

COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Cares

SPRING 2015

Welcome to our Spring 2015 Newsletter

This issue of Compassionate Care focuses on continued strength. From the positive voices of young ALS advocate Matt Bellina and determined seven-time Falmouth Road Race runners, as well as Director Ron Hoffman's stance on new ALS research, you will encounter a will to continuously seek the positive, even in the face of adversity.

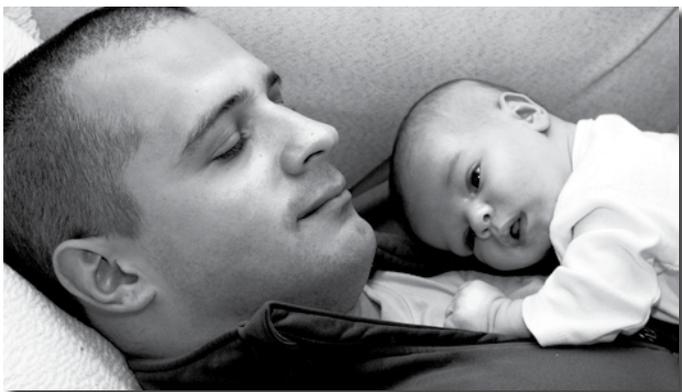
Matthew Bellina: Grounded but Still Soaring High

Google “Matthew Bellina” and the search results will tell the story of a young man who has set out on a path of advocacy. A now retired naval aviator, Lt. Commander Matt Bellina is followed in headlines by “Lou Gehrig’s Disease” and “Young Faces of ALS.” Matt was diagnosed with ALS last April at age 30.

“I was a naval aviator. This disease cost me my career. I was initially grounded and while they tried to figure out what was wrong I did administrative work. When I found out I had ALS I retired in February. The disease really stopped my career in its tracks.”

Matt was first introduced to CCALS and Ron Hoffman by Jan Cellucci, wife of former Massachusetts governor Paul Cellucci, at the annual Cellucci 5K. Matt Bellina has met with Ron on several occasions to discuss what to expect. “CCALS has a very holistic approach. They help people yield into this disease and accept it, and offer a degree of mentorship through the journey,” Matt says.

“Ron and I have talked a lot about what to expect and how to deal with changes as they arise. There’s comfort in the idea that services are there. It has made a really big difference. You try not to think of what awaits so far in advance, but it’s so good to know that organizations like CCALS are there to support us. CCALS provides not only this support network, but also the physical assistance I need. It’s like a security blanket.”



Matt and his son



Matt Bellina and his family

Matt works with many organizations to support the ALS community, but he says that “There are not a lot of organizations like CCALS. They look at a person as more than a number or an accounting line, and that’s what attracts me to CCALS. It’s about people, not statistics or numbers or signatures on forms. It’s about one individual and another connecting on a personal level, and the support that provides during this journey.”

Bellina also has two young sons, 3 ½ and 18 months old. He says because they are so young “that makes it really easy to think about things I won’t be able to do, especially with them. The last time Ron saw me I was scraped up from falling while playing tag with my kids.”

Yet, Matt continues to shed light on the circumstance. He is determined not to let ALS detract from the things that he loves. “What I would suggest is to write a list a list of things this disease can’t take away from you. I made one that includes reading, watching my kids play, watching movies, being with my family. I always go back to that, even after things like my recent fall. I also made a list of things I hate to do that I don’t have to do anymore: Running to exercise, hand writing cards, changing diapers. This helps a lot too and can shed some positive light on a hard situation.”

Thoughts From Ron...

GM 604

Make it happen, Now!

Here we go again! Lots of conversation, lots of activism and unfortunately lots of disagreement about whether GM 604 should be made available to those living with ALS today. Keep in mind I don't specialize in research, I am not a scientist nor a doctor. My knowledge and expertise is on tending to those living the ALS experience from diagnosis to end of life and all that happens in between.

I have profound thoughts and opinions on the institutionalization of our healthcare system as I write in my book, *Sacred Bullet: Transforming Trauma to Grace While Tending the Terminally Ill*.

In 1997-98, Myotrophin was a drug in the pipeline that showed great promise. Gordon Heald, the gentleman I cared for, wanted very much to be part of this trial. The trial was closed, yet Gordon was adamant about obtaining the drug at whatever the cost. For him it was about hope, a last chance at life. The drug was being tested in Japan at the time, very much out of his reach even though he would have written a check for any amount. Unfortunately, the check did not matter as he was unable to procure the drug. The fact it was found to be ineffective mattered not. It was his choice, his decision, his desire. He had absolutely nothing to lose, except hope.

GM 604 has been shown to have some positive results. Eric Valor, a man living with ALS, picked up the mantle in leading the charge to make it available to those living with ALS now without waiting for the three plus year process involved in clinical trials. A handful of individuals including my friend Matt Bellina have joined the cause. I have read that Genervon, the biotech company, has been working on this for 20 years. Accelerated Approval, in the world of big pharma, is a big ask, yet until we are willing to think outside the box, those living with ALS and their families continue to live in extraordinarily difficult circumstances beyond imagination, often suffering in ways most people have no reference for. To diminish hope can be a cruel punishment.

