

# Compassionate Cares

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## Reflections on the 7<sup>th</sup> annual David's Old Silver Swim by our Friend David Garber

As I round the corner of my 66<sup>th</sup> revolution around the sun, I still feel like a teen-aged, loafer-wearing Holden Caulfield. I can connect to the insecurities of my youth as well as to the dreams I had for a future, tempered only by the range of my imagination, certainly not by any limitations fate might have in store for me.

I have many wonderful memories of my youth, college, starting a dental practice, getting married and becoming a parent, and of my incredible friends, family, and community – all the parts of life that many fortunate people have (minus, perhaps, the dental practice). I continue to feel fortunate because giants of friends continue beyond expectations to visit whether in person or by email, drone, or just to forward jokes, articles, or pictures. They help bring the outside in. These memories of times past and new memories being created daily, sustain me. We never know what we are capable of until we are confronted with an improbable situation. We all carry our own bags of cement. I didn't choose to have this disease, but with strength I have the ability to continue to live life to the utmost.

I recently saw a picture of me and to my surprise I resembled a turtle in a shell (alas, not a ninja). And although I feel normal on the inside, it was obvious that externally I had changed significantly: my physique (I like using that word) was bloated (I don't like using that one); I had a tube in my throat, gauze around my windpipe, my hair and beard had turned to grey and I had many more laugh lines than I remembered. One advantage of ALS is that it's hard to be vain! Of course, as I've said many times before, life doesn't stop with illness, even ALS, it just changes. And one's changing appearance is really the least of it.

Back in the day, pre-ALS, I had been a swimmer. It was my great joy to plunge into Buzzard's Bay evenings and weekend afternoons and take a solitary swim for well over an hour. I was the weird guy out there, competing, not always successfully, with the jellyfish, for my little bit of heaven in the sea. Those days are gone, but my devotion to swimming has been transformed into a cause of far more importance than my own personal enjoyment.

David's Old Silver Swim, this year planned for Saturday, August 12th, is my way to try to give back to Compassionate Care ALS, the organization that enabled me to keep going even after the lost, hopeless and frightened feeling that an ALS diagnosis brings. CCALS provided practical help and expertise, they problem-solved problems before I even acknowledged I had them. They were and are the lifeline that enables me to thrive while living with ALS. And I really mean thrive. In my head I can do everything you can do: dance, sing, drive around in a vintage Olds convertible, sink a fifty foot putt, and even grow fabulous tasting beefsteak tomatoes. Ron Hoffman, the man at the helm of CCALS, was the calm at the center of the storm that meant the end of life as I had known it and the start of my new life that I am living now to the fullest, living large and swinging for the fences, albeit metaphorically.

CCALS has provided care for over 1600 ALS families since it's inception and our dollars make an enormous impact. Last year, with the immense generosity of people from all walks of life, we raised an astonishing \$70,000 for CCALS. This year we want to do even better – \$100,000 and counting.

I have said that we were striving for the Swim to grow in size to compete with the Tour de France, but now I'm thinking even bigger: the Super Bowl, the Oscars (without the Best Picture glitch), hey, maybe the World Cup. I know, it's silly, but goals are what we set, dreams of achieving them are what keep us going.

Thank you!  
David Garber



## Thoughts From Ron...

20 years ago

Spring 1997...

I remember it almost like yesterday...

Little did I know the choices I'd soon make would lead me to discover the work that was before me. Some may call it fate. It was twenty years ago I tended to and cared for Gordon Heald. A man who with his wife Betsy and myself embarked on a journey few could imagine.

My tending to and caring for Gordon began in the Spring of 1997. As weeks and months passed he became a friend...a mentor...a teacher and a benefactor. We spent a great deal of time together talking, sitting and discussing life in the way that Gordon could at the time. In a quiet moment of contemplation, early on in his diagnosis, he would ask "Why me?" My response was, "maybe having this diagnosis now will impact the life of a person you would meet along the way, the paperboy, someone at work, a person you saw at the hockey game, you may have no idea how or why or what it means, but they will be impacted. Little did I imagine what was to follow.

