That, put simply, is what we do. ALS is, of course, not the kind of cloud from which one anticipates a cleansing and refreshing rain. It’s a foreboding and threatening cloud with promises of a devastating storm and, for now, there is no getting around that.

But if we work together, there are ways to support and uplift our ALS patients and their families – ways to give them hope, ways to give them peaceful moments, ways to help them have a little peace of mind.

But – it’s time to be frank – we need more support to continue this mission. More and more patients are being referred to us, but the financial and other practical resources going to the ALS cause are more and more widely distributed. Hopefully this soon leads to a cure. In the meantime, what about the people who are already living with ALS? For those with ample resources, there are truly amazing ways to improve quality of life. For those with no financial resources, programs are available.

However, for those with modest or limited resources, there is the prospect of quickly shrinking resources as employment becomes untenable, not only for the pALS, but very often for the caregiver spouse as well. This is where most ALS patients fall – neither able to purchase everything they need nor eligible for the maximum support from state and federal programs.

These are the people for whom we try to be a rainbow to their cloud of increased need, diminishing resources, and declining health. I cannot emphasize strongly enough how much we need your help. Whether you are donating, spreading the word to those who may also be interested in donating, or helping with events, the need is great and growing and we ask that you do what you can. If we are to meet the demands of the patients we have, let alone the ones that are being referred, we will need more help.

Please help us strengthen our mission to address the reality that our patients and families face every day. As you make your year-end donations, we hope you will remember the A.L.S. Family Charitable Foundation and the patients and families we serve.

We are grateful for your continued support and wish you and your loved ones a safe and happy 2020.

Mary Ann (Sciaba) Singersen
President and Co-Founder

Scholarship Helps Finish Nursing Degree

Our Scholarship Fund helps pay tuition for college-age children of a pALS. One recipient of our 2019-2020 scholarship is Mariella Martin, who is completing her nursing degree at Curry College with assistance from our Scholarship Fund.

Mariella’s father Brad was diagnosed with ALS when she was in high school, and she tells us that although she has, at times, been tempted to put off nursing school to spend more time with family given the huge changes ALS brings, her father has continually encouraged her to fulfill her dream to become a pediatric nurse. “All he wants is to see me happy,” she says, “and even though he can no longer speak or move, I can tell how proud he is just from the simple smile on his face....”

Congratulations to Mariella for pushing through and to Brad for inspiring her!
Families, volunteers, donors, patients, and sponsors came out to the Cape Cod Canal on a lovely sunny day to support our 2019 Cliff Walk, sponsored by Superior Rail & Iron Works, on Sunday, September 8, 2019 at DCR Scusset Beach Reservation in Sagamore, MA. The day began with a beautiful ceremony at our ALS Family Tree, where families placed bricks engraved with their loved one’s name in the walkway around the tree.

This year we raised over $150,000 for the fight against ALS. These funds support our In-House Patient Programs and research headed by the ALS Therapy Development Institute in Cambridge, MA.

2019'S TOP FUNDRAISERS

Adult Division
1. Jeremy & Shelly Dorfman & Team David (Again. Yes, they’re that good!)
2. Mary Vagenas & Team Georgios
3. Patricia O’Connell & This Little Light

Children’s Division
1. Nick Coolen & Team Bab’s Buddies
2. Kylee Shubert & Team ALS Haters
3. Olivia Heffernan & Team Martha

Coloring contest winners this year were Stella A & Jodi G!

BIG BIG THANK YOU to ALL the teams and individuals for their fundraising efforts and to our generous volunteers, sponsors, and staff for all their hard work and dedication. We truly could not do it without you!

We especially thank Ellen Corindia, our long-time friend and pALS, for a truly moving speech. You are an inspiration to all!

