



## CELEBRATING THOSE WE LOST: JAMIE HUDSON

In an ongoing feature, we are going to explore the lives of some of the remarkable individuals with ALS who came to be part of the CCALS family.



JAMIE HUDSON

Compassionate Care ALS lost good friend Jamie Hudson in 2016. Executive Director and Founder, Ron Hoffman, recalls "I can't think of anyone we were more involved with than Jamie. I met him when he was in an assisted living facility, where he was very uncomfortable, for many reasons. Over many, many months we searched for alternative living arrangements for him. In time Jamie decided to move into a hospice house where he was able to pay room and board for the last few months before he passed. He found this was the best fit for him. Jamie was a very kind and caring man and I am grateful for the time I got to spend with him and his family." This is his story.

An ALS diagnosis is hard to grapple with, especially with the uncertainty of how long each individual's journey will be. Jamie Hudson's response to this unforeseen diagnosis in 2014 was, "I'm not emotional about this disease, and I am going to spend my time organizing my estate," and that is exactly what he did.

During his two-year journey with ALS, Jamie supported two organizations that he was passionate about. He gave a major gift to The Trustees of the Reservations

and one to the Berkeley Divinity School. Jamie's father, Don, said "he was not particularly religious, but he was raised in this church and thought they deserved the gift. He let us decide how it was to be used, and my wife and I decided it should go toward helping the senior class make their annual pilgrimage to Canterbury Cathedral in England. We made the trip with the senior class 2 years ago, and it was a very moving experience." Even though Jamie was not able to make this trip with his parents, they knew he was with them in spirit and they were grateful to feel connected to him through this event.

Since a young age, Jamie loved the outdoors. From skiing and hiking to badminton and tennis, Jamie loved to get out in the fresh air. His gift to The Trustees of the Reservations allowed the organization to purchase a former dairy farm called Jewell Hill that spans the Massachusetts towns of Ashby, Ashburnham, and Fitchburg. As a longtime member, trustee, contributor to numerous committees, and hiker of every single reservation, Jamie felt this gift would allow him to continue to support activities he loved, even when he was no longer physically present.

Jamie once noted that he had "a relentless focus on making the world a nicer, more attractive, prettier place." Through his support, Jewell Hill's 2,000 acres of trails and land are now protected and visitors will be able to enjoy the beautiful vistas, open fields, and forest trails forever. Don expressed that his son "was always a deep believer of aggressively conserving special landscapes for future generations." His legacy and passion to create a bigger foundation of life will live on through Jewell Hill, which will be dedicated in his memory this summer.

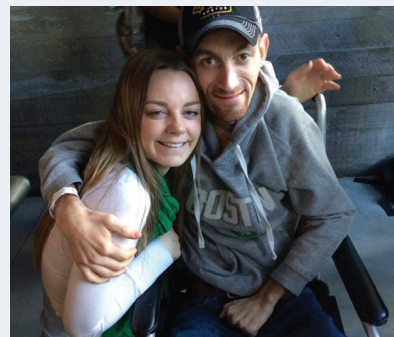
There is a silver lining to an ALS diagnosis when individuals like Jamie are able to identify the aspects of life they are most passionate about. Jamie passed away on April 4, 2016 after a two year battle with ALS. His father, Don, remembers that "he was just skin and bones when he passed at this stage and Ron, my wife and I were with him when he died. I remember Ron would visit him every few days and this was extremely helpful for us." Although he is no longer with us, Jamie's love for the outdoors and his generosity will forever represent him in his community.

# BOSTON MARATHON FUNDRAISERS – SPRINGING FORWARD TO FALL

Three runners are ready to complete 26.2 miles in the Boston Marathon while supporting Compassionate Care ALS. COVID-19 has put the race on hold, but the runners' fundraising continues with more opportunities to set CCALS records for this year's marathon. Each runner has been touched by ALS, through either a brother, a husband or a friend who lived with an ALS diagnosis.

**Lauren Bruce**, a long-time supporter of CCALS, lost her brother Matt in 2014. Matt was only 26 years old when he passed away with ALS. Lauren has run the Falmouth Road Race with CCALS a number of times. Last year she ran alongside her father, Jim Bruce, and CCALS staff, Chris Curtin, as they took turns pushing Renier Debeer along the 7-mile course in the CCALS racer chair. Lauren is excited to triple her distance this fall as she runs her first Boston Marathon in honor of her brother. To donate to Lauren's run visit [ccals.org/brucemarathon](https://ccals.org/brucemarathon).

LAUREN WITH HER  
BROTHER MATT



**Jessica Connors** is proud to run in memory of her husband, Luther Halwadjian, and her grandfather, Philip Hopkins. Jessica witnessed this devastating disease firsthand after caring for Philip, who passed away in 2007 from ALS. Jessica and Luther were not prepared for the news when they received Luther's diagnosis in 2019. Luther passed away this past November at 40 years old. Only six weeks after his passing, Jessica committed to run the 2020 marathon for CCALS with a goal of raising money so more families can receive services from CCALS. To donate to Jessica's run visit [ccals.org/connorsmarathon](https://ccals.org/connorsmarathon).

