STATE OF WISCONSIN

C O U R T O F A P P E A L S

DISTRICT IV

Case No. 2014 AP 135

DISABILITY RIGHTS WISCONSIN,

 Plaintiff -Appellant,

 v.

UNIVERSITY OF WISCONSIN HOSPITAL AND CLINICS, DONNA KATEN-BAHENSKY, UW SCHOOL OF MEDICINE AND PUBLIC HEALTH, BOARD OF REGENTS OF THE UNIVERSITY OF WISCONSIN SYSTEM AND KEVIN P. REILLY,

 Defendants-Respondents.

ON APPEAL FROM A FINAL ORDER OF THE DANE COUNTY CIRCUIT COURT DATED DECEMBER 3, 2013, THE HONORABLE C. WILLIAM FOUST PRESIDING

*AMICUS CURIAE* BRIEF OF THE AUTISTIC SELF ADVOCACY NETWORK, NOT DEAD YET, ADAPT, AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES, AMERICAN COUNCIL OF THE BLIND, ASSOCIATION FOR AUTISTIC COMMUNITY, ASSOCIATION OF PROGRAMS FOR RURAL INDEPENDENT LIVING, AUTISM WOMEN’S NETWORK, NATIONAL ASSOCIATION OF THE DEAF, NATIONAL COUNCIL FOR INDEPENDENT LIVING, NATIONAL DISABILITY RIGHTS NETWORK, QUALITY TRUST FOR INDIVIDUALS WITH DISABILITIES, UNITED SPINAL ASSOCIATION, AND WISCONSIN BOARD FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

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# TABLE OF CONTENTS

[INTRODUCTION 1](#_Toc388463624)

[1. The Court must recognize limits on guardians’ authority to withdraw treatment. 3](#_Toc388463625)

[2. In cases where guardians have a duty to secure lifesaving medical treatment, hospitals and hospital physicians must also be recognized as having such a duty with respect to persons under their active care. 6](#_Toc388463626)

[3. The individual physician defendants should be considered state actors, as they were subject to University of Wisconsin Hospital ethics policies and their recommendations were backed by the prestige of the Hospital. 8](#_Toc388463627)

[CONCLUSION 9](#_Toc388463628)

[CERTIFICATION 11](#_Toc388463630)

[CERTIFICATION OF COMPLIANCE WITH RULE 809.19(12) 12](#_Toc388463631)

# TABLE OF AUTHORITIES

Cases

*Eberhardy v. Circuit Court for Wood County*, 102 Wis.2d 539, 573 (Wis. 1981) 5

*In the Matter of the Guardianship of L.W.*, 167 Wis. 2d 53, 482 N.W. 2d 60 (Wisc. 1992) 3

*Wisconsin v. Neumann*, 832 N.W.2d 560 (Wis. 2013) 1, 4

Statutes

Wis. Stat. § 46.90(4)(ab)(3), (1)(f). 6

Wis. Stat. §§ 948.01(3), 948.03(4). 6

Other Authorities

National Disability Rights Network, Devaluing People with Disabilites: Medical Procedures that Violate Civil Rights 17, 26-30 (2012) 4, 5

Norman Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 Critical Care Clinics 145, 156 (1986) 5

Todd Richmond, *Madeline Kara Neumann Prayer Death: Conviction Upheld For Parents Who Only Prayed For Sick Daughter*, Huffington Post, Jul. 3, 2013 1

UWHealth.org, “Find a Doctor: Norman Fost, MD, MPH,” *available at* http://www.uwhealth.org/findadoctor/Provider.action?id=6022 8

# INTRODUCTION

Madeline Kara Neumann, an eleven-year-old girl with undiagnosed diabetes, died on Easter Sunday in 2008. Her parents, who believed that bringing their child to see a doctor would constitute idolatry, had instead attempted to heal their child through prayer. Charged with homicide, Kara’s father testified that he never imagined that his failure to seek medical attention for his daughter could lead to her death. Nevertheless, both he and Kara’s mother were convicted of reckless homicide. The Wisconsin Supreme Court affirmed their conviction in July of last year; the lone dissenter based his reasoning on the possibility that the parents had not appreciated the danger that their child faced. *See* *Wisconsin v. Neumann*, 832 N.W.2d 560 (Wis. 2013).

Around the time of the Wisconsin Supreme Court decision, Norman Fost, the director of the bioethics program at the University of Wisconsin-Madison and one of the individual defendants in this action, told a reporter that he wished the court had taken an even stronger stance against parents whose decision to forego medical treatment results in “serious disability or death of a child.”[[1]](#footnote-1)

Almost exactly seven years before he made that statement, however, Fost took an apparently different position with respect to one of the patients whose stories underlie the instant action. According to the parties’ briefings, in August 2006, Dr. Fost opined in an email to defendant Hoover-Regan, also a University of Wisconsin Hospital physician, that she could act to deprive a thirteen-year-old boy of antibiotics for a potentially life-threatening infection – and also to discontinue nutrition and hydration – without the need of hospital ethics committee approval. Because the boy, referred to as Patient 1 in plaintiff’s filings, had a history of responding well to antibiotics and had been receiving artificial nutrition and hydration for years, the only apparent justification for this course of action was the fact that the boy had a significant developmental disability and therefore was perceived to have a “low quality of life.”

