

# COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND

LEADING A NEW VISION IN ALS CARE SINCE 1998

## Compassionate Cares

SPRING 2014

### Welcome to our Spring 2014 Newsletter

This issue of Compassionate Cares focuses on stories of *resiliency*. In reading about CCALS Founder and Executive Director Ron Hoffman's life story, to Jon Imber's painting, to the many friends and families holding events to benefit the mission of CCALS, you will soon see how ALS brings out the caring nature of our community.

### Determined to Paint:

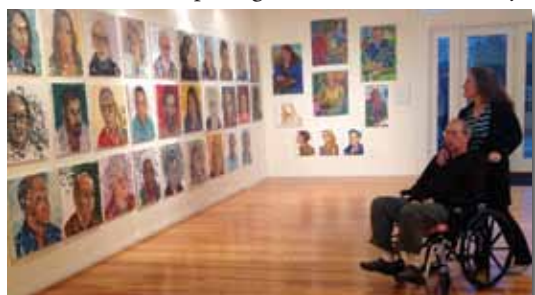
### Renowned Artist Jon Imber Continues to do What He Loves

Jon Imber, whose work has been shown at the Museum of Fine Arts in Boston as well as in other major institutions across the US, is a determined, successful painter. His creative spirit has allowed him to rise above the challenges he has faced after being diagnosed with ALS in September of 2012. Imber has had to shift the focus of his paintings as well as his technique to compensate for the loss of mobility. With the progression of ALS he has switched focus of his paintings from his specialty of landscapes to portraits of the friends, family, and visitors who support him.

Physically, Imber has had to overcome ALS's challenges twice by switching his painting technique. "Because of all the changes," Imber says, "I have to invent new ways of getting paint on to the canvas." When he could no longer control his right hand, Imber was forced to reassess the way he approached painting. "Now, an assistant mixes my paint, places the brush in my hand and gets me up and holds me. The size of my canvas keeps shrinking and my diminishing energy has shrunk my painting time."

He successfully switched to his left hand, and soon after made yet another change when he no longer had full control over either hand. The new methods to deal with this challenge involve extensions for brushes, and a technique of impulsive thrusts that result in brushstrokes.

Despite all of the improvisation, some things never change. Imber notes that "In some ways getting ALS has changed my artwork completely, but other things have stayed the same. I still try to make the most surprising and beautiful work every time I paint."



Jon and Jill view some of the portraits he started painting in August of 2013

portraits are spare, I do not waste any energy. I trust myself. Now the real subject is energy... or harnessing my energy."



Jon Imber and his wife, Jill Hoy

Imber says that CCALS is one of the reasons he is able to continue painting, and to accept his diagnosis. "CCALS has helped me in every aspect of life. I am not scared. Ron's knowledge and understanding and the compassion with which he shares, and teaches has made my time with ALS manageable, and at times a memorable journey. I don't see how I could have worked so steadily and with daily success without CCALS's huge support."

When asked what counsel he would give to someone recently diagnosed with ALS, he said "My counsel would be the same thing I tell myself every day- make the most exciting, most challenging, most beautiful painting that is honest and true. That takes forever to learn."

To learn more about Imber, check out the film *Jon Imber's Left Hand* made by Maine-based director Richard Kane. This documentary dives into Imber's journey with ALS and painting, and also portrays the relationship between he and his wife, painter Jill Hoy. To view Imber's work, visit the *Carry On* exhibit at the Danforth Museum of Art in Framingham, MA now through May 18th. It is an astounding exhibit spanning his figurative work in the early 80's through the present. Imber will also be featured in an exhibition, *Jon Imber: Force of Nature*, a 10-year retrospective at the Center for Maine Contemporary Art, which will run May 24-July 6, 2014. This will feature the progression of his work, including recent paintings. To learn more visit [www.jonimber.com](http://www.jonimber.com).

## Thoughts From Ron...

In a hard winter in which we lost so many friends, I reflect on the many examples of resiliency I see every day.

