

NOTES FROM THE EXECUTIVE DIRECTOR

I have been humbled by the amount of generous support that our young organization has received, both in financial contributions and in our growing list of people wanting to get involved throughout Ohio.

LEARNING FROM OUR COUNTERPARTS

Part of our recent board development work involved talking with similar organizations in other states. What valuable lessons we've learned! We found out how these groups got started, what worked in moving forward and how to continue building support.

From Val Lovelace of Maine's It's My Death to Cindy Merrill's group in Texas, we found that what they had in common was a great passion for the concept of individual control at the end of life. From Robb Miller, former Executive Director of End of Life Washington, I learned the importance of taking control of our message and the wording used early on.

Because of this, new terminology was added to our website and presentations; Ohio End of Life Options believes in patient-directed end-of-life care and expanded choice for the terminally ill. We do not suggest, encourage, or promote suicide or euthanasia. This process has enabled us to build networks of support that reach beyond Ohio and will hopefully lead back here.

ASSISTED DYING IN OHIO

There has been action underway in Ohio with regard to medical aid in dying. Unfortunately, it has been by opponents.



Most recently, U.S. Representative from Ohio District 2, Brad Wenstrup, co-authored legislation that would block Washington D.C.'s bill, "The Death with Dignity Act of 2015" because he fundamentally disagrees with it. The bill had been studied, debated, passed by a council vote of 11 to 2 and then signed by Mayor Muriel Bowser. Please remind Rep. Wenstrup that his work should focus on the needs of Ohioans and that for those who disagree with this legislation, the ability to opt out is built in. Ask your U.S. Senators and Representatives to vote no on the resolution to block D.C.'s bill.

I've also had many discussions with people concerned about the recent passage of Ohio HB 470 that made assisting suicide a third-degree felony. It was tucked into legislation focusing on positive changes regarding palliative care facilities so it is hard to know how much attention that portion of the bill received. It certainly got a lot of press from well-organized opposition groups. These are usually pro-life

groups (that support life through a “natural” death) and the Catholic Conference. Many states have this type of legislation.

However, passing death with dignity-style legislation is an entirely different matter. Under these laws, medical aid in dying is considered a legal, confidential medical option that is initiated and carried out by the terminally ill individual.

When more Ohioans understand this and truly differentiate aid in dying from assisted suicide, we will make progress. Our voice needs to be as strong, confident and organized as those who vehemently oppose this basic human right.

CALL FOR ACTION

Senator Charleta Tavares (D–District 15) plans to introduce legislation *this year*. She will need support! Be ready to contact your state legislators. We will plan to have clear and concise educational material about the laws as well as talking points for the predictable arguments made against them.

I look forward to working with more and more of you on this important mission.

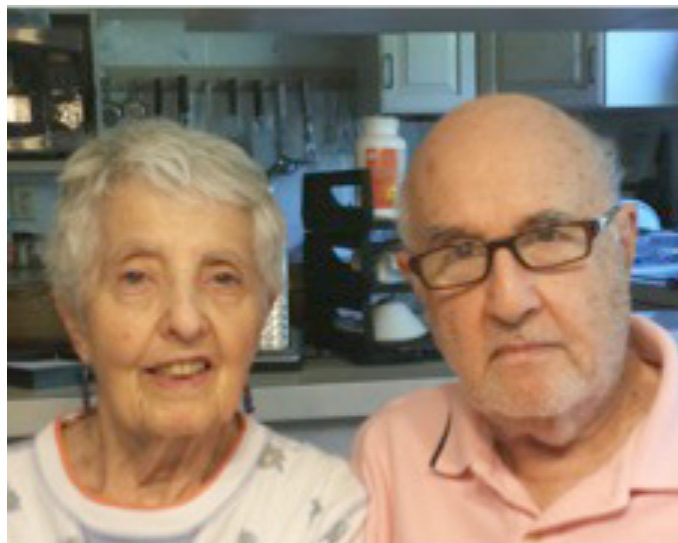
Lisa Vigil Schattinger
Executive Director

VOLUNTEER HIGHLIGHT: RONI BERENSON

Roni and Elliott, her husband of 65 years, were in the front row of Vigil Schattinger’s presentation at the Gates Mills’ branch of the Cuyahoga County Public Library on February 9. It turns out that this was their 2nd time attending the talk about Death with Dignity laws. Roni felt so strongly about the subject that she had written emails to 100 friends inviting them to the presentation.

