



2018

[WWW.JoeMartinALSfoundation.org](http://WWW.JoeMartinALSfoundation.org)

*"You are the only organization that treats the family - Instead of the patient or the disease."*  
- Husband and ALS caregiver served by the Foundation



August 5-9, the first overnight Joe's Camp was held at Camp Canaan in Rock Hill, S.C. Campers and counselors enjoyed kayaking the Catawba River, campfire meals, s'mores, swimming, zip-lining, and making friends with others who understand ALS. On Sunday, we held our family day, and parents and caregivers shared their ALS stories and offered suggestions for caregiving techniques. One counselor said, "ALS has many negative impacts on families, but it brings everyone together to do remarkable things. Joe's Camp is important for ALS families because it gives the kids and adults the opportunity to take a step out of a difficult reality and take a fun break, as well as providing discussion and reflection." Plans are underway for Joe's Camp 2019. Stay tuned for more information.



## Services & Programs Offered by The Joe Martin ALS Foundation



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**Did you know: Joe's Camp is the only over-night camp in the Southeast dedicated to helping children whose families have been touched by ALS.**



## Live Every Day Dinner

Heroes were among us at the Live Every Day Dinner! Heroes Among Us was the theme at this year's Live Every Day Dinner held on Aug. 23 at Carmel Country Club. Hero, N.C. State Baseball Coach, Elliott Avent, stepped in to pinch hit as keynote speaker for originally scheduled speaker, former baseball player, Chris Combs. Coach Avent talked about his hero, Chris, and his fight with ALS. Coach Avent shared Chris' belief that like on the field, ALS must be battled with a team approach, both with



Coach Elliott Avent

research and services for people with ALS. Coach Avent discussed the important part The Joe Martin ALS Foundation plays in this battle, with the free support and services we provide our clients.

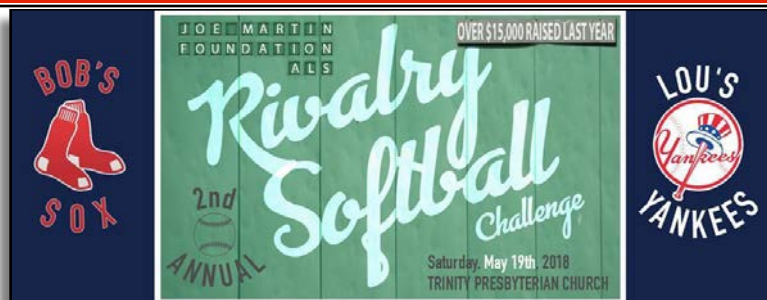


Marta Roberts, Julie Freeland, Claudia Tate, and Jen Zahos

Guests enjoyed the intimate atmosphere of the dinner, with David Martin serving as emcee, and Joe B. Martin starting the dinner off with a prayer. Kirsten D'Amore eloquently shared her family's fight with ALS and how all families need help with the many challenges presented by ALS. Beautiful floral centerpieces were donated by Cheri Lindblom of C.blooms, and home-made sweets by Tracy Campbell of Cookies on the Side. The star of the evening was a video produced by Aaron Putnam of JoyRide Productions. Aaron captured what being a hero means to people with ALS, whether it's a doctor, caregiver, or donor, all are heroes and can help in the fight. You can watch this great film on our website. The night culminated with caped super heroes collecting generous gifts from attendees. The evening raised \$138,000 to help families live actively with ALS. Thank you to our volunteers, sponsors, and supporters who made this year's Live Every Day Dinner a success!



Watch the film:  
[joemartinalsfoundation.org/live-every-day-dinner/](http://joemartinalsfoundation.org/live-every-day-dinner/)



The tradition continues! Bob's Sox teamed up against Lou's Yankees to play a friendly game of softball to raise funds and awareness for The Joe Martin ALS Foundation. Bob Taylor, avid Red Sox fan who lives with ALS, inspired the Bob's Sox team name and of course



Bob Taylor (Front, Right) enjoys the event



John Cantrell (Left) and Andrew Taylor (Right) present Sarah Hayden a big donation check!

Lou's Yankees are in honor of Lou Gehrig, baseball great who lived with ALS and an inspiration to many. Spectators enjoyed the game, silent auction, raffle and ballpark franks from Miller's Meats and Sweets. Donations totaled just over \$20,000 to help people with ALS with care and support! Plans are underway to bring more family fun to this event through interactive

activities, and kid games. Interested in learning more? We are forming a committee to plan an amazing 3rd annual event! Please contact Sarah Hayden at [sarahhayden@joemartinALSfoundation.org](mailto:sarahhayden@joemartinALSfoundation.org) if you are interested in getting involved.

