



2019

WWW.JoeMartinALSfoundation.org



Finding Your Tribe at Joe's Camp

What an incredible and inspiring weekend! We welcomed 19 campers, six teen assistant counselors, and six counselors for our second annual Joe's Camp this past August 7-9 at Camp Canaan in Rock Hill, SC. From kayaking, zip lining, swimming, crafts, climbing wall, campfires, to meaningful activities to discuss ALS with their peers, these kids had a blast with new friends who are also experiencing ALS in their family. Parent, Akilah Cameron, shared, "I just wanted to send this email to say THANK YOU again for the awesome camping weekend.

My kiddos are still raving about how much fun they had. Your team must put a lot of hours into planning this, and trust me your efforts did not go unnoticed. What a great thing you all do. I'm so thankful for your overwhelming support to the cause and to each and every family that participated."



Joe's Camp is unique and special because all of our counselors have experienced ALS in their own families, allowing them to relate to what the campers are going through. Kelly Sullivan, camp nurse shared, "I want these kids to look forward to this weekend all year, and to emerge feeling stronger. I want them to know without a doubt, that this tribe will always be there for them. That happened this year, and that is so important."

We are thankful to the families and volunteers that helped create this amazing "tribe" of support at Joe's Camp! We are grateful to the NC Chapter of ALSA for being our presenting sponsor, Jersey Mike's of Gastonia for being our lunch sponsor, and Carolina Printwear for the awesome camp shirts. The weekend was such a rewarding and fun experience for all involved. Stay tuned for details on Joe's Camp 2020!



"They give us home care, transportation, medical equipment, information, and make it easier to care for my wife while at the same time allowing me to focus some of my attention on our kids."

- Family served by The Joe Martin ALS Foundation

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Did you know: The average age of onset of ALS is 64 years old.



Cindy Monteith

Spotlight: Cindy Monteith

Cindy Monteith is first and foremost the proud mother of three grown children and seven granddaughters.

Over the last 25 years, Cindy Monteith has traveled a diverse journey, but in all its diversity her life has had one constant passion and focus: children, youth, and families. She has been mentor, coach, teacher, director, lecturer, and supporter of children, youth, and families that spans across the globe.

Cindy holds a Bachelor of Arts degree from Columbia College (Theatre Arts, Directing) and a Master of Divinity (Theology) Duke Divinity School, Duke University. In her most recent full-time position, Cindy served as the State Chaplain and Director of Well Being & Support for the largest ambulance company in Australia, where she served a workforce spread over one-million square miles.

Currently, Cindy still consults as the Founding Director of ArtSpoke, a non-profit organization that creates intentional



Watch Cindy's "The Power of Your Story" Ted Talk. Google: Cindy Monteith Ted Talk

programs where children, adolescents, and young adults build strength, resilience, and embrace vulnerability.

Her new favorite past-time is racing her granddaughters around in her new power chair. Living with ALS is now a new way of life for Cindy. She tries to live each day embracing every part of herself—to find gratitude in each day. Fe Stevenson, The Joe Martin ALS Foundation caregiver who assists her enjoys her visits and getting to know Cindy. The Foundation is grateful to Cindy for her "Happy Village" fundraiser. Cindy Monteith's son, Addison, first hosted a fundraiser at his restaurant, The Happy Village in Chicago, this past summer. He sold Cindy Lou cocktails and donated the proceeds to support ALS research. We wanted to bring the good cheer and support for ALS to Charlotte to Cindy's "Happy Village" of friends and supporters. See the info box above for the details.



We're A HAPPY VILLAGE to support ALS!



Sunday, November 24th, 4-7pm

The Flying Biscuit Café

Park Road Shopping Center, Charlotte, NC

Help raise 50K for The Joe Martin ALS Foundation, to support home care and services for those with ALS!

RSVP, donate, & learn more here:

joemartinalsfoundation.org/events/cindy-lou/

ALS Ultra Pushup Challenge

September 2019 marked the 10th anniversary of the passing of Tina Burson. To honor his mother and raise funds for the Joe Martin ALS Foundation, Greg Burson created the ALS Ultra Pushup Challenge. He ran 28.2 miles, did 2,300 pushups in only 8 hours, and raised over \$20,000!!!



