



Learn about our new initiative,
The Lighthouse Project on the back page

CCALS: TRANSFORMING THE ALS JOURNEY



CCALS' heart-centered approach is often revolutionary for people navigating an ALS diagnosis. Charles Edens is one of our families who talks about how CCALS' focus on listening to an individual's unique story transforms the ALS journey.

In 2023, Charles was diagnosed with ALS. As life changed rapidly for Charles and his wife, Donna, a social worker recommended reaching out to CCALS to receive support.

"The people I spoke to at CCALS were just wonderful," Charles says. "They listened to me. What CCALS did differently from any other place we worked with was that they said, 'What can we help you with?' and 'Let's go through your story and find out what you need.'"

Because of this compassionate approach, CCALS provided assistance that changed the journey for Charles. "It was the things I didn't know I needed that have been lifesavers." A lightweight wheelchair, a bed handrail, a transfer swing so Donna can assist him, and a specialized formulation of hemp oil to improve sleep were among the list of items that have changed his experience.

CCALS also introduced Charles to voice banking, ensuring he could still communicate with loved ones as his speech declined. "It is remarkable how much an AI-generated voice can sound like your own," Charles explains.

CCALS' full array of services, paired with our belief that every person and their journey with ALS is unique, means that CCALS provides support that people actually need.

Through tears, Charles expressed his gratitude. "I know I am on a short runway, but I couldn't be more grateful. Angels are real people who offer you something and don't want anything in return. Miracles are things that happen unexpectedly. You guys [CCALS] have offered me both."

RUN THE FALMOUTH ROAD RACE



Race or cheer with CCALS friends and families on Sunday, August 17th, 2025 as we join over 11,000 runners at the Falmouth Road Race.

This year marks the 50th wheelchair race and we are proud to announce that CCALS is the 2025 sponsor of the Falmouth Road Race Adaptive Athletes Program! CCALS staff and friends will start the race for the Wheelchair Division and will be the first to congratulate our winners as we hold the tape at the finish line.

In 2024, our incredible team of 140 runners raised over \$389,000—the third highest total of all charities. CCALS is proud to be not only a leader in ALS care,

but also the highest fundraising Cape Cod-based charity in this iconic event.

Run 7 miles to help us surpass our 2024 total and continue to provide high quality care to those living with ALS, their families, and their caregivers.

Details on how to participate are available on falmouth.ccals.org and all proceeds go to support people living with ALS, their families, and their communities. The Falmouth Road Race is a popular event within our community—we had a 40-person waitlist last year—so make sure to sign up soon!

ROLL OR WALK AT STROLL & ROLL



Bring the whole family (and your furry friends!) to Bourne Farm on Saturday, May 31st, 2025 for the biennial CCALS Stroll & Roll.

Starting at 11 a.m., this wheelchair-accessible two-mile walk winds through the beautiful Bourne Farm and

culminates in a fun-filled afternoon with food trucks, inflatables, and face painting. Support CCALS and take part in our most family-friendly event of the year! Plus, earn special prizes for reaching fundraising milestones. Sign up or learn more at strollandroll.net.

IN MEMORIAM

Janice Abdelnour, Worcester, MA
David Adamian, Cambridge, MA
Diane Adams, Sarasota, FL
Ron Agrella, Hamilton, MA
Steven Agueda, Valley Center, CA
Frank Albrecht, Lancaster, PA
Tom Allen, Prescott, AZ
Santos Alvarez, Lawrence, MA
Russell Amoroso, Westerly, RI
Judie Arroyo Goldstein, Bethel, CT
Bob Balaban, Lexington, MA
David Benoit, Wilbraham, MA
Dennis Benoit, Charlton, MA
Ursula Bergstrom, Mashpee, MA
Thomas Birdsey, Delmar, NY
Mary Blake, Wilmington, DE
Irwin Blau, New Castle, NH
Valerie Boudreau, Haverhill, MA
Ruth Brand, Houston, TX
Alisa Braverman, Sunderland, MA
Bruce Brownawell, Cutchogue, NY
Anita Buckley, Cumberland, RI
Edmund Burke, East Falmouth, MA
Melissa Bynum, Brooklyn, NY