JESSICA WITH HER HUSBAND  
LUTHER HALWADJIAN

**Gillian Zettler** moved to South Carolina six years ago, and made friendships that will forever impact her life. Gillian's friends Katie Penta and Keith Benjamin have both lived through the pain of saying goodbye to a parent because of ALS. Katie's mom, Wanda, and Keith's dad, Robert, both managed to find blessings in every breath. Rather than being hardened by their circumstances, they found gratitude in the gift of life – even when days became numbered. Through their journeys, Gillian found gratitude for the ability to move and was inspired to co-found and launch Motivated to Move which raised \$30,000 for CCALS last fall. Gillian jumped at the opportunity to run and raise funds for CCALS, an organization she cares for deeply, and she knew that this was a life goal she must accomplish. To donate to Gillian's run visit [ccals.org/zettlermarathon](https://ccals.org/zettlermarathon).



MOTIVATED TO MOVE FOUNDERS,  
KEITH BENJAMIN, GILLIAN ZETTLER,  
KATIE PENTA AND JOEY WELLING

# MEET OUR NEW STAFF



In the past few months, we have added an additional Senior Care Coordinator, Eileen Garry. Eileen began working in social services after being the caregiver for her mother, Claire, who passed with ALS in

2009. Eileen is trained and certified by the Executive Office of Elder Affairs as a SHINE Counselor. In this role, she is able to advise in many areas of health insurance including Medicare, Medicaid, prescription drug and other programs, adding a great deal of value to our team. Eileen has always had a passion for making a positive difference in people's lives and she brings this by "showing up and being present" for every ALS family she meets.

# IN MEMORIAM

Doreen Allen, New Bedford, MA  
Jean Anderson, Grafton, MA  
Louis Arcidy, Bedford, NH  
Jean Armata, Wellesley, MA  
Nancy Atkinson, Hollis, ME  
Karen Audette, Woonsocket, RI  
Michael Ballon, Great Barrington, MA  
Theresa Bandy, Plymouth, MA  
Robert Bass, New York, NY  
Robert Beaudoin, Southington, CT  
Robert Benjamin, New York, NY  
Edward Boelzner, Ashland, MA  
Kevin Brown, West Orange, NJ  
William Brown, Taunton, MA  
Carmen Cadavid Norwalk, CT  
James Caddell, Franklin, MA  
Julie Caires, West Wareham, MA  
Deborah Camacho, Chelmsford, MA  
John Casey, New City, NY  
Richard Clifford, Chatham, MA  
Anerio P. Cincotta, Stoneham, MA  
Dan Coakley, Gloucester, MA  
Patricia Collinge, Cambridge, MA  
John Conroy, Milton, MA  
Bromley Cook, Swampscott, MA  
Kendall Cowes, Shrewsbury, MA  
Robert Crawley, Holbrook, MA

Timothy Cuthbert, Rochester, MA  
Deborah Daniels, Dudley, MA  
Don Decain, Valhalla, NY  
Drew Dixon, Louisville, KY  
Jackie Ellis, Belmont, MA  
Gary Fisher, Eastham, MA  
Flora Fasolya, Brooklyn, NY  
James Hathaway Dean, Cohasset, MA  
Stephen Farenga, Tarrytown, NY  
Mary Jane Ferraro, Wellesley, MA  
Patricia Finkle, Andover, MA  
David Flaherty, South Kingstown, RI  
Pete Frates, Beverly, MA  
Robert Gadigian, Katonah, NY  
Jacqueline Gamache, Acushnet, MA  
Michael Gay, Dedham, MA  
Thespina Glidden, Brockton, MA  
Jane Gorman, South Yarmouth, MA  
John Gullage, Bedford, MA  
Luther Halwadjian, Wakefield, MA  
Scott Hamilton, Cambridge, MA  
Kenneth Hardy, Norwood, MA  
Maryanne Healey, Weymouth, MA  
Jo Lynne Hohl, Provincetown, MA  
Charles Hurst, Dedham, MA  
James Jacobs, Norwood, MA  
Maryann Jonaitis, Tuckahoe, NY

# CCALS UPCOMING EVENTS

Due to the ramifications of COVID-19, CCALS has had to rearrange our fundraising schedule. As always the health and safety of our clients, staff and supporters will always be the number one priority in any decisions we make regarding holding in-person events. For full details and updates follow us on social media and visit [ccals.org/upcoming-events](https://ccals.org/upcoming-events).