Months later, Patient 1 died of pneumonia after Dr. Hoover-Regan implemented the plan that Dr. Fost had approved. Although the long-term care facility where Patient 1 resided had begun treating him with antibiotics and intended to continue doing so, his parents had him transferred to the University of Wisconsin Hospital so that Dr. Hoover-Regan could order discontinuation of the antibiotics, food, and hydration that were keeping him alive. Weakened from his untreated illness and deprived of food and water, Patient 1 was transferred to hospice care and died after administration of morphine.

In yet another episode, a University of Wisconsin doctor counseled the family members of an adult woman with developmental disabilities to withdraw her from the antibiotics she needed to treat an acute respiratory infection. Although the woman’s guardian initially acquiesced, the guardian and family later changed their minds after the woman’s condition began to improve and she asked to eat. Although the doctor issued an order reinstating the antibiotics, she refused to allow the patient to continue as an inpatient at UWHC and discharged her to hospice care, along with a “no rehospitalization” order. The family discontinued hospice services two weeks later, as they were unnecessary and inappropriate.

Defendants now argue that, despite established Wisconsin law that parents are liable for homicide if they cause a child’s death – even unintentionally – through deprivation of medical treatment,[[2]](#footnote-2) this court lacks the authority to enjoin physicians employed at state hospitals from advising and assisting in that exact same course of action. Defendants’ argument appears to be based on the assumption that state-run hospitals and their staff do not have any affirmative duties toward patients who are currently admitted to inpatient care at their facilities, and that parents and guardians have unlimited authority to withhold medical care from those under their care *so long as those individuals have disabilities*.

Such a result would effectively reverse Wisconsin’s longstanding recognition that the authority of parents and guardians does not extend to decisions to end the lives of their children or wards by depriving them of necessary health care, and would set a dangerous precedent for other states. People with disabilities are at particular risk of being deprived of medical care if state-employed physicians are granted immunity for their participation in plans to end life through withdrawal of lifesaving care. Amici therefore urge the Court of Appeals to recognize state-employed physicians’ legal duty to avoid abetting courses of action that, under Wisconsin law, constitute homicide through deprivation of care.

## The Court must recognize limits on guardians’ authority to withdraw treatment.

Less than one year ago, the Supreme Court of Wisconsin recognized that parents and guardians lacked absolute authority to refuse lifesaving medical treatment for their children. *Wisconsin v. Neumann*, 832 N.W.2d at 592. Because children and adults with disabilities are at heightened risk of deprivation of medical care as a result of a surrogate’s decision, it is crucial that this court recognize that limits on parents’ and guardians’ decision-making authority are no less applicable when the child has a significant disability than when the child has only minor or no disabilities.

Withdrawal of medical treatment, food, and water from people with disabilities for the purpose of causing or hastening death – even when the person with a disability is conscious and objects to withdrawal of treatment – is disturbingly common. In a recent report, the National Disability Rights Network (“NDRN”), an umbrella network of Protection and Advocacy organizations such as Disability Rights Wisconsin, discussed numerous cases in which doctors or guardians withheld potentially lifesaving medical care from people with disabilities who were neither dying nor in a pervasive vegetative state or coma.[[3]](#footnote-3) Both exemplars in this action were included in NDRN’s report.[[4]](#footnote-4)

Many of the individuals discussed in NDRN’s report were able to regain access to medical treatment as a result of the intervention of their state Protection and Advocacy organization. For example, the North Dakota Protection and Advocacy Project successfully helped one man with end-stage liver disease fight against his guardian’s imposition of a “no code” barring doctors from providing lifesaving care in the event of a medical emergency. The individual strongly objected to the “no code,” but it was only after legal advocacy by the Protection and Advocacy organization that it was lifted.[[5]](#footnote-5)

In part due to pervasive undertreatment of people with disabilities, state and federal courts have long recognized limitations on parents’ and guardians’ authority to withhold medical treatment from people with disabilities. As NDRN notes, these limitations stemmed from recognition that “simply doing what parents, guardians and care providers deemed was in the best interest of an individual with a disability may conflict with the expressed interests of the individual and was often based on incorrect assumptions about the person’s disability.”[[6]](#footnote-6) In accordance with this trend, the Wisconsin Supreme Court recognized in 1981 that:

Those who normally would speak for the incompetent — parents, guardians, or even social workers — may in actuality speak, consciously or unconsciously, in their own interests: Diminished worry, convenience, a wish to be relieved of responsibility for close supervision, or frustration at their inability to deal with a most difficult problem.

