Cystic Fibrosis Canada™

Connections

FALL/WINTER 2014

KIN CANADA AND SHINERAMA CELEBRATE 50 YEARS IN THE FIGHT AGAINST CYSTIC FIBROSIS

25 YEARS SINCE FIRST CF DOUBLE-LUNG TRANSPLANT

CYSTIC FIBROSIS CANADA'S FIRST CHAIR IN ADULT CYSTIC FIBROSIS RESEARCH

CELEBRATING CF MILESTONES

25TH ANNIVERSARY OF THE CF GENE DISCOVERY

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Cystic Fibrosis Canada™

Seamus Labonte-Dolan

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Just Breathe: Portraits of Adults Living with Cystic Fibrosis by Ian Ross Pettigrew: www.ianpettigrew.com/just-breathe-cystic-fibrosis.html

Madi Vanstone, Advocacy Champion

MESSAGE FROM THE CHAIR
JIM MOUNTAIN

In 2014, Cystic Fibrosis Canada has so much to celebrate. We hit several important milestones – starting with Kin Canada and Shinerama's 50th anniversaries. The support from Kin Canada, our longest-standing partner, and the thousands of student volunteers who take part in Shinerama, have been unremitting in raising awareness and critical funds to advance the fight against cystic fibrosis (CF).

This year, we are also celebrating one of the greatest breakthroughs in human genetics in the last 50 years – the 25th anniversary of the discovery of the CF gene. In 1989, a Cystic Fibrosis Canada-funded researcher, Dr. Lap-Chee Tsui, and his team of scientists at the Hospital for Sick Children stunned the medical community by isolating the gene that causes cystic fibrosis. Since the CF gene's identification, the life expectancy for a Canadian born with cystic fibrosis has steadily risen each year and according to the most recent Cystic Fibrosis Registry data the median age of survival has now surpassed 50 years of age, among one of the highest in the world.

The first successful double-lung transplant for a CF patient also happened 25 years ago in Toronto. Dr. Shaf Keshavjee, a Cystic Fibrosis Canada-funded researcher, has become a pioneer in lung transplant techniques and revolutionized lung transplantation with the development of the Ex Vivo Lung Perfusion System.

Over the years, we have achieved remarkable progress in our work to discover and develop new treatments, but the lives of Canadians with cystic fibrosis are still cut far too short and our work is far from over. As we commemorate the successes we've achieved over the last 25 years, we must also look forward in pursuit of the next medical breakthrough and the highest standard of CF care.

We can make a difference in the lives of Canadians with cystic fibrosis.

Jim Mountain, Chair

"We can make a difference in the lives of Canadians with cystic fibrosis."

CELEBRATING OUTSTANDING PROGRESS

A MESSAGE FROM CELEBRITY PATRON, *Céline Dion*

I have had the distinct privilege to work with Cystic Fibrosis Canada for over 30 years, and in that time, I have witnessed the great evolution of cystic fibrosis treatment and care. I've seen radical changes in the research being conducted, and I have seen once unimagined advances greatly improve lives for people living with cystic fibrosis and their families.

Cystic Fibrosis Canada has always been at the forefront of this remarkable progress. This fall, Cystic Fibrosis Canada is celebrating the 25th anniversary of the gene discovery, and the progress that has been made since 1989.

Twenty-five years ago, Dr. Lap-Chee Tsui, a Cystic Fibrosis Canada-funded researcher, discovered the gene responsible for cystic fibrosis. This breakthrough has had tremendous effects on our understanding of the disease, and has been recognized as one of the greatest findings in the history of human genetics.

Research is critical to the well-being of all Canadians with cystic fibrosis and gives hope to their families, friends and caregivers. Thanks to medical and research advances, the median age of survival is now 50.9 years, a milestone that may not have been possible without this genetic breakthrough just 25 years ago, but there is still so much more work to be done.

I know that we won't be fighting this disease forever. We are closing in on a cure, and we are bringing the greatest minds together to help make it a reality. We have the momentum, we have the talent, and we have the passion. Cystic Fibrosis Canada will find a cure in our lifetime, but it is something that cannot be accomplished alone.

We all have heroes in our life that encourage us to give our time, talents and resources to make the world a little better than how we found it. My hero is still my niece, Karine who lost her battle with cystic fibrosis at the age of 16. She faced cystic fibrosis with such courage and tenacity, and because of her, I am committed to the CF cause.

Together, I am confident that we will beat cystic fibrosis.

Céline Dion

LOOKING BACK ON THE BIGGEST BREAKTHROUGH IN CF RESEARCH

Dr. Lap-Chee Tsui and his team of researchers discovered the cystic fibrosis gene in 1989

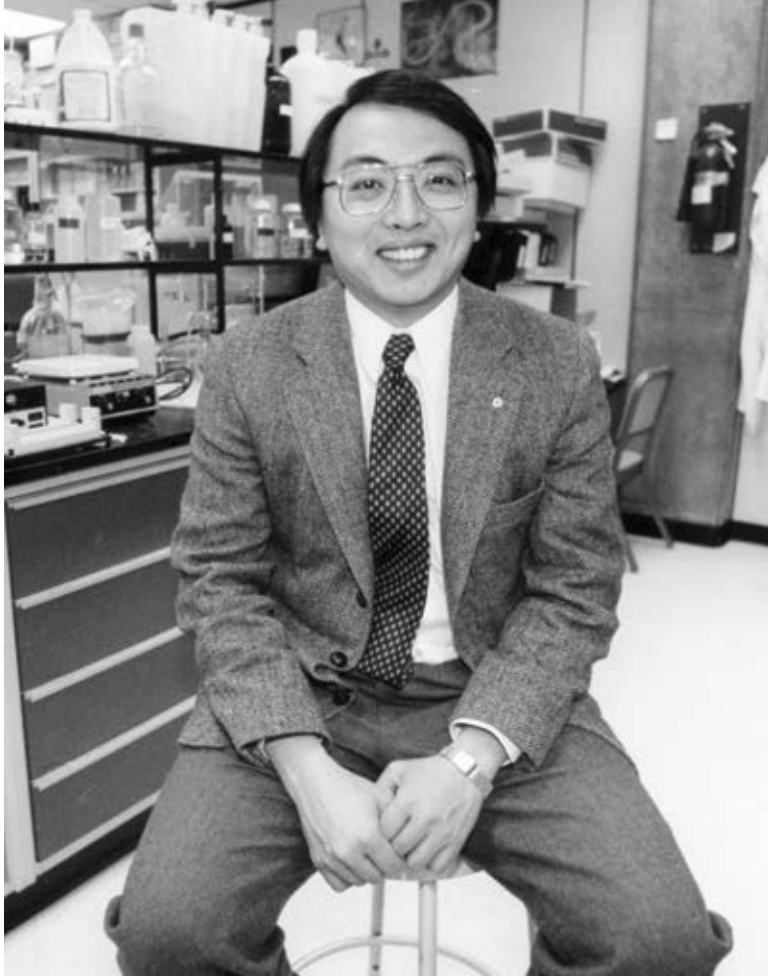
TWENTY-FIVE YEARS SINCE THE LANDMARK CF GENE DISCOVERY

One of the key achievements in cystic fibrosis (CF) research that has played a major role in the health of people living with the disease in Canada, and around the globe, happened in 1989. A landmark discovery at the time, Dr. Lap-Chee Tsui, a Cystic Fibrosis Canada-funded researcher led the team at the Hospital for Sick Children in Toronto that discovered the gene responsible for cystic fibrosis in collaboration with scientists at the University of Michigan. Now, more than 25 years later, this remarkable moment is still considered to be one of the most significant breakthroughs in human genetics in the last 50 years.

Tuesday, May 9, 1989, seemed like any other day in Dr. Tsui's lab. A researcher analyzed a printout of what seemed to be yet another variation of the same experiment. But, something stood out that night – the data showed a small deletion in a DNA sequence that had not been detected previously. A mutation like this might cause something as simple as a change in eye colour or could be as serious as the cause of a deadly disease, a solid clue that Dr. Tsui and his team had been looking for, but it wouldn't be until months later that further research in their laboratory confirmed they had found a mutation specific to CF patients. What Dr. Tsui and his team discovered that night in May turned out to be a mutation in the CF transmembrane conductance regulator (*CFTR*) gene – the gene responsible for cystic fibrosis, the most common fatal genetic disease affecting Canadian children and young adults.

“To call the path direct would be an overstatement. The CF gene discovery happened in stages. There was no eureka moment, it was more of a slow jump,” says Dr. Tsui. “We had to investigate several elements, including how the gene affected patients and support that with further research before we could officially celebrate.”

Dr. Tsui’s discovery of the cystic fibrosis gene improved the understanding of how the disease works and led to newborn screening for early detection of cystic fibrosis and carrier testing for parents. The incredible discovery has also opened the doors for today’s research that is resulting in innovative new treatments for people with cystic fibrosis.



Dr. Lap-Chee Tsui

Since the CF gene discovery, the median age of survival for Canadians with cystic fibrosis has climbed to 50.9 years. But, there is still a lot more work to be done before cystic fibrosis is cured. “The 21st century is the century of our medicine and now is the time to focus on finding effective CF treatments,” says Dr. Tsui. “More research will bring better treatments for the disease and this can only happen through collaboration from researchers, CF families, volunteers and donors all working together.”

Twenty-five years later, Dr. Tsui’s breakthrough remains a monumental achievement in the history of cystic fibrosis research and compels us to work harder to find a cure or control for this devastating disease.

