

CCALS

COMPASSIONATE CARE ALS

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Care

f CompassionateCareALS t @comcareALS

FALL 2019

Roger Clemens raises funds for CCALS



Ron Hoffman thanks Roger Clemens for supporting CCALS at the Oldtime Baseball Game

This August, on the heels of the Falmouth Road Race, Compassionate Care ALS was the charity recipient of the Old Time Baseball Game in Cambridge. This year's game featured former major leaguer and Boston Red Sox Pitcher Roger Clemens and was played in memory of CCALS friend and longtime Fenway Park security supervisor, John Welch, who passed with ALS in December of 2018.

John's son Johnny, a former baseball player at St. Anselm College and a veteran of seven seasons in the minor leagues, batted against Clemens in the first inning. Clemens pitched two scoreless innings and stayed in the game to play first base and to bat until the bottom of the fifth. The near-capacity crowd watched Clemens collect two RBIs and break a bat, now signed and to be raffled off at our gala auction on May 9th.

Starting on the mound against Clemens was Shrewsbury High School senior John West, whose dad Ken passed with ALS in 2014 and who was also a friend of CCALS.

The game was started by sportswriter Steve Buckley in response to the major league baseball strike in 1994. Since that time, many future and former major league players have donned throwback uniforms and taken the field to entertain the crowds at St. Peter's Field in Cambridge, MA. The game raised more than \$60,000 for CCALS which will be used directly for our ALS patient, family and caregiver program.



Johnny Welch and John West with their moms, Mary and Nancy, at the Oldtime Baseball Game

Thoughts From Ron...

ALS and the Art of Timing

I received the following email last week:

Hi Ron, I reached out to you five months ago when my husband was diagnosed.

Everyone told me CCALS was fabulous, but I just couldn't set up a meeting. Now I need to. So many questions, concerns and fears have come up since I first wrote. Hope to see you soon.—Selma

I get a lot of messages like this from folks who have heard about us, know they need the support but, for a variety of reasons, are unable to take action. It is important to acknowledge the trauma of receiving an ALS diagnosis. Most people, to one degree or another, shut down. They freeze.

I had another gentleman contact me, wanting to know how to convince his dad to see me. "I don't know what to do, Ron. I'm sure that speaking with you would be helpful, but he resists the idea every time I bring it up."

"Does he keep his doctors appointments?" I asked.

"Yes, of course."

"Then tell him I'm a doctor!" I said, joking.

People will go to their doctor hoping for some kind of a fix, because that's what doctors are supposed to do. Our services are harder to understand – not quite as mainstream – so there is resistance, even though we can really make a difference.

That's why, in my perfect world, people would be able to move through the initial trauma of the diagnosis, and get connected with us right away. This way we can avoid a lot of haphazard information and advice given from unreliable sources. It's a timing issue, and a very important one. Think of it as a long walk through the wilderness. There are paths that are much smoother and enjoyable, routes that are incredibly beautiful. Then there is bushwhacking through the bramble. That's what can happen when those first few steps aren't well guided. The art of walking this path is very much about what to do and when to do it. What to learn and when to learn it – and more importantly how to learn it. That's one of our specialties. To anticipate future needs. We're not here to tell you what you don't want to know or don't need to know. We are here to ask questions, show up with our radar fully engaged and really listen; to find out where you are. Exactly where you are. And then invite you to learn what may be around the bend, and how to prepare for it. We are here to invite you to embrace the path and grow from it in the best possible way, and most importantly to honor you and your ways.

With gratitude,



To see the full version of this article, visit Ron's blog at ccals.org/blog



Ron Hoffman
Founder

In Memory Of...

