



PROPELLED INTO PURPOSE WITH CHRIS AND KATANI

Chris Sumner became an active member of the CCALS community shortly after he was diagnosed in March of 2025. He and his wife, Katani, visited the CCALS Heald Retreat Center, hosted fundraisers for CCALS, and shared their experience of living with the disease with their community.

Thanks to the Heald Center's proximity to the Shining Sea Bikeway, Chris was able to enjoy plenty of restorative time outside on his bike. "It was transformative," Katani told us. "The way the CCALS staff treated us – like we were so important – that's how they treat everybody. We looked at each other and said 'we are going to be raising money for these people.'"

That commitment soon became Propelled into Purpose, an event Chris and Katani hosted with CCALS in April of this year. "It was as much a celebration of our lives as it was providing information to our community, particularly the African American and Latino community, who might not know what this ALS thing is, what the symptoms can be, and what resources are available to everyone."

For Katani, sharing what they had learned was an important part of finding purpose in their experience. "You don't know what you don't know. This is the great bridge that CCALS provides – they know what you need to ask for and what should be available to you. CCALS provided a life preserver in the dark murky waters of this disease."

Chris Sumner was a beloved pastor, husband, father, grandfather, and pillar in his Boston community. Throughout

his journey, he continued giving sermons at his church through a speech generating device. "We take it as a part of our mission. We are believers," Katani told us. "God allowed this to happen to us so let's try to help other people who are in the midst of it. Which I know was part of Ron's mission in the beginning. You're called into your purpose."

Chris passed on July 5, 2026. His obituary states, "His legacy of compassion, leadership, and unwavering commitment to others will continue to inspire generations to come." The sentiment was echoed by Katani when she told us, "Once you become part of this family you did not want to be a part of, you want to help out whoever is coming next. Since we're here, let's try to make it as loving and compassionate of an experience as we can."



Chris and Katani Sumner

THOUGHTS FROM RON, FALL 2026

We've just finished up the Falmouth Road Race with another exceptional event and a record amount of funds raised. How is this possible? It is you, our community, our families, who toil on the race route, but also toil for months and years ahead, reaching out on our behalf. And not just for events like the Road Race, but also, on your own, all over New England and beyond, creating events at an unprecedented level in order to keep our vision of ALS care not just alive, but thriving.

I'm recalling an event from earlier this summer presented by Pastors Chris and Katani Sumner, called "Propelled Into Purpose." Chris was living with bulbar onset ALS, and it was progressing rapidly (he passed in late July). Right in the middle of ALS, mind you – which often makes life about as difficult as it can be – they organized a major fundraiser for us!

Why, you might ask yourself, would they take this on? As Katani said at the event, "We fell in love with CCALS because

of how they treated us, how they took us in and cared for us. No red tape. What do you need? They asked us. And it shows up. Before we even knew we needed it, it shows up."

It was out of gratitude for who we are and what we provide that inspired this amazing couple, their children and worship community to rise above the disease for just a few hours and make what they received available to those who may follow.

Blessings, love and gratitude to all of those on the unique and difficult path of ALS. And thank you, thank you, thank you, for helping us continue to bring what we bring to those in need.


Ron

To read the full article, please visit Ron's blog at ccals.org/blog



Ron Hoffman
Founder

DEEP, DEEP GRATITUDE AND LOVE FOR OUR DEAR BETSY HEALD



It is with tremendous sadness that I say goodbye to my dear friend, Elizabeth Partridge Heald, who passed on June 12, 2026. Betsy, along with her husband Gordon, got me started on the path of creating Compassionate Care ALS in 1997, when I became Gordon's full-time caregiver. I could not be

more grateful to any single person in this world than I am to Betsy Heald. Betsy was incredibly compassionate, had an enormous heart and cared for families living with ALS as deeply as anyone I know.

Through our journey together caring for Gordon, we saw a need, something different in ALS care, and she got behind the vision. Without her and Gordon, this organization, which has now grown to over 32 staff with clients in every state of the U.S. and many countries around the world, CCALS would not have come to be. Because of her commitment, her understanding of just how demanding ALS can be, many, many thousands of lives have been touched by our work. The ripples continue to spread out far and wide, thanks to you, our dear, dear Betsy. — Ron

CCALS BREAKS RECORD AT THE FALMOUTH ROAD RACE

This year Compassionate Care ALS raised a record fundraising amount for the second year in a row. The over \$640,000 we raised will go to support our ALS Patient, Family and Caregiver Program.

Cheryl Cunningham and her children Emma and Dylan with Ron Hoffman at the pre race dinner. Team Mike, in memory of Cheryl's husband, raised more than \$167,000 for CCALS.



FROM SONS AND DAUGHTERS OF ALS TO THE ICE BUCKET CHALLENGE

The CCALS Sons and Daughters of ALS gathering has become an integral part of our Cultivating Compassion Education Series. This gathering provides a space of belonging for individuals who have a parent or close loved one with ALS.

Allison has been participating in the Sons and Daughters gathering since her father was diagnosed with ALS last year. Never having been to a support group before, she did not know what to expect but was met with open arms and has continued to return since. CCALS Founder/CEO Ron Hoffman emphasizes the need to care for loved ones as much as the need to care for the individual navigating ALS.

