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10
11 **IN THE UNITED STATES DISTRICT COURT**
12 **FOR THE NORTHERN DISTRICT OF CALIFORNIA**
SAN FRANCISCO DIVISION

13 LONNY SHAVELSON, M.D.; SANDRA)
14 MORRIS; RHIANNON CERRETO; ROBERT) Civil Action No. 3:21-cv-06654-VC
USLANDER, M.D.; GARY PASTERNAK,)
15 M.D.; and RICHARD MENDIUS, M.D.; on)
behalf of themselves and all others similarly) **MOTION OF THE GOLDEN WEST**
16 situated,) **CHAPTER OF THE ALS**
) **ASSOCIATION, END OF LIFE**
17 Plaintiffs,) **CHOICES CALIFORNIA,**
) **CRIPJUSTICE, and THE**
18 v.) **DISABILITY JUSTICE LAW &**
) **ORGANIZING PROJECT FOR**
19 STATE OF CALIFORNIA; ROBERT BONTA,) **LEAVE TO FILE BRIEF AS *AMICI***
Attorney General of the State of California, in his) ***CURIAE***
20 official capacity; NANCY O’MALLEY, Alameda)
County District Attorney, in her official capacity,)
21 Defendants.)
22

1 The Golden West Chapter of the ALS Association (“Golden West”), End of Life
2 Choices California (“EOLCCA”), CripJustice, and the Disability Justice Law and
3 Organizing Project (“DJL”) (collectively “Movants”) respectfully move this Court for
4 leave to file a brief as *amici curiae* in support of Plaintiffs’ opposition to Defendants’
5 motion to dismiss (ECF. Nos. 46, 48). A copy of the proposed brief is attached as
6 Exhibit 1 to this motion.¹

7
8 **I. MOVANTS HAVE SUBSTANTIAL INTERESTS IN THIS CASE, WHICH
DIRECTLY IMPACTS THE COMMUNITIES THEY SERVE.**

9 As set forth in the proposed brief,² Golden West is a not-for-profit organization
10 dedicated exclusively to serving clients with Amyotrophic Lateral Sclerosis (“ALS”) and
11 their families. Golden West is among the largest ALS care-services organizations in the
12 country, and its mission is “to discover treatments and a cure for ALS, and to serve,
13 advocate for, and empower people affected by ALS to live their lives to the fullest.”
14 Golden West is dedicated to improving the lives of people living with ALS by providing
15 essential medical devices and services to its clients and their families. This includes
16 accessibility and mobility resources, speech devices, feeding tubes, as well as emotional
17 support and mental-health resources. Golden West has a substantial interest in this case

18 _____
19 ¹ Counsel for *amici* conferred with counsel for each of the parties seeking their
20 consent to file the proposed brief. Counsel for Plaintiffs consented to Golden West’s
participation as *amici curiae*, and counsel for the State Defendants did not object. At
the time of this filing, counsel for Defendant O’Malley had not provided a position.

21 ² No party’s counsel authored the brief in whole or in part. No party’s counsel or any
22 other person contributed money that was intended to fund preparing or submitting
the brief.

1 because the outcome will have a direct and significant impact on its clients. The
2 proposed brief explains how the prohibition on assistance with ingestion set forth in
3 California’s End of Life Option Act (“EOLOA”) harms Golden West’s clients (and other
4 similarly situated individuals) by depriving them of an equal opportunity to seek aid in
5 dying if they so choose. Golden West remains committed to empowering its clients and
6 their families to live their lives fully and on their own terms—but as explained in the
7 proposed brief, EOLOA (as currently enacted) is yet another potential source of
8 frustration in an already difficult experience. While ALS eventually causes nearly
9 complete physical disability, patients’ cognition remains fully intact. As such, Golden
10 West and its clients are especially likely to encounter the inequities raised by Plaintiffs
11 and are particularly interested in the outcome of this case.

