



Bringing liver research to life

2012 ANNUAL REPORT

CANADIAN
LIVER
FOUNDATION



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COVER STORY

Jack was born with biliary atresia, a condition in which the bile ducts leading from the liver to the intestines are blocked or absent thus leading to severe damage. To save his life, Jack had to undergo surgery – known as the Kasai procedure – at only six weeks old to attach a piece of his intestine to restore bile flow. Today, Jack – pictured on the cover holding his grandmother's Reggae Marathon finisher's medal – is a happy, energetic five year old who loves building with Lego and playing with his younger brother. Because the Kasai procedure isn't a cure however, Jack may still need a liver transplant someday.



Research can remove the obstacles in the race to save lives.



As both a researcher and a clinician, I have been faced with the challenges of not only finding the answers to liver disease but also putting them to work in the treatment of patients. Unfortunately, getting from point A (the lab) to point B (the bedside) is a race against time – a race fraught with obstacles and life and death consequences for failing to finish.

For a patient, the first hurdle is getting diagnosed. Liver tests are rarely included as part of regular doctor or clinic visits and few physicians routinely perform tests for liver diseases like viral hepatitis because they do not perceive their patients as being at risk. When and if a patient is diagnosed with hepatitis or fatty liver disease, the question is, what comes next? Another hurdle. Liver specialists are few and far between in Canada and their waiting lists can be up to a year. Once a patient is able to see a liver specialist, he or she may find out that there is a treatment available for the disease – but again, another hurdle. The treatment needed may not be eligible for reimbursement and if the patient does not have private coverage, it may be beyond their reach financially. So herein the race can be lost.

Doctors too are in this race. Many forms of liver disease still do not have effective treatments. This means doctors must try different interventions with the hope that one will reduce the symptoms and delay the progression of the disease thus buying time. In other cases, the hurdle is that effective treatments exist but they cannot be used because of financial constraints. This is a situation that my colleagues and I are all too familiar with and nothing is more frustrating than having the skills and knowledge to help but not being able to access the tools you need.

In 2012, the Canadian Liver Foundation (CLF) initiated the creation of a report – *Liver Disease in Canada: A Crisis in the Making* – that highlighted the race against time that exists in liver health care in this country. It showed that a bleak future awaits us if we stick with the status quo: liver cancer rates skyrocketing, fatty liver disease overtaking hepatitis C as the leading cause of liver transplants and most alarming, Canadians suffering and dying from preventable and sometimes curable liver diseases.

And yet there is cause for hope. Research can save lives – if we let it. Over the past 20-30 years, research has fueled a greater understanding of many forms of liver disease. We now know how to recognize them, test for them and, in some cases, treat them. What we have to do now is remove the obstacles standing in the way of us using this research for the benefit of all Canadians at risk of or living with liver disease.

Our liver disease report shows where we can intervene to change the future. We have made 21 recommendations that could help reduce morbidity and mortality rates over time, including liver testing as part of annual physicals, universal hepatitis C testing for adults born between 1945 and 1975, hepatitis B testing for immigrants and expanded facilities for managing liver cancer. If we act upon what we already know about liver disease, we could save lives and health care dollars.

Admittedly, there are still gaps in our knowledge and this is where more research is needed. In 2012, we continued our commitment to seeking answers by funding more than \$800,000 in new grants to both established researchers and new investigators. These 11 projects covering a variety of diseases including autoimmune hepatitis, hepatitis B and C, liver cancer, primary biliary cirrhosis (PBC) and fatty liver disease, will help to further our understanding of how to prevent, diagnose and treat these conditions.

Ultimately, to win the race, Canada needs a national liver disease strategy. The CLF has taken the first step by publishing our report and we look forward to working with governments, health agencies, professional associations and other stakeholders to find innovative ways to improve prevention, surveillance, research capacity and patient care.

In closing, I would like to thank my colleagues who assisted in the creation of our landmark report as well as the CLF's loyal donors, volunteers and staff who continue to support our efforts to improve liver health care in Canada. Together we can – and will – improve the future for all Canadians with liver disease.

Morris Sherman, M.D., FRCPC
Chairman & CEO

Liver disease, a problem too big to be ignored any longer.



To be treated or cured of a disease, you must first realize that you have it. Therein lies the challenge with liver disease. The liver is a complex, multi-tasking and uncomplaining organ that continues to function when up to 70 per cent of it is damaged. By the time you see obvious symptoms, it may be too late.

No one knows this better than comedian Mike MacDonald who was diagnosed with hepatitis C in 2012. The diagnosis took him by surprise, as did the idea that he would need a liver transplant to save his life. Wanting to help others avoid his fate, Mike partnered with the Canadian Liver Foundation to film a public service announcement encouraging people to get tested for hepatitis C.

Unfortunately, Mike is only one example of a person who has been blind-sided by a liver disease diagnosis – there are many, many others. In his case, Mike falls into the ‘baby boomer’ category – a demographic that carries the highest risk of having been exposed to hepatitis C. In 2012, the CLF issued a recommendation that everyone born between 1945-1975 should undergo a one-time hepatitis C test. We know that there are a lot of people like Mike who may have contracted the virus decades ago but have no idea that their livers are slowly deteriorating.

What happened to Mike is a microcosm of what is happening in Canada and throughout the world on a larger scale. Liver disease has been unseen, misunderstood or simply ignored to the point where it is now too big and too serious to avoid any longer. Symptoms of this health crisis are now making themselves apparent in increasing liver cancer rates, rising acute care costs and liver-related mortality rates. The CLF has been working to educate the public, the media and government policy makers that ignoring liver disease is only going to make things worse, not better.

The CLF is not alone in our efforts to raise the alarm. Liver disease organizations around the world are seeing the impact of this health crisis on their populations and their health care systems. In 2012, we launched the International Liver Health Alliance (ILHA) – a collaboration of our global counterparts committed to sharing education and research resources to help put liver disease on a world stage. In our discussions, we have uncovered many common themes – ignorance and stigma associated with liver disease and a lack of public policies, treatment capacity and research to address this serious health issue. By working together, we can learn from one another and unite our voices in calling for change.


