A Brief History of the Indiana Chapter of Compassion & Choices

Ву

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January 13, 2012 (revised January 16, 2020)

Historical Overview

The Indiana Chapter of Compassion and Choices had its kickoff meeting on November 11, 1989 as Hemlock of Indiana, a chapter of the National Hemlock Society started in 1980 by Derek Humphry, author of *Final Exit*. The chapter serving the state of Indiana was organized by Stephanie Thomas, a Spanish instructor at Indiana University, Bloomington. Thus, the organization was headquartered in Bloomington. Ms. Thomas was a very energetic, skillful, and well organized leader of Hemlock of Indiana. In November 1991, Stephanie Thomas was elected to the Board of Directors of the National Hemlock Society. She served as president on the Indiana Chapter until 1994, as newsletter editor until fall 1996, and was an *ex-officio* board member until 2001, when she relocated to another state.

The Bloomington area always had many members, second only to Indianapolis in the state. In Hemlock Society of Indianapolis was formed, with Alexander "Sandy" Monro as president. By September 1993, the decision was made to merge Hemlock of Indiana with the Indianapolis-based organization. The articles of merger were signed by the presidents of both organizations on December 8, 1993, but Hemlock of Indianapolis continued to exist under that name for several years after that date. (There was also a Hemlock chapter that served southern Indiana, but members there belonged to Hemlock of Kentucky.)

In the first decade of this century, the names of both the national and state organizations were changed, first to End-of-Life Choices in 2003. The national organization merged with Compassion in Dying in November 2004 to form Compassion & Choices, but the Indiana Chapter retained the End-of-Life Choices name until 2006, at which time it became Compassion & Choices of Indiana.

The Indiana chapter saw rapid growth in its early years. In January 1991, Hemlock of Indiana had 93 dues-paying members, but by the end of the year, that number had increased to 184. In April 1993, there were 234 members. Membership dropped from a high of about 300 in 2000 to around 200 at the beginning of 2012. After the national Compassion & Choices office decided to eliminate state chapters around 2017, it was no longer relevant to speak of state members. Under the new approach, Action Team leaders were to be selected for various geographic areas of the state. The state chapter designation was abandoned in 2019 in favor of the Action Team approach.

Interest in the cause of medical aid in dying remains high in Indiana, judging from the number of Indiana subscribers to the statewide e-mail distribution list, CCIND-L, based at Indiana University. At the beginning of 2020, there were 1,995 e-mail addresses among the subscribers. CCIND-L continues to serve as a vital source of information about end of life matters, complemented with a web site and Facebook group page.

Mission Statements

By October 1992, Hemlock of Indiana had adopted a mission statement that read, "Our mission is to assure the ultimate personal freedom of a dignified, peaceful and compassionate death." The spring 2004 End-of-Life Choices of Indiana *Newsletter* stated that the mission is "to increase the available options for people to die with dignity, including the right to physician-assisted dying." At the January 2005 Board Meeting, the current version of the mission statement was approved. It reads

For some, death comes without warning and pain is brief. For others, death may come only after an agonizing, protracted illness. Compassion & Choices of Indiana believes that we all deserve a peaceful death with dignity. It defends the right of mentally competent adults to have advance directives such as Living Wills and Do-Not Resuscitate orders, these defended by our Health Care Power of Attorney representative. Ultimately, our final wishes should be clear, understood and honored by our loved ones and health care providers. Our organization also promotes legalized physician aid in dying as practiced in Oregon.

Board Members

The board originally met quarterly to plan programs, review other activities and involvements, discuss developments on issues of interest, and approve and review budgets, income, and expenditures. Gradually, the frequency shifted to twice a year, and now only one annual meeting is held that includes all areas of the state.

Initially, there was only a Steering Committee of the Hemlock of Indiana organization with coordinators for various activities. Stephanie Thomas served as Spokesperson, Diane Leirer (Secretary), Sue Swanson (Treasurer/Bookkeeper), Russ Washburne (Correspondent), Lee Nehrt (Publicity & Growth), Steve Baer (Program Coordinator), and Ken Bardonner (Special Projects).

