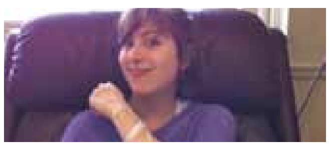
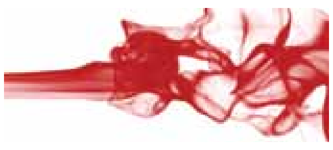
AN INDEPENDENT SUPPLEMENT FROM MEDIAPLANET TO THE NATIONAL POST



Beyond the diagnosis
Coping with Hodgkins Lymphoma



The power of a match
How stem cell research is saving lives

MEDIA PLANET
September 2011

BLOOD CANCER AWARENESS

3
STEPS
TO UNDERSTANDING THESE LITTLE KNOWN CANCERS

"SHE IS OUR HERO"

How David and Rebekah Campbell are facing down the devastating diagnosis of their infant daughter, Molly

PHOTO: PRIVATE

CHALLENGES

FACTS

1

BLOOD CANCERS ARE THE FOURTH MOST COMMON CANCER IN CANADA

Did you know that every 33 minutes a Canadian is diagnosed with a blood cancer? This month, the goal is to increase awareness of these little-known cancers—and create positive change.

Awareness is critical when it comes to blood cancers

Imagine the feeling when you are diagnosed with a cancer that you have never heard of before. Imagine that it took eight months to diagnose your cancer because your symptoms were the same as those of the common flu. Imagine not being able to pinpoint exactly where your cancer is in the body, unlike other cancers that have more apparent locations. These are some of the challenges faced by many Canadians who are dealing with blood cancer today.

A little understood cancer

1 For many people diagnosed with cancer, the journey often begins with symptoms stemming from a specific organ or area of the body, such as a small mass found during a routine examination, or a persistent and unexplained pain. The challenge with blood cancers is that unlike the better known solid tumour cancers that develop when cells grow abnormally and form a mass in a specific organ system, blood cancers are made up of something called "liquid tumours," which occur in the blood, bone marrow and lymph nodes. We all know where our lungs, or prostate, or breasts are, but how about our lymph nodes? In addition to having nebulous symptoms which can make it difficult to diagnose, learning that you have a blood cancer often carries with it the additional burden of having to understand, and then explain to others, exactly what it is you have.

One Canadian every 33 minutes

2 September is Blood Cancer Awareness Month, and having a whole month dedicated to such an unknown group of cancers (which include lymphoma, myeloma and leukemia) is alone a major milestone. But it is also a much warranted designation, since over 15 900 new cases of blood cancers were diagnosed in Canadians in 2010 alone—that's one every 33 minutes. Blood cancers are the fourth most common cancer in Canada, account for more than 43 percent of all childhood cancers, and are rising in incidence rates in young adults, aged 18 to 35. Fifty years ago, there were very few effective treatments for blood cancers and the prognosis was very poor. Significant advancements in research into cause and treatments have been made since then, survival rates have more than doubled, but there is still work to be done.

Sue Robson
Executive Director,
Lymphoma Foundation Canada

AWARENESS IS KEY

- **Take the quiz** at www.knowyournodes.ca, developed by Lymphoma Foundation Canada to educate people about the signs and symptoms of lymphoma.
- **Blood cancers are increasing in people aged 18-35.** Young people have their own complex and unique set of needs when it comes to cancer, so be sure to seek out resources specific to those needs.
- **September 15 is World Lymphoma Awareness Day.** Use this day as an opportunity to learn more about this cancer.

Join our fight

3 Blood Cancer Awareness month is an opportunity to increase the public's understanding of blood cancers and to encourage people to support organizations that deliver educational programs and fund the research that will discover new treatments and, ultimately, a cure. We need to work together to lobby our governments to support blood cancer issues, such as the urgent need for timely access to treatment and care. In addition to supporting these efforts, we hope to bring awareness to every Canadian about the signs and symptoms of blood cancers and the importance of self advocacy in diagnosis and treatment. Only when there is no longer a need for Blood Cancer Awareness Month will we truly be satisfied that our work is done.

New advancements in cancer research

For many blood cancer researchers, it begins and ends with the immune system.

Doctors rely on bone marrow transplants (BMT), to give patients a new immune system to help fight leukemia when regular therapies fail. This can be risky says Dr Kirk Schultz, paediatric oncologist and director of the research program at the Childhood Cancer & Blood Research cluster, University of British Columbia.

"One of the main concerns with BMT is graft versus host disease where the new donor system not only fights the leukemia but also attacks the leukemia patient's body," Dr Schultz explains. "It's a bit like Dr Jekyll and Mr. Hyde. We are trying to learn ways to rein in Mr Hyde's unwanted manifestations, and keep Dr Jekyll's ability to kill the leukemia," he says.

