

COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND

SUPPORTING ALS FAMILIES SINCE 1998

Compassionate Cares

FALL 2010

Welcome to our Fall 2010 newsletter. This issue of the CCALS newsletter is dedicated to our families present and past and pays tribute to four CCALS clients who all passed away. Their journeys and those of their families and caregivers serve to inspire us to fulfill our mission of helping those living and dying of ALS to do so with peace and dignity and with the best quality of life.

Margie Lambton

A Matriarch's Legacy

This year, Chris Lambton, The Bachelorette runner-up, ran for CCALS at the Falmouth Road Race in memory of his late mother, Margie Lambton, who passed away in 2008. CCALS helped the Lambton's cope with Margie's illness by providing durable goods and equipment as well as emotional and spiritual counsel and care. Through many hours of conversations, Ron formed a strong bond with every member of the Lambton family and provided them with guidance, emotional support and friendship. Even now, Chris Lambton, describes Ron as "one of the family."



Ron Hoffman and
Chris Lambton

cherished by those she touched the most. On what would have been her 59th birthday, May 27, 2010, friends and family held a celebration in her honor, sharing stories and drinking margaritas on the porch: a celebration that Margie would have approved of and been more than happy to participate in before being diagnosed with MSA.

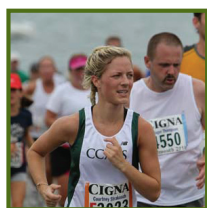
CCALS became involved with the Lambton family in the fall of 2005, even before Margie was definitively diagnosed with MSA, but exhibiting early symptoms. For Margie, these symptoms started with her constantly tripping. Ron Hoffman visited the family, providing practical as well as spiritual counsel throughout this uncertain period, after the diagnosis, and well into the late stages of this fatal disease. Like ALS, MSA robs individuals of their physical abilities

To her son Chris and to so many others, Margie Lambton was the most amazing individual. "She was loved by everyone and other people loved to be around her" is how Chris, the eldest of three brothers, describes his mom. It's been almost two years since Margie passed away from Multi System Atrophy (MSA), a motor neuron disease whose symptoms are similar to ALS, but her memory is still

while their mind remains alert. Margie described her ailing body as a "jail cell." One can only imagine how frustrating this disease was for a woman who spent her professional life as a registered holistic nurse, helping others to cope with illness. Over the years, and as her disease progressed, CCALS gave the family equipment that greatly improved Margie's day-to-day life, including a wheelchair, a bathroom chair and ramps, all of which helped her to remain mobile and at least temporarily, escape her jail cell.

When a family member is struck with such a devastating disease, it affects each person profoundly. What is most touching about Margie Lambton's story is her son's unquestioned devotion to his mom. In early 2007, Chris left his life in New York, including a position in a highly competitive graduate program for aspiring school principals, to join his brothers, Erik and Mark, and his father, Ed, in caring for his mom full-time. For him, it was clear then as it is now that this was the right thing to do. He was almost 29 at the time and just beginning to flourish in his chosen career. Not many people would have made such a selfless choice and dedicate the next year and a half to the care of a loved one. Without a doubt, Margie Lambton was truly an amazing individual, and she raised three great sons; all of whom chose to show their unconditional love by putting their lives on hold so that they could be there for her during the final years of her life.

2010 Tree of Compassion Walk/Run to benefit Compassionate Care ALS



Come join Courtney Strakosch, CCALS supporters and families along with Courtney's colleagues at The River 105.9 and The Bachelorette runner-up, Chris Lambton, on Saturday, December 04, 2010 @ 10:00 AM for the Tree of Compassion Walk/Run. The 5K course will be run on the beautiful Middlebury Greenway and will start and end at the Middlebury, Connecticut Fire Station.

Check out the Tree of Compassion website (treeofcompassion.ccals.org) for more information about the event, the post race party, fundraising tips and starting your own team in honor or memory of your loved one with ALS. Plus, we need your help in spreading the word about the event. How many of your friends and family members can you recruit to join in the fun?

Huge thanks to Courtney for her creativity and hard work in putting this event together on behalf of her beloved Mema. We look forward to seeing you there!

Thoughts From Ron...

This newsletter is our attempt to share the profound impact we at CCALS have experienced and continue to experience through relationships with individuals living with ALS as well as their caregivers. On occasion, the relational model we use at CCALS, manifests connections and friendships that enrich my life experience beyond anything I could have imagined. You are invited to read about some of my dear friends in this newsletter.



Ron Hoffman,
Founder &
Executive Director

- **Coach Jim Cotter**, of Boston College High. Meeting Coach Cotter instantly transported me to my pee wee football days. He so reminded me of my coaches who were important mentors in my young life. The impact he had on the lives of so many, both as a coach and guidance counselor, were profound.
- **Margie Lambton**. A woman who was a lover of life, holistic nurse and dedicated mother and wife. She cared for her family, her circle and her community with extraordinary depth. Throughout her ordeal she continuously extended her caring hand to all.
- **Jim Lester**. A man who I would call a modern-day renaissance man. His many credentials included author, psychologist, photographer, musician, and member of the first American expedition that climbed Mount Everest in 1964.
- **Billie Joe Patterson**. A career educator who, without a doubt, inspired and shaped so many young minds in his lifetime. He also intensely loved the land. He used his hands to build on it, to grow on it, and to nurture it.

