



THE INSPIRING OUTLOOK OF CCALS CLIENT, TOM HODGES

"It's all a matter of chasing the light. There is a lot of darkness that can pop up with an ALS diagnosis, but the light is there if you keep looking for it."

Compassionate Care ALS provides guidance for families living with ALS, and in turn our families give us beautiful perspective on how to perceive each day. Tom Hodges and his wife have been an inspiration to our staff and their three children as they continue to live life to the fullest.

Tom was diagnosed with ALS in October 2019 in the midst of supporting his wife, Jenn, through chemotherapy with breast cancer. Stepping into the unknown world of ALS can be overwhelming, but after connecting with CCALS Founder/ Executive Director, Ron, they were relieved by all of the resources CCALS offered.

"CCALS has been incredibly helpful providing not just equipment, but all the information to help us navigate this illness," Jenn says.

Tom has continued to show up for his family with the help of CCALS. Renovations that made their home wheelchair accessible, nutritional support with daily Ka'Chava Superfood, and a toilet with a bidet and a lifted seat have all helped Tom maintain a sense of independence.

Tom's enthusiasm to adapt to new challenges has been a constant in his life. Years of balancing a career in real estate, staying physically active with multiple hobbies, and enjoying quality family have given Tom the ability to be flexible and live a dynamic lifestyle. Tom has modified his life in a way that's fulfilling while living with ALS.

An ALS diagnosis has also shined a spotlight on what matters most to Tom and his family. Tom finds joy in watching his kids compete in sports, hosting friends for dinner, escaping in a book, and going on family walks with their two golden retrievers.

The Hodges family takes life one day at a time. As Jenn describes it, "If you watch nature and think about the seeds in the ground during winter – things will bloom again in the spring... each day we find that in the small wins or when we see our kids have those wins."

We at CCALS are so proud to support Tom and his family as they continue to celebrate the small wins and bring a sense of possibility to each new day.

THOUGHTS FROM RON, SPRING 2024

As our caseload continues to grow, we find more young families joining our community. These instances when someone in their twenties, thirties, or forties receives an ALS diagnosis get our attention. The tragedy that is ALS feels beyond cruel when a life just gaining traction is, in a sense, knocked completely off the track.

The circumstance usually involves the enthusiasm of what lies ahead together, plans for a family, dreams of big accomplishments and so forth. It all feels so natural, almost a right of youthfulness, to have that vista spread out before us. Then along comes the uninvited guest of ALS holding up a big sign, "Road closed. Detour ahead."

And man, is it ever a detour. What may have appeared as a smooth, well-paved road veers into the outback with potholes and rocks, gullies, a tree down blocking the way, and what can feel like no path forward.

There may be a sense of futility. How is this possible? Who's to blame? Why me? It can be an incredibly oppressive time that reminds me of an important stage in Joseph Campbell's hero's journey. The hero has gotten lost in a dark woods and is ready to give up the quest. At just that moment, a wise elder shows up with a little magic that helps the hero to carry on.

I would like to think, in all humility, that Compassionate Care ALS can play that role in the particularly tragic, heroic journey that is ALS. We might show up early on with a few simple tools or a bit of wisdom to make these new challenges a little smoother. We might provide some knowledge that brings clarity to the sometimes vague and complicated landscape ahead. The real magic,

I believe, is our ability to walk alongside our friends, be they living with ALS or caring for someone, with calmness and an open heart. We don't have a magic wand, but being able to see that a hero's journey is taking place can be transformational.

Our hero is being challenged to be okay in not knowing and not having answers. To be okay with what it takes real courage. The quest here is to embrace the reality of the experience we find ourselves in—be in the reality and not close down. Yes, the road ahead we thought was promised has been closed. We have to take a detour.

