

FOCUS

Quarterly Newsletter
2nd Quarter, August 2013

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Newsletter

Quarterly newsletters are a wrap-up of the events and activities that have taken place over the last three months. Our monthly newsletters include upcoming events and activities at our chapter.

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Hyperlinked

This issue is interactive. Click on underlined text, icons and logos to visit websites, send emails, and move within the document.





Great Strides™

Sunday, May 26th, 2013

It was a beautiful day for the 4000+ participants who gathered at the Toronto Zoo for the ninth annual Great Strides™ walk. Our most successful walk to date, 280 teams and almost twice as many participants compared 2012 took part. Together, they raised \$710,000!

We would like to extend a huge thank you to all of our fundraisers! You are truly helping us make great strides in our mission to advocate for and cure cystic fibrosis.

We would also like to thank our generous local sponsors: BMO Capital Markets, GM Financial, Luminex, Mondelez, Metroland Media, Brita (Clorox Canada), and the Toronto Zoo.

Planning for our 10th anniversary Great Strides™ walk is already underway and we look forward to seeing you there!

Top Teams and Awards

Top Individual Fundraiser
Lovisa McCallum - \$38,800

Top Fundraising Team
SJL Zoo Crew - \$47,031

Super Strider
Nicole



Dream Team Draw
Kelly Schembri, Team Sami

2013 Team Flag Winner
Amazing Grace



Planning ahead? Next Great Strides™ walk is Sunday, May 25th, 2014.

[Click here for 2013 Event Photos](#)



Valentini Blue

Cabaret!

Guests braved the snow storm of the year to make it to the Capitol Event Theatre for Valentini Blue on Friday, February 8th. It was a sumptuous evening of glitz and glamour, featuring delectable hors d'oeuvres and big band entertainment. Tia Brazda and dance troupe The Sugar Shakers kept the night lively, while participants bid on cruises, salon packages and other select items.

This razzle-dazzle event was sponsored by Investors Group Midtown Toronto, and brought in over \$38,000. Guests could have their hair styled at the Blow Bar, capture the festivities at an accessorized photo booth, and were treated to a variety of sweets at the Candy Bar on their way out. The ambiance of the Capitol Event Theatre provided the perfect setting for this Cabaret-themed throw-back.



The Robbie International Soccer Tournament

<http://www.robbiesoccertournament.com>

The 47th annual Robbie was held at soccer fields across the city, bringing together boys and girls soccer teams from around the world. This incredibly successful event raised more than \$65,000 for Cystic Fibrosis Canada's Toronto Chapter.



Jessica Raposo from the Toronto Chapter, accepting the tournament donation on Canada Day



Kicked off by the Mini-Robbie on June 22nd & 23rd, for players aged 10 & under, the full tournament took place June 29th, 30th and July 1st. The event was attended by more than 18,000 players, parents and coaching staff, with 234 teams in 17 divisions. We are so grateful to the 400+ volunteers that gave their time and expertise to make the event run smoothly! As well, special thanks to our generous sponsors BMO and Winners.



WINNERS

Mark it in your calendar: the next Valentini is Friday, February 7th, 2014

[Click here for 2013 Event Photos](#)

Volunteer of the Year

Rachael Pinsky

On Thursday, April 25th, the Toronto Chapter held its annual volunteer appreciation night, honouring many volunteers for their contribution to chapter events in 2012/2013.

Rachael Pinsky has been working with Cystic Fibrosis Canada since high school, and joined our chapter in 2011. She was honoured as volunteer of the year. Inspired by her sister's struggle with cystic fibrosis, she said "CF is a tough disease, but I truly believe we will beat it one day, and I want to be part of that success story. No matter what happens, I can honestly say that I tried to make a difference, and that means a lot to me."

Driven by her passion for the cause, Rachael has given of her time and many skills to ensure the success of our endeavors. She was a volunteer captain for our Great Strides™ walk, looking after the walk activities and volunteers. She also took on a leadership role with our inaugural Lawn Summer Nights event, joining the planning committee, as well as helping out as needed at the events. In addition, Rachael was the Chair of our 2013 Valentini Blue event. Her leadership and vision for the event helped propel it to be the highest earning Valentini to date, at which she delivered a powerful and moving keynote to attending guests. She said her involvement with CFC has brought about even greater rewards. "I have gotten so much out of volunteering these past few years."

Rachael has left Toronto to attend the University of British Columbia Medical School, on her path to becoming a doctor. She assures us "I'll remain involved both here and in Vancouver as much as I can...if I have any free time!". We wish her all the best!



Rachael Pinsky & Laura Ferguson



The Toronto Chapter hosted a second year of the popular lawn bowling tournament at Leaside Lawn Bowling Club this July. Lawn Summer Nights is a unique fundraiser, combining style and sportsmanship, and featuring delicious food and drink and fantastic team attire.



Fashion Nod: The Yacht Bowlers were nominated best dressed for their sportingly fresh ensemble's.

This year, the 40 teams that hit the rink each Thursday through July, fundraised over \$25,000, and the event raised more than \$56,000. Across the country it has raised over \$300,000 for Cystic Fibrosis Canada since 2008. After three successful years in Vancouver, the event expanded to Toronto last summer. This year, Ottawa, London and Victoria also launched their own Lawn Summer Nights.