Berenson shared that they have been long time supporters of Death with Dignity National Center and Compassion & Choices. They leave magazines from these national organizations out on the coffee table when entertaining to help raise awareness and start conversations.

They have long been supporters of end-of-life planning and options. In fact, she and Elliott have committed to leaving their bodies to Case Western Reserve University for study after they



die. They have shared this information with their family and have had frank discussions about their end-of-life plans for many years.

We thank Roni and Elliott Berenson for their advocacy on behalf of Ohio End of Life Options, Death with Dignity laws and proactive end-of-life planning.

UPCOMING EVENTS

PUBLIC EVENTS

Our event list are updated constantly. Please check our website OhioOptions.org for the latest.

Death with Dignity

When: Wednesday, February 15 at 7 pm
Where: Orange Branch of the Cuyahoga County Public Library, 31975 Chagrin Blvd., Pepper Pike, OH
Lisa Vigil Schattinger, MSN, RN will share her personal experience and information about medical aid in dying laws.

Oregon's Death with Dignity Law: Explore the Issue through Local Family's Experience

When: Sunday, April 2, 2017 at 12:45 pm
Where: Unitarian Universalist Society, 2728 Lancashire Road, Cleveland Heights, OH

Why We Need a Death with Dignity Law in Ohio

When: Friday, April 21, 2017 at 6:30 pm
Where: Jewish Secular Community of Cleveland, The First Unitarian Church (Fellowship Hall), 21600 Shaker Blvd., Shaker Heights, OH
A presentation by Lisa Vigil Schattinger.

If you wish to join us, we ask that you RSVP by the Wednesday prior to the program by calling Lynn Salzbrenner at 330-388-9393 emailing lynnsalzbrenner@gmail.com

FROM THE NEWS MEDIA

Paula Span has written an excellent and comprehensive overview of assisted dying in our country.

“Physician Aid in Dying Gains Acceptance in the U.S.,” *The New York Times*, January 16, 2017. <http://nyti.ms/2jnFhUy>.

In his farewell address, Governor Peter Shumlin shared that his father, George, used Vermont's Patient Choice and Control at End of Life Act in 2014. “It was a very peaceful and beautiful end to a very productive life,” Gov. Shumlin said.

“In Farewell, Shumlin Reveals His Father Used End-of-Life Law,” by Terri Hallenbeck, *SevenDays*, January 4, 2017. <http://bit.ly/2kcxel1j>.

Dr. Stuart Youngner, Professor of Bioethics and Psychiatry at Case Western Reserve University School of Medicine in *Medscape*: “The change in physician attitude toward assisted death reflects greater respect for patient autonomy. However, the trend doesn't necessarily mean supporters of physician-assisted death are ignoring the age-old injunction to ‘do no harm.’ We're having a paradigm shift about what's viewed as harmful. People are getting used to the idea that death is sometimes the least worst alternative. It can be a deliverance. We've already accepted that legally and culturally when it comes to stopping life-sustaining treatment.”

“Assisted Death: Physician Support Continues to Grow,” by Robert Lowes, *Medscape.com*, December 29, 2016.

ADVANCED PLANNING WITH MOM

By Lisa Vigil Schattinger, MSN, RN

The day before Thanksgiving, my mother and I were in the small room that serves as her office. Vibrant reminders of friends and family who've died surrounded us. There were also mementos from her trips afar, as well as things that she loves for her own special reasons. It's a distilled sample of all that makes my mother who she is.

In my mind, we were there for a couple of reasons. One was because, since starting Ohio End of Life Options, a 501(c)3 non-profit organization, we have been talking to a lot of people about filling out their advance directives and appointing a healthcare power of attorney. We had realized that we needed to make sure we were walking the talk and have all of our own paperwork in order.

The other reason was to honor my mother, Janet Rowe. She's a caring person who is a retired nurse and has been a Hospice volunteer for over twenty years. We both have been through the process of supporting loved ones as they aged and then died, died unexpectedly or died from a long, drawn out disease process. We've come to understand just how unique each person's experience is with regard to health, financial resources and family dynamics.

