	Case 2:20-cv-01306-KJM-KJN Documer	nt 33	Filed 11/19/21	Page 1 of 3
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18	FULL CIRCLE OF LIVING AND DYING, et	t (Case No. 2:20-cv	-01306-KJM-KJN
19	al.,			OMPASSION & LEAVE TO FILE
20 21	Plaintiffs, v.			F IN SUPPORT OF MOTION FOR
22	GINA SANCHEZ, in her official capacity as Bureau Chief of the Cemetery and Funeral		Hearing Date: De	
23	Bureau, et al.,	,	Time: 10:00 am Place: 3, 15th Flo	
24	Defendants.		Judge: Hon. Kim	berley J. Mueller
25]	Date of filing: No	ovember 19, 2021
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Compassion & Choices respectfully moves this Court for leave to file an amicus brief in support of Plaintiffs' motion for summary judgment, a case that involves important public policy and Constitutional issues regarding the end-of-life. A court has broad discretion in deciding whether amicus counsel should be appointed. *Missouri v. Harris*, No. 2:14-cv-00341-KJM-KJN, 2014 WL 2987284 at *2 (E.D. Cal. July 1, 2014). An amicus brief is ordinarily allowed when it provides unique information or perspective that can help the court beyond the information provided by the parties. *Id*.

8 Compassion & Choices is a non-profit organization whose mission is to improve end-of-9 life care, expand end-of-life options, and empower everyone to chart their end-of-life journey. Its 10 services include educating the public about the importance of end-of-life planning and about the 11 range of end-of-life services available, advocating for expanded end-of-life options and medical 12 practices that prioritize patients, and defending against efforts to restrict access to existing end-of-13 life options.

Given its mission and services, Compassion & Choices has a substantial interest in and is
uniquely positioned to comment on the issues at stake in this litigation; namely, whether death
doulas should be regulated as funeral directors. If granted leave to file, Compassion & Choices
can offer its unique perspective about the importance of death doulas in the end-of-life process
and the impact that regulating death doulas as funeral directors will have on the individuals who
benefit from their valuable services.

For these reasons, Compassion & Choices asks this Court to grant its motion for leave tofile the attached amicus brief.

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MOTION OF COMPASSION & CHOICES FOR LEAVE TO FILE AMICUS BRIEF CASE NO. 2:20-CV-01306-KJM-KJN

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1	Dated: November 19, 2021		
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3		HANA O O'MELV	OH VENY & MYERS LLP
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5		By:	/s/ John Kappos
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1 2 3 4 5 6 7 8 9 10	JOHN KAPPOS (CA Bar No. 171977) HANA OH (CA Bar No. 300846) (admission per O'MELVENY & MYERS LLP 610 Newport Center Drive 17 th Floor Newport Beach, California 92660-6429 Telephone: +1 949 823 6900 Facsimile: +1 949 823 6994 KEVIN DÍAZ (pro hac vice forthcoming) COMPASSION & CHOICES 101 SW Madison Street Unit 8009 Portland, Oregon 97207 Telephone: +1 503 943 6532 Facsimile: +1 503 228 9160 JESSICA PEZLEY (pro hac vice forthcoming) COMPASSION & CHOICES	nding)
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16	EASTERN DISTRIC	T OF CALIFORNIA
17	FULL CIRCLE OF LIVING AND DYING;	Case No. 2:20-cv-01306-KJM-KJN
17 18 19	BONNIE "AKHILA" MURPHY; DONNA PEIZER; PAMELA YAZELL; KAY HOGAN; JANAIA DONALDSON; AND ROBIN	BRIEF OF AMICUS CURIAE COMPASSION & CHOICES IN
18	BONNIE "AKHILA" MURPHY; DONNA PEIZER; PAMELA YAZELL; KAY HOGAN; JANAIA DONALDSON; AND ROBIN MALLGREN,	BRIEF OF AMICUS CURIAE
18 19	BONNIE "AKHILA" MURPHY; DONNA PEIZER; PAMELA YAZELL; KAY HOGAN; JANAIA DONALDSON; AND ROBIN	BRIEF OF AMICUS CURIAE COMPASSION & CHOICES IN SUPPORT OF PLAINTIFFS' MOTION FOR SUMMARY JUDGMENT Hearing Date: December 17, 2021
18 19 20	BONNIE "AKHILA" MURPHY; DONNA PEIZER; PAMELA YAZELL; KAY HOGAN; JANAIA DONALDSON; AND ROBIN MALLGREN, Plaintiffs, v. GINA SANCHEZ, in her official capacity as	BRIEF OF AMICUS CURIAE COMPASSION & CHOICES IN SUPPORT OF PLAINTIFFS' MOTION FOR SUMMARY JUDGMENT Hearing Date: December 17, 2021 Time: 10:00 am Place: 3, 15th Floor
18 19 20 21	BONNIE "AKHILA" MURPHY; DONNA PEIZER; PAMELA YAZELL; KAY HOGAN; JANAIA DONALDSON; AND ROBIN MALLGREN, Plaintiffs, v. GINA SANCHEZ, in her official capacity as Bureau Chief of the Cemetery and Funeral Bureau; KIMBERLY KIRCHMEYER, in her	BRIEF OF AMICUS CURIAE COMPASSION & CHOICES IN SUPPORT OF PLAINTIFFS' MOTION FOR SUMMARY JUDGMENT Hearing Date: December 17, 2021 Time: 10:00 am Place: 3, 15th Floor Judge: Hon. Kimberley J. Mueller
 18 19 20 21 22 23 24 	BONNIE "AKHILA" MURPHY; DONNA PEIZER; PAMELA YAZELL; KAY HOGAN; JANAIA DONALDSON; AND ROBIN MALLGREN, V. GINA SANCHEZ, in her official capacity as Bureau Chief of the Cemetery and Funeral Bureau; KIMBERLY KIRCHMEYER, in her official capacity as Director of the Department of Consumer Affairs; and LOURDES	BRIEF OF AMICUS CURIAE COMPASSION & CHOICES IN SUPPORT OF PLAINTIFFS' MOTION FOR SUMMARY JUDGMENT Hearing Date: December 17, 2021 Time: 10:00 am Place: 3, 15th Floor
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I.

