

Compassionate Cares

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ALS House Call Program establishes groundbreaking partnership



Compassionate Care ALS (CCALS) has partnered with Massachusetts General Hospital (MGH) on The ALS House Call Program, an innovative new pilot program that will give homebound ALS patients of all socioeconomic circumstances access

to medical services in their own homes. ALS patients will receive high quality, patient-centered care from both CCALS and MGH. The exciting partnership is being led by Dr. Merit Cudkowicz, Chief of the Department of Neurology at MGH, and CCALS' Founder/Executive Director Ron Hoffman.

The development of this partnership was facilitated by a long-standing respect on both sides. "I met Ron in the late 1990s; really from day one, I saw the great work he did back then as a caregiver and was fortunate to watch the growth and evolution of CCALS," says Dr. Cudkowicz.

The ALS House Call Program, made possible by the generosity of a donor, is aligned with CCALS' relational care model which emphasizes meeting individuals where they are, both physically and emotionally.

The MGH and CCALS teams will approach caring for people in a compassionate manner. Both organizations bring experience and knowledge of the illness, and a great desire to help each individual in the way that resonates with them. Dr. Cudkowicz anticipates that opportunities for patients to be part of research will expand greatly through this effort.

CCALS and MGH have been collaborating on patient care for a number of years and have developed a release form that patients sign, so that we can share information. This allows us to coordinate and collaborate more effectively in support of our families and those living with ALS. Dr. Cudkowicz says, "Ron and his team have a huge heart and are there for our patients. They provide much needed support in the home to our families. I strongly believe that my patients should know about everything available to them – resources



MGH's Kristen Drake, Ron Hoffman, MGH's Darlene Sawicki and Dr. Merit Cudkowicz at the 27th International Symposium on ALS/MND in Dublin, December 2016.

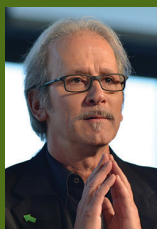
in community, research opportunities, the latest information on ALS. It is part of my responsibilities as their doctor to share that information. CCALS is something all people and families with ALS should know about."

Hoffman agrees, saying, "I've admired Merit and her team since I first came to know their work at MGH. This partnership makes so much sense for both of our organizations and serves to benefit our families. CCALS has been doing house calls since 1998. It's what we do. For years I have dreamed of working closely with the ALS team at MGH in order to enhance the quality of life for families. They care for patients in a way that few other hospitals can match."

Ron points to MGH's medical prowess as another invaluable resource for current CCALS families. "Merit and the ALS Clinic Co-Directors Dr. James Berry and Darlene Sawicki along with their extraordinary team, bring not only the research component to our families, but also extraordinary medical care and additional skills, which allow individuals to stay informed of upcoming and ongoing trials. Combined with CCALS' guidance, individuals will have the most expansive array of options available to them."

Thoughts From Ron...

Through this past summer and into fall life at Compassionate Care ALS has exceeded my wildest expectations. New families continue finding their way to us and soon we'll begin the search to hire new staff to keep up with the need. In this newsletter you will read about the many different programmatic and fundraising happenings, for example;



