

CCALS

COMPASSIONATE CARE ALS

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Cares

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CCALS 20th anniversary gala

\$425,000 raised to support care for ALS families

Compassionate Care ALS' 20th Anniversary Gala was an incredibly touching evening filled with friends, family, and caregivers who have journeyed with CCALS throughout the last twenty years. Individuals who have been with CCALS since the beginning and those who are just getting to know our work gathered at the Fairmont Copley on May 18th to honor and celebrate the thousands of individuals we have served.



Board Member Darlene Salatto Rose presenting Ron with a gift from the board

The evening was full of surprises, from the auction of a giant CCALS baseball bat signed by the 2018 Red Sox, to the cause auction which raised \$215,000 to support the CCALS Education

and Retreat Center. However, the biggest surprise of the evening was saved for CCALS founder/Executive Director Ron Hoffman. The CCALS board and staff honored him for his twenty years of service with a tribute video, live testimonials from board members and the gift of Kaz Tanahashi calligraphy called "The Miracle of Each Moment."

Former Channel 5 Boston Anchor Natalie Jacobson hosted the evening's program, which featured New York Times Best-Selling Author Lisa Genova. Ms. Genova has spent a great deal of time with Ron while researching her recently published book *Every Note Played*, which centers around an individual living with ALS. Also during the evening, Martin Carter, who is currently living with ALS, shared his



Jane Lapriore, Natalie Jacobson, Lisa Genova and Ron Hoffman celebrating 20 years of CCALS

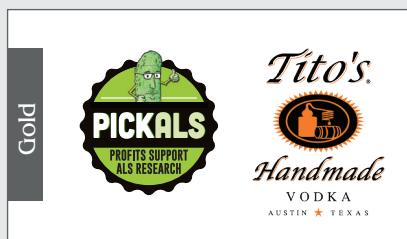
experience with CCALS and Ron honored David Garber, whose annual Old Silver Swim has raised over \$400,000 to support CCALS programs.

Overall, with the generosity of our community, CCALS raised \$425,000 to support our work with individuals and families living with ALS and to help build the Compassionate Care ALS Education and Retreat Center, which will serve as a place of respite for those living with ALS, families and caregivers.



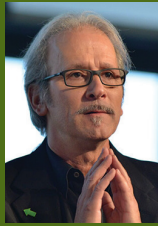
Featured speaker Martin Carter and Family

Thank you to our generous sponsors:



Thoughts From Ron...

Twenty years of service... just sitting with those thoughts and words fill my eyes with gentle tears. Remembering in this moment the enormous number of families we have served, the circumstances I have witnessed and the stories they have shared, is a bit staggering. As I was about to speak at our recent gala I scanned the packed house of many friends and families and was awash in those thoughts and feelings. Twenty years!



Ron Hoffman
Founder

As I often do, I was thinking of Gordon Heald who passed on October 30, 1998. I was also thinking of Gordon's dear friend, Phil Robertson, who passed away recently. For those of you who have participated in the Falmouth Road Race, we have always gathered at the five mile mark in front of the home of Phil and his wife Anne. For all these years the Robertsons have generously given us a place to gather to cheer our runners on. Phil was the gentleman who was up on the ladder for the last 35 years or so, hosing runners down as they ran past. I mention this because it brought me to a pause, to reflect on the extraordinary winding path I have walked with families, a path filled with obstacles, uncertainties, challenges, visions, triumphs and successes.

Scanning the crowd, realizing twenty years... In that moment of pause I felt grateful for the opportunity to serve and to remember. To have been able to create an organization that enabled us to tend to and care for individuals and families, navigating the extreme and unfathomable complexities of ALS. To enhance quality of life and to explore end of life, we have become ever more familiar with this uninvited guest, this intruder who becomes part of the larger story. Acknowledging impermanence as a reality rather than an imaginary construct is something I invite all of us to explore and something that I dance with regularly.

My staff and I give thanks for the continued faith and trust in the work and skills that we bring to the bedsides of all of our families.

Always,

Twenty Years of Care

A member of the CCALS community, Kim Baxter, shares the story of her partner, Michael's, ALS journey with CCALS.



Michael Fogarty was diagnosed with bulbar onset ALS in December of 2016 at 48 years old. Always a healthy, fit, and active man, this diagnosis was surreal. Michael is the loving husband of Kim, the devoted father of Demi and Michael Jr. and stepfather of Zoe. Michael has a job that he loves, working in a successful small business with coworkers that are like family.