INTEREST OF AMICI CURIAE

Compassion & Choices is a non-profit organization whose mission is to improve care, expand options, and empower everyone to chart their end-of-life journey. Its services include educating the public about the importance of documenting their end-of-life values and priorities, empowering individuals to control their end-of-life care by providing information about the fullrange of available options at the end of life, advocating for expanded end-of-life options and improved medical practices that prioritize patients, and defending existing end-of-life options from efforts to restrict access.

9 Given its mission and services, Compassion & Choices is uniquely positioned to comment 10 about the importance of death doulas-service providers who support individuals and the 11 relatives of individuals nearing the end of life-and why they should not be regulated as funeral 12 directors. It submits this brief to inform the court that ruling in favor of Defendants will force 13 most, if not all, death doulas out of practice. This will have adverse consequences for the many 14 individuals who benefit from the services and information that death doulas provide. Such a 15 ruling will significantly reduce access to key information for individuals nearing the end of life 16 and their relatives, the control individuals have over their end-of-life and after-death care, and 17 their ability to die and have a post-death ritual in accordance with their values and beliefs.

18

II.

SUMMARY OF ARGUMENT

Death doulas are laypeople who support individuals nearing the end of life and their
family members. They do so emotionally, spiritually, and practically. Death doulas also educate
these individuals by providing information about end-of-life and after-death care options, such as
at-home funerals, cremations, and green burials. In providing these services, death doulas
empower individuals to feel confident in making important end-of-life decisions about their care
so that individuals can remain true to their values and beliefs as they go through the dying
process.

The services that death doulas provide play an important role in furthering patient-directed
care at the end of life. They do so in a number of ways. First, they complement traditional end-of-

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life medical care services by providing non-judgmental emotional, practical, and spiritual support.
Second, death doulas fill a void in the healthcare system by acting as a patient advocate. They do
so by helping individuals make more informed and personalized decisions about their care
through education about end-of-life and after-death options. Third, death doulas fill a void in
conventional funeral home and funeral director services by assisting families with the grieving
process and by supporting the availability of affordable funeral alternatives through transparent
information about those alternatives.

8 Death doulas should not be subject to the same regulations as funeral homes and funeral 9 directors. Death doulas offer fundamentally different services than funeral homes and funeral 10 directors and do not touch the activities that legislators intended to regulate through the Cemetery 11 and Funeral Act. Moreover, strictly regulating death doulas as funeral directors will effectively 12 put death doulas out of business as many lack the financial resources to comply with the 13 expensive regulations of that industry. This will consequently extinguish their ability to provide 14 information about end-of-life options and will hurt dying individuals and their loved ones by 15 limiting their ability to make informed decisions about their end-of-life and after-death care. 16 Lastly, regulating death doulas as if they were funeral homes or funeral directors infringes on 17 their First Amendment free speech right to provide information about end-of-life and after-death 18 care options and of their clients' rights to receive this information.

- 19 III. ARGUMENT
- 20 21

A. <u>Death doulas are laypeople who provide support and information to empower</u> <u>individuals at the end of life.</u>

A "doula" is a trained companion who supports others through a significant health-related
experience. The term "Doula" is Greek in origin and roughly translates to "a woman who

serves."¹ Notably, a doula is traditionally a layperson with no formal medical education.² They do

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26 Coburn Dukehart, *Doulas: Exploring a Tradition of Support*, NPR (July 14, 2011), https://www.npr.org/sections/babyproject/2011/07/14/137827923/doulas-exploring-a-tradition-of-support.

27 ² Marian Krawczyk & Merilynne Rush, *Describing the end-of-life doula role and practices of care: perspectives from four countries*. 14 J. Palliative Care & Soc. Prac. 1, 1 (2020), available
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not provide medical support or advice.³ Rather, doulas provide information, emotional support,
and physical comfort during major medical events.⁴ While the term "doula" traditionally referred
to those who assist women giving birth,⁵ the term has expanded to also include those who help
guide individuals and their loved ones through the dying process.

A death doula, also known as an end-of-life doula, is an emerging form of communitybased caregiver whose job is to help individuals nearing the end of life—as well as their loved
ones—navigate that experience as peacefully and supportively as possible.⁶ The death doula
movement is growing,⁷ as is the recognition of the unique care and contributions they provide at
the end of life.⁸

Consistent with the definition of a traditional doula, death doulas are laypeople that have
 no specialized professional training.⁹ They do not provide medical treatment or advice, legal
 advice, or formal counseling or therapy.¹⁰ Nor do they provide embalming, funeral, or

transportation services.¹¹ Rather, death doulas provide four important things to those nearing the
end of life.

First, death doulas offer non-judgmental emotional, spiritual, and practical support to dying individuals and their loved ones. This support—whether it is holding a dying individual's hand or keeping an individual's grieving family company—is immeasurably important to an individual and their loved ones at the end of life. Some doulas continue to provide care after an individual's death, such as helping the grieving family wash and dress the body or assisting with

⁵ Merriam-Webster (November 6, 2021), available at https://www.merriam-webster.com/dictionary/doula#:~:text=%3A%20a%20woman%20experienced%20in%20childbirth,during%2C%20a
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24 $\| {}^{6}$ See Krawczyk, supra note 2 at 5.

 7 *Id.* at 2.

⁸ Hannah Hagemann, Death Doulas Are Becoming Part of the End-of-Life Equation (January 3, 2020), available at https://www.npr.org/2020/01/03/793257344/one-way-to-die-hire-an-end-of-life-doula.

⁹ Krawczyk, *supra* note 2 at 1.

27 10 See id. at 5-7.

 $28 ||^{11}$ See id. at 8.

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 $^{20 \}quad \boxed{\frac{3}{Id. \text{ at } 8.}}$

²¹ $||_{4}$ *Id.* at 5.

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home funerals.¹² Second, death doulas provide education about end-of-life and after-death
planning. They may do this on an individual level, speaking directly to a dying individual about
their specific priorities and to help them understand their end-of-life and after-death options.
Death doulas may also provide education at a community level, hosting community education
events and advance care planning workshops, to help remove stigma from conversations about
death and encourage the public to engage in end-of-life planning.¹³ This education assists
individuals in making fully informed end-of-life decisions.

