

# Compassionate Cares

## Welcome to our Spring 2016 Newsletter

*This issue of Compassionate Cares highlights CCALS services, but also focuses on the individual fundraising that allows us to continue our work. Whether running the Falmouth Road Race, organizing a swim, or attending an event, your support allows us to continuously provide individuals, families and caregivers with services and guidance.*

### Compassionate Care ALS announces \$500,000 Challenge Grant

Compassionate Care ALS is thrilled to announce the receipt of a matching gift up to a total of \$500,000 from one of our families for the Education and Retreat Center Capital Campaign. This dollar for dollar match will occur through November 20, 2016 and could provide up to \$1 million towards the \$3.5 million Capital Campaign. Each dollar contributed will have its impact doubled.

The CCALS ALS Education and Retreat Center will meet the needs of individuals living with ALS, their families, and their caregivers as well as healthcare

professionals by improving access to ALS information and resources. The Center will serve as a handicapped accessible respite location as well as a home for CCALS Educational Gatherings.

The announcement of the match was made at the 2016 CCALS Gala on May 20, where a cause auction at the end of the evening raised over \$66,000 towards the goal.

To donate, track our progress and learn more about the project visit [www.ccals.org/retreat](http://www.ccals.org/retreat).

### Spotlight on CCALS Services: Augmentative Communication



When CCALS Augmentative Communication Coordinator Kristine Copley arrived at the Rhode Island nursing home, Doris was an eighty-three year old who had lost all means of communication. Her Speech and Occupational Therapists were at a loss; not only was Doris unable to speak, but due to an ALS diagnosis, she was unable to write words. Neither healthcare worker has experience with ALS, and they struggled to find a way to help her.

Kristine has been a member of the CCALS team since 2014. She is the resident tech guru, keeping up to date on speech technology, tools, and computer accessories. She provides advice, implementation,

training and support to CCALS families and brings communication back to hundreds of individuals who have lost their ability to speak or write.

"I help people find the most efficient way to communicate once traditional speech becomes problematic," Kristine explains. This usually means using a computer to 'speak,' and then figuring out how to tailor the system to the specific individual. "Some people use adaptive mice, trackballs operated by their feet, head-mice, and even their eyes."



Kristine assessed Doris' situation, and provided her with a technology that was customized to reflect the fact that Doris has never used a computer. With a bit of finagling,

Continued inside

## Thoughts From Ron...

As I sit here contemplating what the last year has brought to CCALS, I am amazed at what has happened. It is beyond my wildest imagination. We have added new staff members who allow us to meet the needs of the continually growing number of families requesting our services, we have developed partnerships with major research institutions, we have made great strides in realizing my dream of building our ALS Education and Retreat Center and we have seen many individuals and organizations support our work. The highlights of the last year for me include:



Ron Hoffman, Founder

### CCALS' becoming a founding member of ALS One

ALS One is a partnership between Mass. General Hospital, UMASS Medical Center in Worcester, ALS TDI and Compassionate Care ALS to bring CARE and a CURE to ALS. Through this organization CCALS has assisted in developing a release agreement with MGH and has worked with the ALS clinic to share information about treatment and care for over 70 patients. CCALS has also dedicated one of our handicapped accessible vans to transport ALS patients to clinical trials at all three research partners and hired new staff members to support additional referrals from ALS One partners. This is just the beginning and we are looking forward to a long partnership with these institutions.

### CCALS held an enormously successful Gala that raised more than \$250,000

The Fairmont Copley hosted a star-studded evening on Friday, May 20 to benefit Compassionate Care ALS (CCALS). The Gala raised over \$250,000 in support of care for patients and families living with ALS. The evening was hosted by former WCVB-TV news anchor Natalie Jacobson and featured a talk from best-selling author Lisa Genova. Also in the audience were former WCVB-TV weatherman Dick Albert as well as Chris and Peyton Lambton of *Bachelorette* and *Bachelor* fame.

### A Challenge Grant that will allow us to complete construction of our Education and Retreat Center

One of our families has issued a dollar for dollar challenge grant that will match donations supporting our new Education and Retreat Center. All donations towards the campaign will be matched up to a total of \$500,000 through November 20, 2016. When fully realized this generous grant will allow us to complete construction and begin programming at the Center. For more information and to contribute to the center please visit [www.ccals.org/retreat](http://www.ccals.org/retreat).

As you can see, we continue to be very busy in great ways. I hope to cross paths with many of you along the journey over the next six months to ensure we maximize our challenge grant.

In Service,



Ron

## Letter from our Anonymous Match Donor

### Read at the May 20 CCALS Gala to announce the match

ALS strikes deeply as everyone here knows. We are a community in this room and in the world. We share a deep understanding of how much it means to experience true care, in all the meanings of the word. And sometimes to experience celebration, even transcendent joy despite it all.

Ron is our common bond, sharing the whole of it, with unconditional devotion to all of us. Who better can you find anywhere in the country to build this community of compassion, partnering with researchers and healthcare providers who themselves can learn from our community of compassion.

