

COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Cares

SPRING 2011

Compassionate Care ALS: Leading a New Vision in ALS Care

Over the past 12 years, Compassionate Care ALS has created a new approach to caring for and supporting individuals living with ALS, their families and caregivers. Our approach shifted the focus from simply addressing the needs of individuals coping with a devastating disease, to serving the entire network affected by each individual diagnosis. Research has repeatedly shown that providing psychosocial support to caregivers improves their ability to care for their loved ones, particularly in the case of caring for individuals with ALS, which is both emotionally and physically strenuous.

Compassionate Care ALS's mission is to model compassion to individuals with ALS by providing support and guidance, subsidized living aids, durable goods and respite opportunities. Driving this goal is our desire to improve the quality of life for individuals with ALS, enabling them to both live and die with dignity, peace and comfort. In encouraging intimate dialogues with these individuals and their families and caregivers and through organizing both educational workshops and support gatherings, CCALS is working to ensure that an ALS diagnosis does not lead to additional isolation for all those impacted by the disease.

The need for support is greatest when we encounter our own mortality and that of our loved ones. Our efforts to improve the quality of life for individuals with ALS include providing critical support to caregivers. Experience has shown that quality of life for paralyzed individuals increases dramatically when their caregivers are better equipped to facilitate their care. In a 2004 study reported in the *Journal of Neurology*, the highest predictor of quality of life for ALS patients is self-perceived quality of social support. Psychological, supportive, and spiritual measures influenced quality of life more than physical factors, highlighting

the importance of caregivers' well-being and adeptness over physical support.¹ By providing support to families and caregivers, we are helping to ensure that those with ALS receive the care and support that they need, while empowering caregivers to be as effective as possible.

In providing our families with essential equipment necessary for improving their quality of life, we are also seeking to reduce the strain on caregivers. The equipment that we provide makes an enormous difference in the ability of a family to maintain dignity and effectively care for a loved one at home, while preserving the individual's independence. The equipment eases life around the house and includes items that cost hundreds to thousands of dollars and are not typically covered by insurance. Among the equipment that we provide at no cost is our ALS Medicine Bag, which contains innovative non-institutional items we have found. We also loan our wheelchair-accessible van to families for day trips, outings, trips to the doctor, and other needs that arise.

At Compassionate Care ALS we are continually striving to understand the overwhelming dynamics that ALS families endure. We actively listen to the concerns of individuals and caregivers. We offer contemplative guidance and support in facing end of life issues with dignity and peace. We recognize the immediate impact that ALS inflicts on a family, and we work individually with each family to address their unique challenges and struggles. For all these reasons, we are proud of our efforts to transform ALS care into a collaborative and dynamic approach tailored to the individual needs of families. Despite our progress, our efforts to improve the system of ALS care are far from finished.

¹ Chio, A, Gauthier A, Montuschi, A, Calvo, A, Di Vito, N, Ghiglione, P, & Mutani, R. (2004). *Journal of Neurology, Neurosurgery, and Psychiatry*, 75(11), 1597-601

Compassionate Care ALS Appeals to Foundations

Over the past few years, Compassionate Care ALS has been making a concerted effort to diversify our funding sources both by recruiting new individuals and foundations to support our work. In the current economy, garnering support from new foundations is more challenging than ever before. CCALS is thrilled to report that in 2010, we witnessed a 20% increase in our grant awards, exceeding \$100,000 in grant revenue.

We are immensely grateful to the Rite Aid Foundation, the Flatley Foundation, Cape Cod Five Cents Savings Bank Charitable Foundation Trust, the Jay and Laurie Roche Family Fund, and the Donovan Family Fund. We are equally excited to have received our largest grant award on record from the Hermann Foundation. We hope to make 2011 as big a success.

Falmouth Road Race Registration Opens



Compassionate Care ALS is excited to announce the opening of our 2011 registration for the Falmouth Road Race. For the past 12 years, we have raised a significant portion of our annual income

from our participation in the Falmouth Road Race, which is now sponsored by New Balance. In 2010, CCALS raised nearly \$250,000 from the Road Race, thanks to the amazing efforts of more than 110 runners and 44 teams. We invite you to join us on Sunday, August 14 for the 2011 Road Race. We hope to make this year's Race an even bigger success, with our new goal to raise \$300,000. To register for the race or for more information about the event, please visit Falmouth.ccals.org.

Thoughts From Ron...