8 Third, death doulas often act as a patient advocate, helping ensure an individual gets the 9 care they want. Death doulas achieve this by amplifying a patient's voice and assisting them as 10 they navigate the complexities of obtaining the care they want. For example, death doulas can 11 discuss an individual's priorities and provide information helpful to an individual as they 12 memorialize their end-of-life wishes in an advance directive or help an individual navigate the 13 complicated statutory requirements of obtaining a medical aid-in-dying prescription.¹⁴ 14 Lastly, death doulas empower an individual to make decisions about their own end-of-life

15 care or assist in the care of a loved one.¹⁵ By providing support and information to dying
16 individuals and their loved ones, death doulas help ensure that individuals receive the care that is
17 best for them at the end of life.

18 Death doulas provide these services in a variety of settings, including at an individual's
19 home, hospice centers, hospitals, and long-term care facilities.¹⁶ While some death doulas charge
20 modest fees for their services, many death doulas work on a volunteer basis.¹⁷

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¹² *Id.* at 5-6.

- ¹⁴ See Kim Callinan, Medical Aid in Dying: The Role of Death Doulas, Compassion & Choices (February 1, 2021), available at https://compassionandchoices.org/news/medical-aid-in-dying-the-role-of-death-doulas/; see also Cal. Health & Safety Code § 443.2-3 (West).
- 25 1^{5} Krawczyk, *supra* note 2 at 7.
 - ¹⁶ *Id*. at 6.

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 ¹⁷ See generally Kara Mason, Embracing End-of-life doulas growing in popularity, Associated Press (May 15, 2021), available at https://apnews.com/article/coronavirus-pandemic-lifestyle-health-business-

- 3b4e6af60889b69fde4f8fc14d01f7af; see also Abby Ellin, 'Death Doulas' Provide Aid at the End of Life, New York
- 28 Times (June 25, 2021), available at https://www.nytimes.com/2021/06/24/well/doulas-death-end-of-life.html.

¹³ *Id.* at 1-2.

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B. <u>Death doulas fill a void in traditional healthcare and funeral services and advance patient-directed care.</u>

Medical care is only one aspect of the support an individual needs at the end of life. Death doulas help to make end-of-life care more holistic, focusing on an individual's spiritual, emotional, and practical needs, while also educating and empowering individuals to make the end-of-life and after-death decisions that are best for them. Working with medical professionals, death doulas fill a void in the traditional medical system, helping to ensure an individual's care is self-directed and fits their unique needs.

9 The medical profession has traditionally been focused on treating patients' illnesses through a physician-directed approach.¹⁸ Under this approach, healthcare workers provide care 10 11 based on evaluating the signs and symptoms presented by a patient, recommending medically 12 indicated courses of treatment, observing and assessing the outcome of that treatment, and then repeating this cycle if necessary.¹⁹ While this approach can be effective in curing illness, the 13 patient's individual wants and needs are largely ignored.²⁰ Under this model, physicians, and not 14 15 patients, are the decision makers. In essence, a patient's limited role under this paternalistic 16 method is to trust and comply with the directions of trained medical staff. 17 In response to physician-directed care, a new healthcare ideology has emerged that 18 focuses on a patient's individual needs and desires, allowing the patient to direct the care they

19 receive.²¹ Patient-directed care offers a more holistic approach tailored to meet a patient's

20 medical needs *and* individual priorities.²² Patients are the decision maker and have a high level of

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¹⁸ Raman Kumar & Vijay Kumar Chattu, *What is in the name? Understanding terminologies of patient-centered, person-centered, and patient-directed care,* 7 J. Fam. Med. Prim. Care 487, 487 (2018), available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6069658/.

control in choosing or refusing treatment in accordance with their individual values.²³ This

- 24 ¹⁹ See id.
 - ²⁰ See id.
- 26 22 *Id.*

27 ²³ Id. at 488; see also Barbara Coombs Lee, From Patient-Centered to Patient-Directed Care, Compassion & Choices (March 1, 2019), available at https://compassionandchoices.org/news/from-patient-centered-to-patient-directed-care/

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1	approach thus shifts decision-making power into the hands of the patient, allowing them
2	autonomy to direct their own medical care. Patient-directed care is especially important at the end
3	of life, allowing an individual's values and beliefs to guide the kind of care they receive in their
4	final moments of life. ²⁴
5	Death doulas play an important role in advancing patient-directed care in two ways. First,
6	they assist in ensuring that patients are provided with the full spectrum of care at the end-of-life.
7	Second, they help to fill a void in end-of-life care provided in traditional healthcare settings.
8 9	1. Death doulas further patient-directed care by providing information and services that support an individual's practical, emotional, and spiritual needs at the end of life.
10	Death doulas help to enhance the full spectrum of care by offering the support and
11	education necessary for individuals to feel empowered and make fully-informed end-of-life
12	decisions. The full-spectrum of care at the end of life offers comprehensive and holistic treatment
13	to patients nearing the end-of-life, addressing an individual's medical, psychological, social,
14	cultural, and spiritual needs. ²⁵ Providing an individual nearing the end of life with the full
15	spectrum of care options helps to manage the discomfort, symptoms, and stress of what they are
16	experiencing and improves the individual's quality of life by ensuring that <i>all</i> of their needs are
17	met. ²⁶
18	A death doula's services complement the full spectrum of care at the end of life in myriad
19	ways. First, death doulas provide important education to individuals nearing the end of life and to
20	their loved ones that would otherwise be difficult to obtain. For example, death doulas provide
21	information about after-death options, such as at-home funerals and cremation, as well as about
22	the laws that govern a decedent's body. ²⁷ Without the valuable services that death doulas provide,
23	individuals would be forced to rely on funeral homes and funeral directors for this information—
24	24 Coombs Lee, <i>supra</i> note 23.
25 26	²⁵ See generally Derek Doyle, <i>Principles of Palliative Care</i> , International Association for Hospices and Palliative Care (November 6, 2021), available at https://hospicecare.com/what-we-do/publications/getting-started/principles-of-palliative-care/.
20 27	 ²⁶ Palliative care: A spectrum of support, NIH Medline Plus Magazine (April 24, 2018), available at https://magazine.medlineplus.gov/article/palliative-care-a-spectrum-of-support.
28	²⁷ Krawcyzk, <i>supra</i> note 2 at 7.

