PATIENT ACCESS

HOW BEING AN **EMPOWERED PATIENT** HELPED SAVE THIS LIFE

Dave deBronkart speaking at TEDxMasstricht by Mirella Boot

Eleven years ago, Dave deBronkart was diagnosed with stage 4 kidney cancer and given a life expectancy of about six months. "I went from almost dead to all better in less than a year," says Dave, also known as e-Patient Dave, who's doctors attribute much of his remarkable turnaround to participating in his own health care and connecting to an online patient group.

> "I would be dead if I had been a disengaged, passive patient, but because I was empowered, I thought about what I could do to help my doctors save me,"

says Dave, now a leading advocate for the e-patient movement and the author of *Let Patients Help!*

Although e-patients use the internet to find medical information and connect with others, the "e" also refers to patients who are empowered, engaged, equipped, and enabled.

Faced with a life-changing decision

At the encouragement of his doctor, Dave joined an online community for kidney cancer patients. It was there that he found out about high-dose interleukin-2 (HDIL-2), a treatment that only works for a few patients and has sometimes-fatal side effects. "I was on the edge of a cliff, and, sooner or later, I was going to fall off," says Dave. "The question was, if I take this other route, will it throw me off the cliff sooner, or will I survive?"

Dave participated in a clinical trial, proactively asking his doctor how to prepare. When his doctor did not have all the answers, Dave ultimately benefited from the experiences of other patients who had taken HDIL-2 in his online community. "My oncologist said if I had not been so prepared for the side effects, he's not sure I could have survived," says Dave.

In addition to receiving crucial information from other e-patients, Dave also benefited from their emotional support. Even if you don't use the online forum for gathering info, "At the very least, you can connect with other people who are in the same boat as you," he notes. "I had never known anybody with kidney cancer, so it gave me hope to connect with people who had been through it 10 years ago and were still alive."

Taking an active role in his health care

Before his diagnosis, Dave, who did everything in his power to assist his doctors, "assumed that they knew everything that was worth knowing." Later, he realized doctors may not always be aware of all the latest relevant medical information, because it typically takes two to five years for medical research to be distributed.

Dave doesn't just encourage patients to join online communities and research medical information. He also suggests they ask to see their medical records, which, he says, frequently contain errors.

Although some doctors might be insulted by the idea of patients participating in their own health care, "The e-patient movement is not about patients rejecting their doctors. It's about patients acting as information bloodhounds, trying to help bring new information to the doctors," says Dave. "We're at the stage that the early suffragettes were at in the late 1800s. While some of us are speaking up and saying, 'Excuse me, I'd like to be involved in my own health care,' we are being increasingly — but not yet always — accepted by the mainstream."

Dave's advocacy is needed more than ever in today's health care landscape. With an aging population and increasing amounts of people living with chronic diseases, many health care practitioners are seeing an overwhelming number of patients daily. Patient involvement — being proactive and advocating for one's self — is essential in improving health outcomes and sustaining our health care system.

Katherine O'Brien

HIGH BLOOD PRESSURE: WHAT YOU DON'T KNOW CAN KILL YOU

Everyone has passed their pharmacy's blood pressure kiosk, but there's good reason to stop and take a seat. With over 15 million Canadians at risk for or living with high blood pressure or hypertension, chances are that you have it, too.

High blood pressure, or hypertension, means there is too much pressure in the body's blood vessels. Similar to pumping too much air into a tire or balloon, this damaging force can be deadly.

"The challenge is that hypertension has no symptoms," says Angelique Berg, CEO at Hypertension Canada. "This silent killer is the leading risk factor for diseases like congestive heart failure, stroke, and kidney disease and is also linked to dementia."

A staggering 7.5 million Canadians today have hypertension, which measures at 140/90 mmHg, and an additional 7.4 million have elevated blood pressure that will advance to hypertension without healthy behaviour changes.

