Never Surrender
40 Years of Fighting Liver Disease

2009 Annual Report
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National Office
2235 Sheppard Avenue East, Suite 1500
Toronto, Ontario M2J 5B5
Tel: (416) 491-3353 Fax: (416) 491-4952
Toll-free: 1 800 563-5483
Email: clf@liver.ca
www.liver.ca

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2009 marked the Canadian Liver Foundation’s 40th anniversary. In the past four decades, much has changed in the field of liver health and as the Foundation’s new Chairman, I am proud that the CLF has made a significant contribution to advancing the knowledge, resources and approach to liver disease prevention, diagnosis and treatment.

Forty years ago there was essentially no treatment for liver disease, with the exception of steroids for autoimmune hepatitis and diuretics for ascites. While identifying liver disease involved many of the same liver tests used now, there were no CT scans, MRIs or even ultrasounds. Today we could not practice without these tools.

In 1969 when the CLF was founded, hepatitis C, D and E were unknown. Forty years later, we not only have a good understanding of these diseases, but have also identified several other liver diseases, including some of the inherited disorders that affect bile flow. The tools of molecular biology have allowed us to pinpoint the mutations responsible for Wilson disease, genetic hemochromatosis, alpha 1 antitrypsin deficiency and several other less common liver diseases, such as polycystic liver disease.

Molecular biology has also led to the development of a hepatitis B vaccine and effective therapy for chronic hepatitis B and in the near future hepatitis C. Universal hepatitis B vaccination, introduced initially in the 1980s, has reduced the incidence of childhood liver cancer, and has the potential to eradicate hepatitis B in the same way that small pox has been eradicated.

Today, liver diseases like primary biliary cirrhosis can be treated and patients have a much better prognosis. Liver transplantation has also come of age, with five-year survival reaching 80 per cent or more for some indications.

This progress has all come as a result of research. With our $20 million investment in liver research over the past 40 years, the CLF has contributed to these advancements and continues to support the search for new discoveries.

Looking to the future however, we still have a long way to go. We do not have effective treatment for advanced liver cancer. Pediatric liver diseases continue to take a toll and the causes of many liver diseases remain unknown. Research is the only way to solve these problems – but research takes money. While the CLF is currently the largest non-profit liver research funder in Canada, the demand for our financial support will only continue to grow.

And yet funding research is not the only challenge. Canadians with liver disease continue to face obstacles in accessing care. There are not enough hepatologists in the country, and both our experts and facilities are concentrated in larger urban centres. Patients can also have difficulty obtaining reimbursement for their treatments from provincial drug formularies. To rectify these inequities, the CLF will need to take a stronger advocacy role to ensure that liver disease patients benefit from the very advancements that our funds have helped support.

The future holds great promise for new breakthroughs in the science of liver health and for improvements in the care and treatment of liver disease patients – if governments, corporations and individuals treat these as priorities for support and funding. It is my hope that the CLF will be the catalyst to keep the momentum going for the next 40 years.

Morris Sherman, M.D., FRCPC
CHAIRMAN & CHIEF EXECUTIVE OFFICER
In the midst of World War II when Britain was under constant attack and things looked particularly bleak, Winston Churchill inspired the British people with the declaration: “We shall defend our island, whatever the cost may be, we shall fight on the beaches, we shall fight on the landing grounds, we shall fight in the fields and in the streets, we shall fight in the hills; we shall never surrender.”

For 40 years, the Canadian Liver Foundation (CLF) has been fighting a war against an enemy that is just as relentless. And yet, we too have stayed the course, pledging to continue our battle against liver disease on all fronts – in the lab, in the schools, in workplaces, in the community, in our homes, in the halls of government and the boardrooms of industry – and refusing to surrender.

History has taught us that to win a war, you must achieve victories in countless small skirmishes. Defeating a disease that has over 100 different forms requires the same kind of incremental progress – and it is these very successes that we want to highlight in this year’s report. Alongside the medical breakthroughs that have led to vaccines, treatments and better diagnostics, there have been advocacy efforts that have resulted in universal immunization programs, education initiatives that have taught the public and health care professionals how to recognize risk factors and fundraising efforts that have helped fund research studies. Behind it all, there have been legions of volunteers who have made it all possible.

Among those volunteers were a visionary group of doctors and business leaders who founded the CLF four decades ago with a mandate to reduce the incidence and impact of liver disease. This group saw research and education as the keys to conquering liver disease and we – along with similar organizations around the world modeled on the CLF – have continued on this path achieving many significant milestones that you will read about in the pages to follow. Patients, researchers and doctors have combined forces with CLF volunteers, donors and staff to tackle liver disease through awareness, advocacy, professional and public education, research and fundraising. Some battles we have won, others we are still waging.

As with any war however, there have been many casualties – men, women and children whose lives were lost because we did not have the knowledge, time or resources to save them. It is the memory of these lives lost and the reality of those who still live with liver disease that inspire a sense of urgency in everything we do.

The last forty years have brought incredible breakthroughs in our ability to prevent, diagnose and treat many forms of liver disease and we are grateful to the researchers, volunteers, donors, corporate supporters, government and community partners who have helped make this progress possible. Unfortunately, there are still liver diseases we do not fully understand, people living with liver disease who cannot access the treatments they need and others who remain undiagnosed until their disease has progressed to its most severe stage. These are the battles that remain ahead of us and we need reinforcements. As we move into our next decade, we must inspire more Canadians to get involved in the fight against liver disease – as donors, volunteers or advocates.