It is only fitting that the theme of this year’s report is ‘*Bringing Liver Research to Life*’ since the end of liver disease begins with research. Everything we understand today about how to prevent, diagnose, treat and even cure liver disease, came as the result of research. The CLF is proud of the role that we are playing in getting these key learnings into the hands of those that can put them into action – whether that be doctors, patients or the public. Throughout this report, you will see a few examples of how we translate and share knowledge.

None of this would be possible however without our dedicated donors, volunteers, partners and staff across the country. We are grateful for your commitment to our cause and your contributions to helping all Canadians with liver disease.

While liver disease is looming large, the good news is that we are continuing to marshal forces against it. Together we can act now to save lives.

A handwritten signature in dark ink, reading 'Gary A. Fagan'. The signature is fluid and cursive, with a large, stylized 'G' and 'F'.

Gary Fagan
President



It is estimated that 3.4 million people in this country are living with some form of liver disease. Some know it, some do not. To reach those that are unaware that they are at risk, the CLF uses public awareness campaigns to encourage people to learn about liver health and to talk to their doctors about getting liver tests to ensure liver problems are identified as early as possible.

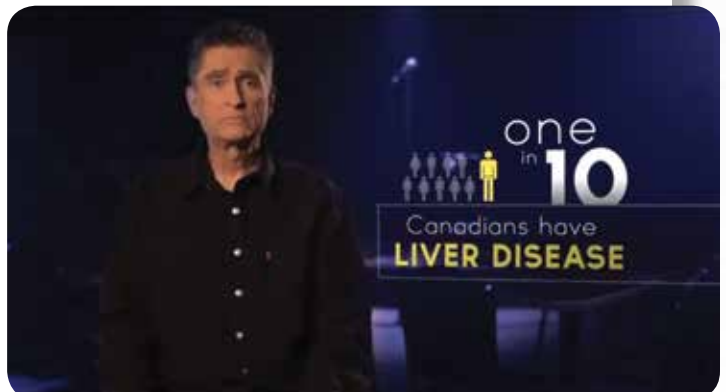
For the thousands of Canadians who have been diagnosed and are living with the day-to-day challenges of liver disease, the CLF offers information, support and a way to connect with others in the same situation.

The following are a few examples of our outreach efforts in 2012.

Hepatitis C: It's no laughing matter

Mike MacDonald, a Canadian comedian, was diagnosed with hepatitis C in 2012. The diagnosis took him by complete surprise and unfortunately came too late for treatment to be effective. Only a few short months later, Mike launched a public search for a living donor because doctors told him that he might not have time to wait for a deceased donor organ.

Mike soon realized that his experience was not unique. There were thousands like him unknowingly living with hepatitis C. Mike wanted to do what he could to help others avoid his fate. His timing was perfect since the CLF was about to launch a hepatitis C awareness campaign targeting baby boomers – the age group with the highest prevalence of the disease. We called and asked if Mike would be willing to film a public service announcement for us. Despite his ill health, Mike agreed to donate his time for this important initiative. Thanks to Mike's help, the PSA combined with the CLF's outreach efforts put the issue in the spotlight achieving more than 22 million media impressions.



World Hepatitis Day

July 28 marks World Hepatitis Day, a global effort to attract attention and provoke action on a health issue that affects more than 750 million people in virtually every country. The CLF spearheaded the launch of Canada's first World Hepatitis Day in 2008 featuring the theme 'Am I Number 12?' which highlighted the fact that one in 12 people around the world have hepatitis B or C. Heading up a coalition of patient organizations and medical associations, the CLF led the development of 12 asks for federal and provincial governments covering prevention, surveillance, treatment and research for hepatitis B and C.

For World Hepatitis Day 2012, the CLF launched its new hepatitis C 'Get Tested' campaign featuring Mike MacDonald and CLF staff and volunteers in Winnipeg, Toronto, Ottawa and Montreal collaborated with other community-based organizations in events which attracted both public and media attention. In Winnipeg, 100 volunteers, including eight people living with hepatitis, lined up over the noon hour in a popular downtown area wearing 'Am I Number 12?' t-shirts. This 'In the line-up' event offered media and the public an opportunity to listen to the stories of patients to help dispel some of the myths around hepatitis. In Toronto and Ottawa, World Hepatitis Day barbecues and health fairs helped promote hepatitis awareness, while in Montreal, CLF partnered with a variety of sponsors to hold an all day event with music, dance and health promotion activities like quizzes for prizes.



Photo credit: Betty Esperanza

Providing answers when they are needed most

Liver disease often takes people completely off guard resulting in confusion, fear and a lot of questions. While doctors can help answer some of these questions, they often do not have time to cover everything they might want to with their patients in the midst of jam-packed appointment schedules. Facing a bewildering array of information on the internet and through other sources, patients need a resource they can rely on, and that's where the CLF comes in.

For patients and families with more questions than answers, the CLF is just a phone call, email, visit, tweet or Facebook post away. In 2012, CLF staff and volunteers responded to more than 4,000 phone and email enquiries in English, French, Cantonese and Mandarin. We reached an additional 120,000 via our print materials and our website hosted an average of 50,000 visitors per month. For patients and caregivers who want to talk about their daily challenges with others who have gone through the same experience, we offered Living with Liver Disease sessions as well as a Peer Support Network. Last year, the Peer Support Network expanded to 70 volunteers who help ensure that no one has to live with liver disease alone.

Each year, thousands of Canadians show their support for the Canadian Liver Foundation by doing what they enjoy the most, whether that be running, walking, shopping, dancing, bowling, golfing or pedaling a really big bike. Regardless of what they choose to do, the end result is they all help raise funds for research and education which benefits the estimated 3.4 million Canadians with liver disease.



LACE UP for LIVER

In 2012, the CLF revamped our marathon training program giving it a new name – Lace Up for Liver – and a new tropical destination – the Reggae Marathon, Half-marathon and 10K in Negril, Jamaica. This year's team was made up of first-timers ranging in age from 25 to 60 and hailing from Alberta to Newfoundland. Each team member was running or walking for a different reason: for Liz and Emil Magera, it was their five-year-old grandson Jack (pictured on the cover) who has biliary atresia; for Marsha Doucette, it was her Dad who has hepatitis C and did the race with her; and for Scott Hearn, it was his Mom who had had a liver transplant.

After months of training and fundraising, the team members all achieved their goals and celebrated at the finish line. Together the team raised more than \$40,000 for liver research!