The first thing is to measure your blood pressure, at least annually if you're otherwise healthy, and more often if your blood pressure is high. Pharmacy kiosks are readily available, and home devices can be purchased for more regular monitoring. A list of recommended home devices is available at hypertension.ca.

If your blood pressure is high, the good news is that control is in your hands. Incorporating small changes into your daily lifestyle, such as being physically active, eating a healthy, low-sodium diet, limiting alcohol intake, and living smoke-free will have big pay-off in blood pressure control and prevention of disease. For additional help, the GetDownBP.ca online community helps encourages new, healthy habits.

> "Knowing your numbers is critical to detecting high blood pressure," says Berg, "and managing your blood pressure can help us to live longer and healthier."

Hypertension Canada

Why Canada Still Needs an Orphan Drug Policy

When Canada's draft Orphan Drug Regulatory Framework suddenly disappeared from the government website, my immediate reaction was "it's the kiss of death" for rare disease drugs in Canada. Not because we disbelieve Health Canada's claim that they are able to approve orphan drugs without new legislation — but without an Orphan Drug Policy, there has been little incentive to do orphan drug research, to conduct clinical trials, and to bring in drugs in a timely fashion.

Only half of USA-approved orphan drugs come to Canada, and often with long delay. Which is why, in 2007, the Canadian Organization for Rare Disorders drafted an Orphan Drug Policy, and why we were thrilled when, in 2012, the Health Minister produced an Orphan Drug Regulatory Framework. This framework would allow clinical trials and orphan drug approvals to take place in Canada at the same time as in the USA and the European Union. But the Conservative government failed to implement it and the Liberal government has now removed the framework from its website.

Even worse, more than half of Canadian - approved orphan drugs are not funded by the public drug plans.

In many countries, orphan drugs are reimbursed through their own review process. In contrast, the Canadian Agency for Drugs and Technologies in Health, which reviews drugs for funding, disproportionately recommends against rare disease drugs, primarily because they apply, inappropriately, standards for evidence and cost-effectiveness designed for "common" drugs. The result leaves more than half of Canadian approved orphan drugs not funded by public drug plans.

Even OHIP+, Ontario's total pharmacare program for those under 25, will not cover most rare disease drugs.

What is more frightening is the likelihood that access will get worse under the government's proposed changes to the Patented Medicines Prices Review Board, which will create additional barriers for new drug entry, especially rare disease drugs. Now, more than ever, an Orphan Drug Policy is needed to ensure that Canada does not fall even further behind other developed countries in serving some of the most vulnerable patients, those affected by rare diseases.

Durhane Wong-Weiger
President
Canadian Organization of Rare Disorders

Patient Support Programs: Improving Health Care Access for Patients with Rare Diseases

About one in 12 Canadians has a rare disease or disorder, two-thirds of whom are children, according to the Canadian Organization for Rare Disorders (CORD). Access to medication and services for these patients can be challenging and costly.

> "About half of the drugs available for rare disease in Europe and the U.S. are not available in Canada, and more than half of those that get approved in Canada are not reimbursed by public health plans,"

says Durhane Wong-Rieger, President and Chief Executive Officer of CORD.

To ease this burden, pharmaceutical companies have developed Patient Support Programs (PSPs). "PSPs help patients navigate access to reimbursement from both private and or public health insurers and ensure that patients can get access to the appropriate therapy, " says Sandra Anderson, Vice President, Consulting and Business Development at Innomar Strategies. PSPs can also help patients and their families through logistical care support, such as coordinating out-of-hospital treatments within private clinics, providing access to specialty pharmacies, and arranging appropriate patient and family education and counselling.

Health outcome studies – Real-world data to guide decision making

Rare disease drug treatments are often higher priced and treat diseases that are difficult to diagnose, with only a few specialty physicians in Canada who understand the disease. They also treat small unique populations, which makes it challenging to measure the efficacy of these therapies. Payers may want to seek out more information, but there is a lack of real-world data available.

