



MARY, BRUCE AND FRIENDS WITH THE TRIONIC WALKER PROVIDED BY CCALS DURING THEIR 31 DAY CAMPING TRIP TO NEWFOUNDLAND.

FOLLOWING THE POSITIVITY OF CCALS CLIENT, MARY BROGAN

“This is not my choice or the future I thought I was going to have, but with a positive attitude and CCALS’ support I am continuing to enjoy my life.”

Mary Brogan is a model of inspiration to everyone around her. She and her husband, Bruce, do it all; biking, hiking, bird watching, camping – you name it. The couple faced a hurdle in their fast-paced life when they discovered Mary’s future was unfolding differently than they had anticipated. Since receiving an ALS diagnosis in September of 2021, CCALS has been an essential resource and guide throughout her journey. CCALS has worked to ensure Mary can continue to live her life to the fullest, enjoying many of the activities she did before her diagnosis in a manner that is adjusted for ALS.

Mary’s goal this September was to participate in a 10 mile bike ride with 319 other riders, fundraising to support people with ALS. The CCALS staff was inspired by Mary’s determination and connected her to an outdoor equipment company that specializes in gear for various disabilities. The company outfitted Mary with a new tricycle that complements her strength on the right side of her body, so she feels confident with braking and balancing on her own.

With this hobby close to her heart, Mary successfully pedaled across the finish line as the only person with ALS to ride solo in the race. “I was able to do this race due to where I’m at in my journey, but also through the resources provided by CCALS so I can continue to do my passions.”

It can be challenging having to question activities that were once so natural before experiencing ALS. Mary and Bruce turned to CCALS with concerns about the livability of their home in the future. Ron quickly responded, connecting them with a local contracting company to brainstorm modifications to ensure Mary feels comfortable navigating within her home in the months ahead. “Everytime I worry about the next step, CCALS is right there along the way.”

Our goal at CCALS is to support every individual and family as they navigate the uncertainty of this disease. Whether it’s a piece of equipment to improve mobility or modifications that allow people to continue their hobbies, we believe each person should feel motivated to continue to pursue their passions. Clients like Mary are a true testament to living life to the fullest.



RON AND THE CCALS COLORADO-BASED GRIEF AND BEREAVEMENT LIAISON BRENDA FOX.

Colorado Kick Off Event

Tuesday, October 11, 2022 | ccals.org/colorado

We're pleased to announce our CCALS community is expanding to include a presence in Colorado! The new location will allow us to better support those diagnosed with ALS as well as their communities in the Western region; we're excited to continue our growth and development across the U.S. We celebrated our expansion with a Kick-Off at the Boulder Theater in Boulder, CO where attendees met with our local team while enjoying refreshments. Additionally, the event featured virtual appearances by Dr. Merit Cudkowicz, Director of the Sean M. Healey & AMG Center for ALS, Chief of Neurology at Mass General, and the Julieanne Dorn Professor of Neurology at Harvard Medical School, as well as Lisa Genova, Neuroscientist and *New York Times* bestselling author of the novels *Still Alice* and *Every Note Played*. We're looking forward to getting you know better, Colorado!



ELIA PEREZ TESSICINI AND FRIENDS AT A RECENT ALES OVER ALS.

Ales Over ALS

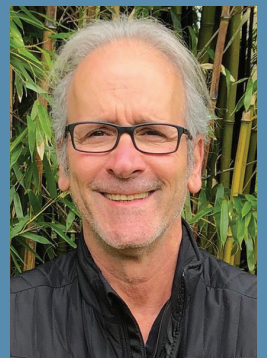
Saturday, November 5, 2022 from 2-8pm | ccals.org/ales-over-als

The 11th Ales Over ALS: A Crafter's Delight will take place at the scenic Lake House at Centennial Grove, where the movie *Grown Ups* was filmed. Tickets include a selection of fresh, local craft beers, a taco bar, homebrew tasting and competition, and live music! Over the years, this event has raised more than \$100,000 to support the CCALS Patient, Family and Caregiver Program. CCALS is thrilled to have the ongoing support of board member Elia Perez Tessicini as well as Nathan Woodman and Christine Woodman, who have made this a "can't miss" event of the fall.