Donna Abate, Bronx, NY
Raymond Barron, Suffield, CT
Wanda Ellen Batchelder, Londonderry, NH
Judith Brown, W. Springfield, MA
Lisa Bullen, Franklin, MA
Judith Carroll, Waltham, MA
Martin Carter, Lowell, MA
Sarah Clark, Narragansett, RI
Royce Cowan, Waynesville, NC
Peter Delvecchio, Oldsmar, FL
Barbara Ann DeMarco, Mashpee, MA
Mario Demaria, Bayonne, NJ
Cheryl Eder, E Falmouth, MA
Walker Farrar Jr., Canton, MA
Michele Frechette, Scarborough, ME
Clifford R. Fuller Jr., Bellingham, MA
Eugene A. "Bud" Garceau, Cumberland, RI
Adele Gentry, Whitinsville, MA
Kathleen Gill, Winthrop, MA
Jean Haffenreffer, Needham, MA
Barbara Heap, Kinnelon, NJ
Jenny Hoff, Spokane, WA
Frank M. Jefferson Jr., Carver, MA
Donna Marie Johnson, Brockton, MA
Peter J. Karlovits, Cohasset, MA
Katja Krumpelbeck, Stamford, CT
Leslie Labrecque, Atkinson, NH
Michael LaMarra, Scituate, RI
Maurice L'Heureux Jr., Amherst, NH
Vincent Lorigan, Haverhill, MA
Catherine M. (Spillane) Luna, Dedham, MA
Grant Lynch, Trumbull, CT
William "Woody" Mackintosh, New York, NY
Carol Marshall, Somerset, MA
Bryan Todd Mayurnik, Manhattan, NY
Jean McCaffery, Chelmsford, MA
Mamie McDuffie, Boston, MA
Timothy McHugh, Bensalem, PA
Linda McNally, Palmer, MA
Robert Miller, Indianapolis, IN
Ronald Mills, North Easton, MA
David Mollon, Avon, MA
Emanuel Moniz, Braintree, MA
Janet Monroe, Easton, MA
Joanne O'Brien, Natick, MA
Teresa Passaretti, Baton Rouge, LA
Richard Pate, Plymouth, MA
Jill Pisano, Franklin, MA
Janet Riccio, New York, NY
Mary Ellen Robinson, Windham, CT
Gihan Sakr, Oxford, CT
Maria Santos, Woburn, MA
Beverly Scarlett, Cotuit, MA
Richard Scott, Berrien Springs, MI
Ernesto Sendoya, Quincy, MA
Theresa M. St. Maurice, Marlborough, MA
Argie Staples, Cambridge, MA
Elyse Staropoli, Hillsborough, NJ
Jerry Stone, Springfield, OR
Thomas W. Sullivan, Torrington, CT
Natalie Swift, Warren, RI
Kelly Teed, Norwalk, CT
Chris Thalacker, New Canaan, CT
Dr. Richard Vinici, Easton, PA
Toming Wong, Walpole, MA
Laurie Wood, Milford, MA

ALS One License Plates

Compassionate Care ALS is a founding member of ALS One, a partnership of world-leading ALS researchers, doctors, and care practitioners focused on finding treatments for ALS and novel approaches to improve care. CCALS receives a portion of the funds raised by ALS One.

Currently, ALS One offers the only license plate in the state of Massachusetts to fund ALS research and care. We are proud that the plate debuted on the road in July of 2018, helping to raise critical awareness and much needed funding for CCALS as well as our ALS One research partners. There are roughly 850 cars currently

registered with our plate and we are eagerly looking forward to surpassing our next milestone of having 3,000 registered cars by June of 2023.

Each plate costs just \$40, of which \$12 goes to the state and the remaining \$28 goes to ALS One programs. Every time you renew your registration, the entire \$40 supports ALS One. The plate is available to owned or leased cars and can be purchased at any full-service RMV or online at alsoneicenseplate.org.



Team Café Martin's first seven miles for John

The Falmouth Road Race starting line is packed with thousands of runners, jostling for space as they prepare for their seven mile run. Clumped among the thousands is a group of ten runners, anxious to begin and tackle this race with their shared sense of purpose. Team Café Martin has come to run in memory of their beloved friend, John Martin, who passed with ALS in 2018.

Adrienne Martin, John's wife and one of the ten runners on Team Café Martin, sits down with us to talk about her experience running her first Falmouth Road Race.



Adrienne Martin visits The Heald Center, sharing her amazing morning smoothie and scuffins with us!

Adrienne arrives at The Heald Center brandishing a gallon of green smoothies in one hand and a box of homemade scuffins (her original scone/muffin hybrid) in another. She is energetic, passionate and thoughtful; she's brought these delicious treats to show her gratitude to CCALS staff for all that they have done to support her family. Adrienne settles in, and begins to discuss the driving force behind Team Café Martin's decision to run for CCALS.

"After John's passing we wanted to give back as much as we could and kept asking each other what was next," she says. The timing was perfect; Adrienne saw that CCALS was recruiting runners for the road race and rallied nine of her and John's closest friends and family. This was their chance to support other families living with ALS.

"About six months after John's diagnosis he asked me if I reached out to the organization whose information we had received. I hadn't, of course. I remember I was sitting in the Stop & Shop parking lot one day and broke down. I needed support, so in that moment I reached out to that organization, CCALS, and sat on the phone with Erin. An instant wave of relief came over me."

At that point, CCALS entered John's journey and came to know the Martin family very well. "I did not have to reinvent the wheel," Adrienne says, "CCALS had the answers to our questions and concerns."

One of the biggest headaches and obstacles Adrienne dealt with through John's journey was health insurance. "There are so many edges that need to be touched and it is impossible for one person or family to touch and tend to all of the aspects that come with this disease. That is exactly what CCALS does; it brings everything full circle. The amount of stress they were able to take off of me as a caregiver was tremendous."

Sitting in the library of the newly completed Heald Center, Adrienne admires the space and the detail in each room. These details are immediately evident to any individual or caregiver who has lived with ALS. Toilet seats with automatic washlets, ADA accessible entryways, shower chairs, and ramps, relaxing

water installations, all designed with care and consideration for anyone caring for or living with an ALS diagnosis.

"Vacationing on the Cape has always been a part of our life as a family. Several times during John's diagnosis we stayed at the Sea Crest in Falmouth," Adrienne said. "They have pretty spacious handicap accessible rooms that are very nice, but at times it would be overwhelming and busy for us as a family. The Center would have been a great place to go and actually retreat to and feel relaxed. This would have just been a gift to have if he was still here."