In truth, Gordon's circumstance reached far beyond what any of us could have envisioned. He unknowingly impacted thousands upon thousands of lives through his and Betsy's support for CCALS. Because of Gordon's diagnosis and circumstances an extraordinary organization has been created. He inspired the unique model of CCALS, that in a perfect world would be replicated many times over.

And today, 20 years later, I have seen the growth and evolution of CCALS to serve thousands of individuals and families in Massachusetts, across the US and around the world. We have held many workshops and gatherings. We have developed productive partnerships through ALS One; through our work with the neurologists and clinical staff at Mass General Hospital and UMASS Medical in Worcester; and through the extraordinary research group, ALS TDI. We are building our Education and Retreat Center which will begin operating at the end of 2017. And I have been blessed to find my life's work. These are a few examples of what is possible and how one life can transform so many.... *the work continues.*

Twenty years...I look back with gratitude in honoring Gordon's life and the memory of countless others as well as honoring all those we serve.

With deep Gratitude, thank you Gordon and Betsy,

In Service



Ron Hoffman  
Founder

## In Memory Of...

Sally Abrahams, Newton, MA  
Gaetan Andre, Brockton, MA  
Evangeline Austin, Springfield, MA  
Victor Bailey, Fredericksburg, VA  
Emma Bastarache,  
Marlborough, MA  
Ted Beriau, Osterville, MA  
Sandra Blanchard, Auburn, MA  
Judith Bradley, East Weymouth  
Larry Bybee, Amesbury, MA  
Nancy Carroll Butler,  
Marlborough, CT  
John Bryant,  
South Burlington, VT  
Laurie Callahan, Woburn, MA  
Claire Carty, Litchfield, MA  
Michael Cavanaugh, Mystic, CT  
Richard Ceurvels, Abington, MA  
Joseph Chabot,  
North Grafton, MA  
Sharon Chauvin, Dudley, MA  
William Checchio,  
Plymouth, MA  
Mitchell Cook, New Berlin, WI  
Chris Connors, York, ME  
Lois Costa, Longmeadow, MA  
Frances Daly, Concord, MA  
Michael Day, Brewster, MA  
Jane Demers, Mansfield, MA  
Kathleen Devine, Millis, MA  
Dr. Robert Diener, Milton, MA  
Winifred Dunn, Jersey City, NJ  
Steve Dusseault, Manchester, NH  
Jack Fahey, Jamaica Plain, MA  
Christopher Engstrom, Eastham, MA  
Charles "Chip" Fanelli,  
Needham, MA  
James Fels, Myrtle Beach, SC  
Sue Fennel-Ivas, Pittsfield, MA  
Cheryl Jeannette Felton,  
Wichita, KS  
Ifitkhar Feroz, Quincy, MA  
Kevin James Forster, San Diego, CA  
Crescenzo Frederico, Peabody MA  
Marie Galvam, Randolph, MA  
Ida Gamble, Dorchester, MA  
Bob Gibney, Dorset, VT  
Diane Gordon, Bristol, RI  
Bernie Kelly, Plainville, MA  
Jeffrey Hallowell, Maize, KS  
Mark Harty, Westport, MA  
Ronald Wayne Holmes, Cotuit, MA  
Craig Hosley, Hardwick, MA  
Thomas Healey, Marshfield, MA  
Nick Hines, Goffstown, NH  
Laurie Anne Horn,  
West Yarmouth, MA