Welcome to our Spring 2011 newsletter. This issue of the CCALS newsletter is dedicated to the caregivers who dedicate their time, energy and physical strength to caring for their loved ones. Their strength and perseverance is an inspiration to us all, as they personally see to it that individuals living and dying of ALS do so with peace and dignity and with the best quality of life.



Ron Hoffman,
Founder &
Executive Director

During my time as Gordon Heald's caregiver I often thought, 'there must be another way, there has to be.' This was in response to my frustration at the lack of tangible services available for those with ALS. These circumstances served as our impetus for a new vision in ALS care. Today we continue that vision as we cultivate our relational and holistic model, honing our services in our continuous attempt to bring outstanding care and support to our families.

I share with you the following commentary written by our colleague Julie Yau. For six years now, Julie has been instrumental in bringing extraordinary care to many of those diagnosed with ALS, their caregivers, their children and their communities. I find her work with trauma and grief to be of great benefit and importance, as have those who have experienced this innovative, explorative process..... Her medicine bag runs deep.

I am also excited to share with you in this newsletter information for the 2011 New Balance Falmouth Road Race. As in the past, the Race is sure to be an exciting event and one of our biggest fundraising efforts of the year. We are also thrilled to announce that CCALS is holding our first fundraising dinner in honor of Betsy Heald Arthur on May 5th at the Fairmont Copley Plaza Hotel in Boston.

I deeply hope to see all of you at our upcoming events as we celebrate our visionary approach to ALS care.

Yours in service,

Trauma and ALS by Julie Yau

"A rock pile ceases to be a rock pile the moment a single man contemplates it, bearing within him the image of a cathedral."

– Antoine de Saint-Exupery

The last ten years, 'the decade of the brain' has yielded innovative new information on trauma, unveiling the intense physical, mental and emotional costs as well as possibilities that trauma encompasses. As we apply this new understanding of trauma to the ALS community, it sheds a light of empowerment and freedom, helping to promote healing. Unhealthy reactivity often arises when faced with traumas destructiveness, which adds to the suffering of ALS, however, given the right tools the transformative possibilities of trauma and deep stress come about.

Multiple internal and external challenges arise while living with ALS. Looking through the lens of somatic psychology, we are able to identify trauma related symptoms and syndromes addressing them with pioneering techniques, solving current issues, all the while opening a whole new awareness, laden with positive insight. The reality of ALS brings trials; emotions and sensations are often too strong and threatening, they become fragmented, split off, or caught in a pattern of unhealthy repetition. We have guides whose presence and skill allows you to find resolution, build resilience, and an ability to contemplate, to possibly see the 'cathedral', the potential that lies hidden in your being that you may have yet to discover.

In our work we witness the strenuous trauma and deep stress that seeps into families lives. Often the trauma that surfaces comes from beyond the diagnosis, but is connected to past events that were incomplete in our physiology and biology, the circumstances around the disease gives rise to old wounds. Trauma left untreated is disruptive and discernible in numerous mental, emotional, physical and interpersonal effects which adds to overwhelm and suffering. Trauma resolution with Somatic Experiencing®, Yoga Nidra, and other somatic practices enhance healing, not only from stress and trauma, but from any place in which we feel stuck or unresolved.

Somatic Experiencing (SE) defines trauma as occurrences that challenge and overwhelm our capacity to cope and respond, causing our body/mind to be or feel stuck, leaving us unable to recover a sense of balance in our lives. A rich inner beauty unfolds as deeper truths are

harvested for our highest good and that of the world around us.

There is not a simple recipe for resolving stress and trauma; since conception each of our lives has been complex and intimately connected to our environment. Our environment being an infinite display of congruent and incongruent events perceived as threatening, safe and everything in-between, that shape our lives. Yet, SE and other techniques we offer families, are powerful and fashioned to fit the individual, based on their own needs and inherent wisdom. The techniques help regulate the autonomic nervous system and heal symptoms, discharging, or deactivating, excess energy still trapped in the body long after the difficult event passed. Often it is the symptoms of anxiety and panic, sleeplessness, depression, anger or hyper-vigilance that we address, sometimes the need to build resilience – the capacity to cope and not go into overwhelm – as the disease progresses in the family.

The possibilities are many as we overcome the holding patterns in our bodies which influence our minds and vice versa, to find a new freedom and level of awakening. Becoming aware of our bodily sensations and sensory awareness with the assistance of a trained guide, the terrain of difficult life experiences can be navigated with an ease that leads to deep inner healing and transformation. This allows us to move through life experiences grounded, connected with an ability to view our soul's destiny rather than be subject to fate.