## Who benefits from our programs?

### What Your Dollars Support

Service:	Cost To Clients:	Agency Fees:	Cost To Foundation:
One home care session	\$0	\$22.00/hour	\$18/hour
Wheelchair Transportation	\$0	\$100.00	\$66.00
Community Caregiver Workshop	\$0	n/a	\$250
Lodging, meals, and activities at Joe's Camp for one camper	\$0	n/a	\$500
Weekly free homecare for one family for 6 months	\$0	\$3,432	\$2500
Weekly free homecare for one family for a year	\$0	\$6,864	\$5,000

The Joe Martin ALS Foundation is a 501 (c)(3) organization that helps families meet the challenges of living actively with ALS by providing free homecare services.

We are able to provide our services because of the generous support of our donors. Thank you for your support!

## Everyday Heroes with ALS



# Family Spotlight: The Rizzos

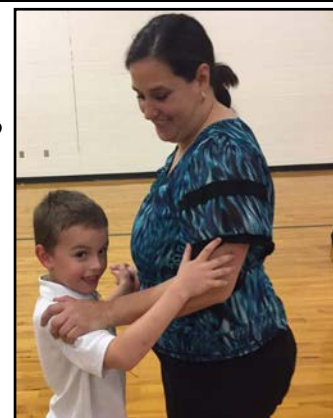


*Meghan with Gianna*

Meghan Rizzo is a wife, mother of four, and she also has ALS. She needs help to stand up, but her resolve and courage are unrivaled. The Joe Martin ALS Foundation provides home care, transportation to the ALS clinic, equipment loans, and meals from volunteers for the Rizzos and they are very grateful for the services you are making possible. Before her diagnosis, Meghan volunteered with her church and enjoyed helping others in need. She says it is difficult for her to be on the receiving end, but she remains positive, saying, "It could be a lot worse. My kids are healthy and I am grateful for that."

Meghan's children, Bylan (21), Alexas (19), Zayden (9), and Gianna (4) give her inspiration and encouragement. She is also bolstered by Lynne's cheerful spirit. Lynne, our staff member, provides home care and enjoys visiting with Meghan. Chris, Meghan's husband, enjoys the meals Lynne brings every week. This saves him from at least one more task after he gets home from work. Chris gets his kids ready for school, helps Meghan get up and works 6-7 days a week. He appreciates Lynne and the Friends of the Foundation who have helped with house work and donated meals. Meghan and Chris are grateful for all the help YOU have

provided through the Foundation. We thank YOU for being heroes to this family! If you would like to help with meals and other assistance for the Rizzos and other families please call 704-332-1929 or email [sarahhayden@joemartinALSfoundation.org](mailto:sarahhayden@joemartinALSfoundation.org)



*Meghan with Zayden*

## 10th Annual Golf Tournament

Congratulations to Tom DeJuneas, Tommy DeJuneas, Seth Holloman, and Jason Brett for winning The Joe Martin ALS Foundation Golf Tournament presented by CDI Southeast. Over \$32,000 was raised! Players enjoyed a great game at Ballantyne Country Club, special "Ting" cocktails at the Tings on Ten hole in honor of Bernie Martinelli, and a great dinner, program and auction after the tournament. Guest speaker, Kelly Sullivan, shared her connection with ALS and her experience of serving as camp nurse for this year's Joe's Camp. Thank you to all who came and joined us at this annual event!



*Golfers with our summer intern, Meredith Haddock*

## Friends of the Foundation



There are so many ways to support The Joe Martin ALS Foundation. Many people and businesses have shared their time, talents and treasures this year. Here are just a few. In early November we learned that one of our families we serve did not have a working refrigerator. They were having trouble with replacing it and we asked our supporters if anyone had an old one they could donate. No one responded with a used one, but we did get an offer that if one was not donated they would buy the family a new refrigerator! The family is thrilled and greatly appreciates this generous donation.

Jerry Dawson, President & CEO of ALSA North Carolina Chapter, received the 2018 Partner of the Year Award on behalf of The ALS Association North Carolina Chapter. Our foundation works with ALSA in many ways and this year they were the presenting sponsor for Joe's Camp.



