



balance

... what it's all about

IN THIS ISSUE



**I needed a hand and
found four paws**

• 5 •



Let's play!

• 6 •



A life of traveling

• 9 •

PROP and TIL will be there to support you

By Christine Gordon

The world has changed over the last few weeks and Technology for Living is responding:

- ▶ We know that our services are essential to our members' ability to remain safe and secure in their homes
- ▶ We know that you, your family and your caregivers are anxious about the future
- ▶ We understand that in this time of global uncertainty, you need to be certain about something.

I want to reassure you that PROP and TIL will be there to support you, however long the pandemic lasts. The equipment, technology and supplies that you need are well stocked. Our staff of respiratory therapists and bio-medical technicians are working and will be available to you when you need them.

Here are some of the things that we are doing to be nimble and safe in these unpredictable times:

- ▶ We are meeting by telephone and video conference as often as possible
- ▶ During our home visits, all staff will wear personal protective equipment like masks and gloves and will continue to employ zealous hand hygiene

- ▶ We will maintain safe social spaces when we are teaching people on ventilator courses
- ▶ We will be available by phone to all of our members, every day during business hours and 24/7 for PROP users
- ▶ Discharge planning will go on so that people can safely move from hospital to home.

Here is what we will need you to do:

- ▶ Be patient if our phone lines are busy
- ▶ Only order the supplies that you need, knowing that we have enough supplies to weather a very long run of uncertainty

Don't make yourself afraid by over-estimating the risk. PROP and TIL members are used to risk. We all respect the fact that, although COVID-19 is a new risk, it is a manageable one and we will manage it.

The world has changed but your goal to be safe and secure in your home has not changed. Technology for Living will be with you every step of the way.



Christine Gordon serves as the chair of the board at Technology for Living.



PROP Team during times of COVID-19

BALANCE NEWSLETTER IS PUBLISHED QUARTERLY BY TECHNOLOGY FOR LIVING

📍 #103-366 East Kent Ave. South
Vancouver, BC V5X 4N6

☎ 604.326.0175 📠 604.326.0176

✉ info@technologyforliving.org
🌐 technologyforliving.org

EXECUTIVE DIRECTOR
Ruth Marzetti

ART DIRECTOR / EDITOR
Britt Permien

CONTRIBUTING WRITERS
Omar Al-Azawi • Christine Gordon
Esther Khor • Nancy Lear
Wayne Pogue • Liz Sahlstrom

Technology for Living does not research, endorse or guarantee any of the products or services within the newsletter. We strongly recommend investigating products and companies before purchasing or using them.

Permission to reproduce: All Balance articles are copyrighted. Non-commercial reproduction is welcomed. For permission to reprint articles, either in part or in whole, please email info@technologyforliving.org

Technology for Living houses the Provincial Respiratory Outreach Program (PROP 1.866.326.1245) and the Technology for Independent Living Program (TIL 604.326.0175). PROP is funded by the Province of British Columbia Ministry of Health through Vancouver Coastal Health. TIL is funded by the Province of British Columbia Ministry of Health and other independent funders.

Publications Mail Agreement No. 41682526

© 2020 Technology for Living



During this time PROP have continued to offer the educational *Trach and Vent* courses. Lily, one of our respiratory therapists, is training care givers to provide trach care and to manage the ventilator safely. PROP's continues to deliver community education to support our members and their families for safe, hospital discharges. Education delivery will be provided while observing physical distancing to minimise transmission of community infections.



PROP services are being delivered during the pandemic across the province. Our staff take full precautions when entering your home. You will see our respiratory therapists and registered nurse donning and doffing their personal protective equipment (PPE). Please do not be alarmed if you see members of the PROP team in gowns, gloves, masks and booties to maintain hygiene between visits. Your safety is our priority.



Our PROP respiratory therapists are using technology and video conferencing to stay in touch as they travel throughout the province providing services to people in need of support. Back home, the team members are taking all measures to remain in isolation or are practicing physical distancing to keep safe and healthy.