Dr. Shaf Keshavjee is a Thoracic Surgeon and the Director of the Toronto Lung Transplant Program at Toronto General Hospital, University Health Network. With the development of the Toronto Ex Vivo Lung Perfusion System, Dr. Keshavjee has revolutionized lung transplants and helped improve health outcomes and quality of life for patients post lung transplant. Cystic Fibrosis Canada has supported Dr. Keshavjee since 1999, providing almost $2 million in research funding.

A pioneer in the field of lung transplantation, Dr. Keshavjee continues to innovate the procedure to better the quality of life for individuals with cystic fibrosis (CF). Together with a team of leading clinicians, Dr. Keshavjee leads one of the largest and arguably the top lung transplant centre in the world.

25TH ANNIVERSARY OF THE FIRST CYSTIC FIBROSIS DOUBLE-LUNG TRANSPLANT

Cystic Fibrosis Canada-funded researcher leads revolution in CF lung transplantation and continues to raise the bar in advancing transplant research.

Can you describe the first double-lung transplant you performed on a cystic fibrosis patient in 1988? How has this procedure changed over the years?

Many of the transformational innovations in lung transplantation have been introduced by the Toronto program. The first successful single lung transplant in the world happened at Toronto General Hospital in 1983. And the first successful double-lung transplant in the world also happened at Toronto General Hospital three years later in 1986. I was lucky to scrub in for that. In 1988, I was also part of the team at Toronto General Hospital that performed the first-ever successful double-lung transplant on a CF patient. At the time it was a very high-risk operation. All of these milestones were achieved at Toronto General Hospital and it's a record we are really proud of.

With all of the work we have done, CF patients now have the lowest risk for any lung transplant patient, with a zero percent operative mortality – compared to 50 percent in the 1980s! As we've gained more experience and developed more advanced technology, we continue to push the boundaries.

Canada ranks very high in lung transplants in the world. Why do you think this is?

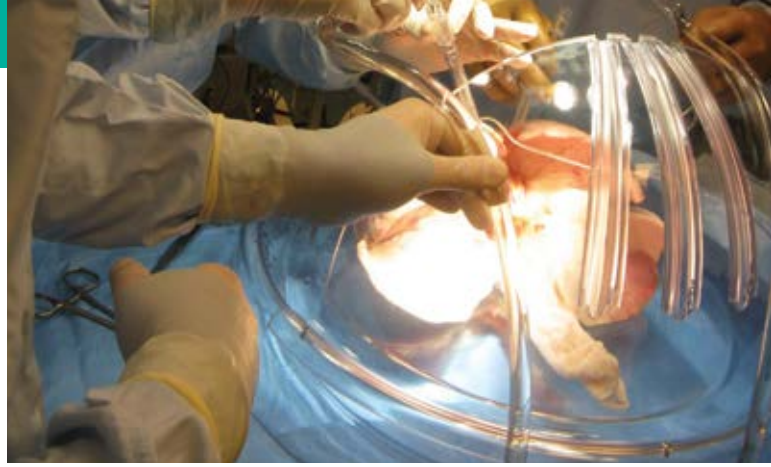
Most people don't realize that Canada has led the way in lung transplants. Lung transplantation is a very important Canadian success story and Cystic Fibrosis Canada has contributed tremendously in supporting this achievement and helping to bring innovations to fruition with the highest per capita rate of lung transplantation. Now more lungs are available more safely to more patients right here in Canada.

Research dollars from Cystic Fibrosis Canada have gone towards improving transplantation processes and developing gene therapy to make major strides in the field. The Ex Vivo Lung Perfusion System (ex vivo means outside the body) has contributed to improve survival rates for CF patients, and they are living the longest of any lung transplant patient.

What has been the greatest advancement in lung transplants over the years?

Firstly, that it was possible. People tried 44 times around the world to successfully transplant lungs and none of those patients survived. As research progressed, lung transplantation became safer and less of a high risk operation.

Secondly, the Toronto Ex Vivo Lung Perfusion System (EVLP) completely transformed lung transplantation. This system allows the lungs to remain outside the body for a much longer time, giving doctors the ability to determine how lungs will function even before they are transplanted.



Lungs in the Ex Vivo Lung Perfusion System

How is gene therapy being used to modify the lungs to better handle the stresses of lung transplant?

Using gene therapy in lung transplantation helps to repair the lungs in the EVLP system. The current system preserves lungs at normal body temperature, with the lungs kept outside the body in a protective dome. The EVLP system continuously pumps a bloodless solution of oxygen, proteins and nutrients into injured donor lungs, providing optimal lung protective conditions.

We are currently working on improving the gene therapy technique that may help further prevent some of the inflammation responses and the organ rejection responses in patients.

Where do you see lung transplantation going in the future?

We continue to develop strategies in using gene therapy to modify the lungs to better handle the stresses of transplant, as well as testing stem cells for repairing the organs. We hope to engineer organs that will function better and last longer after transplantation. I envision creating organ repair centres where organs would be diagnosed and specifically treated to "optimize" them before transplant. Ultimately we hope to be able to build new lungs.

DR. ELIZABETH TULLIS AWARDED CYSTIC FIBROSIS CANADA'S FIRST CHAIR IN ADULT CYSTIC FIBROSIS RESEARCH

Canadians with cystic fibrosis (CF) are living longer, healthier lives thanks to innovative research on new therapies and advances in patient care. Today, nearly 60 percent of Canadians with CF are adults and the median age of survival continues to increase. In light of this exciting progress, it is becoming increasingly important to continue to focus on CF research and to address the unique challenges in care faced by adult patients and their healthcare teams.

Dr. Elizabeth Tullis

CYSTIC FIBROSIS CANADA'S FIRST-EVER CHAIR IN ADULT CYSTIC FIBROSIS RESEARCH

To address these challenges, Cystic Fibrosis Canada has partnered with St. Michael's Hospital Foundation to create the first-ever Chair in Adult Cystic Fibrosis Research at the University of Toronto. Through a matched funding program, $1 million will be invested over the next five years, including $501,000 from Cystic Fibrosis Canada's donors, with the ultimate goal of improving the lives of adults with CF. We are pleased to announce the appointment of Dr. Elizabeth Tullis to the position, effective July 2014. Dr. Tullis is the Director of the Adult CF Program at Toronto's St. Michael's Hospital. The centre, which is the largest of its kind in North America, provides multidisciplinary care to over 400 patients and is extensively involved in clinical research and healthcare training.

"I have spent 24 years caring for adults with CF and am amazed and inspired by the improvements in survival and quality of life that have occurred over this time. This is a result of meticulous patient care and application of treatments developed through research discoveries. It is an enormous privilege to be the recipient of the Cystic Fibrosis Canada Chair in Adult Cystic Fibrosis Research and I am committed to working with my colleagues across Canada to further improve outcomes for our patients."

- DR. ELIZABETH TULLIS, CHAIR IN ADULT CYSTIC FIBROSIS RESEARCH

IMPROVEMENTS IN PATIENT CARE ARE FOUNDED IN RESEARCH

The new Chair in Adult Cystic Fibrosis Research position was created to identify the key issues in adult CF care and ensure time and resources are focused on initiatives that directly impact those living with cystic fibrosis. Dr. Tullis reminds us that CF treatments have come a long way over the last few decades but that continued clinical research is fundamental to improving patient care. With this in mind, a portion of program funding will be used to directly support CF research at the clinic, including the addition of new scientists with vital skill sets to expand the expertise of the research group. The team will also harness the vast amount of data available from the Canadian and Toronto CF registries, which serve as exceptionally powerful tools to inform clinical research studies and to guide quality improvement initiatives.

BENEFITS IN PATIENT CARE

Research tells us what treatments and care practices work best for patients; the next critical step is to ensure that this information is effectively disseminated to all people with CF through the CF clinics. As the Chair in Adult Cystic Fibrosis Research, Dr. Tullis looks forward to working collaboratively with the 42 CF centres across the country in order to prioritize the needs of the healthcare teams. She will work with the expertise of Cystic Fibrosis Canada's Healthcare Advisory Council to create educational tools and practice guidelines to support clinics in improving patient outcomes and optimizing care for adults with CF.

The new Chair in Adult Cystic Fibrosis Research, offers a unique ability to build upon clinical experience to greatly impact the lives of CF patients. As the first to hold the position, Dr. Tullis is excited by the opportunities to continue first-class research in CF and to facilitate vital enhancements in the quality of care for patients across Canada.

THE GOALS OF THE NEW CHAIR IN ADULT CYSTIC FIBROSIS RESEARCH ARE TO:

- ✔ **Create CF care guidelines and develop tools to share information with front-line care providers**
- ✔ **Incorporate quality improvement initiatives in patient care in clinics**
- ✔ **Improve access to care for Canadians with CF through the use of technology**
- ✔ **Increase formal involvement of CF patients and their families in clinics**
- ✔ **Develop strategies and tools to improve patient health**
- ✔ **Use the Canadian CF Registry to guide quality improvement initiatives and clinical research in CF**

MANAGEMENT OF CYSTIC FIBROSIS

UNDERSTANDING AND OVERCOMING THE BARRIERS TO STAYING ON TREATMENT

Dr. Marilyn Macdonald, Cystic Fibrosis Canada funded-researcher

Dr. Marilyn Macdonald has been awarded a Cystic Fibrosis Canada clinical project grant for her work at Dalhousie University in the area of cystic fibrosis (CF) treatment adherence. Successful management of CF requires strict adherence to a long-term, complex therapeutic regimen that takes several hours each day. The term 'adherence' implies that a patient consistently takes a medication at the prescribed dose and frequency, and for the intended duration.

