

2013 New Balance Falmouth Road Race

Just when we think it can't get better – it does! CCALS surpassed our goal of raising \$300,000 at Falmouth last year and has set our sights higher in 2013 with a goal of \$350,000. This is the 14th year that Compassionate Care ALS supporters will be running in the Falmouth Road Race. Running is not the only way to support us; you can sponsor a runner, lead a team or just come down and cheer all the CCALS runners on. Our website has been redesigned and it is up and running! If you or someone you know would like to join the more than 100 runners or 40 team leaders please visit Falmouth.ccals.org and sign up today!



New Program Offerings: Helping Families Navigate the Maze of Health Insurance



Erin MacDonald MSW, LICSW
Senior Family Care Liaison

Conquering the dizzying maze of paperwork and coverage options one encounters when first exploring the world of state health insurance is not an attractive endeavor. Individuals living with ALS and other terminal illnesses need to expedite the application process in order to access necessary services and equipment.

Luckily there are provisions in place that allow individuals that meet certain requirements a fast track to coverage. The difficulty is knowing how to make it all happen.

Last year, CCALS staff member, Erin MacDonald participated in a 12 week training program with Massachusetts Executive Office of Elder Affairs called Serving the Health Information Needs of the Elderly (S.H.I.N.E.). This program trains volunteers to assist elderly and individuals with disabilities in understanding their health care options.

As a S.H.I.N.E. certified counselor, Erin is able to advocate on our families' behalf to see that applications are expedited and everyone is receiving all benefits they are entitled to. She has already assisted nearly 100 families with issues around MassHealth and Medicare coverage and in most cases has been able to expedite the application process. She recently helped a family get approved in 15 days, after they had spent months trying to figure out the system on their own.

With the addition of this service we are closer to our mission of providing a holistic and multi-faceted approach to ALS care. While Erin has been helping many of our families with insurance needs, her impact extends far beyond those needs.

"I love that Erin has helped me so much and even when I think I am at my last nerve she saves me. She has a lot of contacts and helps me understand how to get what I need and what to expect. My husband was given his diagnosis by himself and I was not there for him at the time but Erin came to my house, held his hand and comforted us and we all cried together."

– CCALS Family Member

Thanks to Erin, this family does not have to spend precious time trying to navigate Mass Health. They know they have an advocate who will not only go to bat for them regarding insurance coverage, but is also able to tend to physical and emotional issues that arise on their journey with ALS.

These kinds of experiences and this type of support are what define our organization. Our hope is that our families are able to pick and choose our services that best suit their specific need. For some, support may take the form of a passive-patient lift or a scooter, while for others it may be emotional support and having someone who can truly listen and be by their side throughout the journey. As we grow we are doing everything we can to prepare ourselves to meet an expansive array of requests.

In Memory Of...

Veronica Blakely, Chelsea, MA
Patricia Brinkmann, Weymouth, MA
Barbara Caldwell, Middleton, MA
Larry Callahan, Georgetown, MA
Charlie Canon, Brainard, MN
Joseph Ceurvels, Hanover, MA
Jeannine Civilinski, Wrentham, MA
Zenas Crocker, Vero Beach, FL
Mary Decaro, Gloucester, MA
Dwight Dellert, Ashley Falls, MA
James Elias, Green Harbor, MA

Janet Ferreira, Acushnet, MA
Timmy Guidry, Estherwood, LA
Hazel Hasseltine, Centerville, MA
Donald Heald, West Roxbury, MA
Laurence Heidebrecht, Saugus, MA
Robin Hinceman, Peabody, MA
Jim Kellett, Mendon, MA
Alice Kilduff, Kingston, MA
Dale Landess, Lynnfield, MA
Susan Ledoux, East Bridgewater, MA
Joseph Le Page, Weymouth, MA

Elisa Limone, Medford, MA
Paul Lister, Leominster & Falmouth, MA
Charles Marquardt, Woburn, MA
Danielle Martin, Pocasset, MA
Alan McDonald, Rockland, MA
Muriel McGee, Natick, MA
Ed McKenney, Norwell, MA
John Morales, Jr., Denver, CO
Judy Morris, Haverhill, MA
Susan Murphy, Bryantville, MA
David Noyes, Haverhill, MA

Michael Olenik, Newburyport, MA
Joanne Paquette, Worcester, MA
Paul Seaver, Milford, MA
Don Simonini, Winthrop, MA
Richard Traubner, New York, NY
Laura Tuttle, Raynham, MA
Sher Bano Usmani, Northboro, MA
Robert Weiss, Oak Bluffs, MA
Dorothy Wendell, Sandy Springs, GA
Lauren Wik, Redwood City, CA

Compassionate Cares

Planned Giving Focus: Arthur and Mary Baker

Since the launch of the Gordon T. Heald Society, the Planned Giving Program of CCALS, a number of individuals have included CCALS in their wills. Art and Mary Baker were two of those connected to CCALS who were happy to add us to their legacy of giving.

