

COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Cares

FALL 2014

Welcome to our Fall 2014 Newsletter

This issue of Compassionate Cares focuses on how support and funding from the CCALS COMMUNITY allows us to focus on our mission of providing high quality care and integrative resources to ALS families.

CCALS benefits from the Ice Bucket Challenge



Founder Ron Hoffman takes the Ice Bucket Challenge

Since early August, Compassionate Care ALS has had the good fortune of benefitting from the viral Ice Bucket Challenge, which was championed by CCALS friend and former Boston College Baseball player Pete Frates. The challenge has helped CCALS to heighten awareness and raise much needed funding which is going directly to our ALS Patient, Family and Caregiver Program to help those families directly impacted by ALS. Ice Bucket Challenge donations to CCALS have come from 47 states, Washington D.C., Puerto Rico and 16 countries on four continents.

Many CCALS staff and families have taken the challenge. We have collected some of their videos on our website at www.ccals.org/IceBucketChallenge and our Facebook page. Please visit our page and like us. We are excited to announce that the Pete Frates Fund has chosen CCALS to

benefit from sale of special Pete Frates baseball cards offered by Topps. Please visit www.topps.com and search Frates.

We are grateful that more than 3,000 donors found our organization worthy of their contributions and were willing to dump ice on their heads to promote our mission. At the Falmouth Road Race, CCALS Founder Ron Hoffman even got into the act after being challenged numerous times. Please remember to tag CCALS with your videos and send us links so that we can promote them through our social media sites.



Thoughts From Ron...

From reading this newsletter you will get a glimpse at how much has been going on at Compassionate Care ALS this spring and summer. My many thoughts may be disparate but they are all relevant to the work we are doing and the assistance we bring to those living with ALS. Many positive changes are in process, our future is bright, we are walking on solid ground.



*Ron Hoffman,
Founder*

- I would like to welcome all our new staff members, our new Executive Director Tom Gilligan who in a few short months has been instrumental in improving our internal systems and programming. We also have welcomed Kristine Copley, Jennifer Gauvin and Paul Shea who are now working with us in different capacities to enrich the services we are offering.
- I have been asked numerous times in regard to the Ice bucket challenge had CCALS been the recipient of the more than 3 million donations for more than \$130 million raised what would I do...

Research

I was very excited to see that \$21.7 million is going to fund research collaborations that would not have existed without the funding. Seeing many familiar research names being funded made me pleased, grateful and excited about the future possibilities in the realm of hope.

Beyond research, I would invite the ALS Association (ALSA) to look seriously at these suggestions, some of which they may be already focused on.

Augmentative Speech Devices

I would give serious consideration in support of John Costello, director of Augmentative Communication Programs at Boston Children's Hospital. To support his extraordinary efforts in working with individuals living with ALS in obtaining Augmentative Speech Devices such as the Tobii. These devices aren't for everyone, but there needs to be a greater opportunity and access for those who would benefit from these systems which can cost up to \$18,000. **There is great opportunity for collaboration here.**

Professional Training

Another pressing need is to have trained experts in the field of Medicare and Medicaid, especially state specific training. I am talking nationwide. I know the Massachusetts state chapter often excels in this area. This would bring great relief to families dealing with not only a progressive, terminal disease but also with the nightmare of navigating the bureaucratic system which continues to exist.

The CCALS Model

Most importantly, I would invite ALSA to bring in-depth education and training to your national team and state chapters. This training would be based on the concepts, virtues and practices of the relational model created and implemented here at Compassionate Care ALS. It would bring forth the additional tools and support to your staff that they so richly deserve. **There is great opportunity here for collaboration.**

I would also like to give a shout out to ALS Canada for the fine, innovative and thoughtful work you are doing. I am looking forward to the **opportunity for future collaboration as well**. Also a heartfelt thank you to my friend Pete Frates, for the friendly viral "firestorm" he created. And to his family, who are a beautiful example of walking 'side by side' with their son, brother and husband.

I am pleased to share with you the opportunity to see the extraordinary documentary film "Imber's Left Hand" which will be showing at the Jewish Film Festival at the Museum of Fine Arts in Boston on November 9, 2014 at 3pm. This film had its feature length world premiere at the Carmel International Film Festival on October 17. I encourage you to see this powerful story of a great man and a great artist, who lived with ALS as he danced his dying, a true love story. Visit CCALS.org for film information.

I am also happy to announce that the website for my memoir is now live. Please visit www.sacredbullet.com or www.ron-hoffman.com. The book delves deeply into the world of living with and dying of ALS as well as our broken healthcare system, domestic violence and so much more. I have been told it is rich in many ways. My experiences put forth are relevant to all those working in healthcare as well as all families living with ALS or any other illness, terminal or otherwise. A portion of the proceeds will go to support the work of CCALS.