BITS & BYTES FROM TIL

*TIL will be showcasing their equipment, services and supports for people living with disabilities at the **Rehab Equipment Expo**. This annual Assistive Technology Showcase takes place Tuesday, September 15, 2020 at the **Richmond Olympic Oval**.*

The event attracts vendors, service providers and over 500 attendees, including therapists, clinicians, and consumers. This event is a great place to network and find assistive technology solutions. If that isn't enough of a reason to attend, come for the educational sessions! Bonus: food provided throughout the day!

Come and visit TIL's ever-evolving services at the REE at the ROO!

CONTACT US!

*We are always happy to discuss any member's needs. Simply phone us at ☎ **604.326.0175** or send an email to ✉ info@technologyforliving.org*

TIPS & TRICKS

We are creatures of habit so many people flip a wall switch to the off position when leaving a room. If a wall switch controlling a smart plug or bulb is switched off, the smart device can no longer communicate with your smart home hub, cutting off your voice control of the device. TIL has designed 3D printed covers that magnetically attach to your wall switch to prevent this from happening. Contact TIL if this is of interest.

TIL's Smart Technology Ecosystem

When we started supplying and setting up smart technology for TIL members back in April 2018, we began by investigating which smart speaker/ voice assistant we were going to utilize: Amazon Echo or Google Home. While we couldn't really go wrong with either, TIL chose Google Home as our platform. Unlike Amazon Echo, Google Home does not require 'enabling skills,' an extra step similar to downloading apps to increase functionality. Another benefit, of course, is native access to Google's massive search engine.

After we decided which voice assistant to use, our next task was sourcing devices that work with Google Assistant. We looked for a company that could provide all lighting options in one product: smart light switches, smart light plugs, and smart light bulbs. TP-Link Kasa ticked all those boxes without requiring a hub and it is all accessible via one app. It is also easy to set up.

The TP-Link Kasa and Google Home are the heart of TIL's Smart Ecosystem.

We have since expanded our collection to include other smart devices to allow greater independence for our members in their homes. Below is a list of those devices that we are currently able to install as part of the ever-expanding TIL Smart Ecosystem.

Thermostat

- ▶ **ECOBEE 3 Lite** – voice and app control of low-voltage heating systems (furnaces)
- ▶ **MYSA** – voice and app control of high-voltage heating systems (baseboard heaters)

TV Access

- ▶ **Google Chromecast** – voice control of streaming services (Netflix, Youtube, etc)
- ▶ **Harmony Hub** – voice and app control of TV, cable box (in many cases), DVD players, etc.

Doorbell

- ▶ **Google Nest Hello** – video and 2-way audio, but only through the app or a Google Nest Hub display

Door Lock

- ▶ **August Lock** – voice and app control of your existing door deadbolt

Blinds

- ▶ **Soma Blinds** – voice and app control of your blinds

Other

- ▶ **Switchbot** [see last Balance issue] – voice and app control of almost any button in your home (coffee maker, computer power, etc). The Switchbot also works great to turn on/off paddle light switches if you have no neutral wire in your light switches.
- ▶ **EWELINK Relay** – voice and app control of switch accessible devices, like door openers, intercom systems, etc.

If you use any independence improving smart devices, which may be of benefit to other TIL members please do share that information with us. We are always looking for ways to expand our smart home ecosystem, and in turn, expanding the solutions for independence in our members lives.

Dear Provincial Respiratory Outreach Program (PROP) members across BC

My name is Esther Khor. I am a respiratory therapist at PROP. In an average year PROP provides respiratory home visits to over 700 members across the province. During times of social distancing, our respiratory services have been adjusted to accommodate your needs. These adjustments are a crucial step in keeping the entire community healthier.