Linda Canasta, New Bedford, MA
Tom Canty, Westford, MA
Lisa Carr, Rochester, NY
Augusto Centeno, Orlando, FL
Nancy Chapin, Chelsea, MA
Christine Chromiak, Catasauqua, PA
Donna Church, Hope Valley, RI
David Churchill, Howell, MI
Penny Ciccone, Brooktondale, NY
Mark Civetti, Coral Springs, FL
Cecile Cohen, Jamaica Plain, MA
Scott Cole, Havertown, PA
Jan Connally, Martinez, CA
Mary Connelly, Natick, MA
Kathleen Conroy, Boston, MA
Linda Cook, Edgartown, MA
Margaret Corbett, Plymouth, MA
David Crandall, Tyngsborough, MA
Kelly Crawl, Lake Mary, FL
Carol Crowley, Norfolk, MA
Michael Cunningham, Canton, MA
Carolyn Cunningham, Kingston, MA
Christine Curtis, Westborough, MA
Saleem Dar, North Grafton, MA
Margaret Darlington, Woodstown, NJ
Carole Davie, Kiawah Island, SC
Suzanne Delesdernier, Lowell, MA

Roger Demers, Manchester, NH
Douglas Demitry, Rushville, NY
Steve Desmarais, Brimfield, MA
Peggy DiBello, Farmingdale, NJ
George Dolan, East Northport, NY
Maureen Doren, Duxbury, MA
Nancy Doyle, Onset, MA
Marley Drayton, Charleston, SC
Patricia Drinkwater, Beverly, MA
August Ebeling, Plainfield, IN
Huda Elayan, Emerson, NJ
Brian Enders, Rochester, NY
Ralph Fairbanks, Hudson, NH
Maryanne Fesko, Chicopee, MA
Patti Flynn, Broken Arrow, OK
Billy Flynn, Mount Kisco, NY
Rickey Foreman, Bonita Springs, FL
Maryann Frechette, Northampton, MA
Thomas Friel, New Boston, NH
Michael Geisser, Warren, RI
Robert Goldberg, Tuscaloosa, AL
Kristina Golji, Grafton, MA
Manuel Gomes, Fall River, MA
Mary Goodell, East Falmouth, MA
Jeanne Goodman, Wellesley, MA
Paula Graves, Litchfield, NH
Judi Griffin, Portsmouth, NH

Toby Hale, Murfreesboro, TN
Charles "Chuck" Hardwick, Manchester, MA
Skip Harrer, Andover, MN
Barb Heath, Essex, VT
Herbert Holl, Feeding Hills, MA
Patricia Horvers, Milford, ME
Derek Hunt, Goffstown, NH
Thiruvallam Indira, Wilmington, DE
Eric Johnson, Acton, MA
Hannah Johnson, Siler City, NC
Ellen Jonczak, Perkasio, PA
Chip Jordan, Windsor, CT
David Kalman, Beverly, MA
Bob Kirby, Melrose, MA
Mary Krol, Cresco, PA
Mildred Kuznia, Chittenango, NY
Kelli LaFosse, Gardner, MA
Alana LaLiberte-Phoenix, Uxbridge, MA
Ayeez Lalji, Sugar Land, TX
Michael Lamoureux, Wilbraham, MA
Della Larsen, Canton, MA
Leif Larsen, Watertown, MA
Karilyn Lebron Olmeda, Springfield, MA
Bill Lefebvre, Cheshire, MA
Cody Lenhardt, Charleston, SC
Jeanne Lilly, Brockton, MA