12 EOLCCA is a not-for-profit organization that serves hundreds of people facing
13 end-of-life decisions every year. Many of EOLCCA’s clients have neurodegenerative
14 diseases, like ALS, and regularly express concern that they may lose their ability to
15 exercise their aid-in-dying rights due to the progressive physical symptoms. These
16 clients are at risk of choosing to die sooner than they otherwise might out of fear that they
17 will miss the “window of opportunity” during which they are still able to ingest the
18 medication without assistance, either by swallowing it or pushing a plunger into a feeding
19 tube. EOLCCA believes that its clients should control their end-of-life decisions to
20 afford them peace of mind and precious time with their loved ones, contrary to the real-
21 life effects of EOLOA as enacted. Therefore, EOLCCA has an important interest in and
22 experience with the subject matter of this case.

1 CripJustice is an organization led by people with disabilities to support others
2 with disabilities who are impacted by incarceration. It advocates for and empowers those
3 with disabilities to maintain their bodily autonomy and make their own medical
4 decisions. CripJustice is particularly interested in the outcome of this case because its
5 experience has demonstrated that EOLOA, as currently enacted, restricts the bodily
6 autonomy and integrity of the community that it serves.

7 DJL is a non-profit legal organization that supports people with disabilities' fight
8 against discrimination on the basis of their disabilities. It focuses on serving populations
9 that are particularly vulnerable—for instance, people with disabilities who are
10 incarcerated, low-income, or experiencing homelessness. Because DJL serves the very
11 population that is impacted by EOLOA (and the prohibition on assistance with ingestion),
12 it too has a substantial interest in the outcome of this case.

13 **II. MOVANTS' PROPOSED BRIEF WILL AID THIS COURT**

14 This Court has broad discretion to permit non-parties to participate as *amici*
15 *curiae*, *Hoptowit v. Ray*, 682 F.2d 1237, 1260 (9th Cir. 1982), *abrogated in part on other*
16 *grounds by Sandin v. Connor*, 515 U.S. 472 (1995), and is guided by whether the non-
17 party's participation would be useful or desirable to it. *See, e.g., In re Roxford Foods*
18 *Litig.*, 790 F. Supp. 987, 997 (E.D. Cal. 1991) (“[A]n individual seeking to appear as
19 amicus must merely make a showing that his participation is useful to or otherwise
20 desirable to the court.”). *Amici*'s participation will surely aid the Court in this case.

21 Golden West works closely with its clients and their families every day, and its
22 expertise and unique perspective on the disease will be particularly helpful to this Court.

1 *See Infineon Techs. N. Am. Corp. v. Mosaid Techs.*, No. C-02-5772 JF(RS), 2006 WL
2 3050849, *3 (N.D. Cal. Oct. 23, 2006) (“District courts frequently welcome amicus briefs
3 from non-parties concerning legal issues that have potential ramifications beyond the
4 parties directly involved or if the amicus has unique information or perspective that can
5 help the court beyond the help that the lawyers for the parties are able to provide.”).
6 Similarly, EOLCCA works closely with clients making end-of-life decisions—including
7 many with ALS—and has witnessed the harm created by the rigid application of EOLOA
8 for those whose physical disability prevents them from ingesting the medication without
9 assistance. Moreover, CripJustice’s and DJL’s participation will be helpful to this Court
10 by providing a unique perspective from particularly vulnerable populations of people
11 with physical disabilities impacted by EOLOA; for instance, those who are incarcerated
12 or experiencing homelessness. If Plaintiffs’ claims are successful, the many people living
13 with ALS in California—including Movants’ clients—will be able to explore their right
14 to receive aid in dying without pressure from the State forcing them to make end-of-life
15 decisions sooner than they would otherwise choose.

16 Movants’ proposed brief, which incorporates the stories of Golden West’s clients,
17 provides the Court with crucial insight as to how EOLOA’s self-administration
18 requirement affects people living with ALS and their caregivers every day. This
19 perspective—particularly in light of other *amici*’s suggestion that rigid application of the
20 requirement is necessary to protect patients from coercion—is critical to this Court’s
21 understanding of EOLOA’s impact on physically disabled Californians. *See* Brief for
22 Christian Med. & Dental Ass’n of N. Am. & Coptic Med. Ass’n of N. Am. as Amici