We first met Ron Hoffman, the founder of CCALS, the following spring. As Michael's speech and swallowing abilities began to deteriorate rapidly, we were feeling overwhelmed and overrun. I sent Ron an email. A few days later, during Memorial Day weekend, Ron was sitting at our kitchen table. Ron emanated a sense of calm and instilled within us a confidence that our family was going to be able to live with ALS.

A few months later, CCALS Family Care Liaison Erin Lajeunesse was sitting at our kitchen table. Erin provided expert guidance on insurance, benefits, etc. as well as empathetic and compassionate support. Our meeting ended with a group hug. Then came Jean Batty, CCALS Government Affairs Liaison. Jean helped us successfully petition our insurance company to quickly approve Radicava. Jean has held our hands in navigating the complicated world of medical insurance. I am not sure we would have had the strength to go through this frustrating and confusing experience without her.



This spring, as clinic visits have become increasingly draining, both physically and emotionally, we have been able to access medical care in our home through the ALS House Call Program. Once again, we were sitting at our kitchen table with a Massachusetts General Hospital nurse practitioner and Ron discussing options.



CCALS has showed up for our family. When you have a devastating diagnosis such as ALS, you need people to show up for you. The CCALS team has provided authentic presence, compassion and guidance. We feel truly blessed.

Warmly, Michael Fogarty and Kim Baxter

Building the Compassionate Care ALS Education and Retreat Center

It was the late 90's when Compassionate Care ALS Founder Ron Hoffman first dreamt of creating an organization that focused on providing personal support and guidance to anyone impacted by ALS. In 1998, Ron began working with eight ALS families to address medical expenses that were rarely covered by health insurance and to confront the daily implications of living with an ALS diagnosis. With time, the need for care grew, as did Ron's vision for CCALS.

Ron began to see how far ALS reached and the complexities of the physical and emotional impact it had on each individual. He began reaching out, not only to ALS patients and families, but to caregivers and communities as well. CCALS transformed into

an organization focused on enhancing quality of life and when invited, exploring end of life. His ultimate dream was to build a sanctuary, a place of respite where all members of the ALS community – patients, families, caregivers, healthcare professionals, could come to rest and reflect.

Today Compassionate Care ALS serves over 800 clients, families, caregivers, and communities offering individualized support. CCALS has expanded from our original location in Falmouth to an additional office in Boston. The vision that began in 1998 is underway in the form of the ALS Education and Retreat Center. This handicap - accessible retreat location will provide education, respite, and resources for clients, families, and caregivers.

In April 2014, CCALS launched the Capital Campaign with a goal of \$3.5 million. A matching grant of \$500,000 was awarded to CCALS from a generous donor in November 2016, and the community's support has

helped us raise \$3.1 million of our \$3.5 million goal. With your support, our dream will be realized this fall with the opening of the Education and Retreat Center's doors.

To keep up to date on our progress, visit ccals.org/retreat. Any questions regarding the Education and Retreat Center, please call Founder/Executive Director Ron Hoffman at (508) 951-4644 or by email at ron@ccals.org.



\$3.5 million goal

\$400,000 to go

\$3.1 million raised



Julie Mollo sells clutches to support CCALS



Last year, New York fashion designer and clutch connoisseur Julie Mollo introduced a “Lou Gehrig” baseball-themed clutch designed in honor of her dad, J Mollo. This year, Julie’s raising funds for CCALS through the sale of the new hypocycloid clutch.

CCALS came into the Mollos’ lives following J’s 2016 ALS diagnosis. “CCALS has been incredible in the past year, helping my family with physical and emotional resources, tools and equipment used by my dad both inside and outside of our home. You couldn’t picture the things you might need help with until you can’t do them anymore,” says Julie.

The clutch represents J’s favorite team, the Pittsburgh Steelers, but is sparkly, subtle and versatile enough to be flaunted by a fan of any team. All proceeds from these clutch sales directly benefit CCALS.

Running for CCALS

Erin Donovan has gone the distance to support CCALS. Erin started running on behalf of CCALS in memory of her Grandpa Norm Morais in last August’s Falmouth Road Race and has kept racking up the miles since.

She was so inspired by her experience racing in honor of her grandpa that she decided to tackle the Boston Marathon in support of CCALS in April. Erin set out on a blustery mid-April morning and battled rain, wind and the cold all the way to the finish line. She raised more than \$7,000 to support families living with ALS.

