



THOUGHTS FROM RON, FALL OF 2023

I was at a fundraiser recently when I felt a gentle tap on my shoulder. I turned to find two tall young men standing there. When they told me who they were, I was taken aback. I had met them more than ten years prior, after their father had been diagnosed with ALS and didn't know when or how to tell his boys about it. They were so young and innocent then. Now here they were, grown up, one of them a college baseball pitcher, the other working in his chosen field. They were thankful for what CCALS had done for their family. I cannot imagine how proud their dad would be of them, were he alive to see what they had become.

What we have become...my, my. I ponder this myself, having reached the age this month of what many would consider a true elder, a man of 70. I can still see and feel the boy I once was—like those young men at the fundraiser—who would have never imagined what would turn out to be his calling when he grew up. He would never have guessed that an offer to become the driver of his boss at the catering company where he worked would have turned into an international organization devoted to caring for individuals and families living with ALS. If I could go back in time and tell that boy what was to be, I think he would have looked at me and said, "What's ALS?"

Good question, Ronnie! What the heck is ALS? In the 84 years that have passed since Lou Gehrig was diagnosed with the disease that would take his name, we still don't really know what it is—but we're getting closer. But do we have a clue about the why?

So, what we do at CCALS is wade into this unsolvable mystery of a disease that has a name but very little else. Research continues at a furious pace. More breakthroughs appear to be on the not-too-distant horizon, and we put all of our hopes and prayers into slowing it further, and eventually finding a cure. Until that day comes, though, somebody has to wade into the unsolvable mystery that is the here and now of that fateful day when a person leaves the neurologist's office with the shocking and traumatic diagnosis—it's ALS. What do you do now? My hope is that you find us. Without delay you turn toward someone who will walk along beside you without hesitation, someone who cares in a gentle way. In a way that feels more like hanging out with a new friend who has some helpful information and a medicine bag of useful tools, and a bit of useful wisdom than being cared for.

That's what I've tried to do in the 26 years since I became Gordon Heald's driver, and then moved in as his full-time caregiver. That's what I learned to do the first time I assisted Gordon up the stairs to go to the bathroom during a party at his home. You walk along with your friend. You don't pull him along or push him this way or that. You get close and tune in. You listen with every fiber of your being. You listen without an agenda, without a selfish need to have the answer or provide the perfect fix.



RON HOFFMAN
FOUNDER

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COMPASSIONATE CARE ALS: A LOOK BACK THROUGH THE YEARS

OCTOBER 30
1998

CCALS is founded

Gordon Heald passes with ALS and his caregivers Ron Hoffman and wife Besty Heald co-found The Gordon T. Heald ALS Fund based on his wishes.



JANUARY
2002

CCALS is incorporated in Massachusetts

The Gordon T. Heald ALS Fund grows into Compassionate Care ALS, a care organization with Ron Hoffman serving 85 families. CCALS currently supports 1,049 active families.



Ron Hoffman back when it all began



2003

Linda Burge, one of the first users of our vans

CCALS Van Program launched

The CCALS Van Program which loans out handicapped accessible vans, began with one donated van in 2003. It has grown into a fleet of 13 vans plus many others which have been donated to families.



AUGUST
2003

CCALS runs the Falmouth Road Race

Three runners, led by Amy McGuinness-Tyer, raised \$3,000 to support CCALS through the Falmouth Road Race. In 2023, 112 runners raised \$325,000. Over the last 21 years CCALS has had 1,353 runners who raised \$4,477,000.

Amy at Falmouth in 2003

APRIL
2005

Cultivating Compassion Workshop Series launched

Introduction of the Cultivating Compassion Workshop Series offering support to ALS patients and their communities.

MAY 5
2011

CCALS hosts our first gala

Three hundred people attend the first CCALS Gala at the Fairmont Copley Plaza and raise \$138,000. Our biannual galas have continued to support our ALS Patient and Caregiver Program, with our 2022 gala raising more than \$420,000.



2018

House Calls Program

MGH Medical staff and CCALS staff visit ALS patients together in their homes to provide comprehensive care.

2019

CCALS Staff expands

CCALS hired our 10th employee in 2019. As of 2023, we currently have 26 employees on staff providing exceptional care to ALS families across the country and the world.