My friend Matt Bruce, so full of life, even with the extraordinary challenges he faced, truly displayed his commitment to “never give up.” He not only yielded to the circumstance but faced the reality of his mortality in a way that I’ve not often seen, with a calmness and acceptance as though he was a spiritual master.



Ron Hoffman,  
Founder &  
Executive Director

My friend Wayne Harris’ wife Eileen describes Compassionate Care ALS’s commitment to those living with ALS as “CCALS will walk with you, as Ron often says ‘side by side.’” Wayne’s friends embraced this philosophy during his journey. On the day of the Falmouth Road Race, when it seemed Wayne would be stranded at home without a wheelchair, friends showed at 4 AM to carry him downstairs, and got him to Falmouth for the day. His friends continued to walk beside him till his passing in January.

My friend, master painter Jon Imber continues to reflect this resilience on a daily basis through his painting. I have been so blessed to have crossed path with you, and your wife master painter Jill Hoy and your son Gabe. To me, your talent as one of the finest painters in the world parallels your talent as a man living a full, complete and conscious life within the confines of the disease we know as ALS.

Equanimity is defined as mental calmness, composure, and evenness of temper, especially in a difficult situation. In addition it is the stability of mind that allows us to be present with a good and impartial heart no matter how beneficial or difficult the conditions; being present for the sufferer and suffering in a balanced way; maintaining spacious mindfulness in the midst of life’s changing conditions. When people ask how I continue to do what I do, there is certainly not one answer but this term comes close. Equanimity may be a hard concept for some; it is a very real concept for me. It is one that I certainly have not mastered, yet strive to embody.

Matt Bruce, Wayne Harris, Jon Imber. These three masters lived and living their remarkable lives in remarkable ways. You taught me, your families, your communities so very much... how to live, how to love, and how to die. I honor you, I bow to you.

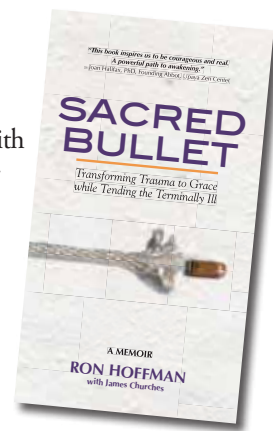
Yours in Service,

  
Ron

## CCALS Executive Director Publishes *Sacred Bullet*

This inspirational memoir by CCALS founder and Executive Director Ron Hoffman sheds light on living with grace in the face of mortality. Beginning with the story of one of his many childhood traumas, Ron details the complexities of his early life, and how he continued his journey to becoming a national leader in the holistic care of people living with ALS. *Sacred Bullet* documents the lessons and knowledge gained by Ron through both his personal experience, as well as through the stories of those diagnosed

with ALS. Meredith Little, co-founder of the School of Lost Borders, says *Sacred Bullet* “support[s] individuals, families, and communities in the ‘art of dying.’ It brings definition to the word healer.” *Sacred Bullet* can be ordered at [www.sacredbullet.com](http://www.sacredbullet.com) or through [www.ccals.org](http://www.ccals.org).



## Upcoming CCALS Events

As the warmer weather finally approaches, we hope you will join us for a number of fun events that will support our important work with ALS individuals and families! These events include:

### The 18th annual “Johnny O Night”

Music, raffles and auctions highlight an event that salutes John Olivari or Johnny O, an incredible human being who succumbed to ALS. Over the past 17 years this event has raised more than \$175,000 for ALS charities and CCALS is once again the recipient. Johnny O Night is May 3, 2014 at the Polish American Citizens Club on Kendall Pond in Gardner from 7pm to midnight.

### Añejo Mexican Restaurant and Cantina’s 4th annual Cinco de Mayo celebration

Local Falmouth restaurant Añejo will donate proceeds from sales on May 5,

2014. Come join us for good food and music as we benefit for the second year in a row from this daylong celebration.

### Movin’ with Compassion

Come Zumba the day away at the Gus Cauty Recreation Center in Falmouth on May 10th. Raffles and an auction will be held as well.

### The 3rd annual David’s Swim

This mile and half-mile swim honoring local dentist and friend David Garber will be held on August 9 with a rain date of August 10 beginning at 8am. Sign up to swim at [www.davidsoldsilverswim.com](http://www.davidsoldsilverswim.com).