The Board in 1990 included Stephanie Thomas (President and Newsletter Editor), Sue Swanson (Treasurer), Margaret O'Neal Tomey (Secretary), Russ Washburne (Membership), Diane Leirer (Publicity), Steve Baer (Program Site Coordinator), and Ken Bardonner (Director).

By June 1991, some Board members had been replaced. Emily Henning was then the Secretary, Rita Hanitchak had taken over Membership, and Maryann Wampler was in charge of Publicity. Program duties had passed to Anne Grossman. A new post of Outreach Coordinator was filled by Barbara Gordon. Margaret O'Neal Tomey had taken on the Site duties, and Steve Baer became the Historian. The size of the Board increased from seven to nine in 1991. Margaret and Richard Rieth were also on the Board about this time. Board Members served two-year terms. On April 25, 1992, Gordon Henning and Margaret Kondrat joined the Board of Directors of Hemlock of Indiana, and Millicent Brubaker was Co-Chair of the Programs & Meetings Committee in August 1992. In 1993, there were only 8 directors.

By October 1992, an external advisory board for Hemlock of Indiana was formed. Members were Lee Nehrt, Dr. Emanuel "Bud" Klein, Mary Oliver, Gal Shifron, and Bill Yarber. There is no mention in the chapter records of the external advisory board after 1993.

By April 1994, the first Board of Directors under the newly organized Hemlock of Indiana (incorporating Hemlock of Indianapolis) was elected. Office holders were:

President: William H. A. Carr Vice-President: Al Rosen Secretary: Susan Kent Treasurer: Suzanne Swanson Director: Sandy Monro (founding president of Hemlock of Indianapolis) Director: Rev. Dr. Bruce Clear Director: Maryann Wampler Ex-officio Board Member: Stephanie Thomas (also newsletter editor).

Just over one year later, by the fall of 1995, the Board was expanded to ten members with the addition of Letitia Alder, Emanuel "Bud" Klein, and Idell Rosen as Directors. New Board member Clifton Bush was added in 1996-97, the period when Al Rosen was president. Al was re-elected for another term, but he died suddenly in early 1998. Alexander "Sandy" Monro, who had resigned as president of Hemlock of Indianapolis in January 1997, stepped in as president. Clarke Miller, newly elected to the Board in 1998, served as newsletter editor from 1998-2002, followed by Meghan Charlesworth (2002-04), and Miren Beristain (2004-12), and Gary Wiggins, 2013-15.

In late 1999, Clarke Miller was elected president. He served in that role through 2012, at which time he stepped down and was honored with emeritus status. Clarke was followed as president by Susanne Gaudin, Gary Wiggins, and Bev Hmurovic.

By 2003, there were 12 people serving on the Board of Directors. Listed below are those who served between 2000 and 2010, with the first year of service indicated in parentheses.

Miren Beristain*(2004)	Carlyn Johnson (2005)
Jim Bethel (2010)	Ronald Katz (2010)
Jon Chaffin (2008)	Susan Kent** (2002)
Meghan Charlesworth (2002)	Hannah Kirchner (2003)
John Cochran (2002)	Elsa Kramer (2003)
Richard Davis (2004)	Peggy Lovett (2003)
Rose Fell (2000)	Mary Ann Mann (2006)
Susanne Gaudin (2002)	Antonia (Tonia) Matthew (2001)
Pam Gilliatt (2006)	Jeanie McElwain (2009)
Allen Grimshaw (2004)	Susan Pratt (2005)
Mike Hamilton (2004)	Gary D. Wiggins* (2010)
Claiborne Handleman (2010)	Bob Zalkin (2002)
Ruth Ann Ingraham (2002)	