"It was comforting to know that CCALS was there to step in when we needed them but was willing to step out when we needed that as well. The work Ron and CCALS does and provides is nothing short of miraculous."

Team Café Martin honored John's memory by raising over \$23,000 as a road race team. They leveraged peer-to-peer fundraising and held a team event at a local restaurant, all to support CCALS. "It was tough running 7 miles, I'm a jogger, not a runner. John always kept going though, so I knew I had to keep going too. Our team was amazing! The heart, time and effort they put in to make Team Cafe Martin so successful was so inspiring. This is yet another way our community shows their love and support for John, our family, and the causes we care about. I am so grateful for our team and our community."

Adrienne recounts her experience running the Falmouth Road Race, noting that, "no matter what cause or organization you are supporting everyone is so encouraging." Adrienne celebrated her accomplishment of finishing Falmouth for John with a victory swim in the cool, cleansing waters of the Atlantic Ocean.

The 2019 Falmouth Road Race raised over \$240,000 to support our ALS Patient, Family, and Caregiver Program thanks to individuals like Adrienne and teams like Team Café Martin. The Falmouth Road Race is one way we ensure all families have the same care and compassion that Adrienne, John and their family experienced and we are extremely grateful to all of our runners for your support in making that happen.



Team Cafe Martin after finishing the 2019 Falmouth Road Race.

The Compassionate Care ALS Heald Center; *Education, Retreat, and Sanctuary* is now open



The Holly Ladd library, located in the main building, contains wheelchair accessible seating, dimming lights, and a variety of reading selections.

Turning into the driveway on Chase Road, you hear the sounds of crushed stone under tires and robins chirping softly in the back yard's nature preserve. Whether you are walking or wheeling around the property, you'll have no trouble navigating; all main floors and grounds of the buildings are handicapped accessible. The only places on the property that are not fully accessible are caregiver's rooms, located on the top floors looking over the koi pond and blueberry patch and offering a reprieve from the daily effort of tending to and caring for those diagnosed with ALS.

Matthew Rothwell, who is living with ALS, reflects on his recent weekend visit to the Center. "Along with all the comforts of home at the Heald Center, the outdoor gardens were peaceful and tranquil for everyone to enjoy. It was comforting meeting other families going through similar challenges, sharing stories, laughing, and forming friendships."

The CCALS Heald Center, *Education, Retreat, and Sanctuary* is a place like no other for individuals living with ALS and caregivers alike. The back yard is perfect for quiet contemplation. To be in the moment or to reflect on the past, present, and future. Have a sensory experience, so rare after a certain point in an ALS diagnosis, picking, smelling and maybe even tasting blueberries in the

accessible blueberry patch. Or perhaps spend your day in discussion in the sunshine on the deck. You decide what your time at the Center looks like, based on what you need from the experience.

"The Heald Center is an extension of CCALS' no-questions asked, it's all about compassion," says Renier De Beer, an ALS patient who stayed at the Center during this year's Falmouth Road Race. "It is a center of peace and a chance to meet those in different stages of ALS, take time to unwind, break bread and be as one. My family and I left reset, with our spirits lifted, fulfilled by the love we felt at this beautiful retreat."

If the West Falmouth weather turns south, head inside to spend quiet time in the library or watch birds swoop by the large windows on the indoor porch. Sessions in the yoga studio or sauna can help caregivers and those in the early stages of ALS take time to unwind and find their center. In the evenings, gather round the fire pit or retire to the cozy, calming space of your room.

The Heald Center is now open, thanks to the support of our astounding CCALS community. Contact Ron Hoffman at ron@ccals.org with inquiries.



The main entrance of the Heald Center features a large accessible ramp that flows over the koi pond and connects to the blueberry patch.

CCALS Gala to be held at Boston Park Plaza

Compassionate Care ALS is excited to announce that our 2020 Gala will be held on May 9, 2020 at the famous Boston Park Plaza and features special guest Jonathan Penner. An Oscar Nominated actor, screenwriter and producer of films and television including the feature films *The Bye Bye Man* and *The Last Supper*, Penner is best known for his three seasons as a contestant on the CBS megahit, *SURVIVOR*. In early 2018, Penner's wife, partner and fellow Oscar nominee Stacy Title, was diagnosed with ALS. After her diagnosis their two adult children moved back into their Los Angeles home

to help Penner in his new role as Stacy's primary caregiver. We are honored to have Penner attend the gala and share the story of his family's journey with Amyotrophic Lateral Sclerosis.

This year's Gala will feature live and silent auctions as well as many surprises. All proceeds from the 2020 CCALS Gala support individuals, families, and caregivers living with ALS.



Jonathan Penner and Stacy Title

How You Can Help:

If you are interested in volunteering at the Gala or have auction items that you would like to donate to our silent or live auction, please contact Richelle at richelle@ccals.org.

JONATHAN PENNER TO SPEAK AT THE 2020 GALA