

CANADIAN
LIVER
FOUNDATION



FONDATION
CANADIENNE
DU FOIE



UNITED VOICES

2013 ANNUAL REPORT

Canadian Liver Foundation National Board of Directors 2013-2014

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SPEAKING WITH ONE VOICE



If I was asked to come up with a profile of a patient who best represented those affected by liver disease, it would be an impossible task. Patients are as varied as the conditions they suffer from making liver disease a health issue with many faces and, by extension, many voices.

Unfortunately, their very diversity can be a disadvantage when it comes to convincing governments, corporate sponsors and the general public that this is a health concern and a group that needs attention.

Over the past year, the Canadian Liver Foundation has sought to bring together stakeholders within the liver community to speak with one voice. In April, we published the first report on liver disease in Canada – the product of a collaboration with liver specialists from across the country who agreed that liver disease truly is a ‘crisis in the making’. When we released the report, we recruited patients to tell their stories to help bring the numbers to life. The reaction to the report and the over 11 million media impressions it garnered showed that uniting our voices was the best way to be heard.

Among its 22 recommendations, the Liver Disease in Canada Report called for widespread hepatitis C screening for adults born between 1945 and 1975. This type of age-based hepatitis C screening would be a first for Canada and this issue has become a rallying point for the hepatology community and patients alike. The CLF launched a public awareness campaign in January to encourage the public to get tested and in the fall the Canadian Medical Association Journal published an article supporting our recommendation suggesting that such an initiative would identify as many as 77% of those infected with hepatitis C. Further endorsement came from experts presenting at the Hepatitis C Symposium the CLF co-sponsored with the Gairdner Foundation in October – one of whom was Dr. Harvey Alter who is one of the doctors responsible for isolating the hepatitis C virus and facilitating the development of a screening test.

We hope that the Public Health Agency of Canada will echo our own guidelines. Yet, this is just the first step. With the advent of drug therapies that have shown they can cure hepatitis C but come with very high price tags, we will need to continue to use our collective voices and

influence to ensure equitable and affordable access to treatment for all patients.

Breakthroughs like the hepatitis C screening test and the new and more effective treatments have become a reality due in part to CLF’s investments in research over the past 44 years. Each new discovery builds upon the one before and adds to our collective knowledge and understanding of how to prevent, diagnose, treat and cure liver disease. With many pressing questions remaining, the work is far from over.

In 2013, we continued to invest in the quest for answers by funding \$1.6 million in liver research and by awarding grants to 11 new research projects in such areas as fatty liver disease, liver cancer, viral hepatitis, tyrosinemia and cirrhosis. In addition, the CLF joined a research partnership with the Canadian Institutes for Health Research to fund transplant research. Our \$500,000 commitment to this program over the next five years will help improve organ donation and the success of liver transplants for recipients.

I am pleased with our legacy of supporting research and our increasing advocacy efforts that will help ensure Canadians with liver disease can benefit from the knowledge and tools that are the products of that research. I would like to take this opportunity to thank our donors, volunteers, corporate partners and staff who have added their voices and energies to our efforts to make liver health a priority for all Canadians.

Morris Sherman, M.D., FRCPC
Chairman

TURNING UP THE VOLUME



Liver disease's stealth and silence is what makes it deadly. This is why the Canadian Liver Foundation must turn up the volume – to prevent people from suffering silently and dying unnecessarily from liver disease.

In 2013, new cancer statistics showed that liver cancer is one of the fastest rising and deadliest cancers in Canada. The rising incidence and mortality rates are a direct result of chronic liver diseases such as hepatitis C and hepatitis B not being diagnosed early enough to prevent their progression. These statistics are the first waves heralding what has been called the coming 'tsunami' of severe liver disease that experts have feared.

Faced with this looming crisis, the CLF has been sounding the alarm. This year we launched a hepatitis C awareness campaign that highlighted the knowledge gaps and missed opportunities for testing and diagnosis based on the results of surveys of the public and general practitioners. In a follow-up initiative, we brought attention to the need for widespread age-based hepatitis C testing by producing an animated video encouraging baby boomers to get tested. The video reached more than 1.2 million people and elicited over 350 comments on Facebook. We also addressed hepatitis B by partnering with industry to pilot a new hepatitis B awareness campaign to urge those living with chronic hepatitis B to have their viral levels tested every six months to prevent liver cancer. Using a variety of media channels, the campaign reached more than three million English, Vietnamese and Chinese speaking Canadians.

Turning up the volume on liver disease is not just about motivating individuals to take care of their own liver health but also about engaging federal and provincial governments who have the power to change systems and policies. Following the release of our report – *Liver Disease: A Crisis in the Making* – we received over 20 invitations to meet with institutions and policy makers across the country. At a time when intensive care units

are filling up with patients suffering from advanced liver disease and access to treatment issues are forcing people to take to social media in desperation, we urged these key decision makers to recognize liver disease as a crisis and take the necessary steps that will ultimately save both lives and health care dollars.

Liver disease can no longer be silent. We need patients, family members, volunteers, health care professionals, donors and the public to turn up the volume and make their voices heard. As you read through our report – appropriately titled 'United voices' – you will learn about the individuals and programs that are helping to give liver disease a voice. We are grateful for all those who have lent their voices and their support to this cause.



Gary A. Fagan
President

RAISING OUR VOICES



We believe no one with liver disease should have to endure this difficult journey silently or alone. Through our patient programs, advocacy efforts and awareness campaigns, we encourage those affected to speak out and those that might not think they are at risk to listen.