Although many patients follow their treatments carefully, others do not because they feel well; some feel their treatments are time-consuming and interfere with their social lives or work demands; yet others forget to take their medications or feel that constant treatments make them different than those around them. Unfortunately, failure to follow a prescribed regime may lead to a decline in health and increased hospital admissions. For these reasons, treatment adherence is a major concern for individuals with CF.

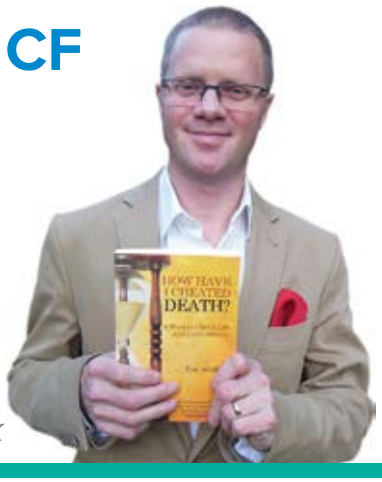
"Successful management of CF requires strict adherence to a long-term, complex therapeutic regimen"

The majority of studies to date have typically focused on issues related to treatment adherence in children and adolescents. Dr. Macdonald is interested in understanding adherence, particularly in adults with CF, in order to support improved medication adherence and contribute to better patient outcomes. The two-year study will be conducted with participants from Nova Scotia, New Brunswick, and Prince Edward Island, and will include adult CF patients, their family members, and healthcare providers. The aim of the study is to identify the primary concerns of adults with CF as they relate to taking medications and what these patients are doing to address their concerns.

An improved understanding of the barriers to medication adherence may lead to the development of important strategies to drive changes in following treatments and in how care is delivered. In the long-term, these strategies have the potential to increase the rates at which adults follow treatment and medication regimens, reduce hospital admissions, and extend survival.

MEMOIR OF A LIFE WELL LIVED WITH CF

TIM WOTTON SHARES HIS TRIUMPH OVER ADVERSITY OF DEFYING THE ODDS FOR OVER 40 YEARS



Tim Wotton, London, UK

London, England-based Tim Wotton has marked his milestone 40th birthday with the publication of his first book, *How Have I Cheated Death? A Short and Merry Life with Cystic Fibrosis*, dissecting his physical and mental battle with cystic fibrosis (CF) and his recently diagnosed type 1 diabetes.

"Reaching 40 was such a dramatic life-affirming landmark for me that I felt I needed to share my experiences and survival lessons. When I was 38, I had the epiphany that still being alive with CF was not a fluke and that I had many useful strategies and anecdotes that needed to be offered to others. Personally, I had an overriding desire to reduce the burden of carrying this horrific condition on my shoulders by opening up more," Tim explains.

By keeping a diary during the year leading up to his 40th birthday, Tim decided to embellish that chronicle into a full-blown book. The provocative title - *How have I Cheated Death?* seemed appropriate and would appeal to both CF and non-CF audiences.

Tim says of the writing process, "I had a deep desire to write profoundly about CF with candour and lack of sensationalism or pity, which is in keeping with the mindset of people with CF. As I began to delve deeper into my daily health challenges and uncover my personal demons it became obvious to me that being authentic meant bringing out my inner feelings on every facet of what I have endured to try to live a normal life."

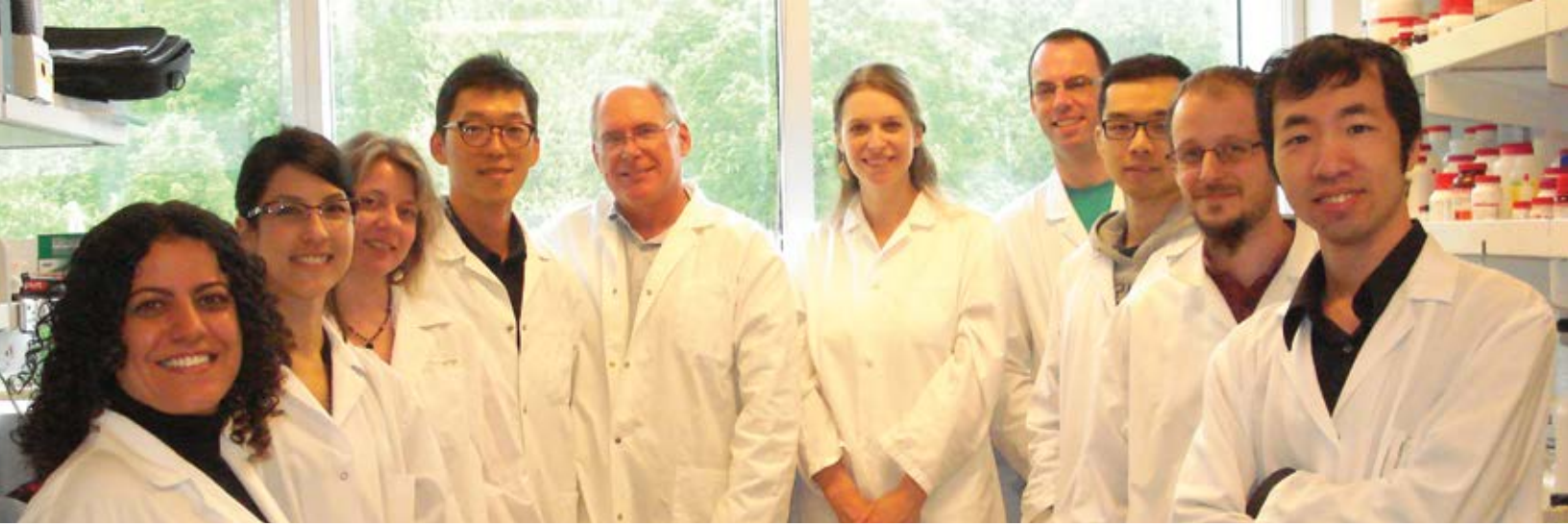
For Tim, writing "The Hardest Part" chapter about the loss of his CF friends was the toughest part of writing his book. "Many a tear was shed onto the paper as I tried to unearth the raw emotion of how it felt to lose fellow sufferers who had every right to live as long as me," says Tim.

The final book is a thought-provoking and amusing memoir, in which Tim discusses his extensive medical regime, hospital appointments, intravenous antibiotics; and shares his experiences of more universal subjects, from going to university and getting a job to the importance of sport (especially field hockey), alternative therapy, faith and positivity.

Tim also highlights the importance of family support, and talks about his marriage to his wife Katie, and their rollercoaster journey with in vitro fertilization (IVF) that led to the birth of their precious son Felix.

Tim concludes: "Having a book published and available for anyone in the world to read feels amazing, humbling and bewildering in equal measures. I am hoping to reach a global audience with this book – the CF community, sufferers and their families, should derive some hope and survival strategies from my story while wider audiences will hopefully understand CF better and appreciate what it takes to combat it on a daily basis. Judging from the feedback received so far, my memoir is making a real difference."

The book, which features an introduction by actress and long-time CF supporter Jenny Agutter, is available to buy now from Amazon (ISBN 9781849637190).



Dr. John Hanrahan (centre) with members of his lab and the Primary Airway Cell Biobank at McGill University

THE PRIMARY AIRWAY CELL BIOBANK

AN INVALUABLE RESOURCE FOR CANADIAN CF RESEARCHERS

The Primary Airway Cell Biobank (PACB), the first of its kind in Canada, was established through a collaboration between Cystic Fibrosis Canada and the CF Translational Research Centre (CFTRc) at McGill University in Montreal. Launched in 2009 by Dr. John Hanrahan, Principal Investigator, and Dr. Renaud Robert, Director, the biobank is intended today to be a nationwide resource of high-quality lung cells for Canadian cystic fibrosis (CF) researchers.

Lung cells are essential to basic and translational research in the CF field. Before an investigational new therapy is approved for use in clinical trials, its effectiveness must be demonstrated within cells at the lab bench. Cells isolated directly from CF lungs are especially valuable because they behave similarly to cells situated within the airways of patients and are, therefore, considered the “gold standard” for CF research. In most cases; however, it is not feasible for researchers to prepare these cells in the lab as the isolation process can be costly, time-consuming, and requires skilled personnel. A centralized program operated by an experienced facility is cost-effective and ensures a reliable supply of high-quality research materials.

The biobank relies on a strong trans-Canada network involving CF clinicians, surgeons and their institutions that work together with the CFTRc to coordinate tissue procurement. Importantly, patient identity is kept strictly confidential by the transplant clinic and the process does not require any additional procedures by the patient beyond those already necessary for their treatment. Following informed consent, CF lung tissue is obtained from the transplant recipient and provided by the transplant centre to the CFTRc. Cells are then prepared by trained personnel using standardized techniques and quality control measures. As a not-for-profit program, the PACB makes the cells available at cost to CF researchers across the country. These cells serve as an invaluable tool to researchers to enhance the current understanding of CF and in translational research efforts that aim to develop new therapeutic agents to fight the disease.

For more information about the PACB and its services, visit www.mcgill.ca/cftrc/facilities/primary-airway-cell-biobank-pacb.