As the situation now stands, the eventuality of death is inevitable. So I ask the FDA and I ask those who oppose to making GM 604 available, what is the harm in researching as you normally would and approving accelerated approval?

Outside the box? ...Yes!

Make it happen, Now!



Ron Hoffman, Founder

Project Portugal

We are excited to announce the beginnings of our new venture: Compassionate Care ALS Project Portugal. CCALS founder Ron Hoffman has built relationships with professionals in Lisbon and Porto. In talks with friends, colleagues and healthcare workers there, we found those living with ELA (ALS) in Portugal are very much in need of our services. Joana Gonçalves Pereira will represent CCALS in Portugal and collaborate with doctors and healthcare professionals to meet the needs of individuals and families living with ELA.

We have set a goal of \$100,000 euros to advance this project and keep it running in the future. We are asking for your help to support this project and the services it provides. Visit www.ccals.org/portugal for more information.

Upcoming Events

As the snow finally melts, we hope you will join us in supporting CCALS at our upcoming events! Events approaching include:

4th Annual David's Old Silver Swim

Swim a mile or half mile course in honor of local dentist and friend David Garber. This year's swim will be held August 8, 2015. Show your support or sign up at www.davidsoldsilverswim.com.

The Remember Beautiful Anne Party IV

CCALS will be one of the beneficiaries of an annual party in memory of Anne Corcoran Galvin, relative of CCALS friend David Leys. The party will be held at the Newport Yachting Center on June 27, 2015 from 7-11 pm. Visit rbaparty.com for more details.

Playing with Compassion

On May 31 from 3-8pm at the Beachhouse in North Falmouth will host a number of local bands for a party with Falmouth

resident Anne Shea. There will be a raffle, door prizes and all funds raised will go to support Compassionate Care ALS. Visit ccals.org for details.

New Balance Falmouth Road Race

Run or cheer on August 16, 2015 as part of a team supporting CCALS at our biggest fundraiser of the year. More than 40 teams and 150 runners will face the seven mile course in Cape Cod's premiere Road Race. Get your number now as we always run out. Visit, Falmouth.ccals.org for more info.

Wear Blue Bring Green

On October 1, 2015 from 7pm-10pm, come join CCALS supporters for this gala fundraising event aboard the Odyssey sailing out of Boston Harbor. Stay tuned to www.ccals.org for more details over the summer.

Falmouth Road Race: Running Through the Years



2005 Pat's Pride – 2 Runners

runners, but also many familiar faces that run year after year.

The Falmouth Road Race running team Pat's Pride has existed since the beginning of CCALS's involvement at Falmouth. In the early 2000's, after Jerry Trupiano's mom passed away from ALS in 2001 Pat's Pride sent two runners to support CCALS. Jerry's wife Anne describes her first interaction with the race as "recognizing the potential to do some serious fundraising for the organization."

What began as a family team of two runners has since expanded to include friends, additional family and co-workers, and jumped in numbers to a steady total of about 20 runners each summer. Thirteen years later, Anne says that the team continues to run and fundraise for CCALS "because the race has been one of the top fundraising tools and we recognize the importance of CCALS continuing to get support from families, to use for families."

Renee Trupiano caught the spirit of Falmouth early on and began running for Pat's Pride in 2007. She says that, "After 2 years of watching and supporting the runners and seeing the pride that they had after finishing the race, I knew I had to try it myself. I started training that following year and ran my first Falmouth Road Race in 2007 as part of Pat's Pride. I've been running it ever since."

Tim MacDonald is entering his 8th year as a Pat's Pride runner this August. Although admittedly not much of a solo runner, MacDonald says that "The crowd is something special – they really give you that edge during the race... your spirit and mood are really brought up with the other runners and the massive spectators cheering and supporting you."

Anne notes that her family, as well as others who have had prolonged involvement with the Falmouth Road Race, "want to make sure that CCALS will be around for other families like they were for ours. Every family living with this disease should have CCALS as a



Pat's Pride 2009 – 13 runners

Compassionate Care ALS has participated in the Falmouth Road Race for the past 14 years, and has watched this event become our top annual fundraiser. Each race season brings new

resource. If we keep spreading the message and gaining support, we can collectively really get this thing moving." The importance of CCALS's involvement in the race is evident. "I know I'm running for all the ALS victims that can't get out there and run, but would give anything to be able to walk or run again," says Renee.

Renee reflects on the community created by the race, saying that

"I've run other races and you just don't get the same feeling as you do with the Falmouth Road Race. Almost everyone running this race is running for something they believe in or to help others in need. There is such incredible support from everyone along the race route and they truly give runners, or at least myself, the power to keep running."