Photo credit: Betty Esperanza



What a Girl Wants...

For women looking for fun and indulgence, What a Girl Wants is the place to be. Our annual 'party with a purpose' features live entertainment, fashion shows, dancing and silent and live auctions with everything from exotic trips and adventures to signature handbags and sought-after accessories.

In 2012, What a Girl Wants events in Vancouver, Edmonton, Winnipeg, Toronto, London, Ottawa and Halifax attracted 1,100 people and helped raise more than \$217,000.

LIVERight

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STROLL FOR LIVER

Each year in late spring and early summer, individuals, groups and families gather in local parks or, in some cases, downtown urban areas, for our annual Stroll for Liver. In 2012, the CLF hosted 11 Strolls in Calgary, Edmonton, Gimli, Grand Manan Island, Toronto, London, Montreal, Moose Jaw, Ottawa, Red Deer and Saint John raising more than \$176,000. The events attracted over 1,000 participants who enjoyed live music, games, activities and great food before, during and after their walks.



Indy Bike Race

Think of it as the Indianapolis 500 without the gas fumes, noise or breakneck speeds. In September 2012, 24 teams in Calgary and Edmonton raced around tracks in 8-person pedal-driven indy bikes. Each team competed in two heats and the team with the best time took the checkered flag and the bragging rights. Regardless of where they finished however, all the teams deserved congratulations for helping to raise \$46,000 for liver disease research and education programs.

LIVERight Gala

The annual LIVERight Gala held in Vancouver honours groups and individuals that have made significant contributions to the community. For the gala's ninth year, the CLF partnered with the World Chinese Business Association of Canada and included a Canadian and Chinese Guan Xi (relationship) celebration as part of the event. In support of the theme of relationships, the CLF honoured long-time event sponsor Scotiabank, the Simpson family who holds an annual bowling tournament for the CLF and presented Diamond Jubilee medals to several outstanding volunteers. Over the course of the evening, the 275 guests and local dignitaries in attendance helped raise more than \$121,000.

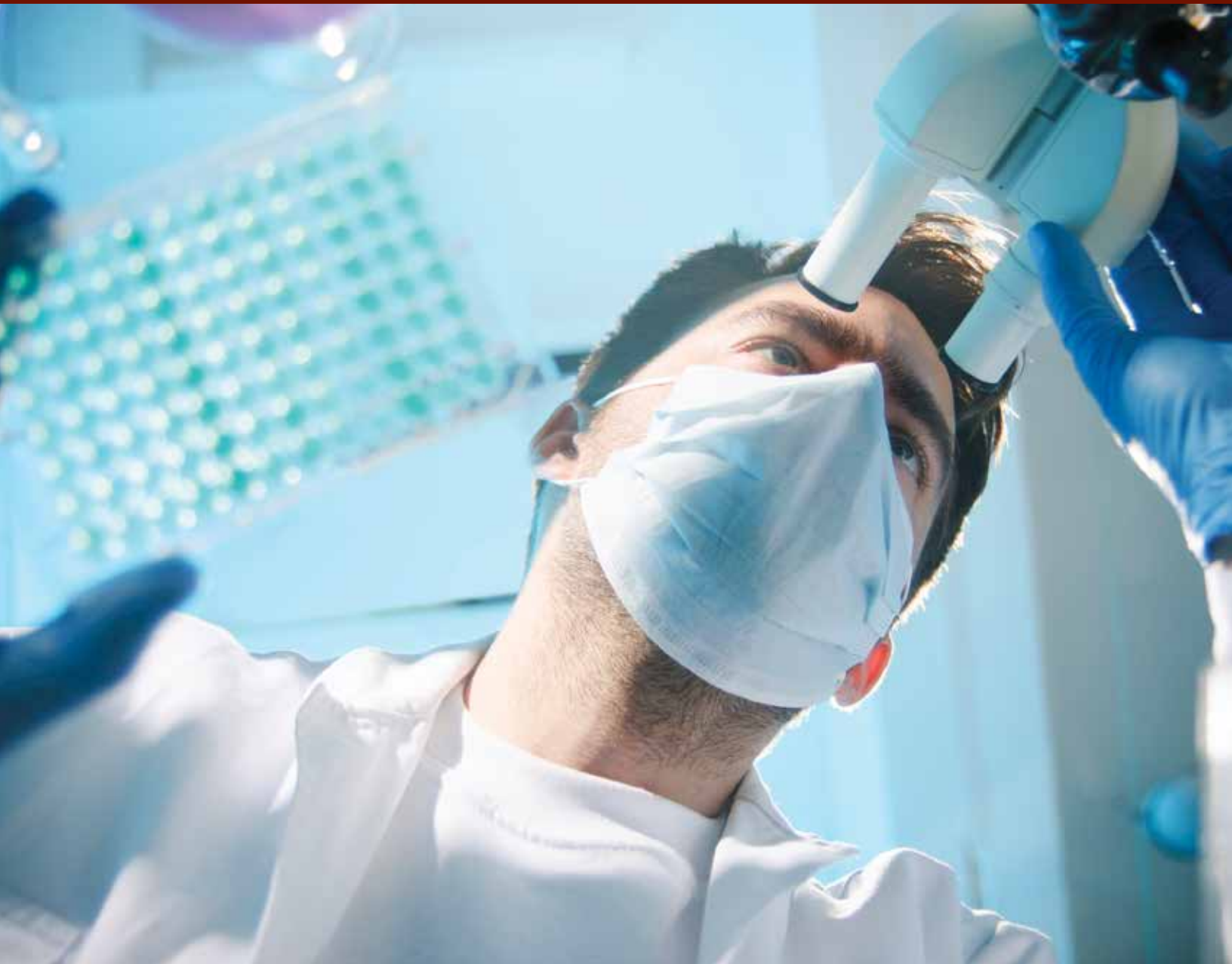


BRINGING LIVER RESEARCH TO LIFE

The liver is a wonderfully — and frustratingly — complex organ. Basic science research advances knowledge about the liver at the cellular level to better understand how it functions and how it falls prey to or fights off viruses and disease.

What is discovered in a lab today may take years to reach the patients it is meant to help – but eventually these breakthroughs will improve the lives of people of all ages living with various kinds of liver disease. What we know about the liver and liver disease today has come from years of research, just as today's discoveries will influence the future.

