



## A NEW WAY TO GIVE BACK: CCALS VOLUNTEER CAREGIVER PROGRAM

The new Volunteer Caregiver Program (VCP) is allowing our community to use their skills to give back to CCALS families.

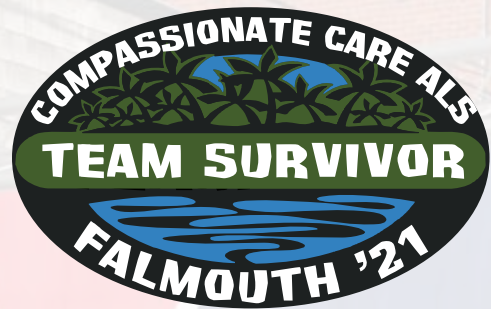
Current and former caregivers and family members of ALS patients receive training so that they can serve as a source of awareness, understanding, and consistency to people living with ALS. CCALS prepares Volunteer Caregivers to support individuals living with a terminal diagnosis by equipping them with the tools and knowledge to enhance quality of life. They attend a two-day, intensive workshop on CCALS' end-of-life work and monthly workshops hosted by guest speakers. Once their training is complete,

individuals are placed with CCALS families. Fourteen volunteers completed our first training in March of 2021. The program launched thanks to funding from MT Pharma and the Adira Foundation.

One of our first cohort Volunteer Caregivers, Darlene Salatto Rose, says, "the program illustrates the essence of CCALS' mission of making the human connection with mindful engagement and listening, as a way to serve the individual needs of each family. Walking side-by-side as a quiet presence on the ALS journey."



A new cohort is currently enrolling for early 2022. To apply or to learn more, visit [ccals.org/caregivertraining](https://ccals.org/caregivertraining).



# FALMOUTH ROAD RACE 2021: A NEW BEGINNING



## SURVIVOR VS. BACHELOR WINNER: CCALS

The CCALS community showed up in full force for the 2021 Falmouth Road Race. After a year filled with virtual events including a fully at-home Falmouth Road Race in 2020, one hundred and nineteen runners took to the course to support CCALS. Most of our runners embarked on the seven mile course from Woods Hole, running along the beach to finish in Falmouth Heights on a beautiful Cape Cod summer day. Some of our runners mapped out and tackled their own 7-mile course at home.



STEPHEN COOK AND HIS ALL-STAR TEAM OF PUSHERS AT THE FALMOUTH ROAD RACE STARTING LINE.



A major highlight of the event was *Bachelorette* star Chris Lambton, *Survivor* star Jonathan Penner, and CCALS Board President Jim Bruce pushing Stephen Cook in our racing wheelchair.

Our community raised \$346,865, the third largest total in our 20-year history running Falmouth as an organization, surpassing our fundraising goal by almost \$100,000. Nearly 2,000 donors supported runners on 32 teams to benefit our CCALS families through the ALS Patient, Family and Caregiver Program.

◀ CCALS FOUNDER/EXECUTIVE DIRECTOR RON HOFFMAN WITH JONATHAN PENNER AND CHRIS LAMBTON AT THE 2021 FALMOUTH ROAD RACE EXPO

## ORDER YOUR LIMITED-EDITION CCALS JAWS T-SHIRT

You can rock a limited-edition CCALS Jaws shirt, just like *Survivor* star Jonathan Penner! Penner popularized the ALS Jaws shirt, designed by artist Skye Volmar, at the 2021 Falmouth Road Race Expo.

Shirts are available in either red or white for \$20 plus shipping. The first 25 shirts ordered come with an autographed 2021 CCALS Falmouth Road Race poster signed by Penner and *Bachelorette* alum Chris Lambton. To order your shirt, visit [ccals.org/jaws](https://ccals.org/jaws).



## RUNNER SPOTLIGHT



Andretti McDuffie-Stanziani is no stranger to the Boston Marathon. His mom ran the race for years, as he sat faithfully cheering her along while wondering what in the world would compel someone to run 26.2 miles. That all changed when his mom collapsed in the midst of running.

