

# Compassionate Cares

## Welcome to our Fall 2016 Newsletter

*Compassionate Care ALS exists to assist those living with ALS, their families and their communities. Our goal is to help people consciously navigate the complexities of the disease. Every family and every individual experiences the disease differently. We provide guidance so that people can explore the possibilities and make the choices that are right for them. This issue of Compassionate Cares focuses on how CCALS and the families we support work together to find innovative solutions*

## Creative Communication: Ang & Pison Tech Team build Assistive Devices

Dexter Ang, an MIT mechanical engineering grad, was immersed in the world of high-frequency stock trading when his mom was diagnosed with ALS in September 2014. By November the family had a list of questions and very few answers. "We were trying to figure out how to make my mom more comfortable in the house. We had a lot of questions going into our first time meeting with Ron. His guidance, his comfort, his care have been amazing since that time. Ron was the first person to really understand all the emotional and familial challenges that we would be facing on our journey helping my mom," Ang explained.

"When my mother was first diagnosed, we saw the best therapists in the world. I expected them to have technology that would allow my mom to communicate and use a computer. We found out that there really wasn't much available and my mom wasn't able to use anything they suggested. I was frustrated with how poor the technology was, so I started researching technology that currently existed."

What started as frustration quickly transformed into a purposeful quest to fill the technological void. And Ang's initial teammate? His mom, of course. "It became our personal mission to find out how to develop new assistive



The Pison Technology Team (David Cipoletta, Wenxin Fang, Dexter Ang, and Bobby Forester) along with Bobby Forester's wife, Casey

technology. My mom saw me enroll at MIT before she passed, and knew I was on the path to finding a solution for ALS patient communication."

Ang enrolled as a student at MIT Sloan School of Management and assembled the Pison Technology Team. The team is creating a device that will allow people who cannot speak nor move to comfortably and effortlessly control a computer, a phone, and other devices.

The technology focuses on electromyography (EMG) sensors that measure activity in nerves, even if there is no ability to physically move. Sensors are attached externally and measure nerve stimulation caused by the action one is *thinking* of performing, even if the muscles can not perform the physical action (like flexing your hand, for instance). The expectation is that these nerve signals can then be used to control a computer or other device.

This technology will be accessible for all people with ALS, even if they have no ability to speak or move. The end goal is "...to see the ALS journey become smoother and allow individuals to communicate what is important to them in terms of the care they receive."



Ang and Forester test EMGs using electrodes attached to Forester's arm.

Continued on back cover

Eric Hansberry of Hingham was diagnosed with ALS on August 21, 2013. Despite his proximity to the CCALS office in Falmouth, we had no contact with him or his family until his daughter Lynn reached out about equipment at the end of November 2015. The outlined journey reflects CCALS' continued involvement, even when help is first met with resistance, and details the myriad of resources we were able to bring to the entire family.

In early December of 2015, while helping the family obtain a reclining lift chair for Eric we received word that Eric was not open to an appointment "right now" - that he was a very private guy.

Our next contact with the family was a March email from Eric's wife Nancy to our Assistant Office Coordinator, Megan.

Email from Nancy Hansberry received March 19, 2016

Hi Megan, My daughter Lynn has been in contact with you before and was grateful for your help in acquiring a lift chair for my husband, Eric. We had a phone call from Ron generously offering to meet us, but at the time my husband was not ready. He is now hoping Ron would still be interested in meeting as Eric has many questions I think Ron could help us with. We seem to be stuck, frozen by the unknown that lies ahead. I hope he can help us, as I am still struggling with my own grief and can not seem to help Eric.



On March 31 Ron was able to visit with the Hansberry family after which we received the following email.

Email received from Nancy on April 2, 2016

Dear Ron,

Thursday more than met our hopes for meeting you, and I want you to know that in the two and a half hours you spent with us, you have already made a huge impact on our lives and our family. Your candid discussion about dying, and the personal stories you have of other ALS patients has begun to unravel the terrible fear surrounding Eric and consequently our family. To reassure our daughter that her father should be able to stay home was huge for her, and although that was the plan, reassured us all that we were not crazy to think we can do that. So, you have brought a measure of peace into our lives that I am very grateful for. And with the best of intentions, I am not sure if anyone else could have had the credibility you carry with your vast experiences. For at least this moment, Eric is more peaceful, and then so am I.

These may be more concrete but still relevant observations....Eric has avoided the bi pap machine, but after you left, asked for it, and did so again today. He has resisted all medical equipment, and yet today was thumbs up for the bed and shower you suggested, and was happy about a bed tray table I borrowed. "little". Changes that are not so little. And there are more, but enough to say that your one visit has already significantly impacted our lives. What can I say but thank you.