Ron Hoffman
Founder

- Lately, I have been wearing my imaginary hard hat over at the Beach Rose Inn, walking among the backhoes and bobcats with Ralph Cataldo, our builder, while he updates me on progress on the CCALS Education and Retreat Center. Recently, CCALS board member Darlene Salatto Rose was in town to help pick out the fixtures, flooring, lighting and wall finishes for the center. She has such a great eye for understated elegance. Tasteful, beautiful and intimately tied to our vision of a sanctuary that immediately brings a sigh of relief and a sense of homecoming to our visitors. Darlene has been an integral part of this project and I am extremely grateful for her time and effort.
- On November 1, 2017, we launched the ALS House Call Program in partnership with Massachusetts General Hospital's ALS Clinic. Thanks to this partnership, we will get to share our way of tending to ALS families with the doctors and nurses from the clinic. It will be like the old days when doctors showed up carrying a black medicine bag and a big appreciation for the relationship with their families—not just their illnesses. I'm really excited about this new program. To me, it is the future of holistic healthcare in the United States, and something I've dreamt of and envisioned for a very long time.
- We have been following and refining our relational model for nearly 20 years and will celebrate that milestone with a Gala on May 18, 2018, at the Fairmont Copley Plaza Hotel in downtown Boston. I can't believe it's been almost two decades since Gordon's passing, October 30, 1998. We've certainly come a long way since then! I look forward to seeing you there.
- In addition, on the eve of our 20th anniversary, WBUR-radio, a National Public Radio (NPR) Station in Boston, ran a story about me and our work. Award-winning journalist Lisa Mullins began working on the story when I met her at our Gala in May of 2016. She rode with me, watching what I do and she interviewed families. The story aired nationally on over 900 NPR stations, resulting in calls from Arizona, Iowa, Louisiana, Alaska and Florida! If you are interested in listening to the story visit the link on ccals.org. Be sure to click on the red button and listen for full effect.

I am very grateful for the continuous unfolding of programs, projects and opportunities presented to CCALS and as always for the incredible support of our families and friends for all of these years. You have been there for us so that we can be there in service for others, not just today, but tomorrow and in the future. Here's to the future.

Always,

In Memory Of...

Mary Audet, Naragansett, RI	Scott Martin, Winchester, MA
Sandra Barker, Pinnacle, NC	Susan Martin, Manhattan, NY
Martin Barr, Worcester, MA	Carol McCaffrey, West Roxbury, MA
Ingrid Bengis-Palei, Stonington, ME	Tom McKrell, Lynnfield, MA
Frances Bernstein, New York, NY	Joao Miranda, Brockton, MA
Dorothy Bongiorno, Ocean Grove NJ	Betty Kugler, Dartmouth, MA
Michael Britt, Castleton, NY	John Landsiedel, Mashpee, MA
Ronnie Brown, Billerica, MA	Todd Lemberger, Littleton, CO
Laurie Burt, Woodstock, CT	David Leys, Jr., Middletown, RI
John Campbell Jr., Arlington, MA	Jonathan Louis, Metcalf, Boyd, MT
Joe Carey, Ridgefield, CT	Ricardo Matos-Figueroa, Wareham, MA
Myrielle Carrolus, Malden, MA	Joyce Moore, Auburn, MA
Arthur Cohen, West Orange, NJ	Tom Murphy, Wellesley, MA
K. Lynnell Connolly, Natick, MA	Paul O'Neil, Durango, CO
Michael Day, Brewster, MA	Taylor O'Shea, Winchester, MA
Vincent D'Augusta, Lexington, MA	Rita Ouelette, Pembroke, MA
Dan D'eon, Lynn, MA	Jonathan Panora, Plymouth, MA
Job Emerson, Wenham, MA	Stephanie Papajohn, Manchester, NH
Lina Escobar, Somerville, MA	Bob Petropolous, Peabody, MA
Thelma Federman, Hudson, MA	Mary Lou Pettit, Eastham, MA
Cory Fenton, Westborough, MA	Nathan Rawls, Coushatta, LA
William Finnegan, Hanover, MA	Ismael Rivera, Puerto Rico
Kevin Forster, San Diego, CA	Kay Roberts, Farmington, CT
Ernest Fournier, Boxborough, MA	Mary Roettger, St Paul, MN
Andrew Gage, Watchung, NJ	Jean Roth, Nashua, NH
Jaqueline Garner, Madison, CT	Mary Santry, Hingham, MA
Ray Haberly, Olean, NY	Robert Scarpato, Osterville, MA
Kenny Hadley, Newburyport, MA	Stephanie Schehl, Bedford, NH
Marcia Hanson, Portsmouth, RI	Jon Shepard, Billerica, MA
John Thomas Hartman, Anderson, IN	Doug Shillito, Duxbury, MA
Alan D Hayes, Clinton MA	Rich Sigtermans, Scottsdale, AZ
Diana Heiskell, Noblesville, IN	Patricia Smith, Norwood, MA
Richard Kelly, Deerfield, MA	John Snyder, Austin, TX
John Landsiedel, Mashpee, MA	Adell Thomas, Worcester, MA
Gail Lanoue, Brockton, MA	Glen Thomas, Tewksbury, MA
Bruce Lehan, Roslindale, MA	Mary Lou Toye, Lake Park, FL
Philip Lemarble, Hopedale, MA	Glen Upton, Falmouth, MA
David Leys, Newport, RI	Theresa Vail, Lowell, MA
Malcolm MacMillan, Newton Center, MA	John Williams, Fort Wayne, IN
	Ray Woishek, Portsmouth, RI