Their Story: Arthur and Mary met in Tripoli, Libya where he was stationed by the Air Force. Mary's father happened to be Arthur's Colonel and when she came to visit on summer vacation from university in Germany it was love at first sight! After courting Mary throughout Europe and the Mediterranean, Arthur proposed in Italy six months after they met. They began their "lifelong honeymoon" on August 9th, 1969 when they were married in Falmouth, MA.

Passions: Travelling together around the world, and sailing around Cape Cod.



Career: After returning from abroad, Mary and Arthur worked together as partners in both love and business for nearly 40 years at Arthur's Optometry practice in Falmouth, MA, where Arthur saw patients and Mary managed the office.

Diagnosis: Mary has had MSA, Multiple System Atrophy, for approximately 5 years.

Experience with CCALS: As MSA is very similar to ALS, Arthur learned of CCALS through the community. They have been visited by CCALS founder and Executive Director Ron Hoffman and were pleased to learn that they have the opportunity to access such personalized assistance.

Why Planned Giving?: Arthur's mother passed away after an eleven year struggle with ALS, and combined with Mary's experience with MSA it was clear that CCALS was something Arthur and Mary wanted to include as part of their legacy. They also wanted to support the community, and are grateful for all the love and care they have received through CCALS. When asked why they have decided on planned giving, Arthur said, "We had such a wonderful life, it is the least we can do."

With the support of our friends and families, CCALS is able to provide high quality services to ALS clients in need. We continue to appreciate the generosity of our donors, and your contributions make all the difference. For information on how you can include CCALS as part of your planned giving visit www.ccals.org/planned-giving.php.

Friends of Bob Pierce Benefit

Biogen Idec employee Bob Pierce has been living with ALS since 2010. Friends and co-workers of Bob supported by Biogen Idec. worked with CCALS to put on the Friends of Bob Pierce Benefit. The event was attended by more than 300 people and raised more than \$120,000 to support CCALS. Bob, his wife Christine and his daughters Katy, 11, and Abby, 9 pictured right, were on hand to celebrate at the event which was held at Biogen corporate headquarters in Cambridge, MA on January 17th.



Thoughts From Ron...

At times in life, we are afforded the opportunity to meet extraordinary people. In this regard, I have been very fortunate. I am excited to share with you a new training program created by one of these people, Roshi Joan Halifax. She has developed this training, G.R.A.C.E., through her years of experience as the founder and abbot of Upaya Zen Center in Santa Fe, NM and as founder of the *Being With Dying* Program for doctors, nurses, and other healthcare professionals. I consider Joan to be not only a teacher and a mentor, but also a colleague and friend. Her abundance of work has had a profound impact on those in healthcare, as well as countless thousands around the world. I invite you to explore her latest offering, which I believe to be of extreme importance to us all.

In Service,



Ron Hoffman,
Founder &
Executive Director

Practicing G.R.A.C.E.: How to Bring Compassion Into Your Interactions With Others



G.R.A.C.E. Training:
www.upaya.org/programs/event.php?id=1010

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By Roshi Joan Halifax, PhD

Compassion can change your life. Developing our capacity
Compassion can change your life. Just ask Dr. Gary Pasternak, the medical director of Mission Hospice in San Mateo, Calif.:

“I’m up late admitting patients to the inpatient hospice unit. Just when I think I’m too old for these late nights without sleep, a person in all their rawness, vulnerability, and pain lays before me. As my hands explore the deep wounds in her chest and my ears open to her words, my heart cracks open once again.... This night, a sweet 36-year-old woman with her wildly catastrophic breast cancer speaks of her acceptance and her hope for her children, and she speaks with such authenticity and authority. Her acceptance comes to me as the deepest humility a person can experience. Then again, once again, I remember why I stay up these late nights and put myself in the company of the dying.” (From *“Humanities: Art, Language and Spirituality in Health Care”*)

Compassion may be defined as the capacity to be attentive to the experience of others, to wish the best for others, and to sense what will truly serve others. Ironically, in a time when we hear the phrase “compassion fatigue” with increasing frequency, compassion as we are defining does not lead to fatigue. In fact, it can actually become a wellspring of resilience as we allow our natural impulse to care for another to become a source of nourishment rather than depletion.

Developing our capacity for compassion makes it possible for us to help others in a more skillful and effective way. And compassion helps us as well. Findings from recent research studies suggest that compassion plays a significant role in reducing physiological stress and promoting physical and emotional well-being. (For a collection of studies and articles on the benefits of compassion, see this list from the Center for Compassion and Altruism Research and Education, based at Stanford University: <http://ccare.stanford.edu/research/peer-reviewed-care-articles>.)

For nearly 40 years, I have been exploring ways to bring compassion into our medical system and particularly into the work of caring for the dying. These efforts came to fruition in 1994 with the founding of the Being With Dying (BWD) professional training program. While the BWD program is based at Upaya Zen Center in Santa Fe, N.M., I have been honored to share this training with thousands of health care professionals throughout the world.



