

# We are bringing liver research to life.



Canadian Liver Foundation  
Fondation canadienne du foie

*Bringing liver research to life  
Donner vie à la recherche sur le foie*

## Annual Report 2014



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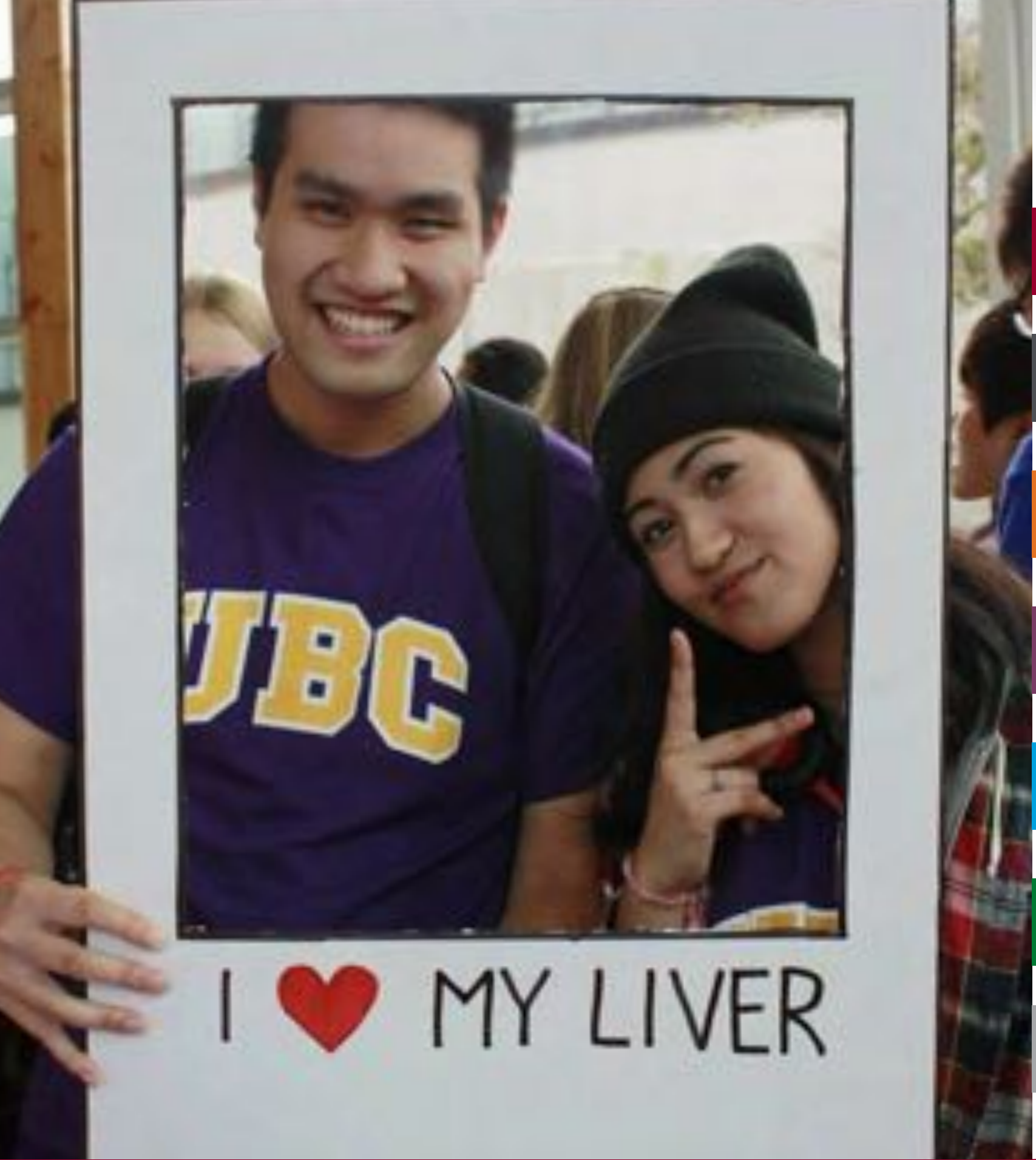
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# Message from Chairperson & President

## We are bringing liver research to life – with your help.

If you ask liver disease patients who is the Canadian Liver Foundation, they might say that we are the people who listen, answer their questions and help them not to feel alone.

If you ask researchers, they might say that we are the ones that helped them get started in liver research. If you ask doctors, they might say that we help them improve their ability to prevent, diagnose and care for their patients.

If you ask us, we would say that these patients, researchers and doctors are all part of who the CLF is.

45 years ago the Canadian Liver Foundation was born out of the passion and concern of a committed group of business leaders and doctors who believed that liver disease needed a champion. Today, as our new tagline says, we are bringing liver research to life with the help of volunteers, patients and families, researchers, doctors, donors and corporate supporters who share our vision of a world without liver disease.

In 2014, we are proud to report that we invested \$1.25 million in research to support seven researchers and three large-scale collaborative projects. These funds ensure that individual labs and multi-centre, multi-disciplinary initiatives that are pushing the bounds of knowledge in the areas of fatty liver disease, liver cancer, transplant, children's liver disease, hepatitis B and hepatitis C have the resources they need to continue their important work.

Two of our joint projects have footprints that stretch across the country and even around the world. 2014 marked the 12th anniversary of the National CIHR Research Training Program in Hepatitis C (NC RTP-Hep C) – an innovative program to connect mentors and students from academic and clinical institutions from coast to coast in a collaborative, multi-disciplinary approach to hepatitis C. CLF is a proud partner providing funds for research, managing non-governmental funding and offering support and input in the areas of knowledge translation, communications and advocacy.

The CLF was also a founding partner in the Canadian National Transplant Research Program involving research teams from 18 transplant centres and 15 universities and research centres worldwide in the pursuit of improved outcomes for transplant patients and ways to increase the availability of organs. In 2014, we contributed \$100,000 as part of our five-year funding commitment to this exciting initiative.



# Message from Chairperson & President

But ‘bringing liver research to life’ involves far more than just funding the pursuit of knowledge. It is in the sharing of what we learn that we can improve the lives of liver disease patients and protect others who are at risk for liver disease. In the past year, through our partnership with the Canadian Association for the Study of the Liver and other medical associations, we were able to provide tools and resources to liver specialists and primary health care providers that assisted them in screening, diagnosing and treating their patients. Our professional education resource centre on liver.ca experienced a 122 per cent increase in visitors demonstrating the rising demand for this type of information.

For patients, caregivers and the general public, we help translate the knowledge gained through research into practical advice and recommendations that can help them protect and manage their liver health. We offer support and information in English, French and Chinese via community level programs, through our website and social media and by one-on-one contact by phone or email. With more and more people

looking for information and connections online, we are seeking new ways to expand our reach and accessibility via our website. We have experienced a steady growth in our website traffic and in 2014, we welcomed almost 1.6 million visitors looking for liver disease information as well as volunteering, special event and giving opportunities. While many may prefer face-to-face communication or learning, our website allows us to be available 24/7 regardless of geographic locations or time zones. It will continue to be a key hub for all CLF activities.

After 45 years, our commitment to liver research and liver health remains the same but we have adopted a new ‘face’ that better communicates what we are about. Throughout this report, you’ll learn more about who ‘we’ are and how together we make an impact on the lives of those living with or at risk of liver disease. We want to take this opportunity to thank everyone who is helping us in bringing liver research to life. We couldn’t do it without you.



A handwritten signature in black ink, appearing to read 'M. Sherman'.

**Morris Sherman, MD, FRCPC**  
Chairperson



A handwritten signature in black ink, appearing to read 'Gary A. Fagan'.