The group wants to learn how to harness the BMT immune forces more effectively, to improve immune therapy for childhood leukemia. "By increasing our understanding of these important immune forces, we hope to also improve the ability to provide safe tissue transplants when needed," Dr Schultz says

Cell conversion

"The ultimate goal of cancer therapy is to destroy cancer cells while leaving normal cells unharmed," says Dr Christine Williams, director of research at the Canadian Cancer Society Research Institute.

The study of cancer stem cells, extensively investigated in leukemia, shows that these cells are highly resistant to radiation and chemotherapy. They are able to "seed" a tumour with numerous progeny cancer cells that grow rapidly. Researchers are trying to identify unique characteristics of these resistant cells in order to target and destroy them. Dr John Dick, a senior scientist at the University Health Network, was pivotal in the discovery of cancer stem cells.

Another area involves converting human cell conversion. For example, at McMaster University, in a project partially-funded by the Canadian Cancer Society, Dr Mick Bhatia showed that adult stem cells can be directly converted to red blood cells and platelets. This breakthrough was published in Nature last November.

"Mick's discovery has important implications for bone marrow transplantation," Dr Williams said. Cancer patients currently either receive matched marrow from a donor or some of their own stem cells taken from their blood which has been previously stored. However, some cancerous cells might be re-introduced into the patient, she said.

In an interview, posted on YouTube, Dr Bhatia said the next step was to take this discovery into the hospital. However, certain questions have to be answered first, such as how many red blood cells can be generated, and can these cells be stored so that they are ready when the patient needs them?

INDRANI NADARAJAH
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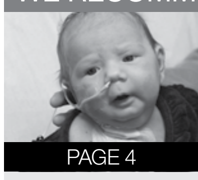
WE RECOMMEND



PAGE 4

"She is our hero"
David and Rebekah Campbell's story of their baby's devastating diagnosis.

"We get a lot of our strength from her. She is a great baby and she's happy. She is our hero."

MEDIA PLANET

BLOOD CANCERS
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DON'T MISS!

How can you get involved?

- Volunteering at one of the many vital associations.
- Participating in one of the many events that happen throughout the year.
- Donate directly to a charity or through one of their fundraising events.
- Put your name on/make yourself available for the stem cell registry.
- Educate yourself about blood cancers and share the knowledge with your friends and family.

AN INCREDIBLY EXCITING TIME FOR MYELOMA RESEARCH

Dr. Donna Reece and her team at Princess Margaret Hospital are on the leading edge of new developments to extend survival of myeloma patients.

There is no hesitation and lots of enthusiasm in Dr. Donna Reece's voice when she's asked to sum up her work: "This is an incredibly exciting time for myeloma research—there's all kinds of potential!"

And Dr. Reece and her research team at Princess Margaret Hospital (PMH) in Toronto are at the forefront. Indeed, since she came to Toronto in 2001 and in 2009 became the inaugural holder of the Bloom Chair in Multiple Myeloma Research, the centre has become a global leader in learning about and treating this incurable blood cancer. The more than $4 million raised to establish the research chair has provided crucial long-term funding which allows the PMH team to do cutting-edge laboratory research while providing innovative clinical care to patients through the more than two dozen studies they usually have running at any given time.

It's all making a difference. "There has been a quantum leap in the management of myeloma," she says. "For years, all we could offer older patients was older oral chemotherapy and, for younger patients for the past 10 or 15 years, stem cell transplants. Now we have several new drug therapies that prolong the period of disease control and add years to survival."

In large part because of recent new treatments such as Revlimid and Velcade, median survival of younger patients has risen from three to five years to close to 10, meaning half live longer than that, and older patients are seeing great benefit as well. "It's the next best thing to a cure," says Dr. Reece, who along with being director of the Program for Multiple Myeloma and Related Diseases at PMH is also professor of medicine at the University of Toronto.

But as yet there is no cure, and treating myeloma requires skilled management of the treatment options. "The goal of treatment is to use each therapy in a way that maximizes how long it will work, before the as-yet inevitable return of symptoms," Dr. Reece says.

Which is why it's crucial, she adds, to have all treatment options available, as well as clinical studies to give patients further options when the first-, second- and even third-line treatments have run their course. The studies also help patients get the newest treatments while waiting for the slow process of the drug being approved and then reimbursed by the health system.

Part of the newest evolution of clinical care is tailoring the treatment choice to the exact nature of the myeloma. "We've discovered myeloma is not just one disease, it's seven or so diseases of different types that vary in aggressiveness and response to particular therapies," Dr. Reece says. The next piece of the research puzzle is finding out what works best, and why, in each disease type.

For example, there is one type of the disease, as identified by chromosome studies, that does not respond well to stem cell transplants. "These patients often get less than a year of benefit from a difficult and costly transplant, but we're seeing they do just as well by starting them right away on the new drugs instead." The next stage of research, which Dr. Reece and her team are very excited to be leading, is to search for a monoclonal antibody therapy that would work against this specific chromosomal abnormality in certain patients. It's the development of targeted therapy.