The new wisdom we awaken too unfolds and points us to act accordingly with a loving purpose. How wonderful it is to find the divine presence that emanates for our own hearts as we dissolve the obscurities that blind us, giving way to compassion. Compassion is far more sophisticated than we may first think, but something to cultivate on a daily basis, helping us awaken our hearts and mind to become conscious participants in our own life and future.

As well as counsel we offer ongoing practices for individuals to do alone or as a family. It is the positive intention to grow, that will flow into a field of compassion which will be reciprocated in your own heart. We will meet you there.

"Love and compassion are necessities, not luxuries. Without them humanity cannot survive."

– Dalai Lama

In Memory Of...

Mary Agis, S. Grafton, MA
George Brawley, Westwood, MA
Shelley Craig, Dedham, MA
Marit Davies, Franklin, MA
Michael Doctoroff, Natick, MA
Theresia Entjes, Netherlands
Paul Foley, Dedham, MA
Steven Fuschetti, Chelmsford, MA

Deborah Goessling, Wayland, MA
Mary Harrington, Haverhill, MA
Bill Johnson, Kittery, ME
George Landon, Boulder, CO
Sandra Lind, Harwich, MA
Virginia Ludwig, Lexington, MA
Jim McCaffrey, Chatham, MA
Edward McCann, Scituate, MA

Thomas Monahan, Sudbury, MA
John O'Donnell Jr., Brewster, MA
Gus Perry, Bridgewater, MA
Ronald Perryman, Woonsocket, RI
Madeline Porrazzo, Acton, MA
Joan Powers, Harwich, MA
Jack Santos, Natick, MA

Robert Silvia, Holden, MA
Michael Sullivan, E. Falmouth, MA
Eric Swanson, Wilmington, VT
Gilbert Tabor, Derbyline, VT
Jim Wallace, Worcester, MA
Faith Wilkinson, Townsend, MA
Yin Yee, Quincy, MA

Caregivers of ALS: Experience of a Lifetime

by T. J. Adkins

*"We look strong on the outside although we fear;
We smile even though we're helpless;
We encourage although we feel hopeless.
We are present in each moment.
We are Caregivers; We show up."* – Anonymous

Helping our loved ones with ALS feel in control of their lives, as we provide more and more care through the progression of their disease, is no easy task. It is an emotionally and physically draining, 24-hour a day job, yet it has powerful rewards. As a caregiver, I may not realize the skills I am using, nor the ability I innately have, skills such as problem-solving, strategy, finding gains in losses, keen awareness in needs of others, meeting challenges, accountability, management and coping skills. I am slowly learning I need to take better care of myself.

Overwhelmed is the word I've heard used most often used to portray caregivers, as we continually give more of our time and make even more personal sacrifices. Before ALS, I understood the reality that things in my world are always changing. As a caregiver, I hope for one outcome: to continue to enhance the life of my ALS loved one and provide every source of independence for him that I can.

"If you realize that all things change, there is nothing you will try to hold on to...there is nothing you cannot achieve." – Lao Tzu

Continuous change involving great difficulty and pain is no fun match for any person to endure, especially over a long period of time. What keeps me going? Anything that enriches my psyche and my heart, like gratitude, appreciation, closeness to my ALS loved-one, and personal growth are just some of the examples of the emotional fuel I need to keep my overwhelmed and tired motor running. For example, I feel 'light' and 'full of pride' when complimented on a job-well-done for anything these days. And, for someone who does not receive compliments without feeling uncomfortable, that says a lot.

Ron Hoffman gave us a variety of reading material upon our first meeting. The Final Crossing by Scott Eberle is one of several books that intrigued me. Eberle describes the cycle of life saying "the sun sets each night, only to rise again in the morning. The moon wanes to nothing, then waxes back to fullness." This sentiment is similar to one expressed in a poem that Ron played at a Caregiver to Caregiver gathering in February, which basically said: the moon, just as the sun, always shows up, and both are always present in their moment of the day.

As a caregiver the demands of the ALS journey are to focus and be here now; now more than ever before in each of our lives. This is my goal, though it is not always possible. It took time, and still does, for me to give up the pressure I put on myself and realize that I am half there with exhaustion and am overwhelmed. As a caregiver, many times I show up, waxing or waning like a crescent moon. On good days, I am fully present as a full moon.

However, I do my best to always show up, no matter what. So does my fiancé, Dale, who was diagnosed with ALS on December 29, 2010. Since learning of his diagnosis, I've tried to protect him by hiding my fear, grief, sorrow and worry. Although I used to try, Dale said it was always written on my forehead like the digital messages on the Good Year Blimp.

