Volunteer Art Share March/April 2021

Melissa Kulig, Untitled, Paint and Collage, 2020

Melissa Kulig, "Green for a Hopeful Spring," Colored pencils, 2021 (following page)

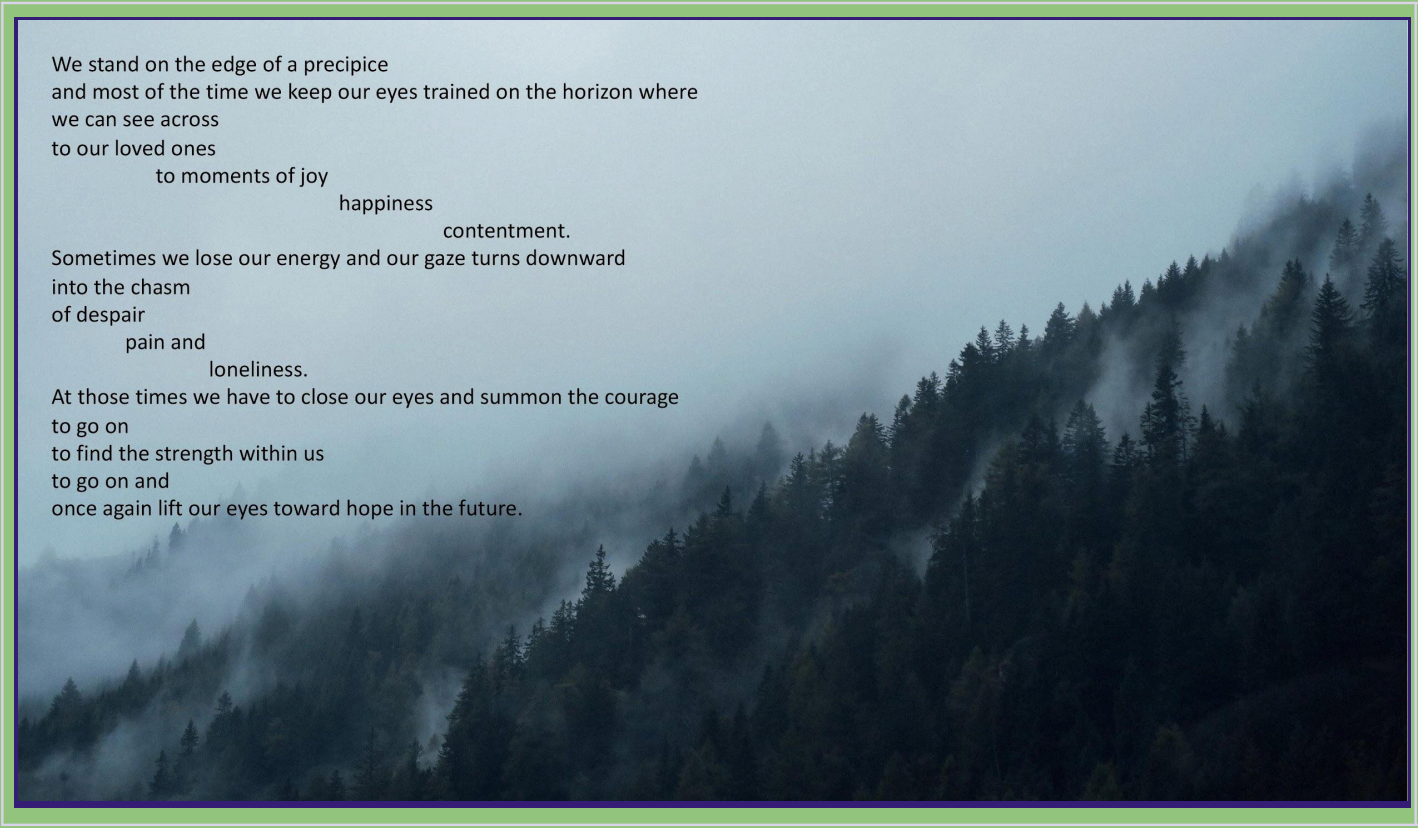
Both Giver and Receivers

I didn't promise to do
I promised to try.
But in my private space
I was going to do
But I fell asleep.
It didn't happen.
I am the sad giver
The sad receiver, both
Ah, but I have disappointed no one and am happy for that.

