours.

You can get the headset at Amazon.com for around \$50. ●







Roger Desmarais

## Light Emitting Diodes

When the power goes out, it's nice to have a little light at the end of the tunnel. This device gives you that light in your closets, cabinets and hallways as well.

The SE Wireless Motion Sensor Light-10 Super-Bright LED is easy to install and is battery powered. It's great for power outages and is activated by motion and infrared (body) heat.

The customer reviews are good and these LEDs are under \$10 at Amazon.com.



## Lung Volume Recruitment Maneuvers

By ELAINA ZEBROFF, RRT



Lung Volume Recruitment Maneuvers (LVRM) or Breath Stacking is a method to increase lung volume. This technique increases inspiratory lung volumes by stacking one breath on top of another without exhaling in between breaths. This maneuver can be done using a mouthpiece, face mask or by attaching to a cuffless trach tube. Do not perform this maneuver if you have a cuffed trach tube.

### Why

LVRM can help to improve chest movement, prevent and clear secretions from collecting in your lungs, improve your cough and prevent areas of the lung from collapsing.

### When

Usually LVRM are best performed 2-4 times a day, but can be used as needed. Each treatment is best described as 3-5 breaths and a short rest, repeated 2-3 more times. It is best to perform LVRM in the morning, before meals and before bedtime.

### What

The Lung Volume Recruitment bag is a modified resuscitation bag with a one-way valve inline. It is used to deliver air into your lungs beyond what you can achieve on your own. It is important to note that this bag **is not used for resuscitation** or for an emergency. If this bag is used for resuscitation, it can damage your lungs.

### How

1. Place nose clips on your nose, take a breath in and place your lips around the mouthpiece forming a tight seal (or attach to your trach tube).
2. Gently squeeze the bag or have your helper squeeze the bag while you breathe in. Maintain that tight seal around the mouthpiece.
3. Squeeze the bag 2-4 more times or until your lungs are full. You may feel a stretch in your lungs.
4. Remove the mouthpiece from your mouth (or detach from the trach tube) and exhale.
5. Repeat the above steps 1-3 more times.

### Helpful Hints

Communication and a tight seal around the mouthpiece or face mask are both key to this treatment. If the timing of the breath stacking is proving to be difficult, say so. If you are assisting with the breaths with the LVRM, speak aloud. For example, say "small breath in, another breath in, one more small breath and hold" or "1, 2, 3 breathe in, 1, 2, 3, breathe in and 1, 2, 3 breathe in and hold."

This will give the client time to prepare for the breath stacking and they will then be able to better guide you if you are applying the breaths too slow or too fast. If air is escaping, check that the nose clips are on and for possible leaks around the mouthpiece, mask or trach. ●

# A Trip to Cuba: To Go or Not to Go?

**BY PAUL GAUTHIER** I recently returned from a family trip to Cuba safe and sound, despite internet warnings that I should stay home due to the complete inaccessibility of the country.

I worked through a travel agent to ensure that I would have what I needed when I arrived. She spent a lot of time with the Air Canada Vacations contact to get as many guarantees of accessibility as possible: they did guarantee a roll in shower, but would not guarantee an accessible vehicle from the airport to the hotel. In short, I went into the trip knowing that I was taking a number of risks and that I would have to be prepared for the worst!

My fears were compounded when I saw my power chair on its side going around the luggage belt! I have travelled to many places in the world and I have to say this was a first.

Entering Cuba and feeling the wonderful, hot weather, I was reminded of why we chose to take this trip, and was prepared for whatever would come next. We were escorted to our van by the Air Canada Vacations contact and then... the driver opened the back to reveal a ramp! My fears were alleviated as I drove my chair right into the van and the driver applied the appropriate straps. So, we were able to make other van-friendly plans during our stay.

The rest of our trip was wonderful and all of my accessibility fears were

put at ease. The hotel did have a spacious room with a roll in shower and I learned that most resorts do because it's now the law for new buildings to have accessible features. People in Cuba are wonderful and will do whatever you need to ensure a comfortable and enjoyable stay. For me, this meant an extra mattress on the bed to make it higher and a few lifts on the beach so I could enjoy the waves from a lounge chair with my family.