**Gary Fagan**  
President & CEO

# Patient Support & Education

## We listen & teach

A liver disease diagnosis comes as a complete shock to most people as well as to their family and friends. There are many questions about how did this happen, what to expect, how to cope and what type of treatment options might be available. Unfortunately, doctors rarely have time in their rushed schedules to answer all these important questions – and that's where we come in.

For patients, families and health care providers with liver disease questions, the CLF is a trusted source of research-based information. Every day we respond to questions via our website, email, social media and our 1-800 National Help Line helping to allay fears, educate and connect people with services, organizations and others with liver disease.

Nothing is more comforting than talking to someone who understands what you're going through because they've been through it themselves. Our Peer Support Network and Living with Liver Disease groups provide personal connections that allow patients, spouses, parents and other family members to share their worries, triumphs, questions and coping advice to benefit one another.



We assisted over  
**2,700** people  
with liver health  
inquiries



# Patient Support & Education

We distributed over  
**60,000**  
brochures and  
infosheets to  
hospitals, clinics,  
patients, caregivers and  
the general public



**Si Yih Wong**

Peer Support Network Participant

When Si Yih was diagnosed with hepatitis B, he and his wife Lai knew very little about the disease. His doctor referred them to the CLF as a place they could go to get their questions answered.

“We gained invaluable information and confidence that there were resources available to help us understand hepatitis B from all angles,” says Lai. “Being in a room with people in the same situation gave us strength and took away our fear of the disease.”

We provided liver  
health information  
to more than  
**882,000**  
Chinese-speaking  
Canadians via  
mass media



# Patient Support & Education

## Ed Van Gennip

Peer Support Network Volunteer



Ed Van Gennip was diagnosed with primary sclerosing cholangitis (PSC) in 1992 and by 1998 he was told he would need a liver transplant within two years or he would be dead. With

three children aged two, four and seven, Ed was worried that they might have to grow up without a father. During this stressful time, Ed discovered the CLF and started attending monthly Living with Liver Disease meetings.

“My wife Nancy and I wanted to learn as much as we could about the liver and my specific disease,” explains Ed. “I wanted to hear not just from doctors but from those who had the same problems, symptoms, struggles, and what they did to deal with the effects of the disease.”

After 22 months on the waiting list, Ed received his transplant and eight days later was home recovering and taking powerful immunosuppressive drugs to keep his body from rejecting his new liver.

Unfortunately, the very drugs meant to protect to his liver triggered a form of cancer called Post-transplant Lymphoproliferative Disorder or PTLN. Ed had to undergo chemotherapy but thankfully was able to eliminate the cancer.

But his struggles were not yet over.

In 2012, after suffering from repeated infections, jaundice and weight loss, Ed was told that PSC was destroying his new liver. He was once again put on the transplant list and 19 months later received his second liver transplant on June 19, 2014. After three months of recovery, he returned to work and has had no problems with rejection or complications.

Throughout his experiences, Ed shared his ups and downs with others in the Living with Liver Disease program and with individuals he connected with via the Peer Support Network.

“By sharing with others, we feel better knowing that we are not alone – others have travelled the same path and come through it,” says Ed. “It gives one hope and encouragement and the opportunity to both give and receive – a wonderful balance. I have become friends with some people who I would never have met if the Peer Support Network had not existed.”

**“By sharing with others,  
we feel better knowing that  
we are not alone – others have  
travelled the same path and  
come through it,”**



# Patient Support & Education



We promoted liver health to over  
**38,070**  
people at  
community events  
across the country

Carol Plathan  
Support Group Facilitator



*Photo credit: Betty Esperanza*

Carol first learned about the Canadian Liver Foundation at a volunteer fair in Montreal but her experience with liver disease began long before when she was diagnosed with hepatitis C. Having experienced first-hand the ignorance and stigma surrounding liver disease, she leapt at the opportunity to provide compassionate support to those living with liver disease and accurate information to the public to help counteract the misconceptions.

Working in partnership with the CLF's Regional Director in Montreal, Carol helped establish a series of support groups which later expanded into educational presentations and one-on-one peer support.

**“We give them information, guidance and, most importantly, ‘listening from the heart’.”**

“For liver patients and caregivers, our meetings are a safe environment for speaking about and sharing their experiences related to their liver diseases,” says Carol. “We give them information, guidance and, most importantly, ‘listening from the heart’.”

After having undergone successful treatment several years ago, Carol is a hepatitis C survivor who understands the challenges of coping with liver disease. Today she serves as the facilitator for the support group meetings, conducts presentations for businesses and community groups and offers telephone support to those patients who are too ill to leave their homes.

“By providing both support and outreach, I try to focus on fighting the stigma which surrounds liver diseases,” says Carol. “It’s an opportunity to use my passion for teaching about liver health.”

# Advocacy

## We speak up

Liver disease is silent. It does not draw attention to itself within the body nor within society at large. That is why the Canadian Liver Foundation and its volunteers, patient and medical advocates and partner organizations must speak up to give liver disease a voice and a platform to reach the public and government policy makers.



We reached  
**124,878** people  
via social media channels

### Access to Treatment

In 2014, the CLF was instrumental in the approval of the newest generation of hepatitis C drug therapies for use in Canada. These medications significantly increase the odds of a cure for patients with the most common form of the disease (genotype 1), while making treatment shorter, simpler and more tolerable. Both patients and doctors from across the country influenced the federal government's decisions by sharing their insights and personal experiences as part of the CLF's submissions to Health Canada. Continuing advocacy efforts including letter writing, government meetings and media stories have also been successful in achieving drug benefit coverage in many provinces – thus removing the financial barrier for patients in accessing these life-saving treatments.

### Hepatitis C Testing

For individuals to be treated for hepatitis C, they must first know that they have it. In 2012, the CLF issued a call for age-based hepatitis C testing targeting adults born between 1945 and 1975 – the age group most at risk for having undiagnosed hepatitis C. In 2014, we continued to advocate for the adoption of widespread screening with meetings and presentations to federal Members of Parliament and provincial MPPs. Although the Public Health Agency of Canada drafted new hepatitis C testing guidelines, they have not yet released them so the CLF – along with partner coalitions like Action Hepatitis Canada – is continuing to push for action.



# Advocacy

## CLF Hepatitis C Stakeholder Summit

Hepatitis C affects people from many different backgrounds in all parts of Canada. As a result, there are a variety of organizations – national, regional and community-based – that represent the needs of specific populations with or at risk for hepatitis C. In 2014, the CLF organized a multi-stakeholder meeting to bring together patient and community groups, health care professionals and researchers, government, insurance and pharmaceutical industry representatives. The knowledge, expertise and passion of the various stakeholders helped define a collaborative and united path forward.

Together, we produced practical and realistic recommendations that we could start executing individually and collectively to improve prevention, diagnosis and treatment, moving towards the elimination of hepatitis C in Canada by 2030. We realize, however, that these recommendations are just the beginning of establishing the path to addressing this very complex and multi-faceted issue. We look forward to working collaboratively with our partners across Canada and internationally to both eliminate hepatitis C in Canada and be part of the worldwide drive to eradicate this serious virus within our lifetime.



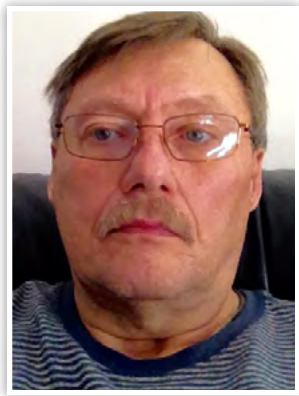
We provided more than  
**1.6**  
**million**  
people with  
liver-related  
information via  
**liver.ca**

# Advocacy

## *Patient Advocate* **Berent Vledder**

Berent, a retired aircraft mechanic and military veteran, was first diagnosed with hepatitis C in 2005 and started his first attempt at treatment the following year. By 2013, he had undergone treatment three times and had had a liver transplant but still had the virus in his blood. After his transplant, Berent tried treatment one more time and almost died within the first three weeks.