I continue to be grateful to all of our current families, those who have gone beyond and to those we have yet to meet.

In service,

A handwritten signature in black ink, appearing to be 'Ron' with a stylized flourish.

Ron

Welcome Tom Gilligan our new Executive Director

In May of 2014 Tom Gilligan became the new Executive Director of Compassionate Care ALS. Tom has served as a devoted volunteer and board member for the past seven years and he is a vocal advocate for ALS awareness and fundraising. His brother Larry was diagnosed with ALS in late 2004, and is his inspiration for joining CCALS. He brings a background in project management combined with a long history of community and civic leadership. Tom works side by side with CCALS Founder Ron Hoffman and has taken on many of the administrative and fundraising responsibilities, while Ron continues to focus on programmatic responsibilities.

Having Tom in place has allowed CCALS to expand our team by adding an additional two staff positions. We have employed a new Assistant Family Care Liaison and Program Specialist, as well as an Assistant Care Liaison/Augmentative Communications Coordinator. Adding these positions allows us to bring new expertise and services to our community, and allows us to reach out to more families while increasing efficiency.



Falmouth Road Race Takes CCALS to new heights!



This year Compassionate Care ALS set an organizational record for the amount of money we raised at the Falmouth Road Race. Our \$414,000 total made us the second highest fundraising charity at the 2014 race and eclipsed our previous record of \$305,000. There were 145 runners on 46 teams who ran the race wearing CCALS colors. They were supported by countless other team members, fans, friends and fundraisers. This year's pre-race dinner held at the Sea Crest Beach Hotel was an especially festive affair with a photo booth and over 130 people attending. After the race the post race party at the Beach Rose Inn in Falmouth was the site of Ron Hoffman's completion of the Ice Bucket Challenge.

David's Old Silver Swim sets a new record!



On Sunday, August 9th, 2014, Compassionate Care ALS held the fourth annual David's

Old Silver Swim. This year's swim was the most successful to date, raising over \$47,000 in support of CCALS's programs. The swim was organized by friends & family of David Garber, a Falmouth resident who was diagnosed with ALS in 2010. There is a one-mile and half mile loop course in North Falmouth at Old Silver Beach, which starts and ends at the Sea Crest Beach Hotel. This year, we had 200 swimmers participate. CCALS would like to sincerely thank the Garber family, race committee members Ali Brubaker, KR MacDonald, Rob Catalano, Joanna Levy, JoAnn Fishbein and all the volunteers and participants!

CCALS holds 2nd Annual Youth Retreat sponsored by the Ed McKenney Youth Fund

During the weekend of September 12-14, young people whose lives have been impacted by ALS attended our youth retreat. The event was a huge success as they enjoyed a campfire, S'mores, nature walks, Tai Chi, great food, making friends, becoming part of a community, a ferry ride to and an afternoon on Martha's Vineyard, and a Corn Hole tournament. It was a nice break for the young people and several have already reserved their spots for next year.



Gaby and Lily had a whale of a time on the Vineyard.

The Johnson sisters enjoy the view on the way to the Vineyard.

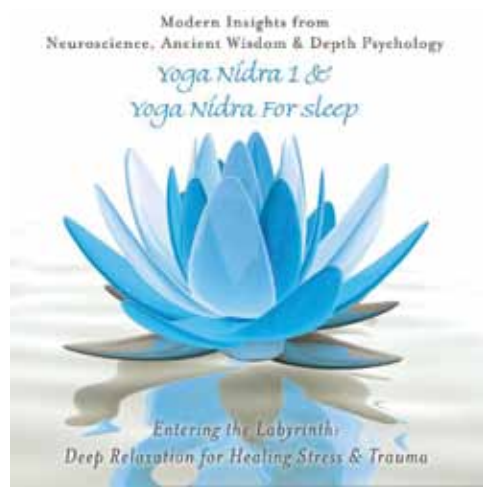


In Memory Of...

