



HELP US *TURN THE SCREEN GREEN* ON NOVEMBER 14!

November 14, 2020
7pm EST/4pm PDT

Join Compassionate Care ALS' first virtual fundraiser, *Turn the Screen Green*, in support of individuals living with ALS, their families and caregivers on Saturday, November 14th at 7pm EST/ 4pm PDT. Funds raised from this event will expand CCALS programs to meet the increased need brought on by the COVID-19 pandemic.



JONATHAN PENNER
AND
STACY TITLE

Turn the Screen Green will be hosted by Oscar-Nominated actor, screenwriter, producer and *SURVIVOR* contestant, Jonathan Penner and his wife, partner and fellow Oscar nominee Stacy Title. The evening will feature appearances by celebrity guests including *Seinfeld's* Jason Alexander, *SURVIVOR* Champion Yul Kwon, *The Princess Bride's* Cary Elwes, Author Lisa Genova and other

surprise guests! You'll hear stories of how your support has impacted people living the day-to-day reality of ALS, have the chance to win incredible auction items, and even mix up a signature Tito's cocktail. Founder/Executive Director Ron Hoffman will also share updates on our programs and expansion.

This year has presented unanticipated challenges for everyone, CCALS included. All of our in-person events have been cancelled until further notice to ensure the health and well-being of our families, supporters, and community. We hope you join us for a unique and interactive experience on November 14th to come together even while we are physically apart!

WAYS TO GET INVOLVED

Visit screengreen.org to learn more

Attend and support the event

Join us on November 14th to celebrate CCALS and honor our ALS community. The event is **free** to attend. Donations are encouraged in order to provide support to our ALS families during the pandemic.

Purchase a Party Package

Enjoy the full experience by purchasing a Party Package full of high-end goodies to celebrate the night of the event. Each party box costs \$300 and contains party materials for two, including insulated wine tumblers, a mood-setting candle, and a Tito's cocktail kit among many other surprises. Each box also contains a special scratch-off ticket and one winner will take home the grand prize, to be announced soon! Order your box before Friday, October 30th for free delivery! Boxes purchased after 10/30 will cost an additional \$40 to cover express shipping.

Bid on auction items

Bid on incredible silent auction items including one-on-one Zoom sessions with celebrities and a personalized design-your-own clutch experience. You can register to bid at screengreen.org and be the first notified when new auction items are added!

CONNECTING WITH THE ALS COMMUNITY

Compassionate Care ALS responded to the COVID-19 pandemic with the same commitment we have with ALS. Our operations changed in a variety of ways, including a temporary halt of in-person visits. Staff share their personal stories of this transition and how they used new platforms and protocols to continue to support the community.

Erin Lajeunesse, Senior Family Care Liaison



ERIN AND HUSBAND, ERIC, AT THE CCALS GALA

Visiting with our families and “showing up” is a major part of what CCALS does. Senior Family Care Liaison, Erin Lajeunesse, does just that. Erin used to drive hundreds of miles every week to meet her families with enthusiasm and dedication to authentic communication. When the COVID-19 lockdown first started, she transitioned to a fully remote role for four months. The time she usually spent driving and visiting with families in-person became meetings with families via phone call or Zoom.

Erin says this shift to virtual contact comes with positives and negatives. “The good thing is that eliminating the travel time made more time for helping people in different ways. I could speak to more people than if I was spending hours driving.”

The downside is not having the same type of communication a face-to-face meeting brings. “I want to be in front of people,” Erin explains. “I want to see the nonverbal communication, the nuances that help me in my job. There’s a lot you can pick up when you’re in front

of someone and that’s tough to get through Zoom.”

Erin and CCALS colleague Eileen Garry regularly conduct Caregiver Gatherings on Zoom in order to provide our community the support they need during this time. These gatherings have been a continuous way to connect while everyone is apart. Erin says that the Zoom sessions can be a release from the surface-level communication we oftentimes have through screens.

“I love when you can see the emotion come out during these meetings. Once it happens, then everyone starts being authentic and real. It’s a release and everyone feels heard and supported. I’ve had many happy moments on our Zoom meetings because I realize how much people still need that connection. I’ve found that using humor and sharing my personal struggle with quarantine isolation opens a lot of doors to honest conversation.”

Now that CCALS has started making in-home visits again following approved guidelines, Erin’s work has shifted to a hybrid model. She’s back on the road visiting families, always with her mask and her purple chair in tow which she sets up so she can stay six feet apart. Some of her families still prefer virtual visits, so she spends a few days of the week working from home to hold those meetings.

“The worst thing is not being able to hug my families,” Erin explains. “My favorite thing about this job is the connection, and I am so grateful to be able to see the families that want me physically there while still supporting those who prefer a phone call.”

She says her time working from home during COVID-19 also allows her to connect more deeply with some of

her families. “I now have a different appreciation for what it’s like to be in lockdown, to be in one space. Although I can’t fully understand living with ALS, I can relate with loneliness and isolation in a different way,” she says.