We were able to use the accessible van and hire a tour guide for day trips. The guide was very good at realizing where I would be able to go and what I would be able to see. The popular flea market was accessible and had a separate wheelchair washroom.

I would definitely recommend this trip and am so glad that I took the chance! If you decide to give Cuba a try, make sure you request the accessible van from the Transgaviota company. Air Canada Vacations will not guarantee it in case it breaks down and is not available. But the van has a manual ramp, so I think it's a pretty safe bet. It doesn't hurt to call the resort that you choose directly to ensure that it has what you need when you arrive. Our details were all arranged correctly by the travel agent and Air Canada Vacations. If you need some sun, and who doesn't at this time of year, and you enjoy learning about a different way of life head to Cuba. Don't listen to those who say there is no accessibility! ●

**We were able to use the accessible van and hire a tour guide for day trips. The guide was very good at realizing where I would be able to go and what I would be able to see.**



From left to right: foster son Derek, Paul, Sarah and baby Matteo

## Lightwriter Maintenance and Troubleshooting

BY SAMIKO GUEST, BMET The Lightwriter is a portable text-to-speech device for clients with speech impairment. It is a very rugged and reliable communication aid device, if it is maintained properly.

In this article, we'd like to give some maintenance and troubleshooting tips.

Lightwriters come in different model types. However its basic maintenance and upkeep are essentially the same (except for the SL40).



Model SL 25, SL 35, SL 38



Model SL 40

### Maintenance

#### Charging the internal battery

Plug the Lightwriter into a wall outlet and let it charge up every night after use. This will prevent unexpected behaviour when the battery level is low.

#### Conditioning the internal battery

When you notice your Lightwriter doesn't last as long as it used to, you may want to try "conditioning the battery" to improve battery capacity. Conditioning a battery means a cycle of complete discharge and fully recharging the battery.

**Step 1:** Plug the Lightwriter into a wall outlet over night to charge it fully.

**Step 2:** Before starting the discharging process, turn off "speech volume" to mute the Lightwriter.

**Step 3:** Press MEM, MEM, MEM then T. You will see a streaming of "stuff,stuff,stuff,stuff,..." in the screen. If a battery is in good condition, this may last more than 4 hours. The Lightwriter will automatically turn itself off when its battery is discharged completely. Before its does this, there will be a warning sound.

**Step 4:** After the discharging process, plug the Lightwriter into a wall outlet for full charge over night.

#### Cleaning

If you spill food or drink on the Lightwriter, you can use cloth moistened with hot water and cleaning detergent to wipe off the affected area. Please be careful not to let any fluid inside of the machine.

### Troubleshooting

Here are some of the most frequent problems with Lightwriters. If you experience any of these issues, you can try the listed actions to correct it.

#### Lightwriter won't start

You can try "resetting" the Lightwriter. Plug it into a wall outlet with the AC adaptor. Make sure the green indicator light is on. Leave it for a few minutes. Then, press and hold the OFF button for 18 seconds and then release. After a few seconds, resetting will start automatically. The battery level may be low, so you should leave the Lightwriter plugged in over night. If the Lightwriter is charged up regularly and still the problem exists, the battery or AC adaptor may need to be replaced. Please contact TIL.

#### Lightwriter freezes or won't respond

This may be a computer glitch. Press OFF and then ON to start up again. If it doesn't start up, try resetting the Lightwriter as outlined above.

#### Lightwriter works strangely (e.g. won't speak or keys delayed)

Your user settings may be changed. If possible, check your user set ups. Or call TIL and we can help you to check the user set ups over the phone. You can also try "resetting."

#### Lightwriter doesn't last as long as it used to

The battery may be getting old. You can condition the battery, as we mentioned earlier. If this doesn't improve, please call TIL for a battery replacement. ●





## Ask the BioMed BY ROGER DESMARAIS, BMET

Once in a while, bi-level units are sent back to PROP with triggering issues. Clients or caregivers will say that the bi-level isn't detecting the client's breathing and fails to deliver the desired airway pressure.