2017

MGH, ALS One and CCALS partnership

CCALS and Massachusetts General Hospital (MGH) developed a mutual release form through ALS One. This form is signed by ALS patients to allow the organizations to share information to facilitate better care.

2013-2018

Building of the CCALS Heald Education & Retreat Center

CCALS launched our \$3.4 million capital campaign to build the CCALS Heald Education & Retreat Center in 2013. Construction was completed and opened in 2018. Since then, CCALS has hosted approximately 200 families annually as well as groups from other organizations for conferences and special events.



JANUARY
2012

ALS Patient Family Caregiver Program grows

CCALS expands, adding three new staff members; Erin Lajeunesse, Travis Schneider, and Shannon Carey. They all continue to be integral parts of the organization today.



David Garber and his family

AUGUST
2011

Garber Swim

After his ALS diagnosis in 2009, longtime Falmouth resident and avid swimmer Dr. David Garber supports CCALS by holding a swim on Old Silver Beach going on to raise over \$1 million in 13 years.

OCTOBER
2019

New York regional office opens

CCALS hires **Chris Curtin** as our Senior Care Liaison for the New York regional Office to allow us to grow regionally. We currently employ three people in the tri-state area.

2020

Speakers Series

CCALS added a monthly speaker series to our Cultivating Compassion workshops featuring prominent individuals speaking on a variety of topics of interest to people living with ALS and their communities.



Roshi Joan Halifax of Upaya Institute

2021

Volunteer Caregiver Program

CCALS developed a Volunteer Caregiver Program led by **James Churches** that trains volunteers in the CCALS model of caregiving. We then match caregivers with our current clients to assist in day to day activities.



OCTOBER
2022

Opening of Colorado Office

CCALS staff expanded into Colorado with two employees to handle increased demand in the midwest. We now have a vehicle and storage facility for equipment in the region.

Brenda Fox, CCALS Grief and Bereavement Liaison, speaks at our Colorado Kick-Off

2023

Steve's Way Partnership communication

CCALS has partnered with Tom Meadows, co-founder of Steve's Way, to bring education around their groundbreaking methods to use the Apple OS for people with ALS who are losing the ability to communicate verbally.



Dr. Julie

Trauma Healing

Trauma Healing is a new monthly gathering developed by Dr. Julie Brown Yau for our community. This workshop will address how traumatic an ALS diagnosis is, and the continuing challenges and trauma that can arise while living with all the complexities of ALS.

MAY 17
2024

CCALS Gala

The 2024 CCALS Gala will be held on May 17, 2024 at the **Park Plaza Hotel** in Boston.

2024
Gala
COMPASSIONATE CARE ALS

THOUGHTS FROM RON, FALL OF 2023 *Continued from front page*

Helping is one thing but being truly compassionate is quite another. Helping implies they need something that only I can provide. Compassion is listening carefully, patiently letting the tale unfold, taking in the intangibles—body language, setting. Compassion is letting the message reach the soul level where intuition resides, noticing if there is a hunch, and sometime later, if time proves the hunch to be true, sharing it with your friend. Compassion is wondering what will truly serve. So often, the most useful caring is to simply bear witness and hold space. That shouldn't be so hard to do, but for many, it is.

I call this the art of showing up. What we choose to say, how and when we say it, I call the art of language. This is what my 70 years has taught me about care...it is not a science. It is an art. Doing it well requires more than anything a great depth of curiosity. Preparing to care is a deep and continual inquiry. If we cannot face our own wounds, our pain, our mortality, those experiences we avoid from our past, then it will be very difficult for us to show up with an open heart and no agenda for others. To be a healer we've got to heal.

These past 26 years, as you can see in the timeline, have been a continual path of change, growth and finding new ways to bring improved programs to the families we serve. It's been a commitment to learning, an eye towards getting better and better at what we do. I continue to be incredibly grateful to Gordon and Betsy Heald for being the catalyst of all that we do, the unfolding of what has come to be my life's purpose. I am deeply grateful for the profound impact CCALS has had on the thousands and thousands of individuals and families we have served. Thank you, always, Gordon and Betsy. You live close to my heart and will never be forgotten.

I hope I can continue to be a calm and healing presence in the lives of those that I serve. To be of service is the greatest blessing one can receive. All of you, my friends, my families, my staff, my board, my dog Maddie—you are my teachers and give meaning to my life. I love you and bow to you.