*Eberhardy v. Circuit Court for Wood County*, 102 Wis.2d 539, 573 (Wis. 1981) (emphasis added).

Disability rights activists and medical ethicists also overwhelmingly agree that there must be some legal limits to the authority of parents and guardians to withhold medical treatment from people with disabilities. Even Dr. Fost, one of the physician defendants in this action, has acknowledged that parents of children with disabilities should not enjoy complete discretion to withhold medical care from their children.[[7]](#footnote-7)

## In cases where guardians have a duty to secure lifesaving medical treatment, hospitals and hospital physicians must also be recognized as having such a duty with respect to persons under their active care.

As the story of “Patient 1” and others discussed in NDRN’s report illustrate, it is important that limits on parents’ and guardians’ authority to withhold treatment be recognized by physicians and other health care providers. Defendants argue that Wisconsin law does not require physicians to provide acute treatment against the wishes of the child’s parents, even if those physicians are aware that following the parents’ wishes would cause the child’s death. On the contrary, Wisconsin law recognizes that an individual who is “responsible for [a] child’s welfare,” including an individual who is “employed by one legally responsible for the child’s welfare to exercise temporary control or care for the child,” must act to prevent bodily harm to the child. Wis. Stat. §§ 948.01(3), 948.03(4). Wisconsin law also requires that health care providers, at the very least, report incidents in which the guardians of an at-risk elder adult (such as the second exemplar in this action) unlawfully fail to secure necessary medical treatment for that adult. Wis. Stat. § 46.90(4)(ab)(3), (1)(f).

If the court were to recognize limitations on guardians’ authority to deny medical treatment, but not impose a corresponding duty on physicians to recognize those limits, the result would be an untold number of otherwise preventable deaths while the guardians’ duty is effectively nullified. Depending on the nature of a person’s health condition, people may die within minutes, hours, or days of the decision to withhold or withdraw treatment – long before social services or law enforcement could be notified or conduct an investigation into whether the decision was consistent with the patient’s expressed wishes and/or within the scope of the decision-maker’s authority. Patient 1 died less than one day after UWHC staff removed him from artificial nutrition and hydration, before Disability Rights Wisconsin could intervene to protect his rights. If the North Dakota man discussed in NDRN’s report had experienced a medical emergency while the North Dakota Protection and Advocacy Project was still working to have the “no code” removed from his medical record, he could have died before it was lifted.

To hold that state-employed physicians have no duty would also lead to fundamental inconsistencies in access to care for disabled and nondisabled individuals. In cases such as *Neumann*, in which the individual deprived of care did not have a significant disability, it is unlikely that a physician would have acquiesced in parents’ decision to forego potentially lifesaving care. Where a patient has a disability, it is more likely that a physician, based on prejudicial beliefs about the “quality of life” of people with disabilities, would not only acquiesce but also actively encourage parents and guardians to forego lifesaving care. These prejudices apparently motivated the actions of Defendants toward the exemplars in these actions, as well as the actions of other health care providers discussed in NDRN’s report on medical devaluation of people with disabilities.

Moreover, the mere fact that Patient 1 had a significant disability does not transform the decision not to seek medical treatment for him into a question of “medical judgment.” (Resp’ts’ Br. at 20.) Indeed, Defendant Fost, who operates as the chair of the UWHC’s Bioethics department, has explicitly acknowledged that decisions to withhold lifesaving care are not merely matters of medical judgment but legal and ethical questions that require, at the very least, establishment of specific decision-making guidelines and procedures such as ethics committee oversight – procedures that were not followed in this case.[[8]](#footnote-8)

## The individual physician defendants should be considered state actors, as they were subject to University of Wisconsin Hospital ethics policies and their recommendations were backed by the prestige of the Hospital.

Although the decision to withhold lifesaving treatment from a person with a disability is essentially not a “medical decision,” it is inevitable that the advice of physicians will carry great weight in the eyes of parents, guardians, or other decision-makers. When physicians are employed both as practitioners and as senior faculty at a state university hospital, their opinions are likely to carry added weight in the eyes of decision-makers, in part as a result of their position.

Defendant Fost, for example, is not merely a physician employed at a state-run hospital but the chair of the University of Wisconsin Hospital Ethics Committee, as he has been since 1984. In this position, he is partially responsible for setting the policy of a state-run hospital, including setting any institutional safeguards necessary for protecting the rights and welfare of patients.[[9]](#footnote-9) His position as Chair of this Committee appears to be the primary reason that Defendant Hoover-Regan sought his advice and approval at all. (Appellants’ Br. at 4.) Likewise, Defendants DeMuri, Hoover-Regan, and Wright both not only practiced at the University of Wisconsin Hospital but also held faculty positions at the University of Wisconsin School of Medicine. (Am. Compl. ¶¶ 16-17, 21.) Their positions may significantly influence patients and families considering withdrawal of medical care.

