

COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Cares

FALL 2011

Welcome to our Fall 2011 newsletter. This issue of *Compassionate Cares* is dedicated to our ever-growing and inspiring community. We want to acknowledge and celebrate your unwavering commitment to helping ALS families.

Boston Fundraiser: A Celebration of Our Community and Our Achievements

Compassionate Care ALS' first Boston fundraiser at the Fairmont Copley Plaza held on May 5, 2011 was a resounding success and a joyous celebration of our community and our many achievements throughout the past 12 years. That night, close to 300 people came together and raised over \$140,000. The evening honored CCALS co-founder Betsy Heald Arthur with the first Gordon T. Heald Compassionate Care ALS Award for her extraordinary contributions to the organization. From the moment the doors opened for the cocktail hour until the final revelers left the majestic Venetian and Oval rooms of the Fairmont Copley, there was an incredible atmosphere of love, hope and community.



Left to Right: Event Speakers: Doug Oakley, Susan Landay and Chris Lambton.

Our three guest speakers, all of whom had personal connections to CCALS; Chris Lambton, Susan Landay and Doug Oakley, moved the crowd with their touching personal stories. They reminded us that we come together to support entire communities touched by the devastating disease known as Amyotrophic Lateral Sclerosis (ALS);

individuals living with ALS, their family members, friends and caregivers. Compassionate Care ALS serves the entire network affected by the disease with the aim of improving quality of life and enabling those diagnosed to live both fully within the parameters of ALS and face end of life with dignity, peace and comfort. As Chris Lambton so articulately said that night, "It's about family." His dedication to the organization began with his late mother's illness, and he along with brothers Eric and Mark

and father Ed remain committed as part of the Compassionate Care ALS community and extended family of supporters who understand the importance of providing help to families living with Lou Gehrig's disease.



Betsy Heald Arthur (center) with her children William Heald and Kim Krawshuk

The evening's success was due to the tireless work of our 18 member planning committee chaired by Sally Hunter and Courtney Strakosch. As key members of our community, each committee member selflessly devoted hours of their time to ensuring the event's success. One person commented on that night that they had never worked with such an organized and dedicated volunteer

committee. Our supporters are not limited to individuals but include our corporate partners and sponsors. We are proud to report that the event attracted more corporate sponsors than any other fundraising event in the organization's history. This can only be a testament to the commitment of our incredible community.

As we reflect on the success of that night, we remember what Ron Hoffman said to Betsy, "Thanks for believing." We would like to take this opportunity to thank our valued friends for continuing to believe in our important work and for supporting our new vision in ALS care. That night was more than a fundraiser for our organization, it truly marked a celebration of our community.

With deep gratitude, Compassionate Care ALS would like to acknowledge our major corporate benefactors of our first Boston fundraiser in honor of Betsy Heald Arthur.

Diamond Sponsor



Gold Sponsors



Thoughts From Ron...

This newsletter is dedicated to all members of our community, our board, our staff, our volunteers, our families, past and present, our corporate partners and our generous donors. You all make it possible for Compassionate Care ALS to potentially bring clarity and support to the lives of so many ALS families.

Earlier this year we changed our tag line, *Serving ALS families since 1998*, to *Leading a new vision in ALS care since 1998*. Personally, when I consider the meaning of this phrase, I am reminded that our ways of caring, and more specifically our way of serving amidst the institutionalization of healthcare, are very old and profound ways; most importantly, ways of the heart, ways of language appropriateness, and ways of skilled listening with the ability and capacity to understand the meaning of holding space in the presence of such difficult circumstances.

I was reminded of these values when I met Dr. G., a 79 year-old gentleman, recently diagnosed with ALS. He reminded me of an old-school family practitioner. As we sat in his garden, I was compelled to ask, "I'm guessing you made house calls in your day?" Indeed he had. Working within the confines of such a regulated system, many practitioners have lost sight of what it means to show up and care for people like Dr. G and many before him. Somehow treating the patient has become synonymous with treating the disease, and the humanity, intrinsic in the word care, was lost, the individual behind the disease just another face.

"A New Vision in ALS Care," are not empty words.

The institutionalization of healthcare, as I see it, is a barrier to the old ways. It certainly could do better, and pay more attention to those doing the tending. I recently read about a \$42 million grant to fund The Buksbaum Institute for Clinical Excellence at the University of Chicago, aimed at "improving medical students handling of the doctor, patient relationship." Three cheers...

Likewise, three cheers for the Schwartz Center here in Boston, and other organizations attempting to pay attention and improve doctor patient relationships. I give props to Harvard Medical School, for their creative and constructive workshops and offerings, also, The Lois Green Learning Community, as well as many others.

And what of the care for those giving the care? Quite simply, the lack of humanity in tending to our people is directly related to the inability of many in healthcare to take a direct look at their own feelings, emotions, and beliefs surrounding the difficult life choices they see every day. There is a need to inquire within the depths of ones own psyche the questions we all face, which, in turn take us to the mirror of our own mortality.

"Please don't be afraid."