The value of the CCALS community created by the race is echoed by Tim. "At the end of every race I have an opportunity to meet old and unfortunately new families affected by the disease. I get to hear their stories and understand CCALS's true value. My belief of what they do becomes stronger and stronger," he says.



2011 Pat's Pride – 15 runners



2014 Pat's Pride – 19 runners

When asked about her favorite part of the race, Anne echoes the sentiments of many other runners: "We love how it brings together our team and the ALS community. We get together that weekend, partake in shared fundraisers throughout the year, and support each other to help each member reach their goal. There's a sense of community created by the team that each member brings back to CCALS in some form."

Just as the FRR and the team Pat's Pride has grown, so has CCALS. Every new runner expands the impact CCALS can have on families affected by this disease. Tim sums it up in saying that "In order for CCALS to continue to raise funds and continue on their journey to help so many, they always need new fresh supporters. We have to stay the course until ALS is beaten."

Ways You Can Help

Matching Gifts

You can double your contributions to CCALS! Many companies will match the gifts made by their employees to charities or match the money employees raise towards organizations. When making gifts, you can submit paperwork to have your gift matched by your employer. Talk to your employer's Human Resources department today to learn about gift-matching opportunities.

Estate and Planned Giving

Join the Gordon T. Heald Society, our planned giving program, to advance our mission to model compassion to those affected by ALS. As a member of this society, you can help us continue to provide vitally needed services to ALS caregivers, patients, and families by including us in your testamentary plans. For more information on how to make a gift or bequest, please visit our online page www.ccals.org/planned-giving.php.

Gifts of Stock

CCALS is set up with a brokerage account that allows us to accept gifts of stock easily and quickly. Donating appreciated stock has great tax benefits for individuals. Please check with your tax or legal advisor to confirm your possible tax benefits. If you need help with stock donations contact ted@ccals.org.

Online Pledges

By making a monthly pledge, you will become a sustaining donor for CCALS. This is a powerful way to show your commitment to our mission. Visit www.ccals.org and click donate – Paypal will allow you to make your pledge recur.

Support CCALS Athletic Events

Please see our article on the Falmouth Road Race elsewhere in this issue for information on an easy and fun fundraiser that we fully support. There are also other opportunities throughout the year; for example, two individuals ran the Boston Marathon for CCALS in 2015. You can also find your own event and run, swim, bike or anything you can think of to raise funds for CCALS. Please visit www.ccals.org throughout the year to see the opportunities we offer or email ron@ccals.org to discuss your unique idea.

In Memory Of...

Cheryle Alderman, Sutton, MA
 Mary Baker, East Falmouth, MA
 Mary Beth Benison, Shrewsbury, MA
 Lawrence Branagan, Natick, MA
 Judith Christine Brown-Cardinal,
 Buzzards Bay, MA
 Elaine Marie Challoner, Kingston, MA
 Danny Cooke, North Providence, RI
 Gloria Deutsch, Burlington, MA
 Bill Dias, Fairhaven, MA
 Rocco Dicenso, Stoughton, MA
 Cathy Dudley, Westwood, MA
 Natalie Ferris, Worcester, MA
 Deb Galvin, Norwood, MA
 Alfred Garber, North Falmouth, MA
 Ed Gibbons, Hollis, NH
 Cathy Gorman, Newport, RI
 Charlie Guenard, Hudson, MA

James Edward Guernsey, Buzzards Bay, MA
 Robert Hughes, Dorchester, MA
 Chris Jasch, Chicago, IL
 Mildred Kampersal, Holliston, MA
 Jean Kaper, Lynnfield, MA
 Peter Kerner, Scituate, MA
 Walter Kittredge, Forestdale, MA
 Robert Laiweneek, Bristol, NH
 Andrew Larosa, Chicopee, MA
 Jerry Larpriore, Kittery, ME
 Lucia Marino, Saco, ME
 Don Melanson, Leominster, MA
 Shekhar Meta, Hudson, MA
 Carole McCarthy, Limington, ME
 Gloria J. Olivari, Ashburnham, MA
 Sam Pawlak, Fitchburg, MA
 David K. Richards, Santa Monica, CA
 and Stonington, ME
 Mary Ellen Riley, Braintree, MA

Kristy Rooks, Merrimack, NH
 Bill Rosenbaum, Topsfield, MA
 Pam Ryan, Ipswich, MA
 Dimitrios 'Jim' Solomos, Peabody, MA
 John Sprague, Bridgewater, MA
 Maryellen Standring, Holden, MA
 Donna Sullivan, Quincy, MA
 Joe Sullivan, Hull, MA
 Mr. Swain, Hudson, MA
 Mary Tangney, Milton, MA
 Mark Tessicini, Rockport, MA
 Debra Trainor, North Brookfield, MA
 John Valenti, Pittsfield, MA
 Ken West, Shrewsbury, MA
 Camille White, Winthrop, MA
 Frank Zinck, Melrose, MA
 Barbara Zinke, Briarcliff Manor, NY
 and Wellesley, MA