We were both there two years ago when my mother's husband, Jack, died peacefully after taking the medication that had been made available to him through Oregon's Death with Dignity Act. His was such a peaceful death, compared to all that we'd seen, that it brought my mother and me even closer together. And it compelled us to start sharing our experiences with others.

My mother has a lot more experience than I, but we have both been healthcare powers of attorney for family and friends. My experience as my grandmother's main long-distance caregiver was difficult. It was filled with emergencies and tough decisions. I felt incredibly fortunate to have my mother to talk to through all of this.

Largely because of our experiences, we both feel—to our very bones—that in order to live well we need to be prepared for aging and dying well.

So there we were. Mom had gotten out the bright pink folder that has lists of important information in case of a sudden illness or accident that leaves her incapacitated. My brother lives much closer than I do (in the same state as Mom) and we plan on working together on her care, if needed, in the future. On that day, we were trying to get familiar with the details.

Since she lives in a Continuing Care Retirement Community (CCRC), she and my stepfather had already made the commitment to living in that type of environment before he died. Where



she lives, as people age, they move up the hill because the independent town homes (where she now lives) are near the bottom of the hill and the skilled nursing facility (where she may or may not spend her final days) is on the top of the hill.

That's the plan anyway. But I found with my grandmother, who also lived in a CCRC, knowing exactly when these moves should happen can also be complicated. By living in a community like this, one may assume that their care while aging will be a seamless process. However, I found that each transition to another level of care required a lot of coordination between the various facilities and our family. Being familiar with the personnel at the CCRC is helpful in figuring out whom to consult when advice or help is needed.

Mom is already very organized with folders that are clearly marked, a copy of her Oregon Physician Orders for Life Sustaining Treatment (POLST) in brightly colored paper on her refrigerator and her POLST registry number clearly displayed. Since the POLST registry is state wide, she also keeps the number prominently displayed in her wallet. My mother also introduced me to the manager at her bank branch so that she would know who I am if I

ever need to take over banking duties. And her funeral plans are already made and paid for so she knows that her wishes will be carried out.

Since she is a young, active and healthy 71 year-old, neither my brother nor I are concerned about needing this information any time soon. But that is exactly the point. Who knows when a health event or accident will occur?

We don't want to be caught unprepared and uninformed of her wishes.

I felt it was a great honor being the primary decision maker for my grandmother. It is both daunting and a great honor to think of doing this for my mother. I do not know if she will ever need the same types of decisions made as my grandmother did. But knowing my mother well, already knowing about her finances, and talking about her wishes for aging and dying well, makes me more confident that I will be carrying out her thoughts and plans to the best of my ability. In my mind, that is a great way to honor this wonderful woman.

Please, make the effort to talk with your loved ones about their plans and the details involved for aging and dying well.

The book *Aging with a Plan*, by Sharona Hoffman, is a great resource for people planning their own aging process as well as caring for aging loved ones.

Please see the Resources tab at our website OhioOptions.org for a link to it and other helpful tools and information.

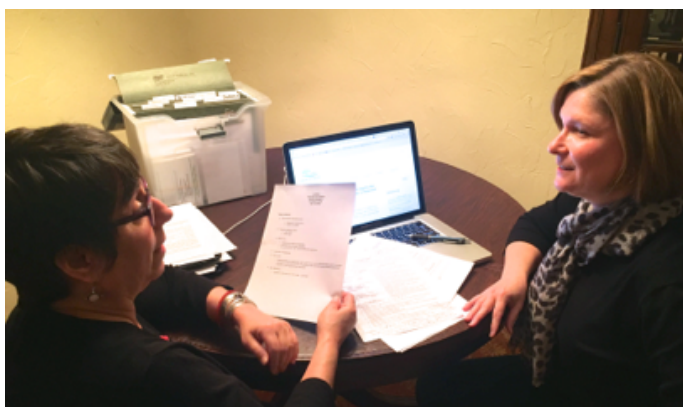


A MESSAGE FROM THE BOARD CHAIR

Welcome to 2017.

We are excited about our work plan for this year! Our organization has come a very long way since the first steering committee formed in 2015.

