

Compassionate Cares

Welcome to our Fall 2015 Newsletter

This issue of Compassionate Care focuses on making connections. Whether teaming up with other families as did the Bruces and Bellinas, or finding your passion in a new sport, with Compassionate Care you will find that you are never alone.

Ted Beriau, 'Curling with Compassion'

Ted Beriau never dreamt that attending a curling fundraiser for Compassionate Care ALS in the winter of 2014 could lead to a spot on the US National Wheelchair Curling Team. Yet, just over a year later, he is deep in the world of curling, competing against international teams from Russia, Scotland, Nova Scotia, Korea and Canada.

The fiery spirit of excitement lights up Beriau's eyes as he discusses his newfound favorite sport. You'd never know that up until the November 2013 "Curling with Compassion" event he had never even attended a curling match in his life. At the event, CCALS Executive Director Ron Hoffman introduced him to the coach of the US national wheelchair curling team. The team was looking to add curlers and he asked Ted to give it a try.

Confined to a wheelchair since his ALS diagnosis in 2010, the inclusiveness of this "gentleman's sport" is a great draw for Beriau: "This is one of the only sports out there that is conducted on good sportsmanship – it is about more than just winning, and the best part is anyone can play it." The results of Beriau's introduction to curling at the 2014 Curling with

Compassion event have been new friends, new experiences...a new passion. "I love the sport because it keeps me busy from October to April, allows me to travel and I have made many new friends. At the curling competitions (called Bonspiels) you meet all kinds of people with different disabilities that confine them to a wheelchair. You form new bonds."

Curling even gave Ted the opportunity to compete with and against Olympians at the Falmouth Wheelchair Bonspiel, where he helped Team USA place second to the Russian team who were runners-up at the 2014 Sochi Olympics.



Ron Hoffman with Ted and Barbara Beriau



Marie Josée Duquette at her book launch

CCALS friend Marie Josée Duquette releases memoir

Marie Josée Duquette, whose husband Stephen Stokes passed with ALS in March of 2014, recently released a book called "A Story of a Life Too Short" about how her family experienced the disease and their interactions with Founder Ron Hoffman and CCALS. The book was originally published in her native French in Quebec and will be published in English in 2016.



Special thanks to Brad & Marianne Martin and Bill & Amy Campbell and the Dog House in Dennis (www.doghousedennis.com) for dedicating all sales on Sunday October 4, 2015 to Compassionate Care ALS.

FALMOUTH ROAD RACE: Remembering the past, running for the future

Trombly finishes twelfth in her age group

CCALS runner Megan Trombly who ran with Doug's Disciples (the running team inspired by her uncle Doug Oakley, great friend to and board member of CCALS), finished twelfth in her age group. This is no small feat, considering she turned 15 just a few days before the race which bumped her into the 15-18 year old group.

Despite being only 15, Megan is a six year veteran of the race. "My family has been participating in the Falmouth Road Race for a really long time and the first time I ran I was super nervous, she says. "My Uncle Doug asked if I would run with him, so I got to run alongside him which made it so much easier. My brother had participated before but had to be carried on my Uncle's shoulders, so I was determined to finish it on my own as a little sibling competition. It was a lot of fun and the race felt like it went by so quickly, with Uncle Doug by my side the whole time."

That was back in 2008, when Megan was 7 years old and before her Uncle, Doug Oakley's, ALS diagnosis. Since then she has only missed one race, and the importance of running to support CCALS has grown since her initial involvement.

"CCALS did so much to help my Uncle Doug through hard times after his diagnosis. They were there for not just him, but our entire family. It means a lot to me to stay connected to CCALS because I think constantly of my Uncle and how much they supported him. Raising money for CCALS through Falmouth is a way to keep happy memories of my time with him."

For many families, the Falmouth Road Race can be a great opportunity to gather as a community to share memories, stories, and enjoy being together. Megan notes that her family is no exception:



Megan Trombly running the Falmouth Road Race in 2015

"I love running by all the CCALS shirts, you feel a real connection. I especially love the get-togethers: the spaghetti dinner the night before, and getting to spend time with my family after. My family has a huge party at my Aunt's house and we have been doing that since before my Uncle was diagnosed, so it is a great way to keep the tradition and my Uncle's memory going."