If you are on ventilation and uncomfortable with your settings, please call us directly. Many of our bilevel units are equipped with modems where your respiratory information is recorded for you to review. The hours of ventilation, breathing rate, breathing cycles are logged, so your respiratory therapy can be optimized. If you contact PROP during office hours, it often only takes 3-5 minutes to download your health information. Together we can look at the information and find a solution that may improve your breathing goals.

If you need to contact us during the weekend or late at night: PROP is still available. If you are getting uncomfortable during ventilation, you or your caregiver can call us to discuss your non-emergent breathing concerns with a respiratory therapist. Between 4:30PM and 8:30AM, the phone support wait time is often less than 30 minutes.

To support a higher volume of calls, PROP has increased the number of respiratory therapists available to answer your concerns. If a "face-to-face" discussion is preferred, this is not a problem. PROP support can be available "face-to-face" with Zoom or Facetime. A short education session can be scheduled too, to

support the development of your caregivers' skill sets. Accessing health services with technology is getting easier and quicker. Please email us for details and let's keep in touch!

Besides respiratory support, you will need supplies to remain independently at home. I want to assure you that PROP's equipment and supplies are in good shape. PROP is in regular communication with our manufacturers to ensure that your supply chain is flowing.

If you need supplies, you can order what you need for a 3-4 month period. Currently, it is quicker to obtain supplies by emailing a list with the inventory numbers.

Our experienced team is led by Rodel Mangahis. Your supplies and equipment will be shipped promptly. For the majority of our members living across BC, the shipping time is typically 3-4 business days.

Soon, we will conduct a survey to ensure that the quality of services meets your standards. If you have any suggestions or concerns, please email us and address

the email to our executive director, Ruth Marzetti or the, manager of PROP, Esther Khor.

In times of social distancing, PROP remains accessible to our members to support their respiratory needs. PROP is a community program and we are always here to support our community.

CONTACT US

If you need respiratory advice
☎ 1.866.326.1245

For supplies, email your list with correct inventory numbers to
✉ prop@technologyforliving.org

I needed a hand and found four paws

Two things happened late in life for Zosia Ettenberg: she started curling and she was introduced to the remarkable world of assistance dogs.

In 2008 she won the Courage to Come Back Award. Attending the ceremony in 2009, Zosia noticed a girl in a power wheelchair accompanied by an assistance dog. She was sold immediately, observing how helpful the dog was. She went home and researched 'PADS' (Pacific Assistance Dogs Society), the organisation that matches assistance dogs with people.

Zosia explains: "I submitted my application to PADS online and my case was assessed. The application evaluates the ability of a potential owner to command the dog and also considers the things you need a dog to do. I was accepted into the program. Wait times to receive an assistance dog are dependent on when a dog matching your personality is available. I was lucky: two weeks after I filed my application, a match was found: Rumour, a yellow lab. She was very intelligent, independent and as determined as I was."

"Having Rumour in my life changed everything including my social interactions with the world," Zosia continues. "People won't necessarily talk to a person in a wheelchair. But as soon a dog is there, everyone wants to talk to him. They start speaking to the dog, then their eyes travel up the leash, they notice my manicured nails and eventually they see *me* and then they talk to me. I have become a person."

Zosia's experience with Rumour was so overwhelmingly positive that when the dog retired it was clear she was going to get another assistance dog to maintain her independence.

"Without the dog, I struggled to get out of my front door because Rumour used to open it for me," explains Zosia. "Luckily I was aware of the Technology for Independent Living (TIL) door program and the technicians were able to install an automatic door opener within a month."

Rumour retired and went to a family with a child with muscular dystrophy. Rumour is still able to help the child retrieve objects and open doors while enjoying his retirement. Zosia wasn't quite as lucky: it took 8 months to get a new assistance dog.

Finally, she was paired with Vanstone. He was named in honour of one of the amazing vets that ensures the safe delivery and care for many PADS pups. Young dogs have to go through two intense training periods before they are able to assist people like Zosia. During the first 12-18 months of PADS training, the dogs are raised by volunteers in their homes. The volunteers take the dog everywhere and teach them over 30 obedience cues. Between 18-24 months the dogs return to the PADS campus to spend 6-12 months learning advanced, specialist skills like opening and closing doors, turning on lights, getting in and out of a car on command and more.