Travis Schneider, Equipment Program Director



TRAVIS AND HIS WIFE, KATIE, CHILDREN SLOANE AND KOLTON, AND DOG, TITO

Part of CCALS programming is providing appropriate Durable Medical Equipment (DME) to individuals and families. If you’ve had equipment installed, you most likely have met our amazing Equipment Program Director, Travis, who drives all over the East Coast to make sure families get the tools they need. Travis’ procedure for handling and delivering equipment has shifted greatly during COVID-19.

“Before COVID I had hands on all the DME we provide to families. I would enter people’s homes, chat with them, set up and demonstrate equipment use. I am still delivering and picking up DME, but I’m leaving it on doorsteps and explaining how things work over Zoom or on a phone call.”

Although he’s still delivering DME from New Jersey to Maine that makes

MUNITY THROUGHOUT COVID-19

always embody; keeping our families safe and providing them the resources they need to live home visits to protect families and staff from potential risk of exposure. Below several of our to support the community we serve.

life easier and more accessible for individuals with ALS, Travis also spends about six hours a week on the phone or on Zoom calls. During these calls, he explains equipment set-up, installation, or use. He often works with caregivers to help them implement new equipment in their day to day lives.

"When I used to bring equipment in, a lot of time I would demonstrate. Now

I ask if they have a nurse or caregiver who is familiar with the equipment. They usually are, which makes it a lot easier and then I can answer any additional questions."

Travis explains that he is grateful that CCALS is still able to provide DME to families during the pandemic, but that he misses the interactions.

"My favorite part of the job was connecting with people. With COVID-19, there's a lot less of that now. It is still encouraging to see people waving from windows, or standing on their doorway to chat while I am out in the yard. But I can't wait until we are able to have that direct contact with people again. Getting to know the families I work with is the most meaningful part of my job."

THOUGHTS FROM RON

Take the Chance to Go Within by Ron Hoffman

The days and times of our lives become vividly more precious when we are confronted with a fatal illness. Our ALS families have taught me that. Everyone reacts to the trauma of an ALS diagnosis in different ways, but unconsciously or consciously we understand one thing clearly: time is precious.

Knowing this encourages us to make clear choices about how we spend our time, and keeps us focused on what is fruitful and has meaning. For my friends with ALS, this often means making time for long postponed activities or relationships that may need tending or cultivating. The COVID-19 pandemic has added another layer of understanding the importance of the moment and making time count.

Dozens of families have called me this summer disappointed that they have had to cancel their fundraisers in support of our work, everything from golf tournaments to beer tasting festivals. Even our largest annual fundraiser, the Falmouth Road Race, had to go virtual resulting in greatly

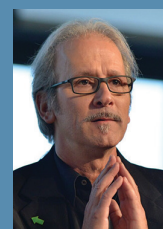
reduced participation and funds raised for CCALS. The pandemic also meant cancelling our biennial Gala. We are so lucky that our generous donors recognized our situation and stepped up with the funding to make it possible to continue our work with the more than 660 families who rely on our services.

The pandemic changed everyone's lives, and very quickly. No dining out. No travel. No sporting events or theater. It limited the activities that make up the fabric of life. For CCALS, the shutdown meant no in-home visits. We usually visit our families where they are most comfortable, we get to know them in their own homes. Our learning curve had to be swift as we transitioned to virtual overnight. I'm proud of our staff for adapting, getting savvy with the technology, and putting into place our services through whatever means were available to us. We are grateful to have been able to start home visits again, under strict safety protocols.

I encourage everyone to greet the challenge of these pandemic times. Yes, we are unable to engage in most of the social activities we have relied on for connection. I find if you look deeply satisfaction comes from our ability to achieve inner peace, no matter what is happening around us. This is why I am always an advocate of contemplative practice and self-inquiry into who we are fundamentally. One of the most important matters is knowing how to live our lives aware that the time we have is finite.

I invite you to truly self-reflect during these times, my friends. Find your deep heart and soul. Reach down inside and touch the depth of your being. Learn what is that makes you achieve inner peace and brings you joy in the most challenging of times.

Always,



RON HOFFMAN
FOUNDER

BOB'S 50TH QUEST SUPPORTS CCALS THROUGH FALMOUTH ROAD RACE

Eighty-two CCALS supporters ran or walked this year's New Balance Falmouth Road Race 'at home edition' and raised over \$75,000 for the Compassionate Care ALS Patient, Family, and Caregiver Program. Participants had the option to complete this year's race on their own terms, some choosing to complete all seven miles at once and others spreading their miles across multiple days. Bob Hamilton created a unique race route for this year's road race challenge. His goal was to run seven miles under 50 minutes to commemorate his 50th birthday.

Bob got connected to the CCALS community through his close friends Bill and Ted Shea. Their mom, Anne Shea, who was a kind and motivating person, lost her battle to ALS in 2015. Through their family experience, Bob learned about the valuable expertise, service, and guidance offered by CCALS. He played music at an event in support of the Hurley family, who also have a family member affected by ALS. Both of

these experiences motivated him to run the 2020 Falmouth Road Race with CCALS.