The triggering function is used when your bi-level unit is set up in ST (Spontaneous/Timed) mode which requires the unit to detect your breathing pattern and respond accordingly. In ST mode, when the unit is unable to detect your breathing pattern, it will default to the Timed mode.

When the unit is set to CPAP (Continuous Positive Airway Pressure) or T (Timed), the triggering function is not used. The bi-level will not re-

spond to your breathing pattern and instead it will continue delivering air at the predetermined respiratory rate.

Once in a while, we have found that the units have been accidentally put into CPAP or T mode when the client should be set up with the ST (Spontaneous/Timed) mode. So the bi-level units do not detect the client's breathing pattern for the triggering function, resulting in respiratory therapy that is not suited to the client's needs.

Keep in mind how your unit is supposed to behave and, when something feels wrong, check to make sure your unit is still in the correct mode! If you're not sure what mode your unit should be in, please don't hesitate to contact us. And, it's a good idea to keep a record of your settings! ●

## City of Vancouver Accessibility Website

The City of Vancouver has added a page to its website with specific information related to accessibility and the City. It covers a wide range of information on transportation (public transit, road closures, ramps, audible street signals, tourism and recreation).

In addition, the site includes seasonal alerts and updates, such as information about snow and ice removal during the winter.

The City welcomes your comments and suggestions on the site. Please contact the City's Equal Employment Opportunity program, at: [equal.employmentopportunity@vancouver.ca](mailto:equal.employmentopportunity@vancouver.ca) or 604-873-7785.

[vancouver.ca/accessibility](http://vancouver.ca/accessibility) ●

## 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)

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

# Legendair Users: Three Things You Should Know

BY WAYNE POGUE, BMET

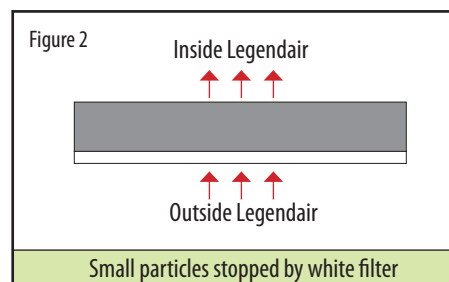
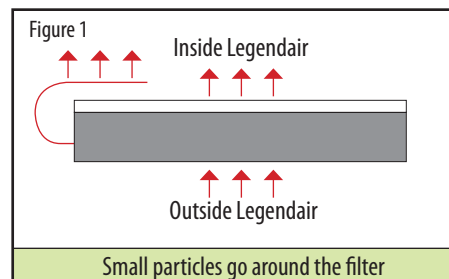
## Legendair Filter Placement

**1** The inlet filter (the black and white filter located in the back of the Legendair ventilator) serves an extremely important purpose: it filters out impurities in the air traveling through the ventilator.

Recently, our Biomedical Engineering department ran some tests and discovered that placing the Legendair air inlet filter white-side-out will remove more air impurities from the air being expelled for ventilation. Although these air impurities are not dangerous, we do recommend that you now place your filters white-side-out to ensure the cleanest air possible.

In Figure 1, the small air impurities are able to travel through the coarse filter (black side) and circumvent the fine filter making it useless.

In Figure 2, with the fine filter facing outward (white-side-out), the smaller air impurities are blocked by the filter, allowing only cleaner air through for therapy.



## Importance of Flat Filters

**3** For Legendair air inlet filters to be effective, they must be installed flat inside the Legendair, like in Image 1, to the right.

If the filter is not installed flat, like Image 2, the air will move around the filter into the Legendair.

If you would like a Biomedical Engineering Tech to visit you and install a louder alarm, or if you would like more information on filter placement, please contact us at PROP. ●

## Louder Alarms Available

**2** We know that the original Legendair alarm is not loud enough in many cases for caregivers, or even sleeping clients, to hear it.

So, we have a stock of loud alarm boards that can easily be installed in your ventilator by your PROP biomedical engineering tech.

From our past experience, most clients like the loud alarm on their bedside Legendair, but on their wheelchair Legendair the alarm is too loud for public places.

However, before you call to request a loud alarm be installed in your Legendair, please watch the video at the following website to see if the louder alarm is for you.

<http://www.bcits.org/legendairalarm.htm>