*also, newsletter editor and webmaster

**rejoined the Board, after having served in the 1990s

In January 2012, the ten officers and board members, with places of residence in brackets, were:

Clarke Miller, President [Bloomington]	Jon Chaffin [Spencer]
Jeanie McElwain, Vice-President [Spencer]	Carlyn Johnson [Indianapolis]
Susanne Gaudin, Treasurer [Morgantown]	Ronald M. Katz [Indianapolis]
Claiborne Handleman, Secretary [Indianapolis]	Susan Pratt [Indianapolis]
Jim Bethel [Indianapolis]	Gary Wiggins [Bloomington]

Board meetings after 2012 included some of the older Board members, but there were many new faces at the meetings. Among them were (with first date of service in parentheses):

- Indianapolis residents Elliott H. Berger (2018), Dr. Ramon Dunkin (2012), Linda Leary (2015), Carole Mitchell (2014), and Lynn Pike (2014).
- From Bloomington and surrounding areas were Susanne Gaudin* (2012), Angela Hays (2018), Rev. Mary Ann Macklin (2015), Kel McBride (2016), and Margie Schrader (2018).
- Board representation from other areas of the state: Mary Anne Butters (2017, Greens Fork), Larry E. Farr (2016, Jeffersonville), Bev Hmurovic (2016, Whiting), Bill Van Horne (Evansville), and Diane Walker (2018, New Albany).

Joining Clarke Miller with emeritus Board Member status in 2018 were Jim Bethel, Carlyn Johnson, Ronnie Katz, Susan Kent, Elsa Kramer, Peggy Lovett, Tonia Matthew, Susan Pratt, Stephanie Thomas, and Gary Wiggins.

Formal Presentations and Participation in Health Fairs

The chapter was always very active in presenting programs. Programs on medical aid in dying, ethical wills, the legal aspects of dying, and other topic were presented at various locations around the state. Sites included universities, churches, public libraries, senior groups, service clubs, and retirement centers.

In July 1990, Hemlock of Indiana hosted 42 people at Bloomington's St. Thomas Lutheran Church to watch the National Hemlock Society's then newly released video "A Time to Die." An October 1991 presentation on living wills and health care powers of attorney was delivered in Shelbyville. Terre Haute and South Bend also had early Hemlock public presentations by Stephanie Thomas. In 1991, she was a guest on the "Jerry Springer Show" when it originated in Cincinnati. At that time, it was a much more moderate show on which guests focused on current topics of national interest.

In 1991, the organization participated in the first of many Indiana University Health Fairs, as well as the Bloomington Senior Expo. Participation in these annual fairs was later expanded to Lafayette and Nashville, and for a while, Indianapolis (including Indiana Black Expo in July 2006) and Terre Haute (both

discontinued now). A display booth promoted living wills, and volunteers passed out free Indiana Advance Directives, national brochures, and other pertinent information.

State Representative (later Mayor of Bloomington) Mark Kruzan was the speaker at an April 25, 1992 meeting on the topic of "Legislators and the Indiana Living Will." Presentations were also given in local retirement homes in 1995 by Margaret Kondrat, Sue Swanson, Bud Klein, and Stephanie Thomas.

Stephanie Thomas spoke at a "Death & Dying" class at Indiana University in Bloomington in 1992 and continued to participate in the class until 1999. Clarke Miller presented these twice-a-year guest lectures after that. In 2005, Clarke Miller began to give lectures at Indiana University-Purdue University in Indianapolis at a "Death & Dying" class. Clarke also spoke several times in the period 2006-2010 at the Indiana University School of Medicine in Indianapolis. Ronnie Katz also spoke at Indianapolis locations after Clarke retired.