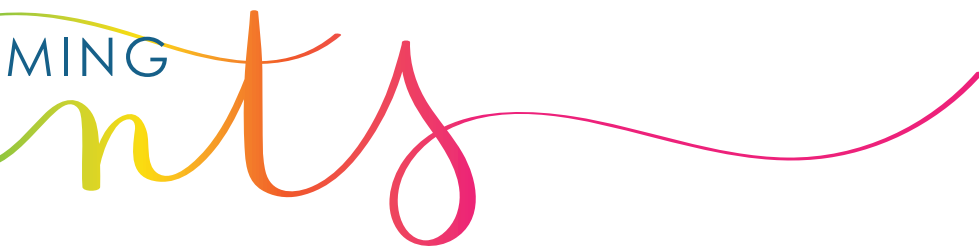
THOUGHTS FROM RON

Not long ago, I was reading a post from an advocate in the world of ALS. He was speaking about his caregiver in terms I found troubling. It was as if he was totally different from his wife because he had ALS, and he was somehow powerless to know her needs or struggles or be of service to her. He was the one in the struggle of a lifetime, not her.

This is a perspective that I find common in the dynamic between a caregiver and the one who is ill. There is an incredible imbalance often present that diminishes the humanity of both people involved. I speak of this in terms of a couple, which is often at the core of the ALS picture. The imbalance I am referring to becomes a one-way circuit, a taker and a giver. What I think we're looking for—and what I have seen work beautifully well at times over the years—is a mutual exchange. In the best of circumstances, what emerges can be called a blessing circuit. A blessing circuit is much more like a circle than a straight line.



RON HOFFMAN
FOUNDER



Curling for Compassion

Saturday, November 19, 2022 | curling.ccals.org

Join us at Cape Cod Curling Club for Curling for Compassion. Previous CCALS competitors ended up as both members of the U.S. National Wheelchair Curling Team and of the curling club. In the great Scottish tradition, finalists will be taken down the ice by a piper, and then offered a "wee dram" or soft drink and wished "good curling." There will be breakfast, lunch, a raffle, silent auction and has plenty of room for fans to cheer. Space is limited to twelve teams, so sign up today!



Walk and Wheel to the 2023 Stroll and Roll

Saturday, May 20, 2023

The Stroll and Roll is back! After a three-year COVID-19 induced hiatus, we are pleased to announce the return of this dog- and family-friendly event. The second Stroll and Roll will be held in conjunction with the Buzzards Bay Eagles on the Canal at Buzzards Bay. The day will feature a full array of food trucks, games, face painters and a petting zoo. The two mile course is perfect for the whole family - we can't wait to see you there!

This idea of a circle, a system in which reciprocity is at the core, is what I would call "co-caring." One person gives something; the other person receives; he gives something in return, the previous giver receives the gift, and so on. It's not like a tit for tat or quid pro quo. Sometimes many gifts are given by one person before something returns. When co-caring is in place, a quality of trust and peace can become the norm. A knowing sets in that I too will be cared for, even though I'm doing a lot of giving right now.

We learn how to consciously carve out those times of solitude for one another, whether it's taking a walk or a roll in your chair, finding a beautiful spot in nature to be in and observe, or listening to music you love or reading a book or being in a place of prayer. These are the ways we co-care, by encouraging our partners to find these sacred times and places. So too, we look for those special times we can share as well. Sometimes that means leaving the words and ideas behind and simply being together in a place that you both love. Just feel the love flowing between you.

In service,

*This article has been shortened.
To read the full story, visit Ron's blog at ccals.org/blog*

STAFF SPOTLIGHT: ERIN LAJEUNESSE



ERIN AND RON DURING A HOME VISIT.

For the past 12 years Erin Lajeunesse has embodied the heart and spirit of CCALS. As our longest serving Care Liaison, Erin brings the perspective of a licensed independent clinical social worker (LICSW) to her interactions with CCALS families.

For the first 15 years of her career Erin worked in child welfare and subsequently with families in the field of domestic and international adoption. When she was introduced to Ron, she was inspired by CCALS to take her career in a new direction. "There were aspects of my job where I didn't feel I could be fully myself, I felt like I was held back from really diving deep with my clients."

Erin felt called to end of life care and had begun volunteering with hospice organizations. After getting to know Ron, she asked him about hospice organizations he could recommend for her to work with, and he soon after suggested they work together. "When I joined CCALS it was just Ron visiting families. I was one of the first people he opened up his world

to. After shadowing him and seeing how he connects with people, I knew this was what I wanted to do." Now CCALS has more than 20 staff members who coordinate to meet the needs of more than 865 ALS patients, families and caregivers.