Thank you also to:

• Lenny & Tony Ferrara and Superior Rail & Iron Works, our Presenting Sponsor, for their support of our Foundation and this event since its inception, in memory of wife and mother, Janice Ferrara.
• Edward and Michael Sciaba and Allied Recycling Center, our Platinum Sponsor, for their support of the Cliff Walk in memory of father and grandfather, Edward J. Sciaba, Sr.
• Media Sponsors Cape Cod Life Publications and Cape Cod Broadcasting Media
• John DeCosta and the staff at DCR Scusset Beach Reservation for all the ways they made this event run smoothly
• Our corporate sponsors: USI Insurance, Rogers & Gray, Bridgewater Savings, Cape Cod Five, Eastern Bank, Akzo Nobel, Home Instead, Tiny & Sons Auto Glass, and One-Stop Painting & Renovating
• Prize sponsors Lynda Kenney & The Azinger Family
• The businesses that donated food & beverages for the walk and cookout: Stop & Shop, Bailey’s Surf N’ Turf, Dino’s Sports Bar, Roche Bros., Vermont Pure Water, Coca-Cola Bottling Company of Cape Cod, Utz, Peggy Lawton Snacks, and Cuoto Mgmt/Dunkin Donuts
• Mass Maritime Academy, Sandwich High School football team, Wareham JROTC, and the Cape Cod Corvette Club for help throughout the day
• David Phillips for emceeing
• The Real Deal for providing musical entertainment
• KVH Graphic Design
• Ed Murphy for use of his RV
• Lily-Belles Florals, Guardian Self-Storage in Pocasset, Hi-Way Concrete Products, and Things to Do in Plymouth, MA
• BIG BIG thank you to Event Coordinators Bill MacLeod and Lynne Florindo

The Cliff Walk for ALS is held every year in loving memory of Cliff Jordan, Jr., Edward J. Sciaba, Sr., and Janice Ferrara.

Family Vacations
For the fifth straight year, our LIFE’S A BEACH Winter Beach Party Fundraiser held on Saturday, February 9, 2019 at Dino’s Sports Bar in Mashpee, Cape Cod brought friends, family and supporters out for a fun and festive night of pretending it wasn’t a cold winter night in New England.

The event featured live music by the BaHa Brothers and a delicious buffet of hamburgers, hotdogs, wings, ribs and pizza, plus delicious baked beans and macaroni and cheese, all provided by our sponsor, Dino’s Sports Bar, and prepared and served by Dino’s wonderful staff.

Martha Carter was the winner of our limbo contest. Best dressed male and female, respectively, were Don Nelson and Stacy Barnes...congrats to all!

Because of the contributions of our beach party participants, sponsors, donors, and volunteers, over $10,000 was raised for our Patient Programs which target the needs of patients and families living with ALS.

Thanks, once again, to our Big Kahuna sponsor Dino Mitrokostas and Dino’s Sports Bar for generously making this event possible for the fifth straight year. Thanks also to Brabo Payroll, TD Bank, Mashpee Pops, CCB Media, 99.9 The Q, Cape Cod Five, Chalker Heating & Fuel, Anchor Self Storage, Cormiers Auto Service, Dunning Kirane, McNichols & Garner, Denmark’s Cleaning Services, and Biedak Law, and to our Liquor and Prize Sponsors, L. Knife & Sons, United Liquors, and Brown-Forman.

Thanks, as well, to our generous and hardworking volunteers, Linda Briggs, Dave Ryder, Ally Charette, Corey McLaughlin, Pat Bettencourt, Heidi Badot, Adrianna Mitrokostas, Andreas Mitrokostas, and Board Members, Terry Chalker, Bill MacLeod, Jacqueline Tome, and Corinne Wickel.

Facebook Fundraisers – Yes, Please!

Facebook fundraisers were a productive means of fundraising in 2019. In addition to supplementing more traditional means of online fundraising for events like the Falmouth Road Race and the Cliff Walk (for which they brought in $11,514 and $2,475 respectively), we also received $6,400 from birthday fundraisers.

These are simple to set up and every cent goes directly to our foundation – Facebook does not take a fee. We encourage you to try this very effective fundraising tool.

If you’d like information on how to create your own fundraiser, please email us at info@alsfamily.org or call the office at 508-759-9696.

Family Supporting Family

Holiday Sponsor-a-Family – In memory of Jeff Lawrence, the Lawrence, Hamilton, and Marshall families sponsored five of our families for the holidays with gifts.

Backpack Drive – We’d like to thank Blue Cross Blue Shield MA employees for supporting a backpack drive to benefit the younger school-age children of our families. Thanks also to Brooke McDonald, Pauline Murnin, Barbara Chester, and Barbara Golz for their work in organizing the drive. We appreciate your support of our Children’s Program.

