

Impact

Newsletter

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VGH
UBC hospital
foundation

> Tuberculosis — it's still a thing



Former patient Jennifer Horkoff with VGH TB Unit Recreation Therapist Courtney Knight.

One sunny day last September, Jennifer Horkoff went to work at University Golf Club in Vancouver despite feeling nauseous and unwell. When she arrived, her boss took one look at her and drove her straight to the Emergency Department at Vancouver General Hospital (VGH). After tests, Jennifer was diagnosed with tuberculosis (TB) and told that she would need to be admitted to the TB Unit for several weeks.

"I was shocked. I didn't even know what TB was," says Jennifer. "I phoned everyone I had been in contact with which was stressful. And I felt guilty. Although I know it wasn't my fault. I didn't even know where I got this from."

Jennifer isn't alone in her unexpected diagnosis. Each year, 1,600 people in Canada and 10 million people worldwide will learn they have TB. They all face the difficult reality of anywhere between six and 20 months of treatment.

The positive power of recreation therapy

Facing a long indoor isolation away from family and friends, Jennifer was cared for by the VGH TB Unit medical team and supported by Courtney Knight — the only Recreation Therapist at VGH and the only one in BC who works with TB patients.

"When I say I work on the TB ward, people say *Is TB still a thing?*" says Courtney. "It is. And with TB patients facing isolation from the outside world, it's my role to help them engage in activities to

maintain cognitive, social and emotional well-being. I worked with Jennifer to create an individualized plan that was engaging and meaningful to her."

With Courtney's help Jennifer learned to knit and launched a scarf and toque business — *Woolly Cute* — all without stepping outside the TB Unit. "It gave me a real sense of accomplishment," says Jennifer who is now fully recovered. "I feel so grateful for Courtney — she was wonderful."

Help make a difference to TB patients like Jennifer. Learn more at vghfoundation.ca/ways-to-give

How funding fights TB

Courtney's role as the VGH TB Unit's Recreation Therapist is made possible by donor funding. For over 30 years, VGH & UBC Hospital Foundation has partnered with BC-based TB Vets Charitable Foundation who have invested more than \$2.5 million to date.

"TB is preventable. TB is curable. The response to TB is investing in health care infrastructure." says Dr James Johnston, TB specialist and Head of Respiratory Medicine at VGH.

The funds have enabled research into new drugs to treat TB and supported the successful Recreation Therapy program.

The truth about TB

- TB is the number one cause of infectious disease death globally, killing more people than HIV each year
- Each year an estimated 10 million people fall ill and 1.7 million people die from TB-related illnesses
- TB is caused by a type of bacteria
- It is a disease that most often affects the lungs and airways
- People with TB need six or more months of a daily, multi-drug therapy



Innovative technology helps restore mobility

Thanks to innovative technology, HSP sufferer Silvester Law can continue to pursue his passion for photography.

Twenty years ago, Silvester Law noticed a growing pain in his legs and it was becoming difficult to walk. After several tests, Silvester was diagnosed with hereditary spastic paraplegia (HSP) — a rare neurological disorder that affects one in 20,000 people. HSP causes weakness and stiffness in the leg muscles which gets worse over time. For all of his adult life, literally every step taken has been difficult for the local photographer.

“It was very painful,” he recalls. “It made life difficult and it was hard to get around. I will never have a regular life, but I go out and do things anyway,” he continues with a smile. “I put so much pressure on my shoes. I wear them out. Within months, I have to get new pairs because there are holes in my shoes.”

To treat his HSP, Silvester had to regularly take a skeletal muscle relaxant called Baclofen and receive painful Botox injections in his legs. The medication helped Silvester recover most of the use of his legs but it impaired his mental function making it cumbersome to perform the simplest of daily tasks like going to the store.

As an avid photographer, Silvester needed his mobility to keep up with fast-paced events during the 2010 Vancouver Olympic Games when he worked for the Vancouver Organizing Committee.

In October 2017, Dr Scott Paquette and a team at Vancouver General Hospital installed a Baclofen

pump into Silvester’s stomach and spine. Less than 100 people in British Columbia use this innovative technology.

“The advantage is that the medicine is delivered directly into the spinal fluid and does not have to be taken by mouth which causes side effects of sedation,” says Dr Viet Vu, the spinal cord physiatrist at GF Strong Rehab Centre who helps Silvester manage the pump.

“The pump changes people’s lives,” says Dr Vu. “It gets them out of the house and allows them to travel. They can get out and engage in the community which Silvester has done.”

Silvester hopes that like him others will be able to benefit from innovations in health care. “I’m so grateful to my doctors at VGH who were able to use this innovation for my very rare condition. My pump delivers more medication where I need it and has lessened the side effects while offering a lot more potential than my past treatments.”

Donors like you enable the purchase of equipment like Silvester’s pump. Join us in connecting the power of philanthropy with the power of health care innovation: vghfoundation.ca/ways-to-give

Help purchase new equipment

Donations to our *Most Urgent Needs* fund help our health care teams purchase much-needed equipment such as:

- Power wheelchair**
\$13,043
- Pressure mat**
\$7,620
- Active/Passive Exerciser**
\$9,539
- CO₂ Monitor**
\$11,452

To make a donation, contact:
604 875 4676
info@vghfoundation.ca

Give online at:
vghfoundation.ca/donate

VGH clinic helps patients find their voice



Paul Tindle with his daughters enjoying a sunny afternoon in North Vancouver.