1 Curiae Supporting Defendants’ Motion to Dismiss, ECF No. 54, at 6-10 (“Christian
2 Medical Br.”).

3 The proposed brief will aid this Court by not only offering further insight into
4 how ALS—a disease many people know little about—affects the body (and how this
5 impacts a person’s ability to ingest the medication without assistance), but shares the
6 stories of Golden West’s clients, who are familiar with the aid-in-dying process, in their
7 own words. The proposed brief provides professional insight and real-life examples as to
8 how the numerous other safeguards built into EOLOA would continue to protect patients
9 even if those with ALS were afforded a reasonable modification, as requested by
10 Plaintiffs. See ECF No. 46, at 10-13; Christian Medical Br. at 6-10. Because the insight
11 and perspectives of *amici* and their clients will assist this Court in understanding these
12 complex issues, Movants ask this Court to consider the proposed brief.

13
14 **CONCLUSION**

15 For these reasons, Movants respectfully request that this Court grant this motion
16 and consider the attached brief in support of Plaintiffs’ opposition to Defendants’ motion
17 to dismiss.

1 Dated: March 3, 2022

Respectfully submitted,

2
3 /s/ David H. Bernstein

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13 *Association, End of Life Choices*
14 *California, CripJustice, and Disability*
15 *Justice Law & Organizing Project*

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EXHIBIT 1

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MORRIS; RHIANNON CERRETO; ROBERT)
15 USLANDER, M.D.; GARY PASTERNAK,)
M.D.; and RICHARD MENDIUS, M.D.; on)
16 behalf of themselves and all others similarly
situated,)

17 Plaintiffs,)

18 v.)

19 STATE OF CALIFORNIA; ROBERT BONTA,)
Attorney General of the State of California, in)
20 his official capacity; NANCY O'MALLEY,)
Alameda County District Attorney, in her official)
21 capacity,)

22 Defendants.)

Civil Action No. 3:21-cv-06654-VC

**BRIEF OF *AMICI CURIAE* THE
GOLDEN WEST CHAPTER OF THE
ALS ASSOCIATION, END OF LIFE
CHOICES CALIFORNIA,
CRIPJUSTICE, and DISABILITY
JUSTICE LAW & ORGANIZING
PROJECT IN SUPPORT OF
PLAINTIFFS' OPPOSITION TO
DEFENDANTS' MOTIONS TO DISMISS**

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1 **I. INTERESTS OF AMICI**

2 **The Golden West Chapter of The ALS Association** (“Golden West”) is a not-
3 for-profit organization dedicated exclusively to serving patients with Amyotrophic
4 Lateral Sclerosis (“ALS”)—a debilitating, deadly disease that causes the progressive loss
5 of bodily function and integrity. Golden West serves 31 counties throughout California
6 and the entire state of Hawaii, making it among the largest ALS care organizations in the
7 United States. Its mission is “to discover treatments and a cure for ALS, and to serve,
8 advocate for, and empower people affected by ALS to live their lives to the fullest.” ALS
9 Association: Golden West Chapter, *Our Mission*,
10 http://webgw.alsa.org/site/PageServer?pagename=GW_homepage (last accessed Feb. 28,
11 2022). Golden West does so by powering the world’s largest ALS research program,¹
12 and also by providing care services directly to patients battling ALS every day, as well as
13 their families and caregivers. As the disease progresses, ALS robs patients of the ability
14 to move, speak, swallow, and breathe. Among other things, Golden West provides its
15 clients with accessibility and mobility resources, speech devices, and feeding tubes, to
16 help them live more freely and comfortably while the disease progresses. In addition,
17 Golden West provides emotional support and mental-health resources to patients and
18 their families grappling with the disease and its unforgiving prognosis.

19
20

21 ¹ Golden West supports active ALS-related projects in more than 150 labs around the
22 world, and engages medical professionals from more than 27 multidisciplinary
clinics and medical centers.

1 **End of Life Choices California** (“EOLCCA”) is a charitable organization that
2 provides its clients with information and support as they navigate their legal end-of-life
3 options. EOLCCA serves hundreds of terminally ill Californians facing end-of-life
4 decisions every year. Many of them suffer from neurodegenerative diseases like
5 ALS. As counselors to and advocates for this patient population, EOLCCA strongly
6 favors a reasonable modification under EOLOA to allow its clients to seek assistance
7 with ingestion if they are unable to fully administer the medication themselves. It is
8 EOLCCA’s position that this modification would provide its clients with peace of mind,
9 and allow them to spend cherished time with loved ones and complete other life projects
10 before they die.