While a 40th anniversary is a wonderful opportunity to celebrate how far we have come, it is not a time to become complacent. As long as there are still Canadians suffering from liver disease, we must continue to fight to raise awareness, to find better treatments and to give hope.

Gary A. Fagan
PRESIDENT & CHIEF OPERATING OFFICER
Health
Education &
Advocacy

$50 million invested in education

Knowledge is a powerful weapon when fighting a disease. Over our history, the CLF has made it a priority to share knowledge with the public, patients and health care professionals about risk factors, signs, symptoms and prevention of liver disease. With knowledge comes power – power to protect health, power to recognize and treat disease, power to overcome the day-to-day struggle of living with liver disease and most of all, the power to bring about change.

Advocating for prevention – Universal immunization for hepatitis B

On Christmas Day 1989, a Langley, B.C. mother lost her 16 year old daughter to acute hepatitis B. When she learned that there was a vaccine available that could have saved her daughter’s life, Bobbi Bower launched a campaign for universal immunization in Vancouver and took her fight all the way to the provincial government. Through this process, she partnered with the CLF and its Victoria Chapter President, George Clark, who was spearheading the CLF’s efforts to achieve the same goal.

At a national level, the CLF had already been advocating for universal hepatitis B immunization of newborns. After having made a presentation to the National Advisory Committee on Immunization (NACI), the CLF’s efforts were rewarded when NACI put the wheels in motion for a universal vaccination program. In 1991, B.C. was the first province to implement a program to vaccinate occupational risk groups, street involved people and grade six students. Over the next four years, all other provinces followed suit and introduced hepatitis B vaccination programs.

When the provinces began rolling out their immunization programs in elementary schools, the CLF provided comprehensive information kits to help students, parents and teachers understand the facts about hepatitis B and the importance of getting vaccinated. In the years to come, the CLF continued to promote the importance of hepatitis B immunization by spearheading immunization campaigns involving the Canadian Football League, Ontario Safety Service Alliance, Alberta school system and other organizations. Thanks to a long-standing partnership with GlaxoSmithKline, the CLF has been able to promote both hepatitis B and hepatitis A vaccination via multi-media advertising campaigns as well as media outreach and education materials for physicians.
丙型肝炎 — 一種肝臟疾病

Hepatitis C - a liver disease

In the early 1990s, Canada experienced a rise in hepatitis C cases that was linked back to tainted blood and blood products. In response to the ensuing public outcry, the CLF worked with liver specialists, the Canadian Red Cross, Health Canada, and volunteers to create the National Hepatitis C Education Program for physicians and the public. Officially launched in June 1995, the program delivered public forums and physician symposia in 16 cities to answer questions and provide the most up-to-date information on hepatitis C. After the sessions, conference proceedings and patient information materials were distributed to more than 30,000 general practitioners across the country.

From this initial program, the CLF played a key role in educating the public, patients and health care providers about hepatitis C. In the intervening years, the CLF produced educational materials, organized support groups, held information sessions and helped organize multi-disciplinary conferences including the first National Conference on Hepatitis C held in Montreal in 2001. In 2002, the CLF held its own national ABCs of Hepatitis Conference in Toronto featuring both Canadian and international experts as well as special guest, Pamela Anderson, who shared her personal story about living with hepatitis C.

Today, the CLF continues to take the lead in hepatitis education targeting both high risk groups and people living with the disease. In 2009, the CLF helped create a comprehensive coping guide entitled ‘LIVERight: Healthy Living with Viral Hepatitis’ for national distribution via public health and community service agencies.

In 2006, the Canadian Liver Foundation and the Canadian Ethnocultural Council partnered with the Public Health Agency of Canada (PHAC) on a research project to determine a community-based approach for communicating with different ethnocultural communities on health issues like hepatitis C. The project entitled ‘Engaging Ethnocultural Communities on Hepatitis C’ focused on four immigrant populations – Chinese, Egyptian, Filipino and Vietnamese – chosen based on Canada’s immigration patterns, the reported prevalence of hepatitis C infection (3% or higher) in their country of origin and modes of hepatitis C transmission. The four-year project involved consultation with 300 ethnocultural organizations, coordination of 40 focus groups in five cities and the recruitment of 56 coordinators/facilitators and 491 participants.

The final report, submitted to PHAC in 2009, illustrated how little these communities knew about hepatitis C and how reluctant they were to talk about these types of health issues due to cultural taboos or fear of being stigmatized. Focus group participants noted that there was a shortage of reliable health information available in their native languages and that health care professionals did not have sufficient training in hepatitis C. This project was an important step toward improving awareness and understanding of hepatitis C in these communities and the insights will help direct future government programs as well as the CLF’s outreach and education efforts.

Hepatitis C – Fighting fear with facts

In the late 1970s and 1980s the national blood supply was contaminated with what was later identified as the hepatitis C virus. In the early 1990s, Canada experienced a rise in hepatitis C cases that was linked back to tainted blood and blood products. In response to the ensuing public outcry, the CLF worked with liver specialists, the Canadian Red Cross, Health Canada, sponsors and volunteers to create the National Hepatitis C Education Program for physicians and the public. Officially launched in June 1995, the program delivered public forums and physician symposia in 16 cities to answer questions and provide the most up-to-date information on hepatitis C. After the sessions, conference proceedings and patient information materials were distributed to more than 30,000 general practitioners across the country.