IMPROVING CARE IN **CANADIAN CF CLINICS**

In cystic fibrosis (CF) clinics across Canada the most common barrier that healthcare workers face when providing care to their patients is having too little time and too few resources. Cystic Fibrosis Canada, in collaboration with professional medical and clinical advisors, has created the ***Health Human Resources Guidelines: Minimum Staffing Standards*** with the goal to provide the best care possible to Canadians with CF and their families.

In an effort to ensure that all Canadian CF clinics are able to operate at levels of the highest quality, with adequate staff available to the population being served, regardless of city or province, the new guidelines define specifically what amounts of time should be allocated for each discipline of CF clinical care. The guidelines also provide a summary of all the roles involved with CF care, reinforcing how healthcare professionals work together to provide comprehensive multidisciplinary care that is consistent throughout the country.

Sophia Schulz

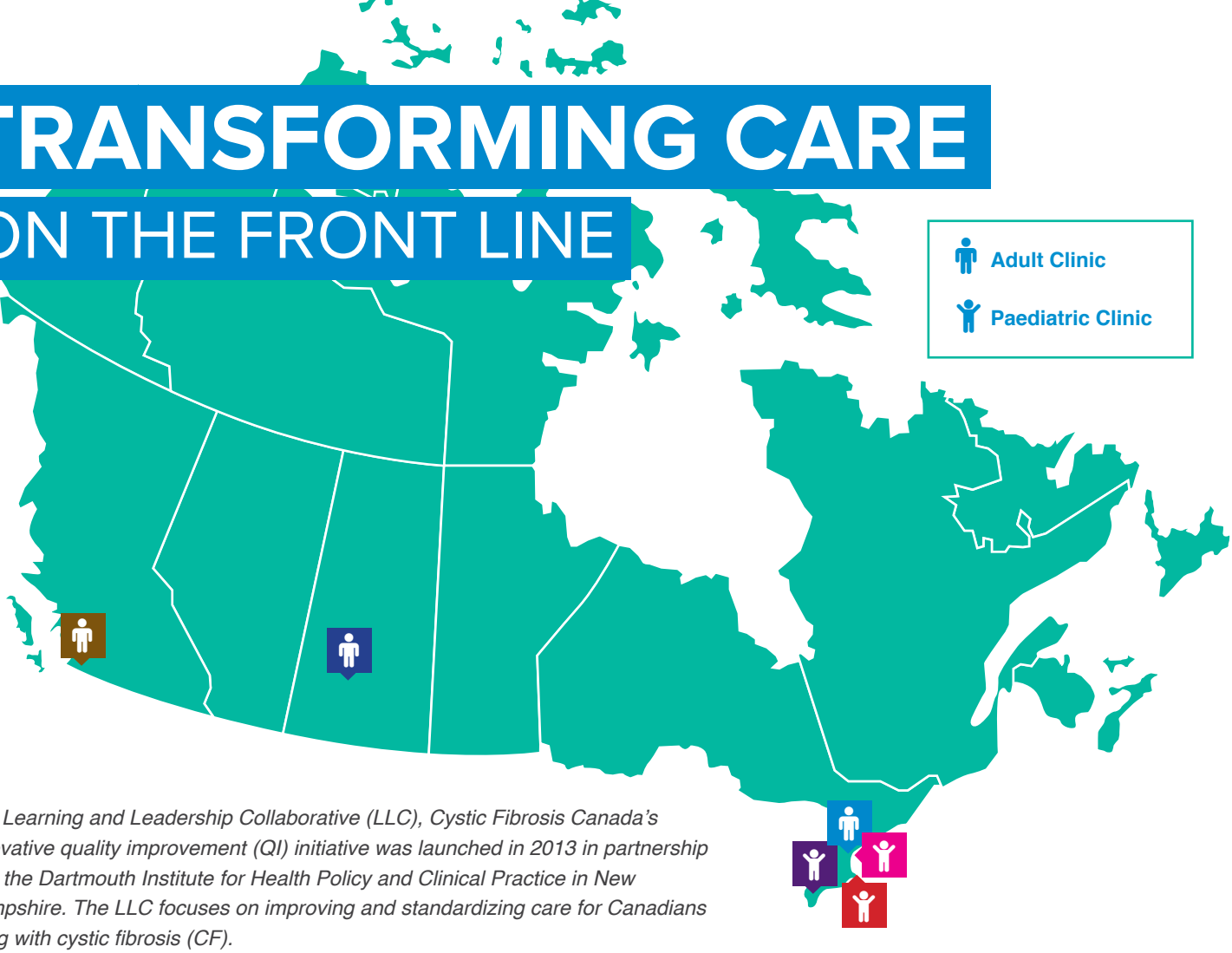
"Patients will directly benefit from these guidelines with improved access to multidisciplinary health team members, which will translate into fewer gaps in care," says Dr. Linda Pedder, Director of the Paediatric Cystic Fibrosis Clinic at McMaster Children's Hospital. "At the clinic level, the guidelines provide metrics to work toward obtaining minimum staffing levels and space requirements for patients."

The guidelines have been incorporated into the Cystic Fibrosis Canada Accreditation Site Visit program, so that there are clear benchmarks when allocating personnel resources to the CF clinics within their institutions.

"Including these standards in the Accreditation Site Visits allows for staffing deficiencies to be addressed with hospital administrators. The guidelines also promote transparency amongst all clinics in Canada," says Dr. Pedder.

As a peer-reviewed document – with involvement from all 42 CF clinics in Canada – the *Health Human Resources Guidelines* is an exclusively Canadian document and the first of its kind that has been endorsed for implementation across the country.

TRANSFORMING CARE
ON THE FRONT LINE



The Learning and Leadership Collaborative (LLC), Cystic Fibrosis Canada's innovative quality improvement (QI) initiative was launched in 2013 in partnership with the Dartmouth Institute for Health Policy and Clinical Practice in New Hampshire. The LLC focuses on improving and standardizing care for Canadians living with cystic fibrosis (CF).

Currently there are six CF clinics across the country working with Cystic Fibrosis Canada in the LLC to improve care for their patients.

The Hospital for Sick Children, Toronto
Goal: Improve BMI percentile of patients

St. Michael's Hospital, Toronto
Goals:
- ✔ Increase the prescription rate of pulmonary medications
- ✔ Improve clinic flow and reduce overall waiting time
- ✔ Improve access to mental health care

Windsor Regional Hospital, Windsor
Goal: Improve adherence to airway clearance therapy

Royal University Hospital, Saskatoon
Goal: Improve patient accessibility to physician and nurse

McMaster Children's Hospital, Hamilton
Goal: Improve number of patients completing annual oral glucose tolerance testing (OGTT)

St. Paul's Hospital, Vancouver
Goal: Reduce waiting time of clinic visits

If you are a clinician, healthcare professional or member of the CF community that would be interested in participating in the LLC program, please contact Ian McIntosh, Program Director, Healthcare, at Cystic Fibrosis Canada to apply.

NEW RESEARCH SHOWS PROMISE TO IMPROVE LUNG FUNCTION IN CF PATIENTS

Canada Research Chair in X-ray imaging Dr. Dean Chapman, graduate student Jay Luan, University of Saskatchewan Assistant Professor and Cystic Fibrosis Canada Researcher Dr. Juan Ianowski

Cystic Fibrosis Canada-funded researchers at the Canadian Light Source synchrotron at the University of Saskatchewan have developed a new imaging technique that reveals a previously unknown component of the immune system in the lungs showing promising insights that could benefit cystic fibrosis (CF) patients.

The discovery suggests that by helping this component function better – for example, through early and sustained use of antibiotics – it may be possible to improve lung function in CF patients. However, principal researcher Dr. Juan Ianowski cautions that this point is speculative so far and patients shouldn't try it on their own.

"You inhale about 1,000 litres of air every day," Dr. Ianowski says. "Every time you inhale, there are particles and there are bacteria, and you don't cough. You don't have a fever. Nothing happens to you. You aren't aware of it, but you're fighting these pathogens."

The bodies of patients with cystic fibrosis don't have this ability to fight the bacteria. Using live animal tissue, the researchers have found a way to look further into the airway surface liquid (ASL) that rids the body of those everyday irritants.

Over the last decade, scientists have hypothesized that in cystic fibrosis, a mutation to a gene called *CFTR* interferes with the production of ASL. The lungs of people with the mutation – as well as test animals such as pigs, ferrets and mice – all fail to respond to inhaled irritants and other threats that would prompt strong ASL production in healthy individuals. Also, the ASL that is produced has poor bactericidal properties.

Until now, it has never been possible to answer two central questions: do bacteria trigger ASL secretion in the airways, and what is the role of *CFTR* in the process? The research team came up with a novel synchrotron-based method that unlocked the answer.

The research supports a growing body of evidence that this inability to clear microbes from the lungs is at the root of airway disease in cystic fibrosis patients and may be the missing link in helping them to start breathing a little easier.

UNDERSTANDING INTERACTIONS OF BACTERIA IN CF LUNGS

Dr. Michael Surette

Q&A WITH DR. MICHAEL SURETTE

Dr. Michael Surette is a Cystic Fibrosis Canada-funded researcher, Professor and Research Chair in Interdisciplinary Microbiome Research at the Farncombe Family Digestive Health Research Institute, Faculty of Health Sciences, McMaster University.

How did you become involved in cystic fibrosis (CF) research and what do you enjoy most about your work?