Dr. Reece has a very non-technical way of summing up what they are doing: "It is really cool!"

She and her team are able to do this world-class research and provide leading-edge treatment through clinical studies thanks to the security of research funding they have through the Bloom Chair, made possible by the leadership and personal funding of Molly and David Bloom, as well as gifts from companies such as Celgene. This allows Dr. Reece to have the infrastructure and the team – there are 13 research nurses and coordinators – to take part in major global clinical studies sponsored by biopharmaceutical companies but also to do their own investigator-initiated research.

It's a complex team and complex work, but at the end of the day there's just one simple purpose, says Dr. Reece: "Our ultimate goal until we find a cure is to help myeloma patients live longer with the best treatment at the right time."

Universal, but far from uniform

In our health system, cancer drug coverage depends on many things, including your postal code

Canadians pride themselves on what they believe to be a universal health-care system, meaning everyone has free access to necessary medical and hospital care from coast to coast. However, dig a little beneath the surface and you discover that this is just not true.

Universality is certainly not the case when it comes to access to medications, and particularly access to cancer medications, including those for blood cancers.

The system of coverage for cancer drugs in Canada is a confusing patchwork that can lead to delays and discrimination in cancer patients getting the treatments they need, when they need them. It can result in outright denial of treatment for some, great financial hardship for others and immense frustration for many - doctors, patients and loved ones alike. In many cases, access to a potentially life-saving drug is decided on the basis of the first letter of your postal code – what province you live in.

Decisions related to drug availability are up to each province, and each province has its own method of deciding not only what cancer drugs will be made available but also to whom they will be made available. There are differences across the jurisdictions based on age, income and in some cases even whether the drug can be taken orally versus intravenously, in hospital. The disparities are many, as is the confusion and often the delay in the decision-making processes. As a result, the mere fact that an innovative cancer drug is authorized for sale by Health Canada as being safe and efficacious is but a first stage in ensuring that all patients who need it will, in fact, get it.

Since early this year, the first step in the reimbursement process for cancer drugs outside of Quebec has been through a new agency called the pan-Canadian Oncology Drug Review (pCODR). This body conducts a review of the clinical benefits and cost-effectiveness of a new treatment to make a non-binding recommendation to the nine participating provinces whether they should fund the drug or not. But, even after a positive recommendation, each province has the right to take its time – and perhaps conduct its own review – before eventually saying either yes or no.

Canadian cancer patients are the ones paying the price for the confusion and delays in the Canadian system of drug reimbursement. Sometimes they have to pay themselves for a treatment they need. As noted in the editorial in the 2010-11 Report Card on Cancer in Canada issued by the Cancer Advocacy Coalition of Canada, "A Canadian who has to choose between the treatment recommendation by the oncologist or the financial solvency of the family has no happy ending."

Writing earlier this year specifically about the clinical impact of drug reimbursement delays on Canadians with the rare blood cancer multiple myeloma (MM), Dr. Richard LeBlanc, a hematologist and oncologist at Montreal's Maisonneuve-Rosemont Hospital, and Aldo Del Col, co-founder and executive director of Myeloma Canada, wrote: "Delays in the access of effective new drugs, which have shown improvement in survival without excessive toxicity, have a negative prognostic impact on MM patients. Evidence-based medicine should prevail over political and financial decisions impacting drug access. In the context of the current system, MM patients potentially face increasingly restrictive access to new, life-extending therapies."

And they concluded: "Political and financial decisions negatively impacting access to life-extending drugs should not be made at the expense of patients with MM. This access limitation to new drug therapies in MM, and cancer in general, raises important ethical issues."

The inequities of the current system and the ongoing progress of new drug development mean that these important ethical questions need to come to the fore of public policy debate across Canada so that the needs of patients and their families are addressed in an appropriate, meaningful and timely way. Until that happens, cancer drug treatment remains far from universal across Canada.

It is tough when your 10-month-old has battled cancer almost all her life, but David and Rebekah Campbell are learning to reap some positivity from their trials.

FACTS
2
LEUKEMIA IS THE MOST COMMON FORM OF CHILDREN'S CANCER

"She is our hero"

CHANGE

It was cruelly ironic—last Christmas Eve, which had promised to be full of joyful anticipation, saw the Campbells at Victoria General Hospital, struggling to come to terms with a devastating diagnosis of their newborn.

Molly, who had been running a fever for one day, was diagnosed with acute lymphoblastic leukemia (ALL).

It came out of the blue. Molly was all of 28 days old, one of the youngest children to be so diagnosed.

She and her reeling parents were immediately airlifted to B.C Children's Hospital for urgent treatment. And there they have stayed, along with their four older children.

One day at a time

It has been eight long months of struggle for the family. Just recently, Molly had a cold and had to be transferred to the ICU for a nerve-wracking stay, says David. Indeed, the simplest ailments can be devastating for Molly's compromised immune system.