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Living with Liver Disease – helping Canadians cope

When you or someone you love is diagnosed with a liver disease, there are a lot of questions and emotions to deal with. Over its 40 year history, the CLF has been helping patients and their families and friends get answers to their questions and connect with others going through the same situation. This support comes in many different forms but it has one goal in mind, showing Canadians with liver disease that they are not alone.

With the wait to see a liver specialist being anywhere from six months to more than a year, the CLF helps to bridge the gap by offering accurate medical information about liver disease via our national website, national and regional toll-free help lines and print materials.

For those seeking reassurance and peer support, the CLF launched its Living with Liver Disease (LWLD) program in 1995 to help liver disease patients and their families learn how to cope and enable them to share their personal experiences and questions with others living with the same challenges. LWLD sessions may take place monthly, weekly or in full day workshops and involve expert speakers who cover topics ranging from nutrition, exercise and treatment options to transplantation and stress management. For those who cannot attend sessions, the CLF offers opportunities for patients to connect one-on-one via peer support telephone networks or via social media platforms such as Facebook.

Living in the service of Canadians with liver disease

Thanks to all our members for your support. Become a CLF Member and receive the most up-to-date information in liver health, learn ways to prevent liver disease and how your donations to the CLF are making a difference.

Join today, visit www.liver.ca and click on

[Contact Information]

[Image]
LIVERight — making liver health part of everyday life

The liver is a misunderstood and under-appreciated organ that plays a vital role in life-long health. In 2007 to combat public apathy toward liver health, the Canadian Liver Foundation launched ‘LIVERight’ – a call to action to all Canadians to recognize the vital importance of the liver and to take steps to protect it.

Built upon the liver’s two most basic life-sustaining roles – to nurture and to protect – LIVERight (pronounced ‘live right’) provides positive, preventative and practical advice and tools to help Canadians safeguard their liver health in daily life. LIVERight messages and materials including print, radio and TV ads, bookmarks, online advertising, print material, presentations and even a LIVERight Awards program show the relevance of liver health to decisions we make everyday such as what to eat, whether or not to exercise and what medications to take to treat an illness. By demonstrating how the liver plays a role in these activities and choices, LIVERight drives the point home that every Canadian should be concerned about liver health.

Do you ever remember learning about the liver in school? It might have come up briefly in a biology class but it is unlikely that in elementary or high school or even university that you heard much about liver disease, risk factors or how to keep your liver healthy. Thanks to the CLF that is beginning to change.

In Edmonton, Alberta, Kool Kids is a fun and interactive program for grade 5 classes that covers a range of liver health topics and risk factors using games and other age-appropriate learning tools to teach students.

Never too young to make smart decisions about liver health

For high school and post-secondary students faced with many lifestyle choices and temptations, the Live in the Moment program, encompassing presentations, web pages and a series of postcards provides activity-based advice to help youth make liver-healthy decisions regarding travel, eating, drinking/drugs, sex and tattooing.

While on campus, university and college-age students can help educate their peers by joining one of the CLF’s student chapters. The campus program, first launched at Mount Allison University in Nova Scotia in 2005, has since expanded to Alberta, B.C. and Ontario. The University of Alberta student chapter was instrumental in the launch of www.liverinfo.ca which provides practical liver health facts and advice as well as information on activities with the campus chapter and on national and local CLF programs.

To reach out to at-risk youth, the CLF partnered with the Public Health Agency of Canada in 2004 for a four-year project entitled “Young Voices”. The goal of the Atlantic Region program was to involve youth in developing messages and tools to educate their peers about hepatitis C. The participants in the program had the opportunity to produce radio ads, videos, resource kits, display materials, presentations and a website (www.streetguru.ca) with hard-hitting information about the risks and realities of hepatitis C.
Encouraging all Canadians to give the ‘gift of life’

Liver transplants are often the last resort for liver disease patients whose lives are in the balance. Unfortunately, a chronic shortage of donor organs often means that waiting lists are long with patients having to wait for months or even years for a match to become available. Many do not survive the wait.

For the sake of these patients, the CLF promotes organ donation and over our history has been involved in many different campaigns to encourage Canadians to register as potential organ donors. In the 1990s, the CLF’s Saskatchewan Chapter held the first of many ‘Celebration of Life’ brunches to honour organ donor families and recipients. CLF staff and volunteers have also been involved in organ donation awareness efforts including walks, butterfly releases and media campaigns.

In 2001, the CLF, in partnership with the federal government and stakeholder advisors across the country, spearheaded the first national organ and tissue donation awareness campaign with the slogan ‘Share your decision. Share your life.’ The initiative involved print and television advertising, posters, pamphlets, green ribbon pins, an hour-long television special and a website and toll-free number that people could call to find out more. During Organ and Tissue Donation Awareness Week, the Governor General hosted transplant recipients and donor families as part of a Celebration of Life ceremony at the official residence in Ottawa.