"Canadian payers are looking to pharmaceutical companies to present real-world clinical data to demonstrate the effectiveness of their products and to ensure the right patient is on the right product at the right time," says Anderson. Real world data is important as it illustrates how these therapies improve health outcomes which supports the payers' investment for these valuable medications. With access to meaningful data and analytics to highlight the value of these therapies, through a PSP for instance, many are hopeful that access to such specialty treatments will improve.

Patient engagement a key component

As Sandra Anderson explains, "PSP services are meant to ease the patient's health journey and to ensure they can access their important therapies at a time when they need it the most." Getting the most from PSPs involves ongoing patient engagement. "We want to engage with patients from the very beginning in identifying what's important to them so that the clinical trials reflect their concerns all the way through, as well as contribute to good science," says Wong-Rieger. "In addition, this engagement helps patients understand not only the strengths and limitations of the drug but also what they can do to fully benefit from it."

Anne Papmehl

Improving Access to Innovative Drugs for Canadians with Obesity

As Canada prepares to celebrate the 100th anniversary of Dr. Frederick Banting's insulin discovery, it feels fitting to reflect on how far we've come. Only a century ago, a diabetes diagnosis was a sure death sentence. "The average life span for a diabetes patient was about six months to two years from diagnosis," says Grant Maltman, the Curator of the Banting House National Historical Site of Canada in London, Ontario. "Then a simple twenty-five-word hypothesis that Dr. Banting came up with here in London led to the great insulin breakthrough." That innovation has enabled diabetes patients worldwide to live long and healthy lives.

Though we have a lot to celebrate in diabetes treatment advancement, our work is not done yet — recent innovations still prove difficult to get into the hands of patients.

For example, many Canadians do not have access to anti-obesity medications (AOMs), which could be used to help patients manage obesity and reduce the risk of later developing type 2 diabetes or other complications. Despite official recognition by the World Health Organization and Canadian Medical Association of obesity as a chronic disease requiring appropriate medication, AOMs are excluded from public health insurance plans and many private plans. If patients are fortunate enough to have a private plan that provides coverage of AOMs, they may still run into issues related to the level of coverage available, because these medications are typically categorized as lifestyle drugs. As a result, less than one percent of Canadians suffering from obesity receive the proper treatment they need.

"Weight bias" preventing access to medication

According to the Canadian Obesity Network, a major barrier to medication access is the perception — or weight bias — among decision-makers that obesity is a lifestyle choice rather than a complex, progressive disease.

"There is a tendency for some individuals and the public to blame individuals with type 2 diabetes or obesity as simply lacking self-control, and therefore categorizing it as a lifestyle disease," says Dr. Daniel J. Drucker, Senior Scientist at the Lunenfeld-Tanenbaum Research Institute of Mount Sinai Hospital in Toronto. "But we have a huge amount of scientific data showing that there are genetic determinants as well as metabolic changes that occur during the development of obesity that make it extremely difficult for individuals to manage the disease."

Not managing obesity raises the risk of developing diabetes and other serious conditions. Excess body weight puts increased demand on the pancreas to produce insulin. When the pancreas is no longer able to meet that demand, glucose (sugar) builds up in the blood instead of being used for energy, resulting in type 2 diabetes. Diabetes complications include nerve damage, kidney failure, blindness, and even death.

Obesity also increases the risk of developing other diseases and comorbidities, such as non-alcoholic fatty liver disease (which can result in liver failure and transplantation), high blood pressure, sleep apnea, arthritis, cardiovascular disease, stroke, cancer, and depression.

Recognizing obesity as a disease, not a lifestyle choice

Many physicians, policymakers and insurers still regard obesity as a lifestyle choice rather than a serious medical condition, with few other diseases receiving as much negative stigma. In reality, obesity is a very complex disease involving a combination of genetics, behaviour, and socioeconomic factors.

Roughly six million Canadians are living with obesity. To improve patient access to obesity treatment and medication, health organizations — both in Canada and globally — are calling for a change in the way people perceive the illness. Without proper management of the obesity epidemic, Canada faces a ticking public health time bomb, warns Dr. Drucker. "Our health care system will end up paying the price, as well as the individuals with obesity, if it's not properly treated."