Throughout the years of our existence, we have also hosted visits and talks in Indiana by officers of the national organizations. Derek Humphry, founder of the National Hemlock Society, made front-page news in Bloomington when he visited in April 1993. Rev. Ralph Mero, founder of Compassion in Dying, made a surprise visit to Bloomington in March 1994 and also spoke at All Souls Unitarian Church in Indianapolis. Senior Medical Director Dr. Richard MacDonald lectured in Indianapolis in March 2001. In April 2002, National Hemlock Society Senior Vice President Faye Girsh made four stops on a speaking tour in our area: twice in Indianapolis (at the Indiana University-Purdue University in Indianapolis Law School and at the Indiana University School of Medicine) and once each in Lafayette and Louisville, Kentucky. Roland Halpern, Director of Local Group Relations for Compassion & Choices, spoke in Bloomington in April 2005, followed by a presentation the next day in Indianapolis. Roland was also here to accept a check for \$1,025 that resulted from an effort by Peggy Lovett. She had challenged the Indiana chapter to raise money for the Compassion & Choices campaign against Attorney General Alberto Gonzales' attempt to overturn Oregon's physician-assisted-dying law. Other chapters supported Peggy's challenge: The EOLC Boulder County, Oregon Chapter donated \$100, and the Greater Cincinnati Chapter contributed \$800. Most recently, Compassion & Choices National President Barbara Coombs Lee visited Indiana in April 2010 and spoke four times in Indianapolis, including at the Indiana University-Purdue University in Indianapolis Law School and twice at the Indiana University School of Medicine.

During his many years of service, Clarke Miller was very active in promoting the Compassion & Choices cause, not only within Indiana, but also outside the state. Clarke made a speaking tour in northern Indiana in November 2003, with stops in Hobart, South Bend, and Fort Wayne. He delivered talks in Terre Haute in March 2004 and February 2007. In October 2005, Clarke spoke in Goshen, in April 2006 in Cincinnati at the local Alliance of Funeral Consumers, and in September 2006 in Davenport, Iowa at the Compassion & Choices Iowa Chapter. In June 2005 and again in October 2009, the Unitarian Universalist Church in Evansville was the site of Clarke's presentations. In between those engagements, he gave two other talks in Evansville in September 2005—one at the University of Evansville and the other at the University of Southern Indiana. May 2008 found Clarke in Iowa again, this time in Cedar Rapids for the Compassion & Choices Iowa Chapter meeting. Attendees at the National Funeral

Consumers Alliance had the opportunity to hear Clarke at their convention in Bloomington in May 2010. In April 2011, he spoke in Norfolk, Virginia at the Tidewater Funeral Consumers Alliance.

In addition to these activities, Clarke also served from 2002-2003 on the national organization's Chapter Development Committee. In May 2010, he was recognized in the national Compassion & Choices *Newsletter* as a "champion for end-of-life choice."

Of course, Clarke Miller was not the only Compassion & Choices of Indiana member who made formal presentations in the state. Board member Susanne Gaudin first presented a program on ethical wills one's recorded heritage of wisdom, experiences, etc. for succeeding family members—in Indianapolis in December 2007. She also gave the program in Indianapolis in November 2008 as part of the Spirit & Place Festival and for several years in the "Death & Dying" class at Indiana University-Purdue University at Indianapolis.

In 2008, Diane Kondrat, daughter of former Board member Margaret Kondrat, developed an interactive theater program on "End-of-Life Choices." She and her actors stage three human dramas involving decisions at the end of life. The interactive theater has been presented several times in Indianapolis and Bloomington, and in the spring of 2011, with funding from the national organization, it was filmed for wider distribution. Diane Kondrat was invited to perform at the national organization's conference in June of 2012, and she returned to give a well-attended performance at the Bloomington Unitarian Universalist Church in 2018.

Board member Claiborne Haldeman presented at All Souls Unitarian Church in Indianapolis in September 2011, and Board member Ronnie Katz spoke in November 2011 in Indianapolis on the legal aspects of end-of-life issues and at an Indiana Continuing Legal Education Forum there in December 2011.