The CLF is proud to have been supporting liver research in Canada for more than 40 years. By funding research and sharing what is learned, we are a bridge between the scientists that study liver disease and the patients who are living with liver disease day in and day out. In the pages that follow, you can learn about the questions that CLF-funded investigators are asking and meet some of the people who live in hope that they find answers.



Operating Grants

Dr. Fernando Alvarez

CHU Sainte-Justine
Montreal, Quebec

Autoimmune hepatitis

Autoimmune hepatitis (AIH) is a liver disease caused by the body's own immune system which attacks the liver resulting in inflammation and scarring. If left untreated, AIH is always fatal. AIH may present both as an aggressive form of acute hepatitis or a chronic illness that can progress to cirrhosis. Recently, Dr. Alvarez and his team have discovered that by using an antibody (Rituximab) to temporarily destroy a type of white blood cell called a B-lymphocyte or B-cell, it could be possible to achieve complete remission of AIH in some patients. Since AIH is believed to be caused by an attack by a different type of white blood cell in the immune system (and not the B-cells) however, Dr. Alvarez is researching how and why destroying B-cells can control AIH. The research findings may lead to new treatments for AIH with fewer side effects than currently available therapy.

Patient Profile:

Catherine (Alberta)



For Catherine, it began as a pain in her chest that wouldn't go away. Six months and countless tests and appointments later, she was finally diagnosed with advanced cirrhosis caused by autoimmune hepatitis.

Her diagnosis led to many more tests – weekly bloodwork, ultrasounds, CAT scans and MRIs. She was prescribed a long list of medications, including the steroid prednisone which is a standard therapy for AIH. Unfortunately, Catherine experienced significant side effects including, over time, the development of glaucoma and cataracts in both eyes. In addition, many of her medications were not covered by the provincial drug plan and because she couldn't work, she had no private insurance plan to fall back on.

After a brief period of improved health in 2011 at which time she was able to return to work part-time, Catherine found herself back in the hospital with extreme swelling in her abdomen, cellulitis in her leg and varices (enlarged veins) in her throat and stomach. Today, she lives in constant pain and is on the waiting list for a liver transplant.

Dr. Klaus Gutfreund

Co-Applicant:

Dr. Lorne Tyrrell

University of Alberta,
Edmonton, Alberta

Chronic hepatitis B

Chronic hepatitis B affects over 350 million people worldwide and an estimated 300,000 people in Canada. Chronic hepatitis B can lead to cirrhosis and liver cancer. Current drug therapy can effectively suppress the virus but most patients will need to stay on these drugs for years and often develop resistance over time. Dr. Gutfreund and his colleagues are working on therapeutic vaccines that can help boost the immune system's ability to fight chronic hepatitis B. His team has identified several molecules that can be targeted to improve antiviral immune responses. This research may eventually lead to the development of vaccines that can work in conjunction with current drug therapies to eliminate the hepatitis B virus.

Patient Profile:

Harley (BC)

Harley was as surprised as anyone when he was diagnosed with hepatitis B after giving blood during his undergrad co-op work term in the U.S. The following year, Harley returned to Canada and started dental school at the University of British Columbia. When he had to undergo a blood test as part of his proof of vaccination and the school physician determined he had chronic hepatitis B, it was reported to the Faculty of Dentistry. Harley was later asked by the associate dean to withdraw from the dental program because they feared that he might infect patients.

Harley ended up pursuing a PhD and finally applying to medical school so he could still fulfill his dream of working in health care. Although his health is very good, he is under the care of a liver specialist and is undergoing treatment to fulfill the requirements of the BC College of Physicians and Surgeons which dictates that students and physicians have a viral load below a certain level in order to treat patients and perform certain procedures.



Dr. Mathieu Laplante

Laval University
Quebec City, Quebec

Liver Cancer

Liver cancer is one of the most common cancers worldwide. Since liver cancer is resistant to both conventional chemotherapy and radiation, patients may be left with no effective therapeutic options and a very poor prognosis. Previous research has identified a protein called mTOR which contributes to cancer growth. Recently, Dr. Laplante has identified a new protein called Deptor that can fight the cancer-causing effects of mTOR. Deptor levels are low in liver cancer cells and preliminary experiments indicate that Deptor loss promotes tumour formation. Dr. Laplante and his colleagues are studying Deptor to better understand how it might be targeted for the development of new treatment of liver cancer.

Patient Profile:

Chung Hing (Ontario)



Chung Hing — or C.H. as he is often called — was born in Vietnam and contracted hepatitis B as a child. He did not discover he was carrying the hepatitis B virus until he went to donate blood in Hong Kong where he lived for 20 years before immigrating to Canada in 1989.

He never underwent any kind of treatment for, or monitoring of, his disease while in Hong Kong or in his first year after immigrating to Toronto, not until the damage to his liver became fatal and developed into the most deadly form of liver cancer.

Thanks to early detection, he had a successful surgery to remove the tumor. The liver cancer was entirely cured but not his hepatitis B. After being treated with a drug for 10 years, C.H.'s liver enzyme levels were still not within the normal range which meant his hepatitis B was not under control and his liver was still developing progressive damage which subjected him to increased risk of developing a new cancer. Fortunately, a new and more effective drug became available to him five years ago and his doctor was finally able to slow down the progression of the disease. Tests in the last two years showed that his viral count was negative. If this trend continues, there is a rare but real chance that he will no longer need to take the drug.

Dr. Andrew Mason

University of Alberta
Edmonton, Alberta

Primary biliary cirrhosis

Primary biliary cirrhosis (PBC) is a type of autoimmune liver disease that results from the body's immune system attacking the liver causing slow, progressive damage to the bile ducts. When the bile ducts are damaged, bile and other substances accumulate in the liver causing damage over time and eventually leading to cirrhosis. While it is not known exactly why someone develops PBC, researchers suspect that both genetic and environmental factors may play a role. Dr. Mason has recently developed a laboratory model of PBC using a virus that is similar to one found in PBC patients that causes similar liver damage. Using this model, he has discovered that the development of liver damage can be blocked by antiviral therapy. Dr. Mason's research holds promise for the development of novel therapies for patients with PBC.