Zosia & Vanstone

Back at the curling rink, Vanstone has become the mascot of the team. He watches Zosia curling with a stick, an achievement that certainly didn't happen overnight. It took a year of training with a Paralympian before Zosia developed the strength to get the rock down the ice. On each trip to the rink, she is accompanied by Vanstone. Reflecting back on her life with wonder, Zosia concludes: "At 6 months of age I had polio and sport was never a part of my life. Now I have been curling for 7 years, starting at 69. I am an athlete for the first time in my life."

Check out PADS at www.pads.ca

Look for an in-depth article about PADS in the next Balance.



Omar's got you COVERED!

by Omar Al-azawi

Hey, did you miss me? If not, you were probably busy testing the romance tips I shared with you in the last issue of the Balance. It is time to show you I am much more than just another wheelin' Romeo. Grab your coffee & 3D- glasses and get ready for some 'nerd talk'!

I am going to bust stereotypes again. Have you heard this one: quadriplegics don't have the capacity to use a computer for the simplest things, how can they possibly do gaming? Plain and simple, people who say that are full of hot air. In this issue's column, I will present to you the top of the top controllers and joysticks you can find on the market today. Let me assure you: I personally owned and tested many of these beauties while searching for the 'holy grail' of adaptive devices to play the top games. These cool controllers are not just drop dead gorgeous, but they are also designed especially for paraplegics.

You see what I am doing, right? I am the guy that is saving you the headache of spending endless time online searching. I am immediately leading you to the winners (according to yours truly!). If you are into Super Mario Bros or Grand Theft Auto Omar's got you covered.

And without further ado: here they are. There are four devices I recommend from the bottom of my gaming heart to any quad who wants to take gaming to Iron Man tech level!

Lipsync

Ok I get it, not everyone is ready to jump immediately into big boy games like Doom. If you like more humble games or are looking to control your computer or cellphone in a very simple, straight forward fashion, let me introduce you to 'Lipsync'. This is a very slick, simple mouth joystick controller built by the *Neil Squire Society*.

Warning: don't eat spaghetti when using the 'Lipsync' since you operate it with simple mouth movements. You can connect the 'Lipsync' via USB to a desktop computer, laptop or even cell phone. The way you move the cursor around on your screen is by controlling the joystick up-and-down-right-left via tongue movement. The built-in sip-n-puff function can be used as a "left click" and "right click" function. This is no more and no less what folks do when using a mouse to control their electronic hardware by hand. So, who says you need a hand to use computer, eh?

The 'LipSync' is available through the *Neil Squire Society*. The price is variable and you may be eligible to get it for free.

QuadStick

Get ready to rob a bank to buy this bad boy because the price tag is indecent: \$500 -750. There are three different

models available, but we are going to talk about the champ: the QuadStick FPS.

The hefty price tag makes it the most expensive adaptive controller on our list. But as they say: you get what you pay for! It works on different consoles/platforms including PS3, PS4, XBOX & PC. This amazing mouth joystick features a hugely customizable sip-n-puff system.

It comes with so many channels and profiles to choose from, your head could spin if it wasn't so super easy to switch between them all.

It's basically like having multiple devices folded into one. And, let's not forget, it is also equipped with a chin button.

QuadStick is absolutely the 'Lamborghini' of gaming. With this baby you'll be able to play the big games like GTA, Battlefield, Call of Duty and more! No more lame excuses, my friends! And you know what: even if you're not into gaming, QuadStick works great for all the regular stuff you want to do on a computer. On their website, there are also more accessories you should check out. Choose what works best for you. They've got good stuff!

www.quadstick.com

Xbox Adaptive Controller

Remember when you thought that finding a customizable controller to fit your needs was harder than finding love? Well, not anymore! Microsoft, the company that gave us the Xbox, has entered the arena. Their adaptive controller is *loaded* with features. It also works as a hub to which you can attach pretty much any joystick, switch, controller or a combination of devices at the same time. That means you won't have to miss out on a button or feature in any of your favorite games.