Sincerely,

IN MEMORIAM

Angelo Cotoni, Westborough, MA
Ann Colonero, Northborough, MA
Anthony Ferolito, Waltham, MA
Anthony DiBartolomeo, Sandwich, MA
Atif Ali, Denver, CO
Bob Majeau, Chelmsford, MA
Bobby Forster, Middletown, RI
Brian Foderaro, Sterling, VA
Candis Hewitt, Jupiter, FL
Carol Garey, Chatham, MA
Chad McClung, Alliance, OH
Charles Finn, Uxbridge, MA
Dale Melanson, Plymouth, MA
David Doran, Robbinsville, NJ
David Pompliano, Marshfield, MA
David Galin, Portland, ME
David Beach, Brooklyn, NY
Deborah Bolduc, Laconia, NH
Deborah Doktor, Waban, MA
Denise Askin, Manchester, NH
Denise Rondinelli, North Andover, MA
Diane Anas, Auburn, MA
Dianne Salcedo, Orange, MA
Doris Gionet, Ashland, MA
Edward Dole, Abington, MA
Edward Mercado, North Kingstown, RI

Elizabeth Robinson, East Falmouth, MA
Ellen Alires-Trujillo, Broomfield, CO
Ellen Wess, Needham Heights, MA
Emmanuel Orfanides, Peabody, MA
Esward D'Elia, South Yarmouth, MA
Eugene Farrell, Leominster, MA
George Mazareas, Nahant, MA
George Hauerstein, Newport, RI
Grace Han, Marlborough, MA
Grace Lomonte, Austin, TX
Jacquelyn Noonan, Cohasset, MA
Jaehyeon Park, Rochester, MI
James Keefe, Arlington, MA
James Demetras, Chelsea, MA
Jeffrey Thompson, Arlington, MA
Jennifer Chavez, Swamscott, MA
Jim Brennan, New York, NY
Joan M. Kenney, Easton, MA
John Fish, Auburn, MA
John Tedeschi, Scituate, MA
John Dubowchik, Little Falls, NJ
John Burke, New Canaan, CT
Julia Eberhart, Chelmsford, MA
Karen Fitzpatrick, Moultonborough, NH
Kathy Brackenridge, New Canaan, CT
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Mariene Ormundo, Danbury, CT
Mary McCarthy, Wakefield, MA
Mary Tornese, Yonkers, NY
Mary Ellen Comeau, Salem, MA
Matt Hogan, Falmouth, MA
Maureen McDermott, Medway, MA
Melanie Perry, Great Barrington, MA
Michael Mishkind, North Bennington, VT
Michael Ernst, Clinton, MA
Michael Chenette, Medway, MA
Michael Levasseur, New Bedford, MA
Michael Zigmond, Falmouth, MA
Nick Zakon-Bourke, Falmouth, MA
Omer Gendron, Lowell, MA
Patricia Haberstroh, Westport, CT
Patricia Dolan, Hanson, MA
Patrick Hawe, Harwich, MA
Paul Baillio, Westford, MA
Peter Emerick, Uxbridge, MA
Preston Curtis, Gloucester, MA
Renier DeBeer, Nashua, NH
Richard Thombs, Tarrytown, NY

Richard Brady, Plymouth, MA
Rita Chad, Southborough, MA
Robert Dyer, Benton, ME
Robert Taylor, York, ME
Robert Vallesio, Carver, MA
Robert Haidul, Canton, MA
Sal Cincotta, Waltham, MA
Sharon Odemool, Harwich, MA
Shawn Kelley, Dover, NH
Sheila Hamilton, Orleans, MA
Shirley D'Este, Falmouth, MA
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Terry Vallette, Loveland, CO
Thomas Long, Livingston, NJ
Thomas Lavin, Meredith, NH
Timothy Connolly, Worcester, MA
Tyler Cline, Cheyenne, WY
Victor Enright Jr., West Yarmouth, MA
Virginia Shekell, Sarasota, FL
Wendy Newcomb, Lunenburg, MA
William Kendrick, Roslindale, MA
William McGovern, Manchester, CT
Xiaozhu "Jane" Zheng, Canton, MA