

BLOOD HEALTH & ORGAN TRANSPLANTS



The Social's Lainey Lui turns caregiver for her mother and helps her deal with a rare blood disorder.

p06

Research on Rare Blood Disorders Can Help Save Lives

We call blood the essential “life force” and blood donations the “gift of life.” But could research on a rare blood disorder save your life? It may already have. People with hemophilia, a rare bleeding disorder, have led researchers to many medical discoveries. In the 1980s, when many hemophiliacs became infected with HIV, it helped confirm that the virus was transmissible through blood. In the 90s, hemophilia research proved that a bioengineered product with no viral risk could control bleeding as well as “blood-based” factor. Today, synthetic blood factors are successfully used in surgery and on battlefields to save lives.

Treatments for rare blood disorders help all

Knowledge about rare blood disorders has benefited more common diseases. For example, sickle cell disease and thalassemia — both rare blood disorders — demonstrated that a single gene mutation offers a protective advantage against the malaria parasite, but two mutated genes lead to a life-threatening condition.

The identification of persons with (rare) inherited high cholesterol demonstrated a link between cholesterol and heart disease. The subsequent development of statins, a class of lipid-lowering medications, has saved millions of lives.

Revolutionary gene therapy: reality today

Canadian rare blood disease researchers and patients are involved in revolutionary gene therapies. In 2012, the European Medicines Agency approved the first medicine that delivers a gene into the body to correct a genetic deficiency. Patients with a rare lipid disorder were recently treated as part of a trial in Quebec. Last year, the EMA approved a gene therapy for children with an ultra-rare immune disorder caused by very low white blood cell counts. Canadian hemophilia patients participating in gene therapy trials are showing signs of a cure, which may allow them to avoid infusions altogether in the future. And Canadian researchers are participating in cellular therapy for acute lymphoblastic leukemia, which reprograms a patient's own T cells to increase their ability to fight cancer.

The Canadian Organization for Rare Disorders calls upon all governments, industry, and other stakeholders to support Canada's Rare Disease Strategy — a five-point comprehensive program for research, diagnosis, treatment, and support of all rare diseases. ●

Durhane Wong-Rieger



Durhane Wong-Rieger
President & CEO,
Canadian Organization
for Rare Disorders

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VON WILLEBRAND DISEASE Common, Treatable, and Often Missed

People with the genetic disorder von Willebrand Disease have a defective or missing protein that plays a vital role in blood-clotting. In men and women with the disease, small blood cells can't properly stick together or attach themselves to blood vessel walls.

This can lead to uncontrolled bleeding after injury, dental procedures, or surgery. People with the disease also experience frequent nosebleeds and bruise easily. Women suffer abnormally heavy bleeding during menstruation and after childbirth.

Most patients have the mildest of the three main forms of the disease, Type 1, in which there are low levels of the protein that helps the blood clot. As treatment, doctors often prescribe desmopressin, which stimulates the release of the protein.

Patients with Type 2 von Willebrand disease have normal levels of the protein but it doesn't work properly, and patients with Type 3 don't produce the protein at all. In these cases, doctors prescribe replacement therapy, which is purified from human plasma.

The disease affects men and women equally but women are more likely to be diagnosed because of problems with menstruation. Still, says hematologist Dr. Michelle Sholzberg from St. Michael's hospital in Toronto, many people aren't even aware they have the disease and suffer silently with excessive bleeding and resultant iron deficiency anemia.

"Getting a proper diagnosis can be empowering for patients, particularly women who have been suffering from heavy periods without knowing why. Ultimately," she says, "the goal is to make people feel safe and strong." 

Randi Druzin

St. Michael's

Inspired Care. Inspiring Science. **Multidisciplinary Clinic for Women with Bleeding Disorders**

Altruistic kidney donors like Nathalie — donors who donate a kidney to someone they don't know — have a big impact on reducing the number of patients on the organ donation wait-list. Photo: Canadian Blood Services

THE POWER OF PAN-CANADIAN COOPERATION

When it comes to organ donation and transplantation, we're stronger together.



Dr. Graham Sher
CEO, Canadian Blood Services



Organ donation and transplantation has the power to save lives, improve health, and return patients to a productive life.

We know Canada's donation and transplantation system is improving, and one of the contributors to this success is effective collaboration among health system partners through newly established co-operative programs.