We continue to check off tasks on our list of milestones; obtaining our nonprofit designation, holding our first annual board meeting to elect our slate of officers and our recently completed board development process which culminated in our first fundraising effort and outreach. It was a success and we raised \$2,200. This brought our first year fundraising efforts to over \$10,000.



Susan Spinell (left) and Lisa Vigil Schattinger (right) with the Ohio End of Life Options' 501(c)(3) application.

We were pleased to have an excellent beginning and donors that are interested in financially supporting our mission.

In addition we have tackled the mundane but necessary: building a website with the support of Death with Dignity National Center and setting up a Facebook page, Twitter account, a P.O. Box and business bank account.

Yet our main and present goal to continue for

this year is engaging those who feel strongly about our issue and educating the community about the right to choose a dignified and peaceful death, using the law, when one has been diagnosed with a terminal illness.

We owe much to our Executive Director, Lisa Vigil Schattinger. Her drive and perseverance to educate the public by bringing this topic to those who will listen is what's necessary to get the message out to Ohio communities. She has made great strides by establishing excellent connections to a variety of people in the medical and theological fields. Her progress continues and her ability to tell her family's story has already made a strong impact and will continue to do so as we expand our outreach to new communities.

We know the road ahead is long and perhaps will at times be rocky and steep, but it is a good road. And one we wish to travel together as we spread the word.

Many thanks to our new board members for joining in and bringing your ideas, energy and commitment to our cause. We look forward to a successful year and hope you will join us in this important endeavor.

Susan Spinell



HISTORY OF NORTHEAST OHIO ORGANIZATIONS

We have known for a while that there has been an active Hemlock Society in Northeast Ohio because I've had people tell me that they or their parents were a part of it. I've also heard of a branch of Compassion and Choices but knew that it is no longer active. In fact, the regional manager of Compassion and Choices in Denver, Roland Halpern, said that he was a part of it when he lived here and went to the First Unitarian Church in Shaker Heights.

Thankfully, Jane McCullam has shared the history of the organizations in our area with us.

Jane wrote:

I'm currently vice-president of the Cleveland Memorial Society. My grandmother was active in supporting the establishment of the [Hemlock] Society in the 1940's, so I grew up with the idea that one's death is just another human problem to be dealt with in a rational way.

The Hemlock Society Cleveland chapter goes back nearly 30 years. Ket Luoma, an elderly bookbinding apprentice, started it. We met her in classes we took with Master Bookbinder Jane Sabota, beginning in 1988.

Ket was also affiliated with the Unitarian Fellowship in Cleveland Heights on Hampshire Rd. We had Hemlock Society meetings there. It was a small organization, probably about 100 members.

We put out a quarterly newsletter. I don't have any print copies now, and the electronic copies were in Word Perfect 5 on 5-1/4" floppies, now gone the way of the disk drives to read them.

Ket was very concerned about having control over her own death, as a widow with no living children. Later it became clear that she was living under the shadow of slowly advancing bone cancer.

The information and support she found from the Hemlock Society gave her the tools she needed to come to terms with dying and feel adequately prepared. She was the prime mover of the chapter, however and, with her death, it ceased to exist. She died in the late '90's.

Ket organized regular talks about end of life topics: living wills, talks with relatives so they know what your wishes are, dealing with the medical establishment when you or a loved one is hospitalized, getting Do Not Resuscitate orders to be respected.

She avoided direct confrontation with techniques of self-deliverance because of the political repercussions. She had several professors at CWRU and the medical schools, and a few ministers who came once a year or so to talk to us.

At this time going to the hospital was fraught with uncertainty. The medical profession took over at the door and was determined to keep you alive no matter what.

The Hospice movement was really in its infancy in Cleveland, and they were not in a powerful or knowledgeable enough position to have much say in end of life decisions.

(I gather this is a place where there could be a lot of improvement—the average hospice stay is still far shorter than it should be.)

A few years later Joan Campbell took up the flag, this time with Compassion and Choices.

Joan's motivation was a particularly painful and moving experience with medical professionals in Phoenix during the final illness of her husband. Her husband and she wanted palliative care for him in the few weeks he had left, but the doctors at the Phoenix hospital had another agenda, and insisted on bombarding him with procedures, extending his pain and misery, and denying him pain relief.