"My mom's last steps on her own before she was hospitalized were taken on Marathon Monday," Andretti says. "She was taken off the race route. Six months later, she was diagnosed with ALS."

Andretti's mom passed away with ALS in summer of 2019. He had always been a runner, but stuck to lower mileage races like 5ks and 10ks. One day, while jogging along a Charles River training route he used to frequent with his mom, Andretti saw a Boston Marathon banner on Storrow Drive. The typical Marathon Monday (in April) had passed, and it was almost his mom's birthday.



He made a decision in that moment - he was going to run the 2021 Boston Marathon.

"As I was jogging and saw this banner, it just hit me. I started bawling my eyes out. I felt my mom come through to me and stopped in my tracks. It was insane; I was

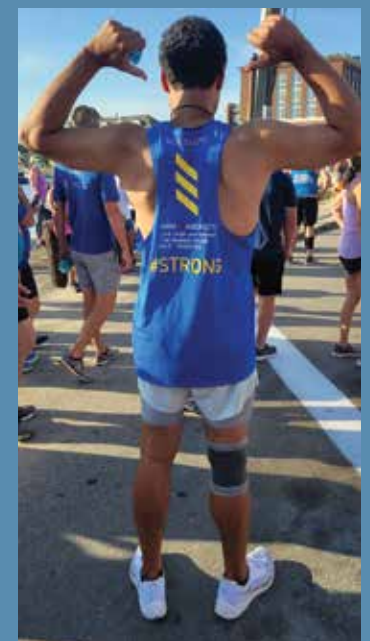
talking to myself, saying 'I'm running the marathon this year.' I knew nothing of how to get a bib, but I knew no one was going to tell me otherwise."

Andretti secured a bib and he joined Compassionate Care ALS in the Falmouth Road Race as part of his marathon training.

"When I got the Falmouth Road Race email soliciting runners, I knew this was a great race prep for the big one. CCALS and Ron were the only ones who reached out when everything with my mom's ALS was happening. Throughout the five or six years she was in the hospital, I remember everyone that was there to help and it meant a lot. When I saw that the Falmouth Road Race was going on, I decided to run and I picked CCALS because we had that relationship, that connection."

Andretti took to the course with his CCALS-branded Boston Marathon singlet and a positive spirit that carried on for all seven miles. When asked why he runs, Andretti's purpose is clear:

"I run for my mom whom I love and miss dearly, I run for myself for all that I have been through, overcome and the many more blessings to come ahead, and I run for all those who stand in their own way of doing something, for anything is possible if you put your mind to it. We are our own worst critic and yet our biggest cheerleader if we allow positivity in."



The CCALS community cheered on Andretti, as he carried his mom's legacy in the Boston Marathon on October 11th.

# CELLO-BRATE, GOOD TIMES!

On August 8, *The Cello-bration: His Way* raised \$63,000 to support CCALS while honoring Celestino "Cello" Ciccone. A businessman in the town of Leominster, Massachusetts, Cello was diagnosed with ALS in 2019. The event brought together thousands of community members at Leominster Eagles Club and featured music, raffles, food trucks, and an auction. Cello and his community are excited to celebrate and support CCALS next year with a three day Cello-Stock!



RON RECEIVED PROCEEDS FROM THE CELLO-BRATION FROM CELLO CELESTINO AND THE PLANNING COMMITTEE.

# THOUGHTS FROM RON

Over the past two plus decades, CCALS has done a lot of little things and big things in ways that truly serve the ALS community. We have done these things so well that we see the need to expand our physical presence in parts of the country where we have a connection and where it makes sense to grow. We are working hard to make sure we can do what is being asked of us.

I've said for a long time—and believe strongly—that what we provide to those living with ALS is unique in the world of healthcare. Our relational model is based first and foremost on the skills of listening, noticing and showing up with calm clarity. It provides something for our families they don't often receive anywhere else. The fact that our approach works is reflected by the increasing number of families we serve.