Anne Papmehl

Dr. Daniel J. Drucker
Senior Scientist,
Lunenfeld-Tanenbaum
Research Institute

Grant Maltman
Curator, Banting House
National Historical Site

This article was made possible with the support from Research Based Pharmaceutical Company

Publisher: **Margot Thomas** Business Developer: **Jesse Adamson** Designer: **Gretchen Romin** Managing Director: **Jacob Weingarten** Lead Designer: **Mike Shea** Digital Content Manager: **Camille Co**
Contributors: **Ken Donohue, Randi Druzin, Katherine O'Brien, Anne Papmehl, Durhane Wong-Reiger** Photo credits: All images are from Getty Images unless otherwise accredited.
Send all inquiries to **ca.editorial@mediaplanet.com** This section was created by Mediaplanet and did not involve Toronto Star or its Editorial Departments.
Made possible through the support of BTG plc, GreenMed Network, Green Relief, Innomar Strategies, Novo Nordisk Canada Inc, and Servier Canada.

Ontario's Failure To Cover **Innovative Medical Technology** Affects Former MPP's Battle to Survive

Delivers 1.2-8 million spheres per infusion

When Norm Jamison was diagnosed with liver cancer in June, the former Member of Provincial Parliament looked into various treatment options with his doctor and settled on radioembolization, an Ontario-made innovative treatment in which radioactive glass or resin beads are injected into the tumour through a liver artery and attack it. But he discovered that the Ontario Government wouldn't cover the cost of the treatment even though it had been recommended by his specialists.

Family members sprang into action and, through a short GoFundMe campaign, raised the $19,000 needed. Jamison, who served in parliament from 1990 to 1995, underwent the treatment in the summer, but by then it was too late. The treatment extended his life but couldn't save it. He passed away in October.

His wife and four daughters are left with a lingering question: Why won't the Ontario Government cover the cost of a therapy with the demonstrated potential to save lives — even though that treatment was made in Ontario and is publicly funded in other provinces in Canada? "My dad has served in government and government has let him down," his daughter Shannon Spoelstra told *The Simcoe Reformer* just before her father underwent treatment.

> "I don't feel this is right. I feel things should change... This is Canada and this procedure is not covered in Ontario. That's crazy."

Interventional radiologists sing praises of Y90 therapy

The Ontario government's stance also confounds interventional radiologists, many of whom have been singing the praises of the treatment for several years now.

They note that radioembolization targets the tumour while leaving the surrounding tissue relatively unharmed. That means radiation can be delivered without damaging the liver, which is difficult to do otherwise. The treatment — which is also known as Y90 therapy because the beads contain the radioactive isotope yttrium-90 — can be used to shrink large tumours down to the point where they can be surgically removed, to keep tumours small so patients can receive liver transplants, and to treat tumours that are not responsive to chemotherapy.

Radioembolization is more expensive upfront compared to chemoembolization, the current standard of care, but could save taxpayers money overall. As an example, Dr. Amol Mujoomdar, an interventional radiologist at London Health Sciences Centre and Associate Professor of Radiology and Oncology at Western University in London, Ontario, cites the fact that most patients are able to be treated on an out-patient basis, able to leave the hospital on the same day without needing an overnight stay, rather than be admitted into the hospital. The procedure also has fewer side effects than conventional treatment, which means most patients don't require as much medical care. "Radioembolization has shown a lot of promise and should be funded at this point," Mujoomdar says.

Canadian patients "need to advocate for themselves"

His views are also shared by MEDEC, the association representing Canada's medical technology industry, which believes many other cutting-edge treatments should also be available to Canadian patients. "The challenge is dealing with each of the silos in the health care system. Each one thinks about its own costs and not necessarily about the big picture," says Gerry Frenette, the organization's executive director of public and member relations. "But each stakeholder should recognize the broader value of investing in new treatments and technologies — so we're working with our partners to break down barriers for innovators and create a paradigm shift toward value-based procurement."