VOICES OF COMFORT AND AUTHORITY

A liver disease diagnosis often leaves people feeling scared, alone, helpless and reluctant to talk about it for fear of what others might think. The CLF's Living with Liver Disease Program and Peer Support Network empowers patients and family members with the knowledge they need to make informed decisions and to have a say in their own care. The Living with Liver Disease Program and other special speaker series held across the country offer the opportunity to meet face-to-face with others coping with liver disease and to learn from experts about nutrition, exercise, coping skills and treatment options. The Peer Support Network connects patients and caregivers with their counterparts one-on-one to share experiences and support.

Through these vital support programs, we encourage individuals to raise their voices to ask for help and to have the courage to share their own experiences with others.

"I first joined the Peer Support Network because I felt isolated and frightened but now I'm part of a community of like-minded and like-afflicted folk supporting and sharing with each other. I benefit enormously from others experiences, feelings, situations, and journeys living with liver disease. No matter how many differences there are between our situations, I find that we share a core of similar experiences such as our feelings, our medical and physical stresses and successes, and that we can all learn from each other."

– Christine

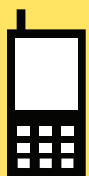
"I personally can say peer support was extremely important to me. When I found out I needed a liver transplant I was very afraid. It was unknown and seemed very extreme. Fortunately the CLF put me in touch with Ed who was a liver transplant recipient. I will never forget how Ed spent several hours one evening on the phone with me sharing his experiences and answering my questions. His gracious and kind act eased my anxieties and helped me face this challenging situation. I benefitted by Ed's kind actions in my time of need and I continue to benefit as I try to pay forward Ed's act of support at every opportunity."

– George

"By joining the Living with Liver Disease program, I was able to learn from exceptional speakers. Knowledge is power and it allows me to make informed, up-to-date important decisions about everything from nutrition to medical treatment. Being part of a support group has also helped me to help many others living with liver disease by simply sharing some of the personal experiences I've had since my diagnosis 8 years ago... and that feels great."

– Eva

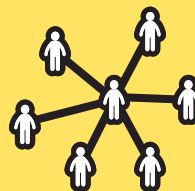
IN 2013, CANADIAN LIVER FOUNDATION VOLUNTEERS AND STAFF...



ANSWERED **1,760 CALLS** TO OUR NATIONAL 1-800 LIVER HELP LINE



CONNECTED WITH **OVER 20,000 PEOPLE** AT HEALTH PROMOTION EVENTS



OFFERED PATIENTS AND CAREGIVERS ACCESS TO **70 PEER NETWORK** VOLUNTEERS



DISTRIBUTED **100,000 PIECES** OF EDUCATION MATERIAL TO HOSPITALS, DOCTORS' CLINICS, PATIENTS, CAREGIVERS AND THE PUBLIC



DELIVERED INFORMATION TO AN AVERAGE OF **80,000+ VISITORS** PER MONTH TO OUR WEBSITE

HEPATITIS C CAMPAIGN – 'YOU'RE BETTER OFF KNOWING'

Adults born between 1945 and 1965 are five times more likely to have hepatitis C but the majority of those that have it do not realize it.

In January 2013, the CLF released the results of two surveys that gauged the knowledge and actions of family physicians and the general public regarding hepatitis C. The findings showed that more than half of the physicians surveyed recognized that hepatitis C was an important health issue but were not testing enough patients. Meanwhile, those in the baby boomer age bracket understood less about hepatitis C than younger generations and were the least likely to have been tested.

To encourage baby boomers to get tested, CLF created an animated video and launched a Facebook campaign targeting adults 49 to 69. The video reached more than 1.2 million people in English and French and garnered 393 comments, 2,005 likes and 1,979 shares. The following were some of the comments we received.

Been there and did interferon treatment in 2010 and was cured. Got it from a transfusion in Europe. Had no major symptoms, just showed up in routine blood tests. Get tested! It is simple and you can get treated.

– L.M.

After losing a brother and a sister to Liver disease in the last 2 years I went for a test and am ok Thank GOD

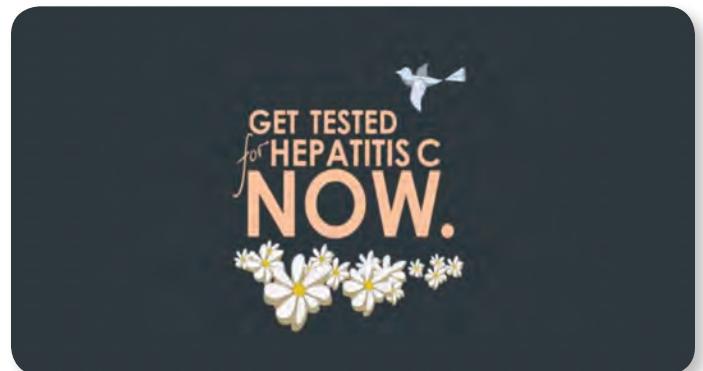
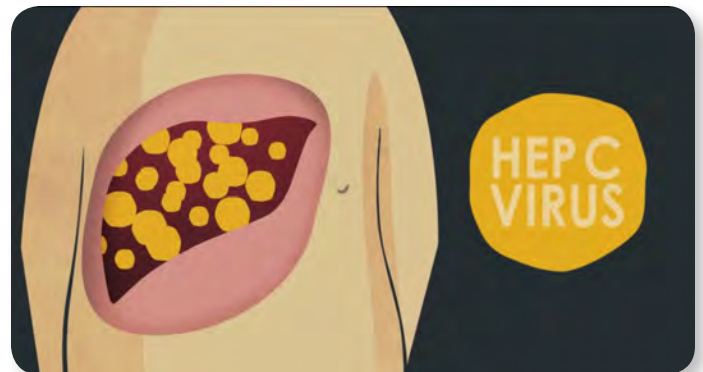
– C.B.L

My doctor decided to test me for HCV in 2006. Resulted in a positive diagnosis and subsequent successful treatment. Thankfully my liver fibrosis was not too far along and the treatment allowed time for even that much damage to heal. I was one of the fortunate ones. Please get tested if you fall into that demographic.