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1	actors that have a vested financial interest in promoting conventional funeral home services-and
2	are thus less likely to learn about alternatives to conventional funerals. ²⁸
3	Second, death doulas work closely with individuals at the end of life to help them better
4	understand their emotions and spiritual beliefs as they navigate their experience. ²⁹ In doing so,
5	death doulas help individuals and their loved ones cope with the difficult emotions that inevitably
6	arise during the end-of-life process. Understanding these emotions gives individuals a greater
7	sense of control over the process and helps to preserve individual dignity throughout the end of
8	life. ³⁰
9	Lastly, because death doulas are able to spend a significant amount of time with their
10	patients, they have a greater capacity to be present with individuals nearing the end of life than
11	traditional healthcare workers. This flexibility allows death doulas to be more responsive to the
12	patient's supportive needs as they arise than traditional healthcare workers.
13	By providing individuals nearing the end of life with valuable information and services
14	that advance the full spectrum of care, death doulas help enhance patient-directed care by
15	empowering them to dictate the terms of their care at the end of life and after death.
16 17	2. Death doulas fill a void in the healthcare system by bolstering informed consent and by complementing care from hospices, hospitals, and senior care facilities.
18	Traditional healthcare systems—such as hospice care, palliative care, nursing homes, and
19	senior-care facilities—are primarily concerned with the medical aspect of end-of-life care,
20	focusing on controlling pain and other symptoms to provide maximum comfort to a dying
21	patient. ³¹ These traditional healthcare providers, however, are generally unable to exclusively
22	focus on the emotional, spiritual, or practical needs of an individual or their loved ones at the end
23	of life.
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25	²⁸ Victoria J. Haneman, Funeral Poverty, 55 U. Mich. L. Rev. 387, 405-06 (2021).
	²⁹ See Krawcyzk, supra note 2 at 7.
26	³⁰ See Jennifer A. Woo, Guy Maytal & Theodore A. Stern, <i>Clinical Challenges to the Delivery of End-of-Life Care</i> , 8 Prim. Care Companion J. Clin. Psych. 367, 368 (2006), available at https://doi.org/10.4088/pcc.v08n0608.
27 28	³¹ <i>NCI Dictionaries</i> , National Cancer Institute (November 6, 2021), https://www.cancer.gov/publications/dictionaries/cancer-terms/def/end-of-life-care.
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1	One reason for this is that healthcare workers often lack resources to assist with a patient's
2	full range of end-of-life needs. ³² In 2003, a poll of 1455 medical students and 296 residents
3	affiliated with 62 accredited U.S. medical schools found that only 18% of participants had
4	received any formal training in end-of-life care. ³³ In addition to a lack of training in delivering
5	difficult news to patients, traditional healthcare workers often lack the resources to provide
6	healthcare that is individually tailored to the needs of the patient given the burdensome demands
7	of caring for multiple patients, even though they may want to. This was especially pronounced
8	during the COVID-19 pandemic. ³⁴ Because of these inadequacies, patients nearing the end of life
9	frequently lack holistic support from traditional healthcare workers.
10	Another reason is that healthcare workers are often uncomfortable in talking about death
11	with patients or with that person's family members. ³⁵ This discomfort may be partly driven by a
12	generational shift in perspective about death. This shift has morphed death from an ordinary part
13	of life into a taboo that should be seldom spoken about. ³⁶ Furthermore, end-of-life healthcare
14	workers are often undercompensated as compared to other healthcare workers and are thus
15	disincentivized from more meaningfully connecting with their patients. ³⁷
16	On top of the challenges presented by the inadequacies of traditional end-of-life
17	healthcare offerings, many patients nearing the end of life often have limited access to these
18	options. ³⁸ This stems partly from restrictive definitions of who qualifies for end-of-life
19	treatment. ³⁹ For example, some health insurance plans only cover individuals who are
20	³² Woo, et al., <i>supra</i> note 30 at 369.
21	 ³³ Amy M. Sullivan, Matthew D. Lakoma & Susan D. Block, <i>The Status of Medical Education in End-of-life Care</i>,
22	18 J. Gen. Intern. Med. 685, 685 (2013), available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1494921/pdf/jgi_21215.pdf.
23	³⁴ See Mason, supra note 17.
	³⁵ Woo, et al., <i>supra</i> note 30 at 370.
24 25	³⁶ See Haneman, supra note 28 at 390; see also Lee Webster, Why Caring For Our Own Dead Is An Act of Social Justice, 8 Wake Forest J. L. & Pol'y 125, 127 (2018).
	³⁷ See Woo, et al., <i>supra</i> note 30 at 369-70.
26 27	³⁸ Michael Ollove, <i>Why Some Patients Aren't Getting Palliative Care</i> , Pew Charitable Trusts (July 10, 2017), available at https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2017/07/10/why-some-patients-arent-getting-palliative-care.
28	³⁹ <i>Id.</i>
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hospitalized or in hospice.⁴⁰ Consequently, these services typically do not cover individuals who
are expected to live fewer than six months or who cease curative treatment, forcing patients into
the uncomfortable dilemma of either continuing treatment and fighting to stay alive or foregoing
treatment and accessing end-of-life care.⁴¹ Moreover, even when insurance plans do cover end-oflife care, they rarely cover home visits.⁴² This is all compounded by a lack of awareness about the
availability of robust end-of-life care, like palliative care, with one recent survey indicating that
fewer than 30% of participants knew about palliative care.⁴³

8 Death doulas help address these healthcare shortcomings in several ways. First, because 9 dealing with death is an everyday part of their job, death doulas are well equipped to provide non-10 medical support to help individuals nearing death navigate that experience. Death doulas do not shy away from death; they embrace it.⁴⁴ They are comfortable discussing and preparing for death. 11 This comfort ensures that they can engage in meaningful dialogue with clients about their end-of-12 13 life experiences, help individuals create an end-of-life plan, advocate for an individual's end-of-14 life needs, and provide the non-judgmental emotional, practical, and spiritual support that these 15 patients often lack.

