



HONEY GRIEF PROGRAM – A JOURNEY OF LOSS AND LOVE BEYOND ALS

In a world that is often “grief illiterate,” CCALS offers a unique approach that acknowledges the complexity of loss and ensures that no step in the amyotrophic lateral sclerosis (ALS) journey is overlooked. We believe that love is like the sweetness of honey, while grief is its inevitable counterpart. By weaving these two experiences together, the Honey Grief program provides opportunities for reflection, connection, and a chance to build a new community with those on a similar journey.

The concept of Honey Grief emerged from a simple yet profound moment at a Beyond ALS gathering. One woman who had cared for her husband of nearly 50 years as he declined with ALS and frontotemporal dementia (FTD) shared that sometimes she just wanted to go to the top of a mountain and scream her heart out. Michael Hodgkins, a CCALS Care Liaison, responded, “Let’s make that happen.”

CCALS organized the first in-person “Grief Pilgrimage,” where a group of ten hiked to Inspiration Point—a lookout where they wept, shared stories, screamed, and even laughed. CCALS brought ten of our ‘Hopes & Dreams’ quilts, and during a closing ritual, each participant wrapped themselves

in a quilt to symbolize the embrace of their loved one—a physical reminder that they are still held and supported.

The Honey Grief program continues CCALS’ commitment to offering unwavering and compassionate support for those impacted by ALS. It delves into the deep work of grieving, which is so often neglected in our modern society. Through rituals, celebrations, and moments of shared laughter, we help cultivate a collective capacity to grieve openly.

“Holding the tears, laughter and silence together is something I will always cherish and continue to learn and draw wisdom from... I personally feel a sense of awe that we all showed up and allowed ourselves to be open to letting our pain and our losses, our grief and our love become a powerful force that we collectively and individually were able to hold.” – Susan

This journey allows our experiences and expressions of loss to be transformed into nourishment for the next season of life—welcomed, cherished, and gently celebrated. To learn more about CCALS resources please visit ccals.org/programs.

MOTIVATED TO MOVE: HOW TWO FRIENDS TEAMED UP TO RAISE OVER \$100,000 FOR CCALS



PHOTO CREDIT: LUKE HIGGS

Motivated to Move offers an opportunity to sweat for ALS. The event consists of three individual workouts by three of Charleston's Premier fitness studios including; The Works, The Works Cycle, and Ethos. That's 90 minutes of movement to sweat because you can, for those who can't. Over the three years, this event has raised \$100,000 in support of CCALS and created an unparalleled sense of community.

The friendships and connections forged while living with an ALS diagnosis can change the course of our lives forever. Katie Penta's mom passed away with ALS in 2015. When her friend Keith Benjamin's dad was diagnosed with ALS in 2019, Katie and Keith teamed up to make a difference.

The friends knew they wanted to improve the lives of families living within this disease. "We both saw the impact ALS has on families. We wanted to do something that would benefit the families living through the diagnosis; to make sure that the money is helping people dealing with it right now, with care," Katie explains.

Although Katie's mom passed before she connected with CCALS, Katie was aware of Keith's experience with CCALS Founder/Executive Director, Ron, and the team. "I was connected to Ron right after my dad was diagnosed," Keith shares. "Within a week or two of reaching out to Ron and telling him my dad was in New York, he said 'I'll be there.' And he was. Ron told us 'I'm a yes for whatever you need.' Support, technology, all of it.

"When we were thinking of who to directly work with on this event, I shared my experience with Katie and she immediately said 'Yes, CCALS is the one.'"

Together, they started Motivated to Move, an exercise-focused event that urges participants to move because you can, for those who can't. "Doing this with Katie is really special," Keith says. "She was the first person I was able to lean on when my dad was diagnosed."

What started as an idea to host a spin class to benefit CCALS grew into a three-part workout event that has brought awareness and funds to CCALS families. Last year's sold-out event brought 225 people together to support the cause.

Their advice to others who want to start a fundraiser? Don't bite off more than you can chew and know that you will need time and many hands to make the event a success. It takes work, but the end result is so rewarding.

"The event itself is such a beautiful morning. We have someone local speak on behalf of their family who has been affected by ALS and it always gives me goosebumps. Seeing people push through these workouts and stay motivated and inspired is amazing," Katie says.