Sincerely, thank you....  
Nancy

After this meeting the CCALS team sprang into action;

Kristine our Augmentative Communication Expert set up an assessment. Ron emailed one of our ramp vendors to

## In Memory Of...

Dave Adox, Orange, NJ  
Robert Allen, Orange, MA  
Dennis Antonucci, Cromwell, CT  
Matthew Balocca, Holden, MA  
Carolyn Barboza, Raynham, MA  
Sharon Bickford, Salem, MA  
Mark Bleasdale, Saugus, MA  
Lewis Budd, Lynnfield, MA  
Diane Campbell, Strafford, NH  
Michael Campbell, Brockton, MA  
Franco Capobianco, Medford, MA  
Maria Cashmon, Maynard, MA  
Mike Cherepov, Lexington, MA  
Ming Yu Chu, Sudbury, MA  
David Dias, Wareham, MA

Terry Dickens, Haverhill, MA  
Marilyn Dickinson, Bermuda  
Mary Farmer, Marshfield, MA  
Jason Ferwerda, Bellingham, MA  
Jay Fishman, New York, NY  
Richard Flynn, Quincy, MA  
Albert Giordano, Monson, MA  
Felicity Goodridge, Randolph, MA  
Kevin Gosnell, Hanover, MA  
Mary Grant, Milton, MA  
Hilde Griffin, Chelmsford, MA  
Eric Hansberry, Hingham, MA  
Ron Hernandez, St. Amant, LA  
Mary Lou Holthaus, Winthrop, MA  
Mark Izzard, Cedarville, MI

Irene King, Waltham, MA  
Tom Knowlton, Gloucester, MA  
Amy Kolbeck, New Bedford, MA  
Janet Lang, Lowell, MA  
Joan Lockhart, Rockland, MA  
John Macleod, Ledyard, CT  
Jose Marques, Ludlow, MA  
Donna McDonough, Bridgewater, MA  
Mark J. Miller, Merrimack, MA  
Kathy Owens, Quincy, MA  
Cynthia Parr, Riverside, RI  
Rambhai Patel, Newton, MA  
Judith Poulin, Eastham, MA  
Ian Pounds, NH/Bangladesh  
Lee Powers, Jamaica Plain, MA

Rita Rannucci, Newton, MA  
Sangye Rinchen, Holbrook, MA  
Flor Rivera, Miami, FL  
Thom Roberts, Athol, MA  
Maryanne Rogan, York Beach, ME  
Antonio Romero, Chelsea, MA  
Bill Serrano, Fitchburg, MA  
Karl Servant, Centerville, MA  
Dagmar Slavin, Weymouth, MA  
Matthew Snow, Lynn, MA  
Timothy Tobin, Quincy, MA  
Sharon Verlezza, Hopkinton, MA  
Paul Vigneault, Worcester, MA  
Patricia Walleston, Newmarket, NH  
Roger White, Middleboro, MA



do an evaluation; Megan sent Eric and Nancy links to our recommended equipment sites. We sent them Medical Order for Life Saving Treatment (MOLST) forms and 5 Wishes (end of life planning form). Travis also dropped off the appropriate equipment Ron had discussed with the family earlier which we had on hand that could be of immediate use.

Ron was happy to hear that the family was going to the MGH ALS clinic and hear the feedback about how much they value our organization. Travis & Adam dropped off, installed and trained the family on equipment that the family purchased. Kristine visited the family on April 22 to offer communication options; both high tech and low tech.

While CCALS has many resources to recommend in terms of augmentative communication devices, Eric was comfortable using his right hand to write his messages on a clipboard. Fortunately he never lost his ability to write with this hand.



On May 9 Ron visited the family again and tried to help Eric get information on his status in a clinical trial. He found out that Eric was put in a pool of patients who are randomly selected and that was why he had not heard back. Ron provided positive input on wheelchair use of which Eric had been quite resistant. He also engaged in dialogue related to the choices and possibilities of living with ALS (feeding tubes, tracheotomy, etc.). Ron spent time facilitating appropriate conversation around hospice, speaking in a language that both Eric and Nancy could understand. This was very important for them to put to rest their fears around hospice so they could move forward with the process of accessing services.

Email received from Nancy & Eric on May 10, 2016

Hi Ron,

Once again we must thank you for such an amazing meeting. Truly, your skill to elicit difficult conversation in a comfortable natural way, and to transition to the next subject and continue on without hesitation...all the time taking in what the responses were, and using that to go to the next subject, ...is amazing. I was astonished to see Eric's thumbs up to the Permobil or wheelchair idea. That

was an absolute first. Usually he becomes deflated, sad and retreats. He actually looked enthusiastic! I was so relieved to see his agreement. My daughter wondered if her dad understands your level of experience and trusts your guidance because of it. That may be part, but your delivery is also important, in its logic, respectful listening and confidence. I told my kids I had emailed you my list of newly acknowledged worries, that you walked in, started a conversation and then proceeded to take the worries off our plate, one by one. Even adding some extra opportunities to consider.

I will admit I am uncomfortable thinking about hospice, and even to know how people can be helpful. Most of the time I feel like I can do it all, until I hear myself telling Eric I don't know if I can do this. And it is more being emotionally tired, frustrated and struggling to accept the continued losses Eric experiences. I know you've heard it all before. But I don't know how hospice can help, or what kind of nursing Eric needs until later.

Sincerely,  
Nancy and Eric

Soon after Ron introduced Eric and Nancy to a hospice medical doctor. It was a positive meeting. She too alleviated Nancy's fears and concerns. They said yes!

