No. 1-22-0851

IN THE APPELLATE COURT OF ILLINOIS
FIRST JUDICIAL DISTRICT

THIS APPEAL INVOLVES A MATTER SUBJECT TO EXPEDITED DISPOSITION SPECIFICALLY ORDERED UNDER RULE 311(b) BY THE REVIEWING COURT

In the matter of JOHN F. People of the State of Illinois, Petitioner-Appellee v. John F., Respondent-Appellant, **Alleged to be subject to involuntary electroconvulsive therapy**	Appeal from the Circuit Court of Cook County, Illinois **No. 2022 CoMH 1728** Honorable Maureen Ward-Kirby, Presiding Judge

MOTION OF NEW YORK LAWYERS FOR THE PUBLIC INTEREST FOR LEAVE TO FILE A BRIEF AMICI CURIAE IN SUPPORT OF RESPONDENT-APPELLANT

New York Lawyers for the Public Interest ("NYPLI"), pursuant to Rules 345 and 361 of the Illinois Supreme Court, respectfully moves this Court for leave to file the accompanying brief *Amici Curiae* in support of Respondent-Appellant John F.

In support of its motion, NYPLI states the following:

1. This case involves whether the trial court erred by failing to consider the doctrine of substituted judgment when deciding that the Respondent-Appellant John F. should be forced to undergo involuntary electroconvulsive therapy.
2. Founded in 1976, NYPLI is a community-driven civil rights organization that fights for disability, health, and environmental justice.

3. NYPLI works to promote and protect the civil rights of people with disabilities through its Disability Justice Program, which specializes in advocating for the least restrictive treatment modality and generally enforcing the rights of persons with mental illness
4. Central to NYPLI's mission, and in particular the mission of its Disability Justice Program, is ensuring that those with disabilities are treated with dignity and respect while holding powerful institutions accountable to their communities.
5. Additional amicus curiae include the American Civil Liberties Union of Illinois ("ACLU of Illinois") is a statewide, nonprofit, nonpartisan organization dedicated to the protection and defense of the civil rights and civil liberties of all Illinoisans. The ACLU of Illinois is committed to ensuring that all people are treated with fairness and dignity, including individuals with mental health issues.
6. The National Association for Rights Protection and Advocacy ("NARPA") provides support and education for advocates working in the mental health arena. Central to NARPA's mission is the promotion of those policies and strategies that represent the preferred options of people who have been diagnosed with mental disabilities.
7. The Connecticut Legal Rights Project was created to serve psychiatric inpatients in state facilities and provide them with their constitutional right to access the courts.
8. Equip for Equality ("EFE") is an independent, not-for-profit organization that administers the federally-mandated Protection and Advocacy System in Illinois. EFE's mission is to advance the human and civil rights of people with disabilities in Illinois.
9. The amicus curiae brief written in this case will provide the court with a broad understanding of the right to bodily autonomy and the correlated right to consent to, or refuse consent to, medical procedures.

10. The brief will also discuss the merits of the substituted judgment approach when evaluating a request for forced treatment under Section 2-107.1 of the Mental Health and Development Disabilities Code.
11. Lastly, the brief will explain the medical implications of electroconvulsive therapy.
12. An understanding of each of these topics is very important for a proper analysis of the issues before the court and no harm to any parties will occur by the court's acceptance of this brief.

WHEREFORE, for these reasons, NYPIL submits that the attached brief will be beneficial to the Court and respectfully requests that this Court grant it leave to file this *Amici Curiae* brief. A proposed order is attached to this Motion and the *Amici Curiae* Brief is attached as Exhibit A.

Dated: July 13, 2022

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EXHIBIT A

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BRIEF OF AMICI CURIAE IN SUPPORT OF RESPONDENT-APPELLANT

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INTRODUCTION

By all reports, for over six decades of his life, John F. was just an ordinary man. He had a steady job, a wife, and a family. He showed no signs of mental illness, was active outside of the home and managed the challenges of everyday life just as well as anyone else. Around August or September 2021, Mr. F's family began noticing some minor differences in his behavior that became more significant in October 2021. Mr. F began being apathetic about life, disengaging from activities, and remaining in bed all day long. By November 2021, his family was so concerned that they brought him into a local hospital that provided him with little treatment or support before he was eventually discharged.

