

Compassionate Cares

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Team Kate Strong raises \$25,000 at the first annual Stroll & Roll



Team Kate Strong preparing to stroll

On Saturday, May 18, 2019 Compassionate Care ALS held our first annual Stroll & Roll fundraising walk. Over 350 participants walked and wheeled to raise more than \$110,000 in support of individuals, families, and caregivers living with ALS. The two-mile course began at Bourne Farm in Falmouth, wove around the Shining Sea Bike Path and finished back at Bourne Farm.

After the Stroll & Roll,

families and friends enjoyed a day full of food, music, games, and activities including a petting zoo and face painting.

Team Kate Strong was the largest fundraising team, with over 50 family members and friends supporting CCALS in honor of Kate Luna. Kate was diagnosed with ALS in January and heard about CCALS from several families. They recommended she contact us to learn more about navigating the ALS journey. Founder Ron Hoffman met Kate at her house with her five children to talk about possibilities and share knowledge. Kate's daughter, Cheryl Ingersoll, expressed how informative it was to meet with Ron to learn about what their mother and the entire family needed physically, emotionally, and spiritually as this diagnosis progresses.

"We knew nothing about ALS, it's never been in our family before. Ron brought both knowledge and equipment we didn't know we needed," said Cheryl.

After hearing about the Stroll & Roll, Cheryl started team Kate Strong in honor of her mother. Cheryl and her four

siblings, who all play a different role in their mother's care, talked to their mother to make sure this was something she wanted to be involved in.

Family and friends across the U.S. came together to support Kate and CCALS. "My mother has always been right there when anyone needed

anything and now people wanted to be there for her." Stroll & Roll was the perfect opportunity for Kate's community to return the kindness. Together, Kate Strong raised \$25,000



The bunnies were a big hit

to support other families who are living with an ALS diagnosis. Cheryl says of her mom, "She has always been a woman of great faith and as difficult as this has been, she's kept a great spirit. She tries to laugh a lot and is upbeat. Everyone always says how kind



Ron Hoffman and Maddy with the Garbers (of David's Old Silver Swim davidsoldsilverswim.com)

she is to work with. Since the diagnosis, my mother has not been out much. It was great to see her out and about, having a great time, and socializing with people."

We can't wait to see Kate Strong and our other amazing teams at the next Stroll & Roll. Stay tuned and join our mailing list to find out about next year's Stroll & Roll on May 16, 2020.

A special thank you to our sponsors!



Mitsubishi Tanabe Pharma America

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Decisions: The ALS Journey

The Compassionate Care ALS team strives to bring guidance, calm, care and information to individuals at every phase of the ALS journey. We know the realities of ALS progression, however each individual living with ALS needs to make their own decisions based on their life story. We enter the scene in what is typically a later act, after many formative life experiences have occurred. Below we share the stories of two women who we worked with in the past year to lend insight into the choices that are involved in different decisions. Both of these individuals were in their early 70s when diagnosed with ALS and both were widows living alone in their homes.



Carla

Carla was a go-getter and a mother of three. Carla accepted her diagnosis, and used it as a call to action. She went on a trip to Atlanta with her granddaughter, planned a family vacation to Iceland, and very proactively began delegating her future plans.

CCALS staff member Kristine Copley, our Augmentative Communication Coordinator, became involved with Carla shortly after her diagnosis because she lost her voice very quickly. Kristine helped Carla with communication technology. She was able to continue participating in book club using an iPad hooked up to her TV where she could live stream and send in questions.

Carla surrounded herself with family, had her college friends visit her, worked on a memorial service with her pastor, crafted the program for the memorial, and wrote her own obituary. She wanted to be at home as long as possible, and CCALS helped her with a lift to get up the stairs and other equipment to meet her needs. She surrounded herself with friends and did everything she needed to do.

At the end she decided she was going to move into a hospice house and passed a week later. She orchestrated her death in an amazingly real way. There were no surprises.

Michelle

Michelle's decision was to make no decisions. Professionally, she was a mover and shaker in international finance, traveling the world and doing deals in third world countries. She was a woman ahead of her time. Childless, she was known to her family as the "cosmopolitan one", who would fly in from some far off country to attend family functions.

As a proud, life-long self-sufficient woman, when her situation started to deteriorate, she chose to not solicit help from her out-of-state family. She was working through insurance challenges and caregiver hirings and firings mostly on her own until she was hospitalized with the flu. Things went downhill quickly, and it was not possible for her to return home and live independently. Care and financial considerations hadn't been finalized before the hospitalization. In the end, she chose to move into a nursing home. Kristine set her up with a computer that Michelle could operate using her eyes, and visited her multiple times a week over the course of her stay. Part of this time was spent reading her emails and advocating for her within the nursing home.

Michelle didn't want to be a burden on anybody and she was proud and content with the life that she had lived. She didn't want to be remembered for ALS. Her choice was to die alone, but she wasn't lonely. She was independent to the end.