Join Erin and 100 other runners supporting CCALS by running in the 46th Annual Falmouth Road Race on August 19! Our goal is to raise \$300,000 to support our ALS Patient, Family and Caregiver Program. You can sign up to run with us or support a runner at falmouth.ccals.org.



In Memory Of...

Debbie Anderson, Charleston, SC
MaryElizabeth Bartel, Manchester, NH
Todd Batt, Mexico City, Mexico
Teresa Bello, Malden, MA
Neal Beltram, Chepachet, RI
Steve Benecke, Wenham, MA
Henry Bennett, Laguna Woods, CA
David Bernardinelli, Kingston, MA
Cindy Bigelow, Medway, MA
Kim Billings, Bowdoinham, ME
John Bindig, West Yarmouth, MA
Roger Blais, Biddeford, ME
Stephen Borque, Wakefield, MA
Frank Brancey, Upton, MA
Betsy Camp, York Beach, ME
Debbie Champagne, Kingston, NH
Carl Charlson, Boston, MA
William Clancy, Whitman, MA
Jimmy Clark, Bentonville, AR
Mary Beth Collins, Malden, MA
Germania Colon, Lawrence, MA
Rose Connolly, Norwood, MA
Janice Costa, New Bedford, MA
Tim Cotz, Longmeadow, MA
Lorraine Cramer, Calera, AL
Elizabeth Cunningham, Plainville, MA
Georgianna D’Alelio, Lynnfield, MA
Jonathan Davis, Middleborough, MA
Thomas DeBartoli, Tracy, CA

Helen Dehni, Methuen, MA
Ray Desrosiers, Dracut, MA
Alison Doane, Malden, MA
Peter Doherty, Arlington, MA
James Dwyer, Littleton, MA
Gordon Dyck, Estes Park, CO
Joel “Ike” Eiserman, Hampton, NH
Margaret Ernst, Manchester, CT
Howard Ertel, Newton, MA
Carole Ann Evans, Dover, NH
Janette Fenton, Bristol, RI
Audrey Fisher, Winthrop, MA
Susan Fortier, Bangor, ME
Felisha “Flea” Foster, Somerville, MA
Krystyna Franczak, Barrington, NH
Helen Friot, Wells, ME
David Galanty, Boston, MA
Loretta Galvin, Weymouth, MA
Carolyn Glenn, Abilene, TX
Michael Gollin, Bowie, MD
William Giudice, Newton, MA
Carolyn Yvonne Glenn, Abilene, TX
David Hardy, Easton, MA
John Howard Hicks, Marlboro, NY
Raymond Hoyt, Westwood, MA
Michael Hubner, Sudbury, MA
Donald Johnstone, Rochester, NH
Thomas Junker, Plano, TX
Thomas Kane, South Easton, MA

Rick Keller, Amherst, MA
John Kelly, Rockaway Beach, NY
Curtis Kesselring, Westminster, MA
William Klingel, Winchester, MA
Louis Krzych, Portsmouth, RI
Susan Kron, Boston, MA
David Lariviere, Templeton, MA
Rick Marks, Winchester, MA
Gail Marshall, Chelmsford, MA
William McDermott, Jr., Norwood, MA
Kathryn McKenna, Salem, MA
Johnny McNeeley, Atlanta, GA
Stephen Yomi Meeks, Denver, CO
Jeremy Mergroz, Norfolk, VA
Shane Milianes, Contoocook, NH
John K. Modugno, Beverly, MA
Dolores Murphy, Concord, MA
Michael Murray, Purcellville, VA
Terry Nash, Franklin, MA
Marcella Nelson, Rochester, MA
Robert “Geoff” Neville, Westwood, MA
Carol Nicols, Pittsfield, MA
Terrell Northcutt, Raleigh, NC
Henry C. Oman, Island Pond, VT
Dr. William Ostaski, Salem, MA
Jose Pacheco, South Dartmouth, MA
Kreg Palko, Barrington, RI
Michael Pohorylo, Suffield, CT
Michael Post, Abington, MA

Margaret Regan, Winchester, MA
Robert Renzi, Marlboro, MA
Marguerite Rogers, Windham, MA
Ron Rounds, Warwick, RI
Pamela Rush, Hampton, NH
Beatrice Salinas, Gardner, MA
Thomas Saunders, Tewksbury, MA
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