After Mr. F was discharged from the local hospital, he was re-admitted in December 2021, this time to Northwestern Memorial Hospital. In December 2021 and January 2022, Mr. F was offered electroconvulsive therapy, also known as ECT. ECT is a medical procedure involving a brief electrical stimulation of the brain in order to produce a seizure, while the patient is under general anesthesia. A patient will typically receive electroconvulsive therapy two or three times a week for a total of six to twelve procedures, depending on the severity of symptoms. For each procedure, electrodes are attached to the patient's scalp and, in addition to having to undergo general anesthesia, patients are often administered a paralytic to prevent movement during the procedure, that could result in serious injury. The seizure brought about by the procedure will typically last about one minute and the patient will wake up without memory of the

events surrounding the procedure. The electroconvulsive therapy results are often just temporary.[1]

At the time of this hospitalization, Mr. F declined electroconvulsive therapy based on his reasoned judgment that the benefits were not worth the risks of suffering side effects such as memory loss. Mr. F gave his consent to receive alternative medication instead. No one contends that Mr. F lacked capacity in December 2021 or January 2022 when he repeatedly declined ECT. Mr. F was again discharged, but was once more re-admitted to Northwestern Memorial Hospital in mid-March 2022. Once again, Mr. F was offered and declined electroconvulsive therapy, but this time his doctors did not take no for an answer.

The question whether or not, or to what extent, Mr. F has the right to choose his own medical treatment, or refuse medical treatment recommended by his doctors, is a question of personal liberty as well as due process. In sum, this case concerns one of the most sacred and closely guarded rights in common law–the right to bodily autonomy.

For months, Mr. F was consistent in his refusal to receive electroconvulsive therapy as well as the reasons for that refusal. Among the many side effects of ECT, Mr. F was most concerned with memory loss. Although not every individual may make this same determination, and although his doctors and family may wish that he would have chosen otherwise, Mr. F explicitly, clearly, and unambiguously decided to forgo ECT.

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[1] Further information regarding electroconvulsive therapy can be found on the websites for Mental Health America, Inc. (https://www.mhanational.org/ect), the American Psychiatric Association (https://www.psychiatry.org/Patients-Families/ECT) and the National Institute of Mental Health (https://www.nimh.nih.gov/health/topics/brain-stimulation-therapies/brain-stimulation-therapies).

His decision was respected multiple times by his physicians who determined him capable of making such a decision.

Yet the trial court failed to consider these clear articulations of his intent to refuse treatment once he lost capacity to make these important treatment decisions. This was an error because the Supreme Court has recognized that when determining whether to authorize involuntary treatment for individuals who lack capacity pursuant to the Mental Health and Development Disabilities Code, *see* 405 ILCS 5/2-107, courts must consider evidence of what the incompetent patient would have wanted if they were competent. This approach, known as the substituted judgment approach, respects each individual's right to bodily autonomy, and the correlated right to consent or not consent to medical treatment, by putting the wishes of a patient first.

Notwithstanding the multiple instances when his physicians recognized that Mr. F had capacity to decline electroconvulsive therapy, the trial court not only disregarded Mr. F's subjective wishes for his treatment, but also refused to address the substituted judgment analysis entirely. By ignoring the substituted judgment approach, despite its endorsement by the Supreme Court, the trial court undermined Mr. F's fundamental liberty interests and due process rights. The decision strips Mr. F of his ability to make decisions about his own body and forces him to undergo a procedure that he has repeatedly refused based on his reasoned judgement that the benefits are not worth the risks.

The trial court's judgement must be reversed to avoid encroaching on Mr. F's most essential rights and interests.