Taking knowledge to the front lines of liver health

Family physicians, nurses and other health care providers are the first line of defence against liver disease. Unfortunately they often do not receive adequate training on the signs, symptoms and risk factors for liver disease. Early diagnosis can have a significant impact on the prognosis of liver disease patients so the CLF has made it a priority to help health care professionals identify liver disease in their patient base.

Over the years, the CLF has launched such knowledge translation initiatives as the ‘Liver Letter’ – a newsletter for family physicians, GPs and other health care providers which provided comprehensive information on one form of liver disease per issue. The Foundation has also sponsored conferences and medical information sessions where liver specialists provide practical diagnostic, treatment and referral advice that physicians can use in their day-to-day practice.

In an effort to educate primary care physicians about liver disease and boost the number of practicing hepatologists (liver specialists) available for referrals, patient care and research, in 2006 the CLF partnered with the University of Manitoba to create a two-part program – Discover the World of Hepatology and Primary Care Hepatology. Discover the World of Hepatology invites medical residents from each internal medicine program in Canada to learn first hand from a faculty of hepatologists about the benefits and challenges of a career in hepatology. Primary Care Hepatology is a continuing medical education program for family physicians, nurses and community gastroenterologists that covers a variety of liver health topics from liver cancer to fatty liver disease. Both programs have received rave reviews from participants and the medical community.

“Overall, one of the best courses I have been to. Practical, current and family-practice oriented.”

— 2009 Primary Care Hepatology participant

“Discover the World of Hepatology offers a good mix of career planning and introduction to hepatology – something that we don’t get enough of during our medical school training.”

— 2008 DWoH participant
Fighting a disease takes money and that is why our research and education programs depend upon the generosity of individual donors, corporations, foundations, community groups and governments. It was thanks to a generous grant from the Knight family that the CLF was first founded in 1969 and was able to begin funding research. Since that time, donations, pledges, grants and sponsorships have made it possible for us to expand our efforts to provide answers and hope for Canadians with liver disease.

Community-based events have always been an integral part of the CLF’s fundraising efforts combining fun, camaraderie and, in some cases, a little friendly competition, for a good cause. The following are some of the highlights from the past few years.

**Spring for Daisies** – CLF Volunteer Benny Falcioni sells daisies at a Sudbury mall as part of the Spring for Daisies annual fundraising campaign. First launched in 1991, Spring for Daisies ran in March each year in communities across Canada.

**Stroll for Liver**

In 2006, the CLF launched its first national family-oriented fundraiser, Stroll for Liver, to mobilize community support for the fight against liver disease. Strolls accommodate all fitness levels with varying lengths and activities including one to 10 kilometre walks and runs through local parks, conservation areas and waterfront districts. Since their inception, Stroll events have attracted participants of all ages in communities across the country and have raised over $800,000.

An exciting development in 2009 was the launch of the Lace Up for Liver program which enables CLF supporters to fundraise for the Foundation while participating in local athletic events. A Toronto/GTA-based Lace Up for Liver team entered the Scotiabank Toronto Waterfront Marathon in September 2009 as part of their Charity Challenge. In 2010, Lace Up for Liver teams will compete in Scotiabank marathon events in Vancouver, Calgary, Toronto and Halifax.
Oliver Weir Memorial Teddy Bear Walk

Oliver Weir may not have lived to see her second birthday but her legacy lives on in the hearts and minds of all who knew her. Olivia was born with biliary atresia which causes blockages in the bile ducts connected to the liver. After undergoing multiple surgeries, a liver transplant and countless complications, Olivia passed away in March 2003 at age 22 months from multi-organ failure.

Luge for Liver – Eight-year old liver transplant recipient Ashleigh Warren tries out a luge sled with a member of the Canadian Olympic team at the first Luge for Liver in 1992 in Calgary Olympic Park. Over its 13 year history as a stand-alone event, Luge for Liver raised approximately $392,000 for liver research and education.

What a Girl Wants

Women play a critical role as the guardians of their families’ health but every once in a while they need a night off. What a Girl Wants is the CLF’s version of a girls’ night out with a purpose. Featuring everything from canapés and cocktails to fashion shows and silent auctions, each What a Girl Wants event has its own personality but they share one goal – raising funds for liver research. Since the first was held in 2005, What a Girl Wants events have raised over $320,000. In 2009, What a Girl Wants expanded to six cities – Vancouver, Winnipeg, London, Toronto, Ottawa and Montreal.

Give’r for Liver

For walkers and runners looking for a higher purpose, the CLF’s Give’r for Liver provides it all – exotic scenery, physical challenge, camaraderie and the joy of knowing that you are helping provide hope for Canadians with liver disease. Started in Calgary in 2006, Give’r for Liver offers team members a 20 week training program and the chance to travel to destinations such as Dublin, Ireland and Maui, Hawaii to complete half and full marathons. From 2006 to 2008, Give’r for Liver teams raised $128,000 and in 2009 alone raised $122,000. In 2010, Give’r teams will be participating in events in Dublin, Kauai and New York City.
Paying tribute

Whether it’s been for a tribute or a roast, over the years medical, political and community leaders have willingly lent their names and reputations to help raise funds for liver disease. The following are just some of the notable names the CLF has celebrated for their achievements and contributions to improving liver health and the local community.