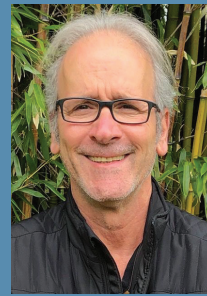
Is it a tragedy or an opportunity? Do we give up on life or learn how to live it differently? Do we harden our hearts or let ourselves be cracked open, and feel all of the emotions—the anger, sadness, grief and the immense beauty and joy that is waiting just around the corner?

Everyone's ALS journey is unique. No two unfold in the same way. However it goes for you, we are here for you. We are blessed to know you and to be of service in your journey of discovery, awe and wonder, profound letting go, and if we're lucky, peace and joy.

In Service,



Ron



RON HOFFMAN
FOUNDER

CULTIVATING COMPASSION EDUCATION SERIES

Our Cultivating Compassion Education Series shares with others the knowledge that we have gained caring for and supporting individuals living with ALS, their families and their communities. Cultivating Compassion helps to improve effective communication among individuals living with ALS, families and healthcare professionals, while shedding light on the realities of living with and dying of ALS. The gatherings and workshops offer a myriad of ideas about caregiving immersed in an experience of connection, belonging and common ground.

Check out our ongoing gatherings:

- Trauma Healing
- Veterans Living with ALS
- Mothers of ALS
- Caregiver to Caregiver
- Women of ALS
- Men of ALS
- Sons and Daughters of ALS

- Beyond ALS: An intimate gathering for those who have begun new lives after loss
- Honey Grief and Healing Hearts



ccals.org/cultivating-compassion

2024 Gala

COMPASSIONATE CARE ALS

CCALS BEJEWELED GALA

Get ready to dazzle for a difference at the 2024 CCALS Bejeweled Gala! Join our host, Natalie Jacobson (former WCVB-TV anchor and reporter), and the CCALS team at the Boston Park Plaza on May 17, 2024.

Delight in delicious hors d'oeuvres, dinner, and creative concoctions from our open bar cocktail reception. We invite you to bid on incredible items in our silent and live auctions, hear powerful stories of Compassionate Care ALS' work

throughout the years, and connect to the Amyotrophic Lateral Sclerosis (ALS) community.

This creative black tie event is the perfect opportunity to don jewel tones and gemstones and get out on the town!

The event will feature live music and dancing from East Coast Soul, a Boston-based band. Your attendance and support will provide care and resources for families living with ALS.

Scan to buy tickets
and view auction items



IN MEMORIAM

Eileen Abenm, Braintree, MA
Seena Abrams, Brookline, MA
Mamoun Al Najjar, Woburn, MA
Atif Ali, Denver, CO
Chris Allen, Harvard, MA
Paul Almeida, Cohasset, MA
Thomas Altieri, Narragansett, RI
Laurie Altschuler, Jericho, NY
Grace Alvarez, Lawrence, MA
Andre Bergeron, Gardner, MA
Patricia Bergin, Pelham, NH
Sharon Billings, Natick, MA
Robert Bourne, Randolph, MA
John "Jack" Burgoyne, Myrtle Beach, SC
James Cahill, West Roxbury, MA
Ellen Campbell, Belchertown, MA
Mario Capparelli, White Plains, NY
Glenda Carling, East Freetown, MA
Jennifer Chavez, Swampscott, MA
Sal Cincotta, Leominster, MA
Linda Clain, Springfield, MA
Elena Coccio, Cranston, RI
Joe Coghlan, Mullica Hill, NJ
Martha Collins, Newburyport, MA
Anne Colonero, Northborough, MA
Leo Cooney, Stoughton, MA
Angela Csezmadia, Lake Ariel, PA
Regina Daly, Melrose, MA
Michael DaPonte, Marshfield, MA
Jeffrey Davis, Greenville, SC
Jeff De La Beaujardiere, Boulder CO
Diane DelBonis, Jamestown, RI
Henry Desruisseaux, Lebanon, ME
Marie Didomenico, Cambridge, MA
William Dobbin, Boston, MA
George Drallos, Highland, MI
Paula Duston, Chesterfield, NH
Donna Eaton, Old Saybrook, CT