STATEMENTS OF INTEREST OF AMICI CURIAE

A. American Civil Liberties Union of Illinois

The American Civil Liberties Union of Illinois ("ACLU of Illinois") is a statewide, nonprofit, nonpartisan organization with more than 60,000 members dedicated to the protection and defense of the civil rights and civil liberties of all Illinoisans. The ACLU of Illinois is committed to ensuring that all people are treated with fairness and dignity, including individuals with mental health issues. The ACLU of Illinois' ongoing work in support of this component of its mission includes representation of the plaintiff classes in two statewide class actions – *Williams v. Pritzker*, No. 05-C-4673 (N.D. Ill.) (class action asserting ADA and other claims on behalf of people with psychiatric disabilities living in specialized mental health rehabilitation facilities), and *Colbert v. Pritzker*, No. 07-C-0437 (N.D. Ill.) (class action asserting ADA and other claims on behalf of people with physical and psychiatric disabilities warehoused in nursing homes). The issues in these cases include protection of class members' rights to make their own choices about the mental health care, service, and support they choose to accept when they have decided to leave institutional care and move to integrated settings in the community.

B. Connecticut Legal Rights Project

Connecticut Legal Rights Project ("CLRP") is a statewide legal services organization whose clients are low-income people with psychiatric disabilities. CLRP was created by a federal consent decree in 1989 to serve psychiatric inpatients in state facilities and provide them with their constitutional right to access the courts. CLRP also provides legal representation to low-income people with psychiatric disabilities who

reside in the community. CLRP's inpatient representation includes assisting clients with commitment, involuntary medication, electroshock/ECT hearings, and conservatorships. CLRP attorneys represented the plaintiff in *Bolmer v. Oliveira*, MD, 570 F.Supp.2d 301 (D. Conn. 2008), *on appeal*, 594 F.3d 134 (2d Cir. 2011) (challenging involuntary commitment, physical restraint and involuntary injection at a hospital).

C. Equip for Equality

Founded in 1985, Equip for Equality ("EFE") is an independent, not-for-profit organization that administers the federally-mandated Protection and Advocacy System in Illinois. EFE's mission is to advance the human and civil rights of people with disabilities in Illinois. Self-determination and bodily autonomy are among the issues EFE focuses upon, including serving as counsel in the case of *In re Estate of K.E.J.*, 382 Ill.App.3d 401 (1st Dist. 2008), which established due process protections for people with disabilities when guardians seek to involuntarily sterilize their wards. EFE then successfully advocated for that court decision to be codified into statute, 755 ICLS 5/11a-17.1.

D. National Association for the Rights Protection and Advocacy

The National Association for Rights Protection and Advocacy ("NARPA") was formed in 1981 to provide support and education for advocates working in the mental health arena. It monitors developing trends in mental health law and identifies systemic issues and alternative strategies in mental health service delivery on a national scale. Members are attorneys, people with psychiatric histories, mental health professionals and administrators, academics, and other advocates—with many people in roles that overlap. Central to NARPA's mission is the promotion of those policies and strategies that represent the preferred options of people who have been diagnosed with mental

disabilities. Approximately 40% of NARPA's members are current or former patients of the mental health system. NARPA members were key advocates for the passage of federal legislation such as the Americans with Disabilities Act ("ADA") (42 U.S.C. §§ 12101 et seq.), the ADA Amendments Act of 2008 ("ADAAA") (Pub. L. 110-325), and the Protection and Advocacy for Individuals with Mental Illness ("PAIMI") Act (42 U.S.C. §§ 10801-51).

E. New York Lawyers for the Public Interest

Founded in 1976, New York Lawyers for the Public Interest ("NYLPI") is a community-driven civil rights organization that fights for disability, health, and environmental justice. NYPLI works to promote and protect the civil rights of people with disabilities through its Disability Justice Program, which specializes in advocating for the least restrictive treatment modality, and generally enforcing the rights of persons with mental illness. NYPLI fights for systemic changes via impact litigation, legislative advocacy and providing trainings for people with disabilities and their families. Central to NYPLI's mission, and in particular the mission of its Disability Justice Program, is ensuring that those with disabilities are treated with dignity and respect while holding powerful institutions accountable to their communities. NYLPI's key related litigation includes *O'Toole v. Cuomo*, 1:12CV04166 (E.D.N.Y.) (enforcing landmark settlement providing "adult home" residents with mental disabilities the supports to live in their own homes); *Brad. H. v. City of New York*, No. 117882/99 (N.Y. App. Div.) (enforcing decision granting people with mental illness in the City's jail system the right to discharge planning and services upon release from custody).