ALL represents about one-third of all paediatric cancers. The annual incidence is approximately nine to 10 cases per 100,000 in childhood, and peak incidence occurs in children aged between two to five years old. While great strides have been made in successful treatment, it is a different matter for infants who have the disease.

David recites the grim information unflinchingly—ALL in infants under three months is extremely rare; infants under one year only have cure rates of about 30 percent. Molly's leukemia has genetic markers that make her more resistance to treatment.

Further research is vital. "Because not many very young children are affected by this disease, it attracts far less funding dollars," he notes.

So, the Campbells are working hard to raise the profile of infant leukemia and childhood cancers. To date, they have raised more than $200,000 through a variety of fund-raising ventures—like yogathons, silent auctions, bottle drives and karaoke marathons. "The support we have had, particularly in Victoria, has been amazing."


1

The bone marrow transplant

On June 23, Molly received a bone marrow transplant, and so far, is responding well. "October 1 will be the 100th day of her transplant and if all goes well, we will be able to return to Victoria as a family," David says.

Molly's specialist, Dr. Kirk Schultz, associate professor of pediatrics at B.C. Children's Hospital says bone marrow transplants offer children a higher survival rate than the 30 percent offered by chemotherapy, he said.

At the moment, Molly is doing "very well and I am cautiously optimistic, but she still has a long road to travel," he adds.

Savouring precious time

For now though, Molly's parents are learning to enjoy life, celebrate all five children's progress and value the family time they have together. Whatever else life hurls at them, they will handle it.

David is honest about the effort it takes to stay positive and be emotionally stable.

"If today is a good day, we celebrate it. If it's not so good, we try to manage our feelings so that we're not on an emotional rollercoaster all the time. We can't afford negative thinking because it will affect the kids." Having their children around helps occupy their time, but it's a different matter when they go to sleep at night. David admits that's when the fears and anxieties bubble up.

However, being at the hospital all the time, witnessing the struggle of other parents and children also reminds them of the blessings they do have, he says.

Despite her health challenges, the Campbells have big dreams for their little girl. "We get a lot of our strength from her. She is a great baby and she's so happy. She is our hero."

They hope she will be a positive force for good in this world. Indeed, she already is. Molly's Facebook page has postings by other parents of children dealing with cancer, who gain inspiration and strength from her triumphs.

"Our dream is that she grows up healthy and strong. If she has learning difficulties, we will deal with that. We hope that she will do incredible things with her life," says David.

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Does "ageism" influence access to treatment?

Aplastic Anemia & Myelodysplasia
ASSOCIATION OF CANADA

Campaign seeks to ensure older patients with myelodysplastic syndrome get chance to benefit from new therapies

The number of Canadians age 65 or over is expected to double over the next 25 years, reaching 10.4 million by 2036. At the same time, more new therapies are being developed to treat diseases that primarily affect the elderly, such as the bone marrow failure disease myelodysplastic syndrome (MDS).

This makes the question that concerns Dr. Richard Wells and the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) all the more relevant – are older Canadians with MDS getting the access they deserve to treatments that could help them?

Dr. Wells is co-director of the MDS program at the Odette Cancer Centre of Sunnybrook Health Sciences Centre in Toronto and chair of AAMAC's Medical and Scientific Advisory Committee. "We don't like to consider that we might be denying people treatment because they are older, but undoubtedly we do," he says. "The supposition too often is that people who are older are reluctant or unable to have certain treatments, but to use chronological age as the main or sole criterion is a mistake."

One of the reasons this issue of "ageism" is more relevant in MDS, said Dr. Wells, is that the median age of diagnosis is 70 and until very recently there were no effective treatments. Doctors have been used to simply being able to help patients with supportive care such as blood transfusions and then palliative care. "Now that there are effective new treatments, we require a change of thinking by physicians," he says. "Older patients should be referred for treatment."


Dr. Richard Wells
Co-Director, MDS Program,
Sunnybrook Health Sciences Centre

> "We don't like to consider that we might be denying people treatment because they are older."

The problem is not just a Canadian one and AAMAC has teamed up with similar associations and physicians in other countries to launch a campaign called "Life Beyond Limits." It aims to provide the education needed to ensure older MDS patients get treatments that could help them. It's not just aimed at doctors – patients need to know that treatments are available so that they can ask their physician about them.

"This is an important cause for AAMAC," says the association's president, Chris Meyer. "We want to help ensure that everyone with MDS has the best possible quality of life regardless of their age."

A recent success story is that of Robert Kupferschmid of Ottawa who, as he says, "had MDS." In early 2010, at age 60, he had a blood stem cell transplant, something that wouldn't have been considered years ago for someone of his age. After five months of recuperation at home, he returned to work.

A vital element to his successful treatment was the generosity of an unrelated donor provided through the Canadian Blood Services' One-Match Stem Cell and Marrow Network.