In 2016, a virtual Legislative Dialogue Committee was formed by then-President Gary Wiggins to help spread the word around the state on legislative issues surrounding medical aid in dying. The committee, that eventually numbered over 3 dozen members from all areas of the state, received monthly communications with advice and tips on contacting legislators. By 2019, it was inactive.

After becoming president of Compassion & Choices of Indiana in 2017 and later as chief Action Team Leader for the state, Bev Hmurovic logged many miles throughout Indiana and made many presentations to a wide variety of groups, including presentations in IU Bloomington's Death and Dying class twice a year.

Legislation

In a 1991 Indiana Chapter *Newsletter* issue, it was noted that the chapter was limited in its political involvement because of its 501(c)(3) tax status as an educational organization. Throughout its early years, however, Hemlock of Indiana was very active in urging legislators to pass reasonable laws that protected the individual's right to die with dignity. To the extent allowable under IRS rules that govern

our not-for-profit status, the chapter continues to have an impact on Indiana legislation relevant to its mission.

Indiana had a living will statute prior to 1991, but in that year, bills pertaining both to living wills and powers of attorney for health care were passed by the 1991 Indiana General Assembly and signed into law. The Indiana chapters of the National Hemlock Society were actively engaged in lobbying for their passage. However, there was a significant omission in the Living Will law as finally passed. Although the Power of Attorney Act for 1991 allowed health care representatives to consent to or refuse artificial feeding as *requested* by patients in an advance directive, the Living Will Act contained no such provision for the individuals themselves to make such a choice. Letters were sent by Stephanie Thomas to all local legislators urging them to remedy this. Especially vocal in opposition to the "Living Will" bill in 1991 and later was the organization Citizens Concerned for the Constitution, Inc. (CCC). Eric Miller, Executive Director of CCC, utilized his radio program to stir up opposition among evangelical supporters throughout the state. Unfortunately, the March 1992 Indiana Chapter Newsletter headline read "Living Will Revisions Lose by 55-43 Vote." The revision would have allowed terminally ill patients themselves the option to accept or refuse artificial feeding. The sponsor of the bill blamed lobbying efforts from the religious right for its defeat. In 1993, revisions to the Living Will Act were again introduced to allow the patient to refuse artificial nutrition and hydration, but the bill was again defeated. (The right of competent adults to refuse medical treatment was affirmed by the U.S. Supreme Court in June 1990.)

In 1993, largely in reaction to the hysteria surrounding news reports about Dr. Kevorkian, an Indiana Senate bill was introduced to make assisted suicide a felony. It was ultimately passed into law. The front-page story in the January 1994 Indiana Chapter *Newsletter* was "Legislative Committee Sabotages Discussion of Assisted Suicide Felony Law." This forestalled an attempt to overturn the statute that carries penalties of a two-year to eight-year prison term and a fine of up to \$10,000 for anyone assisting a suicide in Indiana. The fall 1997 issue of the *Newsletter* reported on the U.S. Supreme Court's ruling that there is no constitutional right to physician-assisted death. The matter was left to the 50 state legislatures to decide.

As of this writing, medical aid in dying legislation exists in Washington, Oregon, California, Colorado, New Jersey, Vermont, Maine, and the District of Columbia. It is also allowed by judicial decision in Montana by judicial decision. In 2019, 19 other states, Indiana among them, had pending legislation on medical aid in dying.

On November 3, 2015, a letter to the editor of the Bloomington *Herald-Times* written by Carrol Krause, a terminally ill Bloomington writer struck a chord around the state. In response, Bloomington State Representative Matt Pierce submitted legislation the following year for medical aid in dying. Although the bill had not made it out of committee at the time of this writing, Rep. Pierce has steadfastly resubmitted it in each succeeding year.

