

COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND

LEADING A NEW VISION IN ALS CARE SINCE 1998

Compassionate Cares

FALL 2013

Welcome to our Fall 2013 Newsletter

This issue of Compassionate Cares focuses on the RESOURCES we offer families and the impact they have. Please visit www.ccals.org/resources.php for an extensive list of resources we find useful.

CCALS Resources: Fostering Community & Support

Focus on: Wally Kittredge

Wally Kittredge first heard about CCALS through a teacher at Falmouth Academy who thought that we could be a useful resource after Wally's diagnosis with ALS. Since that time in the Spring of 2011, Wally has had a tremendous experience utilizing our services.

In addition to the equipment we provide Wally to sustain a higher quality of life, CCALS also provides an extensive list of other resources to allow him to build and maintain networks of emotional support. Wally says that while the equipment provided by CCALS improved his quality of life immediately, the connection CCALS gave him to other individuals who act as a conduit for the emotional navigation of living with ALS has made the biggest impact on him and the lives of his family members.

Wally has been working with Julie Yau (www.embodied-wisdom.com), longtime CCALS friend, colleague and developer of our Cultivating Compassion Education Series. Julie specializes in trauma resolution and has worked with many of our families over the years. "Julie has given me purpose," Wally says. He describes looking forward to their sessions tremendously, and that she has given him and his family a sense of hope throughout the progression of ALS. Julie emphasizes the need

to integrate the physical, emotional, and spiritual elements of her work with Wally and other clients. It is about "looking into those deeper emotions:

love, fear, life and death, and how we experience ourselves throughout life with ALS," she says. Throughout Julie's experience working with ALS patients, she knows that as the disease progresses, it is important for her work to shift from focusing on the physical elements and sensations to "feeling safe spiritually and emotionally in facing the future." In addition to his work with Julie, Wally also talks about his experience working with Don Cox, a shiatsu practitioner referred by CCALS. Don has provided Wally with meaningful conversation and company in addition to his excellent shiatsu skills.

More than anything, Wally and his family feel that CCALS has given them a sense of community and the knowledge that they are not alone in the struggle of living with ALS. They know that if an issue arises and they need to talk to someone, a CCALS staff member will be available to help work through the problem. Overall, Wally's experience exemplifies the universal care that CCALS offers our client community. Seeing the whole picture, and as Wally puts it, helping people deal with ALS "psychologically, mentally, and physically" is the gift that CCALS works to give.



Wally and his wife, Jane



Wally and his son, JT

Thoughts From Ron...

September 26, 1989, As I awoke this morning, I felt this incredible ache around my heart, this undeniable ache, my mom had died this morning, this very morning on September 26, 1989. I knew also the passing of my friend Bob Silberling, three days prior, in California weighed heavily. An extraordinary man, a life extraordinarily lived. The continued loss of those we love, those we know, those we work with and at times come close to can



*Ron Hoffman,
Founder &
Executive Director*

be difficult. Therein lies the challenge, to participate, to witness, to honor, to grieve, to let go cleanly, in order to continue on. Not an easy task, but so very, very important. Wally Kittredge is a man, consciously walking his way through the labyrinth of his life, his way. Alan Melkonian, navigated the complexities of his ALS circumstance in his clear methodical way...his way.

In time, I have found what is important more than all else is to honor all ways.

Choices and possibilities are core issue in living with any catastrophic illness. How does one decide what information he wishes to receive? How does he choose? How do we inform ourselves? How does she take on such an enormous task? For some, a burden beyond all imagination. How?

I don't know!

I have come to hold true for myself the importance of honoring the ways of all people...his choice...her choice...your choice, but always to honor their choice.

I have also learned along the way.....shhh.....listen. Try and listen, feel the stillness and the quiet within yourself. Sense what arises. As time passes, maybe go to the place of the inquiring mind, see what unfolds, share your thoughts, above all share your feelings authentically, with yourself, with your loved ones.

And for us in the world of tending, regardless of modality or practice, be it doctor, nurse, social worker, volunteer, family or friend, please honor that which is being shared. For what is too often forgotten is the sacred ground we walk upon, as we traverse with those living life with a fatal disease. As I sat in a memorial service this morning, I was reminded of all I don't know. I was reminded once again of leaving all I think I know at the door upon entering someone's home. In addition, to be clean and clear of any misplaced judgments or preconceived notions of what I or we think should or should not unfold.

We are but visitors.

CCALS Resources: Youth Program

Focus on: Summer 2013 Retreat

On July 17th and 18th, nine young people joined members of the CCALS team and volunteers on Cape Cod for the first CCALS Youth Retreat. The retreat was made possible by the Edward McKenney Youth Fund. This fund was started by Ed's family to carry on his lifelong work helping young people after he passed away from ALS in January of 2013.