As a leader in this collaborative exchange, Canadian Blood Services proudly works with organ donation organizations, clinical transplant groups, and other key stakeholders to evolve knowledge, policy, and technology related to donation and transplantation in Canada.

In addition to increasing donation and transplantation rates, this work improves the integrity, safety, and transparency of the national system, ensuring the patients who need transplants most — no matter where they live — can get them. Despite this progress, there still is work to do.

In operating and improving the capacity of the Canadian Transplant Registry (CTR) —

a digital technology that links organ donors with potential recipients — we have seen firsthand how working together builds a stronger system. The sharing of kidneys beyond provincial borders is now a reality thanks to this pan-Canadian cooperation. Over the past seven years, the CTR and its integrated programs (Kidney Paired Donation and the Highly-Sensitized Patient Kidney program) have enabled over 800 kidney transplants that might have otherwise never occurred.

Organs are a scarce resource in high demand. Until we stop preventable deaths of those on a transplant waiting list, our collective work is far from done. Together, we will continue the work to save the lives of more patients. 

Dr. Graham Sher



Register your intent to donate at organissuedonation.ca

Learn more about Canadian Blood Services at blood.ca

Patients with Thalassemia No Longer Dealt a Death Sentence

The emerging prevalence in Canada of the blood disorder thalassemia requires awareness of treatment options so patients can live healthy lives.



Nine-year-old Akio Tan has been getting his monthly blood transfusions at Sick Kids Hospital since he was a few months old.

Dr. Jacob Pendergrast says the genetic blood disease thalassemia is affecting a growing number of Canadians.

Thalassemia used to be confined to parts of the world where malaria was common, but changing immigration patterns are helping the disease see a growing prevalence amongst Canadians.

Dr. Pendergrast, an assistant professor at the University of To-

ronto and attending hematologist in the University Health Network's Red Blood Cell Disorders Program, says a new strategy for care is critical.

"We really need to come up with a national, comprehensive care strategy for these patients instead of treating it like an orphan disease," he says.

People born with thalassemia can't produce the normal hemoglobin they need to produce healthy red blood cells. While carriers of thalassemia minor have no or only slight anemia, those with thalassemia major have a life-long dependence on blood transfusions. It is often only after a child is born with thalassemia major that the parents realize they were both carriers of the condition.

Dr. Pendergrast says that evolving strategies to manage transfusional iron overload, and to safely achieve a cure through bone marrow transplantation and gene therapy, will help improve patient quality of life going forward.

Helen Zivavras, president of the Thalassemia Foundation of Canada, was born in the 60s and diagnosed with thalassemia just before her first birthday.

"Back then, my parents were not aware of this disease and were told that I wouldn't live to see my 18th birthday," she says.

Today Zivavras heads the national organization that supports and funds thalassemia research, treatment, and public awareness.

She says the biggest misconception the public has about thalassemia is that it's a childhood disease and that you can't live a normal life doing things like playing sports, working full time, and having kids. Zivavras, a mother herself, is living proof that outcomes have changed significantly for patients.

She says the most significant development is that thalassemia is now seen as treatable instead of being considered a death sentence.

"Despite the challenges that thalassemia patients continue to face, when they receive optimal treatment many can persevere, thrive and follow their dreams." 

Rob Csernyik



To learn more, visit thalassemia.ca



CHANGING HOW WE BLEED

Innovations Improving Lives in Canada's Hemophilia Community



Dr. Shannon Jackson
Department of Medicine,
University of
British Columbia

Over three thousand Canadians live with hemophilia, a lifelong, inherited genetic disorder that affects the ability to form effective blood clots. For those affected, even the smallest injury or procedure can result in bleeding symptoms ranging from mild to life-threatening. Untreated, this bleeding can cause disability and early death. The good news is that effective treatments exist for most patients in Canada, but the treatment itself can be taxing for both the patients and their families.

"In Canada, we're fortunate that the worst outcomes from hemophilia are not seen as often as before, because of the tremendous health system we have that provides replacement recombinant coagulation factors for patients to use at home by self-infusion, and the 25 specialized medical clinics across Canada that oversee their care," explains Dr. Shannon Jackson of the Department of Medicine at the University of British Columbia, who oversees the Adult Provincial Bleeding Disorders program at St. Paul's Hospital in downtown Vancouver. "The burden of treatment on patients, however, can be significant."

