

Candid Facts

50 YEARS  Canadian Cystic Fibrosis Foundation

Volume 1, Spring 2010

www.cysticfibrosis.ca

Breathing life into the future®

Report confirms Canadians are world-leaders in the fight against cystic fibrosis

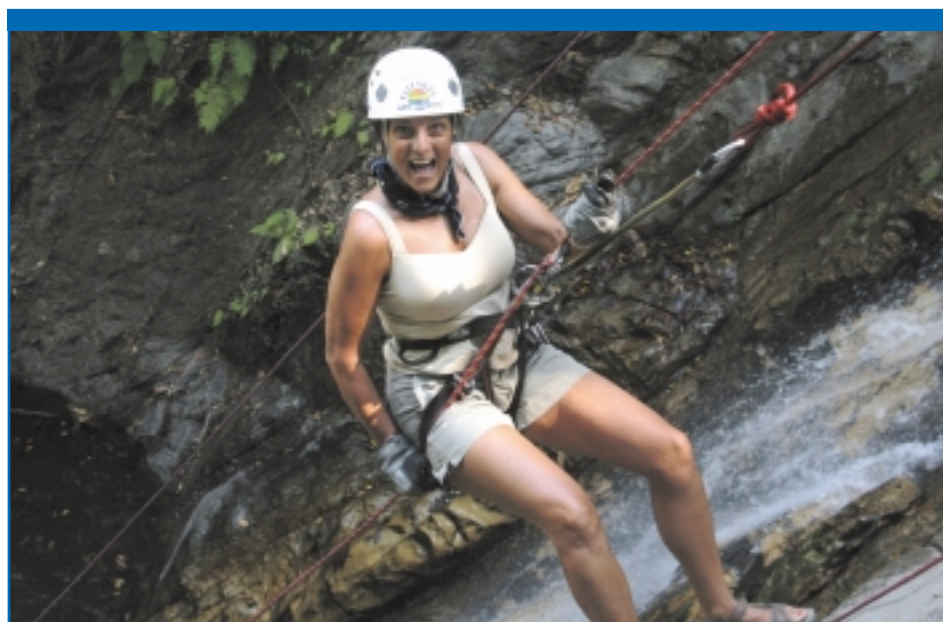
Important new information about the cystic fibrosis population in Canada is now available in the updated Canadian Patient Data Registry (CPDR).

The most exciting news is that the median age of survival has increased substantially in the last five years. Today, half of all Canadians with cystic fibrosis are expected to live into their 40s and beyond, making the median age of survival one of the highest reported in the world!

In addition, adults make up a growing proportion of the Canadian CF population. In 2007, 57% of people with cystic fibrosis were 18 years old or older, compared to just 27% in 1982.

These statistics are very encouraging and show great progress; however, there is still much work to be done to continue to improve and extend the lives of people with CF. For example, half of the Canadians with cystic fibrosis who died in 2007 were 25 years old or younger.

The CPDR also illustrates important trends reflecting other



Thanks to tremendous progress in research and care over the last 50 years, Canadians with cystic fibrosis like Michelle Thornell, 50, of Edmonton, Alberta, are living longer and healthier lives.

aspects of cystic fibrosis, including lung function, new diagnoses, and microbiology.

For example, the incidence of the *Burkholderia cepacia* bacterium has gradually declined since 1992; however, the incidence of other bacteria, including *Staphylococcus aureus* and *Stenotrophomonas maltophilia* has gradually increased. In fact, *S. maltophilia* was not even included in microbial counts before 1997 and is now found in 10% of Canadians with CF. The bacterium's impact on the health

of people with cystic fibrosis is currently being studied by CCFF-funded investigator Dr. Valerie Waters.

The Foundation is grateful to all participants and CF clinic personnel who assisted in the consent and data collection process. The valuable information included in the CPDR is important to researchers, and also allows clinicians to track disease trends and improve patient clinical care.

The full CPDR report is available at www.cysticfibrosis.ca. 

May is Cystic Fibrosis Awareness Month.