ISSUE PRESENTED FOR REVIEW

Whether the trial court below erred by failing to consider the doctrine of substituted judgment when deciding that the respondent-appellant, John F, should be forced to undergo electroconvulsive therapy despite the fact that he consistently and explicitly declined such procedures on the basis of potential side effects, and his decisions to refuse electroconvulsive therapy were previously accepted as reasoned and competent by his physicians.

STATEMENT OF FACTS

The *amici curiae* adopt the Statement of Facts from the brief of respondent-appellant, John F.

ARGUMENT

The right of all individuals to control their own person is deeply rooted in this country's common law. *See Union P. R. Co. v. Botsford*, 141 U.S. 250, 251 (1891) ("No right is held more sacred, or is more carefully guarded, by the common law than the right of every individual to the possession and control of his own person, free from all restraint or interference of others"). From this deeply held and carefully guarded right to bodily autonomy stems the concept of informed consent to medical procedures and the right of patients to refuse to give such consent. *See Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 269 (1990) (explaining the evolution of the informed consent doctrine and noting that the "logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment."); *see also Ficke v. Evangelical Health Sys.*, 285 Ill. App. 3d 886, 889 (1st Dist. 1996) ("The right to refuse medical care has been recognized under constitutional right-to-privacy principles and is deeply ingrained in common law principles of individual autonomy, self-determination

and informed consent."). This right to bodily autonomy persists even in the face of life-threatening conditions. *In re Estate of Longeway*, 133 Ill. 2d 33, 44-45 (1989) (the right to refuse treatment "incorporates all types of medical treatment, including life-saving or life-sustaining procedures").

Furthermore, although the state has a legitimate *parens patriae* interest in ensuring the treatment of individuals incapable of making reasoned decisions, the right of individuals to make their own medical decisions is guaranteed even for those who have a mental illness and refuse psychiatric treatment. *See In re C.E.*, 161 Ill. 2d 200, 213 (1994) (finding that "persons who are mentally or developmentally disabled have a federal constitutionally protected liberty interest to refuse the administration of psychotropic drugs"); *see also In re H.P.*, 2019 Il. App. (5th) 150302, 432 Ill. Dec. 840, 130 N.E. 3d 382 (5th Dist. 2019) (reversing lower court order authorizing involuntary administration of psychotropic medication); *In re Israel*, 278 Ill. App. 3d 24 (2nd Dist. 1996) (holding that, although the patient "clearly" had a mental illness, he could still refuse to take medication). To appropriately balance these sometimes-conflicting interests, and guarantee the continued safeguarding of each patient's right to bodily autonomy, the legislature enacted Section 2-107.1 of the Illinois Mental Health and Development Disabilities Code, *see* 405 ILCS 5/2-107, which sets forth extensive protections ensuring substituted judgment decisions for those lacking decision-making capacity.

I. Patients' Rights are Protected Through Section 2-107.1 of the Mental Health and Development Disabilities Code

Section 2-107.1 authorizes the forced administration of psychotropic medication, including procedures such as electroconvulsive therapy, but establishes indispensable

procedural safeguards such as a mandatory court hearing and a showing by clear and convincing evidence:

> (A) That the recipient has a serious mental illness or developmental disability.
>
> (B) That because of said mental illness or developmental disability, the recipient currently exhibits any one of the following: (i) deterioration of his or her ability to function, as compared to the recipient's ability to function prior to the current onset of symptoms of the mental illness or disability for which treatment is presently sought, (ii) suffering, or (iii) threatening behavior.
>
> (C) That the illness or disability has existed for a period marked by the continuing presence of the symptoms set forth in item (B) of this subdivision (4) or the repeated episodic occurrence of these symptoms.
>
> (D) That the benefits of the treatment outweigh the harm.
>
> (E) That the recipient lacks the capacity to make a reasoned decision about the treatment.
>
> (F) That other less restrictive services have been explored and found inappropriate.
>
> (G) If the petition seeks authorization for testing and other procedures, that such testing and procedures are essential for the safe and effective administration of the treatment.