The coagulation factors (VIII and IX), which replace the proteins absent in the blood of hemophiliacs, are delivered by intravenous infusion into the bloodstream, a process that must be repeated over the entire life of the patient. For most patients with the more common form of severe hemophilia, two to four infusions are required every week.

Completing the circle of care

Though this recombinant factor treatment is an improvement over the options available in the past, it can still present a burden for patients, especially the very young. Treating the disorder itself is, after all, only one part of a complete circle of care. "These patients have great medical, physical, social, and psychological needs that are not always as well supported as they could be in Canada due to underfunding of expert clinics," says Dr. Jackson. "Maintaining and expanding the specialized treatment support network is vital in helping patients manage their burden of treatment throughout their lives."

Hope on the horizon

Fortunately, advances in coagulation factor technology are extending the half-life of the treatment, and thus making it practical to reduce the number of infusions and lessen that burden. "In general, with an extended half-life factor VIII or IX product, in our clinic we're finding that we can usually reduce the number of infusion days needed each week by at least one," says Dr. Jackson. "For example, a patient who was self-infusing three times a week may now only need to infuse twice a week. That one infusion a week has a huge impact, especially for children. It's a big deal for the patients and parents who are living this every day."

In addition to these therapies, the future holds promise for continued improvement in hemophilia care, particularly for patients who develop inhibitors, a serious immune response to their coagulation factor therapy. According to Dr. Jackson, "there are innovations that will hopefully change the lives of many hemophilia patients for the better." ●

D.F. McCourt

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STEM CELLS TO THE RESCUE!

Because hematopoietic stem cells normally make all the red and white blood cells that populate the bone marrow and blood, they are the perfect means for restoring blood components in patients with blood deficiencies. Hematopoietic stem cell transplantation (HSCT), known to the general public as bone marrow transplantation (BMT), is a transplant procedure in which hematopoietic stem cells (HSC) derived from bone marrow, peripheral blood, or umbilical cord blood are infused into patients.

HSCT is by far the most routine stem cell therapy. The procedure is most often performed on patients with leukemia and lymphoma to reverse a side effect of conventional chemotherapy. In addition to killing cancerous cells, the chemotherapy also destroys patients' stem cells within the bone marrow. An infusion of HSC replaces these cells with healthy ones, restoring the patient's immune system. Today, there are thousands of new clinical trials underway to explore how to improve HSCT, how best to combine it with other types of therapies, and how to optimize the source of HSC for patients with blood cancers and other blood disorders.

Cancer immunotherapy, a biological therapy that uses natural or artificial substances to imitate or block the natural reactions of a patient's immune cells, is also very promising for treating blood disorders. The idea is to "educate" the immune system to recognize cancer cells as an enemy that it needs to fight.

While the media talks a great deal about the enormous potential of cell therapies, patients should distinguish approved and effective treatments from unproven therapeutic claims. Many clinics worldwide offer stem cell treatments, including those derived from the patient's own cells, but the efficacy and safety of these treatments have not always been scientifically proven, or have not received regulatory or ethics approval. Some of these treatments may be harmful. Therapies without any demonstrated efficacy or safety can be dangerous, worsen the overall health of patients, and even put their lives in danger. All of this is referred to as *medical tourism*. Regulatory authorities are actively targeting these clinics to ensure patient safety, but the public must be aware of illegitimate claims. Before undergoing any treatment locally or abroad, you should always talk it over with your physician.

Patients should also know that receiving these treatments could prevent them from participating in legitimate clinical trials here in Canada, where eligibility criteria are very strict.

While cell therapy and regenerative medicine is evolving at an unprecedented pace, the time required to develop treatments can seem incredibly long to patients who have incurable or debilitating diseases. Scientists, doctors, and regulators are concerned about the safety and well-being of Canadians; they must ensure treatments will improve a condition and not cause adverse side effects. ●

Craig Hasilo, Chief Scientific Officer, CellCAN



For more information about the development of stem cell therapies, visit ilovestemcells.ca

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Regenerative Medicine and
Cell Therapy Network

Photo: University Health Network



Canadian Innovations in Organ Donation and Transplantation

Canadian health professionals have globally led the way in many aspects of transplant research, policy, advocacy, and organ donation.