Shirley Ellis, Chatham, MA
Bruce Ellsworth, Hopkinton, NH
Paul Eno, Woonsocket, RI
Victor Enright Jr., West Yarmouth, MA
Mark Eskanos, Aurora, CO
Peter Farenwald, Gloucester, MA
Claire Ferrara, Revere, MA
Maureen Fitzgerald, Westfield, MA
Donna Fleury, Amherst, MA
Leny Floresca, Buena Park, CA
Lawrence Forman, Cherry Hill, NJ
Patricia Francis, Nashua, NH
Lisa Freedman, Shrewsbury, MA
Evelyn Fuentes, Springfield, MA
Patricia Gallant, Fairfax, VT
Dr. David Garber, North Falmouth, MA
Lee Getty, Nashua, NH
Virginia Gianelis-McDonough, Hanover, MA
Doris Gionet, Ashland, MA
James Glass, Plymouth, MA
Katherine "Keiko" Goulet, Burlington, CT
Gertrude "Trudy" Grava, Lynnfield, MA
Gayle Grayson, Plymouth, MA
Henry Greenberg, Foxboro, MA
Kevin Grimmer, New Hartford, NY
Sheryl Griswold, Springfield, MA
Harold Grossman, Wantage, NJ
Colleen Guertin, Barre, MA
Richard Guild, Yarmouth Port, MA
Elizabeth Hackbarth, Franklin, MA
Laurie Halloran, Brookline, MA
Mathew Hamilton, Kingston, MA
Grace Han, Sudbury, MA
Gary Heldenbergh, Burlington, MA
Peter Hermann, Chestnut Hill, MA
Douglas Jensen, Makawao, HI
Barbara Johnson, South Dennis, MA

Catherine Jordan, Greenville, SC
Marie Justice, Bellingham, MA
Joan Kaltsunas, Stoughton, MA
Jennifer Kelly, Salem, MA
Frances Kimball, Kittery Point, ME
George King, Boxford, MA
Bruce Kinville, Nashua, NH
Susan Klaw, Watertown, MA
Ron Kostenbauer, Camarillo, CA
Lawrence Labadie, Chepachet, RI
Estela Lane, New Limerick, ME
Thomas Larkin, Wilton, CT
Alan Larrivee, Worcester, MA
James Larson, Marshfield, MA
Joseph Lehane, Wakefield, MA
Raymond Lelievre, Littleton, MA
Diana Levin, Freeport, ME
Immacula Lherisson, Brockton, MA
Debra Lydon, Cohasset, MA
Peter Macaulay, Bellingham, MA
Edwin Magnus, Johnsbury, VT
Kelli Magoon, Harmony ME
Gary Marcolina, Waltham, MA
Jim Masiello, Marlborough, MA
Amy Mattos, Hingham, MA
William McGovern, Manchester, CT
Doris Medici, Warren, RI
Jose Mendez, Valley Stream, NY
Edgar Mercado, North Kingstown, RI
Marcia Messina, North Adams, MA
Eileen Minkley, Holyoke, MA
Stephen Moss, Billerica, MA
Jane Moyer, Concord, MA
Jennifer Mulligan, East Hampton, NY
Patricia Murphy, Bridgewater, MA
Anan Natarajan, Bloomfield, CT
Paul Neronha, Fall River, MA
Janice Nickerson, Exeter, NH