Hats off to Microsoft: it works also for PS4 not just Xbox or a PC. I can hear you thinking: Microsoft? High quality stuff equals piles of money. Not so! This highly customizable piece of gaming equipment can be yours for around \$125!

www.microsoft.com/en-ca

Mouth stick

No, I am not talking about some mouth piercing or body mod! However, if you have some decent neck movement, I think you would totally appreciate a mouth stick. It's a solid and simple piece of equipment. You won't need batteries to operate it and it's super cheap! Myself, I use a mouth stick as the primary method to control my cell-phone, laptop and even pressing elevator buttons. The

mouth stick is what you'll see me with when checking out downtown nightclubs on the weekends.

It is totally useful to anyone with limited hand movements. Make sure to modify a holder for fast and easy reaching. Also make sure you choose the right length for yourself to use it comfortably. You can attach any stylus designed to work on touchscreens to a mouth stick and off you go. There's no particular mouth stick brand I recommend, just check out options online.

Last wise words

Before I leave you and get on with playing games, remember every adaptive controller needs a decent, flexible mount to attach to. Make sure you have a robust set up you can count on when the battles or races get hot and heavy.

There you are, ready and armed with my favourite selection of adaptive controllers. Was I right or was I right? There are no limits for us quadriplegic gamers. What adaptive controller do you like to use? I am curious.

And if you have any questions or comments message me on Instagram: @Omar92canada. Or email Technology for Living at info@technologyforliving.org.



Let me finish with a quote from one of my fave games: "So you're in, big guy? Or are we gonna have to kill ya?" (GTA)

Saddle up

By Liz Sahlstrom

I have a photo of myself, 15-years-old, riding my first horse, a 20-year old gelding. My long hair is flying in the wind and I have a smile on my face that rivaled the sunshine of that day. This was 50 years ago. That joy of being on horseback, feeling his mane whip against my arms, his watchful eyes and snorting nostrils, is a lot more than a memory to me. It defines me. Every horse I've ridden since then has shaped me to become the woman that I am today, through and through.

My bulbar palsy diagnosis which I received in May 2019, did not make me any less of a horse woman. I may not be able to speak but I can still ride my horse.

Bulbar palsy is a motor neuron disease. There is no family history, so I never saw it coming. One day, in July 2018, my husband Dave noticed that I wasn't moving my bottom jaw properly, and when I spoke, some words sounded slurred. I had not noticed any of it. But I did notice that a few days later the left side of my jaw started popping. I knew about my tendency to clench my teeth and thought that might be the issue.

I ended up visiting two dentists and my GP, tried acupuncture, shiatsu massage and saw two chiropractors. All treated me for TMJ (temporomandibular joint disorder). Nothing helped and eventually both sides of my jaw were popping and in a very painful way.

I went to see an oral surgeon who performed a CT scan of my jaw. It didn't reveal anything untoward. After administering some strength tests, he referred me to a neurologist who ultimately diagnosed me with bulbar palsy/ALS.

Life changes after a diagnosis like that. Some things had to stop. I was a trainer, coach and horse show judge for decades. I was in charge of the mounted team of Arrowsmith Search and Rescue on Vancouver Island. When not coordinating the horses for a search, I was the command radio operator, managing the search teams. I also taught people wilderness skills for Adventure Smart. But I can barely be understood at this stage, so I had to give it up.

Now, I ride a few times each week, practicing with a drill team for competitions. I am not judging anymore, so why



not compete and look at it from the other side of the fence? I still love trail riding with one adjustment: I will only ride with a group. My transition from verbal to non-verbal communication is so recent that my head still feels like it wants to explode because I can't chat with people like I used to. When riding with more than one person, I can at least listen to them, even though it makes me sad not being able to join into the chat. I carry a pen and paper to communicate, but I am not yet at

a place where it doesn't feel cumbersome.