However, many challenges remain. Among them are a severe shortage of organ donors and poor deceased donation rates in many Canadian jurisdictions. Canadian transplant teams have developed innovative solutions to this problem. One example is using “ex-vivo” technologies, a revolutionary advancement whereby marginal donor organs can be assessed and potentially repaired outside of the human body. First developed for assessment of lungs, and now for livers, kidneys, and hearts, this technology means that previously unsuitable or damaged donor organs can now be successfully transplanted with positive outcomes. Other solutions to the organ donor shortage have related to strategies to improve living organ donation. Canada has a very successful cross-country living kidney

paired-donation program, where pairs of donors and recipients can exchange kidneys with other compatible pairs from anywhere in the country. Canadian health professionals have also led the way in ethics and policy related to potentially contentious issues such as anonymous living donors and public solicitation of organ donors through social media and other outlets. Canadian researchers have played a major role in improving the long-term outcomes of transplantation. One example is through the development of optimal strategies and international guidelines related to prevention of common infections after transplant, as well as best practices related to antirejection medications.

In summary, organ transplantation is a true miracle of modern medicine and Canadians should be proud of their major contributions to the field. ◉

Dr. Atul Humar, Medical Director of the Multi Organ Transplant Program at UHN

THE POWER WITHIN

Harnessing Cellular Tools from Immune Systems to Help Prevent Graft Rejection

While transplantation saves lives, patients living with a transplant keep the possibility of rejecting their donated graft very close to their minds. Although long-term survival and quality of life for transplant recipients have steadily increased, too many patients will be relisted for a second or even third transplant over the course of their lives. In addition, the immunosuppressive medications that put graft rejection at bay suppress all immune responses, putting transplant recipients at increased risk of infections and cancer. To help make immunosuppressive medication more specific, immunologists and transplant researchers across Canada are working together to harness the tools buried deep within our own immune system to prevent transplant rejection.

T cell therapy

Researchers have long searched for ways to boost the immune system’s ability to fight off infections, battle cancer, or dampen responses that cause autoimmune diseases. Promising discoveries have directed researchers to study a type of white blood cell called “T regulatory cells” or Tregs, which coordinate immune responses and maintain immune tolerance in

the body. In the transplant setting, we believe there is potential to use Tregs as a cell therapy to control the body’s own immune responses without altering healthy immune balance. Tregs can be used to block the response of the recipient’s immune system to signals from the transplanted organ graft which ultimately cause rejection.

There are challenges for bringing a Treg-based therapy into reality: one, designing Tregs that are only active in the presence of a transplant; and two, finding an abundant and stable source of clinical Tregs. Both of these challenges are the focus of intense investigation with teams of Canadian National Transplant Research Program investigators across the country — bringing in cell-manufacturing expertise, chemists, computer programmers, industry partners, and international collaborators. We believe that Treg-based therapies are the future for improving transplant tolerance by building a healthy immune system that strikes a balance between attacking infectious or dangerous substances while not reacting to the recipient’s new organs, cells, and/or tissues. ◉



Dr. Megan Levings
PhD, Lead, CNTRP
Strategies for
Immunomodulation and
Transplant Tolerance Project



Dr. Lori J. West
MD, DPhil, FRCPC
Director, Canadian National
Transplant Research
Program



With over 300 scientists, clinicians, patients, trainees, and collaborators working on seven major projects across Canada, the Canadian National Transplant Research Program (CNTRP) is a multidisciplinary program that aims to increase organ and tissue donation, and to improve the quality of life for transplant recipients. Though the national program’s goals are ambitious, effective teamwork and collaboration have so far yielded excellent results.

Dr. Megan Levings and Dr. Lori J. West





Turning Innovative Science into Value for Patients

Astellas is committed to turning innovative science into medical solutions that bring value and hope to patients worldwide. Every day, we work together to address unmet medical needs and help people living with cancer, overactive bladder and transplants, among other conditions. We remain dedicated to meeting patients' needs, and our support for them will never waver.

www.astellas.ca



The Social and *etalk*'s Lainey Lui Turns Caregiver for Her Mother



Elaine “Lainey” Lui is best known for being in front of the cameras as a co-host on CTV’s *The Social* and the senior correspondent on *etalk*. What fans may not know about her is that off-camera, she focuses on being a caregiver for mother Judy Yeung, who’s receiving treatment for POEMS syndrome, a rare blood disorder.

POEMS is an acronym that stands for the signs and symptoms of the disease:

- ▶ **Polyneuropathy**
— tingling and numbness in the legs.
- ▶ **Organomegaly**
— enlarged liver, spleen, or lymph nodes.
- ▶ **Endocrinopathy**
— abnormal hormone levels.
- ▶ **Monoclonal plasma proliferation disorder**
— abnormal bone marrow cells.
- ▶ **Skin changes**
— more colour than normal, increased leg and facial hair.