11 **CripJustice** is an organization led by people with disabilities to support people
12 with disabilities—particularly those who are impacted by any form of incarceration,
13 including medical incarceration. It advocates for people with disabilities to maintain
14 their bodily autonomy and make their own medical decisions. In light of its mission,
15 CripJustice rejects the assumption that restricting this autonomy under the auspices of
16 “care” actually or fully benefits people with disabilities, including its clients.

17 **The Disability Justice Law & Organizing Project** (“DJL”) is a non-profit legal
18 organization that supports people with disabilities in the fight against discrimination. It
19 focuses on serving particularly vulnerable populations, especially people with disabilities
20 who are houseless, incarcerated, or low-income. DJL engages multi-pronged strategies
21 for change, which are directly informed by the experiences of its clients and the
22

1 population that it serves—the same population that will be impacted by the end-of-life
2 law at issue.

3 Because California’s End of Life Option Act (EOLOA), Cal. Health & Safety
4 Code § 443, *et seq.*, does not adequately protect the patients and clients that *amici* serve,
5 *amici* submit this brief in support of Plaintiffs’ opposition to Defendants’ motion to
6 dismiss. Together, *amici* have empowered thousands of patients and their families to live
7 their lives to the fullest in the face of disability or illness—like ALS, which typically
8 results in death within three to five years of diagnosis. Rather than enable ALS patients
9 to do the same, the State of California requires them to either continuously speculate as to
10 when their physical symptoms will completely take over—a nearly impossible task—or
11 forego their right to seek aid in dying entirely.

12 II. ARGUMENT

13 *Amici* support Plaintiffs’ position that the prohibition on assistance with ingestion
14 impermissibly discriminates against patients with ALS. Indeed, because of the nature of
15 ALS and the way in which the disease progresses—eroding a patient’s physical health
16 while their mental processes remain intact—it is particularly important that people living
17 with ALS, and those with similar neurodegenerative diseases, have an equal opportunity
18 to seek aid in dying as otherwise permitted by the statute.

19 a. *The Nature of ALS and its Progression*

20 ALS, also known as Lou Gehrig’s disease, is a progressive neurodegenerative
21 disease that causes the degeneration of nerve cells in the brain and spinal cord. ALS
22 Association, *What is ALS?*, <https://www.als.org/understanding-als/what-is-als> (last

1 accessed Feb. 28, 2022). This degeneration ultimately causes the connection between
2 motor neurons (in the brain) and muscles (elsewhere in the body) to break down. Johns
3 Hopkins Medicine, *ALS – Amyotrophic Lateral Sclerosis*,
4 www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/als/conditions/als_amyotrophic_lateral_sclerosis.html#:~:text=ALS%20is%20characterized%20by%20a,%20C%20causing%20increased%20muscle%20weakness (last accessed Feb. 28, 22). Once
5
6 that connection is severed, the brain can no longer initiate or control muscle movement,
7 inhibiting the person’s ability to speak, eat, move, and breathe—eventually leading to
8 total paralysis. ALS Association, *Stages of ALS*, <https://www.als.org/understanding-als/stages> (last accessed Feb. 28, 2022); ALS Association, *ALS Symptoms and Diagnosis*,
9
10 <https://www.als.org/understanding-als/symptoms-diagnosis> (last accessed Feb. 28, 2022).
11
12 There is no cure and no known way to stop or reverse the degenerative process. ALS
13 Association, *ALS Symptoms and Diagnosis*, <https://www.als.org/understanding-als/symptoms-diagnosis> (last accessed Feb. 28, 2022).
14

15 ALS is a highly heterogeneous disease, and its initial symptoms vary in kind and
16 severity amongst patients. ALS Association: Golden West Chapter, *Symptoms*,
17 http://webgw.alsa.org/site/PageServer?pagename=GW_1_Symptoms (last accessed Feb.
18 28, 2022). Regardless of the initial symptomatic expression, one thing holds true across
19 all cases—ALS is an “always fatal” disease that will continue to progress until it has
20 weakened nearly every muscle in the body (except for the heart and sphincter). ALS
21 Association: Golden West Chapter, *About ALS*,
22 http://webgw.alsa.org/site/PageServer?pagename=GW_1_about_als (last accessed Feb.

