



INTRODUCING OUR NEW PALLIATIVE CARE DOCTOR, SUZANA MAKOWSKI



DR. MAKOWSKI WITH SYBIL PRINCE, LEAD TEACHER OF THE HARLEY HOSPICE COURSE

staff members, educational programs, and relationships with medical organizations.

"Many people think palliative care is just hospice, but this role is far beyond that. My approach is to provide alleviation of suffering and symptom management for anyone living with a serious illness such as ALS. This disease is far more complex than physical ramifications and can affect someone's sense of self, sense of their future, sense of hope, or their role in society, and I think CCALS provides support in all those aspects like no other organization."

This year, CCALS welcomed Dr. Suzana Makowski to our staff. Dr. Makowski will expand our mission by providing clinical support to our clients. She is a Palliative Care Doctor who has worked and collaborated with CCALS for over 15 years and brings a new expertise to our team. She provides a physician's perspective to our

Dr. Makowski has already made an impact on our CCALS community. She is currently teaching high school students at the Harley School in Rochester, NY on an end of life elective. As part of their class, they have already committed to volunteer at the CCALS Stroll & Roll in May and meet one of our families to gain a deeper perspective on ALS.

Her work goes beyond the borders of CCALS to ensure each patient continues to invest in their personal well-being. As a former professor at University of Massachusetts, one of her students approached her with a capstone project to honor their mother who was a CCALS patient. The pair are currently collaborating with local art museums to arrange discounted tickets for ALS patients and caregivers.

Dr. Makowski is quickly establishing partnerships with hospice teams and universities to educate students and professionals on living with ALS and end of life care with a patient-centered approach. This new approach will increase quality of life to the greatest extent possible. Her role is invaluable in developing specific care plans as we strive to provide the most high quality, appropriate care to our families.

Spring into CCALS Events

PAST EVENTS

January 7, 2023



Rally 4 Nally Raises Money and Awareness

The second annual Rally 4 Nally polar plunge raised more than \$72,000 to support CCALS. Since her passing in 2022, Cathy Nally's children have kept her legacy and spirit alive through this amazing event.

DANNY AND BESTY NALLY
WITH THEIR MOM, CATHY

April 2023



Riding With Compassion

Jim Bruce and Diane Stokes took to the East Coast by bicycle to honor the life of Jim's son Matt, who passed away from ALS in 2014. The pair started in Falmouth, FL and pedaled more than 1,600 miles to their finish line in Falmouth, MA. The trip's highlights include many visits with CCALS families and patients along the way. We are happy to share that this event was featured in numerous news articles and raised over \$80,000 for CCALS.

Visit ccals.org/ride-blog to read more about Jim and Diane's adventures!

April 17, 2023



Patti Shea Runs the 2023 Boston Marathon

Patti Shea ran the Boston Marathon on April 17 to honor Renier DeBeer and in memory of Matt Rothwell who died with ALS in 2001. She raised \$12,400 to support CCALS.

"I carried Matt and Ren with me on this challenging road as I spread the word about ALS and the incredible work that Ron Hoffman and CCALS does on the behalf of those diagnosed with ALS and the people who love them," Patti said.

April 30, 2023



Motivated to Move

The Charleston, SC community got Motivated to Move, sweating it out for CCALS during three separate workout classes. Charleston's premier fitness studios including The Works, The Works Cycle, and Ethos hosted 90 minutes of movement to raise money for people living with ALS. Participants received swag, a delicious brunch provided by local favorite, Bodega, and an unparalleled sense of community.

May 5, 2023



Moved by Music

Music lovers delighted in an evening of chamber music at the Pucker Gallery in Boston thanks to longtime CCALS friend Linda Matchan. Attendees were treated to an eclectic program including works by Haydn, Bach and Gershwin performed by a trio of performers from three countries who connect across geographic boundaries to celebrate music-making. Cellist Michael Kevin Jones of London, Pianist Bruce Vogt, professor of piano at the University of Victoria, and Flutist Thomasine Berg, based in Boston, touched our audience with beautiful performances.

May 20, 2023



Stroll & Roll

Come Stroll & Roll along the scenic Cape Cod Canal to support CCALS! This handicapped accessible two-mile walk will set out from Buzzards Bay Park at 11am and loop back to the park where participants can enjoy food trucks, inflatables, face painting, craft vendors and live music. This is our most family-friendly, pet-friendly event of the year so make sure to bring your whole crew!

Special prizes will be given out to participants who reach the \$200 and \$500 fundraising levels. Sign up or learn more at strollandroll.net.