It’s a type of multiple myeloma, a cancer of the plasma cells which are located in our bone marrow, and affects more than 2,500 Canadians each year. Though incurable, advances in treatment options have boosted the survival rates for myeloma, allowing patients to lead full lives.

POEMS syndrome was something that neither Lui nor her mom had heard of before doctors made their conclusion. It took a few years to get answers, but Lui has been with her mom every step of the way, from a kidney transplant in 2002 to a recent

bout of pneumonia in early summer. She has tended to her physical and emotional needs. “I feed and bathe her,” says Lui, “but I’m also her advocate, her ambassador, and her translator. I’m the one pushing for answers and making sure I get the best work possible out of her doctors.”

It can be very demanding when parent and child reverse roles, with the daughter turning protector and guardian. Lui’s mother prepared her well. She taught Lui a lot about questioning the status quo and being frank and direct. It’s a skill that has served Lui well in her career and as a caregiver of someone living with cancer.

It can be stressful, but there are many moments of joy, too. “My mom is incredibly funny,” says Lui, who lives in Toronto with her husband Jacek and beagles Barney and Elvis. “My friends and family love being around her. She has almost no filter and says exactly what’s on her mind. That creates some hilarious moments.”

Lui’s life is a busy one, split between the demands of being a successful television personality, running her popular website *LaineyGossip.com*, and being a wife and a daughter who helps her mom navigate her way through a complex illness. But Lui has found valuable lessons and things to be grateful for in the midst of it all. “I’ve learned that it’s important to de-stress, whether it’s hanging out with my dogs or exercising,” she says. “And you’ve got to have fun and make the most out of life.”

Michele Spagnole

BECOME AN ORGAN DONOR AND SAVE A LIFE

Time is a precious thing. For the more than 4,500 Canadians waiting for an organ transplant, with 76 percent needing a kidney, it’s often a matter of life and death. Donors have the ability to save up to eight lives, according to the Canadian Organ Replacement Register annual report.

One of the Canadians who can be helped is 10-year-old Nash Overton, diagnosed with kidney disease when he was just two — specifically nephrotic syndrome, which then evolved to focal segmental glomerulosclerosis (FSGS). In the near future, he may need a new kidney.

That’s why Nash, his family, and his community of Williams Lake, BC, have joined The Kidney Foundation of Canada by raising awareness and funds through events like the Kidney Walk: Team Nash has raised over \$38,000 since 2013. “I know what it’s like to not feel good,” says Nash. “I don’t want other people to feel like that, so I want to do what I can to help.”

His mom, Fallon, is happy to share her son’s story. “His illness has been a rollercoaster for us, but it’s important to put a face and a family behind the need for organ donors.”

To become a hero to a Canadian in need, confirm your intention to donate your organs on your health care card, driver’s licence, or online provincial donor registry, and tell someone about your wishes.

Michele Spagnole

Visit kidney.ca for more details



Nash Overton

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Living Life to the Fullest

with a Rare Blood Disorder, Thanks to Innovative Therapies

When doctors see the same diseases day after day, diagnoses can happen quickly. But what happens when a condition is rare? For Barry Kastof, a Montreal businessman, getting answers was a two-year process that ended with a paroxysmal nocturnal hemoglobinuria diagnosis or PNH — a disease that affects only about 100 Canadians with a yearly incidence of 1 to 1.5 in a million.

In May 2001, he was experiencing dark urine in the morning. Doctors didn't know what it was. After seeing two different urologists, a kidney specialist, and then undergoing a number of tests, everything came back negative. "I was determined to get some answers," Kastof says. "I knew something wasn't right, so I kept pushing. I knew that having blood in your urine was not normal."

Finally, a hematologist was able to provide an accurate diagnosis of PNH, a life-threatening blood disease, by determining there was hemoglobin in his urine. This disease originates from bone marrow stem cells that acquire a mutation on the PIGA gene that causes red blood cells to be susceptible to attack by the immune system, thus destroying them faster than the body can replace them. It most often affects younger adults age 35 to 40, and it's difficult to diagnose because of the wide variety of non-specific symptoms, from fatigue and shortness of breath, to severe headaches and abdominal pain, to hemoglobin in the urine.

