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.
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 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 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!
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.

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.
Leadership Gift Club

We would like to recognize the members of our Leadership Gift Club that have grown from 61 members to 93 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
Joseph Bedoskin
Researching
Bob Baisden
Peter & Maria Barrett
David Basini
Carol Barrett
Frederick Biggum
Steven Boland
Rita Bracey
David Burfer
Mike Cabotone
Dianne Cattaneo
Mary Cassi
Joe D'Elia
Sarah Delina
John Denen
Ashley Despres
Franklin Deyter
Daniel & Alisa Doctoroff
Thomas Driscoll
Dos Ninos, Inc
Brian Doyle
Joe Faber
Robert & Joanne Fallon
Richard & Nancy Flynn
Meryl French
Johanna French-Nadler
David & Andrea Garger
Linda Glover
Lucy Hackney
Jean Haffnererer
Elizabeth Heald Arthur
Susan Heidbreder
Kris Hensley
Bill & Audrey Hogan
Rupa & Egidio Houssiaud
Rudy Hoj
M. Domnios Anoss
Alex Joss
Patricia Kennedy
Richard Kenney
Megan Kutch
Audrey & David Ladd
Peter & Deborah Lann
Valerie Lester
Greg Lowry
Malagu M. Lilly
Rachel Liptan
TRU Services
Samuel & Judith Losruo
James McConnell Clark
Michael Melnachain
Medford St. Theatre Inc
David & Beth Melther
Albert & Katie Mergen
Robert & Linda Merk
Rafael Miranda
Christine Mosholder
Rembrandt & Pen Murphy
Meghan Murphy
Erik Nish
Susen Nemetz
Erin Nutter
Patty O'Keefe
Oxys Hotel
Arthur Page
Jaret & Alfred Paliarelo
Steve Petmann
Collin Roche
Jay & Laurie Roche
Germaino & Tilla Romano
Richard Roy
Barry Roy
Ronnie Sanders
George Scangos
Wendy Scholos
Mary Ellen Sherby Reed
Ros & Kathleen Sherbrook
Linda Simonetti
Wayne & Patricia Smith
Maria Stara
Lauret Swett
Jesse Tait
Frederic Taylor
Tara Thibaudeau
Maureen Towle
Maurene Trippino
Jerome & Anne Trippiano
Nancy Vaughn
Maureen Yaco
Thomas & Robin Wheller
Joe Whitmy
Douglas Williams
Chad Wieder

Compassionate Vanguards ($500 and over)

A-1 Concrete Cutting & Construction
Carol & Marc Abrahams
Michael & Marie Angelini
Andrew Baran
Pamela Barry
Bowers & Family Fund
 Hank & Nancy Benjamin
Theodore Beriau
Thomas Biggum
Francis & Margaret Bowles
John & Susan Franco
Brazill's Package Store
Teresa Brennan
Colleen Bringman
John & Barbara Burns
Marie Caccio
Cap's Carlot's Restaurant
Robert Catalano
Sharon & Eugene Chavairin
Dennis Clarke
Stephen & Mary Clements
Michael Colon
Lance Connell
Falmouth Jewish Congregation
Grace Corret-Getter
David Cuyne
Jeanette Coutif
Shadi Daher
E. Victoria Davis
Glen & Jean Dawson
Hermine Doctoroff
Scott Donnelly
Melody Dorfman
Nathanial Dunn
TA. Edwards
Thomson Eckenlocher
Harvey M. Eisenberg
Evans Forbes
John Freitas
Lora Gallavita
Liang-Shang Guan
Robert Garber
William Gleeson
Lisa Grover
Richard Hackel
Timothy Harris
Hotel Malore and Babarba Restaurant
Flayl Jowell, III
Bill Judge
Marlene Julian
Tatiana Kamenyava
Elizabeth Kenisger
Peter King
Paul Lawrence
Christopher & Rebecca Leonard
Francis & Victoria Lowell
Anders Lundstrom
Michael Maclean
Edward Madden
William Maloney
Robert Mancuso
Andrea Marc-Aurele
The Marc J Rebovich Trust
Linda Marich
Philippe & Marguerite Maukin
Daniel McCluskey
Mr. & Mrs. David W. McGaw
William & Linda McLaughlin
Maureen Michael
Michael Michael
Theresa Michael
Michael Michael
Jose Mitchell
Merily Moyhun
Miriam Nepris
Terry Oatley
Conectta & John Oasen
Gordon & Lori O'Dracs
Juliette Palazzo
Anatasias Pafarastas
Paul Chen
Andrew Pach
David & Marlene Perdew
Central MA PHCC
Association
Michael Phelps
Glen Pierce
Wendell & Melissa Pitman
Podska Family
Reed & Wight
Eric & Melissa Roeter
Joseph Santangelo
Eilen Scott
Ryan Shafferman
David Shil
Anthony Spadaro
John & Nancy Spanbauer
William T. Speck
Steven Stoppel
Michael Stein
Gary & Deborah Stein
Asia Strategies
Robert H. Studley
Jack Thompson
James Thompson
Nest & Willi Tevrenn
Jennifer & Arlene Tuck
Turtle Household
Angela Wakerfield
Manfred & Amy Wiesand
Bill Wilkinson
Mary Ellen Woodman