– T.M.

I lost my brother to hep C and liver cancer last year Liver cancer is often linked to people with Hep C.

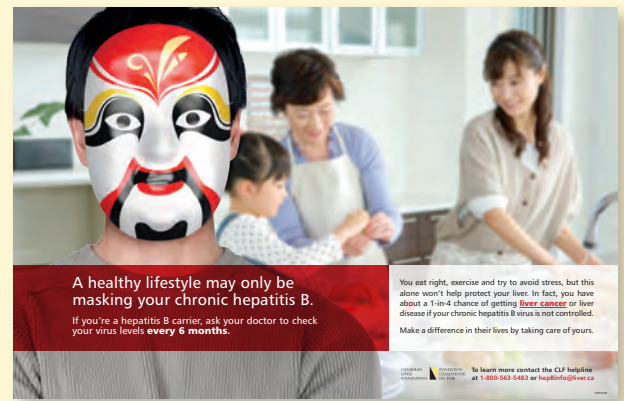
– S. H.



HEPATITIS B CAMPAIGN

Chronic hepatitis B may be a major health issue amongst immigrant communities in Canada but because it is a slow moving virus that may have few, if any, symptoms, it is often taken for granted by those who have it. Unfortunately, if left untreated and unmonitored, chronic hepatitis B can lead to liver cancer and other complications.

The CLF launched a hepatitis B awareness campaign and patient support program in Ontario and BC to encourage people with hepatitis B to have their virus levels monitored every six months in order to prevent liver cancer. Targeting primarily Asian populations, the combination of traditional and social media outreach and advertising in English, Chinese and Vietnamese reached more than three million people and prompted more than 8,000 views of our hepatitis B web pages in English and Chinese.



FINDING HIS VOICE

Sergeant Lance Gibson was trained to face a multitude of external threats during his time with the Canadian Armed Forces which included a tour in Afghanistan. The last thing he expected was that the biggest threat to his life would be internal and come in the form of a diagnosis of hepatitis C. He discovered that he had contracted the virus when he received a transfusion as a teenager and it had been slowly ravaging his liver for more than 25 years.

Lance received the devastating news when he was on the verge of leaving the army to begin a career in the private sector. Over the next five years, his health deteriorated to the point that he was going to need a liver transplant to survive. Fortunately, his sister was a match and she donated part of her liver to Lance as a living donor.

Approximately a year after his transplant, Lance responded to a Facebook post from the Canadian Liver Foundation looking for hepatitis C patients who might be willing to share their stories as part of an awareness campaign encouraging adults in the baby boomer age group to get tested. Although he had not done media interviews before nor had he really spoken about his hepatitis C publicly, Lance took the courageous leap and has not looked back since. This first awareness campaign led to many other interviews, opportunities to educate his armed forces colleagues, and eventually to a role in a new hepatitis C documentary coming out in 2014.



“Although hepatitis C is known as the “silent killer” I felt it was important to take a stand and speak out against the virus in hopes that by coming forward my story and journey may save someone else’s life and encourage them to get tested. At first it was difficult to speak out about hepatitis C, due to the stigma surrounding the issue. The support provided to me from my family, co-workers and medical community convinced me I was doing the right thing. Five weeks ago I started treatment to eradicate the virus and since my viral load has dropped more than six million copies to just only 48. My cure is just around the corner. Yours could be next!”

– Lance Gibson
(pictured above with wife Teresa)

SOUNDING THE ALARM

CLF publishes landmark report on liver disease in Canada

Liver disease is a silent epidemic in Canada due in part to the challenges in quantifying it. Within our health care system, liver disease is often categorized under digestive ailments, infectious diseases or cancer or it may not be tracked at all. In 2013, the Canadian Liver Foundation commissioned a report to show, for the first time, the true scope of liver disease in the country. Using information from various sources including physicians, researchers and government, academic and institutional databases, experts collected facts and figures and extrapolated data on the most prevalent forms of liver disease and made 22 recommendations for change.

One of the most alarming findings was that deaths from liver disease have risen nearly 30% in a period of only eight years, with Ontario, Quebec, Alberta and British Columbia being hit hardest.

Upon the release of the report entitled *Liver Disease: A Crisis in the Making*, CLF Chairman Dr. Morris Sherman who was the lead author, stressed that “liver disease should not be a death sentence. Effective options for screening, diagnosis and treatment exist, but without government support and investment, Canadians will continue to die from preventable forms of liver disease.”

The report has since become an important tool in the CLF’s advocacy efforts with both federal and provincial politicians and policy makers across the country as we encourage them to take action to improve surveillance, screening, access to treatment, patient care resources and research.

Key Findings

ALL MAJOR FORMS OF LIVER DISEASE ARE INCREASING IN CANADA.

- 95% of deaths from liver disease are due to chronic hepatitis B and C, non-alcoholic fatty liver disease, liver cancer and alcoholic liver disease.
- Liver cancer is one of the few forms of cancer on the rise and liver cancer death rates related to hepatitis B are predicted to rise by 50%.
- An estimated 25% of Canadians, or 8.5 million people, are obese. Fatty liver disease linked to obesity is the most common form of liver disease in Canada.

TOO MANY CANADIANS ARE DYING BECAUSE LIVER DISEASE IS UNDER-DIAGNOSED AND UNDER-TREATED.

- Less than 10% of hepatitis B patients and less than 25% of hepatitis C patients have been treated due to high cost, restrictive reimbursement policies, lack of health care resources and poor understanding amongst patients and primary health care providers.
- The only treatment for end-stage liver disease is a liver transplant. In Canada, there are an estimated 5,000 deaths per year due to liver disease and approximately 400 liver transplants. Approximately one third of patients on the waiting list for transplants will die due to a shortage of donor organs.
- Although liver cancer can be successfully detected and treated if caught early, there are no government screening recommendations for at-risk patients.