"I've had wonderful and enriching experiences treating people of advanced age," says Dr. Wells, recalling a World War II veteran diagnosed with MDS at age 88. He got treatment and is now still going strong into his 90s. "The last time I saw him he was so grateful. I told him, 'You fought Hitler for me, it's the least I can do!'"

For information about the campaign, go to www.mdslifebeyondlimits.org. For more about AAMAC, including the free Education Day for patients, families and healthcare providers in Vancouver on October 22, 2011, visit www.aamac.ca or call 1-888-840-0039.

FACTS

What is MDS?

Myelodysplastic syndrome (MDS) is a group of disorders in which the bone marrow fails to make healthy blood cells.

Symptoms can include fatigue, bruising or bleeding and frequent infections. About a third of patients develop acute myeloid leukemia.

The number of newly diagnosed people with MDS is not well known since it is often undiagnosed, but is estimated at 1,600 per year in Canada. Incidence increases with age and the median age of diagnosis is 70, although cases are also found in children and younger adults.

Historically, the main treatment for MDS has been regular blood transfusions to treat the anemia resulting from MDS. In the last few years, new effective drug treatments have become available to treat MDS.

Bone marrow or stem cell transplants is the only known cure, however many patients are not eligible for this treatment due to their health or the lack of a matching donor.

INSPIRATION

2

3

1. Molly was only 28 days old when she was diagnosed.
2. Molly is currently experiencing positive results from her treatment.
3. Molly and her four siblings.

PHOTOS: PRIVATE

!
SPECIAL EVENTS

September

1 Blood Cancer Awareness Month

Thursday, September 15th

2 World Lymphoma Awareness Day

Thursday, September 22nd

3 CML Awareness Day

Sunday, October 16th

4 Multiple Myeloma March

Various Dates in September & October Across Canada

5 Lightthenight.ca

MYELOMA CANADA
MAKING MYELOMA MATTER

Myeloma Canada is the only national organization devoted exclusively to the Canadian myeloma community. Working with leading myeloma researchers and clinicians as well as other cancer organizations and local support groups across Canada, we seek to strengthen the voice of the Canadian myeloma community and improve the quality of life of myeloma patients and their caregivers by:

- Providing educational resources to patients and caregivers
- Increasing awareness of the disease and its effects on the lives of patients and families
- Promoting clinical research and access to new drug trials in Canada
- Facilitating access to new therapies, treatment options and health care resources

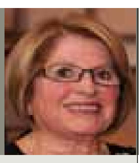
For more information, visit ***myeloma.ca*** *or call*
1-888-798-5771

Multiple myeloma (or simply **myeloma**) is an incurable but increasingly treatable cancer of the plasma cells, a type of white blood cell found in the bone marrow. It can lead to anemia, infections, bone damage, osteoporosis, severe pain and kidney failure. Early symptoms may include fatigue, recurrent infections and bone pain. To date there is no known cause for myeloma.

MYELOMA FACTS

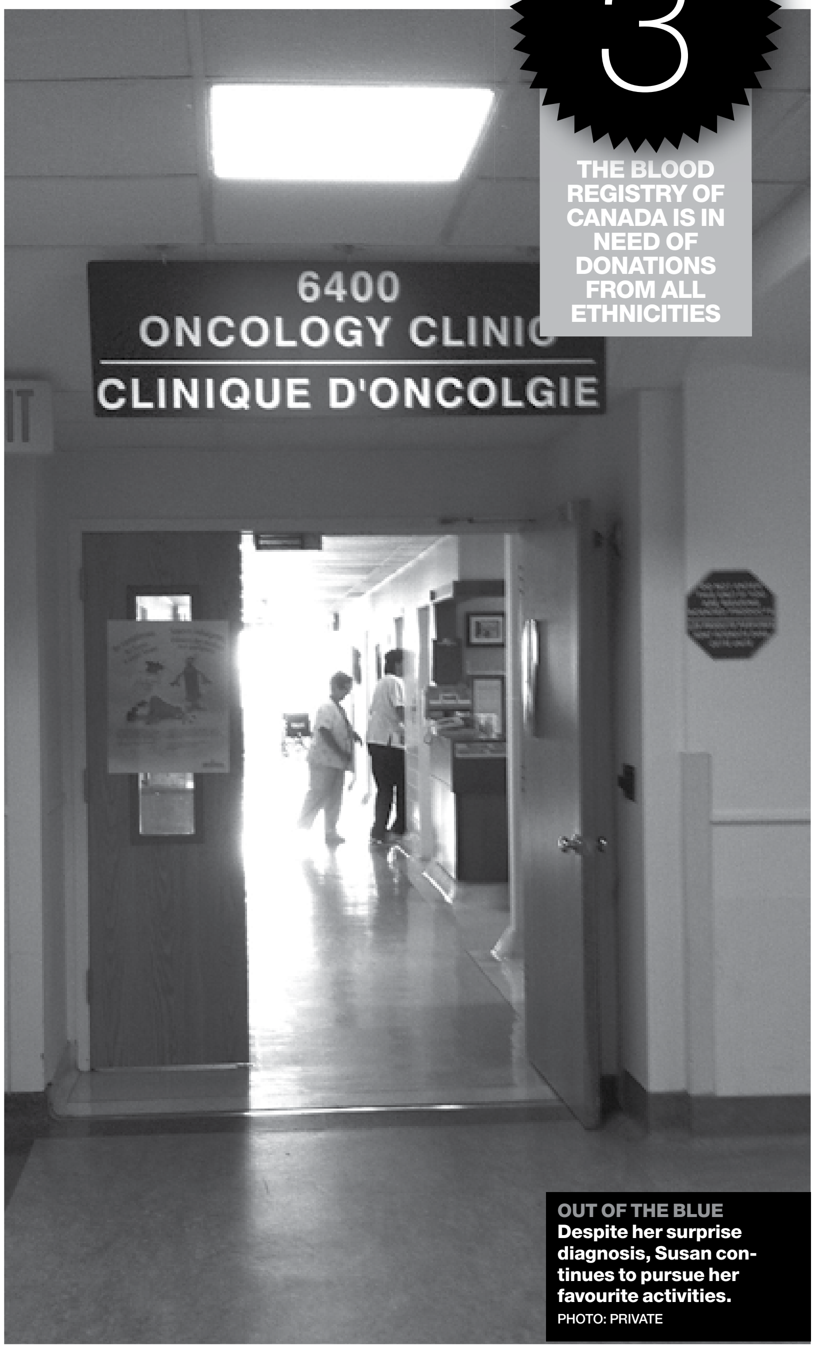
- **7,000** Canadians are living with myeloma
- **2,400** new myeloma cases are diagnosed annually
- **1,370** deaths are attributed to myeloma every year
- **7** Canadians are diagnosed with myeloma every day