What is cystic fibrosis?

Cystic fibrosis (CF) is the most common, fatal, genetic disease affecting Canadian children and young adults. A build-up of thick mucus in the lungs causes severe respiratory problems. In addition, mucus build-up in the digestive tract results in extreme difficulty in digesting and absorbing adequate nutrients from food.

CCFF Mission

The Foundation's mission is to help people with cystic fibrosis. The Foundation:

- funds research towards the goal of a cure or control for CF;
- supports high quality CF care;
- promotes public awareness of CF; and
- raises and allocates funds for these purposes.

Advocacy

Access to life-sustaining drugs

Most children and adults with cystic fibrosis take pancreatic enzymes with every meal and snack to help absorb nutrients from food. Better nutrition has significantly contributed to longer and healthier lives for the persons affected.

The Canadian Cystic Fibrosis Foundation, with the support of an Expert Working Group led by Drs. Peter Durie and Mark Chilvers, is striving to ensure that Canadians with CF continue to benefit from public coverage of pancreatic enzymes, and thus have access to these essential medications.

Historically, pancreatic enzymes have been classified by Health Canada as non-prescription products, although the provinces have treated these products as prescription-requiring. Accordingly, provincial drug plans and private health benefits plans have covered the cost of pancreatic enzymes, which can rise to \$20,000 or more, per person with cystic fibrosis, per year.

A few years ago, Health Canada proposed to transition pancreatic enzymes from products which bear a drug identification number ("DIN") to "natural health product" by 2010. There was concern that this move could introduce a safety risk, and cause refusal of private and public coverage of these essential drugs. Without financial support for the high cost of pancreatic enzymes, Canadians with CF would no longer have access to a product they require, every day, to sustain their lives.

Based on health, safety and

Based on these concerns, the Foundation recommended that Health Canada classify enzymes as prescription-requiring medication for people with CF.

accessibility concerns, the Foundation recommended that Health Canada classify enzymes as prescription-requiring medications for people with CF. Recently, the Foundation learned of Health Canada's intention to propose that pancreatic enzymes become prescription-requiring products. If this change occurs, pancreatic enzymes will not be regulated as natural health products, and thus presumably will remain eligible for public (provincial) coverage. The process to implement this regulatory amendment could take a year, or longer.

The Canadian Cystic Fibrosis Foundation is very encouraged by this news from Health Canada, and the Foundation's members are optimistic that coverage and access to these life-sustaining medications will remain in place. ☺

Candid Facts

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Canadian Cystic Fibrosis Foundation
2221 Yonge Street, Suite 601
Toronto, Ontario M4S 2B4
416-485-9149 • 1-800-378-CCFF
info@cysticfibrosis.ca
www.cysticfibrosis.ca

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Denis Mouton

GRAPHIC DESIGN

Lucie Trépanier

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How many lives will you save?

Organ and Tissue Donation Awareness Week is April 18 – 25, 2010

For people with end-stage cystic fibrosis, a double-lung transplant is often a last chance at life.

A transplant can give people with CF a chance to do things they never thought possible like finish school, get married, or see their children grow up. It means a longer and healthier life.

Unfortunately, many Canadians with cystic fibrosis do not receive their gift of life in time.

Every year, hundreds of people die waiting for a transplant, while many healthy organs are lost because people do not communicate their wish to be a donor.

According to a study published last winter by the Canadian Institute for Health Information, the number of Canadians donating organs increased by 28% between 1999 and 2008. But despite this gain, it has not been enough to keep up with the increasing demand for organ transplants. In 2008, the Canadian Organ Replacement Register Report stated that there were more than 4,000 Canadians waiting for an organ transplant but less than 2,000 organs were retrieved for transplant.


This year, during Organ and Tissue Donation Awareness Week, talk to your family and loved ones about your desire to be an organ donor and be sure to sign your organ donor card. You can also volunteer with a local organ donation awareness group, wear a green ribbon to show your



Brandon Gibson, 17, received a double-lung transplant in 2006. The Scarborough teen is extremely grateful for his new lungs and went on to compete in the 2008 Transplant Games, winning three gold medals and one silver.