CCALS is unique because our work can be healing. We don't approach ALS as this relentless, merciless decline, but more like a wave, with lots of ups and downs, incredible fluidity and mystery, and many opportunities for healing, growth and joy along the way. Our team conveys this attitude beautifully with incredible presence and dexterity in the work they do every day. Every family is different, and sometimes there is significant chaos and suffering. Sometimes our best efforts are not received, and that can be frustrating. That's why I feel it is vitally important to take good care of our staff, so they have the resiliency necessary to continue showing up for families facing such extraordinary circumstances, punctuated with a terminal illness.

A few weeks ago, all of the staff was able to take an in-person weekend together at our Retreat Center (with COVID-19 protocols in place). It was a time of community, sharing meals and stories, exploring our inner lives with open hearts, listening and appreciating who we are and what we do. I feel this effort is unique in the world of healthcare. So often, healthcare professionals at all levels are harried, stressed, and pushed to the edge of breakdown. No one is pausing to hear them, care for them or give them tools to avoid empathic distress and burnout. At CCALS we are taking the time to do this, and I believe it is making the service we provide even stronger.

Most of you who are reading this know what the road of ALS looks like. You understand that having compassionate and knowledgeable companions along the way can make a huge difference. Word of what we do and how we do it has spread, and we are answering the call. Thank you for walking along with us and supporting us every step of the way. I bow to you all.

In service,

A handwritten signature in cursive script, appearing to read "Ron".



RON HOFFMAN  
FOUNDER

# IN MEMORIAM

Aida Dipasquale, Hingham, MA  
Allen Giles, Alton, NH  
Catherine Christine Cullinane, Allston, MA  
Christine Thomas, East Brookfield, MA  
Claudi Skilton, Stratham, NH  
Cynthia Melton, Upton, MA  
David Ferrante, Somerville, MA  
David Kaylor, Greenfield, MA  
Debra Stimson, Wakefield, RI  
Dennis Lafferty, Brielle, NJ  
Eileen Perrelli, Norfolk, MA  
Ernest Spaulding, Hampton, NH  
Frank Nagle, Bedford, MA  
Georgia Autiello, Providence, RI  
Henri Gbantous, Walpole, MA

James Lockler, Dracut, MA  
Jeff Corcoran, Duxbury, MA  
Jeffrey Jacques, Rollingsford, NH  
Jeffrey Roosa, Lee, MA  
Jesse Levine, New London, NH  
Joan Nickerson, Chatham, MA  
John Caristo, Beverly, MA  
John Devine, Springfield, MA  
Johnathan Wilde, Arlington, TX  
Jonathan Bander, Carmel, NY  
Jonathan Greenfield, Westport, CT  
Jonathan Kennedy, Mashpee, MA  
Joseph Beson, Mashpee, MA  
Josias Faria, Hyannis, MA  
Lee Grindheim, Quincy, MA

Lisa Donovan, Saugus, MA  
Marc Abrahams, Wellesley, MA  
Margaret Campeau, Plymouth, MA  
Maria Gouveia, Somerset, MA  
Marilyn Dauphinee, Mashpee, MA  
Martin Tildsley, Wilmington, MA  
Matt Difley, Wells, ME  
Melanie St. Croix, Ogunquit, ME  
Nancy deVillers, Westport, MA  
Nancy "Candi" Skurow, Chelsea, MA  
Nancy Smith, New Bedford, MA  
Nicole Ferrari, Ashland, MA  
Pater Satkwich, Windham, NH  
Patricia Johnson, Worcester, MA  
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Peter May, Wakefield, MA  
Peter Richardson, Cohasset, MA  
Phyllis Fonseca, Cambridge, MA  
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Sabina Caston, Newon, MA  
Susan Tidd, West Newbury, MA  
Sylvia Rios, Lowell, MA  
Terence Magrath, Warwick, RI  
Timothy Briggs, Amesbury, MA  
Theanna Pateropoulos, Gorham, ME  
Thomas McGovern, Belmont, MA  
Tim Paquette, Orange, MA  
Vincent Gallucci, Newburyport, MA  
William Ogg, Plymouth, MA