It was during his first round of treatment that Berent was invited to join a local hepatitis C support group run by a Winnipeg man named Jaik Johanson. The group ran on a 14 week schedule and provided participants with information about the disease and how to cope. But most importantly, it gave them a place to go where they could share their fears, ask questions and learn from one another. Today the group meets every Thursday at the CLF office and everyone is welcome.



“Our group has become an anchor for a lot of very scared people who didn’t know where to turn,” says Berent. “We have a core group of current and ex-patients who are very knowledgeable and help the others with what to expect from the disease, how to deal with the stigma, how to talk to partners and friends and much more.”

Beyond just providing support, the group has taken on an advocacy role in the community. In 2014, the group helped organize an event with the CLF at the Manitoba Legislature for World Hepatitis Day to push for hepatitis C testing and coverage of new, more effective hepatitis C drug therapies. Prior to the event, the group sat down with a Winnipeg Free Press reporter to tell their stories about treatment failures and successes and the challenges of living with a disease that few people understand.

“In our group, we have talked about the shame and stigma associated with hepatitis C,” says Berent. “Sharing our stories and photos was one way we could combat the lack of understanding of this disease and encourage people to take it seriously.”

After his fifth try at treatment with a new, interferon-free therapy, Berent has now been cured of hepatitis C and is looking forward to catching up on the 10 years he lost to this disease.

“Sharing our stories and photos was one way we could combat the lack of understanding of this disease and encourage people to take it seriously.”



# Advocacy

## *Doctor Advocate* **Dr. Jordan Feld**

Dr. Jordan Feld, liver specialist for the University Health Network in Toronto and Research Director for the Francis Family Liver Clinic, is well familiar with the ignorance and apathy surrounding liver disease. He feels strongly that doctors have an extremely important role to play in promoting liver health and countering misconceptions about liver disease.



“Unfortunately, teaching in medical schools about liver disease is very limited, leaving many physicians poorly versed in many basic concepts of liver health,” explains Dr. Feld. “Many, even in the medical community, believe that all liver disease is alcohol-related and have a poor understanding of other risks to liver health. Fortunately the major progress in treatments for liver disease, particularly viral hepatitis, has led to some positive changes. More physicians are aware of liver disease and slowly concepts about viral hepatitis, fatty liver disease and even some rarer liver diseases are percolating into the wider medical community.”

He believes that liver specialists need to give a voice to their patients especially when it comes to government decisions that may impact their health.

“We, as specialists who care for people with liver problems, understand the devastation that these diseases can cause,” says Dr. Feld. “Many of the groups of individuals most affected by liver disease cannot advocate for themselves so it is our job as health care professionals to be their voice. Strong health advocacy can lead to enormous and critically important changes in health policy. The responsibility falls to us in the hepatology community to push for the support for research, care and prevention that is so desperately needed.”

As an outspoken advocate for patients, Dr. Feld has supported the CLF’s efforts to improve access to treatment and have birth-cohort based testing for hepatitis C implemented in Canada. In 2014, he joined the CLF in making presentations to federal MPs and Ontario MPPs regarding the burden of hepatitis C and the need for testing and treatment.

“The CLF has put together outstanding initiatives to raise awareness about liver disease and has supported critically important advances in liver disease through the strong fundraising campaigns and research support,” says Dr. Feld. “As important as it is for hepatologists to speak up for our patients, it is even more important for community organizations of people suffering from liver disease to speak up for themselves and the CLF gives them a place and a voice to make that happen.”

**“As important as it is for hepatologists to speak up for our patients, it is even more important for community organizations of people suffering from liver disease to speak up for themselves and the CLF gives them a place and a voice to make that happen.”**

# Research

## We find answers

Liver disease is like a complex puzzle with many pieces missing. Research is the process of finding and assembling the required pieces to come up with an identifiable picture – the answer to the puzzle.

For 45 years, the Canadian Liver Foundation has been funding the work of investigators at all stages of their research as they seek the missing pieces that will lead to ways to prevent, treat or cure the many forms of liver disease. Regardless of whether they are studying proteins, viruses, immune responses or patient care models, these researchers are committed to finding answers that will improve – or even save – the lives of the children, women and men with liver disease.

The following were our five main research areas for 2014.

### 1) Liver cancer

Liver cancer is one of the fastest rising and deadliest cancers in Canada. While primary liver cancer is most often linked to chronic hepatitis B or hepatitis C infection and increasingly fatty liver disease, it can also result from excessive alcohol use, use of anabolic steroids or from inherited liver diseases such as hemochromatosis. Certain forms of liver cancer can be prevented by treating the diseases that cause it. In many cases, liver cancer can also be successfully treated, and even cured, if it is identified early enough. There is still much to be learned however about how and why liver cancer develops.



### 2) Fatty liver disease

Fatty liver disease begins as a simple build-up of fat in the liver. While for some people this fat may not cause any problems, in others it can cause the liver to become inflamed (swollen) eventually leading to the development of scar tissue (cirrhosis). In its most severe form, fatty liver disease can result in liver cancer or liver failure.

The two main contributors to fatty liver disease are poor nutrition (linked to obesity) and alcohol consumption. Fatty liver disease is now the most common form of liver disease in Canada and promises to one day soon take over from hepatitis C as the leading cause of liver transplants. Research is looking at why a liver with fat deposits will progress to more advanced disease in some but not in others and how it can be prevented or reversed.





## 3) Children's liver disease

Like adults, children can develop a wide variety of different liver diseases, including viral hepatitis, fatty liver disease and liver cancer. They are especially vulnerable to liver diseases that can cause life-threatening complications shortly after birth. Some are linked to gene abnormalities, such as alpha-1 antitrypsin deficiency and tyrosinemia, while others like biliary atresia have unknown causes. At this time, most liver diseases affecting children cannot be cured – early diagnosis is key to ensuring the best possible outcomes.



## 4) Transplantation

Each year, an estimated 500 liver transplants take place in Canada, including those from both deceased and living donors. With demand far outweighing the supply however, liver disease patients must wait weeks, months or even years to receive this gift of life. Once they do, they still face the possibility of rejection, failure of the transplanted organ or complications due to the powerful immune-suppressive drugs required.

With Canada's low organ donation rate, researchers are investigating ways to ensure that every donor organ is usable and that every transplant is successful in both the short and long-term.



## 5) Hepatitis B and C

Both hepatitis B and C are caused by viruses that infect the liver. These viruses are transmitted through blood-to-blood contact and can lead to chronic infections. Hepatitis B and C affect an estimated 600,000 Canadians. They are two of the top three most common liver diseases in Canada and are major contributors to the increase in liver cancer rates.

While chronic hepatitis B can be controlled through drug therapy, recent breakthroughs have made it possible to cure hepatitis C in over 90 per cent of cases. Unfortunately, due to a lack of widespread testing, there are still thousands of Canadians who do not know they have hepatitis C.



# Research

## 2014 Research Grant Recipients

### Graduate Studentship

#### **Zhen Lin, University of Alberta**

*Supervisor: Dr. Andrew Mason*

*Research focus: Liver cancer*

The World Health Organization estimates that liver cancer is the second leading cause of cancer-related deaths worldwide. Many patients cannot be treated with currently available therapies and many do not qualify for liver transplantation. Zhen Lin is part of a team working with small regulatory molecules known as microRNAs that may be able to limit the development of liver cancer.