Students juggle to raise funds for CCALS



Students juggling

Rockport Elementary students Juggled for ALS in honor of CCALS friend, Carolyn Baker. Students fundraised for CCALS and dedicated 25 minutes of their morning juggling scarves

in place of their usual meeting. CCALS has assisted Carolyn and her family since her ALS diagnosis, and these Rockport students found a creative way to give back!

Garber Swim makes a splash

A rainy morning did not keep 154 swimmers from diving in to support David Garber and Compassionate Care ALS at David's Old Silver Swim on August 12th. The 7th annual swim raised over \$94,000, the most in its history despite a one-hour weather delay.

"David's dream of going big and topping \$100,000 next year is right on track," says Robert Catalano who organized this year's swim. Planning for next year's event has already begun. To learn more visit davidssoldsilverswim.com.

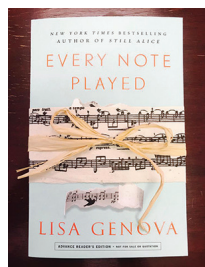


Robert Catalano and David Garber present Ron Hoffman with swim proceeds.

CCALS names three new board members

Compassionate Care ALS (CCALS) is excited to announce that three new members have joined our governing board. The CCALS board will now be comprised of fourteen community members with the addition of:

Jan Cellucci, the former first-lady of Massachusetts, whose husband Governor Paul Cellucci died with ALS in 2013. She is a strong advocate for bringing care and awareness to ALS Families.



Every Note Played
will be released on
March 20, 2018

Lisa Genova, New York Times Bestselling Author and author of the soon to be released *Every Note Played*, a novel about a family struggling with the realities of an ALS diagnosis.

Adrienne Martin, a former acupuncturist and Health and Wellness Coach, whose husband John was a former NESN cameraman who is currently living with ALS.

CCALS has played a role in the lives of all three individuals, by offering counsel



Jan Cellucci



Lisa Genova



Adrienne Martin

and services to the Cellucci and Martin families and providing inspiration and education for Genova's book.

"CCALS is a huge part of how we as a family are able to feel less stressed, figure out what to do, and move forward with more confidence on the path ALS has laid for us," says Martin.

CCALS Executive Director, Ron Hoffman, notes that "these three extraordinary women truly have seen the effectiveness of the work of CCALS. They are great advocates for our community and I am very excited that they have joined our board of directors."

Julie Mollo comes in 'clutch' for CCALS

What do clutches and ALS have in common? Their connection is a New York based designer, Julie Mollo. Julie, who has dressed pop stars like Katy Perry, found her passion in creating sparkly vinyl clutches featuring fun cutouts.

Julie's dad, J. Mollo, was diagnosed with ALS this past March. As an only child living in a different state than her parents, she wanted a way to give back to her dad's support system.

"I've never partnered my work with a charity before, and wanted to do something—this seemed like a good place to start. I spoke about the clutch and the design of it while mom, dad and I were on vacation and they were all on board and loved the idea of a Lou Gehrig baseball-themed clutch."

Julie designed her baseball-themed clutch to pay homage to those affected by ALS. All proceeds from the sale of these clutches were donated to Compassionate Care ALS.



The ALS clutch

"It truly is incredible that an organization exists purely to help make people's lives easier without any red tape," says Julie. Her parents have continued

to meet with CCALS staff member Erin Lajeunesse since her father's diagnosis and Julie decided to make CCALS the charity she donates proceeds to at their suggestion.