Every year, hundreds of people die waiting for a transplant, while many healthy organs are lost because people do not communicate their wish to be a donor.

support, and speak with family, friends and coworkers about organ donation.

For more information, please visit www.cysticfibrosis.ca and www.transplant.ca. 

CCFF Privacy Policy

The Canadian Cystic Fibrosis Foundation is committed to protecting the privacy and the confidentiality of personal information. Details of the Foundation's Privacy Policy may be obtained by sending an e-mail to privacy@cysticfibrosis.ca, with "Attention Privacy Officer" in the subject line, or by contacting the CCFF Privacy Officer at 1-800-378-2233.

Awarding excellence

Each year, the Foundation's Medical/Scientific Advisory Committee evaluates numerous grant applications and funds the most promising. This year, two talented researchers are being honoured with special CCFF awards for their outstanding research applications.

Zellers Senior Scientist Award

The Zellers Senior Scientist Award recognizes the exceptional contributions of an established cystic fibrosis investigator and pays tribute to Hbc's tremendous support of the Foundation's work. This year, Dr. Gergely Lukacs from McGill University in Montreal received this prestigious award.



Dr. Gergely Lukacs

Dr. Lukacs was first funded by the Foundation as a post-doctoral fellow in 1991. He received his first CCFF research grant in 1995 and is now a full professor at McGill. He is also a Canada Research Chair. Dr. Lukacs is investigating protein structure and function, especially as it relates to cystic fibrosis.

Proteins fold in very specific and complex ways and are held together by chemical bonds. The protein's folded structure must be precise in order to function properly.

Gene mutations, such as those that cause cystic fibrosis, alter the structure of the protein and have an effect on the protein's ability to reach its intended destination (i.e. the cell membrane). As well, mutations alter the protein's function. However, it is currently not well understood how one small change in a protein's structure can have such a profound effect on its functionality.

Dr. Lukacs will study the chemical bonds that keep CFTR protein together and the alterations that CF mutations, particularly DeltaF508, have on the protein's structure. This information could lead to the development of new drugs that correct CFTR protein mis-folding.

Robbie Award

The CCFF's Robbie Award is given to a new and outstanding CF investigator. This award pays tribute to the Robbie International Soccer Tournament's long-standing support of the Foundation. Dr. Simon Rousseau, also from McGill University, received the

Robbie Award this year.

Dr. Rousseau set up an independent laboratory at McGill University in 2008. He is studying lung inflammation and how it is regulated in diseases such as asthma and cystic fibrosis.

Inflammation is an important part of the immune system's response to infection. White blood cells are recruited to infected areas and destroy the infecting bacteria. But they can also cause inflammation in the surrounding tissues. In CF lungs, inflammation is chronic and excessive and can cause significant damage. This may be caused by hyperactive cell communication pathways that stimulate inflammation in people with cystic fibrosis.

Dr. Rousseau is studying the signaling molecules involved in stimulating inflammation. His goal is to understand the role of cellular networks, such as signaling molecules, in regulating inflammatory response to infection. His findings could help identify molecules that stimulate inflammation and subsequently target these molecules to combat chronic inflammation.

The Canadian Cystic Fibrosis Foundation is grateful to have these talented scientists on our team in the fight against cystic fibrosis. ☺



Cystic fibrosis research – a family affair!

For Stan Pasyk, a PhD student at the University of Toronto, an interest in cystic fibrosis research runs in the family.

Just like his mother, Ewa Pasyk, did in the mid-90s, Stan works in Dr. Christine Bear's lab at The Hospital for Sick Children in Toronto. Stan joined the lab in his second year of university based on his mother's positive experiences there.

Members of Dr. Bear's lab are focused on correcting the basic defect of cystic fibrosis. The most common genetic mutation that causes CF, DeltaF508, results in the production of a protein that is not able to reach the cell surface to function as a chloride channel. This malfunction causes thick and sticky mucus to form. However, if the protein is assisted to the cell surface, it can function partially. Researchers in Dr. Bear's lab are searching for molecules that rescue DeltaF508 and help it function at the cell surface.

