

FALL 2018

Funeral Consumers Alliance of Central New York, Inc.

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FROM THE PRESIDENTS' DESK

It's about six months since I last wrote to you, and there is change in the air as fall has blessed us again with its wonderful colors and scents. Truly, "To everything there is a season, and a time to every purpose under the heaven."

Let me start with some good news: We have received a significant donation from the Funeral Consumers Alliance of Long Island/New York City. We are ever so grateful for their financial support and, rest assured, we will continue our work as they have charged us to do, using the funds "to enhance the services that we offer to health care consumers in our service area."

We have been very busy lately, starting with our booth at the Westcott Street Cultural Fair manned (and womaned) by a cadre of enthusiastic volunteers, including Mike Goins, Peter Moller, Nancy Aureli, Susan Rainey, Peggy Chestnut and Jae Evangelisti. Peter and Mike provided a new tent and table, which helped us put on our "Sunday best." If you have never been to the Fair, please plan to stop by and visit us there next year as it is a lot of fun, and you'll meet some interesting characters to boot!

Two days later we were at the 14th Annual Senior Fair at the State Fairgrounds, another successful and free event which provides a variety of information on products and services for senior citizens. I want to extend my thanks to Peter Moller and Susan Rainey for their continued participation at this event. Sadly, this is the last year for the Senior Fair. We are hoping that someone will step forward to carry on the torch.

I also want to give a shout out to Cheryl McLeod and Joel Potash, who met at the Skaneateles YMCA with other agencies dealing with problems of ageing. It was an opportunity for them, and us through them, to make new contacts and expand our "footprint" in Central New York.

Last but not least, we will be participating for the first time in Syracuse Peace Council's Craftsfair & Peace Festival (aka Plowshares) taking place December 1 – 2 at Nottingham High School here in Syracuse. We are grateful to our newest Board member, Lanny Freshman, who has encouraged and facilitated our entry into this endeavor.

On another note, we continue to work towards gaining 501 (c) (3) status and have discovered that we need to change our

legal name from the Syracuse Memorial Society, Inc. to Funeral Consumers Alliance of Central New York, Inc. Good things take time, but we now have a new sense of urgency in completing this task.

Speaking of something new, our brochure has been beautifully updated thanks to the talents of Diane Case and Joyce Homan, and Susan Rainey continues to perfect our stand-up table display.

In closing, please enjoy the upcoming Holidays. Try not to eat too much turkey, and we will continue to keep the home fires burning.

Jenifer Breyer, President

Report on the FCA Biennial Rochester, NY 2018

Four members of your FCA of CNY Board attended the Biennial Conference in Rochester this June: Susann Rainey, Joyce Homan, Jenifer Breyer and Nancy Aureli. Joyce served as President of the National FCA 2006-2008. She filed this report of the Biennial.

The FCA's national organization this year held its biennial meeting right next door in Rochester! It was nice to drive, not fly. Besides meeting old friends and FCA members from across the country, these were some highlights:

The keynote speaker was Executive Director of The Consumer Federation of America, Stephen Brobeck with which FCA is closely allied in bringing online funeral prices to the public.

The state of the FCA by Executive Secretary of FCA, Joshua Slocum. There are now 70 national affiliates, those with thousands of members to very small groups.

"Overcoming Barriers to Home Funerals." Yes, even in New York State it is possible.

“Writing a Journalistic Obituary for the Dead and Pre-Dead.” (As a follow-up note: on Nov 11 several folks gathered at the First Unitarian Universalist Society on Waring Road for a lively workshop in obituary writing and journaling.)

“Death with Dignity” was an inspiring presentation about the many aspects of allowing a person to choose his or her right to refuse treatment and end life by an ethicist. This presentation was from the Henry Ford Hospital in Detroit, Michigan.

Discussion/descriptions of the latest in cremation/green burial/hydrolysis...