Glenn Andrews, Pascoag, RI
Virginia Cangemi, Saugus, MA
Demetra Caracostas, Canton, MA
Mr. Chase, North Reading, MA
Jerry Couture, Springfield, MA
Ken Douglas, Fairhaven, MA
Tim Farthing, Portsmouth, RI
Rich Grant, Hudson, NH
Therese Haskins, Savoy, MA
Bill Hogan, Scituate, MA
Ronald Hurston, Wayland, MA
Jon Imber, Somerville, MA
Ernest Kampersal, Holliston, MA
Todd Ketchum, Newton, MA
Ginger Klinefelter, Framingham, MA
Olga Lysenko, Brighton, MA
Holly Ladd, Newton, MA
Anne Maratta, Stoneham, MA
Maria MacLeod, Ashland, MA
Paul McCarthy, Stoughton, MA
John McCormack, Peabody, MA
Siobhan McDonnell, Portsmouth, RI
Jacky Modelevsky, East Falmouth, MA and Sharon, MA
Lorraine Mottola, West Warwick, RI
Mary Murray, Braintree, MA
Ed Pane, Bedford, NH
Bob Powers, Eastham, MA
John Raineri, Marston Mills, MA
John Regan, Boxford, MA
Kathy Rivers, Burlington, MA
Mary Lou Roberts, Weston, MA
Joe Sawyers of Pepperell, MA
Edward Scampoli, North Providence, RI
Andy Scott, Norwell, MA
Annie Smith, Rindge, NH
Michael Soullier, Sr., North Attleboro, MA
Candido Surita, Dorchester, MA
Linda Treadwell, Claremont, NH
Barbara Ward, Worcester, MA
Kevin Waters, Tiverton, RI
Mike Westcott, Cohasset, MA
Brenda Whitmore, Biddeford, ME
Dale Whitney, Marshfield, MA
Paul York, Norwell, MA
David Zuretti, Northborough, MA

Guided Meditation for Healing Stress and Trauma: Entering the Labyrinth

As Director of Education & Program Development at CCALS, Julie Brown Yau coordinates closely with hospital staff, care givers, and chronically ill patients. Her focus on meditation and contemplative practices brings a unique perspective and source of strength to those with whom she works. Julie's knowledge and experience of Wisdom Traditions, Neurobiology, and Depth Psychology shine through in her new CD "Entering the Labyrinth: Deep Relaxation for Healing Stress & Trauma." Each track guides the listener in a Yoga Nidra meditation which promises to relieve bodily and psychic stress and to rejuvenate the spirit by bringing the listener into a state of deep relaxation. Navigating the ins and outs of ALS care can feel like a maze at times, but Julie reminds us that in a labyrinth, though we may weave back and forth, with each step we move closer to the center, where peace is found. Julie's new meditation CD "Entering the Labyrinth" is available online at www.cdbaby.com/cd/juliebrownyau. Her second Yoga Nidra meditation CD will be on sale soon. She can be contacted at julie@ccals.org. To learn more about Julie's work visit www.embodied-wisdom.com.



A Granddaughters' Perspective

The Benefits of Having An Expiration Date

By Emma Elizabeth Higgins, age 14, granddaughter of Elizabeth Ferreira

Most people fear death, fear the unknown. It seems impossible that one day all of us, our loved ones, everyone, will just be gone. I am admittedly one of those people, but I also understand the benefits of having an expiration date. I don't want to die, but I certainly don't want to live forever. When my grandmother was diagnosed with ALS (or Amyotrophic Lateral Sclerosis) I was heartbroken. ALS is a neuro-degenerative disease that affects nerve cells in the brain and the spinal cord. It has a 100% fatality rate. Victims slowly lose motor control until the later stages in which they are paralyzed. They reach a point where they cannot eat, drink, or talk. For my grandmother, it started at her feet which gave her more time than most (five years) because the disease had to work its way upward. I spent more and more time with her when my mum explained to us about her disease because I knew that our time was limited. In our time together I learned more about her than I ever would have expected. She told me stories until it became hard for her to speak. Stories of her incredible life. From the farm she grew up on, to the birth of her triplet daughters. Always remaining positive. Even though I would prefer to still have a grandmother that I can visit, it brings me peace to think about all the extra time we got together. The time I treasured because I knew it was finite. Her death made me think about the fact that we all only get so little time. And I don't want to die without having lived

first. This realization pushed me to work harder so that I could start shaping my future. It's the reason I've written so many stories in order to improve my writing, and spent so much time working on my acting. They're the things that I can see myself spending my life happily and passionately doing. I don't want to be a twenty year old living off ramen noodles and faith because I am still waiting for my life to start. My life has to begin now. I can't put off the big things for too long because no matter how hard I try, I'm not going to live forever. I don't want to wait until I graduate high school or go to college, or until I retire. My friends and family won't be here forever so I should spend my time with them. Spend time being delighted instead of merely being. You can spend your entire life planning for the future, but it only means anything if you actually go ahead and do it. Knowing that you don't have all the time in the world can push you. I'd rather take a leap of faith and fall on my face than spend my entire life wondering how things could have been. Accepting that every story has an end means that you have to strive to make it a story worth living."

Please support Compassionate Care ALS. They provided my Grandmother with the ability to stay involved with her family. Everything CCALS did helped her live while she was dying.

Thank you Emma-we love you-Ron

Leadership Gift Club

The CCALS Leadership Gift Club has continued to grow since it was founded in 2009 with 61 members. This year we had 540 individual donations of more than \$250 during the course of the year. We are truly grateful for the support from our donors. The list was compiled from October 1, 2013.

Compassionate Pioneers (\$1000 and over)

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