Dale enlightened me with these words: "It's something you can't hide in somebody's eyes. Like they say, 'the eyes are the window to the soul,' whether you are feeling good, bad or indifferent. You hear it in the tone of another's voice, too." This from the man who often jokes about his physical situation, and I join in for fun and laughter. We both agree that humor is the best source of medicine, no matter what the circumstances may be. Some of Dale's sarcasm has kept me going when I was exhausted. It is one of the reasons why I fell in love with him.

Dale joked once, "Well, you never have to worry about losing your special silverware, mine are all bent in the shape of an 'L,' and our kid's sippy-cups are amazingly easy to drink from." Sometimes nothing is laughable. Due to exhaustion, depression, anxiety, chronic pain, or simply being overwhelmed, I may not be capable of being 'fully present' all the time. I cannot do it all alone. Caregivers own the right to feel no guilt over not being super heroes just as those with ALS own the right to care for their own needs. Personally, my favorite days are when I'm 'fully present,' and I surprise myself with who I'm becoming each time I give of myself to Dale's current needs.

"It is one of the most beautiful compensations in life that no man can sincerely try to help another without helping himself."

– Ralph Waldo Emerson

One person at the February caregiver gathering I attended that stood out in my mind was Peggy, whose husband passed away from ALS a few years ago. Her humor and wisdom were invaluable to me. As Peggy spoke, she graciously held the HeartStone we passed around. When you hold the HeartStone at a gathering with Ron, the opportunity is yours to speak whatever is on your mind or in your heart. It is an opportunity to be listened to and to be witnessed. One of the most important things Peggy shared was to **take care of yourself!** Go out with friends, nap, eat good food, eat junk food, talk about feelings, and do not be hard on yourself if you get impatient or angry sometimes. Be kind to your loved one, but do both of you a favor, and set boundaries on unreasonable demands or behaviors.

I thank CCALS for its kindness, equipment, educational materials, literature, guidance and most of all the emotional and spiritual support that have been wonder for Dale and I. This support is what sets Compassionate Care ALS apart from all other nonprofit organizations. In a word, they continually 'show up,' and they are definitely living examples of 'being fully present.'

Leadership Gift Club

We would like to recognize the members of our Leadership Gift Club that has grown from 61 members in 2009 to 230 members in 2010. The Club has helped us as we continue to grow and provide services to more people living with ALS, their families and their communities.

Compassionate Pioneers (\$1000 and over)

Richard Amundson	Pat and Paul Foley	Martin O'Regan
John & Barbara Burns	John Foley	Janet and Alfred
Brenda Lee Chapin	David & Andrea Garber	Palmarriello
Rosemarie & Charles Clarke	Susan Govoni	Nancy Plamann
Grace Cotter-Regan	Susan Guthrie	Barbara Pringle
Zenas and Carol	Elizabeth Heald Arthur	Barry Roy
Bennett Crocker	Bob Iwanicki	Mary Scott-Morton
Lawrence & Joan Curry	Alice Joshi	Ross & Kathleen
John Deneen	Patricia Kennedy	Sherbrooke
Mike* & Honey	Lloyd Klickstein	Andrew & Lisa Smith
Doctoroff	Suzanne Laham	William Strakosch
Lawrence Dugan	Hormoz & Joan	Frederic & Judith Taylor
Tadeusz & Michael	Lashkari	Tara Thibadeau
Dziedzinski	Valerie Lester	Salvatore & Lisa Tringali
Claudia & Edward Stern	Mark Lore	Jerome & Anne Trupiano
Julie & William	Sean & Nancy Lucey	Steven Windwer
Edwards	Margaret Marquardt	Milo Zidek
Robert & Joanne Fallon	Albert & Katie Merck	
Donovan Family	Theresa Michaud	
	Amy & Rob Millisor	
	William Muller	

Compassionate Vanguards (\$500 and over)