Sharon Oudemool, Harwich, MA
Paul Palmariello, Mashpee, MA
Bharat Patel, Middletown, NY
Marsha Pavao, East Wareham, MA
John Perreault, Conway, MA
Marlene Peterson, Somerset, NJ
Bonnie Placzek, Granby, MA
Victoria Purdum, Lewiston, ME
Robert Quirk, Blackstone, NJ
Luis Quiyu, East Windsor, NJ
Richard Razumny, Bedford, MA
Jimmy Resendes, Medford, MA
Rosemary Roca, Norton, MA
Bruce Rosenblum, Somerville, MA
Arline Ryan, Norwood, MA
Anna Sanko, Rockville, CT
Charlie Sedell, Waterford, CT
Kevin Sharp, Corpus Christi, TX
William Shea, Marlborough, MA
Virginia Shekell, Sarasota, FL
Edward Sheldon, Gardner, MA
Jim Sheriden, Middleton, MA
Michael Smith, Washington DC
Sherrill Smith, Schenectady, NY
Christine Souza, Lowell, MA
Catherine Stalter, Stamford, CT
Sandra Stephens, Owens Cross Roads, AL
Leslie Straus, Salt Lake City, UT
Arthur Tavares, Wareham, MA
Peter Terrizzi, Middleboro, MA
James "Greg" Thomas, Emory, TX
Teri Tiffany, Grand Rapids, MI
Alvro Urrea, Hondouros
Mark Van Shenhof, Port Washington, NY
Angelis Vlahou, Hudson, MA
Gail Walter, Quincy, MA
David White, Becket, MA
Gregory Yankosky, East Boston, MA

FALMOUTH ROAD RACE

Team Spotlight - Margaret's OARS



The iconic Falmouth Road Race is set for August 18, 2024 in beautiful Falmouth, Massachusetts. This year marks the 23rd time that CCALS friends and families will run the seven mile course. Among them stands a remarkable new team, Margaret's OARS, named in honor of Margaret Dutch. Margaret is a beloved figure in the South Shore educational community.

The Margaret's OARS team name is based on an acronym, "Opportunity, Achievement, Relationships, and Standards". These values reflect Margaret's leadership and impact during her tenure as principal at South Shore Technical High School. Driven by a desire to honor Margaret's legacy and support those affected by ALS, Margaret's OARS have embarked

on a fundraising journey with outstanding success. In just a month, the 16 runners have raised close to \$20,000 from their very passionate community.

As the Falmouth Road Race draws near, the team plans to maintain momentum through group fundraising endeavors, including a gathering at a local restaurant, a walk-a-thon at their school, and a cornhole tournament. They also plan to host team training sessions as the weather gets warmer.

Margaret noted that the team's commitment fills her with gratitude. "As a show of support to me, their fundraising efforts for Compassionate Care ALS will have an immediate and positive impact on the lives of those of us living with ALS. Not all heroes have capes, and not all angels have wings. Some walk among us as educators. I am so fortunate to have had them as colleagues and friends," she says.

Looking for another way to support CCALS? Help our runners meet their fundraising goal by making a donation today!

Donate today at ccals.org/frr-donate



OTHER EVENTS



Aces Fore ALS - July 17, 2024

Join us for our 2nd annual Aces Fore ALS, a golf tournament founded by CCALS Client, Justin Soares. Justin

was diagnosed with ALS in October 2021 and he is giving back by organizing this scramble golf tournament at Pinehills Golf Club in Plymouth, MA. To learn more, visit ccals.org/aces-fore-als.



David's Old Silver Swim - August 10, 2024

Make a splash for the 14th annual David's Old Silver Swim! Dr. David

Garber was the inspiration and driving force behind the Swim. Come and honor David by participating in the first swim since his passing in October of 2023. Choose from a mile or half-mile competitive swim or the half-mile fun swim on the beautiful Old Silver Beach from the Sea Crest Beach Hotel. Sign up to swim at davidssoldsilverswim.com.



Putt for ALS - August 26, 2024

This 3rd annual golf classic is hosted by Heaven Sent Home Care of Nashua, NH. Whether you want to golf in the scramble-style tournament or join for the

benefit dinner afterwards, there is a spot for you! Find more information at puttforals.org.



ShuckALS - September 28, 2024

This 2nd annual oyster fest co-founded by the Lambton Family in honor of Marjorie Lambton.

The Lambtons are dedicated to uniting their love of seafood, music, and philanthropy in support of CCALS. Come out for a shuckin' good time! Check the website this summer to buy tickets.