Greg was 11 years old when his mother was diagnosed with ALS. He explains how it took him years to process and confront how ALS affected his life: "Once she passed, I tried to convince myself that I had already grieved while she was sick and that I should be happy because she was in a better place. Rather than confront the anger and sadness I felt, I ran from it. ALS drained me emotionally and I was not willing to work through those emotions at the time. Eventually, a couple years later, I hit a point of rock bottom and could no longer function. I was overwhelmed with grief and anger. I had no drive, no goals, no purpose. I believed I was irreparably damaged and broken. I used my ALS to justify my anger and depression. A few months after dropping out of college, I finally agreed to see a grief counselor. I needed to confront and explore those feelings. I needed to let myself grieve and that process was extremely painful, especially since I let my grief build for so long. But once I did, and through a difficult and long process, a weight slowly lifted.

I was able reflect on those painful memories and abstract things of great value. I do not want an easy life, I want a full life. I want to have struggles and obstacles that I am forced to overcome. I know that I have something of great value and I want to be able to share that with others. That is what this challenge is about. Until a couple months ago, I had never run a 5k let alone an ultra-marathon while doing thousands of push-ups. I am doing this for my mother and for a foundation that does incredible work. That will allow me to push through any obstacles this challenge presents."



**the
joe
martin
ALS FOUNDATION**

WHY DONATE TO JMALSF?

ALS

(Amyotrophic Lateral Sclerosis) affects all muscle function including the ability to walk, speak, eat, and breathe.

ALS affects the entire family.



The diagnosis of ALS is made in the prime of life, with the average onset at the age of 60-65 but often as early as the mid-20s - 40s.

According to a 2015 financial study on the impact of ALS, **\$62,000** is the average annual cost of ALS to a family.

Annually, ALS families who receive our weekly home care services save an average of **\$5,000**

90 ALS families

will receive help, hope, and direct support from JMALSF through our program of services this year. Since our founding in 2007, we have served over **700 families**.



Free Homecare Services



Joe's Camp Overnight Weekend Retreat



Caregiver Training & Support



Wheelchair Accessible Transportation

Friends of the Foundation

There are numerous ways to support The Joe Martin ALS Foundation. Many people and businesses have shared their time, talent and treasure this year.



Andrew Taylor

Here are a few who have received special recognition.

Andrew Taylor was awarded the 2019 Dan Ramirez Service Award. Andrew's vision, enthusiasm, and love of baseball have been instrumental in making sure our annual Rivalry Softball Challenge is always a success. Andrew's father, Bob Taylor, a former baseball player himself, is served by the Foundation.

Jennifer Yoxtheimer and her team at JD Goodrum received our Partner of the Year award. Whether it's delivering meals to a family we serve, sponsoring both our Live Every Day Dinner and our softball game, or giving guidance and support on our Board of Directors, Jennifer and her team have truly made a difference in the lives of those we serve. Jennifer's father, Bill Orman, was served by the organization.



Jennifer & Jamie Yoxtheimer

Aaron Putnam, of Joy Ride Productions, received our 2019 Ice Bucket Award for donating his talents by writing, shooting and editing our annual Live Every Day Dinner video. This year's film, Stronger Together, highlights how a community comes together to make the lives of a family living with ALS a little easier.

And finally, our own, Felicia "Fe" Stevenson, caregiver for The Joe Martin ALS Foundation, received the first ever Service and Dedication Award. Fe's years of helping families fight ALS with care and compassion have made a lasting impression on all she has served.



Fe Stevenson

Thank you Andrew, Jennifer, Aaron and Fe for all you do to support the Foundation! We appreciate you!



Aaron Putnam

Batter Up for ALS!



Four teams, Bob's Sox, Lou's Yankees, Joe's Twins and The Queen City Cubs, took the field to participate in the 3rd Annual Joe Martin ALS Rivalry Softball Challenge on October 5th at Trinity Presbyterian Church in Charlotte. Over \$21,000 was raised to support the Joe Martin ALS Foundation. Players and spectators enjoyed live music from Jen & Tonic, ball park concessions from Miller's Meats and Sweets, and of course, two great games of softball. We are proud to recognize our event sponsors, JD Goodrum, Mecklenburg Radiology Associates, Mobility Works and Fungo!



Neil Cottrell, Steve Norton, & Bob Taylor (Left to Right)

When asked why her family participates in the event Terri Kletch shared, "JMALSF was a great resource for Steven, his family, and our entire family during that very difficult time. Everything that JMALSF stands for in itself is worth raising money for but when you combine America's favorite pastime with JMALSF, that is a no brainer." Terri not only recruited her family to participate but also several other players including a former MLB player! We appreciate the support from the Kletch/Opladen Family, Taylor Family, and Yoxtheimer/Orman family for recruiting players to fill our teams. We also appreciate all the volunteers that helped make the event possible. We hope to see YOU next year on the field!