### Summer Studentships

#### **Jennifer Liang, University of British Columbia**

*Supervisors: Dr. Orlee Guttman and*

*Dr. Richard Schreiber*

*Research focus: Pediatric liver disease*

Many babies have newborn jaundice (a yellowing of the whites of the eyes) lasting three to five days after birth because the liver is not fully developed. A small portion of newborns who have jaundice (about one in 2,500 births) have cholestasis (a condition in which bile cannot be drained from the liver) which can be a sign of serious liver disease. In the wake of BC's policy mandating that jaundiced infants be tested to determine if they have liver disease, Jennifer Liang investigated the compliance with and the outcomes of this policy.

#### **Rutu Panjabi, McMaster University**

*Supervisor: Dr. Gregory Steinberg*

*Research focus: Liver cancer*

Liver cancer is one of the few types of cancer that affects more people today than it did 40 years ago. Patients are often diagnosed in the advanced stages of the disease with five-year survival rates of only 20%. Rutu Panjabi investigated how metformin – a widely prescribed diabetes medication – is able to reduce the risk of developing liver cancer.

#### **Bridget Anne Pierce, Dalhousie University**

*Supervisor: Dr. Kevork Peltekian*

*Research focus: Transplantation*

Every year about 140 organ transplants (including liver, kidney, heart and pancreas) are performed in Halifax. Many of the transplant patients come from rural communities and their follow-up care is shared between the transplant team and the primary care physician. Bridget Anne Pierce gathered data on how comfortable primary care physicians are in providing post-liver transplantation care to identify areas of improvement for managing the care of post-transplant patients.



# Research

## Research Project Profiles

### Making hepatitis C testing easier and faster

**Gregory Heymann**  
(2014 Summer Studentship Recipient)



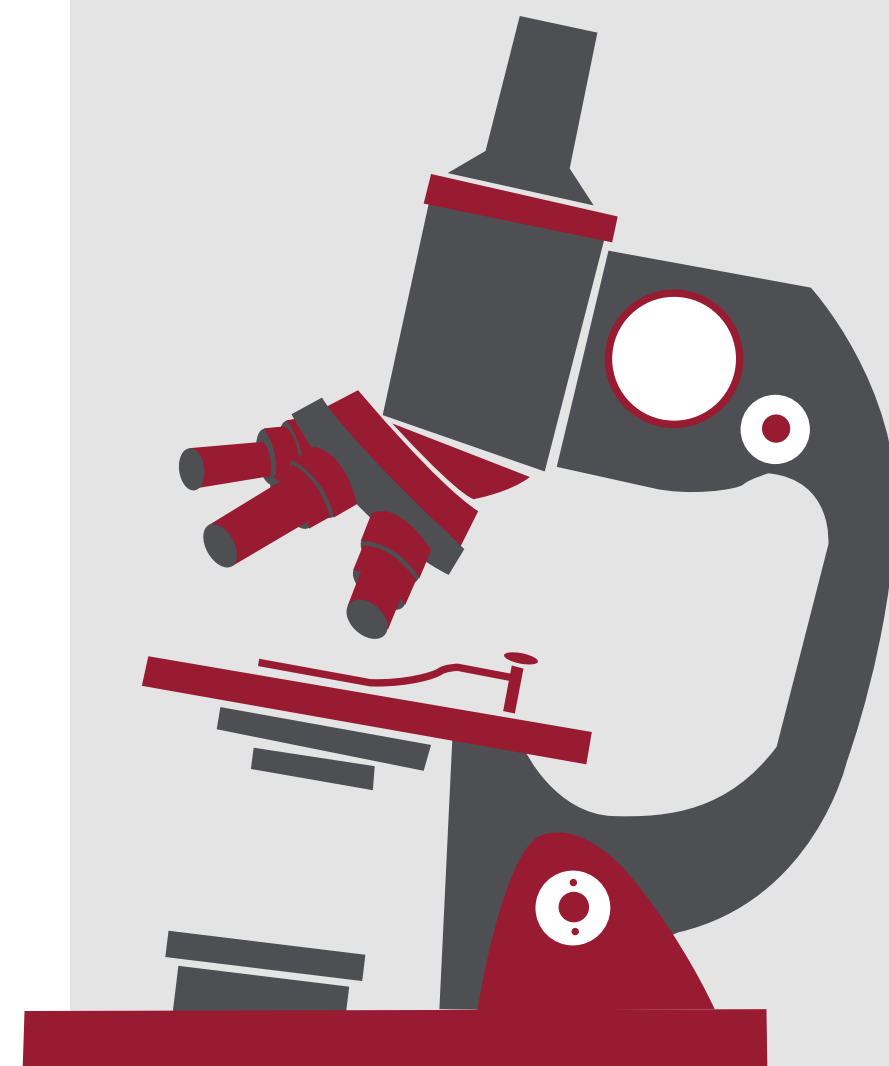
The only way to find out if you have hepatitis C is to have your blood tested. Doctors must run one test to confirm your exposure to the virus and a second to confirm if the virus is still present in your blood. During this process, they can also determine the

genotype of the hepatitis C virus (there are six different kinds) which makes a difference to what drug therapy might work best to treat it. These tests require specially trained experts and sophisticated equipment which are not available in rural areas or in community care clinics meaning that the samples have to be sent away for testing.

Summer Studentship recipient Gregory Heymann worked with Dr. Jordan Feld on developing two point-of-care tests that would detect exposure to the virus, active infection, the virus genotype and the best course of treatment and could be used by virtually any front line health care professional. With easy-to-use, inexpensive tests there would be more opportunity for anonymous testing and for people in rural and remote areas have equal access.

Working with Dr. Feld on such a ground-breaking project was a growth experience for Gregory. “I had to read scientific papers and extract the valuable information from them to back my propositions for the experiment,” says Gregory. “I developed great analytical and critical thinking skills and learned that in research, initial failures make the reward of a successful experiment that much greater.”

“I developed great analytical and critical thinking skills and learned that in research, initial failures make the reward of a successful experiment that much greater.”



We committed more than  
**\$1.75 million**  
to liver research  
in 2014



# Research

## When it comes to liver cancer, your genes and what you eat matter

### Dr. Jennifer Estall

(2014 Operating Grant Recipient)



Liver cancer is on the rise in Westernized countries. Dr. Jennifer Estall at the Institut de recherches cliniques de Montréal (ICRM) believes this may be due to the increasing incidence of obesity, poor diet, and sedentary lifestyle causing a

condition known as “metabolic syndrome”, in which fatty liver disease plays a major role. Metabolic syndrome is a combination of factors that include increased blood pressure, high blood sugar levels, excess body fat around the waist and abnormal cholesterol levels. Despite clear links, not much is known about how metabolic syndrome influences the development of liver cancer.

“There is a lot of evidence that poor liver health is actually the starting point of many metabolic diseases, including diabetes, cardiovascular disease, and even mental illness.”

Dr. Estall’s team has established that low levels of a protein called PGC-1 alpha makes fatty liver disease worse and may also directly impact the chance of developing liver cancer and/or its severity. Dr. Estall is testing whether having reduced levels of this protein increases liver cancer risk and whether the risk is further worsened when combined with poor diet and obesity. The results of this research could lead to therapies that will target this protein or the development of new screening tools to identify people at a higher risk of liver cancer due to specific genes that are more harmful when combined with certain diets.

“There is a lot of evidence that poor liver health is actually the starting point of many metabolic diseases, including diabetes, cardiovascular disease, and even mental illness,” Dr. Estall explains. “Unfortunately, this organ receives far less attention than more visibly affected ones, such as the heart in cardiovascular disease, the brain in dementia, and the pancreas in diabetes. Reasons for this are that we lack tools to easily measure liver damage in patients and we are only beginning to understand how liver disease has such a large effect on many aspects of our health.”