1 28, 2022). For about two-thirds of patients, ALS first affects muscles in the arms, hands,
2 and legs. ALS News Today, *What Is Amyotrophic Lateral Sclerosis?*
3 <https://alsnewstoday.com/what-is-als/> (last accessed Feb. 28, 2022). As patients
4 gradually lose the ability to control their muscles completely, they often experience
5 uncomfortable muscle twitching and cramping, slurred (Dysarthric) speech and difficulty
6 speaking, as well as difficulty breathing, chewing, and swallowing. ALS Association,
7 *Understanding ALS*, <https://www.als.org/understanding-als> (last accessed Feb. 28, 2022);
8 ALS Association, *ALS Symptoms and Diagnosis*, [http://www.alsa.org/about-](http://www.alsa.org/about-als/symptoms.html)
9 [als/symptoms.html](http://www.alsa.org/about-als/symptoms.html) (last accessed Feb. 28, 2022). Once ALS begins to impact the
10 muscles necessary for breathing, patients require around-the-clock ventilation and
11 respiratory support to survive. ALS Association, *Ask the Doc: Q&A With Edward*
12 *Kasarskis, MD, PhD*,
13 http://web.alsa.org/site/PageServer?pagename=ALSA_Ask_January2012#:~:text=A%20r
14 [respiratory%20infection%20can%20pose,of%20your%20health%20care%20team](http://web.alsa.org/site/PageServer?pagename=ALSA_Ask_January2012#:~:text=A%20respiratory%20infection%20can%20pose,of%20your%20health%20care%20team) (last
15 accessed Feb. 28, 2022). Similarly, because ALS weakens the muscles required to
16 swallow, patients are often prescribed a diet of pureed foods and thickened liquids until
17 they are unable to swallow at all, at which point they must eat and drink through a
18 feeding tube. ALS Association, *FYI: Information About Feeding Tubes*,
19 <https://www.als.org/navigating-als/resources/fyi-information-about-feeding-tubes> (last
20 accessed Feb. 28, 2022).

21 As the disease progresses, patients move toward becoming “locked in”—meaning
22 that they will experience near-complete physical paralysis while their cognitive processes

1 remain intact. A “locked in” patient is mentally present and aware of their thoughts and
 2 surroundings, and is able to see, touch, hear, taste, and smell. ALS Association: Golden
 3 West Chapter, *Symptoms*,
 4 http://webgw.alsa.org/site/PageServer?pagename=GW_1_Symptom (last accessed Feb.
 5 28, 2022). This means that while the disease progresses—even if they are unable to
 6 easily communicate as much²—patients are fully aware of their prognoses, and remain
 7 conscious as ALS destroys their ability to move and care for themselves. *See, e.g.*, Brief
 8 for The ALS Association New Mexico Chapter as Amici Curiae Supporting Plaintiffs-
 9 Appellees, *Morris v. Brandenburg*, 356 P.3d 564, No. 33-630, at 2-3 (N.M. Ct. App.
 10 Sept. 12, 2014).

11 **b. *The Impact of EOLOA’s Prohibition on Assistance***

12 EOLOA allows adult patients with terminal illnesses to request a “prescription for
 13 an aid-in-dying drug,” provided that they have the “physical and mental ability to self-
 14 administer” it. Cal. Health & Safety Code § 443.2(a).³ As currently enacted, the statute
 15 provides little comfort to individuals with ALS.⁴ Due to the prohibition on assistance
 16

17 ² ALS patients who have lost their ability to speak can still communicate using certain
 18 devices. Patients who retain the use of their arms and hands can communicate with
 19 keyboards; those who do not can communicate through eye-tracking software. *See*
 20 Mary Chapman, *ALS Ice Bucket Challenge Co-Founder Pat Quinn*, ALS News
 21 Today, <https://alsnewstoday.com/news-posts/2020/07/08/eye-tracking-device-gives-voice-to-als-ice-bucket-challenge-co-founder-pat-quinn/> (July 8, 2020).