Patient Profile

Liz (Nova Scotia)

It was fatigue that first prompted Liz to ask to have her blood checked. Her husband had just been diagnosed with high-cholesterol so she did not want to take any chances. After several blood tests and a visit with a specialist, Liz was finally diagnosed with primary biliary cirrhosis or PBC.

Over the next 20 years, the disease progressed slowly but steadily. At first, Liz was not taking any medication and she only visited the hepatology team once a year. In 1997, things had advanced to a point where she started treatment and had to undergo testing more frequently. Eventually, she was told that the liver damage was at a point that she would need a liver transplant.

After undergoing all the tests to qualify for the waiting list, Liz's health continued to deteriorate. She gained 15 lbs in only two weeks due to the build up of fluid in her abdomen, legs and ankles which also caused breathing difficulties as the fluid put pressure on her lungs. Having the fluid drained helped alleviate some of her symptoms but it was a very special phone call that brought the greatest relief. The transplant team had a donor organ for her — a perfect match. Her transplant was a success and today she is continuing to gain strength and looks forward to being able to spend many more years with her children and grandchildren.



Dr. Christopher Richardson

Co-applicant:

Dr. Eric Arts

Dalhousie University
Halifax, Nova Scotia

Hepatitis C

The hepatitis C virus is responsible for 170 million infections worldwide and is a major cause of cirrhosis and liver cancer. However, 30% of those infected with the hepatitis C virus never develop chronic disease because their immune systems manage to fight off the virus during the acute stage of infection. Dr. Richardson's research team believes that the body's ability to clear the virus is related to the rapid development of antibodies that neutralize the specific hepatitis C strain that is infecting the patient. To test this theory, the team has developed a unique yeast-based cloning system to produce copies of specific hepatitis C virus strains based on proteins derived from recently infected patients that either get rid of the infection or go on to develop chronic disease. Findings of this research will lead to the development of more effective treatments of chronic hepatitis C.

Patient profile:

Linda (Manitoba)



For four years, Linda, a retired nurse, had been noticing her allergies were getting worse and she had been living with an odd collection of symptoms including continuous coughing, muscle cramps, nose bleeds and body pain. One day she visited a health food store and the owner mentioned that allergy problems can be connected to a compromised liver. After undergoing tests, Linda's doctor diagnosed her with hepatitis C.

Linda eventually discovered that she had contracted hepatitis C through a blood transfusion while giving birth to her son in 1976.

After seven weeks of drug therapy, Linda started to lose her vision as a side effect of interferon treatment. She now has stage 4 cirrhosis and is managing her disease as best she can through diet and natural remedies.

Dr. Naglaa Shoukry

Centre de Recherche du CHUM (Hôpital St-Luc)
Montréal, Quebec

Hepatitis C

While hepatitis C research has come a long way in the last two decades, we still do not understand how a small fraction of people exposed to the hepatitis C virus can get rid of it while the rest cannot. Recent studies have established that a person's genetic makeup may play a role. There is a correlation between the variations in one gene known as IL-28B and the body's ability to eliminate hepatitis C infection. Dr. Shoukry believes that this gene controls the type of immune response that develops when the body is infected by the hepatitis C virus. Patients who have the 'bad' gene variant do not seem to be able to clear the infection and will go on to develop chronic disease. Her findings may lead to a personalized approach to hepatitis C treatment in which patients carrying the bad gene variant can be identified early and offered more robust interventions to boost their immune response – thus increasing their odds of eliminating the virus.

Patient Profile:

Dion (Alberta)

Approximately 10 years ago, Dion, a trucking company dispatcher, was diagnosed with hepatitis C. He was feeling very sick and after going to the hospital and undergoing several blood tests, he was told he had both diabetes and hepatitis C.

Back in the late 1980s, Dion was a member of various musical groups and while living the rock star lifestyle he experimented with drugs. This may have been how he contracted hepatitis C but back then no one knew about the risks of contracting this serious liver disease.

Today, Dion's liver function is about 20% and treatment has not worked for him. He has been on the waiting list for a liver transplant for nearly three years.



Summer Studentships

Mr. Andrew Collins

McMaster University
Hamilton, Ontario
Supervisor: Dr. Gregory Steinberg

Non-Alcoholic Fatty Liver Disease

Non-alcoholic fatty liver disease (NAFLD) is the most common form of liver disease in Canada and the growing incidence is tightly linked to the obesity epidemic. NAFLD can lead to health problems like diabetes and heart disease, as well as to progressively more severe liver damage – in some cases requiring a liver transplant. Fat metabolism in the liver is regulated by an enzyme that is switched on by exercise and drugs such as metformin and aspirin. Mr. Collins studied whether metformin and aspirin might be effective in reversing NAFLD which in turn could lead to new ways to treat this condition.

Patient Profile:

Burt (Quebec)



Burt credits his family doctor for taking the time and ordering the tests necessary to confirm that he had advanced non-alcoholic steatohepatitis (the most severe form of fatty liver disease). Although Burt wasn't feeling ill, his doctor became suspicious when preliminary blood tests showed that Burt's liver enzyme levels were abnormal. After more blood tests, an ultrasound and a CT scan showed severe liver damage, Burt was referred

to a liver specialist and quickly thereafter to the liver transplant unit at Royal Victoria Hospital in Montreal.

Ten months later Burt was added to the transplant waiting list and his phone rang one month after that telling him to rush to the hospital because a donor liver was available. His transplant was successful and today Burt feels very grateful for the timely diagnosis and transplant that saved his life.

Ms. Emma Torbicki

The Hospital for Sick Children
Toronto, Ontario
Supervisor: Dr. Nicola Jones

Pediatric liver transplantation

Thanks to research, the short-term survival rates are very high for pediatric liver transplant patients. Long-term prognosis still needs improvement however, in part due to damage a donor liver can suffer when it is deprived of oxygen during the transplant process. Having the blood flow cut off (when the organ is removed from the donor) and then re-established (once the organ is transplanted into the recipient's body) can result in tissue damage from the formation of toxins and invasion by white blood cells. Recent studies indicate that a specific cellular recycling pathway called 'autophagy' may help to remove the toxins and limit inflammation triggered by the body's immune system. The results of this study will be the first step in determining if autophagy can be effective in protecting a transplanted liver.