BRITISH COLUMBIA
Dr. Frank Anderson, hepatologist
Natalie Rock, RN, hepatology nurse

Vancouver General transplant team

ALBERTA
Anne McClellan, former Minister of Health
Dr. Sam Lee, hepatologist
Dr. Lorne Tyrrell, hepatologist

ONTARIO
Dr. Victor Feinman, hepatologist
Dr. Jenny Heathcote, hepatologist

NOVA SCOTIA
Senator John Buchanan
Fred MacGillivray, Halifax business leader

Reaching new heights for liver health – In January 2007, a team of 16 Canadians embarked upon a once-in-a-lifetime journey to Africa as part of the Canadian Liver Foundation’s Mt. Kilimanjaro Extreme Challenge. For several on the team, the climb was a personal tribute to family and friends who had been lost to liver disease. The team spent five days trekking through everything from forest to glacial landscapes before finally reaching the roof of Africa. The climb not only helped bring attention to liver disease as a global health issue, but also succeeded in raising nearly $300,000 for liver research and education.

Music for a Cause

Montrealers have many loves – good food, good hockey and especially good music. For the past 15 years, the CLF’s Montreal chapter has brought together the city’s music lovers with Quebec’s most gifted musical talents for an annual fundraising concert. Each year has featured a different musical style – jazz, opera, gospel, classical, pop – and has attracted a veritable who’s who of Montreal corporate and government elite including the province’s Lieutenant Governor. Thanks to corporate and community support, this highly anticipated annual event has successfully raised over $650,000.
A Cause for Celebration

We are grateful for the many companies, families and individuals who over the years have organized special fundraising events or donated the proceeds from their own events or celebrations to the CLF. Although we do not have the space to recognize all our supporters from the last 40 years, we would like to offer a special thank you to those who made us a ‘cause for celebration’ in 2009:

» Alpha Bartending Inc. Fundraiser (Vancouver, BC)
» 3rd Annual Simpson Family Bowling Tournament (Vancouver, BC)
» Mama Rosa Restaurant’s Annual Giacomo Day Fundraiser (Kelowna, BC)
» Kenroc Building Materials Co. Ltd. golf tournaments and “Yes we can… succeed in 2009” t-shirt sales (Manitoba, Alberta, BC)
» North Winnipeg Nomads vs. St. Vital Mustangs Fundraising Football game (Winnipeg, MB)
» 50th Birthday Celebration for Andy Cumming, (Toronto, ON)
» Eigna – Swarovski Crystal Jewellery sales, (QC)
» Classique Jean-Pierre Boissonneault-Golf Tournament, (Montreal, QC)
» Groupe Elite Capital Christmas Party (Montreal, QC)
» Everyday Heroes Foundation – Lower Deck Charity Golf Tournament in Memory of Barry Martin (Halifax, NS)

Ultimate Goal

Hockey fans all have what they would consider their ‘ultimate’ goal-scoring moment from a playoff game, the Olympics or a World Cup showdown. For the CLF however, every goal scored by Wendel Clark during the 1993-94 NHL season was ‘ultimate’ because they each raised money to help fight liver disease. That year, not only did Wendel Clark lead the Toronto Maple Leafs into the Stanley Cup finals but he also scored 55 goals – each one worth $500 to the CLF thanks to the generosity of program sponsor Midland Walwyn. While the Leafs did not take home the cup that year, the CLF raised an estimated $55,000 (with sponsor contributions and other spin-offs).

After Wendel Clark was traded, the CLF in partnership with the FAN 590 radio station and the City of North York hosted a “Wendel Clark Fan Appreciation Day” to say farewell and thank you to the popular player. The 7,000 fans in attendance also helped raise an additional $13,000 for the CLF.

In the years that followed, the Ultimate Goal program with the NHL involved other players including Tie Domi and Larry Murphy. It was also expanded into the Ontario Hockey League and CLF chapters raised funds with local players in Guelph, Kitchener, Owen Sound, London, Sarnia and Sudbury.

Taking a ‘swing’ at liver disease – In the past 40 years, many golfers have taken a swing for liver disease at charity golf tournaments benefiting the CLF. Whether it was our own events such as Ottawa’s Million Dollar Hole-in-One, Edmonton’s 100 Hole Golf Marathon, BC’s Charity Golf Classic or Halifax’s Tee Up Fore Liver or the many other tournaments held across the country, golfers have given generously of their time, talents and money to help fight liver disease.

Big Names with Big Hearts

Over the past 40 years, many different celebrities, business leaders, political figures and sports heroes have partnered with the CLF to help raise awareness and funds for liver disease. Although we cannot possibly name them all, the following are a few of the names that you might recognize. We offer our heartfelt gratitude to them and all the other ‘big names with big hearts’ who have helped us give hope to Canadians with liver disease.

Carol Alt, model, fashion designer and author
Pamela Anderson, actress
Paul Anka, entertainer
Don Cherry, sportscaster
George Chuvalo, professional boxer
Wendel Clark, NHL hockey player
Tie Domi, NHL hockey player
Mike Duffy, journalist
Joe Fraiser, professional boxer
Antoine Gaber, artist
Jeff Garcia, CFL football player
Jody Holdren, Olympic beach volleyball player
Ken Houston, NHL hockey player
Russ Howard, champion curler
Don Martin, journalist and author
Paul Masotti, CFL football player
Larry Murphy, NHL hockey player
Freeman Patterson, photographer
Oscar Peterson, musician
Martin Short, actor/comedian
Beverly Thomson, journalist
Brian Williams, sportscaster
The real cost of liver disease

Many families have lost a loved one to liver disease because the knowledge or the means were not available to save them. The following stories represent the real cost of liver disease – the sad part is that there are many, many more. With the help of these families and assistance from corporate, individual and community donors however, we are funding the research and the resources to ensure that one day other families will not have to endure the same heartache.