Second, death doulas help provide affordable end-of-life care to individuals who may not
be able to access expensive, traditional end-of-life care options. This is because unlike traditional
end-of-life care providers, many death doulas work on a volunteer or donation basis.⁴⁵ Because of
this affordability, death doulas serve a segment of the population that would otherwise be without
meaningful end-of-life care. Lastly, death doulas provide important information about end-of-life
planning options and help raise awareness about traditional healthcare offerings like palliative

- 22
- 23 ⁴⁰ *Id.*

⁴¹ Id.

24 || ⁴² *Id.*

27 ⁴⁴ See John Leland, *The Positive Death Movement Comes to Life*, New York Times (June 22, 2018), available at https://www.nytimes.com/2018/06/22/nyregion/the-positive-death-movement-comes-to-life html.

 $28 \parallel 45$ Ellin, *supra* note 17.

 ⁴³ Signe Peterson Flieger, Kenneth Chui & Susan Koch-Weser, *Lack of Awareness and Common Misconceptions About Palliative Care Among Adults: Insights from a National Survey*, 35 J. Gen. Intern. Med. 2059, 2059 (2020), available at https://link.springer.com/content/pdf/10.1007/s11606-020-05730-4.pdf.

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care that many patients may be unaware of.⁴⁶ In doing so, death doulas help patients navigate
 complex healthcare systems to get the care that works best for them medically, personally, and
 financially. As such, death doulas help ensure that individuals can exercise their autonomy by
 making fully informed decisions.⁴⁷

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Death doulas fill a void in conventional funeral director services by assisting families with the grieving process and by educating the community about affordable funeral alternatives.

Death doulas perform a fundamentally different role than that of funeral directors
operating out of a funeral home. Death doulas work with dying individuals and their loved ones to
help ascertain the after-death ritual that is best for them, whether it is a conventional burial,
cremation, or home funeral. After an individual dies, death doulas assist their loved ones as they
navigate the grieving process and help effectuate an individual's after-death decisions.

12 By contrast, a conventional funeral director's services are focused on providing logistical 13 and administrative services, not emotional support. According to the Bureau of Labor Statistics 14 Outlook Handbook, a funeral director's typical responsibilities include removing and transporting 15 corpses, confirming signs of death, embalming corpses, planning funerals, preparing obituaries, 16 coordinating burials and cremations, and handling administrative tasks such as obtaining death certificates and notifying the Social Security Administration of a person's death.⁴⁸ While a 17 18 funeral director may also provide information and resources on support groups to help the 19 grieving friends and family, most outsource these services rather than provide them themselves.⁴⁹ 20 However, many people cannot take advantage of these conventional funeral services 21 because they have become prohibitively expensive. Today, the median funeral costs are close to ten thousand dollars.⁵⁰ This is particularly troubling given that a recently conducted survey by the 22

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- ⁴⁶ See Krawcyzk, supra note 2 at 7.
- ⁴⁷ See *id.* at 8; see also Woo, et al., supra note 30 at 368.
- ⁴⁸ Bureau of Labor Statistics, *Occupational Outlook Handbook, Funeral Service Occupations*, Department of Labor
 (*last modified* October 21, 2021), https://www.bls.gov/ooh/personal-care-and-service/funeral-service-occupations.htm#tab-2.
- 27 49 See id.
- 28 ⁵⁰ Haneman, *supra* note 28 at 412.

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Federal Reserve found that a quarter of Americans identified that they would be unable to afford an unexpected \$400 emergency expense.⁵¹

Death doulas help fill the gaps in conventional funeral services by providing services not
usually offered by funeral directors and by shedding light on more affordable alternatives.
Through this service, death doulas help ensure that a grieving family's needs are met and that a
dying individual and their loved ones know the full range of after-death options so they can
choose the option that best fits their spiritual, cultural, and individual needs.

First, while most funeral directors do not offer grief support to a decedent's family
members, grief support is an integral part of a death doula's responsibilities. This includes
providing emotional and spiritual support to a decedent's friends and loved ones to help them
navigate the grief associated with death and the dying process. Beyond this, death doulas offer
emotional support to dying individuals throughout the entire process, and sometimes long before,
unlike funeral directors who typically become involved only after a person's death.

14 Second, death doulas help educate consumers in a transparent manner about the full range 15 of after-death options, including alternatives to expensive conventional funeral home services, so 16 that individuals can meaningfully select between those options. For example, death doulas 17 regularly inform individuals about at-home funerals, cremations, and green burials as part of their 18 after-death care-planning sessions. These options all cost substantially less than a conventional funeral service,⁵² and may better align with an individual's cultural, spiritual, or environmental 19 20 beliefs. In providing these educational services, death doulas help ensure that individuals are 21 informed about *all* after-death options, including conventional funerals and funeral alternatives. 22 Individuals may still decide that a conventional funeral best suits their needs. A death doula's job 23 is not to dissuade them of that decision. It is simply to ensure that individuals know their full-24 range of options before they make *any* decision; conventional and at-home funeral alike.

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28 \parallel ⁵² See Haneman, supra note 28 at 429-30.

 ⁵¹ Board of Governors of the Federal Reserve System, *Report on the Economic Well-Being of U.S. Households in* 2020, at 21 (2021), available at https://www.federalreserve.gov/publications/files/2020-report-economic-well-beingus-households-202105.pdf.

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C.

<u>Death doulas should not be subject to the same regulations as a conventional</u> <u>funeral home or funeral director.</u>

Death doulas should not be regulated as funeral directors for several reasons. First, death doulas are laypeople who do not provide funeral director services. Second, regulating death doulas as funeral directors will force most out of existence, undermining patient-directed care and reduce options for end-of-life care. Third, the strict regulation of death doulas as funeral directors violates death doulas' rights to provide such information and the rights of patients and their loved ones to receive it.

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1. Death doulas do not offer services that touch the operations of funeral homes or funeral directors and are thus outside the scope of services that legislators intended to regulate.