My initial foray into CF microbiology came about largely through having the opportunity to work with Dr. Harvey Rabin (head of the Calgary Adult CF Clinic) when I was an Assistant Professor at the University of Calgary. Harvey educated me about CF and the unanswered questions about the microbiology of airway infections. It was clear there was a research problem for us to investigate.

From the very beginning, our research in CF has been a team effort and we worked closely with the clinical team. It has been a great pleasure to work with everyone, and all of them have contributed to our research. Of course the patients have also been very supportive and it has been very fulfilling getting to know and work with them. They have been such an inspiration to the lab and they are the reason we do this work.

Why is your research important for people with cystic fibrosis?

Pulmonary exacerbations and the irreversible lung damage they cause are responsible for most of the loss of lung function in patients. These are driven primarily by bacterial infections and the pathogens we are all familiar with (such as *Pseudomonas, Staphylococcus* and *Burkholderia*). But it was clear from the data that Dr. Rabin had collected over the years and from his clinical observations that these organisms did not explain all of the exacerbations.

Our CF research is simply to try to understand what causes exacerbations in each patient. This has led us to identify new pathogens (sometimes quite common) that have been previously missed, and has allowed for more effective treatment in some patients. Over the last decade or so, we and others have changed the view of CF microbiology from the lungs being infected by one or two of the traditional CF pathogens, to the understanding that the lower lungs are, in fact, colonized by many different species of bacteria. How these different bacteria interact to promote exacerbations is one of our main areas of CF research.

In the case of CF patients, bacterial infections can cause irreversible damage to the lungs, ultimately leading to death. Can you describe how your research is committed to finding ways to control lung infection in CF patients where the most dramatic lung damage occurs?

Effective antibiotic treatment and airway clearance (which also reduces bacterial burden in the airways) are responsible for most of the improvements in CF disease management over the last few decades. Treating the primary pathogens is still critical; however, when other pathogens are involved, we can use antibiotics more effectively against them. Similarly, there are cases where antibiotics directed against bacteria other than the usual suspects may show great benefit.

How is your research advancing treatment options and enhancing the quality of life for CF patients?

The goal of our research is to have a personalized medicine approach to managing infectious exacerbations in CF patients – using the most effective therapy for each patient to reduce the frequency and duration of these events.

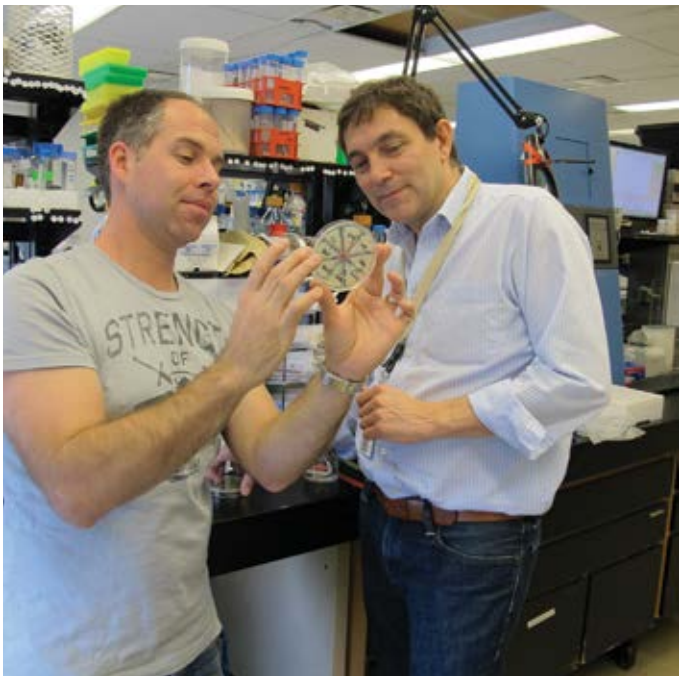
What are your recent findings to share with the CF community? What are the next steps in your current research in developing new therapies?

In recent years we have seen very dramatic changes in DNA sequencing and other technologies that should translate into more accurate and comprehensive microbiology in CF. However there are limitations and challenges to realizing this. One need is a better understanding of the spectrum of organisms that cause exacerbations. This would allow us to use currently available antibiotics more effectively. Another area of interest is to study interactions between bacteria to control infections and predict susceptibilities to CF pathogens.

Dr. Surette and Dr. Steve Bernier work in lab

What is needed to help Canadian researchers find a cure for cystic fibrosis?

Basic research into the fundamental defects in the *CFTR* gene has led to the new classes of drugs (correctors and potentiators) that are showing dramatic results in some groups of patients. At least in the foreseeable future, this will be the closest to a cure. However, these drugs will not eliminate the complications of CF. Airway infections will continue to be an issue for many CF patients. These new drugs will not be effective for patients with less common *CFTR* mutations. Older patients will already have significant airway disease and will be vulnerable to infections, and perhaps a new spectrum of pathogens will emerge in these newly treated patient populations. These are exciting times, but there is still a need for basic research in all aspects of CF disease.



MY TRANSPLANT STORY

Sean Edwards (double-lung transplant recipient, 2011)

BY SEAN EDWARDS

I was born with cystic fibrosis (CF). I was first diagnosed when I was a few weeks old when the doctor discovered I had a bowel obstruction. A sweat test was performed and it came back positive for cystic fibrosis. My parents were told that it was highly unlikely that I would live past my 13th birthday, that was back in 1976.

Growing up I lived a pretty normal childhood, taking my daily medications, and hour of therapy that included my parents clapping my chest to free up the thick mucus in my lungs. I was never really sick until I was 17 and ended up with pneumonia, spending 2 weeks at McMaster University Hospital, where I also attended the CF clinic.

After high school, my lung function was slowly declining. At my next clinic appointment I was informed that my lung function had dropped significantly and that I should consider a lung transplant. This was all very scary for me as I had not heard of this option at the time.

In December 2008, I caught a bad cold and was waking up in the mornings with extreme headaches that left me short of breath. I spent two weeks at St. Michael's Hospital with a lung infection and had to be put on oxygen. Home oxygen was arranged and I went home for Christmas, only to be readmitted in January. I had a hard decision to make – did I want to go through with a double-lung transplant?

The doctors had explained that I may get five years before rejection would happen, did I really want to go through all of that for just an extra five years? After researching and talking to many others that had lived 10-20 or more years post-transplant, I decided my answer was yes!

I was 33 at the time and was still working full-time at a very physical job. I couldn't go a minute without wearing an oxygen mask, and I only had a lung function of 25 percent. I was a true fighter and I wasn't letting anything stop my daily routine. I was then listed for a lung transplant and took a year leave from my job.

I waited five and a half months until I got the call, two days before my 35th birthday. Everything went well and I was back to work three months post-transplant. I am now almost 39 and almost 4 years post-transplant. I have had no problems, I am very lucky.

Along the road I have lost many friends to CF, either before they got their transplant or after. With so much progress in CF research, it has let people like me live a longer life, and hopefully one day CF will not be known as a fatal disease.

An organ donor saved my life. Organ donation can help save many lives; consider being a donor. To learn more about transplantation, visit www.cysticfibrosis.ca/transplantation/.

MADI VANSTONE MAKES CHANGE HAPPEN

YOUNG CF PATIENT WINS LONG BATTLE FOR LIFE-CHANGING DRUG KALYDECO®

For 12-year-old cystic fibrosis (CF) patient Madi Vanstone, not having to worry where her next KALYDECO® treatment will come from is a dream come true. The past year has been a roller coaster ride for Madi and her family, but they never stopped fighting to have the drug covered by the province of Ontario.

Madi and her mom Beth began advocating for KALYDECO® in September, 2013 – including visits to Queen's Park for meetings with Ontario Premier Kathleen Wynne and then Health Minister Deb Matthews. On one trip to Queen's Park, Madi was accompanied by several of her peers in Grade 6, 7 and 8 from Sir William Osler Public School who helped in championing Madi's cause.

"We contacted the Ministry of Health a number of times to bring attention to the need for this life-changing drug. We also circulated petitions everywhere we could and gathered thousands of signatures. My classmates joined me and all wrote letters to the Minister of Health in Ontario, explaining why it was important to fund KALYDECO®," says Madi.

At the local level, Beth and Madi were supported by their Member of Provincial Parliament who brought up the subject of KALYDECO® at Question Period in the Legislative Assembly of Ontario.

Madi's hard work paid off and in June 2014, the Ontario Health Minister announced that KALYDECO® would be covered for CF patients with the G551D mutation through its Exceptional Access Program.

Ontario PC Health Critic Christine Elliott, Beth Vanstone, Madi Vanstone, and Simcoe-Grey MPP Jim Wilson at Queen's Park

"I was so happy when I found out that KALYDECO® would be funded, I felt a lot of pressure off my shoulders and knew it would help a lot of people," says Madi. "Speaking up, even though I was afraid at times was the right thing to do and never giving up really paid off. Nobody said it would be easy, but anything worth having is worth fighting for."

Since starting treatment on KALYDECO®, Madi has seen a significant improvement in her lung function. KALYDECO® is now covered in Alberta, Saskatchewan, Manitoba, Ontario and Nova Scotia for patients ages six and above with the G551D gene mutation.

"Madi's courage has helped dozens of others across Canada access this life-changing medicine," says Ken Chan, Cystic Fibrosis Canada's Vice President of Advocacy, Research and Healthcare. "Madi is a champion in the fight against cystic fibrosis and our organization is proud to have recognized her efforts publicly at her school."