Bob began his first three miles in his hometown of Falmouth. He ran the first two on the new Falmouth High School track and the third along the bike path. He then drove over 700 miles to Blacksburg, VA to drop his daughter off at college, and there he finished miles four and five on the Blacksburg High and Virginia Tech track.

Bob completed mile six back on the Falmouth High track and began his seventh and final mile at the six-mile marker along the Falmouth Road Race course, crossing the finish line with more than three minutes to spare. Bob celebrated his 50th year by crushing his goal, finishing his personal Falmouth Road Race in 46 minutes and 54 seconds.

"It was fun to have the whole family involved in the virtual event this year,



BOB WITH HIS DAUGHTER KATE AFTER FINISHING MILE 5 AT VIRGINIA TECH

including finishing our one mile 'legs' of the race in different places. My wife has been seeking ways to make the proverbial lemonade out of lemons with all the challenges 2020 offers - this was a good example," says Bob.

The response to Bob's direct outreach to a small group of trusted friends and family was overwhelmingly positive. This group came together to support Bob and Compassionate Care ALS through donations, awareness, and words of encouragement. Bob says, "The human spirit is powerful, and everything makes a difference!" He encourages everyone to challenge themselves, get others involved, and raise awareness for a cause important to you.

IN MEMORIAM

Lauralee Almeida, Somerset, MA
Lily Anderson, Eastham, MA
Lizanne (Surette) Beaudoin, Tewksbury, MA
Scott Beels, Marston Mills, MA
Manuel Bernal, Springfield, MA
Lori Blanco, Raymond, NH
Matthew Brennan, Marlboro, MA
Dennis Ceruti, Upton, MA
Linda Clayton, Wellesley, MA
Maria Collazo, Lunenburg, MA
Kim Conklin, Peekskill, NY
Ann Copparini, North Kingstown, RI
Ivan Daniel, Dorchester, MA
Annette Dann, Danvers, MA
Jason Desantis, Billerica, MA
Lydia Dorner, Lexington, MA
Jeffrey Driscoll, Harwich, MA
Edna English, Hingham, MA
Mark Feldman, Brighton, MA
Douglas Flower, West Roxbury, MA
Rose Frank, Westport, CT

Glenn Gardner, Fairhaven, MA
Elliot Ginsburg, Bloomfield, CT
Janet Golden, Rockport, MA
Dorothy Green, Shutesbury, MA
Jim Grimsley, Pittsfield, MA
Robert Grosjean, Addison, NY
Donna Guevremont, North Smithfield, RI
Glen Haab, East Hampton, NY
James Harris, Chandler, AZ
Janine Hartwell, Merrimack, NH
Ann Heston, East Sandwich, MA
Eric Hollis, Taunton, MA
Michael Keller, Brighton, MA
Jake Kennedy, Salem, NH
Mike Koeth, Euclid, OH
Litsa Kourkoutas, Cambridge, MA
John King, Hudson, NH
Darlene Levesque, Raymond, NH
Sigrid Olsen Lindo, Rockport, MA
Xiaomei Liu, Malden, MA
Lucivalda Maciel, Buzzards Bay, MA

Keith Mauro, Port Jefferson Station, NY
Timothy McBride, Bristol, RI
John McCann, Yonkers, NY
Laurena McCarthy, Newtown, CT
Carol McDermott, Rockland, MA
Michael McMahon, Cranford, NJ
Silvina Medeiros, New Bedford, MA
Noel Mermer, Johns Island, SC
Derek Michaud, Groton, MA
Patricia Mitchell, Dracut, MA
Robert Monroe, Wellesley, MA
Rogelio Moreno, Stoughton, MA
Edward Mullen, Everett, MA
Noel O'Connell, Pearl River, NY
Sergio Olivia, Norwalk, CT
Chan Park, Canton, MA
Myra Perez, Westwood, MA
Thomas James Perszyk, Muskego, WI
Dean Phillips, Old Orchard Beach, ME
Rob Pontes, Somerset, MA

Donald Poole, Northbridge, MA
Douglas Potter, Plymouth, MA
Robert Reese, Salem, NH
Wesley Roussel, Fairfield, CT
John Schott, Plymouth, MA
Stephen Schroeder, Fairhaven, MA
Shannon Scull, Noxen, PA
Bob Sickles, Yorktown Heights, NY
Teresa Simpson, Lynn, MA
Sharon Singer, Newton, MA
Daniel Sullivan, Proctorsville, VT
Scott True, Lee, NH
Maureen Valkanas, Canton, MA
Dennis Vadenais, Harrisville, RI
Nathan Patrick Vincent, Pittsfield, MA
Betty Westgate, Somerville, MA
Alice Wheeler, Medfield, MA
Jessica White, Centerville, MA
Thomas Wilson, Methuen, MA
Brenda Wolfe, Quincy, MA
Bernard Yenelouis, New York, NY