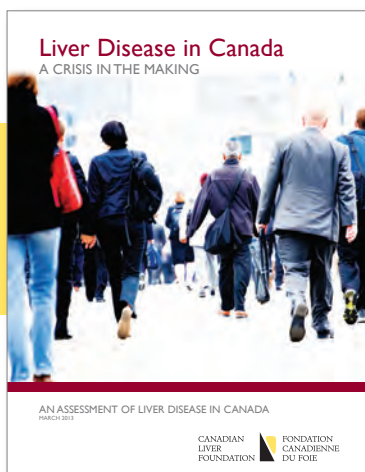
TREATING LIVER DISEASE IS COSTLY BUT IGNORING IT WILL COST EVEN MORE IN LIVES AND RESOURCES.

- From 2006-2009, in-hospital procedures for liver disease patients (including transplants) cost in excess of \$157 million and this estimate does not include all procedures, nor hospital stays and physician costs.
- Liver transplants cost more than \$100,000 per person including hospital costs and immunosuppressive drugs. Treating hepatitis B may cost \$7,000-\$9,000 per year for 10-20 years while a course of treatment for hepatitis C may be \$20,000-\$70,000.

#1 Key Recommendation

Health Canada, in conjunction with the provinces and territories, must establish a national liver disease strategy.

TO VIEW OR
DOWNLOAD THE
FULL REPORT, VISIT
WWW.LIVER.CA



VOICES OF CELEBRATION



If you listen, you will hear voices rising in triumph, ringing with laughter and sometimes breaking with emotion. These are the voices of the thousands of participants and volunteers who contribute their time, energy and enthusiasm in support of the Canadian Liver Foundation. Together they not only help us raise funds for liver research and education but also help break the silence surrounding liver disease.



What a Girl Wants...

Celebrating its 7th year, the What a Girl Wants event in Ottawa was once again the place to see and be seen. From the crab claws and filet mignon to the designer fashion show and, of course, the firefighters, Ottawa's hottest 'party with a purpose' had something for everyone. On stage, comedian and liver transplant recipient Mike MacDonald brought home the laughs while his brother, entertainer Johnny Vegas and his All-Star Band, kept everyone dancing. By the end of the evening, What a Girl Wants had raised over \$73,000 for liver research and education.



LIVERight™ Gala

In 2013, both Vancouver and Toronto hosted LIVERight Galas and honoured individuals who have made contributions to liver health and the community. For its 10 year anniversary, the Vancouver gala once again partnered with the World Chinese Business Association and recognized several local business people for their community contributions. The keynote speaker for the evening was CLF Chairman Dr. Morris Sherman who talked about the increasing prevalence of liver cancer and a local volunteer gave a poignant story of her family's experience with the disease.

In Toronto, the CLF handed out LIVERight Awards to two influential health and wellness experts, Bryce Wyld and Tosca Reno (see photo), for their efforts in encouraging healthy lifestyles. The evening also featured retiring liver specialist Dr. Jenny Heathcote and two-time liver transplant recipient Matthew Ayuen.

Thanks to the stellar turnouts at both events, the CLF raised \$210,000 to fund research and education programs.



KNOCK, KNOCK...IT'S YOUR LIVER

The liver is the butt of so many jokes that it only seems fair that it gets to benefit from all the comedy it has inspired. In March, the CLF hosted Knock, Knock...It's Your Liver comedy fundraisers at Yuk Yuk's and other participating comedy clubs in cities across Canada. Inspired by comedian Mike MacDonald, the comedy events featured a line-up of local comedians with ticket proceeds going to liver research and education. Mike himself even made a cameo appearance at the Yuk Yuk's in his hometown of Ottawa proving that laughter is good for the soul...and the liver!