PANEL OF EXPERTS

	Aldo Del Col Executive Director, Myeloma Canada 	**Sue Robson** Executive Director, Lymphoma Foundation Canada 	**Cheryl-Anne Simoneau** President, The CML Society of Canada 	**Lorna Warwick** Senior National Director, Leukemia & Lymphoma Society of Canada 
Question 1: What is the most important thing people do not know about blood cancers?	**Because multiple myeloma,** lymphoma and leukemia are all commonly referred to as blood cancers, people tend to view them as being alike, and although there are similarities, each in fact is quite different. This is especially true in the treatment approaches used, where a drug that is effective for one blood cancer unfortunately has no effect on another.	**To begin with,** many people do not realize that lymphoma is even a cancer, and for those that do, that it is not necessarily a death sentence. Though we do not have a cure for all lymphomas, many people diagnosed with lymphoma can live a wonderful life for many years. I would say that most of the awareness needs to come around learning the signs and symptoms of lymphoma, especially around knowing your nodes, since the general symptoms are similar to other ailments.	**Every day, 55 Canadians** will be diagnosed with some form of blood cancer—Every day approximately 20 Canadians will die from some form of blood cancer (Canadian Cancer Society Statistics). Chronic Myelogenous Leukemia is a very rare form of Blood Cancer. Up until a decade ago 50 percent of the 450 people diagnosed every year would die within the first few years of diagnosis, making it a nearly always-fatal disease as with some of the other forms of blood cancer.	**Blood Cancers affect people** of all ages, from newborns to our most elderlycitizens. While it's true leukemia and lymphoma account for almost half of childhood cancers, far more adults are diagnosed than children, with lymphoma being the fifth most common cancer in Canada. Almost 16,000 Canadians will be diagnosed with blood cancer this year, or someone every 33 minutes. Survival rates vary a great deal depending on the type of blood cancer diagnosed, but a Canadian dies from a blood cancer every 76 minutes.
Question 2: How has living with blood cancers changed over the last 10 years?	**The last 10 years** have witnessed a step-change in the treatment landscape, especially for multiple myeloma. The introduction of the "novel agents" (thalidomide, bortezomib and lenalidomide) in new treatment protocols has had a significant positive impact on patient outcomes. Ten years ago, with very limited treatment options, average survival rates were between three and five years. Today, many patients can look forward to much longer and productive lives. Although no cure has thus far been found, the hope is that myeloma will soon be transformed into a chronic condition.	**In the last 10 years,** new treatments have been developed that are far less toxic and much more tolerable than chemotherapy, and some of these new treatments are extending people's lives by many years. We are very excited about the number of new treatments that are available now and coming down the research pipeline. Another change we've seen in recent years is that, for some demographics, the incidence of lymphoma is rising... but of course, this just motivates us even more to find a cure	**While much progress has been made** in treatments and Stem Cell Transplants, we still need major research and developments done in this area. Blood cancer ranks as the number four killer, following Lung, Breast, Prostate, Pancreas (Canadian Cancer Society Statistics). With Chronic Myelogenous Leukemia, we are starting to use the word cure and some patients can stop treatment and not have a recurrence of their disease. We need to pursue these studies here in Canada. We need to replicate this success for other blood cancers as well.	**More people survive** due to new treatments discovered through successful research. Targeted drugs called TKIs have increased five-year survival for Chronic Myeloid Leukemia from 55 percent to over 90 percent. Most patients take one pill/day to keep their cancer in remission without having to change their lifestyle. Amazing! These drugs are now also used to treat other cancers and potentially auto-immune diseases. Another class of drugs, monoclonal antibodies, has increased survival for some lymphomas and chronic lymphocytic leukemia. Traditional chemotherapy regimens have also been 'fine'-tuned' to decrease side effects.
Question 3: What advice would you give someone newly diagnosed with a blood cancer?	**Educate yourself.** Join a support group. Become involved. Advocate for yourself. Although a blood cancer diagnosis is a significant life-changing event, life will continue, and with new treatment choices available, patient outcomes continue to improve. Everyone has their own personal approach in coping with the new reality, but taking charge of the situation by learning about the disease and treatment options is a constructive and affirmative approach. Reach out to other patients to share your experience. And don't be afraid to ask for help from friends, family or your healthcare team.	**Being diagnosed is scary,** but I always tell people not to panic; there is much hope. It is important to empower yourself by being informed and knowing your options. Get the opinion of a key opinion leader in lymphoma but remember that you are a partner in your healthcare plan. Join a lymphoma community so you don't feel alone, and remain hopeful. Reach out for support—we're here to help.	**Do not abdicate** your responsibility to get informed and get involved in your treatment. Your health care team needs you to work with them, in a partnership to improve your care and success at survival. No one can advocate better for you than you. Become aware and active of patient led organizations for your disease, support them with your involvement at whatever level you can. As patients we must always remember – "Nothing about us without us"!	**A Cancer diagnosis** is overwhelming. There's a lot to absorb in a short timeframe and most patients are not cancer experts. Please get support and information from a credible resource to help you understand your diagnosis and make treatment decisions. Advocate for your own health. Don't be afraid to ask for a second opinion. Ask about clinical trials to see if there is a new treatment being studied that may be a better choice for you. There is very promising research under investigation. Be hopeful!