Friendship & Purpose



Hugh McColl

Stronger Together was the theme of the 4th Annual Live Every Day Dinner. More than 300 guests gathered at Carmel Country Club to benefit the mission of The Joe Martin ALS Foundation and hear special guest speaker, Hugh McColl. Joe Martin and Mr. McColl were friends and colleagues for

more than 33 years. Mr. McColl's inspiring message included humorous stories about him and Joe at Bank of America as well as inspiring examples of how Joe stood up for what he believed in, whether it be improving race relations in Charlotte or helping people live actively with ALS.

Guests enjoyed an evening of cocktails, dinner and a silent auction of artwork created by children who attended Joe's Camp. A highlight of the event was the premiere of a moving video, created

by Aaron Putnam of Joyride Productions, featuring Meghan Rizzo and her family. Aaron's piece documented how we are Stronger Together when a community comes together for a cause.

The evening raised more than \$140,000 thanks in large part to our Sponsors: Legacy Sponsors Bank of America, and Joan Martin and Pat Burgess; and Gifts of Joy Sponsors, Atrium Healthcare Foundation, Carolina Asphalt, Grace & Stone Communications, Martha Ann and Craig Wardlaw, Meda Whitescarver, Velve and Tom Woollen, and Joan Zimmerman. In-kind donations also attributed to the evening's success: beautiful floral centerpieces by Cheri Lindblom of C.blooms, delicious cookies from Tracy Campbell of Cookies on the Side, and our special video by Aaron Putnam of Joyride Productions. Thank you to our sponsors, donors, Board of Directors, Live Every Day Committee, and volunteers for helping make the evening possible!



Joan Zimmerman, Hugh M. and Bob Taylor (Left to Right)

Do Politicians Really Listen to Us?

- by Neil Cottrell



Neil Cottrell

I know I'm not the only one who questions whether our lawmakers ever really listen to their constituents. I can see you're nodding. Before my first visit to Washington, D.C. for ALS Advocacy Day I wondered if I was wasting time and money by trying to inform our legislators about the needed changes in laws and additional funds for finding a cure for ALS. The Advocacy Day/Conference provides people with ALS(PALS), their caregivers, and organizations like The Joe Martin ALS Foundation an opportunity to learn about the latest in ALS research, treatments, and to engage our congressional representatives with legislative "asks" that are crucial for families fighting ALS. I enjoy this event because I am able to meet PALS and their caregivers from all over the U.S. It is encouraging to hear their stories and unite to help all families who have been touched by ALS. But - back to the point - **Does it make a difference???** I can without a doubt report, **yes it does.** Senator Richard Burr explained before announcing new legislation: "Each year, I meet with North Carolinians who have been diagnosed with or affected by ALS, who share the unexpected challenges that come with a devastating disease. It's through these visits I had the honor of meeting Kathryn Manginelli and her husband Joe. They brought my attention to the unintended impact penalties from early retirement withdrawals have on families like theirs who are struggling with terminal or debilitating illnesses. This is a problem we can fix. Americans who responsibly contribute to their retirement accounts, and who are later diagnosed with a degenerative, terminal illness, shouldn't be penalized for using retirement funds to help cover unplanned living expenses that are a direct result of their diagnosis. This is especially true for those who will not live to the retirement age. Inspired by Kathryn's story and others, I am proud to introduce this legislation with my colleague Senator Bennet." The Kathryn Manginelli Act will allow families in these circumstances to use retirement savings without incurring an additional 10 percent penalty if withdrawing before the age of 59 ½. And the following accomplishments were also led by ALS Advocates:



N.C. ALS Advocates with Sen. Richard Burr (1st row, 4th from left)

- ✓ Annual government funding for ALS research has increased from \$15 million a year to **over \$80 million a year.**
- ✓ **Eliminated the 24 month Medicare waiting period** for people living with ALS, the only time the law has ever been changed.
- ✓ Helped to implement historic regulations at the Department of Veteran Affairs that **designate ALS as a service connected disease**, ensuring veterans living with ALS and survivors have access to VA benefits.
- ✓ Led effort to enact the **ALS Registry Act**, which created the National ALS Registry and is the largest ALS research project ever created.

There is much work left to be done, but it is encouraging that our voices are being heard and **ALS advocacy is making a difference.**

On Any Given Day



Joe Martin and Ross Yockey

Download the eBook!

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."

Mission:

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



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