The Donaldson family

It is a sad truth – and one that comes as a surprise to many – that liver disease can strike anyone at any age. Shirley Donaldson knows this only too well. At age 15, Shirley’s son Shaun was diagnosed with primary sclerosing cholangitis or PSC – a progressive liver disease in which the ducts that carry bile out of the liver shrink due to inflammation and scarring. The resulting build up of bile in the liver leads to liver damage. In Shaun’s case, the damage was so extensive that he required a liver transplant. Shaun was the first recipient of a live donor liver transplant in Western Canada, and due to complications, he underwent a total of three liver transplants. Despite a valiant fight, Shaun passed away on August 1, 2008 at age 29.

In the wake of her son’s death, Shirley has become a committed volunteer for the CLF’s Calgary chapter assisting with both awareness and fundraising events including providing support to the Give’r for Liver marathon team, selling LIVERight shopping bags and flowers for the Calgary Spring for Daisies fundraisers and volunteering at the Stroll for Liver and Shiver for Liver events.

Hope for the future

The origins of primary sclerosing cholangitis are still unknown. Under the supervision of Dr. Andrew Mason, Kelvin Leung studied the possibility that PSC might be caused by a retrovirus that had been linked with another liver disease – primary biliary cirrhosis. He worked on developing a screening system to identify retrovirus genetic sequences. Dr. Richard Schreiber has also researched the possibility that PSC and inflammatory bowel disease might result from a common cause.
The Harris family

In 2007, Melissa and Sean Harris were eagerly awaiting the birth of their first child. In her third trimester of pregnancy however, Melissa started experiencing severe vomiting, heartburn, extreme thirst and high blood pressure.

After three days of these symptoms, she went to Emergency and was told she had lost her baby. Melissa later lapsed into a coma, her liver and kidneys began to fail and she was air-lifted to Toronto General Hospital where she was put at the top of liver transplant list.

Miraculously, she slowly began to improve and over the days and weeks that followed she was able to walk and talk and was finally released from the hospital on Christmas Eve.

Melissa had suffered Acute Fatty Liver of Pregnancy (AFLP) and Hemolysis Elevated Liver Enzymes and Low Platelet (HELLP) Syndrome – rare but serious conditions which are often confused with other pregnancy induced symptoms. Because the conditions are often misdiagnosed, estimates of the incidence 1 in 10,000-15,000 pregnancies for AFLP and 1 in 200-1,000 pregnancies for HELLP are probably low.

In the wake of their family’s tragedy, the Harris family committed to raising funds for research. Their ‘Butterfly Power Team’ participated in the Toronto Stroll for Liver and they helped secure additional research funds through the Silver Birch Centre Bouleau D’Argent (formerly known as Elliot Lake Centre 2000).

Hope for the future

Dr. Gerald Minuk, Dr. Vivian Schutt and Dr. Edward Tam at the University of Manitoba studied the possibility that lowering fatty acid levels in the liver of a pregnant woman will have a positive impact on AFLP and HELLP.

“The impact of having received a scholarship from the Canadian Liver Foundation in 1974 is that I have gone on to basically dedicate my career – and my life – to liver research.”

Wayne Lautt, Professor of Pharmacology and Therapeutics, Faculty of Medicine, University of Manitoba. One the CLF’s first Research Scholars in 1974. Quote from 1990 issue of CLF newsletter Communiqué.
Special Projects

National Canadian Research Training Program in Hepatitis C

From Dr. Victor Feinman’s first characterization of the hepatitis C virus in the late 1980s, Canadian hepatologists have continued to make significant contributions to hepatitis C research. To ensure this legacy continues, the Canadian Liver Foundation in cooperation with the Canadian Institutes for Health Research (CIHR) and industry sponsors has funded a virtual mentoring and training program to help foster learning and collaboration amongst various clinical, scientific and social disciplines.

First initiated by world renowned hepatologist Dr. Jenny Heathcote and now headed up by Dr. Marc Bilodeau, the National Canadian Research and Training Program in Hepatitis C (NCRTP-HepC) involves a transdisciplinary team of 31 experts from 11 academic institutions across Canada who work together to identify, recruit and tutor the next generation of trainees who will lead the initiative for improved care and research in hepatitis C.

Since 2002, NCRTP-Hep C program has provided support for 32 trainees and 22 summer students interested in pursuing studies in hepatitis C. With the support of industry sponsors and individual donors from across the country, the CLF has contributed nearly $1.5 million towards this internationally-recognized research training program.

The Nagpal family

To lose a child is tragic – to lose a child with no real warning, a child who had seemed in perfect health, poised on the threshold of a promising future, is even more heartrending.

In March 2005, Daljit and Kamal Nagpal’s second daughter Trisha, a brilliant student and popular teen, complained of swollen feet and mild bloating. Eleven days later in the midst of an emergency liver transplant, Trisha’s heart gave up and she passed away. It wasn’t until after the autopsy that the family found out that Trisha’s death was directly related to Wilson disease, a genetic liver condition leading to copper build-up that had quietly and insidiously caused the deterioration of her liver with no warnings or symptoms.