405 ILCS 5/2-107. In addition, any order authorizing involuntary treatment must specify the ranges of dosages authorized, as well as names of individuals authorized to administer the treatment. *See id.* The procedural safeguards established by Section 2-107.1 are critical to the protection of the patient's liberty interests, and strict adherence to the provision's requirements is therefore required. *See In re Frances K.*, 322 Ill. App. 3d 203, 208 (2nd Dist. 2011) (finding that a patient was denied procedural due process when certain provisions of the Mental Health and Development Disabilities Code were not followed); *In re O.C.*, 338 Ill. App. 3d 292, 298 (4th Dist. 2003) ("The procedural safeguards enacted by the legislature are not mere technicalities. Rather they are intended to safeguard important liberty interests of the respondent which are involved in mental

health cases.") *quoting In re Luttrell*, 261 Ill. App. 3d 221, 230-31 (4th Dist. 1994); *In re Gloria*, 333 Ill. App. 3d 903, 905 (3rd Dist. 2002) (noting that "a court's order that does not comply with the [Mental Health] code should be reversed").

As set forth more fully below, the trial court erroneously interpreted Section 2-107.1 when it failed to consider the respondent's proven and unwavering wish to forgo electroconvulsive therapy, which he consistently communicated to his physicians at a time when he was competent to make that decision.

II. The Doctrine of Substituted Judgment Respects Patient's Fundamental Rights and Interests

The doctrine of substituted judgment was first conceptualized as grounds for the courts to permit a guardian to make gifts (*i.e.*, to family members in need) from the disabled ward's estate when the disabled ward had no legal obligation to support the person, but would nevertheless have wished to provide such support. *See In re Marriage of Drews*, 139 Ill. App. 3d 763, 775 (1st Dist. 1985) (explaining the history of the substituted judgment doctrine). Since its conception, the doctrine has expanded to allow guardians to consent to certain medical treatments on behalf of their wards. *See id.* Put simply, the substituted judgment approach requires guardians making medical decisions on behalf of incompetent persons to first determine, to the best of their abilities, what the subjective wishes of the patient would be if they were competent. *See In re Estate of Longeway*, 133 Ill. 2d at 44-45 (explaining that the actual, specific, and express intent of the patient is both helpful and compelling).

This substituted judgment approach respects the incompetent person's subjective views, and many courts have acknowledged the merits of the approach for its ability to protect an incompetent person's rights to privacy, self-determination, and informed

consent. *See e.g., Cruzan,* 497 U.S. at 271-74 (gathering cases); *see also Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 750-51 (1977) ("The 'substituted judgment' standard … commends itself simply because of its straightforward respect for the integrity and autonomy of the individual"); *New York City Health & Hospitals Corp. v. Stein*, 335 N.Y.S. 2d 461, 464 (Sup. Ct. N.Y. 1972) ("But since obviously the greatest suffering from an incorrect decision will be borne by respondent herself, the Court must permit her refusal to be determinative unless the evidence is sufficient to convince the Court that she lacks the mental capacity to knowingly consent or withhold her consent."). Illinois also has embraced this approach, and courts in this state often respect the wishes of the patient above all else. *In re Estate of Greenspan*, 137 Ill. 2d 1 (1990) ("If it is clearly and convincingly shown that Mr. Greenspan's wishes would be to withdraw artificial nutrition and hydration, and if the other established criteria for permitting such withdrawal are met, Mr. Greenspan's imputed choice cannot be governed by a determination of best interests by the public guardian, AUL or anyone else.").

In the context of Section 2-107.1, the Supreme Court has held that a "recipient's subjective perceptions may well be an integral part" of the proof required. *In re C.E.*, 161 Ill. 2d at 221. As a result, courts applying this provision should "respect the wishes expressed by the mental patient when the patient was capable of making rational treatment decisions on his own behalf," and only "when those wishes cannot be clearly proven," may the court instead be guided by an objective standard of relevance. *Id*. In sum, when a court is presented with an application pursuant to Section 2-107.1, it must first consider the substituted judgment approach and take into consideration the

subjective wishes of the patient while the patient was competent. *See id.* In fact, since the Supreme Court's decision in *C.E.*, courts have interpreted the holding to require the consideration of substituted judgment when there is evidence of the patient's competent, subjective wishes. *See Matter of Jeffers*, 272 Ill. App. 3d 44, 47 (4th Dist. 1995) ("Had any evidence regarding the 'substituted judgment' standard been offered, *C.E.* would require the trial court to consider it.").