For the most current updates on Cystic Fibrosis Canada's advocacy efforts, visit www.cysticfibrosis.ca/advocacy.

BRINGING CF NEWBORN SCREENING TO NEWFOUNDLAND AND LABRADOR

John Bennett and son John, St. John's, Newfoundland and Labrador

Q&A WITH CYSTIC FIBROSIS CANADA PROVINCIAL ADVOCATE JOHN BENNETT

Early diagnosis for cystic fibrosis (CF) through newborn screening allows for immediate intervention and treatment. Without newborn screening, irreversible damage to the lungs and digestive system may occur. Ultimately, CF newborn screening can lead to longer, healthier lives.

John Bennett is the father of a four-year old son who lives with cystic fibrosis. John has steadfastly lobbied for the disease to be added to Newfoundland and Labrador's Newborn Screening Program since June 2012.

Newfoundland and Labrador announced in its budget in March 2014, that the province would begin to screen newborn babies for cystic fibrosis.

What actions did you take to lobby for CF newborn screening in the province?

Every avenue you can think of – writing letters to the Health Minister and Premier; reaching out to the media and using social media as a platform to get our message out. The Céline Dion campaign really helped raise awareness too. At the end of the day it was the personal stories that really hit home.

What was your experience like with your son John, before he was diagnosed with cystic fibrosis?

My son, John, was diagnosed with cystic fibrosis when he was two-and-a-half months old. He struggled with weight gain in his first months of life while doctors started testing him to find the cause. We were fortunate enough to have a paediatrician press for cystic fibrosis testing. When the test came back positive, treatment was started right away. Within a week, John's condition improved. This was a time of uncertainty and fear for my family.

How did you feel when you heard the news that the province would start screening newborns for cystic fibrosis?

I was home with John that day, sitting on the computer catching up on social media and watching the budget announcement on TV. I'm not an emotional person, but I was quite emotional when the announcement was made. I'm really glad the government of Newfoundland and Labrador stepped up to the plate and listened to our concerns and included newborn screening in the budget. Countless people put in so much hard work and seeing it come to fruition, knowing that newborn screening will help so many families not have to go through what we had to go through was so rewarding.

Cystic Fibrosis Canada continues to advocate and work with decision-makers in Quebec and Prince Edward Island (PEI) — the only jurisdictions that have not committed to screening newborn babies for cystic fibrosis. Once both provinces agree to implement CF newborn screening, Canada will join the United States, Australia and the U.K. in offering the program as a universal standard of care. Raise your voice for newborn screening in PEI by adding your name to Cystic Fibrosis Canada's online petition at www.cysticfibrosis.ca/advocacy.

I DON'T HAVE CF, BUT I *Live* WITH CF

BY STEFANIE CALI

This year marks the 25th anniversary of the discovery of the *cystic fibrosis (CF)* gene. The last 25 years have brought much progress and hope in terms of new effective treatments and an extension of the average life expectancy for Canadians living with cystic fibrosis.

One of those Canadians is my husband, Erick Bauer. When he was diagnosed 25 years ago, he, like other CF patients was not expected to live a full and complete life. Today, Erick, is 29 years old and like fellow CFers he has had the opportunity to realize many goals: he has graduated university, found a career he is passionate about, started an MBA program, purchased a home and got married.

There are certainly reasons to be optimistic as we have come so far over the last few decades. However, despite these developments, it is hard to ignore the fear, anxiety and angst associated with living and loving someone who has CF.

Although I am not one of those 4,000 Canadians living with the disease, I often say I don't *live* with CF but I *live* with CF.

Two years ago I married Erick. By doing so I gained a loving husband, a lifelong friend, and the burden of a terrible disease – cystic fibrosis.

Despite our best efforts to share a relatively normal life together, the disease has managed to invade every facet of our relationship. Everything we do is affected by CF. From the smallest decisions to the most important life choices, the disease is always front and centre, rearing its ugly head; a constant reminder that our life together is anything but normal. In fact, this past summer was spent dealing with a hospital admission that lasted for more than two months.

Many people tell me that I am a strong woman, an inspiration, a fighter. The truth is that most of the time I feel like a fraud.

The last 18 months have been the scariest months of my life. I've cried, I've worried, I've doubted, and I've second-guessed. I always thought that we would be able to deal with any circumstance CF might throw our way. I did research, I asked questions, I became informed. But despite my best efforts, I realize now that nothing could have prepared me for the realities of this terrible disease.

Erick Bauer and Stefanie Cali

The challenges have been hard to bear. Shortly after our wedding, Erick's health took a sudden and drastic turn for the worse. What scared me wasn't the fact that it happened, but that it happened so quickly. The first year of our marriage (also known as the honeymoon stage) was spent managing frequent hospital visits and specialist appointments and struggling to find ways to bring Erick's health back up to par. The second year of our marriage was spent managing more medical setbacks, enduring the side effects of medications and navigating the logistics of lengthy hospital admissions.

Needless to say, there has been little time for romance.

While I don't necessarily believe in fate or destiny, I do believe that we have little to no control over who we fall in love with. CF has stolen my ability to live a predictable life, which is a difficult reality for an A-type personality who relishes control and structure. However, it has also been a lesson in self-control and acceptance. The disease has forced me to shift my perspective and re-evaluate what is truly important in life. Instead of focusing on the unpredictability of living with CF, I strive to enjoy each moment that Erick and I have together – the good and the bad.

Cystic fibrosis has forced me to reframe traditional notions of achievement. As Erick always says, sometimes success means going from failure to failure with a positive attitude and a smile on your face. It has taught me to slow down and to enjoy the journey.

Regardless, this is my life. This is my reality. And no matter what may happen next, I know that Erick and I are in this battle together.

And so we continue to fight… together. Waiting for a day when CF stands for *cure found*. A day when both Erick and I can finally breathe easy… together.

You can follow our journey on Facebook by searching Surviving Cystic Fibrosis.

COMPANIES THAT PAY IT FORWARD: **SPOTLIGHT ON ELLISDON**

EllisDon has consistently been ranked as one of Canada's top employers with a corporate culture that encourages innovation, excellence and giving back to the communities where they work. EllisDon employees gave back to Cystic Fibrosis Canada this spring by participating in the Great Strides™ walk.

Through corporate matching donations and employee participation, EllisDon was able to contribute more than $30,000 in their first year of taking part in the walk on a national level.

Employees from seven locations across the country banded together and helped contribute vital funds towards finding a cure for cystic fibrosis (CF).

"We're closer than ever to a future without cystic fibrosis, but we can't stop now," says EllisDon's Vice-President of Atlantic Canada, Brian Strecko, whose son Stefan, is living with cystic fibrosis. "We strive to build a dynamic and meaningful working environment for employees to get involved in their communities, the Great Strides™ walk is a great avenue for us to give back."

EllisDon is a company that understands the remarkable progress that has been made since the discovery of the gene responsible for cystic fibrosis; and knows that now is – more than ever – a critical time to invest in a cure for this devastating disease. Thanks to the employees at EllisDon, an incredible contribution has been made to vital CF research and care and towards a future freed from cystic fibrosis.

Front row LR: Stephen McPhee, Brian Strecko, "Tusket", Tom Falkenham, Stefan Strecko, Cindy Strecko, Krista Mason; Back row LR: Camden Zakrevsky, Danielle Barnaby

"Cystic fibrosis is a very personal disease for my family. We have committed to supporting Cystic Fibrosis Canada's first-ever Chair in Adult Cystic Fibrosis Research. We want to ensure people living with cystic fibrosis have the care and support they need to live longer and healthier lives. We want to help in the fight against CF."

- Laura Arrell

BRINGING HOPE TO CANADA'S CF COMMUNITY

Matthew McCallum

"In 2002, my son who was barely 36 hours old had emergency bowel surgery. That same day we were told this was a complication of cystic fibrosis, a fatal genetic lung disease that also affects the digestive system. My family was in shock. We had not heard of CF until that day. Then the surgeon who gave us the diagnosis told us that there was also hope because a strong organization, Cystic Fibrosis Canada, was dedicated to researching for a cure or control. For the last 12 years, my family including my son have volunteered, donated and fundraised for Cystic Fibrosis Canada. We have witnessed extraordinary progress. Now my family is confident that soon CF will no longer be the number one genetic killer of children and young adults. We are confident that our son and all other children diagnosed with cystic fibrosis will be able to grow up to live long and full lives."

- Lovisa McCallum

"The discovery of the CF gene in 1989 changed our family's life. For the first time there was real hope that there might be an eventual cure. Hope is vital to live a positive, productive life. Our daughter, Eva Markvoort, was born in 1984 and was diagnosed with CF one year later. From a young age Eva worked to increase awareness of CF, and to raise money for CF research. Before she died, she championed support for fellow CF patients through social networking when blogging was in its infancy, and she touched the lives of thousands of people around the world through the documentary film '65_redroses'. She charged us with carrying on her cause. Eva's legacy has inspired us, and many others to raise almost $2 million dollars for CF since her death in 2010. We continue to donate to help to fund the research that is so necessary for ongoing breakthroughs in CF treatment and for providing hope for CF patients and their families."