Ron checked in many times throughout May and June. Erin, the CCALS Senior Family Care Liaison began working with the family on Medicare issues. Ron's **last visit** with Eric occurred on June 12. Ron saw changes in Eric and knew he was winding down. Ron reached out to Eric's hospice doctor. She visited that evening to bring additional expertise, comfort and support to the family. After Eric passed on June 15, 2016, CCALS kept in touch to offer support services to the family. Kristine visited for tea in July and Ron stopped by to check on Nancy in August.

Email received from Nancy on August 9, 2016

Hi Ron,

Now, I am about signing forms, transferring titles, paperwork! I have been fortunate to know a very supportive group of women in church who have been available and fun to be with. Keeping busy is key. The down side to a close relationship is how often I miss Eric, and how often I know we are together! Your work is very important, and echoes in the lives of the children and grandchildren, as well as in ours.

*CCALS has the privilege of working closely with hundreds of families as we did with the Hansberry's throughout Eric and Nancy's experience with ALS. Families are always our first priority, and our team ensures that we tend to and care for families through every step of their unique journey if that is their wish.*

*Ron and Nancy continue to stay in touch.*

## Juicing for Nutrition



CCALS is constantly on the alert for innovative solutions to the problems faced by people living with ALS.

These new ideas help us improve the services and types of equipment we recommend. Our medicine bag and myriad of resources include items that many families do not know exist.

One of our clients and good friends, Jamie Hudson, was recently faced with a diminished ability to eat. Jamie's former colleague Emily Farr and her husband Patrick own Quench Juicery in Scituate and Quincy. Ron brought Emily in to speak with Jamie about transitioning to smoothies in his final stage of life. CCALS worked with Emily to organize the daily delivery of fresh, wholesome and delectable smoothies.

Emily saw first-hand the benefits of the change in diet: "I saw an incredible impact in the 6-8 weeks Jamie's diet changed to smoothies and juices. Once he began drinking fresh smoothies and juices for about 3 days, I saw a lift in his energy and spirits, and he appeared to be much more alert, happy, and strong."

At 500-800 calories per drink, Quench juice is a great, nutrient-rich alternative for those who can no longer process solid foods. You can check out Quench's website for further information at [www.quench-juicery.com](http://www.quench-juicery.com) or you can reach out to [shannon@ccals.org](mailto:shannon@ccals.org) to learn how juice may benefit you or your family member.

## Thoughts From Ron...



Ron Hoffman  
Founder

I am constantly reminded of the strength of our CCALS community, and the opportunities that result directly from our relationships with families.

I am pleased to announce the opening of our new office in Boston which came about as a direct contribution from members of our community. This space will allow us to meet locally with ALS families as well as with hospital staff members.

A 24 hour RadioThon commencing at 6am on November 4th that will fundraise for CCALS in honor of Brad Martin was organized by the radio station for which he works, Cool 102.

I invite you to see the trailer of a feature length documentary titled *Being There* (available at [www.being-there.ch](http://www.being-there.ch)) which I was asked to be part of. It will be screened in Switzerland in November and December. We will post further details of the US release on [www.ccals.org](http://www.ccals.org).

With the families I have worked, there is an opportunity for the exchange of ideas and knowledge. A give-and-take of conversation, the sharing of thoughts, a lending of expertise. Our families are what make the CCALS community so strong and resilient.

It is with your continued support that we are able to make the *reflective* space of the **Education and Retreat Center** a reality.

It is with your constant care that we are able to serve an ever-growing numbers of families caught in the extreme web of the ALS circumstance. You make it possible.

Side by side,

A handwritten signature in cursive script, likely belonging to Ron Hoffman.

## ALS One License Plate



Our friends and partners at ALS One launched their new license plate initiative at the Massachusetts State House on October 26<sup>th</sup>. The vanity plates are sold for \$40, with \$28 of each purchase supporting ALS One's mission for an ALS care and cure. Visit **ALS ONE License Plate - Drive to End ALS** on Facebook or call Shannon 508-444-6775 for an application to order yours. CCALS receives 10% of donations made to ALS One.

## Dexter Ang

Continued from front page

Ang's chief of engineering is friends with ALS patient and CCALS client Bobby Forster. Ang and Forster met in January and became close friends. Forster is a very tech-savvy guy and he quickly became an essential part of the team. "Bobby is our main tester and designer. Along with him we have dozens of clients who will be prototyping this product to the point it's usable for everyone."

The Pison team has plans to launch a large-scale testing program; this fall they will test with 20 people with ALS and plan to expand to hundreds the following year. Ang is asking for all the help the team can get: "One important aspect of this project

is for people across the country to beta test our prototype. We welcome feedback from anyone interested in our work, including individuals with ALS, therapists, engineers, and neurologists. Keeping costs low or subsidized for people with ALS is an essential part of what we are doing. So much of the technology out there has an exorbitant cost, and we want a price and distribution model that works for ALS patients."

If you are interested in providing input, testing the prototype, or have ideas about how to grow Pison Technology, please email [dexter@pisonotechnology.com](mailto:dexter@pisonotechnology.com).