She says this campaign not only allowed her to give back, but also brought so many individuals into her life. "Many people reached out to both me and my family, which I very much appreciated. I received dozens of emails from people who have been affected by this horrible disease but who praised the work that CCALS did for their loved ones. It's amazing how a seemingly rare disease has touched SO many people."

To date, Julie has sold more than 160 clutches and raised over \$1500 to support CCALS families. Julie's message to her new found fans is "I hope all of you everywhere are enjoying your baseball clutches!"

Learn more about Julie and her clutches at juliemollo.com or follow her on Instagram @juliemollo.



Julie and her father J. Mollo

An EVENTful Fall

October 1



Matt Siegel from Kiss 108 with Ron Hoffman, Barry Berman, CEO of Chelsea Jewish Lifecare and CCALS friend and Leonard Florence Center resident Steve Sailing at the Walk.

Greater Boston Walk for Living

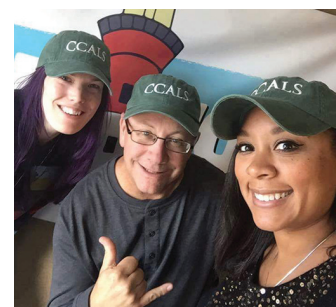
On October 1st, CCALS partnered with the Leonard Florence Center for Living (LFCL) to host the Greater Boston Walk for Living. The beautiful fall day set the scene for more than 700 attendees, including many living with ALS and MS, as well as 35 dogs who walked the 2 mile course through Chelsea. The partnership raised over \$128,000 to support patient care and services through CCALS and the LFCL.

The day was full of fun activities. Coffee and donuts were provided by Dunkin' Donuts and hamburgers and chicken sandwiches by Chili's. Kids and adults enjoyed baby farm animals, a face painter, a photo booth, and popcorn and cotton candy. The event was kicked off by special guest emcee Matt Siegel from Kiss108 with Ron Hoffman providing inspirational words. We were happy to see both new and familiar faces out on the course and we look forward to seeing at next year's walk.

October 20-21

CCALS Radiothon

Cape radio station Cool 102 held the 2nd annual Radiothon to benefit CCALS from Friday October 20 to Saturday October 21. Inspiration for the Radiothon came from longtime DJ Brad Martin, who has been living with ALS since 2014, and his wife Maryanne who both worked at the station for many years. CCALS staff and volunteers answered phones around the clock as listeners pledged more than \$20,000 to support the CCALS Education and Retreat Center. Many CCALS staff and friends were interviewed on air, including Ron Hoffman, board member Lisa Genova, our builder Ralph Cataldo, and long-time friend and Falmouth Resident David Garber who has been living with ALS for more than 8 years. Visit ccals.org to listen to some of these stories.



Tracy, Joe and Nina from Cool 102 sporting CCALS gear.

October 21



Ron Hoffman with Ales over ALS organizers Nathan Woodman and Elia Tessicini.

ALES over ALS

On October 21, the CCALS community gathered in Essex for Ales Over ALS: A Crafter's Delight. The annual event is in its sixth year and was conceived and initially planned by Mark Tessicini who died with ALS in 2014. Mark's wife, Elia, and CCALS friend Nathan Woodman organized this year's event. The community raised more than \$22,000 to support CCALS programming while mingling over music and locally sourced food from Woodman's of Essex, Kate's Table and Iggy's Bread. The highlight of the afternoon was a home brewing competition for amateur brewers set in the historic Essex Shipbuilding Museum.

Update

CCALS partner ALS ONE has opened a new donation center and retail boutique called The Back Hall Bench. All proceeds from the boutique go directly to ALS ONE to support ALS Care and Research. The store is located at 30 Corporate Drive, Unit 200, Pembroke, MA, 508-272-0091 or on Facebook @thebackhallbench.



Springing Ahead

SAVE THE DATE

20^{years} 18 Gala
COMPASSIONATE CARE ALS

CCALS 20th Anniversary GALA
May 18th, 2018
Fairmont Copley Plaza, Boston