Amanda Hudson, Acton, MA  
Patricia Hume, Naples, ME  
Stacey Huth, South Burlington, VT  
Joseph Hrezo, Connellsville, PA  
Robert Irvine, Preston, CT  
Larry Jacknin, Pittsburgh, PA  
Maryanne John, Framingham, MA  
Eric Anderson Johnson,  
Andover, NH  
Elinor Kane, Concord, MA  
Paul Klenowski, Bucksport, ME  
Richard Leandri, Franconia, NH  
Nick Littlefield, Cambridge, MA  
Thomas Lividoti, Arlington, MA  
Glen Macon, North Andover, MA  
Czeslaw Marchwinski, Danvers MA  
Dominic Mazzocoli, Hartford, CT  
Jimmy McCarthy, Weston, MA  
Barbara McCarthy, Mansfield, MA  
Mary Ann McCarthy, Weston, MA  
Kimberly McGrory, Newport, RI  
Luis Medeiros, Bristol, RI  
Jonathan Metcalf, Boyd, MT  
Norm Morais, Manchester, NH  
Iris Olive Moremen, Fullerton, CA  
Irene Morin, Hudson, NH  
Paul Moritz, Sheffield, MA  
Donna Mygatt, Dedham, MA  
James Nault, South Grafton, MA  
Roland "Ron" Nault,  
Worcester, MA  
Ellen Nix, Manomet, MA  
Evelyn Nuberger, Harvard, MA  
Georgia Osborne, Milwaukee, WI  
Kevin Jameel Parker,  
Randolph, MA  
Shirley Robinson, Brunswick, ME  
Judy Rodenizer, Westminster, MA  
Cheryl Rosato, Middleton, MA  
Suzette Ruby, Millbury, MA  
Lee Salkovitz, Lake Mary, FL  
Nicholas Scheetz, Newport, RI  
Thelma Sears, North Dighton, MA  
Carmen Sierra, Lynn, MA  
Nancy Southworth, Somerset, MA  
Susan Speranza, Vestal, NY  
Ziad Shahin, Topsfield, MA  
Evelyn Sutera, Gloucester, MA  
Janet Suydam, Dennis, MA  
Linda Taylor, Haverhill, MA  
Mary Thompson, York, ME  
Kathy Vital, New Bedford, MA  
Kathy Walsh, Westford, MA  
Judith Ward, Milton, MA  
Neal White, Warwick, RI  
Chester Wawicki, Merrimac, MA  
Nancy Winder, Acton, MA

## New ALS Drug

On May 5th, 2017 MT Pharma America received approval from the FDA for their new drug RADICAVA™ (edaravone) after clinical trials involving over 350 ALS patients. It is the first prescription medicine used to treat people with amyotrophic lateral sclerosis (ALS) approved in over 22 years. The indication is that it can be used by all ALS patients. RADICAVA™ slows progression of disability by 33% as measured by ALSFRS-R. It will be available in August of 2017.

For more information visit [ccals.org](http://ccals.org) or call 844-772-4548.





## Capital Campaign update

In November of 2016 CCALS successfully raised \$500,000 to match a challenge grant from an anonymous donor. At the time the million dollars realized from this match brought our capital campaign grand total to over \$2.4 million and allowed us to begin construction of the CCALS Education and Retreat Center. To date we have raised over \$2.6 million of our \$3.5 million goal. The Center, located in West Falmouth, consists of 1.4 acres and includes three buildings. The main building has two floors and it will be renovated to be ADA compliant. It will house a grand meeting room, a library, a kitchen and guest rooms for caregivers or family members of ALS patients to use for respite or while their loved ones are staying at the center. The carriage house is also two floors and will be renovated to have first floor rooms that can accommodate those living with ALS at every stage of the disease. The current cottage has been demolished and will be replaced by a one floor building that will include living quarters, a counseling room, office space and kitchen.



It's hammer time in Falmouth at our ALS Education and Retreat Center.

CCALS, along with construction partner Ralph Cataldo of Cataldo Builders and architect Denise D'Ambrosi Bonzoli, have completed initial plans for the design and construction. Demolition has begun and we anticipate a grand opening before the end of 2017. Many construction partners have decided to contribute time, services and materials to make this project a success. We are grateful to these partners. Please follow us on facebook, twitter and instagram for real time updates on construction!