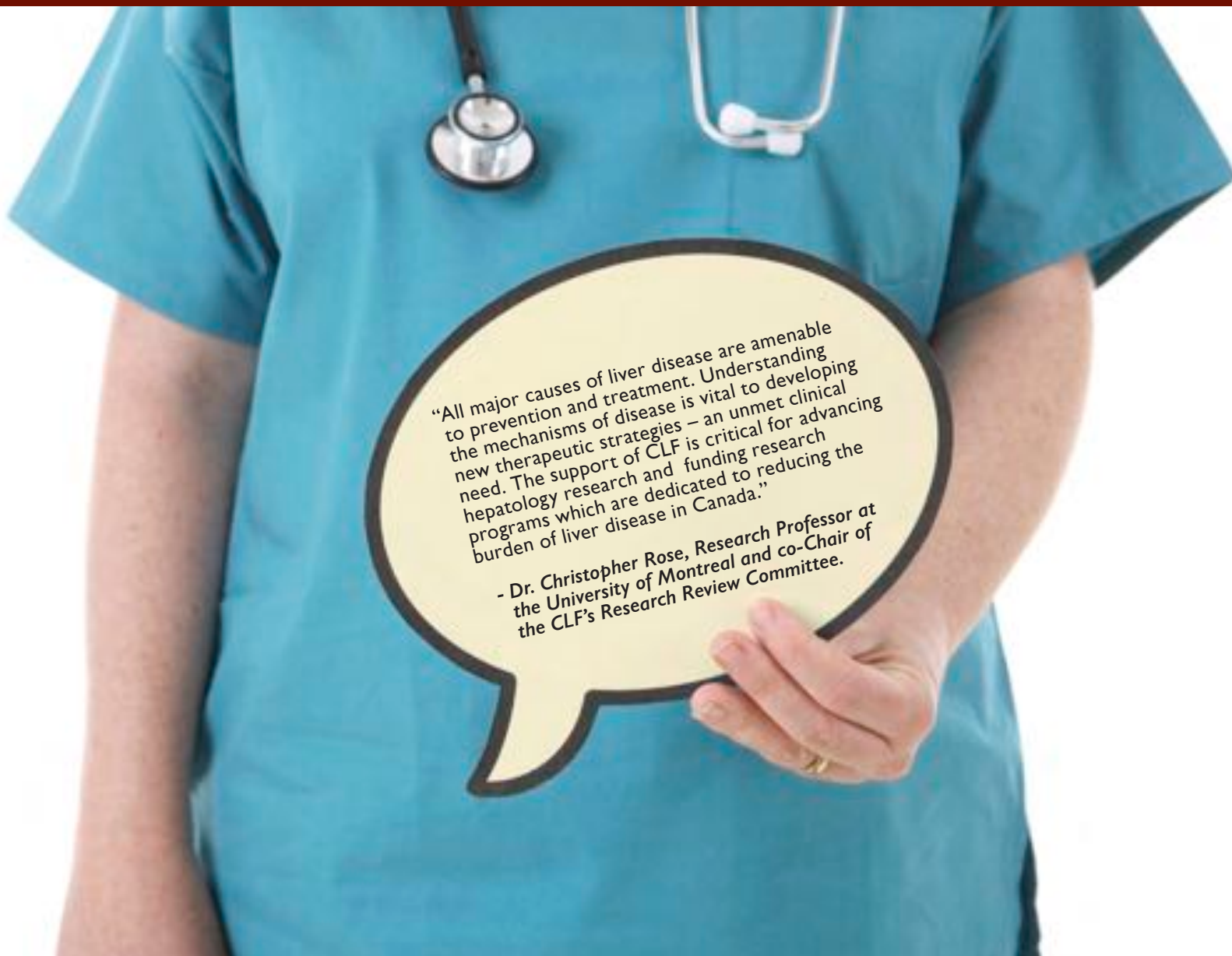
They walked, they ran, they strolled – and some even challenged their inner Viking – all for the sake of liver research. Twelve communities across Canada hosted Stroll for Liver events in 2013 raising more than \$160,000. We congratulate all the participants, especially those who braved the pouring rain, for showing their commitment to changing the future for Canadians with liver disease.



Our Lace Up for Liver team earned more travel points in 2013 by participating in both the Long Beach Half Marathon and 10K as well as making a triumphant return trip to the Reggae Marathon in Negril, Jamaica. Team members included both veterans and newcomers but they shared a common goal – to challenge themselves and raise much-needed funds for liver research. These dedicated runners and walkers raised more than \$40,000, thus earning themselves not only finishing medals but a well-deserved celebration in the sand and sun!



VOICES FROM THE LAB



Research requires patience and time. Often what appears to be a dramatic breakthrough may be the result of years, even decades, of research taking place in labs and clinics across the country or around the world. The Canadian Liver Foundation is proud of our legacy of supporting researchers at all stages of their careers from undergraduate to senior investigator.

Over the past 44 years, our investments in basic science and clinical research have contributed to breakthroughs in the diagnosis, prevention and treatment of the most prevalent liver diseases in Canada.

GRADUATE STUDENTSHIPS

MARC-ANDRÉ CLÉMENT

Université de Montréal

Supervisor: Dr. Christopher Rose

Research focus: Tyrosinemia and hepatic encephalopathy

Tyrosinemia is a childhood liver disease caused by defective genes. Children with tyrosinemia lack an enzyme which is essential in the metabolism of an amino acid called tyrosine. This leads to accumulation of toxins in many body tissues. While approximately one in 100,000 people world-wide has tyrosinemia, the disease is particularly common in the region of Saguenay-Lac-St-Jean, Quebec. In this specific area, one in 20 people is a carrier of the defective gene, and one in 1,846 has tyrosinemia. In this project, Marc-André Clement is studying the link between the increased activity in tyrosine metabolism and the development of a build-up of toxins in the brain called hepatic encephalopathy which is often observed in children born with tyrosinemia.

ZENGINA LEE

University of Calgary

Supervisor: Dr. Carla Coffin

Research focus: Hepatitis B and HIV Co-infection

The hepatitis B virus (HBV) and human immunodeficiency virus type 1 (HIV-1) are leading causes of death worldwide. Chronic hepatitis B infection is common in HIV-1 infected individuals because these two viruses are transmitted in similar ways. Although drug therapies are now able to control HIV-1, co-infected patients experience more complications from their hepatitis B than do patients who are not co-infected with both viruses. Zengina Lee is studying whether the hepatitis B virus targets different immune cells in co-infected patients than in those that have hepatitis B alone. The results may help improve future therapies that could lead to the eradication of both viruses.

JASON ALEXANDER JI-XHIN WONG

University of Alberta

Supervisor: Dr. Michael Houghton

Research focus: Hepatitis C vaccine

With an estimated 170 million people worldwide with hepatitis C and several million new infections occurring every year, there is an urgent need for a vaccine against the hepatitis C virus. Dr. Houghton's work has led to a trial vaccine that has been tested in a phase 1 clinical trial. Jason Wong is conducting further research to determine which antibodies bind to the surface of the virus and how they prevent or limit the infection process. The results will help in designing the optimal vaccine against this serious liver disease.