In support of CCALS' important and ambitious new project, our family decided to offer a matching grant to help create a place of nurturing in West Falmouth. It is a space for an ALS community we all share by virtue of coming through the fires.

It is a safe space in nature for respite, for sharing and for learning. Let's make our funds work together, matching one for one.

## In Memory Of...

Susan Anderson, Foxboro, MA  
Lisa Addison, Plymouth, MA  
Paul Aiken, New York, NY  
Chiu Ang, Boston, MA  
Carolyn Barboza, Raynham, MA  
Maureen Bolognese, Swampscott, MA  
Wendy Bolster, Jamestown, RI  
Michael Britt, Castleton, NY  
Lewis Budd, Lynnfield, MA  
Donna Burke, Abington, MA  
William Burke, Marlborough, MA  
Allan Irving Burnstine, Lake Mary, FL  
Arthur Burt, Rehobeth, MA  
Paul Caldwell, Buzzards Bay, MA  
Martin Castlebaum, Bondville, VT  
Richard Clancy, Norwood, MA  
Vernon Dawson, Savoy, MA  
Terry Drewes, Harwich, MA  
Paul Dussault, Mashpee, MA  
Marlene Marie Ernst, Clinton, MA  
Rene Ethier, Worcester, MA  
Jason P. Ferwerda, Bellingham, MA  
Sheila Frisch, Swampscott, MA  
Tim Gemelli, Wrentham, MA  
Eileen Stuckus, Grafton, MA  
Anne Downer Hazell, Somerville, MA  
James Flynn, Jr., Merrimack, NH  
Thomas George, Yarmouthport, MA  
Manny Glin, Sudbury, MA  
Hilda Griffin, Chelmsford, MA  
Carey Hinkley, Pittsfield, MA  
Egide Houndegla, Pelham, NH  
Jamie Hudson, Weathersfield, VT  
Joseph Killelea, Ashby, MA  
Irene King, Waltham, MA  
Shirwin King, Randolph, MA  
Susan Klaucke, Auburn, MA  
Amy Kolbeck, New Bedford, MA  
Janet Lang, Lowell, MA  
Derek Lange, Lowell, MA  
Mary Lucey, Malden, MA  
John MacLeod, Ledyard, CT  
Ted Malley, Scituate, MA  
Susan Malloy, Wellesley & N. Falmouth, MA  
Marjorie Medas, Bridgewater, MA  
Charlene Molina, Taunton, MA  
Diane Norton, Rochester, MA  
Betty O'Connell, Gloucester, MA  
Jennifer Oliver, Edgartown, MA  
David Patacchiola, Burlington, MA  
George "Bill" Phillips, Middleborough, MA  
Terry Pickard, North Chatham, MA  
Rita Ranucci, Newton, MA  
Carol Rec, Bourne, MA  
Gennaro Romano, Dedham, MA  
Paul Rosette, Center Harbor, NH  
Robert Rothstein, Gloucester, MA  
Francis Slusarz, Dighton, MA  
Carol Sullivan, Raymond, NH  
David Swetman, Smartsville, CA  
Evi Theofanous, Thessaloniki, Greece  
Paul Thibodeau, Saugus, MA  
Catherine Tiffany, Kingston, NH  
Jamie Toy, Bridgewater, MA  
Julie Tyska, Hollis, NH  
Tom Urbon, Marston Mills, MA  
Sharon A. Verlezza, Hopkinton, MA  
Rolando Vieites, Cambridge, MA  
Paul Vigneault Jr., Worcester, MA  
Jeffrey Webber, Milford, MA  
Peter Weiblen, Naragansett, RI  
William Wichman, Amherst, NH  
Alex Wylie, Salisbury, VT  
Bryan Young, Plaistow, NH  
Judy Young, North Andover, MA



## Comm Ave Charity Classic takes to the ice July 15

On a warm July night fans grabbed their coats, hats, and mittens and filtered into the Walter Brown Arena at Boston University. The Comm Ave Charity Classic (CACC) drew crowds of college students, alumni, and hockey fans of all ages to watch as Hockey East rivals Boston College and Boston University faced off in an alumni game to benefit Compassionate Care ALS.

The event was organized by former Boston College hockey captain, Pat Mullane (BC '13). Teams were comprised of former and current NHL/AHL players, and the Terrier vs Eagles dynamic brought in a sold out crowd of more than 3,000 spectators. The first annual CACC raised over \$55,000 to support CCALS services for individuals and families living with ALS.

Players came from teams all over the map and included Brian Leetch (BC'87, ret. New York Rangers), Adam Clendenen (BU '14, Vancouver Canucks) and the Hayes brothers, Jimmy (BC '12, Boston Bruins), Kevin (BC '14, Calgary Flames) and 23 others.

