

## 2016 SWF Road Race Team, Falmouth MA Does It Again!

A group of 52 runners with a goal; to raise awareness and funds for the Sturge-Weber Foundation. For the 7th year, that is exactly what they did! The team works for 6 months or more, training for the race itself and spreading the word about Sturge-Weber syndrome and the need for funding the critical programs of the SWF. This year the team grossed over \$125,000!



Seven years ago, Jessica Melo called us to see if we would be interested in applying for Falmouth Road Race Numbers. Of course we said yes and that 1st year we were granted 5 numbers. (we actually received 2 additional numbers that year because of the team's fantastic fundraising efforts!) After acceptance, Jessica teamed up with Pam McIntyre, another mom from the Boston area with a young son with SWS. Jess and Pam met a few years earlier through the SWF support system. Their first venture together was the Cooking for a Cure Cookbook that they had published in 2009. The cookbook had delicious recipes and raised over \$9800.00 for SWF programs. The SWF is grateful for Jessica and Pam's energy and dedication to making the SWF Road Race Team a reality again this year.



Thank you to a great corporate friend of the SWF, for sponsoring the team for a 6th year!

Honor Roll of Runners: 7 years: Pam McIntyre, Jessica Melo; 6 years: Kevin Melo; 5 years: Helen Collins, Chris Marino; 4 years: Jonathan Desmarais, Charlene Johnson, Michelle O'Connor; 3 years: Nancy Carpenter, Stefan Dalan, Erin Kelley, Ellen LaMarche, Octavio Melo, John O'Day, Kate Sanders, Ryan Stevens, Jamie Trickett, Heather Wicken; 2 years: Jennifer Battaglia, Julie Brady, Mike Collins, Coralee Craig, Don Craig, Brent Crouch, Woody Crouch, Matt LaMarche, Kathleen McTeague, Austin Morgan, Rob O'Neil, Dana Patrick, Rebecca Wiencek; We Welcome Melanie Arena, Scott Auen, Kim Auen, Paul Cardamon, Mark Banks, Nina Conway, Mike Conway, Carol DiPietro, Alicia Fannon, Samantha Garvey, Chelsey Garvey, David Hannigan, Keith Mathews, Kelly Mathews, Greg Mello, Olivia Melo, George O'Connor, Maria Puglielli, Peter Sullivan, Dan Torgerson, and Maureen Wiencek as 1st year runners on our team! Check out their Classy Fundraising pages and show your support!

Check out their Classy Fundraising pages and show your support at <https://contribute.sturge-weber.org/falmouth/events/2016-swf-road-race-team-falmouth-ma/e75095>

Runners/fundraisers do a great job reaching out to friends, family, co-workers and their entire community to support the SWF. They also do a great job promoting matching gifts as well! This is super fantastic!

In addition, some take it further by having a fundraising/awareness event in their local community:



Fit Revolution: Fit Revolution held their 3rd “Sweat for SWF” class in support of the SWF Road Race Team, Falmouth, MA. Michelle O’Connor, great friend of the McIntyre Family and creator/owner of Fit Revolution is a team member for a 4th year. Her husband, George is running the race too this year for the first time. Sweat for SWF participants sweat heard and had some fun while raising \$4214 for team!



Whiskey on Water Fundraiser for SWF was held Saturday, July 30th in Worcester, MA, and hosted by Helen and Mike Collins. This is Helen's 5th and Mike's 2nd year as members of the Falmouth team. They are neighbors and great friends of the Melos

Some team members share their thoughts about the experience:



The race has come to mean so much more than just the hot , hilly 7 mile jaunt that it is. It has come to represent a weekend full of love and friendship. Most of our teammates plan a mini vacation in Falmouth around the race giving us the opportunity to spend precious time with so many friends actually celebrating Sturge-Weber Syndrome. Celebrating because it has brought so many wonderful friends into our lives. We are always humbled by the generosity and

outpouring of support that we continue to receive every year. It's impossible at times to find the words to thank everyone. Pam McIntyre (Co-Captain - 7 years strong)



When Pam McIntyre & I started this fundraising event in 2010 with the help and support of the SWF, we could not have imagined that our team would grow from 5 to 52 runners and be close to hitting the \$500,000 (gross) mark in our fundraising efforts. Through the hard work and dedication of our team members, we have also spread awareness amongst thousands of people over the past seven years from this annual event. When you are the parent of a child living with Sturge-Weber Syndrome it can often be a very lonely road to navigate. This event and our family, friends, and co-workers who make up our team, is a great reminder that we have an incredible support network wrapped around us like a blanket especially when the tough times of unstable health, related to this illness, hit unexpectedly. My family and I are beyond grateful for the continued support of so many who make this event a huge success year after year. Jessica Melo (Co-Captain - 7 years strong)