Along the way, I looked into each of their eyes, and they into mine Sometimes momentary glances and at other times, longer and sustained moments of profound connection. For me, these silent times were intensely special, filled with an understanding and unspoken knowing between us.

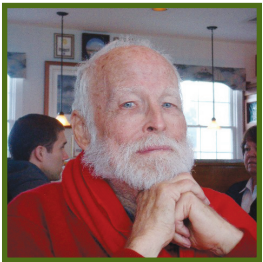
All of them were and continue to be inspirational individuals with powerful spirits who never let the disease define them. Instead, they were defined by the love they shared for their spouses, their families, their community, their work and their own extraordinary life journeys. How fortunate and enriched I have been to have known them. To have witnessed these individuals and others, in the most intimate of times. These people, so very much aware and conscious of their profound circumstance. Circumstances that included not only the suffering, grief and trauma within their environment, but the extraordinary joy, compassion, and happiness that played out before them as their loved ones surrounded them with authentic love and the ultimate of gifts...themselves.

I salute these remarkable individuals, their spouses, children and grandchildren who navigated, embraced, and danced with the reality they faced. For a glimpse into their reality, please see the articles throughout this newsletter.



Jim Lester

Gratitude and Appreciation for CCALS



Before the end of his ALS Journey on April 27, 2010, Jim Lester shared his thoughts and feelings for CCALS. Jim sent the following for his kind words and shall miss him dearly. Through his many notable achievements, Jim showed the world that is possible to achieve the impossible.

I came across the Compassionate Care website a few months after I was diagnosed with ALS. I was searching around for support that might help with the inevitable decline I knew was coming. I had no idea what a treasure I had stumbled onto. Ronald Hoffman and his colleagues then entered my life and my wife’s, with a compassionate and caring presence like I had never known.

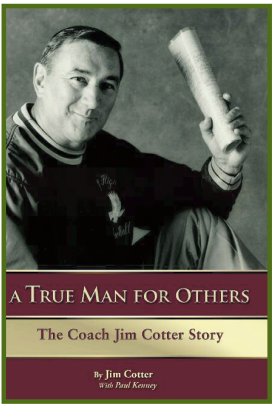
He and they added a dimension that I’ve found almost totally missing from the medical model of caring for disease. For Ron and his people, it’s all about the experience and not about the medical symptoms. Since there’s almost nothing medicine can do about the symptoms, Ron’s approach is doubly important and doubly helpful. He has been always ready to show up whenever we felt the need of his presence and wisdom and with his long experience of helping ALS patients, he always “gets” what one is going through.

He is there with you in a way that medical personnel are usually not. Beyond that, he has access to all kinds of aid equipment that he is happy to provide, matching it to your needs. The stuff he’s brought in to us has been enormously helpful, much of it stuff I didn’t even know existed. He is very well connected with the medical and hospice communities, too, and can often move things along there when they’re going sluggishly.

The bottom line is, I couldn’t recommend Ron and his organization more highly to any ALS victims and their caregivers.

Coach Jim Cotter An Inspirational Life

Prior to his death on July 20, 2010, Coach Jim Cotter completed an autobiography of his extraordinary life with help from veteran sports writer Paul Kenney. The book is an illustrated memoir that celebrates the career and life of the Boston College High School teacher, counselor and football coach. Coach Cotter and his family became involved with CCALS in the summer of 2008. A portion of the proceeds from his book benefit CCALS. You can purchase his book at www.ccals.org.



Billie Joe Patterson

A Granddaughter’s Tribute

Ayana Ottoman us the granddaughter of CCALS client, Billie Joe Patterson, who passed away July 17, 2010. The following essay was inspired not only by Ayana’s direct ALS experience, but also her inquiry, “How do I say goodbye to my grandpa?”

I had never known death before. It was foreign and uncomfortable. I had never faced the sheer permanence of it. Pets had passed, friendships had gone, but no one had died that left a pit in your stomach and tears in your eyes for more than a few days. My grandfather was diagnosed in November 2007. That was the beginning of the end. For a while, we all hoped for a quick fix, something to take it all away. That day was not meant to come, but we sure got a miracle.

It was summer, and I was doing weird teenage “love” things like spending all day in a golf cart, even though I hate the sport. One day, I was with my boyfriend, when I called my mom to see how things were going up at Grandma and Grandpa’s house. Grandpa had been weak lately, and all of us could tell his fight against the ALS beast was taking a toll on him. She answered the phone. The swallow I heard was a dead give away. It’s the swallow that forces down the lump, the swallow that suppresses the floodgates, and the swallow that inevitably fails. “How’s it going ma?” I asked tentatively. “Not well,” she returned. She proceeded to explain that Grandpa had decided to stop eating. He was ready to throw in the towel.

I headed to Fort Collins to see him the next day. My heart hurt so bad as I entered the room where he had been for the last months. Our eyes met, and the glimmer was still there. It was a glimmer of recognition, adoration, and total respect. Hymns were playing, candles were lit, and we were saying goodbye.