We have supported  
**519** researchers  
since 1969

# Research

## Hope for chronic hepatitis B patients

**Dr. Denis Grant**  
(2014 Operating Grant Recipient)



Hepatitis B is the one of the leading causes of liver cancer worldwide. This disease produces chronic inflammation and progressive damage to the liver, which in turn allows damaged cells to grow out of control and eventually form liver tumors.

Liver cancer is one of the most difficult cancers to treat. The team led by Dr. Denis Grant, a professor and researcher in the Department of Pharmacology and Toxicology at the University of Toronto, discovered that by removing one particular type of liver enzyme that can turn chemicals into cancer-causing agents, they were able to protect mice against getting liver cancer when they were exposed to a chemical found in cigarette smoke and some dyes. Dr. Grant's team is looking at using this same process to determine whether the elimination of this enzyme can also prevent the development of liver cancer caused by the hepatitis B virus.

If this is the case, this work will provide evidence of a broader role for this enzyme in cancer cell growth, and it may eventually lead to the identification and development of new treatments for liver cancer.

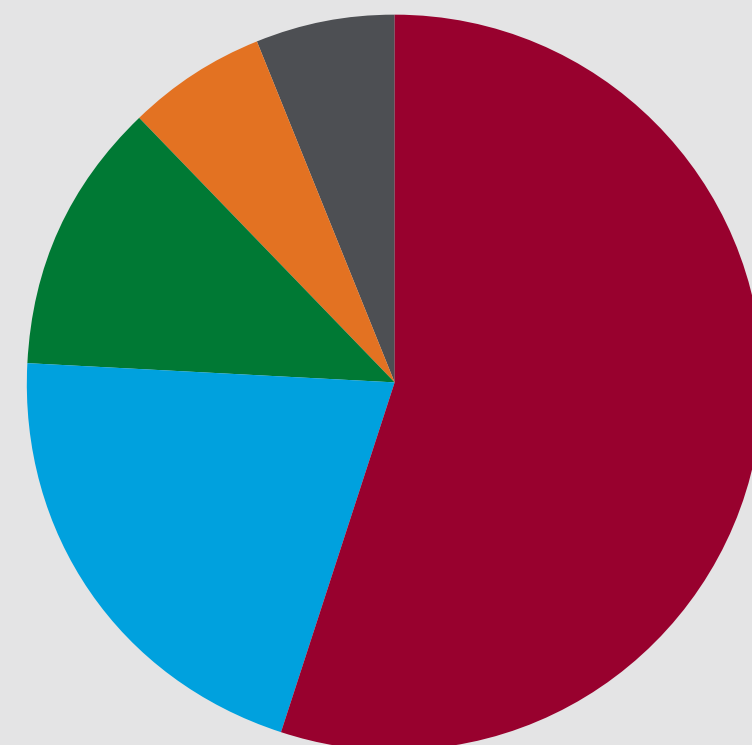
“Although my bias may be showing here, I think that the key role of the liver in such a broad range of vital bodily functions is often underappreciated,” says Dr. Grant. “After all, the liver is pretty much the only organ in the body that you simply can’t live without – and this central importance of the liver to our survival is likely why nature in its wisdom has given the liver the unique ability to regenerate large parts of itself after damage or injury.”

“Although my bias may be showing here, I think that the key role of the liver in such a broad range of vital bodily functions is often underappreciated.”

## Where our research funds go\*

The liver is a complex organ and discovering how it functions and how liver diseases develop is a long process. Many liver diseases may begin early in life but not manifest themselves until much later, meaning that all liver research – no matter what the focus – benefits the overall understanding of the liver and liver disease for all age groups and types of liver disease.

*\*research funds paid out in 2014*



Hepatitis C = 55%

Liver Cancer = 21%

Transplantation = 12%

Autoimmune liver disease = 6%

Other = 6%

# Research

## Going for Gold in Liver Cancer Research

The Canadian Liver Foundation has a proud legacy of supporting and promoting liver research both in Canada and around the world. 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.



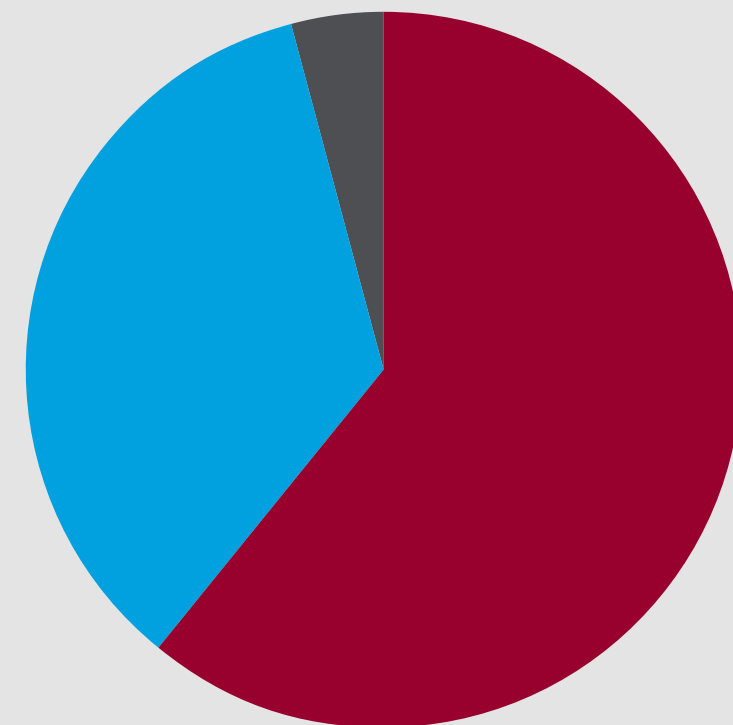
Liver cancer is the second leading cause of cancer-related death worldwide according to the World Health Organization. In light of the increasingly devastating toll this disease is taking on the world's population, it is fitting that the CLF, in partnership with the Canadian Association for the Study of the Liver, awarded the 2014 Gold Medal to Dr. Jordi Bruix, Head of the Oncology Liver Unit at the Hospital Clínic de Barcelona. Dr. Bruix is a liver cancer specialist recognized internationally for his work in the field.



Dr. Bruix received the gold medal not only in recognition of the success of what is known as the Barcelona Clinic Liver Cancer (BCLC) but also for his contributions to and his teaching of the BCLC model which categorizes patients according to the severity of their disease and links them with an appropriate treatment recommendation.

## How we fund research

The CLF is committed to funding the best liver research regardless of where it happens across the country. In order to spread our funds as widely as possible, we invest in different kinds of research projects. **Research partnerships** usually involve multiple funders (government, industry and non-profit) and support studies or initiatives that include teams at various sites in Canada. **Research grants** support individual researchers at various stages of their careers working on specific projects. **Fellowships** allow doctors to further develop their clinical experience in liver health.



Fellowships = 4%  
Research grants = 35%  
Research partnerships = 61%



# Research

## Research Partnerships



National CIHR Research Training  
Program in Hepatitis C

Subvention nationale de formation  
des IRSC sur l'hépatite C

In 2002, the Canadian Liver Foundation supported the launch of an innovative initiative to combine expertise with raw talent to nurture the next generation of hepatitis C researchers. Today, 12 years later, the National CIHR Research Training Program in Hepatitis C (NCRTP-Hep C) is helping to foster learning and collaboration amongst various clinical, scientific and social disciplines in an effort to lessen the effect of hepatitis C and prevent infection.

Funded by the Canadian Institutes for Health Research (CIHR), CLF and a variety of industry partners and private individuals, the program boasts a transdisciplinary team of experts from ten academic institutions from coast to coast who identify and tutor the next generation of trainees in fields including behavioural, clinical and biomedical sciences, and public health. Led by co-principal investigators, Dr. Naglaa Shoukry and Dr. Julie Bruneau, the NCRTP-Hep C has built research capacity in Canada and has helped redirect the attention and resources of established scientists in related fields toward research in hepatitis C. With the aid of donors and corporate partners, the CLF supported the ongoing success of this program by contributing \$575,000 in 2014.