*Jerry Dawson with the 2018 Partner of the Year Award*



*Neil Cottrell presents Aaron Putnam the Dan Ramirez Service Award*

Aaron Putnam, of JoyRide Productions, won the 2018 Dan Ramirez Service Award. This is the fourth year that Aaron has donated his talents by writing, shooting and editing our annual Live Every Day film. His most recent work, Heroes Among Us, is an especially moving tribute to JMALSF clients and their heroes. Cheri Lindbloom of C.blooms received our 2018 Ice Bucket Award for sharing her talent of floral design by creating all of the centerpieces for our Live Every Day Dinner, which provided a beautiful atmosphere for our annual event.





Laurie Foster and Neil Cottrell

## ALS Advocacy Day

Laurie Foster and Neil Cottrell traveled to Washington, D.C. in May to support legislation that will help people living with ALS and attend the National ALS Advocacy Day Conference. The conference brings together people with ALS (PALS), their families, caregivers, those who have lost someone to ALS, and those who assist PALS. This affords attendees the opportunity to meet people from diverse backgrounds with a common cause.

We met PALS whom we could not tell had an ALS diagnosis, and also those who needed a ventilator to breathe. We listened as scientists presented the latest in ALS research and how we can lobby our representatives to support these initiatives: 1) Ensure at least \$10 million in appropriations for the ALS Registry at the Centers for Disease Control. 2) Ensure at least \$10 million in funding for the Department of Defense's (DOD) ALS Research Program. 3) Support increased funding for the National Institutes of Health in 2019, especially the National Institute of Neurological Disorders and Stroke. 4) Pass the ALS Disability Insurance Access Act (S.379/H.R.1171) to waive the five-month waiting period for patients with ALS

before receiving benefits under Social Security Disability Insurance.

The conference was a success as all of the funding goals were achieved and the ALS Disability Ins. Access Act is currently being studied. All of the legislators we visited appreciated hearing our ALS stories and vowed to help our cause. If you are interested in attending this conference on June 9-11, 2019, please call 704-332-1929.



Sen. Burr listens to a PALS share her story using a speech generating device



N.C. ALS Advocates with Senator Richard Burr (front, kneeling)

## Super Steve ALS Walk

Birkdale Village in Huntersville, N.C. set the stage for a successful Super Steve ALS Walk in honor of Dr. Stephen Hix, who lived with ALS for seven years. We thank Linnea Meletioui and Meletioui & Meletioui, The Smile Architects, for all of their efforts in coordinating this year's walk. We are proud to share that we raised over \$20,000 to support the Foundation's services.

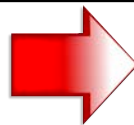


## On Any Given Day



We have converted Joe Martin's On Any Given Day to an ebook! Go to <http://joemartinalsfoundation.org/joe-martin/> to download your copy. This inspiring publication chronicles his experience of living with ALS. Co-author Ross Yockey explained: "In 1994, Joe was diagnosed with amyotrophic lateral sclerosis, Lou Gehrig's disease. The doctors told him his life would be over in twenty months or less. After a brush with despair and terror, Joe decided with his family and friends that he would recover, if not from the disease, then from the diagnosis. No doctor could predict what

might be accomplished on any given day. Unable even to work a keyboard or speak, Joe was seemingly powerless. Yet he found the power to change his world. Unlike Tuesdays with Morrie, a book about a man dying with ALS, On Any Given Day is a book about a man **living** with the disease. This is both an inspiration story and a how-to book about contributing to life as a full human being - even when most of the basic tools of humanity are taken away. This is a book for anyone who's been tempted to stop hoping, a book on recovering hope and discovering possibilities. It is a blueprint for making the best out of every day, one day at a time. It's a book, too, about and for caregivers. Joe's wife, Joan, lead a strong supportive cast. Family, friends and young assistants learn to redefine caregiving through commitment, to sustain dignity through love."



## UPDATES

Check out our redesigned website that has been optimized for mobile devices and tablets. We have also updated our mission statement. We made a few minor changes to better communicate how we help families in many more ways than just home care.

## Mission:

To empower families as they face the challenge of living actively with ALS by providing free home care and other services at no cost. (updated Oct. 2018)



## Staff:

Neil Cottrell - President  
Sarah Hayden - Director of Development  
Laurie Foster - Office Administrator  
Felicia Stevenson - Home Care Provider  
Lynne Stinson - Home Care Provider  
Doug Larter - CNA II

## Services Provided:

- Activities of Daily Living Assistance
- Range of Motion/Exercise
- Wheelchair Accessible Transportation
- Adaptive Technology and Support
- Travel Planning
- Medical Equipment Loans
- Home Accessibility Assessment
- Caregiver Training
- Joe's Camp