It is only when there is insufficient evidence of the patient's subjective wishes so the patient's subjective wishes that the court may instead seek to objectively determine what is in the best interests of the patient. *See Matter of Jeffers*, 272 Ill. App. 3d at 47. This objective approach requires the court to evaluate all relevant advice, medical or otherwise, to reach an independent conclusion of what a reasonable person, if competent, would do. *See In re C.E.*, 161 Ill. 2d at 221. Although the objective approach might be easier to apply given the evidence required, it has also been criticized for ignoring individual views in favor of the hypothetical reasonable person's views. *See id*. The Court in *C.E* thus observed that this hybrid approach, when the patient's subjective desires are considered before an objective determination is made, strikes the appropriate balance. *See id.*

Here, Mr. F was first offered ECT in December 2021. Throughout his hospitalization, and as recently as January 2022, Mr. F declined ECT, but consented to alternative treatment. During this particular hospitalization, Mr. F's physicians determined that he was not only competent enough to consent to the alternative treatments, but that he was also competent enough to refuse the electroconvulsive therapy

offered. On this particular occasion, Mr. F's physicians respected Mr. F's wishes and did not seek to administer ECT against his will.

The trial court below was presented with this clear evidence of Mr. F's subjective wishes, but declined to even consider it. *See* Hr'g Tr. Pg. 98-99 (declining respondent's counsel's invitation to consider the substituted judgment argument). Instead, the court reviewed Mr. F's refusal in April 2022 in a vacuum, determined that Mr. F lacked capacity to refuse treatment again, and ignored any prior indications of Mr. F's medical preferences. *See id.* ("We're not talking about January because that was a petition that wasn't filed. I'm talking—right now this man has been in the hospital since mid-March.").[2] Notably, the state failed to present any evidence to counter the respondent's substituted judgment arguments. Specifically, the state did not argue, and the court did not find, that Mr. F lacked capacity when he previously declined ECT. Furthermore, the state has offered no explanation for why Mr. F's doctors previously relied on his capacity when accepting his refusals to be administered ECT. To the contrary, the court actually noted that Mr. F may have had capacity at some point during his earlier hospitalizations. *See id.* at 99:16-20 ("Because I'm looking at the time frame when this petition was filed. That capacity does ebb and flow, as we know from many cases, and that's what sort of [happened] in this case.").

Therefore, the evidence presented by Mr. F was uncontroverted, but also unconsidered. The court's failure to take Mr. F's wishes into account, despite the manifest weight of evidence proving he did not and does not want to undergo ECT procedures, is a clear error that must be reversed.

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[2] The amici curiae have accepted, for the purposes of this brief, that the respondent was not competent in April 2022.

III. Appellant's Refusal to Undergo Electroconvulsive Therapy is Justified Based on the Dangers Associated with the Procedure

Underpinning an individuals' right to refuse psychotropic medication and other procedures for mental illness are two fundamental concerns: (1) the substantially invasive nature of such treatments and their significant side effects; and (2) recognition that such treatments may be misused to control patients rather than for their treatment. *See In re C.E.*, 161 Ill. 2d at 214-15. Both of these concerns are present here which further compounds the harm of the trial court's error. *See In re Branning*, 285 Ill. App. 3d 405, 411 (4th Dist. 1996).

A. Side Effects of ECT

In *C.E.*, the Court noted that the possible side effects of psychotropic substances include, among other things, drowsiness, fatigue, and dry mouth and throat. *See id.* at 214. Similarly, in *Israel*, which reversed a lower court's order authorizing the involuntary administration of psychotropic drugs, the court noted that the possible side effects of the treatment were serious, although the physician testified that the chances of the patient experiencing these side effects were minimal. *See In re Israel*, 278 Ill. App. 3d at 29.