LAURA MICHELLE ZENITH

University of Alberta

Supervisor: Dr. Puneeta Tandon

Research focus: Exercise and Cirrhosis

Most forms of liver disease will eventually lead to liver cell dying and the development of cirrhosis (scarring of the liver). Among the many complications associated with cirrhosis, patients will lose muscle mass and consequently tire easily when performing daily activities. They will also experience reduced quality of life and have a higher risk of death. Regular exercise (e.g. walking, riding a bike) has been shown to decrease fatigue. Dr. Tandon and her team are in the midst of completing a randomized trial evaluating the effects of exercise in early cirrhosis. As part of the next step, Laura Zenith is working with her colleagues to investigate the impact of exercise in patients with more advanced cirrhosis, many of whom may be on transplant waiting lists. The research is comparing patients on an exercise regimen to those who are not via measurements of the effects of exercise on heart and lung function, muscle mass, quality of life and safety. The findings of this study may lead to improved quality of life for all patients suffering from end-stage liver disease.

PRITAL PATEL

Mount Sinai Hospital

Supervisor: Dr. Jim Woodgett

Research focus: **Liver Cancer**

About 70% of patients with liver cancer that undergo treatment experience recurrence of the cancer within five years. Stem-like cells have been shown to play a role in the development of liver cancer and its recurrence after treatment. Dr. Woodgett's team has created a new laboratory model in which they have deleted a certain gene mutation found in one third of all liver cancers. This new model is allowing Prital Patel and her colleagues to study the activity of the stem-like cells. Their findings will have tremendous implications for the development of better therapies that may prevent recurrence and spread of cancerous cells.

EVETTE YASSA

McGill University

Supervisor: Dr. Peter Metrakos

Research focus: **Liver Cancer**

The incidence of liver cancer has been steadily increasing alongside rising incidences of viral hepatitis and obesity in Canada. Very few liver cancer studies have focused on fat metabolism, which may play an important role in the development and progression of liver cancer as well as many other cancers. Fat metabolism in the body is regulated in part by specialized structures within cells called lipid droplets (LDs). Evette Yassa is researching LDs and other important proteins surrounding and regulating the LDs to determine what role they play in the development and progression of liver cancer. The findings of this research may lead to the development of new treatments for liver cancer.

SUMMER STUDENTSHIPS

LAURA BOSCO

University of Toronto

Supervisor: Dr. Johane Allard

Research focus: **Fatty liver disease**

Currently the most common liver disease in Canada, non-alcoholic fatty liver disease (NAFLD) can lead to cirrhosis and liver cancer as well as other health problems including diabetes and heart disease. During her summer studentship, Laura Bosco worked on collecting and analyzing data to help determine which genes are likely to be involved in the development of NAFLD. Targeting these genes could lead to the development of treatments for NAFLD and ways to prevent this liver disease.

VALÉRIE BROUSSEAU

Université Laval

Supervisor: Dr. Olivier Barbier

Research focus: **Cholestatic liver disease**

Impaired bile flow (cholestasis) is one of the most devastating consequences of liver disease. Liver diseases that involve impaired bile flow – including primary biliary cirrhosis (PBC) and primary sclerosing cholangitis (PSC) – are among the leading causes of liver transplants in all age groups. Valérie Brousseau researched whether Omega-3 fatty acids could protect liver cells from damage by the build-up of bile acids and whether this may have a potential for the treatment of these liver diseases.

EMILY DAY

McMaster University

Supervisor: Dr. Gregory Steinberg

Research focus: **Fatty liver disease**

Fat metabolism in the liver is regulated by a specific protein. During her summer studentship, Emily Day tested whether a commonly used drug for the treatment of arthritis might be effective in reversing fatty liver disease. The findings of this research may lead to new therapies for treating this very common liver disease.

CYNTHIA DÉSAULNIERS-LANGEVIN

Université de Montréal

Supervisor: Dr. Fernando Alvarez

Research focus: **Hepatitis E & liver transplant patients**

All liver transplant patients have to take immunosuppressive drugs to prevent rejection of their new organs. This makes these patients more vulnerable to infections in some cases caused by viruses that may be harmless to healthy individuals. Hepatitis E Virus (HEV), which is common in developing countries with poor sanitary conditions, is also highly prevalent in livestock in Canada. Since there has been a high prevalence of HEV infection in children who had received liver transplants, the goal of this project was to develop better diagnostic tools to detect this virus and to understand the impact of HEV in children.

IRENE KIM

University of Alberta

Supervisor: Dr. Diana Mager

Research focus: **Fatty liver disease in children**

Non-alcoholic fatty liver disease (NAFLD) typically occurs in children who are overweight or obese but it is not well understood why some children develop fat in the liver and others do not. During her summer studentship, Irene Kim studied how consumption of foods with significant levels of high fructose corn syrup and saturated fats can influence liver function, inflammation of the liver and levels of lipid and lipoproteins in children with NAFLD. This information will lead to the development of better treatment strategies for children with NAFLD.

“Our study provides the first stepping stone for the use of exercise as a therapeutic method to improve fatigue, quality of life, muscle mass, and functional capacity in patients with advanced cirrhosis. Improving these outcomes has significant potential to positively affect patients living with liver disease.”

– **Laura Zenith,**
2013 Graduate
Studentship Recipient

“The liver is both a fascinating and an important organ to understand, as the global implications to health care and well-being are immense. Studying the molecular mechanisms of liver diseases can aid in providing a better understanding of the organ and by learning more, we can develop better targets for drugs to prevent end-stage complications. It’s inspiring to think that I could be directly helping patients better manage their disease.”

– **Prital Patel,**
2013 Graduate
Studentship Recipient

“My experiences this summer have further substantiated my passion for medicine, and has taught me the vast implications associated with NAFLD, and its wide array of contributing factors: dietary, physiological, epigenetic and genetic. It has allowed me to further appreciate how little we know regarding the mechanistic pathways underlying pathological disease, and how often we underestimate dietary changes as a potential method of treatment or prevention.”

