

THE



# Dignity Report

*A publication of the Death with Dignity National Center*

SPRING 2019



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Cover photo: Marcia Partridge. See “A Right We Should All Have”, p.10.

## GIVE DIGNITY

Death with dignity laws provide peace of mind to qualified terminally ill residents in **California, Colorado, District of Columbia, Hawai'i, New Jersey, Oregon, Vermont, and Washington**. Help us expand the option to all Americans with a generous contribution:

- a one-time or recurring gift;
- a gift in honor or in memory of a loved one;
- a gift of stock or mutual funds;
- a legacy gift.

Please visit **DeathwithDignity.org/Support** to learn more and contribute.

THANK YOU!

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## A Movement Matures



For two days in April, I witnessed what happens when a social movement matures.

I traveled to Maine to attend an event hosted by our grassroots partner organization, Maine Death with Dignity, and to testify at a legislative hearing in support of LD 1313, an aid in dying bill. I was honored to speak alongside advocates and lobbyists I've known for years, as well as Mainers I'd never met who shared deeply personal stories I'll always remember.

### THE POWER OF STORIES

Every time a state adopts a death with dignity law, it is thanks in large part to dying patients and their loved ones who step forward to share their stories. Their moving testimony has the power to move votes.

### HOW WE WIN

Years of relationship building at the grassroots and in the State House are starting to pay off as well. We have worked collaboratively with state-based

advocates and lobbyists to build bipartisan support for death with dignity among legislators and the general public. Our shared success is reflected in the state's major newspapers, all of which have editorialized in support of LD 1313. The combination of moving personal stories and behind-the-scenes political strategy offers a case study in how we win.

### ACROSS THE COUNTRY

From Nevada to New York to New Jersey, which just last month enacted a death with dignity law, our movement continues to gain ground nationwide.

Read on to learn more about our work across the country—work that is only possible because of your generous support. Thank you for standing with us every step of the way.

A handwritten signature in black ink, appearing to read 'Peg Sandeen'.

*Peg Sandeen*  
Executive Director

# Maine Legislative Hearing Draws Passionate Testimony

On April 10, Mainers traveled through sleet and snow to testify to the State Legislature's Health and Human Services Committee on LD 1313, the Maine Death with Dignity Act.

## A PHYSICIAN'S SUPPORT

The bill's chief sponsor, State Rep. Patricia Hymanson (D-York), said her 32 years practicing medicine informed her support of death with dignity, saying, "I have witnessed many people dying. It is for [them]—my patients—that this bill is before you."

## "STRINGENT SAFEGUARDS"



Our Executive Director Peg Sandeen emphasized the safeguards in the Maine bill, which is modeled on the Oregon Death with Dignity Act.

Valerie Lovelace, chair of Maine Death with Dignity and our longtime grassroots partner, said, "Mainers have waited long

enough. We should be able to make our final decision under the protection of a safe, legal, merciful process."

## "I WANT THE RIGHT"

Lawmakers were particularly moved by testimony from dying patients seeking a peaceful death. One such Mainer, Cyndie Rogers, who has Stage 4 cancer, said, "I want to live. But when I get to the end of my life, I want the right to choose death with dignity in my home state."

Visit [DeathwithDignity.org/ME](https://DeathwithDignity.org/ME) for the latest news and to watch the testimonies.  



*Cyndie Rogers testifying before the Committee.*

# Silver State Update: Death with Dignity in Nevada

The Nevada State Senate considered the Death with Dignity Act for the third straight legislative session thanks to Senator David Parks who assembled a record number of co-sponsors.

As in previous sessions, we worked closely with Sen. Parks on shepherding SB 165 through the legislative process. Our executive director, Peg Sandeen, helped Sen. Parks introduce the bill at the Senate Health and Human Services Committee hearing and answered questions from members about Oregon's experience with the law.

Following a work session in March, the Committee passed the bill 3–2.

## OUR COMMITMENT


We are devoting our resources to the Silver State because the majority of Nevadans support death with dignity— 72 percent, according to a 2017 poll—and because Nevadans like Debbie Black, who has Stage 4 cancer, are sorely in need of this end-of-life option.

"I want to be able to make the choice about how I spend my final days," Debbie told the Committee. "It is a right all of us should have."

