

CCALS

COMPASSIONATE CARE ALS

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Cares

f @CompassionateCareALS t @comcareALS

FALL 2018

Compassionate Care ALS announces first fundraising walk

Compassionate Care ALS is excited to announce our first fundraising walk.

Stroll & Roll for CCALS will be held at 11am on Saturday, May 18th 2019. The 2 mile walk will stretch along the scenic Shining Sea Bike Path in Falmouth and past our new

Education and Retreat Center. Stroll & Roll festivities will be held at nearby Bourne Farm and will include music, food, games, and fun! Visit ccals.org for updates and announcements for the 2019 Stroll & Roll for CCALS!



Mariah Fenton Gladis



Mariah Fenton Gladis

Throughout our travels, CCALS has met many exceptional people. One such person was Mariah Fenton Gladis, who passed away suddenly this year. Despite being diagnosed with ALS in 1981 and being told she had 6 months to 2 years to live, Mariah got married, had

two sons, and built a thriving therapy practice. As a trained Gestalt therapist, she practiced a patient-centered approach to psychotherapy that helps clients focus on the present and understand what is happening in their lives in the moment rather than focusing on the past. Patients reenact past situations and become more aware about how past thought patterns block true self-awareness and cause discord in the present.

Mariah was the Founder and Clinical Director of the Pennsylvania Gestalt Center for Psychotherapy and Training. She received a Social Worker of the Year award from NASW, a Living Legacy Award from Women's International Center, and an International Stevie Award For Women In Business. She authored *Tales of a Wounded Healer*.

Mariah has been an inspiration to CCALS since Ron Hoffman met her many years ago. In July of 2017 she came to Falmouth to present her workshop "Arrive Already Loved" to the CCALS community and was met with resounding support. In addition, she provides a powerful example of living life to the fullest with ALS. After her diagnosis, she began a nutritional regimen supported by various natural and alternative healing modalities that work in tandem with the drug therapy. She said, "Through my personal healing odyssey, I've accessed a wealth of intuitive wisdom, love and compassion that not only has made me a better person, but also has deeply sensitized me to the healing needs of others." We will miss you, Mariah.

In Memory Of...

Richard Allendorf, Norwood, MA
Gary Alsheimer, Plymouth, MA
Carolyn Baker, Hudson, MA
Cynthia Barlow, Shrewsbury, MA
Henry Bennett, Laguna Woods, CA
James Broquist, North Grafton, MA
Janice Cheshire, Jamaica Plain, MA
Theresa Clifford, Milton, MA
Gene Connolly, Concord, NH
Marsha Cosetllo, Yarmouthport, MA
Sean Neil Curtis, Manchester, NH
John "Jack" Drago, Boxford, MA

John Driscoll, Salem, MA
Steven Firstenberg, Milton, MA
James Flaherty, Maynard, MA
Susan Flaherty, Lincoln, RI
John Gaydos, Coventry, RI
Gail Giblo, Douglas, MA
Margaret Gillis, East Dennis, MA
Mark Gionet, Concord, MA
Greg Graziano, Acton, MA
Donna Greenleaf-Grzywacz, Merrimack, NH
John Hayes, West Yarmouth, MA
John Hines, Troutville, VA

Ken Johnson, Mendon, MA
Allen "Butch" King, Salem, MA
John Martin, Newton, MA
Mike McDuff, Westport, MA
Jay Mollo, Grafton, MA
Danielle Kurtzer, Norton, MA
Paul Lapierre, Worcester, MA
David Mitchell, Brentwood, NY
Robert Naud, Norfolk, VA
John Neugent, Taunton, MA
Noreen O'Neil, Tewksbury, MA
Jamie A. Robitaille, Hanson, MA

Mark Rosen, Sudbury, MA
Antonio Semenilli, North Merrick, NY
Joshua Shafer, Brookline, MA
Judy Smith, Norwood, MA
Nina Smith, Middletown, RI
Stephen Smith, Dennis, MA
Kit Taylor, Wenham, MA
Donald Vincent, Dunstable, MA
Greg Van Vliet, Bridgton, ME
Elsie Wilmerding, Boston, MA
Sylvia Woodhouse, Natick, MA

Showering Runners with love for 40 Years



Phil and Meg Robertson before the 2017 Falmouth Road Race

For over 40 years, Phil Robertson provided Falmouth Road Race runners a spot to cool off as they passed his family's summer home. Phil would position his six-foot ladder and gardening hose along the left side of the race route and wait for motivated runners to approach the five mile mark. Over the years, returning runners

looked forward to seeing his straw hat and flannel shirt as they came around the Clinton Ave bend.

"I am not sure how this tradition started, but it has to be over 40 years of my father doing this. All I remember is him setting up his ladder and hose every year since I was three or four years old."