– **Laura Bosco,**
2013 Summer
Studentship Recipient

“One of the most important things I gained from this research experience was an understanding and appreciation for the importance of liver research. Even with ongoing research, there is still so much left for future researchers to tackle, which could make profound differences in the lives of children living with liver disease.”

– **Irene Kim,**
2013 Summer
Studentship Recipient



GOING FOR THE GOLD IN LIVER CANCER RESEARCH

When we think of gold medalists, we may envision runners, skiers or hockey teams – few would think of liver researchers standing atop a podium. And yet every day there are medal-worthy performances in liver research around the world where the competition is liver disease itself and the ultimate goal is to save lives.

In 1983, the Canadian Liver Foundation established a Gold Medal Award to recognize the outstanding work of doctors and scientists who have made significant contributions to liver disease research.

In 2013, new cancer statistics showed that liver cancer is one of the fastest rising and deadliest cancers in Canada. It is only fitting that this year's Gold Medal recipient has been fighting the battle against liver cancer throughout his career.

Dr. Jordi Bruix is a Professor of Medicine and Chief of the liver cancer group – known as the BCLC – at the University of Barcelona in Spain. He has been the Principal Investigator of several studies and clinical trials that have changed practice in the field of hepatocellular carcinoma (HCC), including development of diagnostic criteria, prognostic models and establishing chemoembolization and sorafenib as conventional therapy. He also developed the BCLC staging and treatment strategy that has been endorsed by several international scientific associations to guide management of patients with HCC.

With liver cancer on the rise in many parts of the world, there is a n increasing demand for expert advice regarding the best screening, diagnostic testing and treatment options. In response to this need, Dr. Bruix led production of practice guidelines for HCC both in the USA and Europe and even for the World Gastroenterology Organization.



CANADIAN NATIONAL TRANSPLANT RESEARCH PROGRAM

The liver is the second most transplanted organ in Canada with an average of 400 liver transplants taking place across the country each year. With liver diseases such as fatty liver disease and liver cancer on the rise and expectations that many in our aging population may have undiagnosed liver disease, the need for liver transplantation is destined to increase dramatically.

Unfortunately, there is already a shortage of available organs for those that need them meaning that many Canadians will die while waiting for a much-needed liver transplant.

With demand outweighing the supply, it is vital to ensure that every liver transplant has the best possible outcome and research holds the key. To demonstrate our commitment to improving liver health through research and education, the CLF has partnered with the Canadian Institutes of Health Research (CIHR) to support the Canadian National Transplant Research Program (CNTRP).

Groundbreaking in scope, the objective of this program is to enhance the survival and quality of life of Canadians who undergo transplantation, through multi-disciplinary, collaborative and leading-edge research. Led by Dr. Lori West of the University of Alberta, the CNTRP involves 116 investigators and 72 collaborators

from 21 transplant centres and universities spanning nine provinces plus collaborations with international researchers from Europe, Asia, Australia, United States and South America. The CNTRP is committed to creating a transformative program that will improve the lives of Canadians for whom transplantation offers a 'second chance' at health.

Researchers in CNTRP will focus their energies on stem cell and solid organ transplants to achieve the following goals:

1. Increase the number of transplants
2. Extend the life of transplant patients
3. Improve the quality of life of transplant patients
4. Develop and enhance training for transplant specialists and researchers
5. Develop and coordinate a collaborative transplant network
6. Enhance transplantation data management systems

As one of the founding partner organizations, CLF has made a \$500,000 commitment to CNTRP over five years. Funding is also being provided by the CIHR, academic institutions, industry, and provincial organ procurement organizations, for a total investment of \$23 million.



"We are incredibly excited to partner with the CLF to develop this groundbreaking technology in liver transplantation across Canada. Better livers and more livers means more Canadian lives saved."

– *Dr. James Shapiro, Director, Clinical Islet and Living Donor Liver Transplant Programs, Alberta Health Services*

CARE & TRANSPORT OF DONOR LIVERS

The liver may be the body's most resilient organ but once it is outside the body and cut off from its blood supply it is very vulnerable. Donor organs have traditionally been transported in cold storage to reduce the possibility of damage prior to transplant, but the CNTRP team is testing a new method using a device known as the OrganOx 'Metra' to keep the liver in an optimal environment during transport (meaning that it is still warm and having blood pumped through it) revolutionizing organ preservation. During clinical trials in the UK, the device helped ensure more livers were still usable and undamaged when the time came to transplant them.

TREASURER'S REPORT

For the past four decades, the Canadian Liver Foundation has relied upon the generosity of individuals, corporations and organizations to allow us to deliver on our mandate to fund research and education programs to benefit the liver health of all Canadians. We are grateful to all our past and current donors and partners whose support has contributed to our strong financial performance.

In 2013 we paid out \$820,000 in research grants to fund projects in fields ranging from liver cancer to fatty liver disease. Under our multi-year grants, we have ongoing research commitments totaling over \$1 million to be paid from 2014 to 2017. This includes amounts approved for funding in 2014 for which the peer review process will commence in 2014.

Our expenditures on Programs in 2013 were approximately \$2.2 million compared to \$1.9 million in 2012. The research trust funds have paid nearly \$800,000 in research programs compared to \$309,000 in 2012, together with \$820,000 in research grants we paid out over \$1.6 million in research in 2013, a 58% increase over 2012.

Operating costs were \$3.2 million in 2013 compared to \$3.3 million in 2012 reflecting our ongoing cost containment measures.

The Foundation's Donations and Chapter Revenue was \$5.8 million in 2013. The research trust funds revenue increased to approximately \$1.3 million due to increased support of our existing partnership programs as well as support from new partnerships and donor-designated research funding.