This sentiment hit home for Allison, who told us, "I felt like I was carrying the weight of the world and I didn't know who to share it with. CCALS has been so profoundly helpful since the diagnosis. They have not only helped my father, but have helped me personally through the Sons and Daughters gatherings."

This summer, Allison launched an Ice Bucket Challenge on her birthday to honor her father and raise money for CCALS.

Friends and family near and far have shared their videos and donated to support our work. She told us, "it has brought so much joy to my family this summer when there has been a lot of pain. My dad is overwhelmed with the amount of generosity. He watches the videos over and over again." Allison's event has been a huge success, raising over \$45,000 to provide care to all those on an ALS journey.



Allison and her dad, Jim.

Look out for a sweet compilation video of all those who participated in Allison's Ice Bucket Challenge on the CCALS website at the end of the summer! For more information on Sons and Daughters of ALS and other CCALS gatherings, visit ccals.org/programs.

A CONVERSATION WITH CHRIS LAMBTON: SHUCKALS 2026

We are so excited for the 4th Annual ShuckALS on October 3, 2026 on the Cape Playhouse lawn in Dennis! ShuckALS is an oysterfest founded by the Lambton family. It is dedicated to their love of seafood, music and philanthropy and in memory of their matriarch, Margie Lambton.

ShuckALS founder Chris Lambton, who lost his mom to ALS in 2008, spoke with us about what he is most looking forward to at this year's event (including a special guest announcement!)

What is your favorite part of ShuckALS?

I love this event because it is super personal to me. Not only is it in my hometown, but I get to celebrate my mom's life and the positives of meeting Ron and the CCALS community because of the journey she went through with ALS. Anyone who has a friend or loved one who has battled ALS knows you're in this sort of family together and it's really nice to meet this family and share stories. Battling a disease is not something you can do alone, it takes a community and thankfully I live in a community that is amazing and gives back so much.



What is new and exciting about ShuckALS this year?

We're excited to share that we are going to have a special guest musician – **Jim Mayer from Jimmy Buffet's Coral Reefer Band!** I'm so excited to have one of my favorite artists of all time there to play – it's going to be incredible.

What would you say to someone who is considering attending ShuckALS?

ShuckALS is hosted in a quintessential, picturesque Cape Cod setting – on the grounds of the Cape Playhouse which is the oldest active running playhouse in the United States. You get some of the freshest, best oysters in the world from literally two miles away, amazing beer, great barbecue, and so much more, all donated by people in the community. Everyone comes together and gives and gives and gives.

We try to make this event family friendly and our children's tent has expanded each year – facepainting, mermaid hair, chicken fingers, and more. I guarantee you'll have a good time if you come to this event and you'll go home feeling good about the community which nowadays is something we really need.