## THE NEXT STEPS

Despite unprecedented support among their colleagues and constituents, a number of legislators caved in to our opponents' fear-mongering and failed to respect the will of the people. SB 165 did not come up for a vote in the Senate and did not advance.

While Nevada will not get a death with dignity law this year, we made significant strides forward, including assembling a stronger-than-ever coalition of organizations and advocates. We are not giving up—and neither are our legislative allies.

We are grateful to Sen. Parks and all the legislators who put their names on the line to support death with dignity. **Help us recognize their leadership and courage by sending them a thank-you note at [DeathwithDignity.org/NV](https://DeathwithDignity.org/NV).** 

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# From First Bill to Final Win: Death with Dignity Across America



## **NEW JERSEY**

On April 12, Governor Phil Murphy signed the Aid in Dying for the Terminally Ill Act into law. In a statement, Murphy said, "Allowing residents with terminal illnesses to make end-of-life choices for themselves is the right thing to do. I thank the Legislature," which had passed the bill on March 25, "for its courage in tackling this challenging issue."

New Jersey joins six states and D.C. in adopting a death with dignity law; one in five Americans now have access to medical aid in dying.



## **MAINE**

We continue to provide support to the grassroots group Maine Death with Dignity. See p. 4 for more on our work in the Pine Tree State.



## **NEVADA**

We continue to work closely with our allies in the state legislature and beyond. See p. 5 for more on our work in the Silver State.



## **MARYLAND**

Death with dignity legislation advanced farther than ever before in the 2019 session. The House of Delegates approved the End-of-Life Option Act in March but the Senate defeated the bill by a single vote. Maryland remains one of our priority states.



## **MINNESOTA**

Legislators in both chambers of the Minnesota State Legislature are sponsoring companion End-of-Life Option Act bills, both of which were referred to the respective health committees.



### **NEW YORK**

State legislators are considering the Medical Aid in Dying Act, which has been referred to the Assembly and Senate Health Committees. The New York Coalition for Medical Aid in Dying, of which we are a founding member, hosted a Lobby Day at the state Capitol in Albany on May 14 and is leading a sustained advocacy campaign to bring death with dignity to the Empire State.



### **NEW MEXICO**

Two House and a Senate committee passed the Elizabeth Whitefield End of Life Options Act. However, the bill did not come up for a vote in either legislative chamber. We are proud to support advocates on the ground who are laying the groundwork for the next session.



### **NORTH CAROLINA**

We continue to support the work of Dying Right NC in their advocacy for the End of Life Option Act. Support for the bill is not only truly bipartisan, the number of sponsors has tripled since 2017.



### **ARKANSAS**

For the first time in Arkansas history, the state legislature considered a death with dignity bill. At a March 12 hearing in the Public Health Committee, the bill was not brought up for a committee vote.



### **VIRGINIA**

Virginia State Delegate Kaye Kory introduced the state's first-ever death with dignity bill on January 14; we participated in the working group drafting the bill. The bill failed to meet a committee deadline and did not advance this session.

To learn more about your state and take action, visit  
**[DeathwithDignity.org/Take-Action](https://DeathwithDignity.org/Take-Action)**.



# Growing Grassroots Partnerships in Massachusetts

For the past eight years, John Berkowitz has led support groups focused on “aging gracefully” in western Massachusetts, where he lives. In candid conversations, he says, “End-of-life care comes up all the time, including stories of people who have had difficult dying processes.”

**“RIGHT AND JUST AND NEEDED”**  
In 2017, John began researching medical aid in dying as an end-of-life option that “seemed right and just and needed.”

He learned a death with dignity bill had been introduced by state legislators—and that his representative was not a sponsor.

**FORMING AN ORGANIZATION**  
“I sat down with [the legislator] and had a conversation,” John recalls. “Once he signed on [to the bill], I thought, OK, let’s keep going.”

He formed a local nonprofit advocacy group, Western Massachusetts Death with Dignity, and is recruiting

citizen advocates to meet with legislators and organize community events.

**STATEWIDE ADVOCACY**  
The organization’s recent accomplishments include persuading multiple town councils to pass resolutions supporting the End of Life Option Act; meeting with legislators across the state; and hosting events featuring doctors who support death with dignity.