Led by Trisha’s sisters Sonya and Simrin, the family has found many positive ways to celebrate Trisha’s life and to motivate others to get involved. The Nagpals have become the driving force behind the annual CLF Stroll for Liver in Ottawa, they held their own Valentine’s Dance and have organized other fundraising events at the University of Ottawa.

Hope for the future

Thanks to CLF alumna Dr. Diane Cox and her team, the defective gene that causes Wilson disease was identified in 1993. Under Dr. Cox’s supervision, Braden Teitge studied the different variations of this copper-transporting gene to determine which ones cause Wilson disease and Cynthia Yu researched the application of a rapid testing method to improve diagnosis. Dr. Eve Roberts has also studied the mechanism of liver injury in Wilson disease to help improve diagnosis and treatment.

“The Canadian Liver Foundation helped set me on the path to becoming a hepatologist by providing a summer studentship grant at a critical time in my schooling. I am proud to be one of the CLF’s alumni and am grateful for their support in launching my career.”

The Kusisto/Sexton family

Joan Kusisto (née Sexton) was a 44-year-old special education teacher in Regina who loved to make quilts as a hobby. In February 2003 while on a plane going to visit her eldest daughter at Queen’s University, Joan felt a sharp pain in her side. By the next morning, the pain was so severe that Joan doubled over while trying to get out of bed. After a trip to Emergency, she was later diagnosed with an aggressive form of liver cancer. She underwent surgery but two months later the tumors were back and spreading. Only seven months after her diagnosis, Joan died at home leaving behind her husband, Brian and three daughters.

Recognizing that research could change the future for others, Brian Kusisto joined Team CLF for its Mt. Kilimanjaro climb in 2007. Thanks to the support of friends, family and business associates, Brian raised over $75,000 for liver research in his wife’s memory.

Ken Sexton, Joan’s father and President of Kenroc Building Supplies Co. Ltd., adopted the CLF as his company’s prime charity. Over the past five years, Ken has motivated friends, family, employees, customers and suppliers to collectively donate nearly $500,000 for liver research through corporate donations, golf tournaments, t-shirt sales and other community-based initiatives.

Hope for the future

Dr. Gerald Minuk has studied whether a specific protein receptor is present in liver cancer cells and if so, whether their activation results in increased, decreased or no change in the cancer cell’s ability to spread. His research holds great potential for the future treatment of liver cancers, and possibly even the treatment of other forms of cancer.

Dr. Chow Lee has researched the process that allows liver cancer cells to grow rapidly which involves the overproduction of different proteins. His studies focused on particular enzymes that might have the potential to degrade these proteins and therefore help with liver cancer treatment.

Dr. Michel Charbonneau has advanced the understanding of how liver cancer develops on a molecular and cellular level.

“If not for the CLF, we wouldn’t have been able to accomplish so much. We wouldn’t have even been able to buy the equipment… It is only through research that we can start to unravel the mysteries of liver disease and prolong the quality of life for liver disease patients. That’s why the CLF funding is so important.”

Dr. Frank Burczynski, Professor of Pharmacology and Therapeutics, Faculty of Pharmacy, University of Manitoba. Recipient of CLF Bridging/Operating Grant 1995. Quote from 1995 issue of CLF newsletter Communiqué.
Special Projects

Novartis/Canadian Liver Foundation Hepatology Research Chair, University of Montreal

After Claude Legault, a senior executive at real estate investment firm SITQ, had a liver transplant he got out of his hospital bed and walked down to the CLF’s Montreal Chapter office in St. Luc Hospital to talk about how he could make a difference for liver disease patients. Claude and his wife Christiane got involved in the Montreal Chapter Board of Directors and what transpired from those early conversations post-transplant eventually became a Chair of Hepatology campaign at the Centre hospitalier de l’Université de Montréal. The couple personally raised over $350,000 over a five-year period and at the conclusion of the campaign had secured close to two million dollars for an endowment fund that continues to fund the Chair to this day. Novartis Pharmaceuticals was a major donor to the campaign and shared the naming rights to the research chair – a position that has helped attract new talent to the field of hepatology. Dr. Michel Huet, former CLF board member, served as the first Novartis/Canadian Liver Foundation Hepatology Research Chair. The position is currently held by Dr. Daniel Lamarre.

2009 Summer Studentships

Summer Studentship program awards $4,000 over a period of three months to undergraduate students to allow them to pursue liver-related research projects under the guidance of leading liver researchers.

Henry Nguyen
University of Calgary
Project Supervisor: Dr. Mark Swain

Hepatitis – which literally means inflammation of the liver – can be the result of viruses, toxins, fat build up (fatty liver) or other factors. The liver becomes inflamed when immune cells within the liver are activated and over time the inflammation can permanently damage the liver tissue. Henry studied one particular kind of immune cell (myeloid derived suppressor cell) to determine what role it plays in determining whether hepatitis goes away or becomes a chronic condition.