20 ³ Another individual may be “present” when the qualified patient ingests the drug, “so
 21 long as the [third] person does not assist” with ingestion. *Id.* § 443.14(a).

22 ⁴ As described in the complaint, EOLOA has generally “improved the well-being of
 Californians by providing them with the comfort of knowing that they can choose to

1 with ingestion, a significant number of people with ALS may be forced to either (1) not
2 take advantage of the law at a time of their choosing, even if they are otherwise qualified;
3 or (2) ingest aid-in-dying medication sooner than they would otherwise feel ready to do
4 so. Every person living with ALS who qualifies for care under EOLOA will eventually
5 lose the ability to ingest the medication without assistance (if they have not already done
6 so by the time they seek to qualify). This means that, to receive aid in dying in
7 California, ALS patients need to either ingest the drug without assistance while they are
8 still physically capable of doing so, which may occur early on in their diagnosis, and
9 while they are still living full and meaningful lives. As a bleak alternative, ALS patients
10 risk waiting until after they have lost the ability to ingest without assistance, forcing them
11 to forego their aid-in-dying rights altogether—even if they otherwise qualify, and while
12 being fully aware of their prognosis and inevitable outcome. It is not surprising, then,
13 that EOLCCA’s clients frequently express concern that they will lose the ability to
14 swallow or otherwise fully ingest the medication without assistance due to their disease.
15 Based on its experience, EOLCCA worries that these clients, and people in similar
16 situations, may choose to ingest the medication sooner than they otherwise would to
17 avoid losing that “window of opportunity.”

18
19 seek medication to precipitate a peaceful death,” but prevents “dying individuals
20 with certain physical disabilities,” like those with ALS, from accessing that care and
21 relief. *Class Action Compl. for Declaratory and Injunctive Relief*, ECF No. 1, ¶¶ 29-
22 30.

1 For instance, one of the many patients whose symptoms begin in the upper body
2 (*e.g.*, arms and hands) may be forced to explore their options under the statute in the very
3 early stages of their illness. Because of the assistance prohibition, a patient still capable
4 of walking, talking, communicating with their loved ones, and breathing without
5 assistance—may nevertheless feel pressured (by the State) to seek aid in dying before it is
6 too late. Patients who experience difficulty swallowing—an inevitable symptom of
7 ALS—may also be precluded from ingesting the medication without assistance. While
8 the law seemingly allows for the option of ingestion of the medication through a feeding
9 tube, this assumes (without any basis) that an ALS patient would still be able to control
10 the other parts of their body necessary to introduce the medication fully without any
11 assistance. *See* Compl. ¶ 29.⁵ A patient who must decide whether to (1) ingest life-
12 ending medication before they are ready or (2) forfeit their aid-in-dying rights altogether
13 (while consciously progressing toward a “locked in” state) has no meaningful choice
14 under the statute.⁶

15 ⁵ For instance, the law assumes that a patient incapable of swallowing would still have
16 sufficient control over the other muscle groups (*e.g.*, their hands) necessary to
17 complete the ingestion process without assistance, which is not true for many ALS
patients in advanced stages of the illness.

18 ⁶ Patients at any stage of the illness may, and do, continue to maintain a good quality
19 of life. As such, some patients choose to take advantage of every life-extending
20 medical intervention available, even if that means living out the rest of their lives in
21 a “locked in” state. For others, knowing that they will eventually require around-the-
22 clock care while being unable to move or easily communicate is too heavy to bear.
Amici have great respect for all patients battling ALS, as well as the private medical
decisions that they make. *Amici* take no position as to whether any particular
individual “should” seek aid in dying, but believes that all qualified patients must
have a meaningful opportunity to seek protection under EOLOA if they so choose.