prc

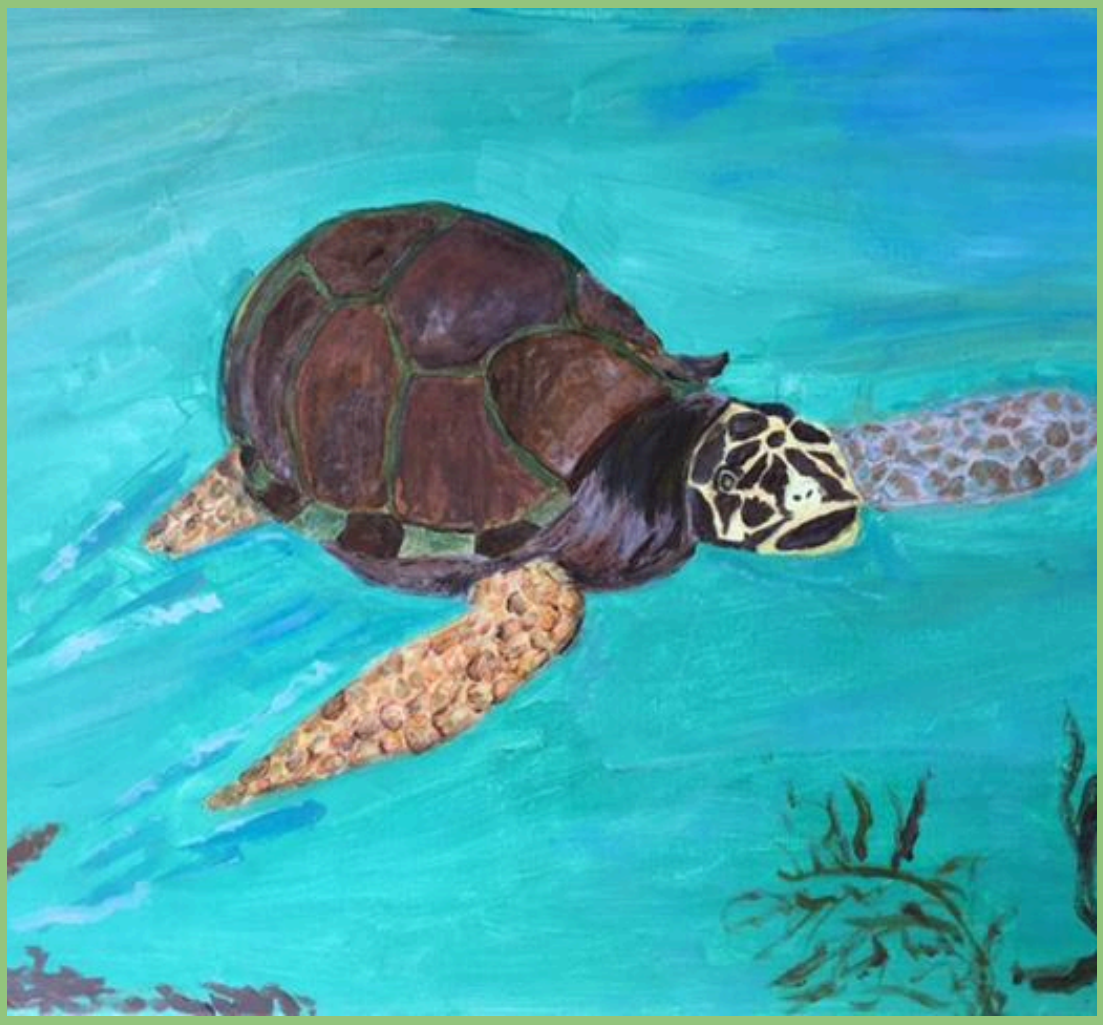
Dyana/Diana, jewelry
Sea-Gems-n-More

https://www.facebook.com/SEA-GEMS-n-More-104709494825734/



Ann McDonald, 2021

Diana Sabella, “Turtle Boy,” Mixed media



Looking Healthy

By Maggie McKenzie II

Looking healthy,
Sounding 'in charge'
Putting on make-up,
Bravado at large.

Simultaneously
Groggy,
Weak
And fatigued,
Fighting the battle
Of CFIDS in me.