My horse Breeze is a lot smarter than many humans. Clucking to a horse means "let's trot". A kissing sound says: "Time to lope". But I am not able to perform those sounds anymore. Breeze was unsure for a while about the lack of regular vocal commands. But now, we both are getting used to new ways to communicate. I am able to make a humming sound which she understands to mean "come on over and say hi". She has learned to move by "listening" to my movements in the saddle or with the reins.

I love riding Breeze. We have a unique bond and partnership. I know physically I will get weaker, and I will need further adjustments to my life. Right now, I can still carry the saddle but it's easier to just jump on. So, I bought a bareback pad.

I always liked mucking out paddocks, which is a good thing since cleaning up manure is a daily chore. Breeze lives on our property. Mostly I carry the feed and hay into the barn myself though sometimes my husband keeps me company and helps as well.

My condition may move down my body and selling our property to downsize is a reality we would have to face then. If that happens, I will board Breeze providing I can still ride. If I can't ride any longer, I will have to sell her :>('

For the moment, I am looking forward to going camping with Breeze when the days get warmer. She gets a pen or stall, in exchange she lets me use her trailer. And we both get to enjoy each other's company in the quiet of a BC night.

Blessed are the travelers for they will have adventures

By Nancy Lear

These are definitely weird times to write about travel, but also perfect times to write about it. We are all at home, having moved even more online than before the Covid-19 pandemic hit. Is there a better time to research our next trip? Here is how my passion for travel began and how it continues to this very day.

Finding my passion

In 1976, 15-years-old, I attended grade 10 at Queen Elizabeth Regional High School and the opportunity for a school trip during Easter break came up. I wanted to go so *badly* but there were obstacles in my way. I was already living with the repercussions of early onset muscular dystrophy (MD). At the time, my mom was my full-time caregiver. She also had her hands full caring for my two brothers both living with MD *and* she managed the rest of our large household. I knew she couldn't accompany me.

This was the very first hurdle in my traveling life that I decided to challenge and overcome. Here is the plan I concocted. Since age nine, I was "in the system" and knew a lot of health care professionals at the Children's Rehabilitation Centre in St. John's. I was convinced one of them, Bernadette (fondly called 'Bernie'), would accompany me. One second I asked her, the next it was official: she agreed!

I pitched my plan to my parents as this trip would have remain a pipe dream if they weren't willing and able to foot the bill. I must have been convincing as next thing I knew I met up with Bernie in St. John's to go over my daily routines, to discuss the school trip itinerary and to sort out the financial aspects. All went very smoothly. In those days I still used a manual wheelchair and I wasn't ventilated yet. I could still also walk a little. All those factors were of great help during that trip.

Easter break arrived, and I was ready to take on the world. We flew from St. John's International to London Heathrow, twenty 15-year-olds let loose in London and Paris for one week. Amazing! There were also four chaperone teachers ... so not that 'loose' but we still managed to have a great deal of fun!

Our trip started with three days in London. London is huge. Arriving at our hotel, we discovered it was located close to the airport. We definitely needed transportation to get to the main sights. We watched the famous 'Changing of the Guard', saw the crown jewels, circled around the grounds of Buckingham Palace and visited Westminster Abbey. In hindsight it was remarkable to see where the royal family holds their elaborate state dinners, but at the time it didn't leave too much of an impression on a bunch of teenagers.

Our Paris hotel was perfectly situated, close to the Seine, offering ample opportunity to walk out and explore. Our three days were spent seeing the Eiffel Tower, Versailles and the Louvre. It was magnificent.

Sadly, the Eiffel Tower was not wheelchair accessible in 1976 but I didn't let that interfere with my joy of seeing it all lit up at night!