Here, Mr. F. has repeatedly based his refusal to receive ECT on the risk of memory loss—a risk that is well-recognized by physicians and common in patients who receive ECT. *See In re Estate of Austwick*, 275 Ill. App. 3d 769, 781-82 (1st Dist. 1995) (listing potential side effects of ECT, including memory loss); *see also* Nita A. Farahany, The Costs of Changing Our Minds, 69 EMORY L.J. 75 (2019) (gathering sources and noting that "[e]ntire memories from the days and weeks prior to ECT have been permanently degraded."); Elizabeth R. Newell, Competency, Consent, and

Electroconvulsive Therapy: A Mentally Ill Prisoner's Right to Refuse Invasive Medical Treatment in Oregon's Criminal Justice System, 9 LEWIS & CLARK L. REV. 1019, 1024 (2005) (describing the risk of memory loss as one of the "true long-term cognitive effects" of ECT). In fact, although earlier studies had left an important empirical gap about ECT's long term effects, in 2007 researchers published the results of a study funded by the National Institute for Mental Health which revealed that adverse cognitive effects can persist for an extended period of time and such deficits can be substantial. *See* Harold A. Sackeim, Joan Prudic, Rice Fuller, et al., The Cognitive Effects of Electroconvulsive Therapy in Community Settings, 32 NEUROPSYCHOPHARMACOLOGY 244, 244-253 (2007).

There are other potential side effects of ECT, however, that are equally serious and include, among other things, heart attack, stroke, death, increased heart rate, increased blood pressure, confusion, nausea, headache, jaw pain, and muscle aches. *See* Richard D. Weiner, Ethical Considerations with Electroconvulsive Therapy, 5 VIRTUAL MENTOR 352, 352 (2003); Mayo Clinic Staff, Electroconvulsive Therapy (ECT), MAYOCLINIC.ORG, available at https://www.mayoclinic.org/tests-procedures/electroconvulsive-therapy/about/pac-20393894. In fact, although there is a divide in opinion among psychiatrists, some literature on the effectiveness of ECT concludes that, because there is strong evidence of persistent and permanent brain dysfunction compared with so little evidence of any lasting benefit, ECT can never be scientifically justified. *See* Mary Stefanazzi, Is Electroconvulsive Therapy (ECT) Ever Ethically Justified? If So, Under What Circumstances, 25 HEC F. 79, 86-89 (2013); *see also* 83 Fed. Reg. 66103 (2018), Wednesday, December 26, 2018, page 66115 (the U.S.

Department of Health and Human Services, when considering rules for the reclassification of ECT devices, noted that ECT labels must warn that the procedure "may be associated with: disorientation, confusion, memory problems and is limited in its long-term effectiveness (greater than 3 months).").

The reality is that, even though we know seizures change many chemical aspects of brain function, physicians still do not know exactly how or why those changes treat a patient's mental illness. *See* Mayo Clinic Staff, Electroconvulsive Therapy (ECT), MAYOCLINIC.ORG, available at https://www.mayoclinic.org/tests-procedures/electroconvulsive-therapy/about/pac-20393894; Mental Health America, Inc., Electroconvulsive Therapy, available at https://www.mhanational.org/ect. This uncertainty has led some to suggest that ECT merely acts as a negative enforcer to depressed behavior so that patients will only change their behavior to avoid further punishment. *See* Daniel T. Gilbert, Shock Therapy and Informed Consent, 69 ILL. B.J. 272, 272 (1981) (discussing informed consent in the context of the Illinois Mental Health Code).

Furthermore, ECT requires the administration of general anesthesia for each procedure, which itself carries a number of significant risks. *See Curran v. Bosze*, 141 Ill. 2d 473, 509 (1990) (recognizing the additional risks of anesthesia in the context of a request compelling children to submit to a bone marrow harvesting procedure). The most serious risks of general anesthesia include heart failure, cardiac arrest, slowed heart rate, abnormal heart rhythm, atrial fibrillation, myocardial infarction, thrombosis, renal failure, apnea, pancreatitis and pulmonary edema. *See* Prescribers' Digital Reference, Propofol

Drug Summary, available at https://www.pdr.net/drug-summary/Diprivan-propofol-1719.3436.