July 19, 2023



Aces Fore ALS

We are excited to announce the launch of Aces For ALS, a golf tournament founded by Justin Soares. Justin was diagnosed with ALS in October 2021 and CCALS has helped Justin's family navigate the difficulties that ALS brings. Justin is giving back by organizing this scramble golf tournament at Pinehills Golf Club in Plymouth, MA.

To learn more, visit ccals.org/events/aces-fore-als.

August 12, 2023



David's Old Silver Swim

It's time to make a splash with David's Old Silver Swim! This year's goal is to break last year's record number of 231 swimmers, hailing from 20 states and provinces, and participants from ages 7 to 97. This thirteenth annual swim honors the life of David Garber and raises funds to support CCALS families. Sign up to swim at davidoldsilverswim.com.

August 20, 2023



Falmouth Road Race

CCALS friends and families will be lining up with 12,000 runners for the 22nd time this August. The seven mile course kicks off from Woods Hole and winds through the woods and by the beaches of beautiful Falmouth, Massachusetts. CCALS runners can attend the race in person, or a virtual option is available for runners who prefer to map out their own course near home. We require all participants to raise a minimum of \$1,500 to support people living with ALS, their families, and their communities.

Lace up your sneakers and register today at falmouth.ccals.org.

THOUGHTS FROM RON

Compassionate Care ALS provides the best in service and equipment, delivered with an understanding of people and relationships more than any diagnosis, progression, or fear of the future. We are dedicated to showing up on all levels; physical, emotional and spiritual. And we do so without passing along the material costs of what we are supplying. I am often asked, "How do you do it, Ron?"

My first thought is to answer why we do it. That comes down to decades of experience recognizing how traumatic an ALS diagnosis can be, and how a sense of confusion and chaos can prolong and intensify the trauma—unless somebody shows up with an open heart. We arrive on the scene with a great deal to offer and no red tape. If we have what you need, we get it to you without delay. The arrival of something simple like a transfer belt or a comfortable neck

brace the day after we came for a visit can bring a deep sense of relief.

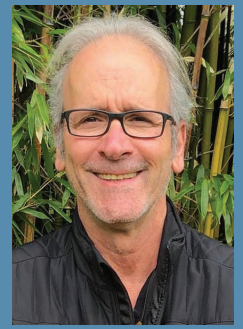
So that's part of the why, and there's a whole lot more. The how-do-you-do-it part comes down to the incredible "work behind the work". Some of it is the several big events we sponsor and organize with our incredible fundraising team as well as our families.

Since the beginning of CCALS, our families have always shown up for us, paying forward the support they receive. There have been parties and concerts and bowling tournaments and golf scrambles, runs and raffles and bike rides and motorcycle tours. I look back on everything that has been created and it warms my heart. 2023 is a huge year for family events supporting CCALS. You can read about many of them in this newsletter.

We have never been busier, and I say this every year.

Is it because there are more ALS cases? Maybe. Or is it because our reputation is growing? People are becoming more aware of how we show up in a way that no one else does. I have to think that's a big part of it. And so I write to you with huge gratitude for all that you do to keep us rolling. I am so blessed by our extraordinary team. We are all in this together, wherever you may find yourself on the journey of ALS. We are family. We will always care.

In service,



RON HOFFMAN
FOUNDER

IN MEMORIAM

Alan Cox, Merrimack, MA
Albert Regele, Marshfield, MA
Andrew Shoerke, Shaftsbury, VT
Ann Hamilton, Greenfield, MA
Ann Sermos, Andover, MA
Antonio Silveira, Fall River, MA
Austin Eadie-Friedman, Thompson, CT
Barri Sue Falk, Brookline, MA
Bob Pierce, Melrose, MA
Brent Desautel, Derry, NH
Brett Treganowan, Northampton, MA
Brian Blouin, Pawleys Island, SC
Bryan Stanton, Norfolk, CT
Carol Ann Richardi, Hanover, MA
Carol Goldberg, West Orange, NJ
Chad Deroy, Griswold, CT
Charles Rollins, Mystic, CT
Cheryl Guidry, Beverly, MA
Cindy Gasser, Hopkinton, NH
Claudio Mapelli, Morrisville, PA
Cynthia Pica, Hatfield, MA
Darlene Walker, Halifax, MA
David Kelly, South Weymouth, MA
Deb Manyin, Quincy, MA
Deborah Geller, Chatham, MA
Deborah Hadlock, Webster, MA
Denise Fish, Mashpee, MA
Diane Sponholtz, Saugus, MA
Donna Damalas, Concord, MA
Donnage Testa, Virginia Beach, VA
Dorothy Hague, Tewksbury, MA
Doug Sawyer, Seekonk, MA