Indeed, in his article discussing end-of-life decision-making regarding children with disabilities, Fost acknowledged that public support for ending the lives of children with disabilities by withdrawing artificial nutrition and hydration is “largely affected by the support of physicians and hospitals” for such a course of action.[[10]](#footnote-10)

The court must recognize that when the state empowers physicians to influence patients and their families, they should be held responsible for any use of that influence that is in conflict with patients’ constitutional, civil and other legal rights. At the very least, doctors should not use their position at a state-run facility to persuade parents, guardians, and families to acquiesce in an unlawful plan to withhold treatment in order to bring about the death of a person who had not himself or herself expressed an opposition to treatment.

# CONCLUSION

Based on all the foregoing, and in conjunction with the arguments presented in appellant’s brief, *amici* Autistic Self Advocacy Network, Not Dead Yet, ADAPT, American Council of the Blind, Association for Autistic Community, Association of Programs for Rural Independent Living, Autism Women’s Network, National Association of the Deaf, National Council for Independent Living, National Disability Rights Network, Quality Trust for Individuals with Disabilities, United Spinal Association, and Wisconsin Board for People with Developmental Disabilities respectfully request that the court reverse the decision of the circuit court dismissing appellant’s state law claim in the Amended Complaint.

Dated this 23rd day of May, 2014.

 Respectfully submitted,

 BY:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
Roy Froemming, Bar No. 1016628

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Attorneys for Amici

# CERTIFICATION

I hereby certify that this brief conforms to the rules contained in Wis. Stat. § 809.19(8)(b) and (c) for a nonparty brief. The length of this brief is 2,702 words.

Dated this 23rd day of May, 2014.

Signed:

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# 809.19 NoteCERTIFICATION OF COMPLIANCE WITH RULE 809.19(12)

I hereby certify that 809.19 NoteI have submitted an electronic copy of this brief, excluding the appendix, if any, which complies with the requirements of Wis. Stat. § 809.19(12). I further certify that t809.19 Notehis electronic brief is identical in content and format to the printed form of the brief filed as of this date.

809.19 NoteA copy of this certificate has been served with the paper copies of this brief filed with the court and served on all opposing parties.

Dated this 23rd day of May, 2014.

Signed:

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1. *See* Todd Richmond, *Madeline Kara Neumann Prayer Death: Conviction Upheld For Parents Who Only Prayed For Sick Daughter*, Huffington Post, Jul. 3, 2013, *available at* http://www.huffingtonpost.com/2013/07/03/madeline-kara-neumann-prayer-death\_n\_3539974.html. [↑](#footnote-ref-1)
2. In *In the Matter of the Guardianship of L.W.*, 167 Wis. 2d 53, 482 N.W. 2d 60 (Wis. 1992), the Wisconsin Supreme Court carved out a limited exception to this principle for situations in which the individual is in a persistent vegetative state. Amici note, without commenting on this exception, that it does not apply in this case. [↑](#footnote-ref-2)
3. National Disability Rights Network, Devaluing People with Disabilites: Medical Procedures that Violate Civil Rights 17, 26-30 (2012), available at http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing\_People\_with\_Disabilities.pdf. [↑](#footnote-ref-3)
4. *Id.* at 17. [↑](#footnote-ref-4)
5. *Id.* at 28. [↑](#footnote-ref-5)
6. *Id. at* 14. [↑](#footnote-ref-6)
7. Norman Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 Critical Care Clinics 145, 155-156 (1986), available at https://mywebspace.wisc.edu/rstreiffer/web/CourseFolders/MHB558S06/Fost%20-Treament%20of%20Critically%20Ill%20Newborns.pdf. [↑](#footnote-ref-7)
8. *See generally* Norman Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 Critical Care Clinics 145, 155-57 (1986), available at https://mywebspace.wisc.edu/rstreiffer/web/CourseFolders/MHB558S06/Fost%20-Treament%20of%20Critically%20Ill%20Newborns.pdf. [↑](#footnote-ref-8)
9. *See* UWHealth.org, “Find a Doctor: Norman Fost, MD, MPH,” *available at* http://www.uwhealth.org/findadoctor/Provider.action?id=6022. [↑](#footnote-ref-9)
10. *See generally* Norman Fost, *Treatment of Seriously Ill and Handicapped Newborns*, 2 Critical Care Clinics 145, 154 (1986), available at https://mywebspace.wisc.edu/rstreiffer/web/CourseFolders/MHB558S06/Fost%20-Treament%20of%20Critically%20Ill%20Newborns.pdf. [↑](#footnote-ref-10)