Patient Programs

- The A. George Kerr Patient Program assists patients with financial needs.
- The Heath Millward Vacation Fund provides patients and families with memorable excursions.
- The Children’s Program provides financial assistance for expenses such as the holidays, back to school shopping, and summer camp.
- The Jan Ferrara Get Away for a Day Fund provides funds for individuals or groups of patients or caregivers to enjoy an outing of their choosing.
- The ALS Family Charitable Foundation, Inc. Scholarship Fund offsets the financial strain of a college education for a child of an ALS patient.
- The Respite Care Grant Program provides assistance to patient caregivers.

Please watch for info on our 6th Annual Life’s a Beach Party on February 29

Over $4,000 was raised at the August 24th Waterfront Festival in Plymouth, MA in support of our Patient Programs. Our thanks to Ken Holmes and all the generous volunteers who showed up to help us with the ALS Ice Bucket Challenge in memory of Ryan Holmes. Thanks also to the Holmes Family, the Caruso Family, Texas Roadhouse, John Carver Inn, Dan Shea, and Tom Winn for their contributions.

www.alsfamily.org
2019 Host-Your-Own Fundraisers Contributed Nearly $10,000

A significant portion of our fundraising came from events organized independently by individuals or small groups. We also benefited from corporate programs that help give employees ways to make a difference.

These are some of the third party fundraisers that benefited ALS Family in 2019:

- The Kittery Rib Cookoff featured the local police, fire, and public works departments in competition to grill up Kittery’s best ribs. The event raised $1,075 in memory of Genevieve Benton. Thanks so much to Detective Brian Cummer, to all who competed, and to Kittery Estates for hosting the event. And a very big thank you to Erin O’Connell, Genevieve’s daughter, for choosing our Foundation to be the recipient of these funds as a way to give back to other patients because of the way our Foundation helped her mom...very much appreciated, Erin!

- The Annual Shrewsbury High School ALS Awareness Basketball Game continued their trend of raising more money each year, this year bringing in an impressive $2,585 through admission and raffle ticket sales. We thank faculty member Andrew Moran for coordinating the event, as well as the players and all who helped with the event. A big thanks to the West family who started this tradition in memory of Kenneth West a few years ago, and to the players and all who helped with the event.

- Middletown Music Festival donated $500 from festival beverage proceeds to our Foundation. Thanks to the Turkington family and to Jennifer Wood of the JCherry Foundation, which produces the free arts and music festival.

- Jeans Day is an innovative program run by Granite Telecommunications of Quincy, MA. In exchange for a $3 donation, Granite employees get the option to wear jeans on Fridays. Each week, employees nominate a 501c3 charity to receive the proceeds. We were one of their fortunate beneficiaries: with the company’s matched funds, we received an amazing $6,300 donation! Thank you so much to Granite, to David Sullivan and his team, Gina Menconi and Eileen Johnson!

  Thanks also to:
  - Franny Spitaleri and our friends at Eastie Halfball for their very generous donation in honor and in memory of Fran’s husband, Bob Spitaleri. Thanks so much for thinking of our Foundation and the families we serve!
  - Kristen Dunderdale for holding a tee shirt fundraiser in memory of her dad, Jack.
Thank You to our Generous Sponsors

- Trader Joe’s
- Elfstone Silver & Gold
- ECOTourz
- Bayside Resort
- Red Robin
- Cheesecake Factory
- GFWC Taunton/Raynham Junior Women’s Club
- Patriots Foundation
- Cape Cod Coffee
- Cape Cod Life Publications
- Blast from the Past
- Whydah Pirate Museum
- Plimouth Plantation
- Olive Garden
- Pirate’s Cove Adventure Golf
- TGI Friday’s
- Plymouth Philharmonic
- Hotel 1620
- Chili’s
- Hy-Line Cruises
- Locally Yours
- Hair Cuttery
- Fairfield Inn and Suites
- Hampton Inn
- Waterfront Bar & Grill
- Uno’s Pizzeria & Grill
- Town & Country Carpet Cleaning
- Alice Lester
- Carol Oliveira
- Cindy Parisien
- Chris Fox
- The Lawrence Family
- Martha Burns
- Patricia Perry
- Tom Winn

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