1 Contrary to Defendants’ argument, allowing an accommodation to the assistance
2 prohibition for ALS patients would not disrupt the remainder of the statute. The
3 numerous informed-consent and other requirements would remain to safeguard against
4 the very “risks” that other *amici* caution against. See Brief for Christian Med. & Dental
5 Ass’n of N. Am. & Coptic Med. Ass’n of N. Am. as Amici Curiae Supporting
6 Defendants’ Motion to Dismiss, ECF No. 54, at 6 (“Christian Medical Br.”). To be
7 eligible under the statute, patients must first (1) make two oral requests for the
8 medication to their physician, and (2) submit another written request, signed in the
9 presence of two witnesses. EOLOA then requires the patient to be (3) counseled by their
10 physician as to their diagnosis, prognosis, any “potential risks,” and “feasible alternatives
11 or additional treatment opportunities.” Cal. Health & Safety Act § 443.1(i). Before
12 writing any prescription, the doctor must be certain that (4) the patient is fully informed
13 and capable of making “medical decisions,” and that (5) their request is not the result of
14 “coercion or undue influence by another person.” *Id.* § 443.5(a).⁷ A physician also must
15 (6) remind the patient that they have the opportunity, at any time, to withdraw or rescind
16 the request. *Id.*

17 If, after thorough consideration and analysis, the physician believes the patient is
18 not of sound mind or has been unduly pressured, the patient would not be qualified under
19 EOLOA, and a prescription would be denied. Even if an accommodation were made,
20 physicians would be mandated to verify, multiple times, that a patient is well-informed

21 ⁷ If the physician has any doubt as to the patient’s mental capacity, a specialized
22 mental-health assessment can be ordered to obtain further information.

1 and acting on their own free will. To be sure, if ALS patients were afforded the
2 modification sought by Plaintiffs, they would—at a time of their choosing—still perform
3 an affirmative, conscious, and physical act to administer and ingest the medication, but
4 would simply be afforded some assistance in doing so.

5 Rather than opening the floodgates to an influx of State-sanctioned “euthanasia”
6 (as suggested by *amici* in support of Defendants), Christian Medical Br., ECF No. 54, at
7 10, the accommodation sought by Plaintiffs would simply ensure that physically disabled,
8 but otherwise-qualified patients are not excluded from the protections afforded by
9 EOLOA. Indeed, as the statute stands today, terminally ill patients with cancer can avail
10 themselves of EOLOA, while otherwise-qualified ALS patients who are physically
11 disabled may not be able to do so, exclusively because of neurodegenerative symptoms
12 over which they have no control.

13 **c. *Experiences of Golden West’s Clients***

14 The importance of the relief sought by Plaintiffs is underscored by the
15 experiences of Golden West’s clients.⁸ As described below, people with ALS and their
16 caregivers often find comfort in the idea that the patient—after months or years of living
17 with an unpredictable illness—maintains ultimate control over their end-of-life decision,
18 and how much suffering they will endure before they die. Placing yet another obstacle in
19 a physically disabled person’s way (without offering a reasonable modification) simply

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21 _____
22 ⁸ Golden West would like to express its gratitude to Ms. Infante and Ms. Cline for
sharing their stories in connection with this brief.

1 exacerbates an already difficult situation. Additionally, the other statutory safeguards
2 ensure that ALS patients will remain adequately protected even if a modification is made.

3 **Kathy Infante & Brian Cason.** Kathy Infante, a registered nurse and client of
4 Golden West, lost her husband, Brian, to ALS in the summer of 2019. Brian worked in
5 the medical profession as an anesthesiologist, and quickly understood how the disease
6 would progress following his diagnosis. As his symptoms worsened, Brian lost the
7 ability to speak, swallow, and breathe without assistance. Kathy and Brian began to
8 explore his aid-in-dying options, and were initially relieved when they learned about
9 EOLOA. As time went on, however, Kathy and Brian were left with the impression that
10 the law, as enacted, was primarily designed to protect the provider from liability—rather
11 than help the patient.

12 Among other things, as her husband “wither[ed]” away, Kathy recalls making two
13 separate in-person visits (15 days apart) to see Brian’s provider so that he could request
14 the medication in compliance with the statute. In addition to EOLOA’s statutory
15 requirements, the price of the prescription may be cost-prohibitive for some patients, and,
16 as Kathy and Brian soon learned, some providers impose additional obligations. For
17 instance, Brian’s provider requested that he provide 48 hours’ notice to the hospital
18 before he ingested the medication. Kathy and Brian also endured difficult conversations
19 with Brian’s providers, who, at times, seemed to personally disagree with Brian’s
20 decision—even though he fully qualified for aid-in-dying care. Kathy worries about how
21 patients and caregivers in other circumstances—*e.g.*, those who do not live close to their
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1 providers or otherwise lack resources—are able to navigate the statute, regardless of the
2 assistance prohibition.