The lasting impact that CCALS has in keeping families, friends, and the ALS community connected is clear during the race. "Running past all the CCALS fans at mile 5 was so cool, it really makes it all worth it. There were a lot of supporters this year, I feel like I've never seen so many green shirts! I saw a couple of Doug's Disciples who I didn't know, which was really cool seeing how so many people are still connected to the organization and my Uncle."

OVER \$377,000
RAISED



Team Never Give Up poses for a selfie at the start of this year's race.

Bruce and Bellina team up for a strong finish

Jim Bruce had planned to push his son Matt in a wheelchair at the Falmouth Road Race in 2014. Unfortunately, Matt passed away with ALS a few months before the race and as a tribute to Matt, Jim ending up pushing an empty wheelchair with his picture instead. This year, Jim was going to push the empty wheelchair again when Ron Hoffman introduced him to Matt Bellina. "When I first met Matt, he had been recently diagnosed. His young son was playing in the sandbox and he reached up for me. His mother told me he never does that, and I felt like my Matt was bringing us together," says Bruce. They quickly bonded and decided to run the 2015 Road Race together.

"I am truly honored to be able to push Matt. Not only is he a veteran of our country, but I feel such a connection to him and his family. They are wonderful, and he embodies the spirit that my Matt had about not letting this diagnosis get him down and taking each day as it comes. I think it is more than a coincidence that we were brought together."

Bellina hosts the same sentiments about the Bruce family, and shares his excitement at this uncanny match: "I never met Matt Bruce, but everything I have heard about him is that he was an amazing young man who handled this disease with unmatched courage. After meeting his father Jim, I can see where he got it from. I am so honored that Jim asked me to do this race with him, and for such a worthy cause. My parents also [ran] with us and my dad's name is Jim too. Coincidence? Maybe, but surely some things happen for a reason."

Ron Hoffman, who has established deep friendships with both men, said, "I can't imagine a better duo to team up. Both Jim and Matt have such a positive spirit, and a drive to continuously support others and spread ALS awareness. We are honored that they chose to combine efforts to support CCALS."

Jim recounted, "The race was really, really great. We had perfect weather, just a little humid as usual. Matt was amazing." The pair not only had a great race, but also some great laughs.



Jim Bruce with Matt Bellina and his parents Jim and Debby at the starting line.

"When we got there, I brought one of my Matt's big goalie bruins jerseys. Bellina wore this jersey even though he's a huge Devil's fan. I got a good laugh as everyone on the route was yelling "Go Bruins!" and he was rolling his eyes, but he was a trooper about it. He held out and wore the jersey through the whole race. I told him next year we will let him wear the Devil's or put their logo on the wheelchair."

"The race was very emotional for me", said Bruce. "Besides the physical aspect of pushing up the hills the other difficult part was doing it in my Matt's memory and wishing that he was there."

It was bittersweet crossing the finish line wishing my Matt was there, and that Bellina didn't have the disease, but being so thankful to have been connected with the Bellinas on so many levels. Not only on the name and medical level, but they are a wonderful family. Their Matt is handling ALS much like our Matt did. Matt Bellina's parents Jim and Debby are just the most wonderful people. They have an incredible amount of strength and focus on raising funds. We really love them a lot and hope we can keep the friendship and connection going. Our hope is that there are some good, positive things out there that will be able to help Matt."

152 RUNNERS

45 TEAMS

Thoughts From Ron...

CARE

I awoke the morning of October 9 to the news that CCALS friend Rob Millisor had died. Rob, husband and father, was in Nepal on a philanthropic mission with *Doctors of the World*. As I understand it, they were hiking, Rob felt ill, sat down and in moments died, "Gone Beyond." We knew Rob through his wife Amy whose cousin Pam Crease was one of our people and passed with ALS in 2010. We met Pam through Amy's father, Paul Dussault, former owner of a local pharmacy here in Falmouth. Another cousin is Beth McLaughlin, who is married to one of our board members Michael McLaughlin, who originally shared news of CCALS with her uncle. Likewise it was Beth who introduced Doug Oakley to us some years ago. Doug also became a board member, an advocate of our work and most importantly, a friend. He lived with and died with ALS. I am very much saddened by the sudden passing of Rob Millisor, 51 years old, father of a 10 year old daughter and a 7 year old son. He was a caring man loved by many.

I am reminded of the impermanence we face. How instantly we can go from living our lives to "gone beyond" in the blink of an eye.