Compassionate Guides ($250 and over)

Leonard Adelson
Bruce Albert
American Risk
Andrew Stevenson
Elli Wong Wigard &
Asociates
Sheila Balint
David Ball
John Barrie
John & Helen Barnes
Teresa Baruro
Dennis Becker
Bill Wite Ford, Inc.
John & Jean Begg
Leonard Bello
Matthew Benjamin
Joseph Berlando
Diane Bernstein
Ronda Buxton-Robbins
Thomas & Lauren Bingle
Kathleen & Marc Bless
Boroud & Williams Enterprises Inc
Megan Brennan
Alisa Brownson
John Brown
David Brown
Stephanie & Peter Brown
Grigory Brasseau
Leslie Callahan
Endocrine Associates
of Cape Cod
Roy & Donna Cahn
Christopher Carezutti
Jacqui Chapman
Jennifer & Christopher
Charland
Gary Dean
John & Karen Ciccione
Bob Cipani
Joseph Cipriano
Ian Clare
Merrill Cohen
Marilynn Cohen
Bomash Cartage
Company, LLC
Complete Building Services
Eileen Comstock
Karen Constantino
Kathy Contois
Robert Couts
Sara Cross
Jodi Cross
Candie Cuddy
Caralado Custom Builders
Christian Carick
Dana Motor Co., Inc.
Doe Dinger Ford Inc.
Matt Davis
David DiBello
Edward De Janet
Margaret Hansen
William & Catherine Hald
Paul Helfrich
Virginia Hodge
John IMber
Lisa jamison
B.J. Lee, Ltd.
Jeanette Jerome
Keith Johnson
Hugh Jones
Karlan Joshi
Allen Kimer
Edward Kimer
Margo Lamart
William Lamart
Bob Landis
John Landis
Mary's Cupboard
Bill & Susan Laundoff
Sara Laskoff
Steven Landis
David Lane
Lisa & Steven Laundoff
Susan Ledoux
Martine Bertrand Leiser
Ken Ludwig
Carolyn Lussard
Lettuce & Ewan Mackenzie
Bruce & Denny Martin
Cory Mayer
Peter McAvinn
Dede McCarry
William McFarland
Bill & Susan McMahon
Gina McCullough
Chris McDaniel
Robert Mcelroy
Kathy McDevitt
Kelly Marlin
Merrin Martin
James Marlin
Elena Mitchell
Thomas Moore
Mary Ellen Moteney
John Morgan
Mary More
William Munro
John Murphy
Traci Nearne
New England Wheel, Inc.
Kenneth & Janet Niclak
John O'Connell
Gaelie O'Hall
Kathleen O'Keeffe-Cavanaugh
Judy ONeill
Matt Otter
Christopher Patten
Bradley Pizzuti
Kathleen Puckett
Plygm Congregational
Church
Adam Parnsey
Lorraine Quinn
Marc T. Raisch
Joseph Reilly
Scott & Elizabeth
Ricketson
Anne & Philip Robberson
Lorna Reddie
Christopher Rasoun
Jason Russell
Wendy Raso
Tamara Khoury Saba
Jim & Nancy Scannell
Shelley Schaefer
Narana Schill
Pamela Stanley
Cynthia Shapley
Malcolm & Nicole
Michael & Carol Sleep
K. Smith
Joe & Mary Spadaro
Brian & Maryann Storms
Nicol Sullivan
James Marchetti & Susan
Shepard
Anne Tangen
The Pamped Chef
Norman Thomas

FALL 2013

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!