These are just a few of the highlights of what we hope will be a fun spring and summer for the CCALS community. For a complete listing of our upcoming events, please like us on Facebook or visit [www.ccals.org](http://www.ccals.org).

## In Memory Of...

Marilyn Aldrich, Middleboro, MA  
Christine Allen, Williamsburg, MA  
Celia Alsheimer, Plymouth, MA  
Clara Barrett, Hingham, MA  
Jack Bindig, West Yarmouth, MA  
Barbara Blake, Meredith, NH  
Robert Bossman, Harwich, MA  
Marie Boucher, Gardner, MA  
Kathie Bruce, Dartmouth, MA  
Matt Bruce, Northboro, MA  
Lillian Burnstein, Ormond Beach, FL  
Mary Ann Che, Ronkonkoma, NY  
Robert Cipriani, Wellesley, MA  
Earl Clinton, Framingham, MA

John Coleman, Milford, NH  
Debra Daniels, Dudley, MA  
Reginald Davis, Plymouth, MA  
Mark Dion, Watertown, MA  
Larry Dugan, Somerville, MA  
Eileen Dunne, Medford, MA  
Elizabeth Ferreira, West Wareham, MA  
Claude Fontaine, Arlington, MA  
Janice Gendron, West Brookfield, MA  
Ed Gilfix, Lexington, MA  
Marion Goldberg, Marston Mills, MA  
Wayne Harris, Uxbridge, MA  
David Israel, Newton, MA

Richard Kelley, Watertown, MA  
Helen Grimm Ledger, Southboro, MA  
Stuart Lehman, Mashpee, MA  
Lauren McClellan, Wellfleet, MA  
Carol McCracken, South Yarmouth, MA  
Karen McIver, Abington, MA  
Florence McManus, Weston, MA  
Mary Nagbe, Lowell, MA  
Janet Palmariello, West Roxbury, MA  
Sondra Peskoe, Brookline, MA  
Roger Petrone, Stamford, CT  
Nancy Sampson, Whitinsville, MA  
Clifford Sherman, Plymouth, MA

Donald Simonini, Winthrop, MA  
Sharon Smith, Georgetown, MA  
Bradley Snow, Lynn, MA  
Michael Soullier, Sr. Attleboro, MA  
Daniel Souza, Plymouth, MA  
Ephroyim Stein, Brooklyn, NY  
Stephen Stokes, Westwood, MA  
Elaine Streeter, Hubbardston, MA  
Dick Sundstrom, Westborough, MA  
Keith Taylor, Westbrook, ME  
John Trubiano, Sudbury, MA  
Dale Whitney, Marshfield, MA  
Sharyn Wilk, Cranston, RI



## Cape Cod Curling Club Raises over \$38,000 for CCALS

By Jeanie Yaroch

Compassionate Care ALS was the recipient of over \$38,000 generated by the efforts of the Cape Cod Curling Club members and CCALS volunteers and donors. In accepting the check from curling club president Steve O'Neil, founder Ron Hoffman acknowledged the "extraordinary" efforts of the many participants and volunteers who made the event possible and successful.



Team Oakley



Jenna Weldon throws a stone

Pairing novice curlers, who'd committed to raising a minimum of \$1,000 to field a team, with experienced volunteer coaches from the club, the competition showcased the spirit and camaraderie of curling combined with the gratitude, loyalty, and friendship of many kindred spirits familiar with the challenges of living and dying with ALS.

The winning team was coached by Falmouth's Pete Mitchell and Brigid O'Connor and was made up of Falmouth Airpark residents Bob and Lori Bisbee, Joe Chronic, Roger McDowell, Pete Walsh, and Joan Garner.

Among the competitors was Patty Oakley, whose husband Doug died from ALS in April of 2013. A sizeable and passionate group of Doug and Patty's friends and relatives were on hand, some of them curling and some of them vociferously cheering. "The work CCALS does is unbelievable," Oakley said before leading the audience in a brief, energetic and heartfelt cheer in honor of Doug.