As I often ask, "are we willing to become more familiar with the reality of our mortality? Our death?" I feel it is imperative we do so. We must explore that reality. I invite you to not squander the opportunity.

Someone recently called me an expert on living with and dying with ALS. After 18 years of working in this field, this may or may not be true. I have seen, experienced and witnessed a great deal with so very many. One thing I learned and hopefully embody is the ability to bring calm amidst the chaos. And as many of us know often there is a raging storm brewing in the world of living with this devastating disease. I feel it is necessary that

we learn to bear witness to this storm. To do so we must hold space in order to allow whatever needs to unfold for those we are in service of.

I have recently been in meetings with the nursing staff at the Massachusetts General Hospital ALS Clinic. Gordon Heald, who I tended to in 1997-98, was a patient there. Thus, I have a long history with the clinic. I am grateful beyond words that our meetings and sharings have bared fruit in finding pathways for our mutual efforts in tending to and caring for our common people/patients. I have learned so much more of the challenges that these wonderful folk of the ALS clinic face. I look forward to continuing our work with them, sharing what we offer to our families and those in healthcare, likewise in learning more about what they bring forth to our people.

It is important to find and define the best possible care we can for those navigating the complexities of living in the world of ALS. The appropriate care is essential and not defined or limited by traditional means or buzzwords. I promise that we at CCALS will continue to do our very best in tending to and caring for our families.

I thank my friend Kevin Gosnell for being a catalyst in bringing us closer together with those at MGH and hopefully other institutions. Much is in the works. Your support is imperative.

In service,



Ron



Ron Hoffman, Founder



ALS Knights – Care and a Cure

Our good friend, Kevin Gosnell, is leading a bold campaign to bring together those working towards treatment and a cure for ALS and those providing care for individuals living with ALS. A portion of the funds raised by this initiative for care will support the efforts of CCALS and our families. For more information please visit www.alsknights.org.

In Memory Of...

Steven Agostinelli, Tewksbury, MA
Sheila Allicon, Derry, NH
Val Altman, Newton, MA
Ben Antonellis, Mashpee, MA
Carlton Askew, Avon, MA
Joan Babul, North Attleboro, MA
Deborah Barrett, Cape Elizabeth, ME
Carlos Bartolomeu, Medford, MA
Arjana Bega, Harperwoods, MI
William Berezniwicz, Quincy, MA
Zainab "Lady Z" Buloushi, Kuwait
George Boynton, Baltimore, MD
John E. Brown, Acton, MA
Edward Campbell, Dennis, MA
Bill Carney, Sudbury, MA

Paul D. Castelline, Framingham, MA
Mary Clements, Weymouth, MA
Teri Cloutier, Hampton, NH
Steve Currier, Bangor, ME
Pamela Daniels, Webster, MA
John P Demoga Jr., Shrewsbury, MA
Lesley Dickinson, Weston, MA
Jeffrey Dietrich, Rockport, MA
Judy Fahey, E. Falmouth, MA
Kenneth R. Ferreira, Wareham, MA
Ricardo Fucci, Greenland, NH
Richard Gaudette, Milford, MA
Sue Gawler, Belgrade, ME
Richard Glasberg, Concord, MA

Joseph Goldstein, Amherst, MA
Susan Barr Govoni, South Yarmouth, MA
James Haines, Lynnfield, MA
Damon Hewlette, Deer Park, NY
Susan Hunter, Amherst, MA
Cynthia Janson, Swansea, MA
Denise Kelly, Carver, MA
Pam LaForge, Peabody, MA
Julia Lapriore, Worcester, MA
Boris Leiderman, Newton, MA
Laurence Long, Vero Beach, FL
Barbara Mahoney, West Chatham, MA
Judi Marks, Wayland, MA
Bob Martel, Tiverton, RI

Rob Millisor, Littleton, CO
Russ Minkwitz, Walpole, MA
Michael O'Toole, Milton, MA
Ezekiel Peach, Jr. Marblehead, MA
Odette Poirier, Holyoke, MA
Armand Rossetti, Andover, MA
Stephen Rubin, Needham, MA
Christopher Rushton, Rome, NY
Mark Shippie, Salem, NH
Anne Shea, West Falmouth, MA
Rocky Smith, Rindge, NH
John "Jack" Tatro, Barnstable, MA
Holly Whiting, Chatham, MA
Cindy Wong, Quincy, MA