Patient Profile:

Jack (Ontario)



Jack is a happy, energetic five year old who loves building with Lego and playing with his younger brother. Jack was born with biliary atresia, a condition in which the bile ducts leading from the liver to the intestines are blocked or absent thus leading to severe damage. To save his life, Jack had to undergo surgery at only six weeks old to attach a piece of his intestine to restore bile flow. The surgery – known as the Kasai procedure – was a success and today it would be hard to tell by looking at him that he was ever sick. Unfortunately, the Kasai procedure isn't a cure and Jack may still need a liver transplant someday.

Graduate Studentships

Ms. Elizabeth Kuczynski

Sunnybrook Health Sciences Centre
Toronto, Ontario
Supervisor: Dr. Robert Kerbel

Liver Cancer

Liver cancer is the third most common cause of cancer-related deaths in the world and is one of the few forms of cancer on the rise in Canada. Sorafenib is a drug that targets blood vessels that supply tumours with blood. Over time however, patients taking sorafenib stop responding and develop resistance. Ms. Kuczynski is studying how this resistance may be reversible through prolonged time off the drug which allows cancer cells to “reset” thereby once again becoming sensitized to drug therapy. This research may have important implications for the clinical management of liver cancer and potentially other cancer drug combinations in which resistance may be reversible.

Mr. Daniel Pang

University of Alberta
Edmonton, Alberta
Supervisor: Dr. Lorne Tyrrell

Hepatitis A

Although they are similar viruses, the hepatitis A virus primarily causes short-term disease while the hepatitis C virus usually causes long lasting disease for reasons that are not fully understood. Mr. Pang is working with Dr. Tyrrell and his team on a newly developed laboratory model to help test the early immune response to hepatitis A. Their work will contribute to a better understanding of how we fight off hepatitis A and hepatitis C infections which in turn may help in the development of a preventative vaccine for hepatitis C, one of the leading causes of liver cancer.

Ms. Mandana Rahbari

University of Alberta
Edmonton, Alberta
Supervisors: Drs. Andrew Mason
and Michael Houghton

Primary biliary cirrhosis

Since the cause of PBC is still unknown, Ms. Rahbari and her colleagues are studying the relationship between an infection with the human betaretrovirus and PBC to see if the infection with this virus plays a role in the development of PBC. This knowledge could be used to design drugs to treat PBC.





The Canadian Liver Foundation has a proud legacy of supporting and promoting liver research both in Canada and around the world. Each year, we recognize investigators that have made significant contributions to the understanding of the liver and liver disease.

Gold Medal

The Canadian Liver Foundation Gold Medal was born from the belief that outstanding work should not be limited by borders. That's why in 1983, the CLF established the Gold Medal Award to recognize individuals – regardless of nationality – who have made significant contributions to the advancement of hepatology. Today, the award is given jointly with the Canadian Association for the Study of the Liver (CASL).

We were delighted to present the 2012 Gold Medal to **Dr. Jaime Bosch, Professor of Medicine and Chief of Hepatology Section at the IMD, Hospital Clinic, University of Barcelona, Spain.** Dr. Bosch was chosen in recognition of his outstanding work in portal hypertension and pathophysiology.

Sass-Kortsak Award

In 1990, the Canadian Liver Foundation, in partnership with the Canadian Association for the Study of the Liver (CASL), created the Sass-Kortsak Award to honour the late Dr. Sass-Kortsak who made tremendous contributions to the field of hepatology and did much to further the work of the Foundation.

Dr. Giorgia Mile-Vergani, Alex Mowat Professor of Paediatric Hepatology at King's College London School of Medicine, received the 2012 Sass-Kortsak Award in honour of her achievements in the field of paediatric immunology, autoimmune liver diseases and liver transplantation.

DIAMOND JUBILEE RECIPIENTS

Heroes in the fight against liver disease come in all shapes and sizes – some study the disease in research labs, others care for patients, still others speak out to bring greater awareness and support. What they all have in common however, is their passion for creating a brighter future for Canadians of all ages living with liver disease. In 2012, the Canadian Liver Foundation presented Queen Elizabeth II Jubilee Medals to 30 outstanding volunteers from across the country to recognize their efforts as champions for the more than three million Canadians living with liver disease.

“Liver disease is a serious health issue that is often misunderstood and overlooked,” says Gary Fagan, President, Canadian Liver Foundation. “What makes our medal recipients exceptional is that they have made a concerted effort to change that. These individuals – be they patients, parents, doctors or business people – have contributed their time, talents and enthusiasm to helping us tackle this disease through research, education, patient support and advocacy.”

2012 marked the 60th anniversary of the reign of Queen Elizabeth II. The Queen’s Diamond Jubilee Medal was created to mark this milestone and Canadian organizations were offered the opportunity present the medals as tributes to individuals whose achievements have benefited their fellow citizens, their community, their organization and this country.

The medals were presented throughout the year as part of CLF events across Canada. We thank all our medal recipients for their contributions and commitment. The following is a list of our recipients:

Alberta

Don Wishart, Executive Vice President, Operations and Major Projects, TransCanada

Dr. Robert Myers, Assistant Professor, Liver Unit, Gastrointestinal Research Group, University of Calgary

Dr. Winnie Wong, Associate Professor, Division of Gastroenterology and Assistant Dean of Education, Postgraduate Medical Education Program, University of Alberta

Atlantic

Dale O’Connor, CLF Chapter President, Guysborough

Dr. Kevork Peltekian, Associate Professor of Medicine, Dalhousie University, Specialist in Hepatology and Liver Transplantation, Queen Elizabeth II Health Sciences Centre

Dr. Thomas Michalak, Senior Canada Research Chair in Viral Hepatitis / Immunology, Professor of Molecular Virology and Medicine, Memorial University

Melanie Weir, founder of Olivia’s Memorial Walk fundraiser for liver research

British Columbia

Dr. Eric Yoshida, Professor of Medicine, University of British Columbia, Head of Division of Gastroenterology, Vancouver General Hospital

Dr. Mel Krajden, Director, BC Hepatitis Services, BC Centre for Disease Control

Dr. Susan Kwan, Co-Director, ICU, Burnaby Hospital

Jo-Ann Ford, RN, Nurse Practitioner, Vancouver General Hospital

Robert Wilson, retired nurse and 12 year volunteer with BC/Yukon region



Ontario

Andy Cumming, Managing Director, Blackheath Fund Management

Colina Yim, RN, Nurse Practitioner, Toronto Liver Clinic, Toronto Western Hospital