In sum, there are serious side effects associated with both the use of ECT and the general anesthesia required to administer ECT. The fact that Mr. F has consistently referred to these side effects as the basis for his refusal to voluntarily submit to ECT is itself a basis to find that his refusal was a rational and competent decision. *See In re Israel*, 278 Ill. App. 3d at 39 (overturning the lower court's order involuntary administering treatment after determining that, despite the patient's mental condition, he expressed reasonable concern over potential side effects to treatment). Mr. F should not be forced to be exposed to these significant risks given his unwavering, subjective determination that these risks do not outweigh the potential, short term benefits of electroconvulsive therapy.

B. Possibility of Misuse

Many physicians agree that ECT can be used ethically to treat certain psychiatric conditions, but there can be no doubt that it may be misused. *See In re Branning*, 285 Ill. App. 3d at 411 (noting the concern of misuse with ECT); *see also* Mary Stefanazzi, Is Electroconvulsive Therapy (ECT) Ever Ethically Justified? If So, Under What Circumstances, 25 HEC F. 79, 82 (2013) (noting that several states have restrictive legislation in place because of the belief that ECT was used as a means of subduing difficult patients and administered without adequate regard for the wishes of the patient); *see also* Judit Sandor, Judicial Monitoring of Psychiatric Confinement and Therapy, 4 E. EUR. Const. REV. 83 (1995) (explaining that the legislative branch of the Council of Europe put in place several procedural safeguards for the administration of

electroconvulsive therapy, including a requirement for written informed consent and overview by a select committee, because of the potential for abuse).

For all of the above reasons, involuntary ECT is uncommon in the United States, and every state requires a judicial proceeding before authorizing the administration of such a forced procedure. *See* 83 Fed. Reg. 66103 (2018), Wednesday, December 26, 2018, page 66114.

Here, Mr. F expressed his desire to forgo ECT multiple times due to its potential side effects, and this wish was respected as a competent and rational choice until Mr. F's physicians became aware of Mr. F's efforts to avoid nutrition and other treatment. *See* Hr'g Tr. Pg. 74 (Mr. F's physician testified that, at the time he filed the petition to perform the ECT involuntarily, he became more aware of Mr. F's actions to evade food as well as other evasive behaviors). A patient's efforts to avoid psychiatric treatment, however, cannot justify forcible treatment. If this was the rule, an individual's right to bodily autonomy would always be overcome whenever a physician's psychiatric treatment recommendations differed from the patient's wishes. In fact, this reasoning appears more akin to a desire for patient control than true evidence of non-competency. *See In re Branning*, 285 Ill. App. 3d at 411 ("Patient control in a nonpenological setting not only does not *support* a decision to administer ECT, but was recognized in *C.E.* as a potential *misuse* of treatment, an objective to which it might be 'subverted'") (emphasis in original) (internal citation omitted).

The trial court should never have disregarded Mr. F's clear and unwavering decision to forgo ECT, but the error is even more glaring in light of the serious side

effects and potential for misuse associated with ECT. As such, the order subjecting Mr. F to involuntary electroconvulsive therapy must be overturned.

CONCLUSION

The Mental Health and Development Disability Code is intended to protect the fundamental right of all patients in Illinois to make their own healthcare decisions. This sacred and carefully guarded right must be protected, even for those who lack capacity to make their own medical decisions. The way that the trial court interpreted and applied section 2-107.1 was clearly erroneous because it explicitly disregarded all evidence of what the patient, John F., would have wanted at a time when he had capacity to make his own medical decisions. As such, the trial court's order should be REVERSED.

Respectfully submitted,

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CERTIFICATE OF COMPLIANCE

I certify that this brief conforms to the requirements of Rules 341(a) and (b). The length of this brief, excluding the pages or words contained in the Rule 341(d) cover, the Rule 341(h)(1) table of contents and statement of points and authorities, the Rule 341(c) certificate of compliance, the certificate of service, and those matters to be appended to the brief under Rule 342(a), is 19 pages.

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NOTICE OF FILING AND CERTIFICATE OF SERVICE

The undersigned, an attorney, certifies that on July 13, 2022, he caused the foregoing **Brief of *Amici Curiae* in Support of Respondent-Appellant** to be filed with the Clerk of the First District Appellate Court using the Court's electronic filing system and that the same was served by e-mail to the following counsel of record:

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