Stan's research is specifically related to helping the DeltaF508 protein function properly at the cell surface. He is studying the DeltaF508 CFTR protein at a molecular level to determine why this protein doesn't work well as a chloride channel. He is also examining whether a small molecule called VRT532 is able to increase the activity of the DeltaF508 CFTR protein at the cell surface.

This information, in combination with the findings of



Stan Pasyk, a PhD student in Toronto, is following in his mother's footsteps and hopes to pursue a career in CF research.

Stan's fellow lab members, will help design new treatments that target the basic defect in cystic fibrosis.

The CCFF awarded Stan Pasyk a two-year, \$41,000 studentship award to support his PhD studies. ☎

DONATING MADE EASY

Consider making a donation to help fight CF today. Your support will help us in the search for a cure.

There are a number of ways to contribute to the CCFF:

- on-line donations are accepted at www.cysticfibrosis.ca
- donate by phone at 1-800-378-CCFF (2233)
- mail your contribution to:

Canadian Cystic Fibrosis Foundation

2221 Yonge Street, Suite 601,
Toronto, ON M4S 2B4.

You may wish to consider joining the Breath of Life® monthly giving program to spread your donation over twelve months through automatic deductions from a chequing account or credit card.

Meet the 2010 Great Strides™ Super Striders!

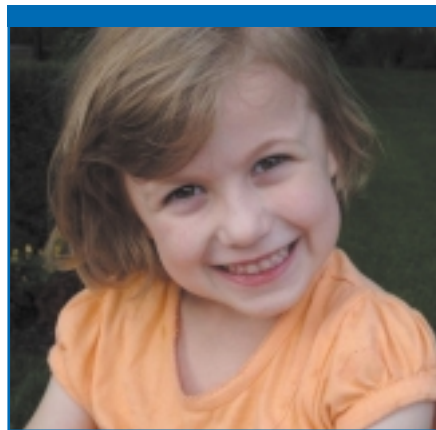
Representing the Canadian Cystic Fibrosis Foundation, this special group will be at a Great Strides™: Taking Steps to Cure Cystic Fibrosis walk near you on Sunday, May 30. By participating in a walk, you are funding research and treatment that will help Canadians with cystic fibrosis live longer, healthier lives. For more information, visit www.cysticfibrosis.ca/greatstrides.



Emma Chenier, 9

Sports are a big part of Emma's life. Her cystic fibrosis doesn't stop her from staying active – Emma loves soccer, cross-country skiing, running track, and playing goalie on her girls' hockey team. Emma is in grade four and loves school, especially art and math.

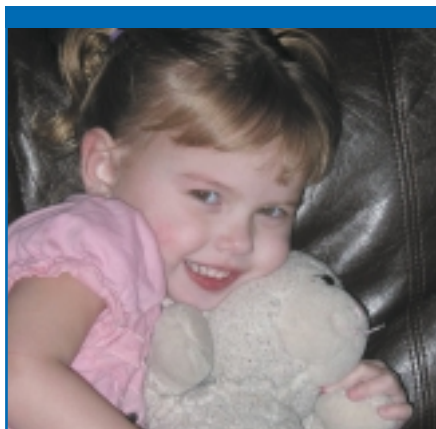
When she grows up, Emma wants to be a doctor to help people grow strong and a veterinarian because she loves animals.



Juliana Eberschlag, 6

Juliana loves to play sports, especially soccer. When she grows up, she wants to become a lawyer, just like her dad!

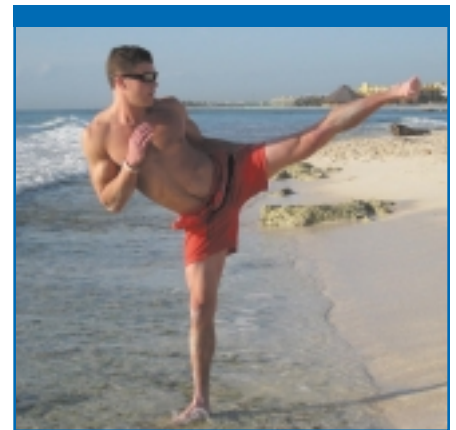
Juliana has cystic fibrosis, and has to take enzyme pills everyday and do "thumpy" (her physiotherapy) since she knows it will make her strong.