- Janet Brine and Bill Markvoort

"My son, Michael, is 24-years-old and has cystic fibrosis. He underwent a double-lung transplant in 2008 and because of the great transplant care he received, is doing really well. Every year, since 2000, I have organized an industry golf tournament, attended the Great Strides™ walk and helped to organize the O'Ryan Project Golf Tournament to help raise money for CF research and care. I believe it is extremely important to support the great work of Cystic Fibrosis Canada, since it is helping to improve the lives of Canadians living with CF."

- Glen Davis

Duncan Gillespie (LSN Co-founder) and the late Eva Markvoort

FUNDRAISER HITS ONE MILLION DOLLAR MARK FOR CYSTIC FIBROSIS

Q&A WITH LAWN SUMMER NIGHTS BRAINCHILD DUNCAN GILLESPIE

Lawn Summer Nights (LSN) started only six years ago in Vancouver, inspired by cystic fibrosis (CF) fighter Eva Markvoort; a passionate advocate for organ donation who provided hope and inspiration to many others who suffered from the disease by connecting with them online. Eva lost her courageous battle with cystic fibrosis in 2010, but her legacy lives on through the Lawn Summer Nights events to help those living with cystic fibrosis.

Taking place in seven cities across the country – Victoria, Vancouver, Calgary, Ottawa, Toronto, London and Halifax, the events raised over $435,000 in 2014. Lawn Summer Nights has now passed the million dollar mark for total funds raised to date for Cystic Fibrosis Canada since the event began in 2009.

How did you come up with the concept for Lawn Summer Nights?

It all started in Sydney, Australia, with fellow co-founders Andrew and Graham Dalik. Andrew and I had been living in Sydney for two years, and near the end of our stay we had some friends come to visit. One sunny day we all headed to the Manly Bowls Club for some barefoot bowls – a more casual approach to the game, which is much more popular among the younger demographic in Australia. It was a great way for our friends from home and our friends from Sydney to meet and get to know one another.

After a great afternoon on the greens, we talked about bringing the idea of casual bowls back to Vancouver. We knew there were a handful of clubs in Vancouver that often sat empty. We thought about holding an event as a way to gather with old friends and new ones, just as we had done in Sydney, but the idea was still missing something.

One of my friends who was visiting, Philip Lyall, had brought a rough cut of his latest documentary titled *65_Redroses*. We all gathered in the living room and watched the amazing story of our friend Eva Markvoort, as she battled with cystic fibrosis and eventually received a double-lung transplant. As soon as the film ended, the idea was clear – we'd make the event a fundraiser for cystic fibrosis.

What do you think has made the events so successful?

Lawn Summer Nights is definitely a unique event – you don't find many other lawn bowling fundraisers out there, especially in Canada. What really makes it successful is the level of engagement from everyone involved. From the very first year we've strived to make it a fun event that people in their 20s and 30s would want to take part in, even if they didn't have a previous connection to CF. Over the four weeks of the event they're able to hear more about the cause and reason behind the fundraiser, then they get involved in fundraising and spreading awareness themselves.

The power of the event comes from the peer-to-peer connection and motivation within the Lawn Summer Nights community. One team might decide to hold a car wash as a fundraiser, and the next thing you know five other teams are doing their own creative fundraising – it's contagious. The participants are the ones who make this event what it is.

Are there plans to further expand the events?

In 2014, we launched events in Calgary and Halifax, adding to Vancouver, Toronto, Victoria, Ottawa and London for a total of seven cities across the country. Over the next few months, our Board will definitely be looking at expansion for future years, but how that expansion will look is yet to be decided.

We've had amazing support from our sponsors, who are keen to grow with us, which is great. But the event is almost entirely volunteer run, including nationally at our Board level, as well as the organizing teams in each city. As we grow, we need to make sure we can continue to deliver a great event experience for everyone involved. Given our focus on engaging young professionals in the cause, some of the remaining larger Canadian cities would be a likely next step.

What has been the greatest challenge for Lawn Summer Nights?

As with any event, there are always a few challenges to overcome. We're so lucky to have such dedicated volunteers; without them, I'm sure we'd have a lot more challenges.

I think the biggest challenge at the moment is ensuring the event can continue to grow and thrive into the future, so that's where a lot of our focus is currently. Legacy is one of our four pillars (along with Fun, Fundraising and Awareness), which speaks to the event being part of Eva Markvoort's legacy, but also the importance of making it sustainable in the long term. Since the event relies so heavily on volunteers, we need to make sure they're happy and stay engaged. We've also been looking for new volunteers to get involved, and eventually lead this into the future.

LR: Tara Clark, Duncan Gillespie, Felicity Clark, Dave Robinson, Morgan McDonald (Team: Blawndie – Heart of Grass)

What have you learned from organizing Lawn Summer nights over the last six years?

More than I could have ever imagined! At the end of the day, we've managed to collectively launch and grow an organization – which now consists of 100+ volunteers, and has raised over $1,000,000. It's no different than starting a successful company, our focus just happens to be 100 percent charitable. I can't even begin to list the things we've learned along the way, but I think the most valuable lesson is seeing the potential of an engaged community.

For more information about Lawn Summer Nights, visit www.lawnsummernights.com.

LSN Toronto, Team: Bros of Torlawnto


LSN Halifax: Thomas Falkenham, Christine Campbell, Vicki Jeha, Jeff Doehler, Stefan Streko

LSN Toronto final night!


LSN Toronto, Team: Drinks Before Dinner


LSN Halifax: Chris Gray, Emily Savage, Payton Hollis, Lauren Matthews


LSN Victoria, Team: Working Grass Heroes

LSN London organizing committee during Week 3 (white night)

LSN Halifax: Nancy Webb, Marsalie MacKenzie, John Nellan, Erin Nowe, Jeremy Arsenault, Erin DiCarlo, Jennifer Power, Hali Sampson

LSN Ottawa: Steve Hu, Josh Frenkel, Mike Novacaska, Heruka Kumararatne

LSN Toronto, Team: Yacht Bowlers

LSN Toronto, Team: ENABOWLERS

LSN Vancouver, Team: Lawn Awkward Pauses

LSN Vancouver, Team: Troop Beverlawn Hills

LSN Toronto: David Tran

LR: Ian F. McClure; Doug and Donna Summerhayes - thank Kin Canada for 50 years of support

CELEBRATING 50 YEARS OF PARTNERSHIP

KIN CANADA AND CYSTIC FIBROSIS CANADA — TOGETHER IN THE FIGHT

Kin Canada is Cystic Fibrosis Canada's longest standing partner whose continued commitment has made a difference in the lives of Canadians with cystic fibrosis (CF). Over the past 50 years, there have been many exciting advancements in ground breaking CF research and care. These milestones would not have been possible without the dedicated and unwavering support from Kinsmen and Kinettes around the country.

A casual conversation between Dr. Crozier, then Director of the cystic fibrosis clinic at the Hospital for Sick Children, and Kinsman Bill Skelly, in 1964 initiated the partnership between Kin Canada and Cystic Fibrosis Canada. The partnership was eventually cemented by Kinsman Ian F. McClure, who dedicated 20 years to making Cystic Fibrosis Canada Kin Canada's National Service Project in 1987.

Since 1964, Kin Canada has raised more than $41 million for cystic fibrosis research and patient care that has contributed to every important cystic fibrosis related discovery in Canada. Cystic Fibrosis Canada commemorated this 50-year milestone at Kin Canada's 94th National Convention in Toronto, where Doug and Donna Summerhayes, co-founders of Cystic Fibrosis Canada, were in attendance and thanked Kin Canada for their continuous devotion to the CF cause.

Kin Canada remains Cystic Fibrosis Canada's treasured partner as they continue to raise awareness and funds in support of crucial CF research and care. To learn more about our partnership with Kin Canada, visit www.cysticfibrosis.ca/our-partners/Kin-Canada.

IAN F. MCCLURE AWARD PRESENTED TO BRUCE LLOYD

A lifetime member of Kin Canada, Ian F. McClure is a pioneer in the fight against cystic fibrosis. In addition to serving as the President of Cystic Fibrosis Canada from 1976-1978, he was instrumental in developing the partnership between Kin Canada and Cystic Fibrosis Canada.

As a tribute to Ian's outstanding commitment and dedication, and in celebration of the 50-year milestone with Kin Canada, Cystic Fibrosis Canada introduced the prestigious Ian F. McClure Award. The inaugural award was presented to Bruce Lloyd by Ian F. McClure at this year's Kin Canada National Convention in recognition of Bruce's exceptional skills in coordinating and motivating groups of donors and volunteers for fundraising projects supporting Cystic Fibrosis Canada and Canadians living with cystic fibrosis.

LR: Ian F. McClure, Bruce Lloyd

2013/14 BILL SKELLY AWARD RECIPIENTS

The Bill Skelly Award is an annual program that recognizes outstanding Kin Canada events that raise funds and awareness for Cystic Fibrosis Canada. The recipients of the 2013/2014 Bill Skelly Award are:

District 1: The Kinette Club of Collingwood

District 2: The Kinette Club of Thompson

District 3: The Kinette Club of Saskatoon and District

District 4: The Kin Club of Fort Edmonton

District 5: The Kinette Club of Port Alberni

District 6: The Kin Club of Russell

District 8: The Kinsmen Club of Milton & District and the Kinette Club of Milton

Congratulations and thank you to all of the award recipients!