This spring, Kristine recently attended a conference entitled, Being with Dying for Healthcare Professionals. She learned about honoring the choices people make without being attached to outcomes. Kristine shares, "One of the realities is that you bring your expectations into it- your values and what you think is right- but you need to remove that. You must inquire about the experiences of the individual you are serving, offer information, and be okay with what they do with it,"

No matter the path chosen, the CCALS team can provide information and guidance through each stage of the ALS journey. We do our best to walk with our families, honor where they are, and support them in the decisions they make. We provide information so that the decisions that are made are right for the people who are making them, because each story is unique.



Welcoming Brenda and Chris to the CCALS team

Compassionate Care ALS has continued to grow throughout the years. As more and more individuals and families hear about our work the demand for services continues to expand. From this growth, we are excited to announce we have welcomed two new staff members to the CCALS team to help with our growth.



Brenda Cvitan,
Care Coordinator/ Assistant
Retreat Center Coordinator

Brenda has worked in end of life care as a Certified Hospice Nursing Assistant for over 18 years. Throughout her experience she has worked with thousands of hospice patients and families with

a high dedication to compassionate and quality care. Brenda's commitment to providing individual care that is unique to each individual and family makes her a great addition to the CCALS team.

As the Assistant Retreat Center Coordinator, she is excited to work with CCALS families and help navigate them through this complex journey. Brenda's favorite part of working with CCALS is meeting with families and listening to their stories. As we celebrate the near completion of the CCALS Heald Center we are grateful to have Brenda's experience and dedication as the new Assistant Retreat Center Coordinator.



Chris Curtin,
Senior Family Care Liaison

Chris began his journey with ALS when his close childhood friend Claire Collier was diagnosed with ALS back in 2004. Chris was quick to jump in and help Claire as one of her caregivers and advocates. He quickly learned first hand what it is like to care for an ALS patient.

Through Claire's strength and determination to live each day to its fullest, Chris was inspired and realized what a gift life is.

In 2010 Chris founded the MAC Angels Foundation, along with Claire's close family and friends, as the founding Board President. In 2015, he joined the MAC Angels staff as the Director of Services and has worked with over 500 families to date. In February, Chris joined forces with Compassionate Care ALS as the Senior Family Care Liaison of Southern New England and Northern Atlantic States. Chris brings over 20 plus years of caregiving experience and is determined to help support families in their journey with ALS. We are elated to have Chris join our team.

The Heald Center for Education, Retreat and Sanctuary



The near complete CCALS Heald Center

On Sunday, May 5th we came together with family, friends, contractors, subcontractors, and tradespeople to celebrate the near completion of The Heald Center. It has been just over five years since we kicked off our capital campaign to build an education and retreat center to serve as a sanctuary for the ALS

community. Thank you to all of the amazing companies we had the privilege to work with during this project and all of their generous support. We are overwhelmed with joy to share this center with our community and are excited to open our doors this fall to our families and friends living with ALS.



CCALS Executive Director, Ron Hoffman and CCALS Heald Center builder Ralph Cataldo of Cataldo Custom Builders



The ramp leading up to the new cottage



Numbers are filling up fast! Sign up for the 2019 Falmouth Road Race

Run with compassion on August 18th in the 2019 Falmouth Road Race to support individuals, families, caregivers, and communities living with ALS. Our goal this year is to raise \$200,000 to support our ALS Patient, Family, and Caregiver program. Runner's commit to raising \$1,500 and are invited to our spaghetti dinner and celebration at the Seacrest Beach Resort. Please visit falmouth.ccals.org to register!

Thoughts From Ron...

The intimate work we do at CCALS is often unseen. Our presence brings light into a dark situation in an understated manner, I call it stealth caring. It's how we move in and out of the lives of the more than 600 families that are in our circle of care. It's an enormous number for an organization of our size.

A day at CCALS can go in a number of ways with hundreds of families at various stages of the process having needs unique to those stages and, most importantly, unique to them. No two people navigate ALS in the same way. What makes us unique is that we listen, we sense, we feel into the situation, and we do our best to give what will serve. No more and no less.

I get asked by people all of the time, "Ron, what is it that you do?" It's a big question. Difficult to capture in a few sentences, but two words sum it up: a lot!

This is what we do.

Not long ago, I received an 8 a.m. text from Will, son of Connie, "Please call." I called Will and he said his mom, Connie, had just passed away. "I'll get there as soon as I can," I said. I pulled up to the home and he greeted me at the door. "Ron," he said, "so good to see you. Mom had a gentle, peaceful death." I gave him a hug and said I was grateful it went smoothly.

I waited with Will for the funeral director to show up. We were there together, being with dying, not saying much, taking it all in – bearing witness and holding space. Just being. It can be incredibly powerful in times such as these.

This is what we do.

When I left Connie's family and headed down the road, my phone rang. It was a man from New Jersey. They had gotten the diagnosis that Pam had ALS, and someone had told them about CCALS. My tears were not yet dry from saying goodbye to Connie, and now I was greeting Pam and her husband, trying to bring some calm to the chaos that had just arrived in their lives.