Incredible folks like Katie and Keith are a huge reason we are able to provide services and resources to people in the ALS community. As Katie says, "I've been really proud of what we've done. I know the money that we have raised has had a huge impact on families."

If you are interested in starting a fundraiser for CCALS, check out our tips on this page or visit ccals.org/hostevent.



3 TIPS TO HOST A FUNDRAISER FOR CCALS

Launch a fundraiser with family and friends to care for people living with ALS! Scan the QR code to submit event details; we can help by sharing with the CCALS community on our website. Or, attend an existing event at ccals.org/events.

1 Keep it simple
Fundraisers can be a lot of work, especially the first year; it's easier to start simple and grow over time.

2 Recruit help
Get friends and family involved. Delegate tasks and check-in regularly to make sure you're on track.

3 Share with the community
Ask for support from friends, family, colleagues, and connections. Leverage Facebook Fundraising and social media sharing to get the word out!

Scan to Host an Event →



CLIMBING WITH COMPASSION TAKES JASON TO NEW HEIGHTS

CCALS staff member, Jason Chorchos, is no stranger to challenges. So when he saw social media posts for the 29029 Everesting at Stratton Mountain in Vermont, he knew he had to sign up.

The event is simple; hike up the mountain, take the gondola down and repeat on October 25-26. Except that Jason will do this 17 times over the course of 36 hours. His repeated treks will add up to 29,029 vertical feet, the equivalent of Mount Everest, all to support people living with ALS.

"I wanted to find unique and interesting ways to reach my fundraising goal. That's how I came up with the sponsorships," Jason says.

Sponsorships can be purchased in honor or memory of a loved one; Jason will carry a photo of all the ascent sponsors for the duration of his climb. "I wanted it to be very spiritual, a way of

acknowledging the people I'm doing this for," he says. "I want to take them with me on this trip."

Jason's goal for Climbing With Compassion is to support the CCALS community, but during his training he has also forged a deeper connection with himself. "I am currently training six days a week. I've learned a lot about how to respect and listen to my body, when I need a day off or when I can push harder."

We will be cheering Jason on as he climbs this mountain for the ALS community. You can support Jason or follow along on his journey at ccals.org/events/climbing-with-compassion.

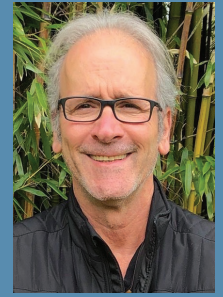


THOUGHTS FROM RON, FALL 2024

The greatest part of CCALS' 23 years of participation in the Falmouth Road Race is seeing how our community steps up. The Road Race has grown to be among our biggest annual fundraisers; this year, our runners raised \$380,000, the second highest fundraising total we have ever achieved. What truly delights me about the Road Race is how it has become such a beautiful expression of our community, who we are, and what we've become together. Many of our 140 runners have been running for years, long after their loved one who had ALS has left us. The memory of those we've lost lives on in the runner's tireless work, the joy and laughter after crossing that finish line.

This year, I saw the joy in the faces of children painting signs during our pre-race dinner. I saw the sense of community this event has created, as 200 of our dear friends gathered at our pre-race dinner to share their experiences and inspiration ahead of the big event. As I looked around the room, I was flooded by memories of families who went through the tumult of an ALS journey. I reflected on the beauty of those who had been through the journey and shared space, love, and connection with those right in the middle of it.

To everyone involved, I say thank you, truly, from the bottom of my heart. Your dedication honors our staff, who work day in and day out to provide the services and guidance that makes CCALS unique in this field. We will continue to do our very best to be there when you need us most.



RON HOFFMAN
FOUNDER

CCALS has many surprises coming this fall, including new staff, new programming, and an exciting announcement about our participation in the 2025 Falmouth Road Race! In the meantime, take care of yourselves. As my dear friend, Sean Lucey used to say before bowing to ALS, "Elongate the joyful moments. Ride them as far as they will take you."