Joan was another Unitarian, this time from the First Unitarian Church in Shaker Heights. She went back to her retirement home in Phoenix after a few years, and that chapter folded after her.

Starting a chapter of any such organization takes more energy and time than the elderly can muster, usually.

As you can see, the mission behind these organizations has remained largely the same.

While I came to this cause because of my stepfather's use of the medication made available through Oregon's Death with Dignity Act to peacefully end his life in the face of his terminal illness, I believed in the importance of end-of-life planning long before that.

I believe that palliative care as provided through hospices has come a long way since Ket Luona's experiences. In our family, hospice care has been a given when facing a terminal illness. Unfortunately, I heard many times that experiences with hospice can vary.

I also believe that once everyone has explored their own thoughts on end-of-life wishes, they absolutely need to document them and have ongoing dialogues about them with their loved ones and medical providers.

I also believe in the necessity of a medical aid-in-dying law in Ohio so that people can be in control of their death in the face of their terminal illness and be surrounded by their loved ones when they die.

We'd love to hear from more members of previous organizations about the past as well as what you see for this cause moving forward in Ohio.

Email us Info@OhioOptions.org or leave a voice mail at 216-512-1151.



Image by ClipArtFest.

VIEWPOINTS: MARK WEBER

Everyone has a reason for being involved in this cause. Some are very difficult to express, some are a matter of philosophy and some are based on painful experiences. In the months to come, our board members will be sharing their viewpoints and what brought them to become involved. Let us know if you would like to share your viewpoint.

Several weeks ago, I turned 70. This “magic number” made me think about how much time I have left and what will be the life quality of those years.

According to the Center for Disease Control (CDC), 55% of us will die from some kind of terminal illness. A terminal illness is an incurable and irreversible condition that will more than likely cause death within a relatively short period of time. Chief among the medical conditions that are likely to do us in are heart disease, cancers, pulmonary diseases, infections, and organ failures. The suffering may involve searing pain and discomfort.

There are some people who want every possible medical intervention or treatment to keep them functioning as long as possible.

However, there are others (and the number is growing) who do not want to be artificially kept alive when there is no hope of any kind of recovery. In other words, there is a growing number of people who want to be able to choose a dignified death over the alternative of simply existing on medication until the body’s final breakdown comes.

I believe they should have that right.

Right now, only California, Washington, Oregon, Vermont and Colorado offer citizens the right to choose a peaceful and dignified death.

Washington and Colorado’s laws were approved by a referendum of citizens. Montana offers the same through a judicial decision.

Religious conservatives decry this as suicide. They are wrong. Suicide is about choosing death over life and is often motivated by a condition such as depression. Often, conditions like depression can be treated so that the person can lead a relatively normal life.

However, a terminally ill person, by definition, is in the act of dying and therefore does not have the choice of life over death. Instead, the only choice they have is one type of death over another.

Brittany Maynard was a 29 year-old teacher from California (before California passed its death with dignity law). She moved to Oregon to take advantage of its law, which allowed her to choose a dignified death rather than being artificially kept alive during which the terminal cancer would have made her last few months a living hell.

Death with Dignity National Center and Compassion & Choices are national organizations that push for death with dignity laws.

Here in Ohio, Ohio End of Life Options is an organization that is working for an “Oregon-type law” in Ohio. Ohio End of Life Options also

wants dying patients to be offered all possible options for the last few weeks or months of their life...including a death with dignity option.

Generally, in order to qualify under death with dignity laws in the few states where they exist, patients must meet the following conditions:

1. They must be terminally ill with no hope of recovery.
2. They must be of sound mind so that they can make an intelligent decision.
3. They must be able to self-administer the drug that would painlessly take their life.

Death is a subject about which no one likes to speak. However, if the last civil right is the right of a terminally ill person to choose a peaceful and dignified death, then we all need to work for a law like the one in Oregon and we need to make our last wishes known to both loved ones and caregivers so that we can have the death we want.

Mark W. Weber
At-Large Member, Board of Directors
Ohio End of Life Options

ABOUT OHIO END OF LIFE OPTIONS

Ohio End of Life Options' purpose is to engage in educational and advocacy activities regarding end-of-life choices, with the aim of helping people legally achieve their wishes for a peaceful and dignified death.

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