Frenette notes that radioembolization is one of several technologies that are the standard of care in other countries but not in all Canadian provinces and territories. He notes that the Canadian Health Policy Institute ranks Canada near the bottom of 75 countries when measuring medical device spending as a percentage of total health spending.

Canadian patients should be mindful of the status quo when making important health decisions, says Mujoomdar, who treated Jamison. "People need to be aware of the situation and to advocate for themselves and their families when it comes to health care — especially when treatment that could benefit them is available elsewhere."

The Canadian Cancer Survivor Network urges Canadians to advocate for improved access to medical devices by sending a letter to your local representative, asking to help make these treatments available for the Canadians who need them.

Simcoe Reformer story: http://www.simcoereformer.ca/2017/07/06/jamison-about-to-undergo-19g-procedure-to-battle-liver-cancer

Randi Druzin

WITH **35,000** CANADIANS EMPLOYED BY THE CANADIAN MEDICAL TECHNOLOGY INDUSTRY, IT PLAYS A ROLE IN PATIENT ACCESS AND CARE AS WELL AS THE CANADIAN ECONOMY, REPRESENTING **1,500** MEDTECH COMPANIES, EXPORTING **$1.8** BILLION OF MEDICAL TECHNOLOGY ANNUALLY.

Despite the fact that research indicates that greater investment in the use of medical technologies is more likely to result in greater potential savings on overall health costs, Canada ranked 62nd of 75 countries studied by the Canadian Health Policy Institute between 2010 and 2015. CHPI published the following statistics:

61/75
of the countries studied spent more than Canada on medical devices as a percentage of total health spending

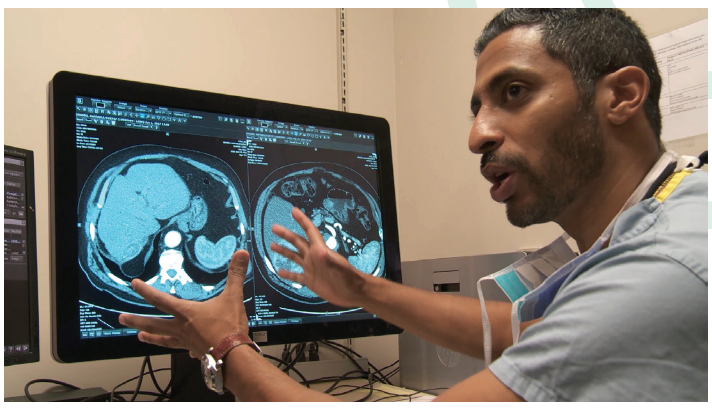
3.43%
of total Canadian health spending accounted for medical devices

33rd
Canada ranked 33rd for medical device spending as a percentage of GDP per capita

0.38%
representing total spending as a percentage of GDP per capita in Canada

The study, *Medical devices and health care costs in Canada and 74 other countries, 2010 to 2015*, is available online at: **www.canadianhealthpolicy.com.**

Norm Jamison with his wife Sharon after treatment.



Dr. Amol Mujoomdar comparing before and after x-rays.

FINDING THE RIGHT TREATMENT FOR ARTHRITIS CAN BE PAINFUL

Rheumatoid arthritis is a painful, debilitating disease with no cure. According to the Arthritis Society of Canada, one in five Canadians live with this inflammatory disease that affects not only the joints, but other parts of the body too.

"It's not just an old person's disease," says Linda Wilhelm, the President of the Canadian Arthritis Patient Alliance (CAPA). "It affects people of all ages, including children and young adults. It's no less serious than other diseases that get a lot of attention."

Wilhelm, who has been living with the painful effects of rheumatoid arthritis for the past 30 years, is a passionate advocate for people with arthritis. One of the biggest issues they face is access to treatment.