Challenges in diagnosing rare blood disorders

In early 2003, few doctors were aware of PNH — and worse, there was very

little they could do to treat it. That was especially troubling because Kastof faced some serious fallout due to his condition, including chronic anemia and blood clots, a major cause of death among those with PNH. The average survival after diagnosis is about 10 years, though patients can live for decades with just minor symptoms.

PNH is a progressive disorder, so by 2007, Kastof was reliant on blood transfusions every two weeks. At that time, they were the best treatment available and the most they could do was curb the chronic anemia that comes with PNH. "I wasn't in good shape," he explains. "I could barely walk up a flight of stairs and anything I planned, like going out to dinner, was subject to how I was feeling and whether I could stay awake long enough."

Living life to the fullest with PNH

In 2008, he started a new therapy that blocks the immune system from attacking and destroying red blood cells. The results of this treatment were encouraging. "I'm turning 70 in March and I now lead a full, normal life," says Kastof. "I cycle. I hike. I'm active. Life has reverted back to the way I was when I was 50 years old."

Atypical hemolytic uremic syndrome (aHUS) is another rare disease that is characterized by blood vessel cells being attacked by the immune system, through a similar mechanism to that of PNH. There are challenges when diagnosing this disease because of its various presentations and symptoms. This genetic disease is equally

life threatening, with more than 60 percent of aHUS patients dying, needing kidney dialysis, or having kidney damage within a year of diagnosis. It is also just as rare — affecting one in one million, split evenly between adults and children.

Kastof's journey demonstrates that there is hope for rare blood disorders like PNH and aHUS. He's keen to play his part in raising awareness by sharing his story and helping fellow PNH patients through the founding of the Canadian Association of PNH Patients, which provides support and assists with connecting them to doctors with specific expertise in PNH drug ther-



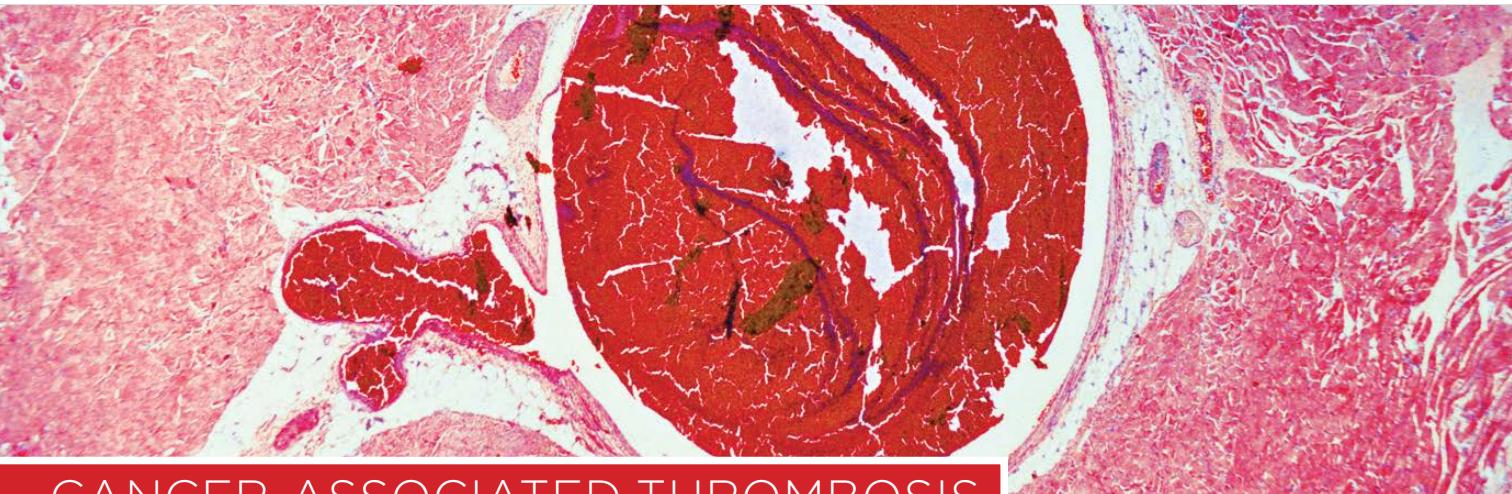
Barry Kastof
President,
Canadian Association
of PNH Patients



I'm turning 70 in March and I now lead a full, normal life... Life has reverted back to the way I was when I was 50 years old.

apies. With better medical treatment available, those with rare diseases can feel good about what lies ahead after a diagnosis. As Kastof points out, "The miracle of these new treatments is that they give people their lives back. Never give up hope!"