3 Brian was eventually able to obtain the medication, which Kathy recalls as the
4 most comforting part of the whole experience because her husband “was finally in charge
5 of something.” Though he maintained more physical mobility than other ALS patients,
6 Brian’s day-to-day existence eventually became “miserable,” and he had “had enough.”
7 Around four months after he obtained it, Brian was able to ingest the medication (through
8 his feeding tube) on a date of his choosing at home with his wife. Though Brian was
9 capable of ingesting the medication without assistance, his story speaks more broadly to
10 the necessity of ensuring equal access under EOLOA. Once Brian had been diagnosed,
11 he and Kathy firmly understood that, in a way, he had no options—there was no magic
12 cure, and not even the best medical care would have been able to save Brian. Armed
13 with this knowledge, Brian was able to maintain control over the last chapter of his life,
14 on his own terms, with the love and support of his family. It is *amici*’s hope that all ALS
15 patients have an equal opportunity to do the same.

16 **Sybil Cline.** Sybil Cline is currently living with ALS, and she would eventually
17 like to obtain a prescription under EOLOA and later ingest the medication on her own
18 timeline. Sybil first learned about EOLOA shortly after it was enacted, when her
19 husband was suffering from terminal prostate cancer. Sybil and her husband discussed
20 his options under EOLOA, and he chose not to take advantage of the statute. For Sybil’s
21 husband, requesting and obtaining the medication would have been a “bureaucratic
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1 nightmare,” and the couple decided not to spend the last chapter of their 40-year marriage
2 navigating that process. Sybil’s husband eventually passed away at their home.

3 Several years later, in the fall of 2020, Sybil received her ALS diagnosis. From
4 the beginning, Sybil knew that she would prefer to seek aid in dying on her own terms
5 before things get “ugly.” But after experiencing the roadblocks encountered by her
6 husband, she has significant concerns about receiving an equal opportunity to do so. As
7 Sybil puts it, “we are the people suffering, and we are in our right mind, and we know
8 what we need, but the barriers make it impossible.” While Sybil (who is in a wheelchair
9 but currently able to speak, breathe, and swallow) has not yet requested the medication,
10 she believes she may eventually reach a point where she is unable to ingest it without
11 assistance—even though she is entirely willing and prepared to do so.

12 Like many other people living with ALS, Sybil is an active, vibrant, and
13 independent person, who wishes to maintain her autonomy and bodily integrity
14 throughout the duration of her illness. Her story echoes *amici*’s position that people
15 living with ALS ought to have a meaningful opportunity to seek aid in dying if they so
16 choose. After all, in Sybil’s words, “why shouldn’t we, as individuals, be able to control
17 the circumstances of our own lives?”

18 **III. CONCLUSION**

19 *Amici* seek to provide compassionate care to terminally ill Californians and help
20 those with ALS live their lives to the fullest—a task made impossible when patients must
21 spend the last chapter of their lives calculating the number of days remaining until they
22 will lose the ability to ingest aid-in-dying medication without assistance. While

1 seemingly well-intentioned, the statute—which makes aid in dying available to ALS
2 patients in theory but not in practice—is another potential source of pain, confusion, and
3 anxiety for patients and caregivers as they navigate life with an unpredictable terminal
4 illness. Plaintiffs’ complaint raises important issues that are critical to an already
5 vulnerable population. *Amici* urge the Court to deny the motion to dismiss so that ALS
6 patients are afforded an equal opportunity to maintain autonomy over their choices, lives,
7 and bodies when seeking aid in dying.⁹

19 ⁹ *Amici* also recognize the critical role of ALS patients in developing a cure for the
20 disease. After receiving their diagnoses, many ALS patients dedicate the rest of their
21 lives to science, research, clinical trials, or otherwise advocating for the ALS
22 community. Without ALS patients to participate in research and clinical trials, there
can be no cure. EOLOA, as currently enacted, encourages an already diminishing
population of patients to prematurely seek aid-in-dying care, and therefore directly
impedes this important work.

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Respectfully submitted,

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3 /s/ David H. Bernstein

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