With love and blessings,

Ron

IN MEMORIAM

Frank Albrecht, Lancaster, PA
John Bailey, Medford, MA
John Barrow, Vineyard Haven, MA
Jeff Beagle, Randolph, MA
Rita Bennett, Chestnut Hill, MA
Judy Bergen, Newton, MA
Mary Binder-O'Connell, Bolton, MA
Audrey Boeri, Burlington, MA
Joe Brown, Bourne, MA
Kevin Butler, Brentwood, NH
Gregory "Mike" Campisano, Belmont, MA
Alessandra Campos, Worcester, MA
Richard Carlson, Minooka, IL
Jerry Carnegie Jr., Stamford, CT
Patrick Chamberlain, Seabrook, NH
Everett Chesley, North Reading, MA
Mark Chevrier, Plymouth, MA
Pery Chock, Holden, MA
Catherine Cormier, Gardner, MA
Peter Cox, North Andover, MA
Deborah Cross, Cape Fair, MO
Theresa Cunningham, Lincoln, MA
Richard D'Ambra, North Scituate, RI
Margaret Darlington, Woodstown, NJ
Terrell Davis, Harper Woods, MI
Joan DeCouto, Franklin, MA
Michael Dennehy, West Yarmouth, MA
Henry Desruisseaux, Lebanon, ME

Bobby Devaughan, Barnstable, MA
Irineu Dias, Lynnfield, MA
Mary DiLorenzo, Woburn, MA
Angela Divirgilio, Hingham, MA
Andrew Douglas, Portsmouth, RI
Peter Doyle, Osterville, MA
Linda Drew, Natick, MA
Denise Farmer, Pontiac, MI
Paul Feder, Hastings-on-Hudson, NY
Robert Feeback, Littleton, CO
Rita Fernando, Brighton, MA
Carol Finn, Mashpee, MA
Marian Fleming, Falmouth, MA
Mark Fletcher, Claremont, NH
Marilyn Flores, Chelsea, MA
Robert Fortin, West Springfield, MA
Caryn Foss, Georgetown, ME
Patricia Gallant, Fairfax, VT
Maria Giorgio, Franklin, MA
Skip (Earl) Greaves, Portsmouth, NH
Frank Griffin, Gloucester, MA
Richard Guild, Yarmouth Port, MA
Carol Harris, Truro, MA
Dennis Hawley, Hanson, MA
Kelly Hazell, Oak Bluffs, MA
Macey Hoaglund, Bloomington, MN
Richard Hoebeke, Chelmsford, MA
Bill Holland, West Newton, MA

Steven Horn, Lopez Island, WA
David Hudgens, Jacksonville, FL
Raymond Jasinski, Brewster, MA
Danny Jones, Ponte Vedra, FL
Richard Kelly, Fremont, NH
James Kent, Duxbury, MA
John Kibildis, Newton, NJ
Janice Kiggen, Norwood, MA
Bruce Kinville, Nashua, NH
Morgan Kuhl, Brewster, NY
Cynthia Kuusisto, Amherst, MA
Diane Lessard, Lunenburg, MA
Noel Lavoisier, Augusta, ME
Helen Levine, Orient, NY
Qiangfa "Ken" Li, Hyde Park, MA
Janet Linehan, Cotuit, MA
Debra Lydon, Cohasset, MA
Fida Martinez, Suwanee, GA
James Maxwell, Harvard, MA
John McHenry, Somersworth, NH
Dorothy McMahon, Narragansett, RI
Joanne Merrill, Chelmsford, MA
Daniel Merry, Danvers, MA
Tammy Michaels, Bangor, ME
Maureen Minkin, Hingham, MA
Bernadette Montasse, Boston, MA
Sharon Moylan, North Providence, RI
Tracy Nigosanti, Branford, CT
Anita Nyssonen, Cambridge, MA
Susana Oliveros, Conroe, TX
Sandra Parent, Longmeadow, MA

Sandra Partlow, Sturbridge, MA
Rob Pellegrini, Preston, CT
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Steven Phavorabouth, Worcester, MA
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Kevin Reilly, Weymouth, MA
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Arthur "Pooch" Tavares, Wareham, MA
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Terry Watson, Lake Placid, NY
Rebecca Wentworth, Davenport, IA
Shannon Williams, Lunenburg, MA
Richard (Dick) Wolnik, Derry, NH
Teresa Wood, Irmo, SC
Elaine Yakubian, Salem, MA