Erin found that the style of care Ron had created at CCALS aligned with her personality. When dealing with death and grief, there is no time to tip-toe around hard truths. Erin says it is this unique level of authenticity combined with her role as an educator that makes her job really special. "Many times at the start, [families] don't even know what questions to ask. It feels so good to bring all the knowledge I have accumulated and really make a difference in their lives."

The CCALS relational model of care enables staff members to form visceral and powerful relationships with clients. As Erin says, "we create a space where families don't have to be fine all the time. We cry together, and get mad together, we have real relationships with our families."

CCALS is different in that when we meet with a family, we bring our authentic selves, not just a list of resources. Thanks to dedicated staff members like Erin, we are able to help families navigate the full range of physical, emotional, and spiritual complexities associated with living with ALS.



ERIN WITH KEVIN GOELLER.

IN MEMORIAM

Ammini Jacob, Billerica, MA
Andrew Cohen, Brooklyn, NY
Andy Schoerke, Shaftesbury, VT
Anthony Abu, Northborough, MA
Anthony Taylor, Sharon, MA
April McArthur, Brentwood, NH
Barbara Sullivan, Boston, MA
Bruce Mead, Woodbourne, NY
Catherine Prato, West Boylston, MA
Cathy Nally, Boston, MA
Clifton Hughes, Burlington, MA
Dan Frey, Concord, MA
David Rogers Burlington, MA
Derrick Savaria, East Longmeadow, MA
Diane Cuddemi, Plymouth, MA
Donna Frost, West Yarmouth, MA
Donna Myers, Lawrence, MA
Donna René, Westborough, MA

Doreen Inman, Lynn, MA
Francis Ferrell, Yorktown Heights, NY
Francis Hayes, Billerica, MA
Georges Hawat, Westwood, MA
Gerard Goyette, Warwick, RI
Grace Hartfield, Dorchester, MA
Greg Allin, Narragansett, RI
Greg Mish, Westfield, MA
Heidi Henson, Gloucester, MA
Igor Sergeev, Boston, MA
Janis Forer Scharf, Davie, FL
Janine Briere, Greenville, RI
Jennifer Vazquez, Saugus, MA
Joanne Watkins, Port Deposit, MD
John Corcoran, Norwalk, CT
John Ledgard, Athol, MA
Joseph Lydon, Uxbridge, MA
Justin White, Cohasset, MA
Karen Itrato, Meredith, NH

Kathryn Walsh Johnson, Bernard, ME
Kathy Carolotti, Everett, MA
Kay White, Whitinsville, MA
Kevin Davis, Centerville, MA
Linda Ahr, Lakeville, MA
Linda Wagner, Assonet, MA
Margaret Liberge, Amesbury, MA
Margaret Vaughn, Martha's Vineyard, MA
Maria Remillard, Manchester, NH
Marie Mansfield, Norwell, MA
Marie Rosen, Beverly, MA
Mary Ann Glennon, Manomet, MA
Mary Coughlin, Maynard, MA
Michael Bourgeois, New Bedford, MA
Michael Sable, Hammondsport, NY
Nancy Morrison, Westwood, MA
Neil Herbst, Boca Raton, FL
Noel Adams, West Palm Beach, FL
Norma Lawson, Caldonia, NY
Olin Thompson, III, East Greenwich, RI
Richard Kearnan, Uxbridge, MA

Robert Carter, Middleboro, MA
Robert Lonkart, Hyannis, MA
Robert Renn, Orleans, MA
Roberto Sebastia, Miami, FL
Robert Washington, Dorchester, MA
Ronald Rainer, Marblehead, MA
Rosemarie Kieffer, Feeding Hills, MI
Roxanne Costa, Fall River, MA
Sandy Morris, Sierraville, CA
Scott Macinnes, Billerica, MA
Stephen Goldman, Lynn, MA
Susan Nickerson, North Reading, MA
Suzanne Norton McCormick Shealy, Columbia, SC
Terry Boyer, Dorchester, MA
Thomas Brady, Farmingdale, NY
Thomas Ginolfi, Stamford, CT
Thomas Hehir, Boston, MA
Thomas Rios, Saugus, MA
William Cowin, Newton, MA
William Murphy, Cranford, NJ
Zamir Kocaj, Medford, MA