2014 Kin Canada National Convention

Davina Thuroo, Bruce and Mary Lloyd,
Judy and Ian F. McClure, Alice Awweh

Kin Canada presents cheque to Cystic Fibrosis Canada

Cystic Fibrosis Canada
Fibrose kystique Canada

Kin Canada
Kinsmen • Kinettes • Kin

Celebrating 50 years of Partnership
Célébrons 50 ans de partenariat

1964-2014

LR Donna and Doug Summerhayes, Mary and Bruce Lloyd,
Judy and Ian F. McClure

Ian F. McClure addresses audience

Members of Kin Canada and Cystic Fibrosis Canada

Cystic Fibrosis Canada celebrated its 50-year partnership with Kin Canada at the 2014 Kin Canada National Convention.

LR Donna and Doug Summerhayes

LR Jim Mountain, Yannick Tchania, Davina Thuroo

Ian F. and Judy McClure

SHINERAMA:

50 YEARS OF SHINING A LIGHT ON CYSTIC FIBROSIS

Shinerama is Cystic Fibrosis Canada's largest post-secondary fundraiser involving over 35,000 student volunteers from 60 Canadian universities and colleges that come together and raise funds for cystic fibrosis (CF) research and care.

This year marks Shinerama's 50th anniversary! Since 1964, Shinerama has raised nearly $25 million dollars for life-saving CF research and care through shining shoes, flipping burgers, washing cars and doing whatever it takes to raise crucial funding to fight cystic fibrosis. The support from Shinerama schools and students over the past 50 years has been instrumental to advancing the battle against this disease.

Cystic Fibrosis Canada relies on the generous support of volunteers, donors and partners in our shared mission to improve the lives of Canadians living with CF, and to ultimately find a cure or control for this devastating disease.

Visit www.shinerama.ca to fundraise or donate to Shinerama today to help breathe life into the future of Canadians who are struggling to breathe every day.

1960s: Cystic Fibrosis Canada is founded, and Shinerama hosts its 1st fundraising campaign that raises $9,318.

1970s: New high fat diets and changes to current enzyme therapy are introduced to help children with cystic fibrosis (CF) gain weight, grow and thrive.

1980s: The first-ever double-lung transplant on a person with cystic fibrosis is performed. The gene responsible for cystic fibrosis is discovered, providing researchers with a target for therapies that may cure the disease.

1990s: Researchers identify a new treatment approach for infections that is adopted as a best practice in clinical care and improve the CF mouse model, a critical animal model for testing new therapies for human use. Shinerama celebrates 30 years, with nearly $12M raised.

2000s: Eight provinces add cystic fibrosis to their newborn screening programs. Cystic Fibrosis Canada introduces new infection control policies to limit the spread of deadly bacteria. Thanks to research and care advances, 60 percent of those living with cystic fibrosis are adults.

Stephanie Duke and family

SHINERAMA CONTINUES TO INSPIRE HOPE AFTER GRADUATION

I was a frosh leader in my second year at York University's Glendon College, leading a group of students over to the corner of Yonge and Eglington in Toronto, to shine shoes for Shinerama. I only knew one person with cystic fibrosis (CF) – a high school acquaintance – and knew very little about the disease itself except that it was serious, and that it shortened the precious lives of those who lived with it.

I recall it was quite difficult to convince passerby's to let us shine their shoes on that particular day, but I felt compelled to push through it with my group so that we could make a decent contribution towards the fundraiser. Little did I know how much the efforts of my frosh group, and the efforts of all the Shinerama participants, would affect my life in the future. Fast forward 11 years, and my four-year-old daughter was diagnosed with cystic fibrosis. It was the most devastating news a parent could get; our child had a life threatening disease.

My husband (also a Shinerama alumni at Laurentian University) and I are proud parents to two beautiful and intelligent girls: Sarah, 15, and Michaela, 18. Michaela has cystic fibrosis. It has been a long journey for our family since Michaela was first diagnosed fourteen years ago. We have watched her battle this disease with incredible amounts of courage and accomplish things we never thought possible.

Because of the amazing ongoing efforts made by Shinerama and other CF fundraising programs, so many positive changes in CF research and care have been made in the past 14 years. These efforts, changes and new research mean hope for our family. Hope for Michaela's future. Hope for so many other CF patients and their families.

Thank you to all the university and college students across Canada who have participated in Shinerama in the past or who will be participating in Shinerama in the future. You have made a generous commitment to help find a cure or control for cystic fibrosis. In my eyes, you are my heroes because you are working hard to save my daughter's life and the lives of so many others.

CALLING ALL SHINERAMA STUDENTS AND ALUMNI

Shinerama
STUDENTS FIGHTING CYSTIC FIBROSIS

Cystic Fibrosis Canada would like to keep in touch with Shinerama participants and encourage them to keep in touch with each other – through the Shinerama Alumni Network.

Your connection to Shinerama and the Canadian cystic fibrosis (CF) community does not have to end after graduation. It's time to ignite your Shine spirit by joining the Shinerama Alumni Network. This new network is designed specifically for Shinerama current participants, past students and volunteers, with the opportunity to:

- Create network connections
- Develop mentor/mentee relationships
- Participate in future alumni events and reunions
- Share Shine stories and experiences
- Keep you updated on Shinerama activities and share recent successes in the fight against cystic fibrosis

Join the Shinerama Alumni Network today to see what opportunity awaits you.
www.shinerama.ca/alumni.

Vancouver, BC - University of British Columbia

St. Catharines, ON - Brock University

Kingston, ON - Queen's University

Moncton, NB - Mount Allison University

Saskatoon, SK - Saskatoon Business College

Saint John, NB - UNB Saint John

Cystic Fibrosis Canada

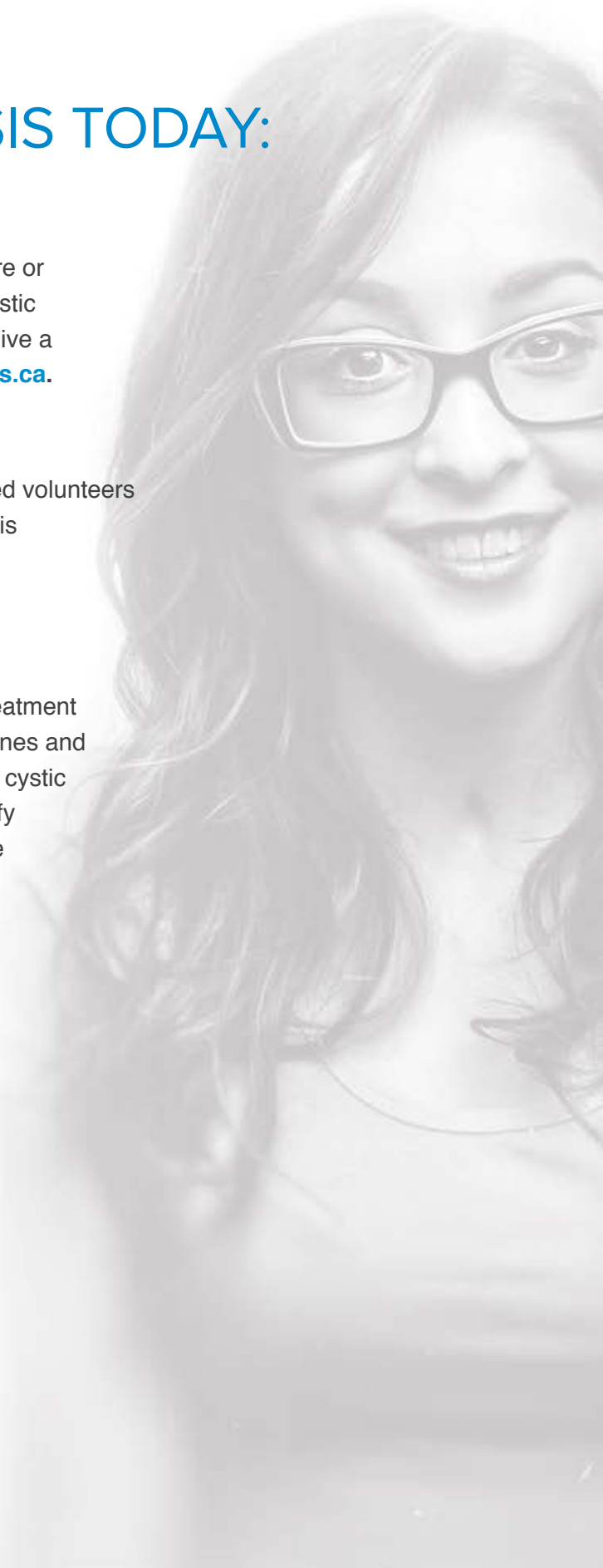
St. Catharines, ON - Brock University

Saint John, NB

Courtesy UNBSJ Shinerama campaign

Vancouver, BC - University of British Columbia

JOIN THE FIGHT
AGAINST CYSTIC FIBROSIS TODAY:



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Every dollar donated moves us one step closer to finding a cure or effective control for cystic fibrosis. When you make a gift to Cystic Fibrosis Canada you are helping Canadians with this disease live a longer and healthier life. **Donate online at www.cysticfibrosis.ca.**

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ADVOCATE

Cystic Fibrosis Canada advocates for public policies, better treatment and care, as well as equitable and affordable access to medicines and therapies that aim to enhance the quality of life for people with cystic fibrosis. We work with members of the CF community to identify issues, develop strategies, and effect change. Together we are raising the voice of Canadians with cystic fibrosis. **Find out more at www.cysticfibrosis.ca/advocacy.**

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2014-11 | Cette publication est aussi disponible en français.

Charitable registration: 10684 5100 RR0001