Are you willing to do the work necessary on yourself in order to better care for those whom you are serving? Healthcare will only improve for our people when those in charge realize that compassionate care isn't just a buzz word. It is through this lens that we hope to make change. My fears and doubts stem from the institution itself getting in the way of such noble efforts.

It is with gratitude that I honor all of those in our community, our board, our staff, our volunteers, our families, past and present, all those working in healthcare and most of all you, our donors.

In Service,



Ron Hoffman,
Founder &
Executive Director

CCALS Named Beneficiary of the Sale of a New CD

While serving the ALS community for the past 13 years, we at Compassionate Care ALS have met many incredible people. One of those individuals was Tom Monahan, a larger than life Renaissance Man who never lost his sense of humor.

We are continually awed by the support we have received from both our clients/friends and their communities. Tom's community has honored his memory by recording a CD of his music and donating the proceeds of sales of that CD to CCALS. The following was written by Tom's wife Mary Lester.



Tom Monahan

Great Music for a Great Cause

An Irreverent Musical Tribute to Tom Monahan

As Hurricane Irene roared through New England in the waning days of August, a determined crew of musicians and friends across six states had something much bigger on their minds than flooding, blackouts and dire weather. The Manic Mountain Boys (MMB) and their far-flung group of friends and fans were on a mission for Tom Monahan, their founder, friend and fellow bluegrass music lover. Tom passed away from complications due to ALS in December 2010, three years after his diagnosis. He was 58.

An incredible man of many talents, Tom brought people together, attracting and connecting a network of friends across all of his areas of interest. He was a creative director at a global media company, an online publishing champion, a gifted furniture designer and an avid sailor. He was also a quick-witted storyteller, a songwriter and a good-natured mischief-maker. Beloved husband to Mary and big brother to five siblings, Tom left a wonderfully warm place in the hearts of countless friends and co-workers.

Yet of all his accomplishments, he was most proud of The Manics and his self-appointed position as their Chairman for Life (CFL). This collection of musicians and friends have camped and played together at bluegrass festivals all over New England for more than 30 years. The Manics excel at tweaking the traditional bluegrass experience, incorporating non-traditional instruments (saxophones, washboards and the occasional whistle) with jazzy swing, gospel tunes and plenty of raucous, rapid-fire on-stage humor.

So an untimely hurricane was no match for their plans to introduce their new tribute CD, "The Manics Pick on Monahan" at the 2011 Thomas Point Beach Labor Day Bluegrass festival in Brunswick, Maine. The CD – dubbed the "Hurricane Irene Special Edition" -- and a stack of Manic-branded t-shirts sold out quickly. The final CD (available for purchase at the CCALS.org store in the near future) will be a brilliant execution that would have delighted Tom: His best pals performing his songs. For updates about the CD release, please visit the "Tom Monahan Secret World Headquarters" page on Facebook. The page includes lyrics, photos and links to the Thomas Point Beach performance videos. Tom's spirit left a joyous and lasting legacy for all of those who knew and loved him. Upon his passing, The MMB unanimously voted to change his title from CFL to CFE: Chairman Forever.

In Memory Of...

Ken Baker, Bourne, MA
Rita Burlingame, Leicester, MA
William Frank, Attleboro, MA
Larry Filiault, Gill, MA
Rikhi Inderjit, Waltham, MA
Bob Iwanicki, Middleton, MA
Jim Jacobs, Missoula, MT
George Kerr, Hull, MA & Fort Pierce, FL

Bethany King, Windham, ME
Donald LaChance, Pawtucket, RI
Sue Levesque, Quinebaug, CT
Allister "Fred" MacDonald, Atkinson, NH
Maureen MacDonald, Marshfield, MA
Doris Mahaney, South Hamilton, MA
Edward Miles, Wilmington, MA

Paulette Muller, Cotuit, MA
Noreen O'Malley, West Roxbury, MA
Margaret Pagliarulo, Winchester, MA
David Richards, Smithfield, RI
Nancy Smolinski, Abington, MA
Carol Swenson, Douglas, MA
Rosemarie Wilson, East Wakefield, NH

His Family's North Star: Allister "Fred" MacDonald

Allister "Fred" MacDonald, a dear friend and client of CCALS, passed away on July 24, 2011. We wanted to share with our community the touching eulogy delivered by his daughter Jeannie. Words like these remind us that we are all working together so that families like the MacDonalds can spend the best quality time with their loved ones.

On Sunday morning, we didn't just lose our Dad. We lost our North Star. Like many of you, our family struggled to understand why such a kind, generous man was stricken by such a cruel illness. Yet today isn't about dwelling on the "tragedy" of ALS.

I want to tell you a love story – of a man for his wife; and of a father for his family. On July 19, 1952, a skinny guy in a bow tie walked up to the front door of 474 Groveland Street to take Mayor Albert Glynn's daughter out on a blind date. Inside, peering from behind a curtain, the Mayor's wife and daughter hoped to get a sneak peek at this 23-year-old telephone man from New Hampshire.

Just last week, my parents fondly recalled that first date; how -- within 3 days -- Freddy MacDonald told Martha Glynn he loved her; and how on June 20, 1954, he made her his wife. Of course, Mayor Glynn didn't make it easy. When Dad met with him privately to ask for Mom's hand, Mayor Glynn told him to "come back tomorrow" for the answer because he wanted to check with his daughter first.