Also competing were brothers Michael and Alex Abrahams of Wellesley, MA, along with friends from childhood and college. Marc Abrahams, the brothers' father, is currently living with ALS and was unable to attend the competition. Although the spirited team joked that they were 2018 Olympic hopefuls, the conversation turned serious when talking about CCALS. "They just facilitate anything imaginable," said Michael. "Ron brings a happiness" into our family situation. "He's a real spark plug," added Alex. Perhaps there was some substance to the Olympic joke, as first-time curler Peter Jennings used the hammer to throw a double take-

out in the final and earn a come-from-behind tie for the team.

In a wheelchair since his diagnosis with ALS in 2010, Ted Beriau and wife Barbara of Osterville found themselves glued to the events on the ice, especially after learning about the wheelchair curling opportunities at the club.

For the Beriaus, CCALS has been "like a family." The couple has received enormous emotional and practical support, such as a lift to facilitate Ted moving from his vehicle to his driveway, a wheelchair designed for bathroom use and a scooter to get around the yard. "All you have to do is make a phone call and they're there," said Barbara.

For veteran curler and long-time club member Paul Ketchum, this event offered the opportunity to blend his love of curling with his love of family. In honor of Ketchum's nephew Todd, who was diagnosed with ALS in 2010, the family put together a team of curlers led by Todd's father Carl and coached by Paul. Todd's three sons, Sam, Toby, and Nevin, battled valiantly as he and his wife Laura watched from the warm room. The family bonds held tight, placing the team in the finals where they finished as runners up.



CCALS Founder and Executive Director accepts a check from Peter & Gretchen Patridge of the Cape Cod Curling Club for over \$38,000

## Falmouth Road Race: Photo Contest and Registration

Spring is fast-approaching and the Falmouth Road Race sign-up is open! Ready your sneakers and gather family and friends for the race day, Sunday, August 17th at 10 AM. This year's goal is to raise \$300,000 to support CCALS's programs and services.

This year we are adding a new aspect to our participation in the FRR. We want to give everyone cheering on the sidelines a chance to get involved by holding a Falmouth Road Race Photo Contest! CCALS supporters, clients, and families will be acknowledged for submitting their best photos of CCALS runners/fans taken before, during, or after the race. This is a great opportunity for non-runners to contribute to CCALS in a unique way.

The winner's photo with photo credit will be featured in the Fall Newsletter and may be used for the 2015 FRR Brochure. The winner will also receive a gift certificate to Añejo.

If you don't win, don't sweat it. Runner-up photos will be used to create a collage, and will also be featured on the 2015 FRR website so that your shots can be enjoyed by the CCALS community.

Photo submissions will be accepted starting the day after the race (August 18th) through September 30th, 2014. And don't fear – if you have too many great pictures to choose from, we'll ease the pressure by allowing each individual to submit up to three photos. Photos can be emailed to [ted@ccals.org](mailto:ted@ccals.org).

So get your cameras, and get ready to take aim. We can't wait to see you there on August 17th, 2014.



These could be your photos!

## Volunteer Spotlight

Extraordinary CCALS Volunteer Ann Ellis is responsible for a lot of the behind-the-scenes administrative work in the CCALS office. Ann's first experience with ALS occurred upon befriending Betsy and Gordon Heald while working at the West Falmouth Library in the 1990s. From knowing the Healds, Ann was introduced to CCALS founder Ron Hoffman. "Gordon was the first person I ever knew to have ALS, and it was seeing how much Ron helped him that really prompted me to get involved," Ann says.

Ann ran into Ron at the local post office and offered to help out. "I saw Ron doing some mailings and I was recently retired from the library, so I thought this would be a great, worthwhile organization to dedicate my time to." Since then, Ann has been helping out with all of CCALS' mailings. When asked the best part of volunteering for CCALS Ann says "I have gone to Cultivating Compassion workshops and just watching how Ron deals with people and his compassion for what he believes in is really powerful. I think that shows in the organization." Ann lives in West Falmouth with her husband of 45 years, Stan Ellis. They have two children and three grandchildren.



Ann Ellis and her husband Stan