In between hosing down runners, Phil would also set up for the annual after-party held at his house. The Robertson's summer home was a welcoming spot for family, friends, and the CCALS community. Meg says of her parents, "it was so natural for them to open their door to everyone, especially the day of the race." Whether it be for someone to use the bathroom, cool off from the hot summer heat, or just to hang out and catch up, the Robertson's door has always been open.

After her father's unexpected passing this February, a family member asked about the fate of the ladder tradition at the 2018 Road Race. "This has become such an iconic thing for him. He is known for so much, both big and small, but this is one of the big- little things he was known for," Meg explains. Meg and her mother quickly decided to set out one of Phil's plaid t-shirts and

his straw hat. On race day, Meg carefully set up the gardening hose and took her perch atop the ladder to shower individuals with water as runners passed their house for the 45th time. This year's race was an overcast 60 degree day, but after five miles runners appreciated the cool mist and cheerful encouragement.

Once Meg was up on that ladder the sadness she felt that morning disappeared. She understood why her father's interaction with runners was his favorite part of the day. New and returning runners shouting out "I love you," "thank you," and "you are awesome" was just what Meg needed. The positive energy was uplifting and inspiring to receive. Meg was not the only family member to celebrate her father's tradition. Meg's cousin, Andi, was visiting from Texas and relieved Meg from her post when she needed a break. Andi jumped right up with a smile, eager to interact with runners. Andi and Meg developed a new appreciation for their uncle and father for doing this solo for so many years.

"It was hard but wonderful all at the same time," Meg says about carrying on her father's tradition. That morning when she woke up she knew she had a long and overwhelming day ahead of her. What kept her motivated was the fact that she was doing this for her father and carrying on his legacy. Family, friends, and loved ones gathered at the Robertson's house to celebrate Phil and enjoy time together. "That day I felt like I was carrying on a tradition, for this race, my father, and this family gathering."

The connection between the Robertson family and CCALS starts from the very beginning when Executive Director, Ron Hoffman was a caregiver for Gordon Heald. Gordon and Phil became best friends in their early 20's and this relationship continued as their families grew. Phil's wife, Anne Newell Robertson, and Gordon's wife, Betsy Heald, are long time childhood friends who attended school together from kindergarten through college. Between Phil and Gordon performing together in the renowned Sangerfest Concert Choir to family vacations together, the Healds and Robertsons have been family friends for over four decades. Ron met the Robertson's through Gordon and Betsy and throughout



Phil Robertson sprays runners from his familiar perch during the 2017 Falmouth Road Race



Meg Robertson honoring her father during the 2018 Falmouth Road Race

the decades became a close friend. “Ron has always been there, he will just stop by to check in or to say hi. CCALS has been a big part of all of our lives for so long.”

Compassionate Care ALS was in high spirits on Sunday, August 19th as we joined the Robertson family in front of their house for the 17th year in a row. This has been an iconic spot for CCALS families and friends where chairs and signs are set up to cheer

on runners and hand out water. As the CCALS team and several families stayed warm and energized with coffee and donuts, we were overwhelmed with joy to see Meg standing on the ladder just like her father. CCALS is thankful to the Robertson family for opening their home to CCALS for the past 17 years. We are excited and honored to see this tradition being passed down to the next generation for years to come.

Thoughts From Ron...

The Words We Choose

Over the course of 20 years doing this work, I continue to be reminded how very important language is. The words we choose to say and when and how we say them make a tremendous impact. When used appropriately, words, ideas and information can be illuminating, comforting and freeing. When used carelessly, or from a place of insecurity, our language can cause needless harm.

For example, some families are not interested in talking about death. They want to focus on living, being excited about a new integrative therapy, hanging out with their children and making every moment last. Our staff emphasizes relationship over information, using our natural instincts to go where people want to go. It's about doing no harm. Communication is a slow and subtle exchange as we navigate the rapidly changing terrain of ALS.

All too often, I encounter healthcare professionals who, in my opinion, are inexperienced or insensitive to helping people navigate a serious illness or end of life. If people in the field have such a hard time, imagine how difficult it can be for family and friends who have no training? I was there myself in the early days of my tending to Gordon Heald. Gordon taught me the basics. I will try to do the same for others.

I do my best not to ask people, “How are you doing?” or “How are you feeling?” It can often bring up the response, “Well how do you think I'm doing? I have ALS.” Questions like, “How's your day?” are often the source of an upset right away. I hear all of the time how these questions can adversely affect people, and I try to avoid them.

I start out by saying, “It's really nice to see you.” If they are working or involved in some project, I ask how that's going. Effective communication with those in difficult circumstances is about knowing who they are. It's taking the time to make a connection, then noticing what's going

on in the moment. It's looking around, being curious about their lives, careers, family, hopes and dreams. Engage with them about who they are. There are no set rules here. It always looks different. Many people are not in a frame of mind to speak about the disease—and honestly, it's not necessary.

In the art of language, the central element is the ability to listen. Just show up with an open heart. If you are new to being with a friend, relative or client with a terminal illness, just be honest. Take the risk to be vulnerable. “I don't know what to say,” is a great place to start. Be with whatever comes next, no agenda, nothing to fix or figure out. Open up and relax. Take a deep breath. If no words are spoken, honor the silence.