## Top Ten Liver Diseases in Canada

1. Fatty liver disease
2. Chronic hepatitis B
3. Chronic hepatitis C
4. Alcohol-related liver disease
5. Hemochromatosis
6. Tyrosinemia
7. Toxic hepatitis  
(drug induced liver injury)
8. Liver Cancer
9. Autoimmune Liver Disease  
(PBC/PSC/AIH)
10. Wilson disease

# Research



## The goals for this research initiative are:

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 the incidence of liver disease rises, so too does the demand for liver transplants. Unfortunately, the demand already outweighs the supply of available donor organs and will only get worse – meaning more Canadians may die without receiving the gift of life.

With such a critical shortage of organs, it is vital to not only find ways to increase the number of registered organ donors but also to ensure that every liver transplant is successful. To help achieve this goal, the CLF is a partner with the Canadian Institutes of Health Research (CIHR) in support of the Canadian National Transplant Research Program (CNTRP).

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 research teams from 18 transplant centres and 15 universities and research centres across Canada plus collaboration with international researchers from Europe, Asia, Australia, USA and South America.

CLF has a five-year, \$500,000 commitment to the CNTRP program which has already produced results.

In early 2015, the first ‘warm liver’ transplant took place using a new organ preservation device. The OrganOx Metra can extend the life of a donor liver by almost 24 hours by maintaining it at body temperature and keeping it infused with oxygen and nutrient-rich blood. Up until now, donor livers were kept in cold storage prior to transplant. This new device not only ensures that donor livers are protected and viable prior to transplant but may allow surgeons to use organs that might otherwise have been considered unusable.

# Donors/Volunteers

## We Give

The Canadian Liver Foundation came into being thanks to the generosity and commitment of volunteers and donors. Today we rely on these dedicated individuals to make our research, programs and outreach possible.



Every year, our volunteers and donors (often they are one and the same) give of their time, talents, expertise and financial resources to support the work of the Foundation. Whether it is organizing a local fundraiser, making presentations, sponsoring an event, answering phones, working a health fair or investing in a field of research, they put their commitment into action for the sake of Canadians with liver disease.



We gained invaluable support from volunteers who contributed over **4,500 hours** of their time.



# Donors/Volunteers

## Donor Profile:



Driven by the loss of a family member to liver cancer, Ken Sexton, founder and CEO of Kenroc Building Materials Co. Ltd. and the Sexton Group, forged a partnership with the CLF that led to the CLF-Kenroc Liver Cancer Research Project. Under this joint endeavour, the Kenroc family of companies named the CLF its 'prime charity' and made a commitment to invest in liver cancer research through both corporate and personal donations in addition to fundraising events organized by its regional branches across Western Canada.

Both Ken Sexton and Kenroc President Brian Kusisto have led by example and made the commitment to liver cancer research part of the corporate culture at Kenroc. In January 2007, Brian joined a CLF team that climbed Mt. Kilimanjaro and not only reached the summit but surpassed his personal fundraising goal by raising more than \$75,000 for liver research and education. In 2012, the CLF was honoured to present Ken and Brian with Queen Elizabeth II Diamond Jubilee Awards for their ongoing support and leadership.

Thanks to corporate donations and local fundraising efforts, the Kenroc family of companies has contributed more than \$1.3 million which has helped fund 15 liver cancer research projects in search of new ways to prevent, treat or even cure liver cancer.



Over the years, the company's vision of a world without liver cancer has attracted support from Kenroc clients and suppliers who have generously contributed to golf tournaments, in-store contests and raffles with proceeds going toward the Liver Cancer Research Project.

Thanks to corporate donations and local fundraising efforts, the Kenroc family of companies has contributed more than \$1.3 million which has helped fund 15 liver cancer research projects in search of new ways to prevent, treat or even cure liver cancer.

# Donors/Volunteers

## Donor Profile:



Scotiabank is Canada's international bank and a leading financial services provider in North America, Latin America, the Caribbean and Central America, and parts of Asia. Through their global philanthropic program, Scotiabank and its employees support causes at a grassroots level. Recognized as a leader for their charitable donations and philanthropic activities, Scotiabank has contributed on average \$50 million annually over the last five years to community causes around the world.

As part of its Bright Future program, Scotiabank has been the presenting sponsor of the LIVERight Gala in Vancouver for the past six years.

As part of its Bright Future program, Scotiabank has been the presenting sponsor of the LIVERight Gala in Vancouver for the past six years.

In 2014, Scotiabank received special recognition for their ongoing support of the gala and the work of the CLF.

"Scotiabank believes that healthy communities make stronger communities," says Winnie Leong, Scotiabank Senior Vice President, BC & Yukon Region. "We are proud to support the outstanding work of the Canadian Liver Foundation because we know that they share in this belief, and are making a positive impact on the lives of individuals and families affected by liver disease."



## Donations for Liver Health



Individuals  
**80,875**

Businesses  
**1,972**

Total donated  
**\$2,477,473**

Total donated  
**\$1,526,019**

# Donors/Volunteers

*Donor Profile:*

## Dr. Francis Ho

Dr. Ho understands more than most how devastating liver disease can be on individuals and their families. As a family physician, he diagnoses and cares for patients with liver disease within his practice. Personally, he and his wife have faced the loss of her mother and youngest brother to liver cancer while her eldest brother is suffering from advanced cirrhosis. Dr. Ho's unique perspective and passion to help is what inspires him to volunteer with the CLF and to help raise funds for liver research.

In 2014, Dr. Ho joined the CLF's BC/Yukon Chapter board and helped recruit key donors for the chapter's annual gala. Thanks in large part to Dr. Ho's efforts, the gala raised over \$283,000 for liver research.

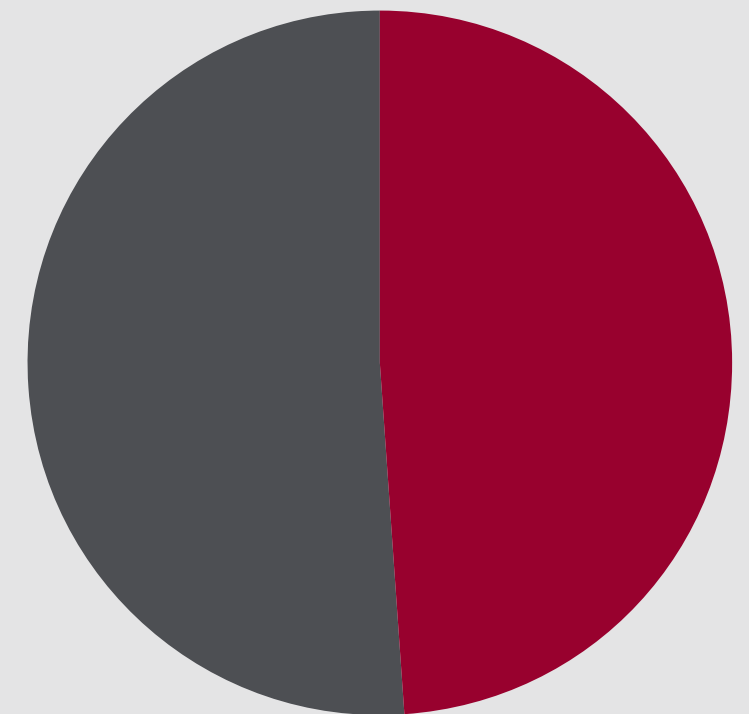
Dr. Ho is thankful for all the opportunities Canada has offered him – from the jobs that helped fund his education at the University of Manitoba and his medical training at the University of British Columbia, to the chance to establish and manage his own family practice.