Wayne & Eileen Harris

For many years, our interdisciplinary team of distinguished health care leaders and educators, including Dr. Pasternak, Dr. Tony Back, and Dr. Cynda Rushton, has worked together in the BWD training, bringing wisdom, sound practicality, and applied compassion to this powerful program in order to transform the quality of countless lives – and deaths.

Recently, in response to the need for tools that can help prevent burnout and secondary trauma in clinicians, I developed the G.R.A.C.E. model. This practice offers physicians, nurses, and others working in stressful situations a simple and efficient way to open to their patient’s experience, to stay centered in the presence of suffering, and to develop the capacity to respond with compassion.

This model has worked so well that we are now adapting G.R.A.C.E. so that it can be used in other settings, including education, corrections, and other relationship-based service endeavors.

G.R.A.C.E. is a simple mnemonic that is easy to remember – an important quality when we are in the midst of a stressful interaction or situation. Recalling the elements of G.R.A.C.E. allows us to slow down and be more mindful and aware in the process of interacting with another so that compassion can arise.

Practicing G.R.A.C.E., continued

It's quite possible to use G.R.A.C.E. in your everyday interactions and allow it to help you cultivate more compassion in your own life. Here's how to do it.

The G.R.A.C.E. model has five elements:

1. **Gathering attention:** focus, grounding, balance
2. **Recalling intention:** the resource of motivation
3. **Attuning to self/other:** affective resonance
4. **Considering:** what will serve
5. **Engaging:** ethical enactment, then ending

You can use the following detailed description of each element as a script for your own G.R.A.C.E. practice:

1. Gather your attention.

Pause, breathe in, give yourself time to get grounded. Invite yourself to be present and embodied by sensing into a place of stability in your body. You can focus your attention on the breath, for example, or on a neutral part of the body, like the soles of your feet or your hands as they rest on each other. You can also bring your attention to a phrase or an object. You can use this moment of gathering your attention to interrupt your assumptions and expectations and to allow yourself to relax and be present.

2. Recall your intention.

Remember what your life is really about, that is to act with integrity and respect the integrity in all those whom you encounter. Remember that your intention is to help others and serve others and to open your heart to the world. This "touch-in" can happen in a moment. Your motivation keeps you on track, morally grounded, and connected to your highest values.

3. Attune by first checking in with yourself, then whomever you are interacting with.

First notice what's going on in your own mind and body. Then, sense into the experience of whom you are with; sense into what the other person is saying, especially emotional cues: voice tone, body language. Sense without judgment. This is an active process of inquiry, first involving yourself, then the other person. Open a space in which the encounter can unfold, in which you are present for whatever may arise, in yourself and in the other person. How you notice the other person, how you acknowledge



Andy and David Garber

the other person, how the other person notices you and acknowledges you... all constitute a kind of mutual exchange. The richer you make this mutual exchange, the more there is the capacity for unfolding.

4. Consider what will really serve the other person by being truly present for this one and letting insights arise.

As the encounter with the other person unfolds, notice what the other person might be offering in this moment. What are you sensing, seeing, learning? Ask yourself: What will really serve here? Draw on your expertise, knowledge, and experience, and at the same time, be open to seeing things in a fresh way. This is a diagnostic step, and as well, the insights you have may fall outside of a predictable category. Don't jump to conclusions too quickly.



Ed & Barbara Mahoney

5. Engage, enact ethically. Then end the interaction and allow for emergence of the next step.

Part 1: Engage and enact. Compassionate action emerges from the sense of openness, connectedness, and discernment you have created. This action might be a recommendation, an open question about values, or a proposal for how to spend the remaining time with this person. You co-create with the other person a dynamic, morally grounded situation, characterized by mutuality, trust, and consistent with your values and ethics; you draw on your expertise, intuition, and insight, and you look for common ground consistent with your values and supportive of mutual integrity. What emerges is principled compassion: mutual, respectful of all persons involved, and as well practical and actionable. These aspirations may not always be realized; there may be deeply-rooted conflicts in goals and values that must be addressed from this place of stability and discernment.

Part 2: End the interaction. Mark the end of the interaction with this person; release, let go, breathe out. Explicitly recognize internally when the encounter is over, so that you can move cleanly to the next interaction or task; this recognition can be marked by attention to your out-breath. While the next step might be more than you expected would be possible or disappointingly small, notice that, acknowledge what transpired. Without acknowledgement of what unfolded, it will be difficult to let go of this encounter and move on.

We live in a time when science is validating what humans have known throughout the ages: that compassion is not a luxury; it is a necessity for our well-being, resilience, and survival. My hope is that the G.R.A.C.E. model will help you to actualize compassion in your own life and that the impact of this will ripple out to benefit the people with whom you interact each day as well as countless others.