If the conversation moves into difficult terrain, slow down and don't make assumptions. Ask permission before asking a probing question. Ask if it's okay to explore this or that. Often I will ask, “Do you want to know what I know?” Asking permission is novel, but I don't think it should be. It comes down to empathy and awareness. Put yourself in the other person's situation. Be sensitive. Learn to know when no means no and move on.

One of the ways I hope to connect and bring calm into people's lives—and possibly make them curious—is to say, “I'm not here to tell you everything you don't want to know.” I say it because it expresses a different point of view. Usually those with knowledge seem compelled to express it, whether wanted or not, relevant or timely. My emphasis is always on the relationship. Developing trust and rapport become the gateways that allow deep and meaningful conversations to emerge over time.

It's not about having answers—even if you do have valid information to share. No two people are alike. No two circumstances will be the same. One person wants to know everything, talk about all of the potentialities and possibilities right away. Another person wants to take them one at a time as they arise, or not at all. Gordon was a wonderful example of a man who made his choices by never making

them. It's a way I often see and have learned to honor.

Last week I visited a woman living in a facility, on a ventilator, unable to communicate. Her daughter arrived and I asked her how she thought things were going with her mom. “Ron, it's in God's hands,” she said. “That's what she's always believed.”

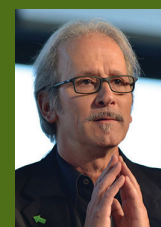
Okay, that was my cue. I heard the sentiment under the words. She wasn't open to talking about end-of-life possibilities. Fine. I didn't bring them up. I did not know this family well and had not had the chance to speak with them about quality of life, which is an important part of the discussion. All I said was, “If things shift and you aren't sure, my team and I are here for you. You don't have to make the decisions on your own.” Just knowing that you're not alone can make all of the difference.

Remember, communication should be on the terms of those in the situation. This is important. We enter the space with humility. We enter in the spirit of service, in the spirit of bearing witness. This is a practice in awareness. We are learning to be sensitive and compassionate, to leave our personal baggage at the door.

If you really want to show up and be of service, the most important step is what you do before you arrive. Take a look into your own heart, into your own mortality and fears. Feel that deeply. Walk into the fire of your wounds and uncertainties. Consider your final days. How do you want to die? What are the blessings you wish to leave behind? Take time for self-inquiry and it will make a world of difference in how you show up for someone with ALS or any other fatal illness. It's a never-ending process of self-inquiry.

Because language is so important.

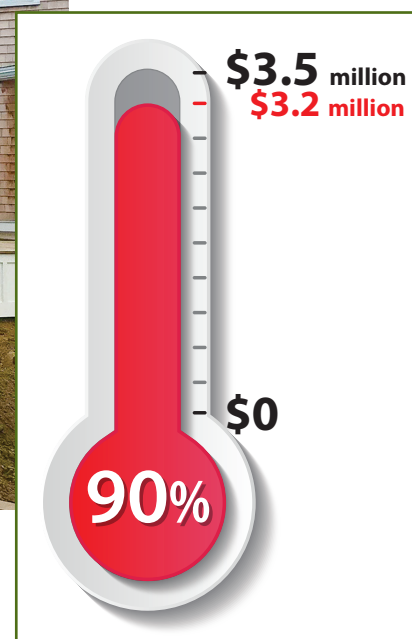
Blessings,

Help us reach the finish line



Compassionate Care ALS Education & Retreat Center



To help us raise the final \$300,000 for our capital campaign we have set up a crowdfunding site www.mightycause.com/story/Ccals-Retreatcenter. The dream of the Compassionate Care ALS Education and Retreat Center (the Center) began in 2001 and fundraising began in earnest in 2014 when CCALS friend Doug Oakley left \$50,000 dedicated for the project. Since then, friends from near and far have supported us to the tune of \$3.2 million.

The Center will be completed by Spring of 2019 and will offer a number of important benefits to the ALS patients, family members, caregivers, and healthcare providers who will use it.

Benefits For Individuals Living with ALS

Individuals living with ALS often suffer due to their lack of mobility; their world becomes very small. They are confined to their house and maybe the occasional trip to the doctor's office. The new facility will be a sanctuary where individuals living with ALS can come to reflect outside of their usual surroundings, in an environment uniquely suited to their needs.

Benefits For Family Members/Caregivers

The stress of caring for a family member with ALS can take its toll on even the most prepared family. Studies

show that the quality of patient care actually improves when caregivers are given proper respite.

Benefits For Healthcare Professionals

The medical community will benefit from the ALS Education and Retreat Center. It will be a resource where healthcare providers can come for educational opportunities, to improve the way they care for, tend to, and sit with those with ALS.

The Center will serve as a handicapped accessible respite location as well as a home for CCALS Educational Gatherings.