Race day for me represents a culmination of all the fund raising and awareness efforts that each member of the team did. And when the course gets tough (those hills and that heat), I imagine Jameson running with me, encouraging me to keep doing my best, with that giant smile of his. Chris Marino

I would like to share that this was my first year running the Falmouth race and joining the SW "Running for Ryan" team. It felt amazing being a part of something so large and helping to make a difference in the lives of others. It was humbling, to look around that day and see thousands of people, running that road to make a change for someone or something. In signing up to be part of this team, I received immeasurable gifts of friendship and kindness, love and fellowship from the McIntyre family and the entire "Running for Ryan" team. This weekend reminded me about what matters most in life: family and friends. At the starting cue, I ran those 7 miles with my heart, touched by gratitude and humbled by the strength and selflessness of love: motherhood, fatherhood, sisterhood & brotherhood. We are all part of something greater and I will never forget this experience. The McIntyre family, Ryan, and all those struggling with disabilities will always be a part of my thoughts and prayers. MariaPuglielli

What does it mean – it is such a reminder for me of what I see as a physical challenge is NOTHING compared to what Ryan and other SWS patients have to go through. A favorite quote

that my friend Steven who made the \$5k donation said is "Ryan and others with SWS didn't "ask" to have the disease...it is our responsibility to help if we can." I love that quote. Being involved with this race and specifically Pam, Dan, Ryan and Ava has made my awareness of the challenges that those with all disabilities face grow exponentially...and even more importantly, it has made my 3 boys far more aware and better people as a result. Nancy Carpenter  
What a great experience! This was my first race ever! While I has always been active, hiking, biking, and paddling, I have never liked running. It seemed torturous and painful every time I tried. But I have been cheering on my incredible friend Kate and the rest of the SWF team for the past two years, and I couldn't stand on the sidelines anymore. Kate inspired and encouraged me to join the team and I am so thankful. Due to knee pain, I wasn't able to train as much as I wanted, and the race was the first time that I have run 7 miles. I was pretty nervous, but what an inspiring atmosphere to run in! There are people of all abilities, dressed in everything from running shorts, to lobster costumes and tulle skirts, and everything in between. The sidelines are almost full of spectators and fans cheering you on the whole way. And every time I thought that I was too tired to continue I pictured my son Evan, and everyone living with and loving someone with SWS, and I knew that I couldn't give up because they don't have the option to. I am so inspired by all of the support that Kate and I received from friends and family cheering us on from home and far surpassing our fundraising goals. Every dollar is another dollop of hope, and our mountain is ever growing!

Ellen shares some FB posts leading up to the event: 1. On this beautiful weekend on the Cape, 52 runners and their families spent time enjoying each other, running this one-in-a-million course, and celebrating the impact we can have TOGETHER. The families who run in support of SWF are truly remarkable. Matt, the girls and I were lucky to be among you all weekend. 🍀 Friendships were strengthened, and new ones made. 2. Speaking of family: we were reminded this weekend that the family members of children like Ryan with special needs (or really anyone suffering) share a unique and challenging road. One that we don't always appreciate. They are often the unsung heroes of these stories - showing constant, selfless, and limitless love. Thank you for showing us how it's done. 3. Matthew and I are now two weeks out from this year's Falmouth Road Race. We've absolutely loved this training season- but more than the running, it's been a summer of fun times with a very, very special Sturge-Weber team. We are beyond lucky to have had the chance to make memories alongside the McIntyre Family with some of the most inspiring people we know. Ryan has a way of motivating others to rise to the occasion - and this team is no exception. Rock stars. Every last one of them. 4. And here's one little nugget for you: This year, I was truly moved by the words of a special soul who donated to one of my teammates on Ryan's behalf. In response to her thanks, the donor said "Ryan didn't ask for Sturge-Weber. It's our responsibility, if we can, to help take care of him." That, it seems to me, is everything we need to remember- right there. Ellen LaMarche 2016 was the first time I ran the Falmouth Road Race. Running it for Ryan made the experience unique and very special. I am very proud to be part of a team which came together and reached its impressive goal. I thank Pam and Jess for giving me the opportunity to be part of their team and to meet some truly incredible people! Peter Sullivan