Daljit Nagpal, Biologist, Health Canada

Elliott Jacobson, CLF Treasurer

Frank Bialystok, University of Toronto professor, Chair of the Canadian Jewish Congress (Ontario)

Haley Millman, liver and pancreas transplant recipient and graphic artist

Laurie Fraser, Human Factors Engineering Specialist, Ontario Power Generation

Luke Chan, Associate Vice President, International Affairs, McMaster University

Morris Sherman, Associate Professor of Medicine, University of Toronto

Nelson Millman, former Executive Producer for Studio Productions at Sportsnet

Pam Johnson, past CLF volunteer and Ottawa chapter president

Pascale Cloutier, LLB, partner, Miller Thomson LLB

Roger Hunter, retiree and nine-year national CLF volunteer

Theresa Stewart, retired CLF Chapter President, Guelph

Quebec

Dr. Bernard Willems, Professor of Medicine, Université de Montréal

Dr. Marc Bilodeau, Associate Professor of Medicine, Université de Montréal, Director, National Canadian Research Training Program in Hepatitis C

Saskatchewan

Brian Kusisto, President, Kenroc Building Materials Co. Ltd.

Ken Sexton, CEO, Kenroc Building Materials Co. Ltd.



FINANCIAL HIGHLIGHTS

Financial Position Summary as at December 31, 2012 and 2011

	GENERAL FUND		RESEARCH TRUST FUNDS		MEDICAL RESEARCH FUND		TOTAL	
	2012	2011	2012	2011	2012	2011	2012	2011
ASSETS								
Current	\$926,112	\$897,199	\$165,618	\$647,885	\$902,917	\$834,220	\$1,994,647	\$2,379,304
Investments	\$216,889	\$158,787	\$1,894,887	\$1,193,724	\$673,083	\$885,780	\$2,784,859	\$2,238,291
Capital Assets	\$157,318	\$176,573					\$157,318	\$176,573
	\$1,300,319	\$1,232,559	\$2,060,505	\$1,841,609	\$1,576,000	\$1,720,000	\$4,936,824	\$4,794,168
LIABILITIES	\$598,579	\$578,088					\$598,579	\$578,088
FUND BALANCE	\$701,740	\$654,471	\$2,060,505	\$1,841,609	\$1,576,000	\$1,720,000	\$4,338,245	\$4,216,080
	\$1,300,319	\$1,232,559	\$2,060,505	\$1,841,609	\$1,576,000	\$1,720,000	\$4,936,824	\$4,794,168

Operations Summary for the Year Ended December 31, 2012 and 2011

	GENERAL FUND		RESEARCH TRUST FUNDS		MEDICAL RESEARCH FUND		TOTAL	
	2012	2011	2012	2011	2012	2011	2012	2011
REVENUE								
Donations and Chapter Revenue	\$4,854,600	\$5,183,566	\$979,188	\$1,227,233			\$5,833,788	\$6,410,799
Interest and Other Income	\$15,594	\$7,814	\$105,632	\$67,960	\$49,037	\$9,157	\$170,263	\$84,931
	\$4,870,194	\$5,191,380	\$1,084,820	\$1,295,193	\$49,037	\$9,157	\$6,004,051	\$6,495,730
EXPENDITURE								
Programs	\$1,543,435	\$1,283,950	\$308,877	\$613,467	\$2,711	\$3,910	\$1,855,023	\$1,901,327
Operating	\$3,311,200	\$3,458,900					\$3,311,200	\$3,458,900
	\$4,854,635	\$4,742,850	\$308,877	\$613,467	\$2,711	\$3,910	\$5,166,223	\$5,360,227
Excess of revenue over expenditure for the General Fund	\$15,559	\$448,530					\$15,559	\$448,530
Excess of revenue over expenditure for the Research Trust Fund			\$775,943	\$681,726			\$775,943	\$681,726
Excess of revenue over expenditure for the Medical Research Fund					\$46,326	\$5,247	\$46,326	\$5,247
Research Grant Disbursements					(\$715,663)	(\$401,295)	(\$715,663)	(\$401,295)
Interfund transfers to support activities of the Medical and Research Trust Funds	\$31,710	(\$207,510)	(\$557,047)	(\$880,539)	\$525,337	\$1,088,049	\$0	\$0
FUND BALANCE - Beginning of Year	\$654,471	\$413,451	\$1,841,609	\$2,040,422	\$1,720,000	\$1,027,999	\$4,216,080	\$3,481,872
FUND BALANCE - End of Year	\$701,740	\$654,471	\$2,060,505	\$1,841,609	\$1,576,000	\$1,720,000	\$4,338,245	\$4,216,080

Complete financial statements including explanatory notes as audited by Grant Thornton LLP are available from the Canadian Liver Foundation National Office.

In 2012, the Canadian Liver Foundation continued to deliver on our mandate of funding liver disease research and education by combining the efforts of our dedicated volunteers, our regional presence, our strong partnerships and our established education and patient support programs. During the year, four new restricted funds were established. The funds are Sexton Liver Cancer Research, Dalhousie Digestive Care & Endoscopy, International Training Program and Canadian National Transplant Research Program. These combined have increased our research funding capacity to support new liver research in Canada. Other highlights include maintaining our strong fundraising performance in an uncertain economy and taking steps in conjunction with our investment advisors to improve the gain from our investment portfolio.

We have exhibited our commitment to research and paid over \$715,000 in research grants in 2012. In addition, we have ongoing research commitments totaling over \$1.5 million to be paid from 2013 to 2017. This includes amounts approved for funding in 2013 for which the peer review process will commence in 2013.

The Foundation's Donations and Chapter Revenue was \$5.8 million in 2012. The research trust funds revenue was stable at approximately \$1 million due to continued support of our existing partnership programs as well as support from new partnerships and donor-designated research funding.

Our expenditures on Programs in 2012 stabilized at approximately \$1.9 million. The research trust funds have paid \$309,000 in research programs compared to \$613,000 in 2011, therefore we continued to pay out over \$1 million in research in 2012.

Operating costs were \$3.3 million in 2012 compared to \$3.5 million in 2011 reflecting our aggressive cost monitoring and our move to a new cost-effective national office location in 2011.