The two-day retreat provided the opportunity for youth whose lives have been impacted by ALS to meet and interact with their peers who are dealing with similar experiences. The goals of the retreat were to provide a safe and supportive environment to share experiences and to build community.

The first day was spent out on the water with Rideaway Kayak, paddleboarding and kayaking around Popponesset Bay. Afterward, everyone headed to Sippewissett Campground for food, games, and s'mores. The following day, participants traveled to Caribiner's Indoor Climbing in New Bedford, MA for more activities, fun, and bonding.

Mike Abrahams, a Youth Retreat volunteer for CCALS whose father is living with ALS, described the powerful impact that the experience had on all of the participants. "It was a tremendous opportunity for participants to experience commonality amongst their differing ALS journeys. Whether it was coming to the realization that they aren't alone, having questions answered, or simply making new friends with similar experiences, all participants took something positive away from the weekend."

At the end of the two days, everyone went home with the knowledge that they are a part of a community of people sharing their experiences and willing to provide support. We can't wait to do it again next year!



Youth Program staff and participants paddle Popponesset Bay

In Memory Of...

Bert Allain, Mattapoisett, MA
Lorraine Creamer, Fitchburg, MA
Denice Cunningham, Braintree, MA
Nancy Finkle, Worcester, MA
Doug Gordon, Chepachet, RI
Sheldon Hackney, Vineyard Haven, MA
Karen Hall, Swampscott, MA
Sue Jones, Weston, MA
Nick Katsiroubas, Natick, MA

David Lewis, Ashland, MA
Daniel Light, Sutton, MA
John Lombardo, Norwood, MA
Stephen Malieswski, Wayland, MA
Bill Mehr, Orange, MA
Alan K. Melkonian, Stoneham, MA
Thomas Morris, Kingston, MA
Shirley Otero, Warwick, RI

Denice Santucci, Templeton, MA
Robert Silberling, West Tisbury, MA & Tarzana, CA
Ida Triano, Framingham, MA
Sandralee Turner, Lunenburg, MA
John Vlacco, Fairhaven, MA
Daniel M. Wegner, Winchester, MA
Sharyn Wilk, Cranston, RI
Deborah Wood, Hanover, MA

CCALS Resources: The Little Things Have a Big Impact

Focus on: The Melkonian Family

Alan Melkonian was diagnosed with ALS in July of 2012. He and his family first became involved with CCALS after being referred to us by their doctor. Alan's daughter Laura said that the first time Ron Hoffman visited the family there was an immediate impact. The initial interactions with CCALS staff helped them to find a way to have honest conversations about difficult issues which lifted some weight off their shoulders. Information CCALS was able to provide touched on issues not covered by Alan's doctors or various ALS websites. Some of this information included suggestions on home health care and counsel on end of life care which was invaluable to the Melkonian family. In addition to access to information and support, Laura said that the provision of equipment, "which," she said, "is too big of a word to describe some of the little handy items that were so simple," helped to preserve her father's dignity in going about his daily routine.

In Laura's opinion, the most important help extended to her family was the emotional support provided by Ron and his staff. Laura told us that CCALS provided a safe space to ask questions and have a dialogue about topics that were hard to handle. Compared to the hospital, where Alan went through a long ALS trial with no positive outcome, and where no psychological counseling was offered, she described CCALS as feeling like "the guardian angel we longed for and the first glimpse of justice behind such an unjust diagnosis."

On Friday, June 7, Alan Melkonian's long battle with ALS ended as he passed away in his home at the age of 58.



Alan and Laura celebrating her wedding in March 2013

Dara's Mitzvah Project

On August 31, Dara Bruck celebrated her Bat Mitzvah in Albany, Georgia. She included CCALS in the festivities by making us her Mitzvah project. In the Jewish tradition, it is taught that happiness surrounding a celebration is deepened when sharing it with people in need. Dara did just that by raising funds for CCALS and encouraging her family and friends to learn more about ALS, our organization, and to support us as well! We'd like to thank Dara for her thoughtfulness in including CCALS in her joyous occasion, and encourage anyone thinking of new and creative ways to support us to think of CCALS during your celebrations, too.



Bat Mitzvah table card



Dara Bruck with her grandmother, Devie Louza

Another Successful Falmouth Road Race

The end of August marked another successful year for CCALS at the Falmouth Road Race. This year we raised over \$280,000, which represents a major portion of our budget. Funds raised through the road race allow us to continue to support all the ALS families that request our services. CCALS was wonderfully represented in the 41st annual New Balance Falmouth Road Race by 125 runners and 30 teams over the sunny seven-mile course.