Bob Baisden	Richard Heidbreder	Deborah Peterson
John Barcelo	Paul Helfrich	Lori Pettengill
J.N. Boone	Pliny Jewell, III	Linda Simonetti
John & Susan Branco	Kieran Joshi	Donna Sola
Kathleen Briggs	Kenneth Juall	Julie Souza
James Carmody	Paul & Pat Kaplan	John & Nancy
Jang Ho & Janice	Steven & Marilyn	Spanbauer
Hayes Cha	Keenan	Gary & Deborah Stein
Brenda Lee Chapin	Robert Lenk & Kyoung Paik	Victoria Stockton
Russell & Susan Cisek	Judith Lamarre	Jessie Tait
Jean Craig	Dan Levine	Elaine Thibault
Michael Cunniff	Margaret M. Lilly	Tom Toman
Daniel & Alisa	William & Linda	Pauline Travis
Doctoroff	McLaughlin	Ted Trevens & Courtney Urick
Melody Dorfman	Michael McLaughlin	Margaret VanHorn
Cynthia Eid	Ray Miller	Marjorie West
David Engelbert	Mary Ellen Morency	Thomas & Robin
Jane Flynn	Michelle Murray	Wheeler
George & Barbara Freehill	Ann & Matthew Nadler	Mary White
Jeff & Amy Glass	Davis Paula & Frank	Paul & Joyce Zimmerman

Compassionate Guides (\$250 and over)

Joanne Ackman	Joseph & Gerardine	Shirley & John
Leslie Altschul	Greene	O'Herron
Daniel Ashworth	William & Catherine	Scott Otteman
Brandon Baisden	Heald	Shawn Otteman
Jim & Elaine Baker	Paul Hincman	Alene Patterson
Marion Baker	William & Rosalie Hynes	Christopher Patton
Donna Baker	Robert Jaffee	Jeffery Phelps
John Barletta	Larry Rosenstock & Jean Kluver	Ann & Richard Phelps
Edward Bennett	Betty Jenkins	Alex Phillips
Peter Blacklow	Richard Kaplan	Bonnie & Michael Pilar
Kathleen & Marc Bliss	James Kearns	Michael Pramis
Peter Borans	Maxine Klein	Peter Rahmer
Kelly Bosma-Thompson	Pamela Kondylis	Barbara Ramsdell
Robert Brinkmann	Kelly & Robert Kozub	Phillip & Anne
Gregory Brusseau	Kimberly Krawshuk	Robertson
Michael Cahill	Bruce Landay	Jane Cyr Robinson
Pamela Chambers	Heidi Larkin	Martin Roche
Gerald Ciccio	J. Kevin Leary	Marilis Rodriguez
James Coghlin	Jane Lester	Robert Rothschild
Lawrence Cohn	Rosemary & Don Lewis	Cheri J Rubin
Martha Conley	Diana Lingafelter	Mary Rushton
Bill Curry	Robert & Joanna	Kimberleigh Sallows
Sandra Darmetko	Longden	Michael & Ruth Sayles
Ryan Davenport	Albert Love	Allison Gray & Scott Beyer
Casimir de Rham*	William Lynch	Susan Scott Smith
Albert & Suzanne	Carlin Lynch	Al & Pat Sevigny
Delorenzo	Shannon MacDonald	Martha & Steven
Kenneth Morrison	Nigel MacEwan	Shuster
& Denyse Gross	Margaret Maistros	Bernard Smith
Andrew Doctoroff	Andrew Marc-Aurele	Rachael Solem
Michael & Amy Dorsey	Mary Marcy	Red Sparrow
Jill Edwards	Eric Markus	Norman Stein
Eric Engdahl	Charles Marquardt	Rachel Stewart
John Ford	Gay Mayer	Dianne Sullivan
M. Taylor & Anna Fravel	Martha McLaughlin	Robert Swanson
Michelle Fuller	Richard McManus	Thomas Tesoriero
Leota Gallivan	Elena Morgan	John & Meg Verret
James Giebel	Francie Mortenson	Chris Virden
Renee Gilson	Frederick Mulhauser	Frederic & Grace
Sheldon Goldstein	Constance Narayanan	Walker, IV
Brian Golemme	Patrick Ng	James Ward
Kenneth & Karla Gonye	Brian North	Jeffrey Wipple
Mond & Ott Gordon	Mary Nunes	David & Susan
Katherine Gould-Martin	Kevin Oakes	Woodbury
Steve Gramps	Ann O'Hara	Bob & Marguerite
Gerald Greeley		Zumbado

The Fairmont Copley Welcomes Compassionate Care ALS Supporters

On May 5, 2011, Compassionate Care ALS invites our families and supporters to join us at the Fairmont Copley Plaza from 6:00 to 10:00 pm for a celebratory fundraising dinner. Please celebrate with us as we recognize our 12 years of providing compassionate service to ALS families and as we present Elizabeth Heald Arthur with the Gordon T. Heald Compassionate Care ALS Award, in commemoration of her contribution. The night will feature a cocktail reception, dinner, music, a live and silent auction, and an award ceremony. For more information about the event or to buy tickets, please visit www.ccals.org/fundraising_dinner.



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