## David's Old Silver Swim

August 8, 2020

## Falmouth Road Race

August 16, 2020

## CCALS Gala

September 4, 2020

Park Plaza, Boston, MA

## Boston Marathon

September 14, 2020

## Stroll and Roll

October

Bourne Farm, Falmouth, MA

## Cycle for CCALS

TBD

## Boston Cycle For CCALS

TBD

## Curling for Compassion

Sept/Oct date TBD

Cape Cod Curling Club,

Falmouth, MA

COVID-19 permitting

Subrahmanyam Kunala, Baldwin Place, NY  
Paul LaHiff, Westport, CT  
Jane Langmaid, Danville, VT  
Linda Lassiter, Framingham, MA  
Mary Lastowski, Northampton, MA  
Rich Lieberman, Stamford, CT  
Lawrence Lisowski, Windham, NH  
Yang Liu, Winchester, MA  
Robert Mannal, Ashland, MA  
Marilyn McCarthy, Salem, NH  
Linda McPherson, Brockton, MA  
Stephen Mingolla, Worcester, MA  
Michael Mizzzone, Orange, CT  
Kevin Moodie, Hollis, NH  
Susan Morris, Acton, MA  
Barbara Morrissey, Framingham, MA  
Michael Mosco, Brooklyn, NY  
Frederick Nelson, Waltham, MA  
Catherine Noyes, South Weymouth, MA  
Maria Paiva, Fall River, MA  
Kalpana Palit, Yarmouth Port, MA  
Susan Paquette, Chicopee, MA  
Mary Paradis, Arlington, MA  
Albert Pedro, Jr. Somerville, MA  
Elizabeth Palleschi, Peabody, MA

Cindy Pasquarello, Arlington, MA  
Jeremy Ponte, North Dartmouth, MA  
Daniel Porrazzo, Acton, MA  
Cathy Quinby, Newton, MA  
Albert Richardson, Abington, MA  
Christine Rizzuto, Greenwich, CT  
Howard Samel, Pittsfield, MA  
James Scanlon, South Yarmouth, MA  
Christine Senftleben, Saugus, MA  
Sara Jane Sherman, Dorchester, MA  
Elizabeth Soli, Boston, MA  
Brian Shifrin, Southborough, MA  
Maureen Spano, Far Rockaway, NY  
Fred Stewart, Westford, MA  
Mary K. Sullivan, Acton, MA  
Marion Sundgaard, Acton, ME  
Randall Swailes, Ridgeland, SC  
May Tse, Quincy, MA  
Matthew Turkington, Colchester, CT  
Bettina Twarog, Weston, MA  
Richard Valliere, South Dennis, MA  
Reinaldo Villalobos, Kingstown, RI  
Calvin Warner, Heartland, ME  
Robert Wunschel, North Dartmouth, MA  
Susan Yohalem, Boston, MA



# HELP US EXPAND OUR STAFF AND MEET OUR MATCH



STEPHEN AND NOREEN SMITH MEET WITH RON IN THEIR HOME LAST YEAR

In the fall of 2019, CCALS launched an initiative to increase our staff in order to meet the needs of the ALS community. One anonymous funder issued a challenge; they offered a dollar-for-dollar **match**, of up to **\$250,000**. It's up to you to help us receive the full amount!

In order to receive the funds, we need to raise **\$250,000** by July 1, 2020. We have included an extra envelope with this newsletter; by using it, or by giving online at [ccals.org/match](https://ccals.org/match), you will double your contribution.

CCALS has grown to be a nationally recognized name in the ALS patient/family care community. We have developed partnerships with medical and research institutions, including Massachusetts General Hospital and UMass Medical Center in Worcester. We are also the caregiving partner of the ALS One alliance. Our growth over the past few years has been extraordinary. We continue to grow busier as more people learn of our services, resulting in our need for additional staff.



CCALS STAFF MEMBER CHRIS CURTIN VISITS THE THALACKER FAMILY

All of our direct service staff members already have extremely large caseloads. Founder/Executive Director, Ron Hoffman, serves many of our 650 active cases, as well as the nearly 200 families who have lost a loved one and still seek support from CCALS. Our five other care coordinators manage between 77 to 204 active cases each. These numbers are unprecedented. The national average for caseworkers is between 25 and 30 annually.



WALKER AND FREDDIE FARRAR MEET IN THEIR HOME WITH CCALS STAFF MEMBERS JEAN BATTY AND KRISTINE COPLEY LAST FALL

CCALS staffing has had very little turnover over the years, and our staff consists of highly skilled, compassionate individuals who truly care about every family we work with. However, the reality is that we need additional hires so we can reduce caseloads of current staff and have the ability to help more people with ALS. We thank everyone who has helped us get to this point and we hope you will help us take the next step forward.

## NEW TAX LAW BENEFITS ALL DONORS

For individuals who **do not itemize** their tax returns, there is a new deduction available thanks to the United States CARES Act, the coronavirus stimulus bill.

Everyone who does not itemize is able to file a deduction of up to \$300 in annual charitable contributions. Donations to CCALS will qualify.