Newsletters, Publications for the General Public, and Our Web and Facebook Sites

The Indiana chapter's newsletters were very useful for communication with members, although the frequency of the newsletters dropped in recent years from quarterly to annually. The first Hemlock of

Indiana *Newsletter* issue appeared in September 1990 as volume 1, number 1. It contained the results of a poll of 153 Bloomington area doctors with some surprising results. Of the 31 respondents, only 14 were familiar with the Durable Power of Attorney for Health Care, but all knew about the Living Will. Seventeen said they would provide a lethal dose of drugs to a terminally ill person if it were legal to do so, and 23 supported a patient's right to ask for aid in dying. Eight years later, the winter 1998 *Newsletter* reported on the Hoosier Poll, which found that slightly more Indiana residents opposed physician-assisted-dying for terminally ill patients than supported it. The same issue contained the article "An Option in Dying: Refusal of Nutrition and Hydration."

Volume 1, no. 2 of the Hemlock of Indiana *Newsletter* (January 1991) contained information about the availability of the documents "Living Will," "Health Care Power of Attorney," and a "Guideline," all of which could be purchased from the organization for \$3.50. An elder care attorney in Bloomington, Thomas S. Emison, and Stephanie Thomas created the first Indiana Living Will/Health Care Power of Attorney kits. Mr. Emison contributed his legal expertise on a pro bono basis. In June 1991, the kit was being promoted in the newsletter, and by the end of the year, 186 kits had been sold. By March 1993, that number had risen to over 600 kits. Since the early 2000s, these have been distributed at no cost, and now many helpful documents are available on the state chapter and national web sites. These include an updated version of Indiana Advance Directives (Living Will and Health Care Power of Attorney) from the national organization.

The first Compassion and Choices of Indiana web site was created by board member Miren Beristain in 2005, and she continued in that role until around 2013 when Gary Wiggins took on the responsibility. It later appeared that the national Compassion & Choices would offer a web service that satisfied all the needs of the state, so the local web site was abandoned. When that proved not to be as expected, a site was established to cater more directly to Indiana concerns. The URL for that web site is: http://hoosierpewter.com/ccind/index.html.

The Facebook group page at <u>https://www.facebook.com/groups/compassionandchoicesofindiana/</u> had 116 members at the beginning of 2020. Gary Wiggins, Tiana Wilson, Kel McBride, and Katie Wingo were the administrators of the group at that time.

End-of-Life Consultants

End-of-Life Consultants (formerly called "Client Support Services" and before that, the "Caring Friends Program") provided both members and non-members with informational support and referrals on their end-of-life options. The Indiana Chapter sponsored three volunteers for special training by the national organization in the mid-1990s, but no one officially serves in that capacity now.

Financial Matters

A note in the March 1991 Hemlock of Indiana *Newsletter* stated that local and state efforts were funded only by local chapter dues, donations, and book sales. Among the books available at that time were the just published *Final Exit* by Derek Humphry and Betty Rollin's *Last Wish*. In June 1991 annual dues accounted for one-third of the chapter income, whereas contributions from supporters made up onehalf of the total budget. The proposed budget for April 1992 – April 1993 was \$2,450.

Starting in 1994, the national office began to send annually \$10 to the chapter for each Indiana membership. Around 2005, that practice was stopped in favor of annual grant requests. In 2006, the grant was \$3,000. In the last couple of years, national has sent smaller amounts in response to specific chapter requests. Private donations also support the Indiana chapter. There was a fundraiser among our membership in 2003-04 which raised \$2,796. Part of the money was used to purchase an attractive lightweight display to use at the health fairs. The chapter also raised money from speaking fees. With the re-organization of the state into Action Teams, funding is now available only through the national organization.

Conclusion

For over three decades, Compassion & Choices has functioned in Indiana as a valuable source of information and assistance for end-of-life decisions. This is the result of the dedicated service of many volunteers. Together they have helped Indiana residents to be better informed on their options for a dignified death.

NOTE: Much of the information in this document was taken from the Compassion & Choices of Indiana *Newsletters*. Correspondence and other historical documents from the organization's archives were also consulted in compiling the history. Stephanie Thomas also provided valuable input and review.