Our financial position remains sound. At the end of 2012, we had current assets amounting to \$2 million. Our investments total \$2.8 million, an increase of approximately \$550,000 (24%) over 2011. The annual investment portfolio yield for 2012 was 4.09%, or \$170,000, which was approximately double the income from 2011.

On behalf of the Foundation's Finance Committee, I want to express our sincere appreciation for the efforts and ongoing dedication of our volunteers, donors, program partners, professional advisors and staff. Their commitment will enable us to continue supporting medical research and education into the causes, diagnosis, prevention and treatment of liver disease for all Canadians in 2013 and beyond.



Elliott Jacobson, CPA, CA, ICD.D
Secretary/Treasurer



THANKS TO OUR SUPPORTERS

MERCI À NOS DONATEURS

The CLF's work would not be possible without the support of generous individuals, groups and organizations. We want to thank everyone who invested in our research and education programs for the benefit of all Canadians living with or at risk for liver disease.

Donors listed are for the period January 1 – December 31, 2012. Every effort has been made to ensure the accuracy of our donors listed below. Should you find any errors or omissions, please contact **Judy Thompson** at **1-800-563-5483 ext. 4945** or **clfdonation@liver.ca**.

Le travail de la FCF ne serait pas possible sans le soutien de personnes, d'organisations et de corporations généreuses. Nous remercions tous ceux qui ont investi dans notre recherche et nos programmes éducatifs pour le bénéfice de tous les Canadiens et Canadiennes vivant avec une maladie du foie ou qui sont à risque d'en contracter une.

Les donateurs inscrits ont contribué durant la période du 1er janvier au 31 décembre 2012. Tous les efforts sont faits pour assurer l'exactitude des donateurs inscrits ci-après. Si vous trouvez des erreurs ou des omissions, veuillez communiquer avec **Judy Thompson** au **1 800 563-5483 poste 4945** ou **clfdonation@liver.ca**.

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City of London
The Printing House Ltd
The Sisters of Saint Ann
The UPS Store 71
Timber Tree Service
TNS Canada
Toronto Congress Centre
Toronto Printing
Townsend's Field Scouting
Tracker Inc
Tyco Electronics Canada Ltd
University of British
Columbia
Upside Engineering Ltd
Vancouver Insurance
Investment Management
Corporation
Walmart
Wawanesa
WCVN Class of 2010
Western Larch Limited
Westlock Community Thrift
Shop
Wilbert Lai Professional
Corporation
Wongs Benevolent
Association
Zachry Canada Ltd

Thank you to all our members listed below for your commitment and support.

CLF Members are an important part of the Foundation's advocacy efforts and help make our research, education and awareness programs possible. Join the CLF community and receive news on liver research and take an active role in improving liver health for all Canadians. To find out how, visit www.liver.ca.

Merci à tous nos membres inscrits ci-dessous pour votre engagement et votre soutien.

Les membres de la FCF contribuent de façon importante aux efforts de la Fondation et aident à rendre possibles nos programmes de recherche, d'éducation et de sensibilisation. Si vous désirez vous joindre à la communauté de la FCF, recevoir des bulletins de nouvelles sur la recherche sur le foie et jouer un rôle actif pour améliorer la santé du foie de tous les Canadiens et Canadiennes, devenez membre aujourd'hui! Pour savoir comment, visitez www.liver.ca.

AIDS Vancouver Island
Osamah ALenezi
Haitham Alsaheed
Jennifer Anson
Nigel Ayers
Richard Ayuen
Kim Bartlett
Tracey Baudry
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Fred Beatty
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Lilian Du
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Magdy Elkashab
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Tom Wiley
Brad Wilson
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Dale Wooden
Grace Wu
Joanne Wu
Winston Wu
Shi Min Yang
Howard Yeung
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Zachry T & E Canada Inc
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Jiangyun (Wendy) Zhu

Estates / Successions

Estate of Edith Bendisch
Estate of Mable Chadwick
Estate of Rudolph Carl Conti
Estate of Violet Fiora
Estate of Vivian Doris Glass
Estate of Morven Campbell Johnstone
Estate of Inge Kramer
Estate of Stanley Maxwell
Estate of Yvonne McCrane-Pearson via
the Vancouver Foundation
Estate of Richard Newns
Estate of Margaret O'Hanley Duffy
Estate of Rachael Propp
Estate of Alexander Scott
Estate of Douglas Graham Seaton
Estate of Anne Doreen Wells

We would like to offer a special thank you to those who made us a 'cause for celebration' in 2012.

Nous désirons remercier plus particulièrement ceux qui ont fait de nous une « bonne raison de célébrer » en 2012.

Community Event Organizers / Organisateurs des événements communautaires

Sonya Basarke, *Wedding Favours*, Toronto, Ontario

Melanie Braga & Michael Teixeira, *Wilson Disease Campaign*, Toronto, Ontario

Meara Cleverdon, *9th Birthday Party*, Cobourg, Ontario

Begin2Believe, *Begin2Believe Volleyball Tournament*, Ottawa, Ontario

Camper Village, *Product Sale Fundraiser*, Alberta

Freedon 55 Financial, *Poor Boy Luncheon Committee*, Chatham, Ontario

Ken & Wendy Hinton, *Liver UP Brunch*, London, Ontario

LoveGives, *LoveGives Volleyball Tournament*, Ottawa, Ontario

MacLaren's On Elgin, *LiveRight Dinner*, Ottawa, Ontario

Marlborough Pub & Eatery, *Second Annual Randy Moore Invitational Golf Tournament*, Ottawa, Ontario

Moksha Yoga, *Registration Sale Fundraiser*, Edmonton, Alberta

Nova Jr X Men Major Bantam Hockey Association, *Last Game of Season*, Antigonish, Nova Scotia

Bianca Pengelly, *Masquerade Party*, Winnipeg, Manitoba

St Vital Mustangs/Winnipeg Nomads Football Clubs, *Stroppa Bowl*, Winnipeg, Manitoba

Tirecraft (Atlantic Provinces), *First Annual Brian Miller Memorial Golf Tournament*, Shubenacadie, Nova Scotia

York Region Senior Wellness Centre, *2nd Annual Remington Markham International Sedan Chair Challenge*, Markham, Ontario