The message for all the FCA affiliates was the need to push web/ Facebook/blogs/etc. as that is the future of growth. People go to the internet first these days. We need to support FCA national’s work to get funeral homes to post prices on their web sites. FCA is putting legislative pressure on the Federal trade Commission to change the Funeral Rule.

Nancy Aureli made a short video about the Biennial and you can watch it and learn more about the many wonderful people who make up The Funeral Consumers Alliance. Just go to Youtube.com and search for Funeral Consumer Alliance National Conference 2018

FCA of CNY BOARD	
President.....	Jenifer Breyer
Membership/Newsletter.....	Peter Moller
Treasurer.....	Susan Rainey
Nancy Aureli	Cheryl McLeod
Josh Goldberg	Joel Potash
Joyce Homan	Robert Sarason
Michael Goins	Diane Case
Lanny Freshman	Fred Davies (ex-off.)

The 2018-2019 Price Survey is Available
 You can view the current price survey of local funeral homes at our website (fcacny.org) or request a printed copy. The survey lists the costs of basic funeral services based on each establishment’s General Price Survey. You can also see a more detailed breakout of costs by going to the funeral home’s website. Not all have those prices on their website, but many do. Our national FCA is working toward requiring that prices be displayed on each website.

REASONS TO GET YOUR NEWSLETTER VIA EMAIL!

An electronic newsletter, rather than a hard copy? It’s a no-brainer! You can easily follow links to related articles; just click on them. Electronic versions of the newsletter are better for the environment. Email

versions of this newsletter save us some money. If you would like to take advantage of this opportunity, please send us an email with your email address: fcacny@gmail.com

**BOOK REVIEW
BY JOEL POTASH**

NATURAL CAUSES by Barbara Ehrenreich.

Ms Ehrenreich, a scientist and social historian and former user of medical care goes on a rant in this book and takes on everything from special diets, exercise programs and some treatments for end-stage diseases which cause more harm than benefit, as well as being costly to society. Her special area of research in the past was on the role of macrophages, natural cells in our body which fight disease, but somehow may enable some forms of cancer. If you watch the TV ads about Immunotherapy, that’s what this is all about. Ms. Ehrenreich has arrived at a stage of her life (as some of us also have) where she is no longer interested in "preventive care", chasing new therapies, or following intensive exercise programs, restrictive diets, or "alternative" therapies. She focuses on enjoying her life and allowing "natural causes" to have their way. A little bit over the top, but a balm for those of us who realize that even medicine and "science" have their limitations. This is an easy read, but may evoke opposing reactions from different readers.

**Learning from Lizzy
By Nancy Aureli**

My son asked to bring home a little anoles (lizard) from school after his 3rd grade class did a science unit on lizards. We had an old 20-gallon fish tank and since his class had to place 6 of these little green lizards, I said we could take one. My son named him Lizzy. We went to the pet store and got him everything he needed and cared for him for almost two years. We even saw some of his relatives clinging to the trees down south in North Carolina when we were on vacation. He was a good pet. He didn’t make much noise or eat too much.

Then one day he got a lump on his side and not much later on he died. My youngest son cried a little and my older son got teary eyed. I was touched by how my children reacted to our Lizzy friend dying. My husband took the cornbread mix out of a Jiffy Corn Muffin Mix box turned the box inside out and placed our Lizzy inside then taped it shut. My older son said we all should all write our names on the box, so after we wrote our names, we took him out back to bury him. We all took turns digging a small grave then we all took turns covering his box with soil. When we finished, my older sons got some rocks from another part of our yard and piled them on his spot. It all came together gracefully. Thank you, Lizzy.

ANOTHER DILEMMA FOR PEOPLE WITH DEMENTIA

By Joel Potash MD

I advise people with early stage dementia to create two documents: a Health Care Proxy (HCP), and a Living Will (LW). Unfortunately, New York does not have Living Will legislation, but a written Living Will should provide clear and convincing evidence of what a person wants done regarding life supporting treatments. Both the HCP and the LW are Advance Directives (AD): they only go into effect when the subject loses decisional capacity.