You may enjoy this archival YouTube video from 1976 of a very vibrant Paris, forty-four years ago.
<https://www.youtube.com/watch?v=ihF3sN3-GLQ>

My personal tale of two cities

I finished university in 2003, ready to plan a much-needed vacation to mark the occasion. For me there was no question: I wanted to return to London and Paris! New things to explore in London were Shakespeare's Globe Theatre and the Tate Modern gallery. I was also looking forward to rolling down the South Bank along the Thames. And a day trip to Paris was going to be the icing on the cake.

The planning of the trip was very smooth. But then, three weeks before departure, disaster struck. I had arranged for two of my caregivers to travel with me. One of the two got into a car accident. Thankfully she wasn't seriously hurt but enough to require some time for her recovery. Worst of all: the insurance company would not allow her to go on the trip! I was devastated for her. I was also distraught for myself. What could I do?

Solving problems and quickly to boot, is a very important 'piece of equipment' you need to pack in your suitcase when you travel. I had taken out travel insurance which gave me a brilliant 'spin-into-action' save-the-day plan. I called my sister who was already vacationing in Denmark and asked her if she wanted to extend her holidays. I offered her the 'job' as my second caregiver and she said one word: "Sure"! So, I canceled my injured caregiver's flights, booked my sister on a one-way flight from Denmark to London, and finally a return flight home for all three of us. With on your feet thinking and quick action, a potential catastrophe can be turned around. Very important travel advice!



London and Paris did not disappoint the second time around. Both cities had become a lot more wheelchair accessible. This time I made sure to book a centrally located hotel in London. We stayed in a spacious, two-bedroom service apartment close to Southwark Bridge with breathtaking views of St. Paul's and the Southbank.

When traveling, you can encounter fantastic surprises but also face unexpected hurdles. Charles Dickens' opening sentence from *A Tale of Two Cities*, "It was the best of times, it was the worst of times..." resonated very much with me in 2003 and also in subsequent visits.

My sister and I boarded a train for a day visit to Leeds. This three-hour journey turned into five hours because the train hit a bird and came to a full stop! While waiting for the train to move again we started chatting with a charming woman who happened to be a Lord's wife. She felt bad

that our plans had come to this unscheduled halt on the track between London and Leeds. To make up for it she handed us her business card and invited us to call her office to arrange a visit to the House of Lords. You need to know that normally no one is allowed into the House of Lords *unless* accompanied by a Lord. We were delighted by this opportunity to see in person where the Queen reads the throne speech.

Another exciting opportunity we took advantage of was the Eurostar train. We travelled under the Channel for a day trip to Paris. This highspeed train is very wheelchair friendly and comfortable; I highly recommend it. Visiting the now accessible Eiffel Tower with my sister by my side was a wonderful moment! We took the passenger elevator to the first and second landings and thoroughly enjoyed the breathtaking views of this white-stoned, passionate city. We finished our day meandering along the Seine before boarding the last train back to London where the next surprise was just around the corner.

A spot of fame

I blew a fuse in my battery charger in our London apartment. Not such a great moment but it swiftly turned into one of the best days of my life! The apartment was just a 10-minute walk from *Guy's and St. Thomas'* hospital. The hospital had a respiratory department and I thought they would be able to help with my battery issue.

The people I met at the respiratory department turned out to be bio-medical engineers. They actually loaned me a battery charger while they fixed mine for free. We all got along like a house on fire, and they offered me a tour of the most massive ventilator-ward I had ever seen. I was introduced to a gentleman who was wearing a hard chest shell underneath his clothing that created negative pressure ventilation, the opposite to my positive pressure ventilation. I was very fascinated. It works on the same principle as the Iron Lung, but affords the person wearing it mobility.

But the adventure at *Guy's and St. Thomas'* didn't stop there. A TV crew happening to do some taping during my time visiting the ward. They approached me and asked if I would be interested in telling my story. It was incredible! The show was called *City Hospital* and followed real patients and staff around the hospital. I appeared in two episodes in 2003. It must have been a very popular show as it thrust me into the limelight: people on the streets of London would come up to me and say, "I saw you on the telly!" I thoroughly enjoyed the experience.