In an interview for Hockey East Online, Brian Boyle (BC '07) from the Tampa Bay Lightning expressed his appreciation for the event. Although unable to play due to injury, Boyle noted that "It was an awesome turnout and raised great money for a great cause. Hopefully we keep this thing going every year, and I can play next year." When asked how important this game was for supporting families with ALS, he said "I get chills talking about it." That sentiment was widely felt through the BU and BC communities, who have been directly affected by ALS.

This year, the second annual CACC puck will drop at 7:05pm on Friday, July 15, 2016. The event will feature a silent auction and a raffle, which included signed hockey memorabilia in 2015. All event proceeds will benefit Compassionate Care ALS and the Travis Roy Foundation, in memory of BC Sports Information Director Dick Kelly, Coach Jim Cotter, Ron Perryman and Richard Armstrong and in honor of Pete Frates and Travis Roy.

Corporate sponsorship opportunities are available. For event information and to buy tickets, visit [www.ccals.org/2016-CACC](http://www.ccals.org/2016-CACC).



Introductions and speeches are made at center ice before CCALS friend Pete Frates drops the puck.



Sean Escobedo (Pittsburgh Penguins, BU '13) defends Kevin Hayes (New York Rangers, BC '14) at the first annual CACC.



CCALS founder Ron Hoffman thanks CACC organizer and former BC hockey captain, Pat Mullane.

### Spotlight on CCALS Services: Augmentative Communication (continued from cover)

the system was attached to Doris' wheelchair. Kristine walked Doris through a tutorial, and implemented extra large fonts so that Doris could easily and efficiently spell out words.

Insurance would not cover the cost of this technology, and Doris' family could not afford to purchase these high-end systems on their own.

The model given to Doris was assembled from equipment donated to CCALS.

After weeks of silence, Doris was finally able to communicate again. She spent the rest of the day "talking" up a storm! Doris was tearful in

her gratitude in having her ability to communicate restored, and Kristine was overjoyed in bringing "speech" back into Doris' life.

"What I love about my work is that maybe, just maybe I bring hope: people are often fearful that they may lose their ability to communicate," says Kristine.

"They fear the loss of their ability to articulate their care directives, but more importantly, their feelings, opinions and ideas. When I meet a family, I get to evaluate

the abilities of each person and can be creative on implementing high tech and/or low solutions that ensure communication throughout the length of the disease."

**“What I love about my work is that maybe, just maybe I bring hope: people are fearful that they may lose their ability to communicate.”**

## Road Trippin' for CCALS

After five years, 35 miles and \$14,107 raised for CCALS, Kelly Lombel just won't stop. In fact, when we caught up with her by phone for this article she was on a training run.

Kelly is gearing up to add 7 more miles to her total at the 2016 Falmouth Road Race in support of CCALS. Running for CCALS was inspired by her grandmother, Elizabeth "Bushie" Bettick, who passed with ALS in July of 2010. After her grandmother's ALS diagnosis Kelly found CCALS through a friend who ran regularly, and she decided to road trip to Massachusetts from Pennsylvania. The next year her family came along to cheer her on.

The road trip has grown into a mini vacation, with more family members joining each year. Not many of them run but they love the 400 mile drive to Falmouth each summer. Kelly's crew, Team Bushie Bettick, enjoys watching the race and supporting her and the other runners. Distance does not allow the family to be involved with CCALS as much as they would like, so they take the Falmouth Road Race very seriously. Each year, the family stays in Falmouth longer, making this trip and race a family tradition. The Falmouth Road Race is their way to support CCALS's work and remember their matriarch.

Kelly's favorite part of the race is seeing the number of fans that show up. She loves the family feel of the CCALS camaraderie; "Everyone is just so nice and welcoming; that is what makes the experience so much fun."

Over the last couple of years she has seen a much bigger turnout in both in the number of runners, fans and dollars. Kelly and her family have seen first-hand the emotional and physical impact of ALS on the patients, their family, and friends. Kelly is excited to see how much money will be raised this year, to reunite with her "Falmouth friends," and to catch up with Ron.



Kelly rounds the bend in the last mile of the 2014 Falmouth Road Race.

## David's Old Silver Swim 2016



Grab your goggles, don a bathing suit, and get ready to swim or float. The sixth David's Old Silver Swim will be held on Saturday, August 13th! The swim is held annually in honor of Dr. David Garber a long-time Falmouth resident and dentist who was diagnosed with ALS in 2009. This type of event is a proper tribute to David, who has been an avid swimmer for most of his life, and a meaningful way to raise money for Compassionate Care ALS.

The swim winds along Old Silver Beach in North Falmouth with two options, a 1 mile and a half mile swim. Both kick off at 9:30 AM from the Sea Crest Beach Resort. There will be a silent auction with bidding open from 8 to 10:45am, and celebrations and awards following the event, so even if you aren't swimming, paddling, or floating come to cheer and support CCALS!

To splash on into the fun, register online at [www.Davidssoldsilverswim.com](http://www.Davidssoldsilverswim.com). Email [davidsswim@gmail.com](mailto:davidsswim@gmail.com) with any questions.