Cheerful and upbeat
Always in charge,
Having the answers
Acting out-large.

Underneath, weak,
Exhausted, fatigued
Devastated, weeping
So very diseased.

Friends reach out
To help
I've learned to accept.

Trust no one
Fear all
Under my breath.

MY HERO/YOUR HERO
By Maggie McKenzie II

I am not one for collecting heroes but I make an exception when it comes to one young man whom I discovered in the late eighties when I first became ill with Chronic Fatigue & Immune Dysfunction Syndrome (CFIDS). By 1989 It was becoming more and more difficult for me to work and I began looking about for support. I found one patient support group in West Hartford, Connecticut, run by a wonderful Patient with CFIDS (P.W.C.) Shirley Kiefer, and another well- run group in Manchester, Connecticut run by another P.W.C. who was also a young mother and wife. (Cheryl O'Donnell). In Massachusetts at that time, I discovered a state organization founded by Bonnie Gorman and at that point, being run by their second board president, Gail Kanski and other very active board members. I learned about this new -to- me CFIDS world from these women who were learning themselves from a young man in South Carolina who was quickly leading his state group into becoming the first national CFIDS organization.

He was a successful young banker, with a wife and two kids at the time he became very ill with CFIDS. He was lucky enough to come from a wealthy family. His dad was in the steel business, I believe. He could have just taken care of himself but because both he and other family members were generous and motivated to help others, this new hero I discovered, was helping to form what in short order became an incredibly successful and much needed national organization for our illness, The CFIDS Association of America, Inc.

Its magazine, The CFIDS Chronicle, quickly became THE CFIDS resource. It was just stuffed with the latest information on our illness and it became my lifeline as I began to investigate forming a state group in Connecticut. This national group hired a lobbying firm, setting up our first annual lobbying day, because they recognized that this national problem would require a national political solution. It was not enough to form support groups. If we were to get attention from doctors and our government it was going to require legislation and research dollars.

This hero also set up a research arm to this organization and he and his family donated and encouraged others to donate a great deal of money to support the research of those physicians (like Drs. Paul Cheney, David Bell, Charles Lapp, Anthony Komeroff, etc) who were actually interested in determining the cause and treatment of this illness.

This new national organization was also able to hire on a small staff of healthy employees (again thanks to my hero) to help run this organization. One of these was Kim Kenney who quickly became my hero's right-hand woman. She got used to his habit of calling her with more great ideas very late at night or early in the a.m. mainly because he didn't sleep well. She too quickly cared about what was happening to all of us. It became a powerhouse organization and today much of what this movement does is from copying what that first organization did for all of us.

Eventually as our Connecticut state group got off the ground, several of us put together the very first international study of P.W.C.s sick for longer than ten years. As we got involved nationally, I got to know more and more about my hero's group and was invited to serve on its executive board. Meetings in those days before zoom, met for 5 and 6 hours at a time on the phone.

There were no pictures but every once in a while, someone's microwave would sound off in the middle of the discussion.

The best part of working with the first national CFIDS organization, The CFIDS Association of America, Inc. was getting to know the staff and my incredibly enthusiastic, caring hero and P.W.C. Marc Iverson. Some twenty years later, Marc Iverson's organization was not only the first but also the nation's largest most active charitable organization dedicated to ending CFIDS. As Kim Kenney (McCleary) stated in one of their publications, "The power of one person, one idea, one vision, permeates everything we do and what we stand for. But it is the force of many that will enable us to accomplish our mission and restore good health to people with CFIDS.

All of us need to know about my hero, your hero too, and to thank him out-loud, that early hero who along with MASS CFIDS got us this far.

THANK YOU MARC IVERSON. WE WILL NEVER FORGET YOU OR YOUR CONTRIBUTION

Myrna D. Altsher, “Healing Hand,” Stained Glass, 2020

THANK YOU to all the wonderful artists who shared their art this month. Look for "More about the Artists" in our next Artshare!

We welcome crafts, music, stories, or any original art created by someone whose life has been affected by ME, FM, and other chronic illness. Patients, caregivers, volunteers, and members are all welcome to share.

Please submit before June 10th for the next MASSME/CFS ARTSHARE by emailing volunteer@massmecfs.org with "Art Share" in the subject line.