Prepare for anything



My friend and co-worker, Ean Price, recently returned from Thailand. He echoes my sentiment that when traveling it is important to always be ready for the unexpected. He had looked forward to a ride on a river boat. But when he arrived at the pier, he discovered that these boats are not wheelchair accessible. It was disappointing. Then Ean started chatting to a local man who turned out to have a modified boat and suddenly it became possible for Ean to explore the amazing sights of a city only a river can offer! Keep an open mind about any place and be prepared for unexpected discoveries. For example, easy access and comfort did not initially spring to my mind when thinking of Tokyo but Ean is blown away by the city's "most organized public transit systems he's ever experienced anywhere"!

I returned to London in 2005. This time my two accompanying caregivers remained injury-free. In London, we stayed at the Copthorne Tara Hotel, South Kensington, in *adjoining* rooms. That was a first for me and it's an excellent solution if you can manage to find this type of set up. It offers a lot of space, provides extra privacy, and easy access to your caregiver during the night.

This London trip turned deathly scary. In July 2005, terrorists targeted commuters travelling on the city's public transport system during the morning rush hour, and we were smack in the middle of it! We weren't injured in any way but felt very on edge after we realized that we had been passing through Kings Cross station the day before. Way too close for comfort. After that, we limited our excursions to only walking distances.

When traveling, bear in mind the 'what if' factor. That's where solid preparation comes into play. Ean suggests: "Practice self-reliance ... think of travelling abroad as camping in the wilderness." This is a great strategy because traveling is a magnet for the 'unknown', just like the wilderness. I forgot this sound piece of advice when I went to Barcelona in 2016 to board my first Mediterranean cruise. A battery fuse blew in my charger due to a power surge. That problem was corrected by replacing the fuse, but the damage created inside the casing of my battery connector went undetected. We kept a close eye on both battery chargers, switching them back and forth throughout the trip. I could have avoided this problem if I had taken spare battery connectors on the trip.

Ean had a similar experience when he was in Cambodia recently. The back-up for his back-up battery failed for his suction machine. He was okay, being an experienced trouble-shooter. He waited for one battery to partially charge and used the portal attached to his wheelchair for the suction machine's AC power source.

Planning takes a lot of work, but the reality is the more planning the less hiccups. Actually, planning can be often as rewarding as the destination itself.

In 2018, I went on a one-week Alaskan cruise with one caregiver. This trip far exceeded my expectations. There were no hitches from start to finish. Our stateroom on the ship was cozy yet spacious enough for two. All the ports were wheelchair accessible, making it very easy and comfortable to explore Juneau, Skagway and Ketchikan. It was a voyage of opposites: on the one hand the astounding crystal-clear waters, on the other hand the environmental destruction of the glaciers.

So, where to next? Ean says "a wildlife reserve in South Africa" sparks his interest. For me, *Down Under* is calling! Since 1976, my passion for travel and adventure hasn't abated and I can't imagine it ever will.

⚡ Join us on **SEP 10** at the **Roundhouse in Downtown Vancouver** ⚡
for a drop-in reception with music,
entertainment, food & drinks
to celebrate 50 years of TIL!



Technology for Living AGM beforehand

HOSTED BY

technology for living 

individualized
FUNDING
resource centre



PATHWAYS TO INDEPENDENCE HAS GONE VIRTUAL

Our first virtual meeting was a tremendous success with over 100 people with disabilities and their families joining **Paul Gauthier** to review, share and discuss how the COVID-19 pandemic is affecting peers.

Peers can attend meetings via email invitation.
Contact us at [✈ Pathways@technologyforliving.org](mailto:Pathways@technologyforliving.org)
to secure your spot for future virtual gatherings.

“Come and join us
to share even
a little of that
powerful unity
of peers!”
Nancy Lear, participant

The TIL tech team is on hand to help you before and during the meeting if you need support.
Training available for those who need it.