**JOINING THE STATE LEADERSHIP INCUBATOR**  
Organizations like Western Massachusetts Death with Dignity are prime candidates for our Dignity50 State Leadership Incubator.

Through this program, we provide technical assistance and training to leaders of state-based organizations to help them become effective advocates for assisted dying.

To learn more about the State Leadership Incubator, visit [DeathwithDignity.org/Dignity50-Incubator](https://DeathwithDignity.org/Dignity50-Incubator).



# A Family Tradition of Giving

## Donor Spotlight: Max Roman

An avid skier and hiker, Kathleen Roman was always on the move. That made the loss of mobility and physical control she experienced from ALS “just devastating,” her son, Max, told us.

### TO DIE PEACEFULLY

As the disease robbed Kathleen of her physical capabilities, she sought a way to end her suffering and die peacefully in her home state of California. She learned more about medical aid in dying and decided she wanted to use California’s End of Life Option Act.

### SECURING THE OPTION

Max and his father, Michael, turned to Death with Dignity National Center for information on how to help her access the California assisted dying law.

### PEACE OF MIND

“Once she secured the option” of aid in dying, said Max, “[my mother]

noticeably relaxed. She could spend the last part of her life enjoyably.”

In December 2016, six months after California’s End of Life Option Act went into effect, Kathleen used the law.

### A NEW TRADITION

After Kathleen died, her husband Michael began giving to Death with Dignity in her memory. Following Michael’s death in November 2018, Max and his wife, Victoria, continued this tradition of giving to honor both his parents. ☸



*Max Roman with his parents Michael and Kathleen.*

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# A Right We Should All Have

By Jonathan Partridge, New York


I was a proud New Yorker and always had been—until I found out lawmakers in my state did not support death with dignity. This end-of-life option would have provided great comfort to my mother, Marcia Partridge, who died last fall after a lengthy illness.

My mom loved her life. At age 69, she went to Jazzercise five times a week, enjoyed dinners with friends, worked as a speech pathologist, traveled the world, and adored her family. She could light up a room with her smile. It was impossible not to love her.

After she was diagnosed with non-Hodgkins lymphoma, she went in and out of the hospital, before eventually entering hospice. My amazing mom became a shadow of her former self. I can't imagine suffering the way she did.

Besides dying at home, her main wish was to have a quick and painless way to hasten her death. Instead, she was deprived of the opportunity to die on her own terms.

My mother's experience moved me to advocate for the rights of New Yorkers with terminal illness so others can have the opportunity denied my mom.

Death with dignity means having the option to take control of your life and your death, and to leave this world with your true self intact. It is a right we should all have. 



*Jonathan Partridge with his mother Marcia Partridge.*

# Save the Date: National Clinicians' Conference on Medical Aid in Dying, February 14–15, 2020, UC Berkeley

We have partnered with Bay Area End of Life Options to convene the inaugural National Clinicians' Conference on Medical Aid in Dying. The conference, scheduled for February 14–15, 2020 at UC Berkeley, will bring together end-of-life care professionals from across the country for in-depth conversations about the role of medically assisted death in the continuum of care for dying individuals.

As the number of Americans with access to aid in dying continues to grow, so too does the need for a forum dedicated to fostering dialogue among clinicians who provide care to patients with a terminal illness. We are proud to be a founding partner of this first-of-its-kind conference and invite all end-of-life care providers to attend. Learn more and register at [NCCMAID.org](http://NCCMAID.org).

## Create a Legacy Through Planned Giving

Every day, Death with Dignity works to ensure terminally ill Americans can die on their own terms with peace of mind. The generosity and foresight of our donors make this possible.

You can create a planned giving strategy that meets your financial priorities, honors your personal values, and reflects your philanthropic vision.

*“You don't need to be wealthy to leave a gift in your estate.”*

—JOYCE AXELROD, SAN DIEGO, CA

To learn more or to leave a legacy gift, contact Amy Lavan at (971) 808-2851 or [alavan@deathwithdignity.org](mailto:alavan@deathwithdignity.org).



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# THE Dignity Report

*Death with dignity means  
having the option to  
leave this world with  
your true self intact.*

—JONATHAN PARTRIDGE, NEW YORK, NY

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