“It is better to give than to receive but the one who receives should give back as much as possible,” says Dr. Ho. “I sincerely hope that my little effort may inspire others to support the Canadian Liver Foundation so we can finally eradicate all liver diseases!”

“It is better to give than to receive but the one who receives should give back as much as possible.”

## Charitable activities supported by donor dollars:



Research = 49%

Patient & Professional Education,  
Public Information &  
Community Support = 51%



# Donors/Volunteers

*Donor Profile:*

## Frank Bialystok

Vaccinated against small pox as a child in post-war Poland, Frank Bialystok discovered many years later that the shared needle used for that life-saving shot had probably given him hepatitis C. He was diagnosed in 1987 when hepatitis C was known only as 'non-A, non-B' hepatitis. Faced with an uncertain future, Frank decided to quit his teaching job and pursue his life-long dream to obtain his doctorate in history. His condition worsened in the intervening years until he finally underwent a liver transplant in 1998. When the hepatitis C virus attacked his new liver, he became the first post-transplant patient in Canada to undergo an experimental drug therapy which successfully conquered the virus.

During his ordeal, Frank promised himself that if he survived, he would dedicate himself to raising awareness of liver disease and the need for organ donation.

During his ordeal, Frank promised himself that if he survived, he would dedicate himself to raising awareness of liver disease and the need for organ donation. He consequently joined the CLF's National Board of Directors where he served for seven years and became involved in the National CIHR Research and Training Program in Hepatitis C (NCRTP-Hep C) as a patient representative and advisor.



As a volunteer, Frank has contributed countless hours speaking and writing about liver disease and his experiences and helping research trainees understand the patient perspective. In 2012, the CLF recognized his many contributions by presenting him with a Queen Elizabeth II Diamond Jubilee Award. The NCRTP-Hep C program has also created a Frank Bialystok Award to be given to the top ranked NCRTP trainee beginning in 2016.

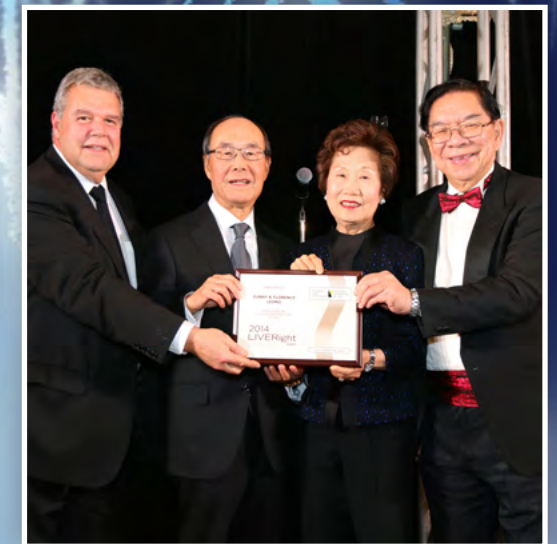
In addition to his time and expertise, Frank has donated more than \$65,000 to support the CLF and the NCRTP-Hep C.



# A 'cause' for celebration

## LIVERight™ Gala

Outstanding volunteers, beautiful venues and terrific entertainment combined to make the perfect formula for our 2014 signature galas. Hosted in Vancouver, Calgary, Toronto, Ottawa and Halifax, the LIVERight Galas each celebrated the contributions of individuals who are committed to the cause of liver health. Thanks to the generous support of sponsors and those in attendance, our galas raised over \$430,000 for liver research and education.







In 10 communities across Canada, CLF volunteers and supporters stepped out for liver health in our annual Stroll for Liver events. By walking, running and yes, strolling, participants helped raise more than \$135,000 for liver research – all the while contributing to their own liver health!

*Photo credit: Betty Esperanza*



## Lacing Up for Liver Health

In 2014, a diverse but determined group of runners and walkers covered more than 100 km in long distance events on behalf of the CLF. In Vancouver and Toronto, teams participated in Scotiabank Marathons achieving not only personal bests, but in one case, a Guinness World Record. Another group took on a more 'tropical' challenge, completing the 10k course as part of the Reggae Marathon in Negril, Jamaica. Each team member had their own inspiration for running but they shared a commitment to conquering liver disease and together raised more than \$44,000 for liver research and education.

*In honour of her brother, Lindsay Santagato became the first woman to complete a marathon in full firefighter gear.*





We are grateful for the individuals, groups and organizations that chose to support the CLF by holding their own fundraising events in communities across Canada.

Thank you for making us your 'cause' for celebration!

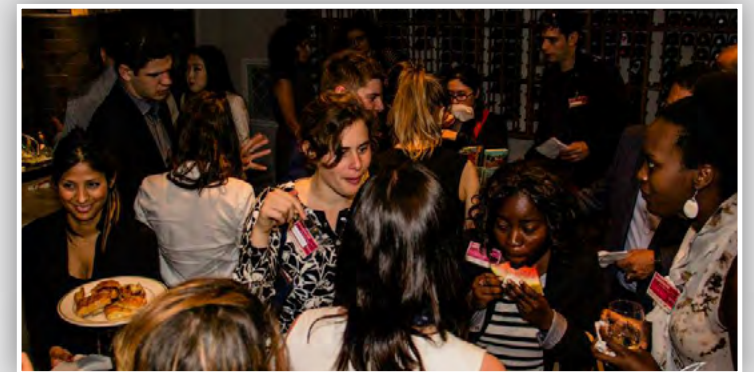


Photo credit: Jennifer Mahon Photography

Danzas Folklorica – Rotary Club – AB  
 Capitol Hill Car Show – Shirley & Len Donaldson – AB  
 Tough Mudder Challenge – Jim Kupczak – AB  
 Millarville Half Marathon – Naomi Merkley & Sarah Schaefer (Merkley Dream Team) – AB  
 HK's 18th District Charity Concert – Angel Tam, Sunny Tam – BC  
 Chopsticks for Charity – Richmond Mandarin Lions Club – BC  
 LIVERight Charity Concert – BC Chinese Orchestera – BC  
 Scotiabank Vancouver Half Marathon and 5k – Run for Lives – BC  
 Campaign for PSC – Sandy VanOstrand – BC  
 Airsoft in Support of the CLF – Xtreme Tactics – Gord Lai – MB  
 Scrim & Swap Meet in Support of the CLF – Eddie Creek Airsoft – Shawn Stone – MB  
 16th Annual Lower Deck Golf Tournament (In memory of Barry Martin)  
 – Lower Deck Inc – Mike Condry – NS  
 Brian Miller Memorial Golf Tournament – Tirecraft (Atlantic Provinces) – Corey Miller – NS

17th Annual Naval Communicators Reunion (50/50 Tickets)  
 – MARLANT Naval Communicator Community – Corey MacNeil – NS  
 Golf Tournament for Liver – Marlborough Pub – Jason Moore – ON  
 Tribute to Sam Larkin – Donald Kerr – ON  
 Shiver for a Liver – Carly Zuk – ON  
 "Shutout" Liver Disease – The Dock Ellis – ON  
 Jeff Musson Memorial Golf Tournament – Laura Lee Moffat – ON  
 2014 Kyle's Run – Randy & Sandy Hall – ON  
 Christmas Elegance Fashion Show – Yellow and Orange Salon & Spa – Maria Baldassarra – ON  
 Women DeLIVER – John Molsen WIBC – Nura Jabagi – QC  
 Tais-toi et mange pour une bonne cause! – Tais-toi et mange Bistro  
 – Sam Park, Daria Iannetta, Stephanie Dugre – QC  
 Foie-La! Month – Cookandetc – Cristina Mucciardi – QC  
 Birdies for Charity – Logan Yanick – US



# Treasurer's Report

Since 1969, the Canadian Liver Foundation has been bringing liver research to life by supporting the work of Canadian researchers and by ensuring that this knowledge reaches patients, families and the public. It is through the generous financial contributions of our supporters and the responsible management of those funds that we are able to continue to fulfill our mandate.