Ella Whaley, 2

Ella loves being active. She especially enjoys playing in the park and dancing with her older sister.

Ella was born a fighter and is a champion in the fight against CF! She takes her medicine and does physiotherapy everyday to ensure she grows up big and strong. Whenever Ella goes to the doctor, Lambie (her favorite stuffed animal), gets a check-up, too!



Jeremy Laferrière, 29

Physical activity and creativity are a large part of Jeremy's life. Though he has cystic fibrosis, he says both have helped him live a healthy, well-rounded life. When he is not weight training or practicing martial arts, he loves to be creative and express his thoughts through writing. Growing up on his family farm has been a huge inspiration for Jeremy, and one day he hopes to run it himself.



Mes Aïeux

Mes Aïeux is proud to be the Quebec Cystic Fibrosis Association's 2010 Super Strider! Mes Aïeux is a popular French-Canadian folklore music group from Quebec City. They are strong supporters of the CF cause and know that when we all come together, great things can happen! ☺

Photo: Sylvain Laquerre



Grace and Merlin make Foundation magic

It's safe to say that the Kitchener-Waterloo District Chapter of the Canadian Cystic Fibrosis Foundation might not exist without the hard work and dedication of Grace and Merlin Jutzi.

In addition to raising three children with cystic fibrosis, the couple made time in their busy schedules to raise awareness of cystic fibrosis through fundraising, education campaigns and establishing the KW District Chapter in 1963.

The Jutzis had four sons, three of whom had cystic fibrosis. Marvin, Kevin and Robin were diagnosed with CF as infants in the 1950s and 1960s. Merlin worked long hours running his auction house and working odd jobs to support his family, while Grace took care of the children, often administering nine hours of treatment a day to the boys.

When their sons were born, Grace and Merlin were told Marvin, Kevin and Robin had little chance of survival, and wouldn't see kindergarten. But all three sons lived into their late 30s and 40s. It was a lot of work taking care of four children, but Grace and Merlin worked hard to provide for their kids as well as create awareness of cystic fibrosis.

The couple attended Foundation meetings in Toronto before becoming chartered members of the KW District Chapter. Grace was the Education Chair for ten years, making numerous TV appearances and speaking to organizations to educate people about CF.

Merlin won the Breath of Life



Grace and Merlin Jutzi's three sons with cystic fibrosis were their inspiration for establishing the Kitchener-Waterloo District Chapter of the Foundation in 1963.

Award in 1983 and was chapter President from 1988 to 1990. Grace was honoured as the Oktoberfest Woman of the Year in 1981, an award that recognizes outstanding women in the Kitchener community. She also received the Commemorative Medal for the Queen's Golden Jubilee in 2002, nominated by the Foundation for her significant contributions to the organization.

Merlin continues to donate to the Foundation, and sponsors the mailing of the KW District Chapter's newsletter, saving the chapter hundreds of dollars a year. He is also the landlord for the chapter's building and rents office

space at a reduced rate.

After decades of loyal service, Grace and Merlin are still dedicated to the Foundation and remain positive that CF research will lead to a cure.

"I think the Foundation has done a wonderful job raising awareness and helping people with cystic fibrosis," Merlin said. "We're always hopeful."

The Canadian Cystic Fibrosis Foundation thanks the Jutzi family for their long-standing support, and the important role they've played in the fight against cystic fibrosis. ☺



High school sweethearts fight cystic fibrosis together

Jeff and Sylvie van Geel began dating in grade 11 and have been inseparable ever since.

"Sylvie is a kind and friendly person," he said. "Falling in love with her was easy."