According to Wilhelm, access to prescription drugs, some of which can be quite expensive, is all over the map. Access is not consistent. It often depends on where you live and whether you have private insurance (which many people don't). To further complicate matters, provincial drug plans are all different. "We work with different levels of government and the pharmaceutical industry so people will have the right drugs," says Wilhelm.

Linda Wilhelm
President, Canadian Arthritis Patient Alliance

Disease-modifying drugs, which target the cells in the body causing the inflammation inherent in rheumatoid arthritis, are the first line of medications used. To ease the chronic pain, some arthritics use opioids, such as Tylenol 3 or other drugs with codeine, but the recent opioid crisis — which has the government implementing new, restrictive policies to combat addiction — has restricted access. Because of this, some people are switching from opioids to medicinal cannabis.

"While more study is needed on the benefits of cannabis, we believe that if people are finding pain relief from it, then they should have access to the treatment," says Wilhelm. "We've come to learn that everyone responds differently to arthritis, which is why we need all forms of treatment approved, so that more people can benefit."

Improved access to medicinal cannabis as an alternative to opioids would increase the pain relief options for patients suffering from rheumatoid arthritis. When it comes to health care, there truly is no one-size-fits-all solution. Wilhelm encourages patients to be advocates for themselves, to fight for their right to access to treatment, and to be open-minded when it comes to that treatment. Although unconventional, cannabis is an all-natural treatment that has been showing results in clinical trials. If you have rheumatoid arthritis, talk to your doctor to see if cannabis may be a good option for you.

Ken Donohue

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4 THINGS TO LOOK FOR IN A LICENSED PRODUCER

Right now, the only legal way to buy medical cannabis is through a medical document completed by your doctor or health care practitioner (HCP) and provided to a licensed producer (LP).

But there are currently 80 authorized LPs to choose from — how do you decide?

As a licensed producer, we hope this article arms you with the knowledge you'll need to make the decision that's best for you.

Green Relief is a licensed producer of medical cannabis under Health Canada's Access to Cannabis for Medical Purposes Regulations (ACMPR).

For an extended version of this article and to learn more, head to www.greenrelief.ca/star

1 COMFORT

Ordering medical cannabis for the first time can be an overwhelming experience. How do you register? What do you say to your doctor? How do you choose the right product to try?

It might sound like a lot, but it's much easier than you think. That's where a licensed producer's website and client care team come in.

Many LP websites have a list of frequently asked questions, as well as background information on the company and what they stand for. But picking up the phone and talking to a producer's support team can really be effective when trying to decide who you should choose.

Make sure you don't feel rushed and that any questions you ask are answered thoroughly. You should feel comfortable, heard, and taken care of.

2 POLICIES

From pricing and shipping to veterans' assistance, it's important you know as much as possible about a producer's policies and other programs.

For shipping, how quickly are orders fulfilled and how long will it take to receive your order? With free shipping, what's the order minimum?

If you have a low income or are on disability, do they offer discounts in the form of a compassionate care program? If so, are you able to order any product, or are there restrictions?

For much more about policies and programs, check out the link to our companion piece at the end.

3 TRANSPARENCY

When we crowdsourced input for this article, one common response we received was that a licensed producer should be as transparent as possible about their products, growing method, and internal processes.

This includes detailed cannabinoid and external testing statistics for strains, as well as explicit detail about how they grow their cannabis and their quality control process. If you come across organic cannabis, make sure to ask a producer how they define organic.

In any case, you're looking for as pure of a product as possible, free of any harmful pesticides, chemicals or bacteria, grown in a way that produces consistent results time after time.

4 A MATCH

Most of all, it's crucial that once you've established what your specific needs are, you find a producer that matches (and meets) them.

For example, you might have been recommended a strain from one LP by a friend, but another LP has an oil you'd like to try — and that's just fine!

You might be told otherwise, but you can absolutely ask to split your prescription between two (or even three) licensed producers if you so desire.

Remember, the more you can learn and teach yourself about medical cannabis, the more empowered you'll be when making your decision.

Jared Macdonald
Director, Content Strategy

Written by Green Relief