In 2014, we paid out \$561,000 in research grants to fund projects in pediatric liver disease, liver cancer, hepatitis C and liver transplantation. Under our multi-year grants, we have ongoing research commitments totaling over \$1.2 million to be paid from 2015 to 2017.

Our expenditures on Programs in 2014 were approximately \$2 million compared to \$2.2 million in 2013. The research trust funds have paid nearly \$690,000 in research programs compared to \$800,000 in 2013, together with \$561,000 in research grants we paid out over \$1.2 million in research in 2014.

Operating costs were \$3 million in 2014 compared to \$3.2 million in 2013, a 5% decrease over 2013.

The Foundation's Donations and Chapter Revenue was \$6.2 million in 2014. The research trust funds revenue increased to approximately \$1.4 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 2014, we had current assets amounting to \$2 million. Our investments total \$3.5 million, an increase of approximately \$433,000 (14%) over 2013. The annual investment portfolio yield for 2014 was 11.1% and we earned over \$111,000 in interest and dividends and a total of \$395,000 in net portfolio appreciation.

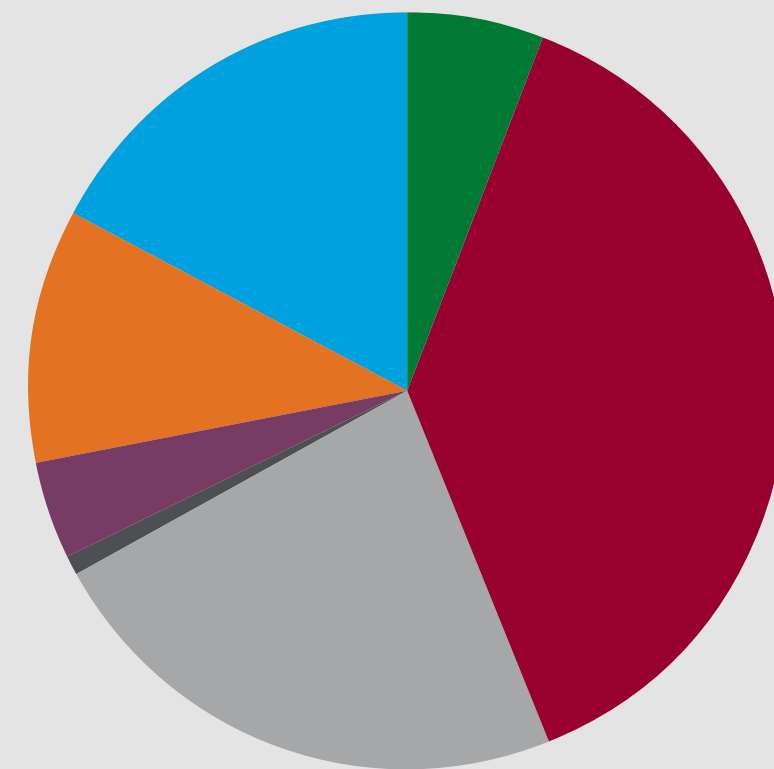
Our fund balances available to support operations increased to approximately \$1.3 million as we seek to ensure our ability to operate in any financial environment. Our funds available to support future research activities increased by approximately \$1 million which enabled us to fund our commitments of approximately \$1.2 million.

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 2015 and beyond.



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

## Where our revenue comes from



Individuals = 38%  
Corporate = 23%  
Government = 1%  
Foundations = 4%

Other = 11%  
Partnerships = 17%  
Estates = 6%

## Financial Position Summary as at December 31, 2014 and 2013

	General Fund		Research Trust Funds		Medical Research Fund		Total	
	2014	2013	2014	2013	2014	2013	2014	2013
ASSETS								
Current	\$812,097	\$969,339	\$508,235	\$337,132	\$747,950	\$234,778	\$2,068,282	\$1,541,249
Investments	\$676,094	\$281,697	\$2,395,404	\$1,944,046	\$436,017	\$849,222	\$3,507,515	\$3,074,965
Capital Assets	\$119,892	\$136,453					\$119,892	\$136,453
	\$1,608,083	\$1,387,489	\$2,903,639	\$2,281,178	\$1,183,967	\$1,084,000	\$5,695,689	\$4,752,667
LIABILITIES	\$350,096	\$428,124					\$350,096	\$428,124
FUND BALANCE	\$1,257,987	\$959,365	\$2,903,639	\$2,281,178	\$1,183,967	\$1,084,000	\$5,345,593	\$4,324,543
	\$1,608,083	\$1,387,489	\$2,903,639	\$2,281,178	\$1,183,967	\$1,084,000	\$5,695,689	\$4,752,667

### OPERATIONS SUMMARY FOR THE YEAR ENDED DECEMBER 31, 2014 AND 2013

	General Fund		Research Trust Funds		Medical Research Fund		Total	
	2014	2013	2014	2013	2014	2013	2014	2013
REVENUE								
Donations and Chapter Revenue	\$5,080,662	\$4,808,513	\$1,129,223	\$1,046,771			\$6,209,885	\$5,855,284
Interest and Other Income	\$83,300	\$60,926	\$266,684	\$243,798	\$44,891	\$48,897	\$394,875	\$353,621
	\$5,163,962	\$4,869,439	\$1,395,907	\$1,290,569	\$44,891	\$48,897	\$6,604,760	\$6,208,905
EXPENDITURE								
Programs	\$1,285,583	\$1,387,963	\$687,446	\$797,897	\$3,488	\$2,283	\$1,976,517	\$2,188,143
Operating	\$3,046,172	\$3,214,891					\$3,046,172	\$3,214,891
	\$4,331,755	\$4,602,854	\$687,446	\$797,897	\$3,488	\$2,283	\$5,022,689	\$5,403,034
Excess of revenue over expenditure for the General Fund	\$832,207	\$266,585					\$832,207	\$266,585
Excess of revenue over expenditure for the Research Trust Funds			\$708,461	\$492,672			\$708,461	\$492,672
Excess of revenue over expenditure for the Medical Research Fund					\$41,403	\$46,614	\$41,403	\$46,614
Research Grant Disbursements					(\$561,021)	(\$819,573)	(\$561,021)	(\$819,573)
Interfund transfers to support activities of the Medical Research Fund	(\$533,585)	(\$8,960)	(\$86,000)	(\$271,999)	\$619,585	\$280,959	\$0	\$0
Fund Balance – Beginning of Year	\$959,365	\$701,740	\$2,281,178	\$2,060,505	\$1,084,000	\$1,576,000	\$4,324,543	\$4,338,245
Fund Balance – End of Year	\$1,257,987	\$959,365	\$2,903,639	\$2,281,178	\$1,183,967	\$1,084,000	\$5,345,593	\$4,324,543

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



# Thank you to our donors!

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

Donors listed are for the period January 1 – December 31, 2014. Every effort has been made to ensure the accuracy of our donor listing. Should you find any errors or omissions, please contact **Judy Thompson** at **1-800-563-5483 ext. 4945** or **clfdonation@liver.ca**.

## \$25,000+

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Tianyan Chen  
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Columbia

## \$10,000–\$24,999

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Foundation  
Bayer Foundation  
Bayer Health care  
Pharmaceuticals  
Franklin Bialystok  
BTG International  
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## \$5,000–\$9,999

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TVCOGECO-  
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Mary Voteary  
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## \$2,500–\$4,999

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# Thank you to our donors!

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