FACT 3

THE BLOOD REGISTRY OF CANADA IS IN NEED OF DONATIONS FROM ALL ETHNICITIES



OUT OF THE BLUE
Despite her surprise diagnosis, Susan continues to pursue her favourite activities.
PHOTO: PRIVATE

Beyond the diagnosis:Hodgkins Lymphoma

I can't remember the first time I ever heard of lymphoma, but I will always remember the first time I heard it in reference to myself.

I was lying on a stretcher in the back area of emergency at the Moncton Hospital. I'd just received my second CT scan of the day. The first one to check out swelling I had in my throat. The second one to see if there were blood clots in my chest after discovering one in my jugular vein.

"Do you think it's Hodgkins Lymphoma?" I heard my family doctor ask on the phone behind the curtain. He'd stopped to make the phone call moments after nodding to me as he breezed passed my bed. I thought he was in the hospital for other reasons and dropped by to check up on me. He was the one who sent me to emergency that day after informing me of the blood clot.

Out of the blue

I, in my infinite 25-year-old wisdom, had been treating the clot with Icy/Hot for the past week thinking it was a neck strain. But once my mother saw the swelling and colourful veins spreading through my throat and chest, it was over. And suddenly I lay in the emergency room, wondering "Hodgkins Lymphoma. I think that has something to do with cancer."

My parents and I watched in anticipation as my doctor hung up the phone and grabbed a chair.

"Oh no," I thought. "Why does he need to sit down to talk to me?"

The rest is history. That second CT scan revealed a 14 centimetre mass in my chest caused the blood clot, with cancerous nodes spreading into the base of my throat and underarms. It was lymphoma. It took three biopsies and a month in the hospital to get my Hodgkins diagnosis. The "Golden Kids" we're called, because of our high survival rate.

Before cancer, I was a personal fitness trainer, nutrition specialist, and lived a healthy and active lifestyle. I ran races and ate big salads, blogging about it on The Great Balancing Act. Cancer was the last thing on my mind. I thought I was doing everything right.

My diagnosis was a complete shock to everyone around me. I was at the gym working out the day before being admitted to hospital. It just didn't make sense. But then again, when does cancer ever make sense?

PHOTO: PRIVATE

Forging ahead

I am currently five treatments into chemotherapy and happy to report the mass is melting away. I still have most of my hair, my appetite is good, and I even just started yoga again.

"Lymphoma" to me is now a word of many definitions. Life does not end with a diagnosis. There are a lot of bad days with cancer, but I take advantage of the good days when I get them. I will never be thankful that I learned the definition of lymphoma at such a young age, but it has opened my eyes to a new way of living. One where health doesn't mean running and big salads, but more about enjoying my days on this planet. And yes, that includes cracking jokes in the chemotherapy chair.