#4Eva: White Night at Leaside Lawn Bowling Club, with a photo of Eva Markvoort - whose struggle with CF inspired the original event in Vancouver.

Gene therapy

For the treatment of cystic fibrosis

Gene therapy uses DNA to manipulate the cells in the body in order to treat disease. In cystic fibrosis, this involves inserting a normal version of the CFTR (Cystic Fibrosis Transmembrane Conductance Regulator) gene into the airway cells, so it can produce enough of the missing/malfunctioning protein to correct the problem. When successful, this type of therapy may provide a potential cure and the final solution for cystic fibrosis. Dr. Shaf Keshavjee's team at Toronto General Hospital is working on identifying early predictors of lung injury to reduce inflammation in transplanted lungs. They hope to use gene therapy techniques to decrease the post-transplant inflammatory response. Dr. Sarah Wootton's lab at the University of Guelph hopes to develop a viral gene therapy to correct cystic fibrosis within the lung, and will test these vehicles both in cell and mouse models.



Dr. Shaf Keshavjee & Dr. Marcelo Cypel with transplant machine.

Kalydeco

This is the first drug that targets the underlying cause of cystic fibrosis. Roughly 100 Canadian CF patients have the rare genetic mutation that can be treated by this drug. Kalydeco helps improve the function of the defective gene - leading to better lung function and weight gain. Many CF patients believe that using Kalydeco will allow them to avoid lung transplantation. Because of its high cost, Kalydeco is beyond the reach of CF patients without private health insurance. Please sign the petition to support those seeking affordable and equitable access to this life changing drug: <http://chn.ge/13ZFqTN>

Newborn screening for CF in Canada

Currently, five provinces have implemented CF newborn screening: Alberta, Ontario, British Columbia, Saskatchewan, and Manitoba. In April 2013, Nova Scotia announced that it will be expanding its newborn screening program to include cystic fibrosis.

Cystic Fibrosis Canada continues to advocate for the addition of cystic fibrosis to newborn screening programs in Quebec, Newfoundland and Labrador, New Brunswick and Prince Edward Island.

You can help support our important advocacy initiatives by making a donation to Cystic Fibrosis Canada. Every dollar helps us raise the voice of Canadian CF patients as we fight for access to much needed medicines and for CF screening for newborn babies.

[Click Here for more information](#)

Name Change

We are looking for a new name for our Quarterly newsletter. You can email rtompkins@cysticfibrosis.ca or call 416.932.3900 x223 to share your suggestion.

Follow Us, Like Us

We are active on our Facebook and Twitter with cystic fibrosis news and chapter updates. Please follow, like and share!



From the Office

Staff Changes

It is with mixed emotions that we see off three talented and dedicated individuals. At the same time we are ushering in new staff to continue our chapter's success.

A Fond Farewell

Laura Ferguson

Volunteer & Communications Coordinator
Laura worked for 2 years at the Toronto Chapter. She kept the office efficient and organized, and was a fantastic liaison for our many, many volunteers.

Andrew Guzzwell

Event Coordinator
After 2 years at the Toronto Chapter, Andrew is moving on to teachers college. He has greatly assisted in the success of our third party events portfolio.

Congratulations

Shannon Carkner

Chapter Manager
In her new position as Chapter Manager, Shannon will continue her duties as Events Manager, as well as take on the responsibilities associated with Jackie's role during this transitional time period.

Welcome! Katrina Zarkel



Our new Event Coordinator is from Humber College's Fundraising and Volunteer Management Post-Grad Program, graduating previously from the University of Guelph. Her energetic personality, and ability to thrive in fast-paced environments, combined with her passion for helping others, makes her a perfect addition to our busy office.

Rebecca Tompkins



Rebecca has taken on the role of Fundraising & Communications Coordinator. She comes from working with York University, Toronto School Boards and Police on multiple projects. Her people skills and tech-savvy inclinations will help her take on the coordination of our volunteers and communications with ease.

Jackie Bloom

After 3 years as Executive director of the Toronto Chapter, Jackie Bloom has moved on to take the role of Director of Resource Development at Spinal Cord Injury Ontario. Her vision, passion and strategic direction brought us much success and pushed our chapter to new heights. We wish her the very best!



Left to right: Andrew Guzzwell, Shannon Carkner, Jessica Raposo, Jackie Bloom and Laura Ferguson at Valentini Blue this February.

Upcoming Events



FLAT • FAST • FESTIVE

OCTOBER 20, 2013

Thank you to our partners!



50 years ago...

... most children who were born with cystic fibrosis did not live long enough to start school. CF parents refused to accept this future for their children. In 1960, they joined together to create what is now Cystic Fibrosis Canada, with a mission to raise funds, awareness and connect the CF community. Thanks to the generosity of Canadian sponsors, donors and fundraisers, CFC has contributed more than \$150 million to research and advocacy, and today Canada boasts the highest median age of survival (48 years) worldwide. As research efforts continue, individuals with CF and their families and friends face the future with a renewed confidence that the cure for cystic fibrosis is in sight.

Writer

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