To try and tell someone exactly what they mean to you is a difficult feat. There are phrases such as “I love you” and “you have done so much for me,” all of which are true, but they never quite encompass all that you have to say. Now, being my normal, prepared self, I had thought of this ahead of time and jotted a few notes down. I had just what I wanted to say to my hero before he died.

My heart raced. It was only the two of us in the room now, and I knew that what I had to say needed to be said now. I walked around the bed and looked him in the eyes. Again, the glimmer appeared. I grabbed his hand and touched it to my heart. And I told him. Told him just what he meant

to me. Told him just how he had impacted my life. Told him just how sad I was that he wouldn’t see me graduate, go to college or start a family. I told him everything I had ever wanted him to know. He wasn’t strong enough to respond verbally, but all he told me in those last moments with his eyes is astounding. I shared the last sentence, “And please know that I love you so much, and you have changed my life for the better.” A small tear slid down his cheek. He nodded and we sat. . .silent. . .in stillness for a long time.



As the family gathered in the room for the rest of the evening, I couldn’t help but to reminisce on all the times we had shared. Trips we took, gifts we gave and received, holidays, meals, fights, tears, and laughter— just good family stuff. The joy we all felt together that night was a joy that hadn’t been present for the two years of Grandpa’s illness. I wrapped my arms around my grandma, listened to stories, and fell asleep with all the love in the world in one room. We all fell asleep that night. . .and so did Grandpa.

My mom woke me, my brother, and my cousin up at 4:25 AM. He had just passed. The three of us grandkids were all crammed into a queen sized bed, it was a comfort thing, and as we found out, our hearts were silenced. We went over to where he was, and needless to say, the hours following were the most emotional of my life. To know that you will never be able to share a smile, a laugh, or a conversation with someone ever again is hard to grasp. I still haven’t managed to wrap my mind around it. No one left the room. We all held him, touched him, tried to let go of him for hours. We cried, and cried, and cried.

To experience death so personally was crazy. It taught me a lot about how to die. I can say that my grandpa did it in a truly admirable way. He died how he lived, and I can only hope I live in a way that will lead to an easy parting. Billie Joe Patterson passed at 2:17 AM, surrounded by family and loved ones. He lived his life just as he died: with immense grace.

In Memory Of...

Henry Andrade, Fall River, MA

Bob Buckley, Pembroke, MA

Danielle Camacho, Ladera Ranch, CA

Doraine Coia, South Attleboro, MA

Coach Jim Cotter, Quincy, MA

Robert Craig, Sandwich, MA

Wilfred Craig, Hull, MA

John Curry, Philadelphia, PA

Cornelia Gvozdenovic, Lemon Grove, CA

Joan Hatem, Methuen, MA

Jane Jordan, Littleton, MA

Jeffrey Lawrence, New Bedford, MA

Paul Lydon, Wilmington, MA

Walter McLaughlin, West Falmouth, MA

Cathy McNamara, Clinton, MA

Billie Patterson, Fort Collins, CO

Joseph Payson, Leominster, MA

Alden Pettengill, Dartmouth, MA

Carol Pollock, Hanover, NH

Mary Prior, Danville, VT

Robert Saunders, Lowell, MA

Robert Silva, Lowell, MA

Fred Siwak, Quincy, MA

Robert Teceno, Middleboro, MA

Pauline Travis, Plymouth, MA

Emmett Tucker, Newton, MA

Ralph Viscarello, Dedham, MA

Bob Vredenburg, Belchertown, MA

CIGNA Falmouth Road Race 2010

Our Best Year Ever!

Thanks to our dedicated community of supporters, this year's Falmouth Road Race raised more funds for Compassionate Care ALS than any other year by leaps and bounds! So far, we have raised more than \$242,000 and counting, as donations are still trickling in. This is an increase of more than 35% from last year's total.

We could not have achieved this milestone without our 111 runners and 37 teams; not to mention their numerous supporters, some of whom cheered enthusiastically for our runners throughout the race. Among this year's remarkable achievements are the 1,803 individuals who donated to CCALS for the race, more than any other year. The Falmouth Road Race is CCALS' biggest fundraiser of the year, and we are so proud and honored that every year, all of our supporters help it to exceed our expectations. Most importantly, the Road Race signifies for us the coming together of the CCALS community to support our important mission: helping ALS patients, families and caregivers. Thanks for making this year the most successful ever. We hope to see you all again next year in Falmouth!

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community is
rapidly growing.
Stay up to date on
all CCALS events
and workshops
by adding us as a
friend or joining
our cause.*



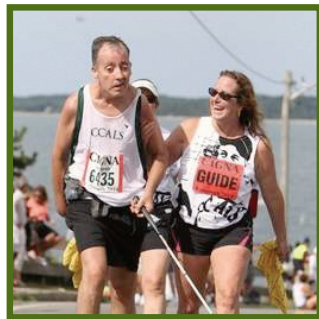
CCALS supporters cheering
the runners along the route



A CCALS runner
leading the pack



CCALS runners young and old



John Barcelo climbs
the final hill

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