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Stem cells: The power of a match

■ **Question:** Why are stem cells so important for cancer patients?
■ **Answer:** They can give them a new lease on life.

"Stem cells saved my life," says former leukemia patient Doug Stiles.

The grandfather and motorcycle lover underwent a bone marrow transplant on September 27, 2009, slightly over a year after he was first diagnosed with acute myeloid leukemia (AML).

He is very grateful to the person, a non-Canadian, who donated the bone marrow, because life is good now.

"This time last year, I was 120 pounds. Today, I am 180," he says. He has also felt well enough to take his beloved motorcycle out for long spins.

What are stem cells?

Stem cells can develop into many different cell types in the body during early life and growth. When a stem cell divides, each new cell has the potential either to remain a stem cell or become another type of cell with a more specialized function, like a red blood cell, or a brain cell.

The Canadian Blood Services Registry's OneMatch Stem Cell and Marrow Network helped Stiles find a matching donor. "Less than one third of patients who need stem cell transplants find a compatible donor within their own family," says OneMatch Spokesperson Mary Lynn Pride.

OneMatch is also a member of an international network of registries, enabling it to search more than 11 million donors on over 50 registries in other countries. This has significantly increased the odds of being able to find a matching donor for any patient.

Going out to the community

Public awareness of the importance of stem cells is higher these days, but one of the Blood Service's most important initiatives is to raise the profile of its OneMatch registry among the different ethnic communities in Canada.

"We need more representation of the multi-racial mix that is Canada, in our own databases," says Pride.

Having booths at community events, for people to get information on the donor program, has been highly successful. The banners also sport slogan that appeal to ethnic pride, for example, "Save a Latin Life."

These efforts are paying off, with the database's ethnic diversity increasing from 12 percent in 2007, to 22 percent in 2011.

"The education of the general population is really important. Also, our online initiative is a highly popular avenue for us, particularly among the university students."

One Match hopes to get more donors from the 17 to 39 age group, as their stem cells have better long term outcomes, she added.

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NEWS

The future of cancer research and drug development

In the last 30 years, cancer drug development and marketing duration ranged between 10 to 12 years.

Recently this timeline has been significantly shortened to about four to seven years due to increased efficiencies in drug development process, rapid patient enrollment through globalization of clinical studies and the introduction of fast track review by some Health Authorities.

Therapeutic clinical trials are necessary to improve current available therapies particularly of serious illnesses such as cancer (oncology). Every year, several hundreds of different clinical studies in oncology are performed in Canadian Cancer Centers bringing several hundreds of millions of dollars in research income, and job creation, into these centers. Some of these studies have been driven by International and National cooperative groups but the largest number remains those financed by the pharmaceutical industry as a sponsor for registration of new drugs. All clinical trials performed in Canada in oncology represent between 15 to 20 percent of the overall available cancer patient's pool.

A deeper look

Canadian physicians and investigators have been renown in delivering high quality and quantity of clinical data supporting study completion with the standards expected by major health authorities (US, Canada, EU). Some of the main drivers of their success in bringing the clinical studies in Canada were related to the high quality of our Canadian investigators' work, skills and then lower drug development costs. Because of these key factors, Canadian investigators earned even greater respect and exposure for their clinical expertise from their International peers while publishing their research in Medical Journals.

Why outsourcing occurs

From a pharmaceutical perspective, there is a fixed global budget allocated to study and bring a drug onto the international market with the highest quality expected by the health authorities for their approval. With the availability of new emerging countries such as China, India and Eastern Europe, it is now easier to recruit faster the number of patients required to complete large registration studies for drug approval and at lower cost to the Pharmaceutical company. Similar clinical services are provided at a lower cost per patients enrolled, Hospital administrative fees, and exchange rates, when compared to the United States, Canada and some of the EU countries. Canadian investigators are slowly being displaced for newer studies, by these investigators from emerging countries contributing to accelerating the process of pushing out Canada's participation in new innovative studies. As an immediate consequence on Canadians, are the opportunity limitations for patients, investigators, provincial governments, hospital / cancer centers, and Academia, to benefit from studying new innovative drugs in Canada, benefiting from early access to new drugs in development.

A toll on taxpayers

By reducing the Pharmaceutical sponsored clinical studies in Canada, the tax payers, will have to pay significantly more to sustain an already overwhelmed healthcare system. The Provincial financial burden in treating cancer patients will increase as those costs, no longer taken care by the pharmaceutical research, will be passed on to Governments.

It is time for our Canadian political Leaders to re-assess some new strategies on how to ensure that new Clinical research is not displace outside of Canada, and offering more attractive options other than the current tax credit offered to the Pharmaceutical Industry.

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Betsy Gross, *Lilies and Carp*
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