11 California Business and Professions Code Section 7622.2 states "A person shall not open 12 or maintain a place or establishment at which to engage in or conduct, or hold himself, herself, or 13 itself out as engaging in or conducting, the activities of a funeral director without a license." Cal. 14 Bus. & Prof. Code § 7622.2 (West). Further, California Business and Professions Code Section 15 7601.1 states that "Protection of the public shall be the highest priority for the Cemetery and 16 Funeral Bureau in exercising its licensing, regulatory, and disciplinary functions" and that 17 "[w]henever the protection of the public is inconsistent with other interests sought to be 18 promoted, the protection of the public shall be paramount." Id. § 7601.1 (West). 19 As discussed previously in Section III.2.B, a key part of a funeral director's 20 responsibilities include confirming signs of death, obtaining death certificates, and transporting, 21 disinfecting, embalming, and disposing of corpses through either burial or cremation.⁵³ Carrying 22 out these responsibilities involves the exercise of technical skill. For example, the embalming 23 process consists of making incisions in a corpse, removing the blood and bodily fluids, and 24 replacing those fluids with disinfecting solutions such as formaldehyde.⁵⁴ It also involves 25 handling potential disease vectors, as blood-borne viruses can be transmitted by coming into 26

- ⁵³ Bureau of Labor Statistics, *supra* note 48.
- 27 Bureau of Eucor Statistics, supra note 10.
 ⁵⁴ Erich Brenner, *Human body preservation old and new techniques*, 224 J. Anatomy, 316, 319 (2014), available at https://doi.org/10.1111/joa.12160.

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contact with the blood or bodily fluids of another-a fundamental part of the embalming 2 process.⁵⁵ Given the nature of their services and their proximity to potential disease vectors, 3 regulation of funeral directors is appropriate to protect the public health and safety.

4 Moreover, regulations imposed on funeral homes and funeral directors were responsive to 5 the funeral home industry's history of exploiting vulnerable consumers. For example, in the 6 1980's, the Federal Trade Commission enacted the "Funeral Rule"-regulations intended to curb 7 deceptive and unfair pricing practices engaged in by funeral providers. St. Joseph v. Castille, 712 8 F.3d 215, 218 (5th Cir. 2013). These practices included failing to disclose price information and 9 "bundling" products and services to force consumers into buying products and services that they 10 did not need. Id. The Funeral Rule now requires funeral directors to provide consumers with itemized price lists so that they are no longer forced into buying such services. *Id.* And in 2013, 11 12 California went a step further by enacting California Business and Professions Code § 7685, a 13 law that requires funeral directors to publish prices on their websites to ensure fairness and accuracy.⁵⁶ 14

Unlike funeral directors, however, death doulas are laypeople who do not offer the 15 services of funeral homes and funeral directors.⁵⁷ Nor do they handle corpses to the same intimate 16 and invasive degree as funeral directors.⁵⁸ They do not offer embalming services, confirm signs 17 18 of death, or obtain death certificates. Rather, death doulas provide emotional, spiritual, and 19 practical support as well as education about the dying process so that individuals at the end of life feel empowered to make decisions about their care.⁵⁹ And while death doulas may sometimes 20 21 interact with corpses as part of at-home funerals, these interactions do not expose them to

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⁵⁵ Nelson Marlborough District Health Board, *The Infectious Hazards of Dead Bodies* (September 28, 2020), 23 available at https://www.nmdhb.govt nz/dmsdocument/61-the-infectious-hazards-of-dead-bodies ("Hepatitis B and C viruses, and HIV pose a particular risk for those in contact with the blood of the deceased. [E]mbalmers, emergency 24 service workers, and forensic scientists are the occupations most at risk.").

- ⁵⁶ Cal. Bus. & Prof. Code § 7685 (West); Licensed funeral establishments: price list: Internet posting, Hearing on 25 S.B. 658 before the S. Comm. on Bus., Prof., and Econ. Dev., 2011 Leg. (2011), available at https://leginfo.legislature.ca.gov/faces/billAnalysisClient.xhtml?bill id=201120120SB658#.
 - ⁵⁷ See Krawczyk, supra note 2 at 1.

27 ⁵⁸ See id. at 7.

⁵⁹ See id. 28

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1	potential disease vectors since corpses do not generally pose a public health risk. ⁶⁰ As such, a
2	death doula's services do not threaten the public health and safety, and consequently do not
3	undermine the legislature's intent in protecting consumers in this regard.
4	Nor do death doulas pose a threat to consumer protection. Unlike funeral directors, most
5	death doulas work on a volunteer or donation basis. ⁶¹ Thus, unlike funeral directors, death doulas
6	do not have a financial incentive to withhold information from patients and their relatives. On the
7	contrary, death doulas further the interest of consumer protection by providing patients with
8	information about end-of-life services in a transparent manner, which allows patients and their
9	relatives to make informed decisions about after-death care. ⁶² Death doula services, therefore, do
10	not threaten consumer protection and do not undermine the legislature's intent in protecting the
11	public.
12	Because death doulas do not implicate either of the concerns that motivated regulating
13	funeral homes and funeral directors, they should not be regulated in the same manner.
14	2. Regulation of death doulas will severely restrict their ability to provide
15	information about end-of-life options and will hurt patients.
16	Strict regulation of death doulas as funeral directors will prevent most from offering their
17	services at all, undermining patient-directed care. Complying with the regulations that govern
18	funeral directors in California is expensive. A funeral director must obtain an associate degree, or
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	equivalent, and must pass an exam that tests 1) recognizing the signs of death, 2) the manner in
20	equivalent, and must pass an exam that tests 1) recognizing the signs of death, 2) the manner in which death may be determined, 3) the laws governing the preparation, burial, disposal, and
21	which death may be determined, 3) the laws governing the preparation, burial, disposal, and
21 22	which death may be determined, 3) the laws governing the preparation, burial, disposal, and shipment of human remains, and 4) local health and sanitary ordinances and regulations
 20 21 22 23 24 	which death may be determined, 3) the laws governing the preparation, burial, disposal, and shipment of human remains, and 4) local health and sanitary ordinances and regulations governing funeral directing and embalming. Cal. Bus. & Prof. Code § 7622 (West). A funeral
21 22 23	which death may be determined, 3) the laws governing the preparation, burial, disposal, and shipment of human remains, and 4) local health and sanitary ordinances and regulations governing funeral directing and embalming. Cal. Bus. & Prof. Code § 7622 (West). A funeral director may only work at a licensed funeral establishment. <i>Id.</i> § 7619.3. And to be a licensed
21 22 23 24	which death may be determined, 3) the laws governing the preparation, burial, disposal, and shipment of human remains, and 4) local health and sanitary ordinances and regulations governing funeral directing and embalming. Cal. Bus. & Prof. Code § 7622 (West). A funeral director may only work at a licensed funeral establishment. <i>Id.</i> § 7619.3. And to be a licensed ⁶⁰ Webster, <i>supra</i> note 36 at 129; <i>see also Risks posed by dead bodies after disasters</i> , World Health Organization (February 6, 2013), available at https://www.who.int/publications/m/item/risks-posed-by-dead-bodies-after-disasters ("Human remains only pose a substantial risk to health in a few special cases, such as deaths from cholera or
 21 22 23 24 25 	which death may be determined, 3) the laws governing the preparation, burial, disposal, and shipment of human remains, and 4) local health and sanitary ordinances and regulations governing funeral directing and embalming. Cal. Bus. & Prof. Code § 7622 (West). A funeral director may only work at a licensed funeral establishment. <i>Id.</i> § 7619.3. And to be a licensed ⁶⁰ Webster, <i>supra</i> note 36 at 129; <i>see also Risks posed by dead bodies after disasters</i> , World Health Organization (February 6, 2013), available at https://www.who.int/publications/m/item/risks-posed-by-dead-bodies-after-disasters
 21 22 23 24 25 26 	which death may be determined, 3) the laws governing the preparation, burial, disposal, and shipment of human remains, and 4) local health and sanitary ordinances and regulations governing funeral directing and embalming. Cal. Bus. & Prof. Code § 7622 (West). A funeral director may only work at a licensed funeral establishment. <i>Id.</i> § 7619.3. And to be a licensed ⁶⁰ Webster, <i>supra</i> note 36 at 129; <i>see also Risks posed by dead bodies after disasters</i> , World Health Organization (February 6, 2013), available at https://www.who.int/publications/m/item/risks-posed-by-dead-bodies-after-disasters ("Human remains only pose a substantial risk to health in a few special cases, such as deaths from cholera or haemorrhagic fevers.")