Health care providers should re-discuss a patient's HCP and LW if a patient's medical condition changes, or with certain life events, such as a marriage or divorce, change in residence, birth of children or grandchildren, etc. Anyone can change her/his HCP or LW or nullify them at any time.

Unlike other diseases, when dementia progresses, a person loses decisional capacity earlier than others with chronic progressive diseases such as diabetes and congestive heart failure, for example. In addition, progression of dementia eventually makes people with dementia unable to feed themselves, toilet themselves, ambulate, or accomplish other activities of daily living. They may appear agitated, or they may appear peaceful. Family members often comment that their loved one seems to be a different person than they have known.

Would this now cognitively incapacitated person with dementia, who seems happy being fed by others or through a feeding tube, want to be fed, even though s/he previously asked that there be no feeding when they were unable to feed themselves? People do

change their minds, but the person with advanced dementia is unlikely to express such a change. Families wonder what to do? Health care providers may suggest that a patient with advanced dementia is not the "same person" s/he was when the LW was completed, s/he seems happy with a feeding tube, so why not provide this (or other) life supporting treatments.

End of Life Choices, a New York organization, has developed an AD specifically for people with dementia, which does not allow family members or others to override a dementia patient's wishes at a later date. Hopefully this will be disseminated in the future. Additionally, while I do not recommend that a patient create a MOLST form (Medical Orders for Life Sustaining Treatments) until they have a life expectancy of a year or less, I would consider having a patient with early or moderate dementia create a MOLST form when they still have decisional capacity. A MOLST form provides current medical orders, which health care providers must follow. HCPs and LWs take effect only when the patient no longer has decisional capacity.

Choices in Dying can be contacted at:

<http://endoflifechoicesny.org/>

CHECK OUT OUR WEBSITE TO FIND MORE VALUABLE INFORMATION:
fcacny.org

HELP US GROW

It's no secret that the membership of the Funeral Consumer Alliance of Central New York is shrinking. We lost more than fifty members this year and found only three newbies.

We appeal to you to help us spread the word of end-of-life planning and bring some new members to the organization. Here are a number of easy ways you can help:

Share this newsletter with friends and family. It's a good way for potential members to discover what we are all about. Tell people about our website (fcacny.org) where they can read previous newsletters, study the price survey and discover valuable resources they can read online or download.

We would be happy to send you copies of our brochure that explains the mission of FCA of CNY and contain a simple application form to fill out and send in.

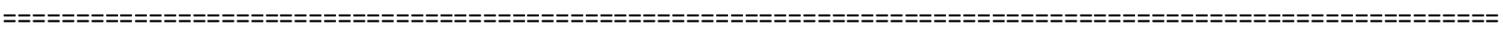
Do you belong to a social or professional or religious organization that might want members of our board to come talk and answer questions? We stand ready to do that at your request. Just contact any member of the board or leave a message on our voice mail (315-446-0557).

Garner-Richards, Nan Gartner, Michael Goins, Jane Guiles, Elizabeth Haswell, Joyce Homan, Ann Lewis, Margaret Muller, Mildred Owens, Caroline Palmer, Audrey Salzman, Vicky Schipper, Janet & Warren Solomon, David Tatham, Ann Tussing, Richard Weiskopf and Linda DeStefano.

THANK YOU FOR YOUR CONTRIBUTIONS

We rely on your donations to continue the work of the organization. We thank these members who made contributions since the last newsletter: Catherine Bart-Patterson, William Billingham, Peter

Is your End of Life Directive up-to-date? You can request a fresh new form from us. Call 315-446-0557 or email fcaacny@gmail.com.



I want to support the work and mission of the FCA of CNY. Please find my check enclosed in the amount of \$_____

Your name: _____

Check here if you would like to receive your newsletter by email. Print your email address as clearly as possible: _____

May we honor your gift with your name in our next newsletter? _____

Please use the pre-addressed envelope enclosed in this newsletter to mail your preferences and contribution back to us.

Contributions to FCA of CNY are not yet tax deductible.