This is what we do.

I recently met with Kelli, who we walked with through her dad's ALS experience, coming up on the 10 year anniversary of his passing. She had taken some time away to heal, and now she was back. She was ready, ready to give back to the ALS community what had been given to her. We sat and revisited some of the experiences we had gone through together with her dad. Quite a journey.

This is what we do.

Through our work and how we operate, an amazing thing has come to be. It's the CCALS Heald Center, for education, retreat and sanctuary. It is here and nearly complete because our community got behind the vision, because you all recognized what it would mean to the individuals and families living with this difficult disease. We are finishing up our capital campaign, and building a solid, sustainable base that will keep our center going strong for years to come.

This is what you do.

Many of you got us this far and I am forever grateful. We appreciate your support now and in the future.

With love,


Ron

*To see the full version of this article,
visit Ron's blog at ccals.org/blog*



In Memory Of...

Eunice Akerblom, Kingston, MA	Mark Lamusta, Lynnfield, MA
Lynne Aronson, St. Petersburg, FL	Bernie LeDuc, Southwick, MA
Elja Bagaco, Gloucester, MA	Claire Marequis-Rutkowski, Danvers, MA
Susan Balleza Swampscott, MA	Brenda Martinez, South Yarmouth, MA
Steve Bang, Manchester-by-the-sea	Ted May, Marlborough, CT
Bob Beaton, Peabody, MA	Thomas McCarthy, North Easton, MA
Mike Bizier, Brunswick, ME	Roger Miranda, Brighton, MA
Donald Bonito, Swampscott, MA	Evelyn Morris, Cochituate, MA
Eric Broezoski, West Stockbridge, MA	Barbara Neill, Forestdale, MA
Vanessa Brown, Littleton, MA	Harold Nelson, Middleton, MA
Irene J. (Mendes) Botelho, Fairhaven, MA	William O'Donnell, Whitman, MA
Doris Bousquet, Falmouth, MA	Patricia Orszulak, Ware, MA
Cecelia Camacho, Pembroke, MA	Ellie Paniagua, Taunton, MA
Miguel Canizares, Carlisle, MA	Judith Peter, Gilsun, NH
Maryann Cannata, Quincy, MA	Steve Pickett, Brockton, MA
John Capici, Saugus, MA	Stanley Pierre-Louis, Fall River, MA
David "Everett" Cashin, Sandwich, MA	Leanne Robinson, Gloucester, MA
Lisa Chalke, Sandwich, MA	Richard Rossi, Lynnfield, MA
Richard Correia, Ashland, MA	Arthur Saran, Warwick, RI
Patricia Cotter, Randolph, MA	Dorothy Sarno, Malden, MA
Janis Cravotta, Chelsea, MA	Francis Savage, Dennis, MA
Nina Cruz, Lawrence, MA	Rick Scanlan, Wiscasset, ME
Betty Dickson, Wrentham, MA	Marty Shultz, Manchester, NH
Mary Diferderico, Braintree, MA	David Sides, West Yarmouth, MA
Josephine DiGirolamo, Cohasset, MA	Stephen E. Smith, Jr., Mashpee, MA
Steve Ertel, Newton, MA	Robert Strider, Centerville, MA
Simonne Fanuef, Blackstone, MA	Amy Stumbris-Truman, Trumbull, CT
Theresa Faria, Fall River, MA	Kathlyn Sullivan, Westminister, MA
Victor Fernandez, Elizabeth, NJ	Melissa Tambolleo, Hyannis, MA
Rod Ferris, Holden, MA	Connie Tegen, Wellfleet, MA
Frank Finocchio, Danvers, MA	Mark Thomas, Medfield, MA
Michael Fogarty, Methuen, MA	Kate Toohey, Newton, MA
Liliane Gamache, Londonderry, NH	Maria Wahnnon, Canton, MA
Gil Gillette, New Bedford, MA	Bill Wechsler, Holliston, MA
Peter Granfield, Brookline, MA	John Welch, Medford, MA
Linda Hank, Reading, MA	David G. Whitenett, Natick, MA
Monica Higgins, Quincy, MA	John Wilson, Southborough, MA
Doris Howe, West Tisbury, MA	Peter Wilson, Newburyport, MA
Gregory Huntington, Danvers, MA	Stephen Winthrop, Wayland, MA
Linda Huppi, Winchester, MA	Arthur Wolfson, Newton, MA
Jerry Kyhill, Castleton, VT	Jonathan Woodman, Newburyport, MA
Charleen Lambert, Eastham, MA	

New commemorative envelopes

Each year we receive an overwhelming amount of support from families and friends through birthday fundraisers, weddings, and family events. Thank you to all the families who have made CCALS a part of your lives and your legacy, your contributions allow us to continue providing care, resources, and guidance to the ALS community. In this spring newsletter we are enclosing a second remittance envelope for your convenience. It may be used for a future contribution in honor of a holiday, a birthday, a special celebration or to commemorate the passing of a loved one. Thank you for your continued support.