We look forward to sharing the sanctuary of the Education and Retreat Center with our friends. Please look for the feature article on the CCALS Retreat Center in the Summer 2017 Issue of Cape Cod Home Magazine. Please visit [ccals.org](http://ccals.org) for updates or to donate to the retreat center.



## New Event - Walk for Living October 1

CCALS is pleased to announce that we were asked to partner with the Leonard Florence Center for Living (LFCL) on their Walk for Living. LFCL is the only facility in the country dedicated to patient centered individualized care for ALS patients. The Walk for Living will take place on Sunday October 1. It is a two mile dog-friendly walk through Chelsea open to all ages. Bring family and friends, sign up for our email list or follow us on facebook, twitter and instagram for updated information as it becomes available.

[www.walkforliving.org](http://www.walkforliving.org)

f t i @Walkforliving

## New staff - Martha Miller

CCALS is thrilled to welcome our new staff member, Martha Miller! Before joining the CCALS team, Martha worked in a secretarial position in the medical field for nine years. She first came to know Ron and Erin in 2010 when her husband, Mark, was diagnosed with ALS. CCALS was an integral part of their lives during the six years Mark lived with ALS.

In her free time, you can find Martha behind the camera, taking pictures during get togethers and scenic photos in her free time. Most of these photos are probably taken during summer or fall, her favorite seasons.



## Nikki Green is no stranger to going the distance.

In 2013, she geared up to tackle the Boston Marathon. She ran 25.6 miles before being stopped less than a mile shy of the finish line because of the bombings.

“Being so close to the finish line and not being able to finish in 2013 has stuck with me for almost four years,” she explains. “I finally decided that this was the year I was ready to tackle this race again and I had just the reason to run – my Dad.”

Nikki’s dad was diagnosed with ALS just over a year ago in April of 2016. It was after this diagnosis that Nikki first interacted with CCALS.

“Once my parents met with Ron it was friendship at first sight. Since they’ve met Ron they are a LOT less stressed about everything. They feel like they have someone to talk to about changes in my Dad’s health, and a friend to lean on. Ron has been essential in dealing with this disease and I really don’t know what we would do without him!”

When she found out CCALS had a Marathon bib available, Nikki knew it was fate. Her training wasn’t always easy:

“Sometimes I would feel like I had solved all the world’s problems by the end of an 18 mile run...other times I felt beat down and asking myself – how did this happen to my Dad?”

But it was always worth it. On April 17, she completed the full 26.2 miles in honor of her father and in support of CCALS. There was no better feeling than seeing her dad was proudly cheering her on at mile 13.

Nikki’s sights are now turned towards the 2017 Falmouth Road Race, where she will continue to pound the pavement and rack up the mileage to support the care of individuals living with ALS and their families.

“I am very excited to run Falmouth again; I have run in past years all for different charities, but it means so much more running for CCALS this year because it’s an organization that is so special and important to me. I absolutely can’t wait.”

To donate to Nikki’s race in honor of her dad or to sign up to run the Falmouth Road Race in support of CCALS, visit [falmouth.ccals.org](http://falmouth.ccals.org).



Nikki Green completes the 2017 Boston Marathon in honor of her dad and in support of CCALS



Three generation of runners: mama Bernadette, daughters Kate & Taren and granddaughter Mack

## Run with us! Sign up for Falmouth Road Race 2017

You are invited to join CCALS friends and family on August 20<sup>th</sup> at the 45th annual Falmouth Road Race. This year we will have more than 130 runners and their communities joining together. We hope to raise more than \$350,000 to directly support those living with ALS and their families. Runners commit to raising \$1,500 and are invited to our spaghetti dinner and celebration at the Seacrest Beach Resort. Our Falmouth website has undergone a user-friendly makeover and runners can now register to run for CCALS online. Please visit [falmouth.ccals.org](http://falmouth.ccals.org).