Sylvie has cystic fibrosis, but for most of the couple's early years, her disease was under control. Their relationship blossomed, and the couple married in 1988.

In 2001, Jeff had an opportunity to volunteer at the summer Canada Games, which were held in their hometown of London, Ontario. It was at the games that Jeff discovered his passion for volunteerism.

When Sylvie reached her 30s, her symptoms began to worsen. Jeff decided to turn his volunteer efforts to the Foundation to learn more about the disease, and to help Sylvie with her battle against cystic fibrosis.

In 2001, Jeff and Sylvie approached the CCFF's London Chapter, and began volunteering for its Bingo night. Jeff has since worn many hats within the Chapter, including Great Strides™ Walk Liaison and VP of Fundraising.

The van Geels also created the successful annual "Cruzin' for CF" fundraiser, merging their passion for vintage cars and motorcycles with their quest for a cure.

"It's a great event. We drive around town and end up at an estate for a BBQ, hot-air balloon rides and games," said Jeff. "In three years, it has become the highest-grossing fundraiser for our



Sylvie and Jeff van Geel

Chapter; we've raised well over \$200,000."

In 2009, Jeff and Sylvie won the Foundation's prestigious Céline Award. Named after the CCFF's Celebrity Patron, Céline Dion, the award acknowledges a volunteer individual, couple or family who have made an indispensable and a sustained contribution to a Chapter at the grassroots level.

Most recently, Jeff became a stakeholder representative on the CCFF's Medical/Scientific Advisory Committee, which is composed of comprises leading CF scientists, clinicians and members of the CF community in Canada. Jeff represents the CF community and offers valuable input on the Foundation's medical and scientific program recommen-

dations. These recommendations are then presented to the CCFF's Board of Directors for approval.

"It's been a great experience so far," he said. "The Foundation is taking a multidisciplinary approach to treating cystic fibrosis. There is so much promising research going on right now that I can't help but feel hopeful for the future."

Though Sylvie has taken a step back from the Chapter, Jeff has no plans to slow down. He hopes to explore other volunteer positions within the Foundation in the future.

"It feels good to help people. You get back so much more than you give," he said. "In 50 years, I hope we will be celebrating the 50th Anniversary of a cure!" ☺



A cure for Matthew

Eight years ago, Olja and Mike Muller were anxiously anticipating the arrival of their grandson, Matthew. Two days after his birth, Matthew was rushed to The Hospital for Sick Children in Toronto, Ontario with a bowel obstruction. Three weeks later, after a life-saving surgery and several tests, he was diagnosed with cystic fibrosis. The family was devastated.

Unwilling to let the diagnosis dampen the joys of grandparenting, Olja and Mike decided to help in any way they could.

"We take Matthew to his cystic fibrosis clinic visits and help him with his treatments," said Olja. "We also take him and his younger brother, Ethan, out on special outings."

In addition to helping their family deal with the trials and tribulations of cystic fibrosis, the Mullers felt it was important to support the work of the Foundation.

This year, Olja and Mike decided to contribute to the Foundation's 50th Anniversary Campaign, a CCFF chapter-led fundraising initiative to raise \$500,000 for the Foundation's 50th Anniversary to support cystic fibrosis research.

"When my daughter approached me about supporting the Foundation's 50th Anniversary Campaign, I knew I had to take part," said Olja. "I wish I had won the lottery, so we could have done more. But because we had the option of making our contributions over a period time, we were able to make a greater



Olja and Mike Muller of Toronto, Ontario with their grandson, Matthew, who has cystic fibrosis. The Mullers have contributed to the Foundation's 50th Anniversary Campaign for the future of their grandson and all Canadians with cystic fibrosis.

commitment to the campaign."

The Mullers are encouraged by the advances in cystic fibrosis research in the last 50 years, and are optimistic about the future.

"Matthew is a courageous boy. One of his goals is to climb the highest mountains in the world," Olja said. "The key for us is to remain positive and do whatever we can to help him reach his full potential. Thanks to the work of the Canadian Cystic Fibrosis Foundation, I believe we can find a cure in Matthew's lifetime."