Janet Linehan, Cotuit, MA
Anna Lipsanos, Stoughton, MA
Luis Lizardo, Boston, MA
Daniel Lomba, Chelsea, MA
Maria Luisa Hunnewell, Wellesley, MA
Joe Mancari, Pittsfield, MA
Luz Maria Pinto, Waltham, MA
Lori Marx, New Bern, NC
Dave Mastropaolo, Seal Harbor, ME
Sam Maukonen, Davenport, FL
Teresa Maynard, Vero Beach, FL
Ernestine Mbodde ze, Tewksbury, MA
Maureen McGovern, Yardley, PA
Janet Messineo Israel, Vineyard Haven, MA
Susan Mikolajczyk, Granby, MA
Wendy Miller, Phoenix, AZ
Kathleen Minnier, Seneca Falls, NY
Frank Mocniak, West Henrietta, NY
Suniti Mohindra, Brookline, MA
Frank Mongiello, Yardley, PA
Richard Monroe, Warren, ME
John Morawiec, South Windsor, CT
Marissa Morentin, Chandler, AZ
Anuraag Mullick, South Setauket, NY
Patty Munoz, Elgin, IL
Andres Munoz, Apopka, FL

Raj Nagaraj, Dix Hills, NY
Tammy Neter, Sarasota, FL
Michael O'Brien, Westminster, MA
Ann O'Shea, Wenham, MA
Odanía Omeus, Quincy, MA
Judith Parenta, Florham Park, NJ
Daniel Patriarca, Bordentown, NJ
Belinda Paul, Acton, MA
Michael Pellegrini, Worcester, MA
Donna Phillips, Gold Bar, WA
Diane Piazza, Wales, MA
Larry Player, Quincy, MA
Michael Pocius, Wallingford, CT
Rafael Polanco, Lawrence, MA
Donna Quail, Clinton, MA
Michael Ragonese, Easton, PA
Cecile Raths, Tempe, AZ
Victor Realini, Weymouth, MA
Ken Renninger, Pottstown, PA
Karen Rice, Breinigsville, PA
Thomas Robinson, Davis, CA
Frank Rondinelli, Springfield, MA
Judith Rosenfield, Farmington, CT
Howard Ross, Cromwell, CT
Deanna Ross, Ham Lake, MN
Carol Sanford, Highway, WA

Gaetano "Guy" Santoro, Bedford Hills, NY
Doreen Scanlon, Holden, MA
Jodi Schwartz, Georgetown, MA
Mahendra Shakya, Arlington, MA
Peter Shovelton, Fall River, MA
Laurie Silva, Littleton, MA
Eddie Simpkins, Brockton, MA
Jennifer "Jen" Simpson, Bullhead City, AZ
Peter Skeen, Roanoke, VA
Richard Smith, Delmar, NY
Maureen Smith, Winchester, MA
Nancy Soisson, Charlestown, MA
Richard Souza, Fall River, MA
Reginald "Reggie" St. Brice, Dorchester, MA
Ed Stefanoni, North Easton, MA
Anthony Stewart, Sharon, CT
David Stone, West Yarmouth, MA
Regina Strang, Beverly, MA
Loren Stuckmeyer, High Ridge, MO
Patricia Sullivan, Milton, MA
Shawn Sullivan, Haverhill, MA
Diane Sullivan, Hanover, MA
Antonio Tartaglia, Stamford, CT
Edward Taylor, Memphis, TN
Michael Terembes, Tamarac, FL

Kathi Tevlin, Saranac Lake, NY
Elizabeth "Kay" Thurman, Mims, FL
Thomas Tobin, Lowell, MA
Daniel Tracy, Nashua, NH
Sharonlee Trefry, Hinesburg, VT
John "Jack" Troy, Eastham, MA
George Tucker, Nashua, NH
Edgardo "Jojo" Umali, Merrimack, NH
Ellen Vaillancourt, Amesbury, MA
Steve Vaillancourt, Marshfield, MA
Emil Van Buren, Oswego, NY
Joe Vasta, Dartmouth, MA
Shonna Vest, Colorado Springs, CO
Jerry Wacks, Lexington, MA
Judy Wagner, Greenville, NC
Bill Wallace, Westfield, MA
Ken Waters, Pottsville, TX
Andra Weber, Georgetown, DE
Ben West, Brentwood, TN
Mark Weston, Lakewood, CO
Paul Wilbur, Ravena, NY
Lynn Willey, Andover, MA
Carol Wilson-Braun, Watertown, MA
Alissa Wolf, Somerset, NJ
Rochelle Wood, Milton, NH
Claudia Young, Framingham, MA