Pre-race excitement built at the spaghetti dinner held the evening before the race at the Seacrest Beach Hotel as runners and their families fueled up on carbs and good company. The post-race celebrations for CCALS took place at Highfield Hall, where runners gathered for their well-deserved recovery.

We are beyond grateful for the runners, supporters, and corporate sponsors who worked to make this event a great success. Your commitment has made all the difference in allowing us to reach more families living with ALS. We can't wait to see you all at next year's race on August 17, 2014!

Leadership Gift Club

We would like to recognize the members of our Leadership Gift Club that has grown from 61 members in 2009 to 383 members in 2013. 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)

John & Pamela Arnold	Krista Hennessy	Janet & Alfred Palmariello
Bedoukian Researching	Billy & Audrey Hogan	Steven Pittman
Bob Baisden	Rupa & Egide Houndegla	Collin Roche
Peter & Clara Barrett	Ron Hoy	Jay & Laurie Roche
David Baskin	M. Donahue Assos.	Gennaro & Tilla Romano
Carly Bassett	Alice Joshi	Richard Roy
Frederick Bigony	Patricia Kennedy	Barry Roy
Steven Boland	Richard Kenney	Ronnie Sanders
Rita Brancy	Megan Kurch	George Scangos
David Butler	Audrey & David Ladd	Wendy Scholes
Mike Carbone	Peter & Deborah Lamm	Mary Ellen Sheehy Reed
Dianne Carrabine	Valerie Lester	Ross & Kathleen
Maria Casini	Greg Lewis	Sherbrooke
Jose Dejesus	Margaret M. Lilly	Linda Simonetti
Sarah Delima	Rachel Lipari	Wayne & Patricia Smith
John Deneen	TRU Services	Maria Stata
Ashley Despres	Samuel & Judith Lorusso	Michael McLaughlin
Franklin Dexter	James McConnell Clark	Medford St. Theatre Inc
Daniel & Alisa Doctoroff	Michael McLaughlin	David & Beth Meltzer
Thomas Donovan	Medford St. Theatre Inc	Albert & Katie Merck
Dos Nino's, Inc	David & Beth Meltzer	RA Millisor
Brian Doyle	Albert & Katie Merck	Christine Mosholder
Joe Faber	RA Millisor	Bernadette & Peter Murphy
Robert & Joanne Fallon	Christine Mosholder	Eric Nash
Richard & Nancy Flynn	Bernadette & Peter Murphy	Nancy Nemetz
Meryl French	Eric Nash	Erin Nutter
Johanna Friedl-Naderer	Nancy Nemetz	Thomas & Robin Wheeler
David & Andrea Garber	Erin Nutter	Joe Whitney
Linda Glover	Patty Oakley	Douglas Williams
Lucy Hackney	Larry O'Keefe	Onyx Hotel
Jean Haffenreffer	Elizabeth Heald Arthur	Arthur Page
Elizabeth Heald Arthur	Susan Heidbreder	

Compassionate Vanguarders (\$500 and over)

A-1 Concrete Cutting and Construction	E. Victoria Davis	Anders Lundstrom	Central MA PHCC
Carol & Marc Abrahams	Glenn & Jean Dawson	Michael Maclean	Association
Michael & Marie Angelini	Hermine Doctoroff	Edward Madden	Michael Phelps
Andrew Barous	Scott Donnelly	William Mahoney	Glenn Pierce
Pamela Barry	Melody Dorfman	Robert Mancuso	Wendell & Melanie Pittman
Beauregard Family Fund	Nathaniel Dunn	Andrew Marc-Aurele	Poduska Family
Hank & Nancy Benjamin	TL Edwards	The Marc J Revocable Trust	Karen Reed-Wright
Theodore Beriau	Thorsten Eickenhorst	Linda Marchan	Eric & Melissa Roiter
Thomas Bigony	Harvey M. Eisenberg	Philippe & Marguerite	Joseph Santangelo
Francis & Margaret Bowles	Ervin Forbes	Mauldin	Eileen Scotti
John & Susan Branco	John Freitas	Daniel McCluskey	Ryan Shefferman
Brazell's Package Store	Leota Gallivan	Mr. & Mrs. David W.	David Shih
Theresa Brennan	Liang-Shang Gan	McGraw	Anthony Spadaro
Colleen Brinkmann	William & Linda	McLaughlin	John & Nancy Spanbauer
John & Barbara Burns	Maureen Michael	Theresa Michael	William T. Speck
Marie Cacciola	Michael Michael	Joe Mitch	Steven Spiegel
Capt. Carlo's Restaurant	Merrily Moynihan	Miriam Neipris	Michael Stein
Robert Catalano	Terry Oakley	Concetta & John Ojanen	Gary & Deborah Stein
Sharon & Eugene Chauvin	Gordon & Lori Owades	Juliette Palazzo	Axia Strategies
Dennis Clarke	Anastasios Parafestas	Paul Chen	Robert H. Studley
Stephen & Mary Clements	David & Marlene Persky		Jack Thompson
Michael Cloonan			James Thompson
Lance Colwell			Newt & Willa Trevens
Falmouth Jewish			Jerome & Arlene Tuck
Congregation			Turtle Household
Grace Cotter-Regan			Angela Wakefield
David Coyne			Manfred & Amy Wiegand
Jeanette Cunniff			Bill Wilkinson
Shadi Daher			Mary Ellen Woodman