Olja invites all grandparents to contact their local chapter and support the 50th Anniversary campaign. [🔗](#)

Share your memories

Share your memories of friends and events in the CF community in the form of photos, stories, videos, tributes, or other reflections on the past 50 years. Please visit the Foundation's 50th Anniversary Facebook page and post your memory. You can find it by searching for the CCFF on facebook.com. Although anyone can view the page, only "fans" can post information.

Once a month, we will select and feature a post.

Mark your calendar! National Kin-CCFF Day: Saturday, May 1

National Kin-CCFF Day will take place on Saturday, May 1 in communities across Canada. This special day was created in 2003 to promote the long-standing partnership between Kin Canada and the Foundation, and to raise awareness and funds in support of the fight against CF. It is held annually on the first Saturday in May to help kick off Cystic Fibrosis Awareness Month.

Kinsmen and Kinettes will host a variety of fundraising and awareness events, from road tolls to barbeques, with proceeds going to the Foundation.



Kin members have raised more than \$37 million since the Kin-CCFF partnership began in 1964. Their ongoing support has helped to significantly improve the quality of life for people with cystic fibrosis and their families.

Contact your local Kin club to find out about National Kin-CCFF Day events in your community. Visit www.kincanada.ca for a club listing. ☎

Shining their way to success!



Students at Brock University celebrate Shine Day in St. Catharines, Ontario. Brock University won the 2009 Shinerama Best Secondary Fundraiser award for the Shine the Falls event.

Students from coast to coast celebrated Shinerama's 45th Anniversary last year with car washes, BBQs, and many Shinerama cheers. Their hard work paid off – Shiners raised a record-breaking \$990,000 in support of cystic fibrosis research and care.

"Everyone worked hard to make the anniversary special. I am so proud of our Coordinators, Committees, Campaign Advisors and Regional Directors", says Serena Hartl, Shinerama Chair. "Our hard work, dedication and enthusiasm was well worth it – everyone deserves a huge Shinerama hug. "Congratulations to the Canadian Cystic Fibrosis Foundation's 2009 National Shinerama Award winning schools:

Best Overall Campaign:

Mount Allison University, New Brunswick

Most Improved Campaign (tie):

Cape Breton University, Nova Scotia and Canadore College/Nipissing University, Ontario

Best Secondary Fundraiser:

Brock University, Ontario for *Shine the Falls*.

A very special thank you to all National Sponsors for their generosity and support of the 2009 Shinerama campaign: studentsawards.com, Domino's Pizza, Breakaway Tours, Mac's Convenience Stores, Much Music and Best Buy. ☎



CARSTAR continues to champion fight against CF

In 2009, CARSTAR Automotive Canada raised more than \$100,000 in support of the work of the Canadian Cystic Fibrosis Foundation. This year, CARSTAR is planning a variety of fundraising events to exceed last year's contributions.

CARSTAR Collision Repair Centres will host the annual Soaps it Up Car Wash, Charity Golf Tournament, and their renowned Casino Night. For the holiday season, the centres will also purchase customized greeting cards from the Foundation to send to customers and business contacts.

The 2010 Soaps it Up National Car Wash will take place on Saturday, June 12. Tickets will soon be available at CARSTAR locations, select CCFF chapters, and on-line at www.carstar.ca.

CARSTAR and its dedicated franchisees have been national partners in the fight against cystic fibrosis for more than a decade and have raised more than \$1.7 million for the cystic fibrosis cause. Thank you, CARSTAR! ☺



Volunteers at the Soaps it Up Car Wash in Essex, Ontario. These dedicated supporters helped make the 2009 campaign a soapy success!

\$250,000 in celebration of 25 years!



2010 marks the 25th Anniversary of the CCFF-Advocis partnership, and Advocis is preparing to make it an extraordinary fundraising year! In recognition of this silver anniversary, the President and Chief Executive Officer of Advocis, Greg Pollock, challenged his association to raise \$250,000 in support of the fight against cystic fibrosis.