Michele Sponagle



Thrombosis in leg vein.

CANCER-ASSOCIATED THROMBOSIS

A Critical Gap in Cancer Care

Cancer-associated thrombosis (CAT) is one of the most common yet preventable causes of death among cancer patients. With over 200,000 Canadians being diagnosed with cancer each year, knowing about causes, prevention, and treatment of CAT will be critical to the quality of life and long-term survival of these individuals.

CAT refers to blood clots that can occur in people living with cancer. They may be related to the cancer, the treatment, or other factors such as the patient's age and genetic risk factors

Two examples of CATs are deep vein thrombosis (DVT), which occurs in legs or arm, and pulmonary embolism (PE), which occurs when a blood clot breaks off and travels to the lungs. "It's quite common as about 20-25 percent of cancer patients develop blood clots at some point during their treatment," says Dr. James Douketis, Staff Physician in Internal Medicine and Thromboembolism at St. Joseph's Health Care Hamilton, Professor of Medicine at McMaster University, and President of Thrombosis Canada.

Despite its seriousness, CAT is often given secondary consideration in cancer care. "It tends to fall under the radar because most of the emphasis is on the treatment of cancer per se, but it's something that deserves more attention because it's a common, preventable cause of mortality in cancer patients," says Dr. Douketis.

Missed or delayed diagnosis

Missed or delayed diagnosis of CAT occurs for many reasons. One is that patients are not adequately informed. "They've not necessarily been given this information when undergoing treatment so they don't know what to look for," says Jackie Manthorne, President

and CEO of the Canadian Cancer Survivor Network, a patient and survivor group that is working to close the CAT information gap.

Another reason is that the signs and symptoms of blood clots in cancer patients may not present as usual or classical symptoms. "The symptoms can be masked or hard to tease out, making it challenging for doctors and other health care professionals to recognize," says Dr. Douketis. For example, patients thinking they have a pulled muscle or a touch of pneumonia may actually have a blood clot.

Diagnosis, treatment, and prevention

Testing for CAT may be done through ultrasound of the legs for a suspected DVT and a computed tomography (CT) scan for suspected PE.

Treatment and prevention can typically include using blood thinners, which work by stopping blood from clotting quickly, with the dose determined by the situation. "For prevention of a blood clot, the dose used is about one-third the dose used to treat blood clots," says Dr. Douketis.

Dosing is critical because blood thinners can also be risky for cancer patients. "These

patients may be at increased risk for bleeding because of their cancer, and the effects of their cancer treatment, so that can make the blood thinning treatment more challenging," says Dr. Douketis.

Survival rates for PE are over 95 percent if the blood clot is identified and treated quickly.

With cancer rates expected to rise as the population ages, so too will the need for education on this potentially life-threatening complication. "Patients need to be empowered with knowledge of DVT so they

can raise it with their health care team before their cancer treatment starts," says Manthorne.

A multi-stakeholder approach is being advocated by many health care professionals and patient support groups to make CAT an integral part of cancer care and ensure patients receive optimal treatment. Increasing preventive measures, early diagnosis, and appropriate treatment of any kind of venous thromboembolism for people living with cancer will help reduce the burden of CAT, including death.

"Greater awareness, research, and advocacy that facilitate open conversations between Canadians and their health care professionals are essential and will help save lives," says Manthorne. ●



Jackie Manthorne
President, CEO,
Canadian Cancer
Survivor Network



Dr. James Douketis
President,
Thrombosis Canada



Dr. Jay Easaw
Medical Oncologist,
Cross Cancer
Institute

Other times, diagnosis can be delayed because "those symptoms are ignored or just attributed to the treatment, like a side effect of the chemotherapy," says Dr. Jay Easaw, Medical Oncologist with the Cross Cancer Institute in Edmonton.

It is therefore critical to recognize the signs and symptoms because some blood clots can be lethal, particularly when they occur in the lungs. "Patients with cancer are at a higher risk of developing these clots, so the sooner the patient recognizes the symptoms and gets proper treatment, the better," says Dr. Easaw.

Symptoms of CAT might be leg or arm swelling and discolouration, persistent chest pain, shortness of breath, and pain or tightness when taking a deep breath.

Anne Pappmehl