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1 funeral establishment, one must maintain a facility containing, at a minimum, a suitable room for 2 storing and embalming human remains. Id. § 7616.

3 Most death doulas operate on a volunteer basis or charge very modest fees. Because of 4 this, many have very small budgets and would be financially unable to comply with these 5 requirements. Full Circle of Living and Dying, for example, operates on a yearly budget of only 6 \$11,000. Declaration of Bonnie "Akhila" Murphy ("Akhila Decl.") ¶ 161. Regulating death 7 doulas as funeral directors will, therefore, decrease the availability of emotional and practical 8 support as death doulas are forced out of practice. Accordingly, dying individuals and their loved 9 ones will be forced to turn to traditional healthcare workers that are ill-equipped to provide the 10 full range of support that patients at the end of life require and to conventional funeral homes and funeral directors who offer limited services and options.⁶³ 11

12 At the same time, regulating death doulas as funeral directors will reduce the availability 13 of information about the full range of after-death options to individuals. This may not have been 14 an issue when conventional funerals were the norm, but individual after-death preferences have changed and continue to change.⁶⁴ Today, a growing number of individuals want access to 15 16 conventional funeral alternatives for emotional, cultural, spiritual, and environmental reasons.⁶⁵ A 17 lack of information about the full range of after-death options will impair an individual's ability 18 to select the after-death option that best fits their values and make it more difficult for individuals 19 to make empowered and informed decisions about what happens to their body after death.⁶⁶ 20 Doing so will undermine informed consent and patient-directed care by depriving individuals of 21 the opportunity to decide the after-death option that is best aligned with their individual needs and beliefs. 22

- 23
- Relatedly, regulating death doulas as funeral directors will reduce the accessibility of information about affordable after-death options. This will disproportionately affect the
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⁶³ See Woo, et al., *supra* note 30 at 369; *see also* Bureau of Labor Statistics, *supra* note 48.

⁶⁴ Tanya D. Marsh, Rethinking the Law of the Dead, 48 Wake Forest L. Rev. 1327, 1340 (2013).

27 ⁶⁵ Id.

⁶⁶ See Woo, et al., supra note 30 at 368. 28

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1 disenfranchised because they are often most dependent on funeral directors for advice after the death of a loved one.⁶⁷ To pay for the expensive funerals these vulnerable individuals are advised 2 that they need, disenfranchised Americans must often turn to loans with expensive interest rates.⁶⁸ 3 4 This outcome exacerbates their precarious financial situation and perpetuates inequality in 5 America.⁶⁹ Depriving consumers of access to information that death doulas provide about 6 affordable funeral alternatives will further encourage these practices. 7 3. Death doulas have a First Amendment right to provide information about end-of-life options and individuals have a right to receive this information. 8 9 The First Amendment, as applied to the States via the Fourteenth Amendment, prohibits 10 the government from passing laws that restrict speech. Nat'l Inst. of Fam. and Life Advoc. v. 11 Becerra, 138. S. Ct. 2361, 2371 (2018). A law that targets speech based on its content is 12 presumptively unconstitutional unless the government shows that the law is "narrowly tailored to 13 serve compelling state interests." Id. 14 As a threshold matter, death doula speech is subject to First Amendment protection 15 because it is constitutionally protected "pure speech." Death doulas educate their clients about 16 after-death care services so that they can make fully informed decisions as they near death that align with their personal values, beliefs, and desires. Part of this education includes offering 17 18 information about services that compete with conventional funeral home services like at-home 19 funerals, green burials, and cremations. Providing this education involves disseminating factual 20 information to clients both verbally and in writing, an activity that the Supreme Court has 21 recognized is protected by the First Amendment. See Bartnicki v. Vopper, 532 U.S. 514, 527 22 (2001) (recognizing that "if the acts of disclosing and publishing information do not constitute 23 speech, it is hard to imagine what does fall within that category" (some internal quotation 24 marks omitted); see also Lovell v. City of Griffin, Ga., 303 U.S. 444, 452 (1938) (recognizing that 25 "[the] liberty of circulating [information] is as essential ... as [the] liberty of publishing [it].")

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27 68 *Id.* at 402-03.

⁶⁷ See Haneman, supra note 18 at 406-07, 412-13.

^{28 &}lt;sup>69</sup> See id. at 416.