Edgar Ngwenya, Brockton, MA
Elena Solomon, Hudson, MA
Elizabteh Vivis, Wellesley, MA
Ellen Corfield, Framingham, MA
Emily Titus, Wolfeboro, NH
Eric Roy, Westfield, MA
Ernest Bienvenue, Hooksett, NH
Eunice DeSilva, Plymouth, MA
Florentina Arenas, Woburn, MA
Gail Hickman, Dudley, MA
Gary, Nacca, Plymouth, MA
George Downs, Acton, MA
George Stokes, Lanesborough, MA
Georgia Supernor, Gardner, MA
Greg Koren, Arlington, MA
Iftikhar Ahmad, Brighton, MA
Ingrid Albee, Wonalancet, NH
Jaime Segura, Menlo Park, CA/Toluca, Mexico
James Alexander, Kennebunkport, ME
James Long, Southwick, MA
James Morrison, Acushnet, MA
Jean Callahan, Plymouth, MA
Jeanne Tierney, Wrentham, MA
Joanne Connell, Pleasantville, NY
Joe Cohen, South Hamilton, MA
Joe Fisher, Jamaica Plain, MA
John Smead, West Gardner, ME
J. Randall Curtis, Seattle, WA
Karen Mey, Millford, MA
Karen Speranza, Vernon, VT
Kathy Richards, Athol, MA

Kelly Gilbert, Bow, NH
Ken Dudzik, Barrington, NH
Kevin Davis, Marstons Mills, MA
Kevin O'Brien, Charlestown, MA
Kevin Teahan, Winchester, MA
Kimberly Surbaugh, Pittsfield, MA
Laura Mott, Lincoln, ME
Laurie Eramo, Sutton, MA
Leonard Sansoucy, Oakham, MA
Lisa Richards, Athol, MA
Lisa Russell, Chelmsford, MA
Luisa Tavares, Brockton, MA
Lynn Wolf, Bedford, MA
Manual Crespo, Somerville, MA
Marcia Zeamer, Winchester, MA
Margaret Parent, West Falmouth, MA
Marguerite Hurley, North Falmouth, MA
Maria Tegan, Lynnfield, MA
Mark Bombelli, Stoughton, MA
Martin Kukkula, Fitchburg, MA
Mary Connie Wilson, Stoneham, MA
Matthew Rene, Warren, RI
Meredith Atkinson, Truckee, CA
Michael Holloway, Sunderland, MA
Michael Tufts, Leominster, MA
Mike Moutsoulas, Beverly, MA
Myrna Solod, Quincy, MA
Nancy Perkins, Westborough, MA
Nancy Poon, Wakefield, RI
Naishia Gray, Norwalk, CT
Nelson Whitney Brown, West Yarmouth, MA
Patrick Marion, Marlborough, MA
Patricia Grant, Townsend, MA
Patricia Medeiros, Fairhaven, MA

Patricia Piela, Exeter, NH
Paul Bergstrom, Blackstone, MA
Paul Berry, Brewster, MA
Paul Gallivan, West Townsend, MA
Peter Badger, Milford, MA
Rebecca Mourey, Hopkinton, MA
Richard Cardarople, Kensington, NH
Richard Dunhoff, Boca Raton FL
Richard McEvoy, Plymouth, MA
Richard Perkins, Waltham, MA
Robert Genesco, Hopkinton, MA
Robert Studley, Jr., Boxford, MA
Robert Thibeault, New Bedford, MA
Rosaura Bracetti, Monson, MA
Rosemarie Romito, East Longmeadow, MA
Robert Bragg, Kingston, NH
Robert McMilleon, Leominster, MA
Ruth Finn, Weston, CT
Sally Nimblett, Winthrop, MA
Sandy DeFreest, Littleton, MA
Sharon Vanburen, Easthampton, MA
Steve Faberman, Needham, MA
Steve O'Reilly, Hingham, MA
Stuart Alford, Summit, NJ
Suzanne Berry, Newtonington, NH
Suzanne Derendal, Kingston, MA
Tara O'Brien, Norwood, MA
Terrence Clancy, Fairfield, CT
Tesla Davis, Jacksonville, FL
Theresa McManus, Medford, MA
Thomas Gannon, Boylston, MA
Verna Pfahl, Mokena, IL
Wallace Osgood, Meredith, NH
William Collins, Grand Haven, MI