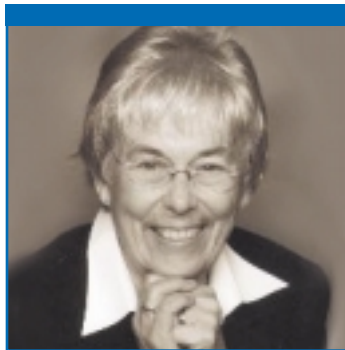
The challenge was announced in November at an Advocis volunteer dinner, and attendees not only accepted the challenge, but donated more than \$25,000 to kick-start the campaign!

Advocis, the Financial Advisory Association of Canada, raises money for the cystic fibrosis cause by hosting a variety of events such as golf tournaments and Poor Boy luncheons, and by making monthly donations through the Advocis 'Friends for Life' giving program. In 2010, Advocis will become a National Team Partner of the Foundation's Great Strides™ walk in May. Advocis chapters across Canada will form teams and participate in their community walk.

Since 1985, Advocis members have raised more than \$4 million for the fight against cystic fibrosis. Thanks to their continued support, Canadians with CF are living longer than ever before. Thank you, Advocis! ☺

Shirley Patola

Shirley Patola was Nurse Coordinator at the CF clinic at the Royal University Hospital in Saskatoon, Saskatchewan for nearly two decades. She was a favourite amongst many of the children and adults she cared for. Shirley also served as Professional Advisor to the Foundation's Adult CF Committee from 1994-1997, bringing her extensive expertise in cystic fibrosis care to the committee.



Shirley Patola

Shirley served as an important link between the Saskatoon CF clinics and the Foundation's North Saskatchewan Chapter, organizing many information sessions about cystic fibrosis for the community, as well as helping to organize chapter fundraising events such as the chapter's annual swim-a-thon. A long-time volunteer with the chapter, she worked hard to raise awareness and important funds for the fight against cystic fibrosis. Shirley was predeceased by her husband, Walt, and is survived by sons, Mark and David.

Shirley passed away October 22, 2009 in Saskatoon at the age of 72. ☹

British Columbia screens newborns for CF

In December, the Province of British Columbia began screening all babies born in BC for cystic fibrosis. Babies diagnosed with cystic fibrosis will receive immediate treatment, thus avoiding months, sometimes even years, of anguish for parents who don't know the cause of their child's discomfort and pain. Currently, some people with cystic fibrosis reach adulthood without being diagnosed, enduring years of untreated CF-related difficulties.

British Columbia is the fourth province after Alberta, Ontario and Saskatchewan to implement newborn screening for cystic fibrosis.

We've come a long way in 50 years!

There has been significant progress in cystic fibrosis research and care since the Foundation was established in 1960. Thanks to tremendous advances in research and treatment, people with cystic fibrosis are living longer and healthier lives. To read more about the Foundation's history, milestones and memories of the CF community, visit www.cysticfibrosis.ca, or the CCFF's 50th Anniversary Facebook page.

Correction

In the winter 2009 issue, we incorrectly printed that Christopher Beausoleil raised more than \$30,000 for the Foundation. Christopher has actually raised well over \$100,000 in support of the fight against cystic fibrosis. The Canadian Cystic Fibrosis Foundation regrets this error and extends its deepest gratitude to the Beausoleil family for their long-standing support. ☹



Chris Beausoleil, 22, was an Olympic torchbearer in December, 2009, in Chatham, Ontario.

PLAN TO GIVE

Many Canadians are choosing to fight cystic fibrosis by making "planned gifts." There are a variety of ways to donate planned gifts—through donations of shares in companies, life insurance, annuities, or bequests.

The Canadian Cystic Fibrosis Foundation has developed a planned giving program to provide friends of the CF cause with information about how they can make a significant contribution to the search for a cure for cystic fibrosis.

To find out how to make a planned gift, or to receive a planned giving information package, please contact Michelle Brome, Manager, Annual Giving & Donor Relations at 1-800-378-2233 ext. 288 or by e-mail at mbrome@cysticfibrosis.ca.