THOUGHTS FROM RON, SPRING 2025

Innovation and Leadership

Here at Compassionate Care ALS, our motto is printed on our business cards: "Leading a New Vision in ALS Care Since 1998." We refer back to our humble beginnings because it was then that Gordon Heald, his wife Betsy and I, his full-time caregivers, looked around at the sparse landscape of ALS care and agreed, "There has to be a better way."

Gordon's legacy directly addressed our determination when we launched the Gordon T. Heald ALS Fund almost 27 years ago. In the beginning, it was just me—what we metaphorically called "Ron's lemonade stand"—so the innovation had to start there. But over time, we've grown and along the way, I sought out like-minded people who recognized the value of what we were doing.

One of our great allies and champions became the renowned neurologist, Dr. Merit Cudkowicz, director of the Healey ALS Clinic at Mass General Hospital. She recognized that our holistic, relational approach to the disease offered a depth of humanity to the journey that she wanted for her patients. Our partnership evolved over time, and seven years ago we launched the ALS House Call program, in which a nurse or nurse practitioner from the clinic, and one of our care liaisons, began visiting ALS families in their homes.

I continued to keep my eye out for leaders and innovators. Some years back, I also got to know Dr. Richard Bedlack,

head of the ALS Clinic at Duke University. He became curious about the edges of ALS research, things that seemed to make a difference but weren't widely understood. With such wide-ranging knowledge, we thought it would be meaningful to bring Dr. Bedlack to our community for individual consultations. To that end, we launched the Lighthouse Project in March of this year. Those who have experienced a 30-minute consultation with Dr. Bedlack found it extraordinarily valuable.

"Through the CCALS Lighthouse Project, people living with ALS are getting answers to their questions about exercises, nutrition, equipment, and experimental treatments," says Dr. Bedlack. "They are being empowered through education to find more options they can discuss with their own doctors and medical teams. I am very proud of the hope that this new collaboration with CCALS brings!"

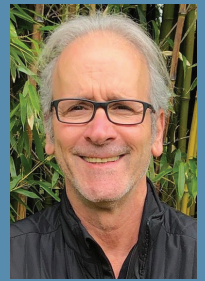
I'm so grateful for our staff and all that they do to serve the ALS community. Each of them enhances our commitment to innovation and leadership.

Blessings and love to you all,



Ron

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



RON HOFFMAN
FOUNDER

THE LIGHTHOUSE PROJECT: ILLUMINATING HOPE FOR THE ALS COMMUNITY

Compassionate Care ALS (CCALS) is thrilled to introduce *The Lighthouse Project*—an innovative new program designed to shine a guiding light for individuals navigating ALS. This collaboration brings together CCALS and renowned ALS researcher Dr. Richard Bedlack of Duke University to provide a unique opportunity for our clients.

their questions. While not a form of medical treatment, these educational sessions equip patients with fresh perspectives and ideas to discuss with their own doctors. Each participant receives a detailed written summary after their visit, including key takeaways and trusted resources for deeper exploration.



*"I am thrilled to partner with CCALS to offer *The Lighthouse Project*. So far, the program has empowered people living with ALS to better understand treatment and research options, including finding clinical trials or expanded access programs they might qualify for, and finding promising alternative and off-label products that are available for self-experimentation."*
— Dr. Bedlack

As one CCALS client wrote after his first session, "Dr. Bedlack and *The Lighthouse Project* are such a gift. This was the most productive ALS clinic we've had in two years."

CCALS is honored to welcome Dr. Bedlack to our community and to continue fostering

Through *The Lighthouse Project*, CCALS clients can engage in exclusive conversations with Dr. Bedlack, who provides personalized insights and expert guidance tailored to

enlightening conversations through *The Lighthouse Project*, empowering individuals and families to navigate the complexities of ALS.