“It was a scary time,” reflects Paul Tindle. “And quite frankly, it was a depressing time.”

About 16 years ago, Paul noticed he was losing his voice. As an energetic salesperson who was always on the phone and in meetings, it was becoming very difficult to communicate. Initially, he thought it was just a persistent cold that wouldn’t go away. But Paul saw a specialist and was diagnosed with papillomas or growths on his vocal cords.

After 13 painful surgeries, Paul still couldn’t speak properly. He was stressed and it was affecting his career. He had almost given up hope when he was referred in 2017 to Dr Amanda Hu, a laryngologist at Vancouver General Hospital.

“I had accepted the fact that I would have a life where I’m struggling to be heard,” recalls Paul.

However, Dr Hu operated on Paul and his life has been different ever since. Dr Hu performed laser surgery to intricately remove the papillomas on Paul’s vocal cords, bringing his voice back.

“My voice has changed completely since she worked on me,” says the 51-year-old. “It’s stronger than it has ever been. I find it effortless to talk now. Dr Hu has changed my life.”

Accurate and effective diagnosis

Before Paul’s operation, Dr Hu used a stroboscopy machine which helps visualize the larynx and diagnose voice disorders caused by irritations, acid reflux or growths like vocal papillomas.

“Stroboscopy is a very important tool to accurately diagnose what’s wrong with my patients’ voices,” she explains. “If I had an additional machine, I could see more patients, more efficiently and help more people. It would also help me train more medical students and residents to accurately diagnose conditions. This is an example of how philanthropy and donors can support the best care for the people of British Columbia.”

Support the only voice clinic in Vancouver

Dr Hu says vocal cord issues are a significant problem for people from all walks of life.

“A big misconception is that I only treat singers and actors but there are many others like teachers, lawyers and receptionists who need to use their voice every day for their job,” she says. “If their voice doesn’t work, it’s not just a quality of life issue, it’s a disability issue. It’s an integral part of people being functional, productive members of society.”

Paul agrees, and is grateful to Dr Hu and her team. “It always brings a tear to my eye when I see her because I never thought I would have the voice that I have now.”

Support Dr Amanda Hu and her team to help more people like Paul re-find their voices. Donate now at vghfoundation.ca/ways-to-give

Getting vocal — the facts

- Each year, voice problems affect one in 13 adults
- Difficulty speaking due to a physical disorder of the mouth, tongue, throat, or vocal cords is called dysphonia
- Dysphonia is responsible for frequent health care visits and several billion dollars in lost productivity annually from work absenteeism
- An estimated two in 100,000 people suffer from recurrent benign tumours in their air passages — called respiratory papillomatosis



Gino De Pieri with his mother Onorina.



Dr Johnston is a tuberculosis specialist and Head of Respiratory Medicine at VGH.

Leaving a legacy for leukemia

Gino De Pieri spent his life being a caregiver. Both Gino’s father and mother suffered life-ending strokes, and his younger sister had terminal leukemia. Tirelessly dedicated, Gino cared for them until their final days.

Even though Gino passed away three years ago from a rare form of cancer, his legacy continues his tradition of taking care of others. In his will, Gino left a generous gift to help the Leukemia/Bone Marrow Transplant (L/BMT) Program of BC, based at Vancouver General Hospital (VGH) in recognition of the amazing care provided to Silvana Pezzutti, his late sister.

“Gino wanted to honour the family name and Silvana by giving to this area,” explains Franco De Pieri, Gino’s younger cousin. “He wanted to make a difference to people with cancer.”

The L/BMT Program provides care for all adults in British Columbia and the Yukon who need stem cell transplants. The team also looks after patients with blood cancers such as leukemia.

“This generous gift is greatly appreciated by the L/BMT Program and the Division,” says Dr Stephen Nantel, Head, Division of Hematology. “It will enable our team to participate in important new initiatives that will have a big impact on patient care.”

Gino’s gift will help a range of areas, including participation in a national trial with a promising new anti-leukemic drug and the recruitment of a new Clinician Scientist specializing in leukemia and stem cell transplant.

Gino’s gift will have a significant impact for British Columbians with blood cancers. Franco says Gino would have wanted that.

Join donors like Gino and help make a difference for patients — today and into the future. Learn more at vghfoundation.ca/legacy

Behind the scenes with Dr James Johnston

Where did you grow up?

I grew up in London, Ontario but lived across Canada throughout my adult life.

Why did you become a doctor?

While at University, I became increasingly aware of the impact and spread of disease, particularly in marginalized groups. I pursued medical training so I could work on the front line to prevent and treat disease.

Why are you so passionate about TB and its treatment?

TB is both a preventable and curable disease, yet it’s the world’s leading infectious disease killer. It’s easy to be passionate about eliminating this disease.

Who or what inspires you?

There’s a community of TB advocates, survivors, front line health care workers and researchers that are all passionate about TB elimination. They are a small but mighty bunch and it’s impossible not to be inspired by them!

Tell us one thing (professionally or personally) that we might be surprised to learn or know.

I once conspired to smuggle a kitten out of Cuba, and failed.

How do you like to spend your down time?

Playing all kinds of sports at a very low skill level and dealing with the inevitable injuries.

To read about the work of dedicated physicians like Dr Johnston, visit vghfoundation.ca/heart-lung