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And, a death doula's clients have a right to receive this information. See Martin v. City of

Struthers, Ohio, 319 U.S. 141, 143 (1943) (holding that the First Amendment protects the right to
distribute and receive literature); see also Stanley v. Georgia, 394 U.S. 557, 564 (recognizing that
"the Constitution protects the right to receive information and ideas.").

5 To the extent that the information death doulas provide is factual and not intended to 6 solicit or advertise a commercial transaction, their speech is not commercial in nature. See Bolger 7 v. Youngs Drug Products Corp., 463 U.S. 60, 66 (1983) (explaining that commercial speech is 8 "speech which does no more than propose a commercial transaction") (some internal quotations 9 omitted). But even if this death doula speech is considered commercial in nature, it is still entitled 10 to First Amendment protection. The Supreme Court has long held that commercial speech enjoys First Amendment protection if it concerns lawful activity and is not misleading. Central Hudson 11 12 Gas & Elec. Corp. v. Pub. Serv. Comm'n of N.Y., 447 U.S. 557, 566 (1980) (holding that "for 13 commercial speech to come under [First Amendment] protection, it at least must concern lawful 14 activity and not be misleading."). Death doula speech is protected, even if commercial in nature, 15 because it concerns lawful activity; namely, disseminating information about legal, conventional funeral alternatives like at-home funerals.⁷⁰ It is also not misleading because death doulas do not 16 17 represent themselves as funeral directors or medical professionals. On the contrary, they represent themselves as laypeople who have no specialized training or skills.⁷¹ 18

Moreover, requiring that death doulas be licensed as funeral directors simply because they
provide information about affordable funeral alternatives is a content-based restriction on speech. *See Nat'l Inst. of Fam. and Life Advoc.*, 138 S. Ct. at 2371 (stating that content-based
discriminations "target speech based on its communicative content.") But the government does
not have a compelling interest to justify this content-based restriction. First, death doulas do not
provide services that undermine public health and safety since, unlike funeral directors, they do
not offer embalming services and do not handle corpses to the same invasive extent.⁷² Second,

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27 7^{1} See id. at 1.

28 7^2 See Krawczyk, supra note 2 at 7.

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⁷⁰ See Krawczyk, supra note 2 at 7.

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1 death doulas do not pose a risk to consumer protection since many of them work on a volunteer or donation basis.⁷³ Even if the government had a compelling interest in treating death doulas as 2 3 funeral directors, requiring *every* death doula to be licensed as one is not the least restrictive 4 means of achieving the state's alleged compelling purpose. Treating death doulas as funeral 5 directors would require them to invest in facilities to store and embalm corpses, even though they 6 do not offer these services-the cost of such a facility alone would force most death doulas out of 7 practice. It would also prohibit death doulas from providing *any* information or services (even 8 information and services that have no bearing on the government's alleged public safety or 9 consumer protection interests) without being licensed.

10 That death doulas view themselves as "professionals" does not diminish their First 11 Amendment right to inform their clients. The Supreme Court has held that professionals have 12 equally as strong First Amendment protections in their communications as non-professionals. In 13 National Institute of Family and Life, pro-life organizations challenged the California 14 Reproductive Freedom, Accountability, Comprehensive Care, and Transparency Act arguing that 15 it violated the First Amendment. 138 S. Ct. at 2370. The Act required pro-life centers in 16 California to post flyers in their clinics notifying women of free or low-cost abortion services as 17 well as contact information for obtaining those services. Id. at 2369. The Ninth Circuit held that 18 the organizations' speech enjoyed lessened First Amendment protection because it was 19 professional speech. Id. at 2371. The Supreme Court disagreed, stressing that speech is not 20 subject to lesser protection merely because it is "professional." Id. at 2371-72. Given this holding, 21 it is clear that death doula speech is subject to the same First Amendment protection as non-22 professionals even if their communications can be classified as professional. 23 Because regulating death doulas as funeral directors would infringe on their First 24 Amendment rights and the rights of their clients, they should not be regulated as such. 25 26 27 ⁷³ Ellin, *supra* note 17. 28 BRIEF OF AMICUS CURIAE

- 18 -

COMPASSION & CHOICES

CASE NO. 2:20-CV-01306-KJM-KJN

1	IV.	CONCLUSION	
2		For the foregoing reasons, Plaintiffs' summary judgment motion should be granted.	
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4		Dated: November 19, 2021	
5		JOHN KAPPOS	
6		O'MELVENY & MYERS LLP	
7			
8		By: <u>/s/ John Kappos</u> John Kappos	
9		Attorneys for <i>Amicus Curiae</i> Compassion & Choices	
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	Case 2:20-cv-01306-KJM-KJN Document 33	3-2 Filed 11/19/21 Page 1 of 2		
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15	UNITED STATES DISTRICT COURT EASTERN DISTRICT OF CALIFORNIA			
16 17				
18	FULL CIRCLE OF LIVING AND DYING, et	Case No. 2:20-cv-01306-KJM-KJN		
19 20	al., Plaintiffs,	[PROPOSED] ORDER GRANTING MOTION OF COMPASSION & CHOICES FOR LEAVE TO FILE		
21	v.	CHOICES FOR LEAVE TO FILE AMICUS BRIEF IN SUPPORT OF PLAINTIFFS' MOTION FOR		
22	GINA SANCHEZ, in her official capacity as Bureau Chief of the Cemetery and Funeral	SUMMARY JUDGMENT		
23	Bureau, et al.,	Hearing Date: December 17, 2021 Time: 10:00 a.m.		
24 25	Defendants.	Place: 3, 15th Floor Judge: Hon. Kimberley J. Mueller		
23 26		Date of filing: November 17, 2021		
27				
28		[PROPOSED] ORDER GRANTING		
		MOTION OF COMPASSION & CHOICES 2:20-CV-01306-KJM-KJN		

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1	The Court has received and reviewed the timely motion for leave to file an amicus brief
2	submitted by Compassion & Choices. The motion is GRANTED, and the proposed brief attached
3	to the motion is deemed filed.
4	SO ORDERED
5	
6	Dated: November, 2021
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8	Hon. Kimberley J. Mueller
9	U.S. District Judge
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28	[PROPOSED] ORDER GRANTING - 2 - MOTION OF COMPASSION & CHOICES 2:20-CV-01306-KJM-KJN