Ron Hoffman with the Lambton family

IN MEMORIAM

Marty Abrahamsen, Arcadia, OK	Daniel Davey, Lansdale, PA	Donald LeBlanc, Colchester, VT	Susan Racine, Center Ossipee, NH
Peter Alberding, Needham, MA	Katie DeGregorio, Falmouth, MA	David Lemanski, Medford, MA	Darcie Riek, Owego, NY
Bruce Alderson, Rehoboth, MA	Bill Devine, Haverhill, MA	Shelley Liston, Shawnee, KS	Paul Ritter, Cherry Hill, NJ
Irene Anderson, Fall River, MA	Martha DiStasio, Quincy, MA	Efrain Lopez, Acushnet, MA	Kathleen Roberts, North Reading, MA
Raymond (David) Ash, Danvers, MA	John Dooley, Raynham, MA	Brian Lynch, Hull, MA	John Robinson, Chelmsford, MA
Sandra Baker, Marlborough, MA	Ed Driscoll, Plymouth, MA	David Marsella, Cranston, RI	Frank Robinson, Nantucket, MA
Olympia Balafas, Newton, MA	Alan Edelkind, Dublin, NH	Steve Marshalek, Dartmouth, MA	Yajahira Rodriguez, Corona, NY
Betty Beckman, Crown Point, IN	Michele Edwards, Salem, NH	Robert "Bob" Martley, Portsmouth, RI	Sheri Rollinson, Novato, CA
Doug Bell, Caribou, ME	Robert Fallon, West Dennis, MA	Dawna Matkevicius, Salem, MA	Bryan Rosica, Doylestown, PA
Tom Berninger, East Boston, MA	Jim Feeley, Lee, MA	Steve McDermott, Lambertville, NJ	Dave Rusness, Fargo, ND
Carol Billings, Shrewsbury, MA	Randall Ferrante, Clinton, MA	Thomas "Tim" McDonald, Bourne, MA	John Russo, Southampton, NJ
Michael Bisol, Atkinson, NH	Frances Finch, New Bedford, MA	Cynthia McGraw, Nokomis, FL	Deborah Rutter, Sandy Hook, CT
John Boyce "Jack", East Boston, MA	Marianne Froese, Walpole, MA	Roy Menendez, Downey, CA	Antonio "Tony" Santos, Andover, MA
David Bradley, Fort Mitchell, AL	Katrina Fuller, Gloucester, MA	Dianna Militello, Beverly, MA	Admir Sarajlic, Mishawaka, IN
Patricia Bradley, Wayne, PA	Neil Gant, Worthington, OH	Patrick Miller, Highland Park, NJ	Deborah Sawyer, Sudbury, MA
Moira Breen, Wayland, MA	Dana Garcia, West Windsor, NJ	Terry Milligan, Cherry Hill Township, NJ	Patricia Scampoli, Plymouth, MA
Bonnie Faulkner Burkhardt, Gloucester, MA	Michael Gates, Cranston, RI	Laura Mitchell, New York, NY	Bharat Shah, Nashua, NH
Edye Caine, Sharon, MA	Andy Goosen, Oviedo, FL	Charlie "Chuck" Moitoza, Norton, MA	Marianna Sharp, Methuen, MA
Anne Carlisle, Dayton, OH	David Gorham, Statesboro, GA	Jeffrey Moore, Delmar, MD	Chuck Shaw, Walpole, NH
Kelly Carlsten, Ringgold, GA	Eileen Gosselin, Northbridge, MA	Mara Moore, Galveston, TX	Carl Shubitowski, Wayland, MA
Tom Carmody, Falmouth, ME	James Graham "Jay", Cohasset, MA	Lori Moyer, Seal Beach, CA	John Silvia, Dartmouth, MA
Robert Cecchini, Woburn, MA	Michael Gravel, Hampton, NH	Judy Mueller, Barnegat, NJ	Chris Sumner, Hyde Park, MA
Laurel Christian, Schaumburg, IL	Mark Gudzak, East Brunswick, NJ	Wil Murtaugh, Syracuse, NY	Candy Sylvain, Stafford, CT
Jeannine Clark, Florence, MA	J. Luis Guerrero, Buzzards Bay, MA	Phyllis Muszalski, Worcester, MA	Michael Thayer, Attleboro, MA
Robert Clements, Brattleboro, VT	Louise Hamel, Orange, MA	Stacey Nanopoulos, Ridley Park, PA	Ben Therrien, Peoria, AZ
Kevin Clohesy, Menomonee Falls, WI	Jay Harris, Newburyport, MA	Susan Nelsen, Kingston, NH	Ron Tracz, North Branford, CT
Christine Coletti, Marblehead, MA	Samuel Harris, Milton, MA	Tom Nelson, Macungie, PA	Kevin Tucker, Prescott, IA
Larry Collins, Malden, MA	Stephanie Henry, New Market, MD	Rachel Nolan, Briarcliff Manor, NY	Linda Tufano, Victor, NY
Hank Conaty, Dighton, MA	Natina Henson, Northfield, OH	Vickie Obermeyer, New Paltz, NY	Janet Turner, South Walpole, MA
Donna Conroy, South Dennis, MA	Bill Hoffman, Medway, MA	Charles Omell, Montville, ME	JoAnn Van Dyke, Millbury, MA
Maureen Conway, Burlington, MA	Leigh Anne Hohlstein, Rumford, RI	Louise Oppedahl, New York, NY	Marypat Velasco, Winchendon, MA
Tania Cordeiro, Westport, MA	Linda Hoover, Ambler, PA	Scott Oremland, Hopkins, MN	Charles West, Smithton, PA
Christiane Cost, Blacksburg, VA	Becki Jameson, Drexel Hill, PA	Ann Pasky, Atlanta, GA	Douglas Wheeler, Harwich, MA
Guy Costello, Warren, OH	Bill Jatkevicius, Hyannis, MA	Louis Paveglio, Homosassa, FL	Cathie Wilkins, Langhorne, PA
Melanie Craig, Morristown, NJ	David Jespersen, Nashua, NH	Christine Pechner, Cary, NC	Ted Winston, Swampscott, MA
Robert Creemers, Tampa, FL	David Johnson, Newcastle, ME	Robert "Bob" Piana, Franklin, MA	Priscilla Wolf, Lakeville, CT
Laura Croasdale-Martin, Orlando, FL	Ed Kaplan, Framingham, MA	Francesco Politano, Arlington, MA	Keith Wood, Brooklyn, NY
Xonia Cura, Union City, NJ	Paula Kelberman, Philadelphia, PA	Bruce Porter, Pine Grove Mills, PA	Roy Woodlief, Garner, NC
Susan Cushing, Roslindale, MA	Paul Koch, Chelsea, NH	Bill Post, Waldoboro, ME	Nicholas Wray, Brooklyn, MI
Nick Dagenais, Dartmouth, MA	Sarah Koopus, Edgecomb, ME	David Puka, Wilmington, DE	Karen Wytas, Ludlow, MA
Regina Dahl, Cave Creek, AZ	Walter Kosloski, West Harwich, MA	Eric Rachdorf, Nashua, NH	Shirley Zaczek, Union City, PA
	Alexander Kosov, Plano, TX		Nikolai Zhitenev, Germantown, MD
	Bo Hing Lau, Brighton, MA		