Then, at their wedding reception, the Mayor informed Dad that he could now stop calling him "Mr. Glynn" and instead, address him by his first name. "It'll be Al from now on!" he told Dad. An ashen-faced Dad walked over to Mom and reported, "Your father just told me it would be Hell from now on!" This "Hell" lasted for the next 57 years and 34 days. In fact, in the hours before his death, he was still winking at Martha... still playfully puckering his lips for a kiss.

From their first date to the final farewell, they never stopped seeing each other, or loving each other. Dad was a wonderful father -- he taught us honesty, loyalty, self-discipline, laughter, friendship and love. He threw in a little magic, too...ringing sleigh bells in the basement on Christmas Eve to convince us that Santa was on his way.

If he said it, he meant it. If he made a promise, he kept it. You had to be careful what you wished for around Dad because he would make your dreams come true. When Ann wanted a horse, he built a barn; when Bill wanted to visit Yankee Stadium, he drove us to the Bronx; when I wanted to go to Boston College, he made it happen.

Heroes don't always wear capes -- or kilts...but what made him even more heroic in our eyes was the fact that he lost his own father at the age of 9. How can you be such a good Dad if you don't have any role models? He gave us the happy childhood he never had. His success as a father and grandfather was one of his greatest achievements, and even then, he attributed it to the well water on East Road!

Yet it was really the "little" things that made him great. I've never met anyone like him, have you? He wasn't just a man of character...he was a character! Have you ever seen such a distinctive style of handwriting? Would any "normal" person say to themselves, "Hey, I think I'll host an antique car show in my yard!"

He loved telling stories, but never spread gossip. He could build anything, and fix everything. He went to church, but didn't preach to others. He treated everyone equally, with humor and respect, whether they were VIPs or janitors. He even matched wits with Ronald Reagan during a campaign swing through New Hampshire.

He'd happily brag about his kids or grandchildren, but never about himself. He lived his life with humility and integrity, and in doing so, earned the admiration of many. He was self-taught...self-made...even self-employed...but always selfless in giving to others. Yet there were some things about him that I'll never understand.

Like his love for Moxie and cherrystone clams. His ability to resist the family's Red Sox addiction. Or his utter lack of self-pity when it came to facing his diagnosis. I think we all felt Dad got a raw deal when he got ALS. But in the end, ALS didn't take Dad away from us -- it gave him back to us.

It gave us time with Mom and Dad...time with each other as siblings... time to cry together and laugh together. ALS gave us time to tell Dad that we loved him, to hear him say he loved us, to care for him, to thank him.

And finally, as we gathered around his bed on Sunday morning, the original family of 5 that grew from a blind date, together again in the little red house on East Road, our hands on Dad as he breathed his last, we were able to walk him up to the gates of Heaven and let him go, our words of love the final sounds he heard on earth. Despite our sadness, we left nothing unsaid or undone. That knowledge gives us peace as we say goodbye today.

And for the rest of my life, whenever I speak these lines, they will resonate in a new way:

"Our father, who art in heaven."

For truly, our Dad...like the North Star...is now a brilliant light, shining above us, always leading us home.

Increasing our Corporate Partnership Community

Compassionate Care ALS is thrilled to report that, over the past few years, we have consistently increased the number of our corporate partners. In 2011, Compassionate Care ALS saw a significant growth in our corporate partnership community. The Falmouth Road Race garnered \$15,000 in corporate sponsorship this year as compared to over \$3,000 last year. Compassionate Care ALS' first Boston fundraiser brought in six new corporate sponsors resulting in over \$53,000 of corporate sponsorship funds. In addition, this year, a few of our corporate partners

have donated services or equipment to Compassionate Care ALS.

In this current economy, we are proud to recruit new corporate partners as well as maintain such strong support from our existing corporate sponsors. We greatly value these important relationships that allow us to better serve ALS families. In this economic downturn, ALS families need our help more than ever to cope with this debilitating disease. We would like to thank all of our corporate partners for their much appreciated support.

A Record Setting Year at the New Balance Falmouth Road Race

Thanks to our amazing community, once again CCALS had great success at the New Balance Falmouth Road Race. We are happy to report that for the fourth consecutive year we have reached a new high in donations by raising over \$256,000, with more donations still coming in. In addition, runner Ari Garber, member of Team David, set a CCALS record with a time of 42:51. She finished 38th among women and 182nd overall.

We would like to thank the 111 runners who participated on 27 teams, their supporters and our corporate partners for another fantastic and memorable year. Seeing the large contingent of

white and green Compassionate Care ALS shirts in the crowd of runners on the race's scenic route is always an amazing moment, as is greeting all our runners, friends and families at the post-race gathering at Highfield Hall.

We know that the race has become a permanent fixture on the calendar of many of our supporters. We are so grateful that, without fail, you continually show up to support us at the race. We are also glad to welcome new runners every year to our Compassionate Care ALS team and hope everyone participates with us again next year.



Ari Garber



Timothy, Ro and Alexandra Fallon



Ernie with Team Kampersal

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