Compassionate Guides (\$250 and over)

Leonard Adelson	Alissa Bronsteen	Eileen Comstock	JoAnn & Michael Fishbein	Keith Johnson	Jane Andrew, Miriam and	William Munro	Lorna Roderick
Bruce Alpert	Jason Brown	Karen Constantino	M. Patricia Foley	Hugh Jones	Edwin Mackenzie	John Murphy	Christopher Rushton
American Risk	David Brown	Kathy Contois	David Foley	Kieran Joshi	Steven Mahoney	Traci Neptune	Jason Russell
Andrew Stevenson	Stephanie & Peter Bruan	Rina Countryman	Cynthia Fontaine	Allen Kamer	Michael Manca	New England Wheels, Inc	Wendy Russo
Ellen Wingard & Associates	Gregory Brusseau	Sara Cross	Robin Fox	Rein Kampersal	Heather Martin	Kenneth & Janet Nicalek	Tamara Khoury Saba
Sheila Babine	Leslie Callanan	Jodi Cross	James Gabriel	William Kane	Bruce & Denyse Martin	John O'Connell	Jim & Nancy Scannell
David Ball	Endodontic Associates of Cape Cod	Candia Cuddy	Tom & Joan Gaidimas	Beth Kerner	Gay Mayer	Gisele O'Hara	Shelley Schaefer
John Bargh	Roy & Donna Carlin	Cataldo Custom Builders	Darian Gambelli	Daniel Koerwer	Peter McAvinn	Kathleen O'Keefe-Kanavos	Natascha Schill
John & Helen Barnes	Christopher Cazault	Christian Cuzick	Robert Garber	Pamela Kondylis	Deidre McCarthy	Judy O'Neill	Patricia Shanley
Teresa Barous	Jacqui Chapman	Danvers Motor Company, Inc.	Charles Gazarian	Steven Krammer	William McFarland	Matt Ottmer	Clinton Sharples
Debra Basler	Jennifer & Christopher Charland	Dave Dinger Ford Inc.	Maryann & Charlie Girardi	Steven Kumin	Bill & Susan McMahon	Christopher Patton	Malcolm & Nicole Silverman
Baystate Ford, Inc.	Gary Chinn	Matt Davis	Sam Goodrich	Kimberly Krawshuk	Ralph Medjuck	Bradley Pearlman	Michael & Carol Sleeper
John & Jean Begg	John & Karen Ciccone	David DeBello	Tracy Greene	Stephanie Krebs	Kelly Melanophy	Kathleen Porkka	K. Smith
Leonard Bello	Bob Cipriani	Edward & Janet D'Entremont	John Gushue	Steven Krammer	Jose Melendez	Pilgrim Congregational Church	Joe & Mary Spadaro
Matthew Benjamin	Jack Civilinski	Devin Doherty	Ann Hallett	David Kurzman	Merrimack Valley Oral Surgeons	Adam Portnoy	Brian & Maryann Storms
Joseph Berardo	Jan Clare	Craig Duquette	Margaret Hansen	Adib I. Lakis	Ann Mikula	Lorraine Quinn	Nicole Sullivan
Diane Bernstein	Merrill Cohen	Lisbeth Eastman	William & Catherine Heald	Bill & Sue Landay	Eileen Miskell	Marc T. Rasich	James Marchetti & Susan Shepard
Ronda Bertrand-Robbins	Marilyn Cohen	Excel Gymnastics	Paul Helfrich	David Lane	Thomas Moore	Scott & Elizabeth Ricketson	Anne Tangen
Thomas & Rebecca Bertle	Bombay Cartage Company, LLC	Lucy Fenn	Virginia Hodge	Luisa & Steven Laudadio	Mary Ellen Morency	Andrew Peach	The Pampered Chef
Kathleen & Marc Bliss	Complete Building Services	Cheryl Ferris	John Imber	Susan Ledoux	John Morgan	David & Marlene Persky	Norman Thomas
Booth/Waltz Enterprises, Inc.		Jacquie Fink	Lisa Jameson	Martine Bertrand Leiser	Carolyn Luond		
Megan Brennan			J-Biz, Ltd.	Ken Ludwig			
			Catherine Jerome	Carolyn Luond			