Christopher Mong
Memorial University
Project Supervisor: Dr. Thomas Michelak

85 per cent of people who contract hepatitis C will develop chronic disease which can lead to fibrosis, cirrhosis and even liver cancer. Hepatitis C has six main strains or genotypes which are divided into more than 50 sub-types. The genotype of the virus has a significant impact on the effectiveness of antiviral therapy and is therefore one of the key determining factors in deciding how to treat the illness. Because current genotype testing methods are not always effective, Christopher worked on a DNA amplification-based genotyping method that promises to be faster, more sensitive, more accurate and less expensive.

Gold Medal Award

The CLF established the Gold Medal Award in 1983 to recognize doctors and scientists internationally who have made a significant contribution to advancements in the field of liver research. We are proud of the many CLF ‘alumni’ on the list (names in bold) who have received research grants that helped pave the way to their discoveries and other achievements.

1983 Dr. Jean-Pierre Benhamou
1984 Dr. Robert Purcell
1985 Dr. Rudi Schmid
1986 Dame Shirley Sherlock
1987 Dr. Aron Rappaport
1988 Dr. Carl A. Goresky
1989 Dr. Hyman J. Zimmerman
1990 Dr. B. S. Blumberg
1991 Dr. Hector Orrego
1992 Dr. Roger Williams
1993 Dr. Telfer Reynolds
1994 Dr. M. James Phillips
1995 Dr. Diane W. Cox
1996 Dr. Laurence Blendis
1997 Dr. Laurie Powell
1998 Dr. William Wall
1999 Dr. Juan Rodes
2000 Dr. Lorne Tyrrell
2001 Dr. Jay Hoofnagle
2002 Dr. Michel Huet
2003 Dr. Roger Butterworth
2004 Dr. Jenny Heathcote
2005 Dr. Ian Wanless
2006 Dr. Harvey Alter
2007 Dr. Victor Feinman
2008 Dr. Eve Roberts
2009 Dr. Jean-Paul Villeneuve

Sass-Kortsak Award

In 1990, the Canadian Liver Foundation, in partnership with the Canadian Association for the Study of the Liver (CASL), created the Sass-Kortsak Award to honour the late Dr. Sass-Kortsak who made tremendous contributions to the field of hepatology and did much to further the work of the Foundation. The award is presented every two years and the recipient is invited to lecture at the Canadian Digestive Diseases Week conference.

1990 Dr. Irmin Sternlieb
1992 Dr. Claude C. Roy
1994 Dr. Daniel Alagille
1996 Dr. Alex Mowat (posthumously)
1998 Dr. William Balistreri
2000 Dr. Frederick J. Suchy
2002 Dr. Jean-Bernard Otte
2004 Dr. André Rasquin
2006 Dr. David Perlmutter
2008 Dr. Milton Finegold

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Treasurer’s Report

2009 marked the Canadian Liver Foundation’s 40th anniversary. This milestone provided an opportunity to celebrate the Foundation’s many successes, including our funding over $70 million in research and education over four decades. The Foundation however has not been immune to the continuing effects of the global financial crisis, as a result, the Foundation’s Donations and Chapter Revenue decreased from $6.4 million in 2008 to $6.0 million in 2009. Interest and Other Income however showed a positive change from a $345K loss in 2008 to a $230K gain in 2009 which was a result of improving equity markets. Our Expenditures on Programs in 2009 totaling $2.7 million were consistent with our expenditures of $2.8 million in 2008. Our Research Grants spending reflected our continuing commitment to funding liver research in Canada. In 2009 we paid out $704K in research grants compared to $916K in 2008. The Canadian Liver Foundation has ongoing research commitments totaling approximately $600K to be paid from 2010 to 2012. Operating costs were reduced from $3.7 million in 2008 to $3.5 million in 2009.

Our financial position remains fiscally sound. At the end of 2009, we had current assets amounting to approximately $1.7 million and investments of $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 2010 and beyond.

Paul Derksen, CA
SECRETARY/TREASURER

Financial Highlights

Treasurer’s Report

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Paul Derksen, CA
SECRETARY/TREASURER

Financial Highlights

Financial Position Summary As At December 31, 2009 And 2008

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<td><strong>$550,473</strong></td>
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<td><strong>$3,692,304</strong></td>
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Operations Summary For The Year Ended December 31, 2009 And 2008

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<td><strong>$5,494,267</strong></td>
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<td>Interfund transfers to support activities of the Medical &amp; Research Trust Funds</td>
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<td>Fund Balance — Beginning of Year</td>
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<td>$2,105,400</td>
<td>$1,968,980</td>
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<td>$735,897</td>
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<td>Fund Balance — End of Year</td>
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<td>$2,535,966</td>
<td>$3,183,789</td>
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</table>

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

Thanks to the investment and commitment of our donors, the Canadian Liver Foundation funds and delivers important liver health research and education programs. Every effort has been made to ensure the accuracy of the donor list below. Should you find any errors or omissions, please call 1-800-563-5483, ext. 4945 to speak to Judy Thompson.

Merci à nos donateurs

Grâce aux investissements et à l’engagement de nos donateurs, la Fondation canadienne du foie finance et offre des programmes de recherche et d’éducation sur la santé du foie. Tous les efforts ont été faits pour faire en sorte que la liste de donateurs ci-dessous soit exacte. Si vous découvrez des erreurs ou des omissions, veuillez appeler au 1 800 563 5483 poste 4945 pour parler à Judy Thompson.