Our financial position remains sound. At the end of 2013, we had current assets amounting to \$1.5 million. Our investments total \$3.1 million, an increase of approximately \$300,000 (11%) over 2012. The annual investment portfolio yield for 2013 was 12% and we earned over \$130,000 in interest and dividends and approximately \$350,000 in net portfolio appreciation.

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 2014 and beyond.



Elliott Jacobson, FCPA, FCA, ICD.D
Secretary/Treasurer

WHERE OUR REVENUE COMES FROM

CORPORATIONS
35%

INDIVIDUALS
52%

GOVERNMENT
1%

ESTATES
5%

OTHER
6%

FOUNDATIONS/ORGANIZATIONS
1%

CHARITABLE ACTIVITIES SUPPORTED BY DONOR DOLLARS

RESEARCH
54%

**PATIENT & PROFESSIONAL EDUCATION,
PUBLIC INFORMATION & COMMUNITY SUPPORT**
46%

Financial Position Summary as at December 31, 2013 and 2012

	GENERAL FUND		RESEARCH TRUST FUNDS		MEDICAL RESEARCH FUND		TOTAL	
	2013	2012	2013	2012	2013	2012	2013	2012
ASSETS								
Current	\$969,339	\$926,112	\$337,132	\$165,618	\$234,778	\$902,917	\$1,541,249	\$1,994,647
Investments	\$281,697	\$216,889	\$1,944,046	\$1,894,887	\$849,222	\$673,083	\$3,074,965	\$2,784,859
Capital Assets	\$136,453	\$157,318					\$136,453	\$157,318
	\$1,387,489	\$1,300,319	\$2,281,178	\$2,060,505	\$1,084,000	\$1,576,000	\$4,752,667	\$4,936,824
LIABILITIES	\$428,124	\$598,579					\$428,124	\$598,579
FUND BALANCE	\$959,365	\$701,740	\$2,281,178	\$2,060,505	\$1,084,000	\$1,576,000	\$4,324,543	\$4,338,245
	\$1,387,489	\$1,300,319	\$2,281,178	\$2,060,505	\$1,084,000	\$1,576,000	\$4,752,667	\$4,936,824

Operations Summary for the Year Ended December 31, 2013 and 2012

	GENERAL FUND		RESEARCH TRUST FUNDS		MEDICAL RESEARCH FUND		TOTAL	
	2013	2012	2013	2012	2013	2012	2013	2012
REVENUE								
Donations and Chapter Revenue	\$4,808,513	\$4,854,600	\$1,046,771	\$979,188			\$5,855,284	\$5,833,788
Interest and Other Income	\$60,926	\$15,594	\$243,798	\$105,632	\$48,897	\$49,037	\$353,621	\$170,263
	\$4,869,439	\$4,870,194	\$1,290,569	\$1,084,820	\$48,897	\$49,037	\$6,208,905	\$6,004,051
EXPENDITURE								
Programs	\$1,387,963	\$1,543,435	\$797,897	\$308,877	\$2,283	\$2,711	\$2,188,143	\$1,855,023
Operating	\$3,214,891	\$3,311,200					\$3,214,891	\$3,311,200
	\$4,602,854	\$4,854,635	\$797,897	\$308,877	\$2,283	\$2,711	\$5,403,034	\$5,166,223
Excess of revenue over expenditure for the General Fund	\$266,585	\$15,559					\$266,585	\$15,559
Excess of revenue over expenditure for the Research Trust Fund			\$492,672	\$775,943			\$492,672	\$775,943
Excess of revenue over expenditure for the Medical Research Fund					\$46,614	\$46,326	\$46,614	\$46,326
Research Grant Disbursements					(\$819,573)	(715,663)	(\$819,573)	(715,663)
Interfund transfers to support activities of the Medical and Research Trust Funds	(\$8,960)	\$31,710	(\$271,999)	(\$557,047)	\$280,959	\$525,337	\$0	\$0
FUND BALANCE - Beginning of Year	\$701,740	\$654,471	\$2,060,505	\$1,841,609	\$1,576,000	\$1,720,000	\$4,338,245	\$4,216,080
FUND BALANCE - End of Year	\$959,365	\$701,740	\$2,281,178	\$2,060,505	\$1,084,000	\$1,576,000	\$4,324,543	\$4,338,245

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

THANKS TO OUR DONORS

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, 2013. 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.

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WE WOULD LIKE TO
OFFER A SPECIAL THANK
YOU TO THOSE WHO
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CELEBRATION' IN 2013.

14th Birthday Party
Madison Mah, Edmonton, AB

Christmas Ornament Fundraiser,
Adriana Percorilli, Edmonton, AB

Birdies for Gramps
Logan Yanick, American Junior Golf Association, BC

Fundraiser for the Canadian Liver Foundation
Don & Debra A Simpson, Chilliwack, BC

PARTY!
Bianca Pengelly, Winnipeg, MB

Brian Miller Memorial Golf Tournament
Corey Miller, Tirecraft (Atlantic Provinces), Dartmouth, NS

15th Annual Lower Deck Golf Tournament (In memory of Barry Martin)
Mike Condry, Lower Deck Inc, Halifax, NS

16th Annual Naval Communicators Reunion (50/50 Tickets)
Corey MacNeil, Marlant Naval Communicator Community, Halifax, NS

3rd Annual Kyle's Run
Niagara, ON

Marina Point Memorial Fundraiser Dinner, In memory of Kim Carter
Committed volunteers of North Bay, North Bay, ON

Third Annual Randy Moore Invitational Golf Tournament
Ottawa, ON

Volley Ball Tournament
Begin2Believe, Ottawa, ON

Volley Ball Tournament
LoveGives, Ottawa, ON

Campaign to raise funds for the Canadian Liver Foundation
Erika Swaby, Toronto, ON

KMCA Spring Gala Fundraiser
Korean Canadian Medical Association (KCMA), Toronto, ON

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