Sarah Kotler
Director, Office of the Executive Secretariat
US Food & Drug Administration
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Rockville, MD 20857

E-mail: FDAFOIA@fda.hhs.gov

28 December 2021

Dear Director Kotler,

I write to appeal your denial of request number: 2020-7319 for the expedited processing of the Electronic Freedom of Information Act request submitted on 9 October 2020. I received your denial October 27, 2020 and have 90 days to appeal your decision. Please note my appeal is an open letter with 97 citations co-signed by 14 Professional and Paraprofessional organizations, 168 Americans, and 49 international citizens whose countries base their guidelines in part on the FDA's decisions. Signatories included up to eight words to describe their perspective on "Real-World Data" and "Real-World Evidence" regarding electroconvulsive therapy's (ECT) post-market safety, adverse events and regulatory decisions.

Here is our appeal:

FOI #2020-7319 requested the following:

- ECT manufacturers' premarket approval applications (PMA) for all uses not presently classified as class II (i.e., schizoaffective disorder, parkinsonism, dementia, bipolar manic state, OCD, autism, etc)
- Notices of completed product development protocols (PDP) submitted to the FDA before March 27, 2019 for any electroconvulsive therapy device with an intended "use to treat catatonia or a severe major depressive episode (MDE) associated with major depressive disorder (MDD) or bipolar disorder (BPD) in patients age 13 years and older who are treatment-resistant or who require a rapid response due to the severity of their psychiatric or medical condition" (21CFR882.5940).

As you stated in your email, "The Electronic Freedom of Information Act (EFOIA) Amendments of 1996 amended the FOIA by adding section (a)(6)(E), 5 U.S.C. 552(a)(6)(E), to require agencies to consider requests for expedited processing and grant them whenever a "compelling need" is shown and in other cases as determined by the agency. The term "compelling need" is defined as (1) involving "an imminent threat to the life or physical safety of an individual," or (2) in the case of a request made by "a person primarily engaged in disseminating information, urgency to inform the public concerning actual or alleged Federal Government activity.""

Imminent threat to the life or physical safety for ECT recipients

The following imminent threats to life or physical safety of people receiving electroconvulsive therapy (ECT) are based on published research which follows guidelines established by the American Psychiatric Association's "The Practice of Electroconvulsive Therapy: Recommendations for Treatment, Training and

Privileging," and the medical device user's manuals and regulatory updates for the Thymatron and MECTA ECT devices presently used in in community settings^{1–4}:

- All-cause mortality during ECT treatment is 0.42 [0.11 1.52] deaths per 1,000 patients. 29% of ECT deaths are Cardiac related."⁵
- "Major adverse cardiac events (MACE) and death after ECT ... occur in about one in 50 patients and after about one in 200 500 ECT treatments. (MACE is defined as "myocardial infarction, arrhythmia, pulmonary edema, pulmonary embolism, acute heart failure, and cardiac arrest.")⁵
- People receiving ECT are 4.8 times more likely to complete suicide within first week after discharge.⁶
- ECT's "severe stress-exposure or trauma" causes pervasive microstructural damages (petechial hemorrhaging, gliosis, astrocytosis, myelin sheath damage, cerebrovascular vascular) most concentrated in the current's path 2,8-15, increased immunoreactivity 16-19, metabolic abnormalities 18,20-25 including acquired channelopathies 26-34, and loss of astrocytes effects tight junctions of the blood-brain-barrier integrity increasing potential for neurodegenerative disorders 15. These microstructural damages, only visible in neuropathological animal and human studies, identify injuries throughout the brain consistent with electrical injury from sources of electricity other than ECT all of which have long-lasting neurological consequences. 27,28,31,36-65
- Though microstructural damage occurs through the entire brain, the brain stem and anterior of the frontal lobes carries the brunt of up to 450 volts, 900 mA current, 576 mC Charge (1200 mC in the UK) electricity because it is the focal point of the electrical path. ^{1,2,10}
- Electroconvulsive therapy is not a singular event. Index courses are 8-12 treatments, typically given three times a week. Like all repetitive brain injuries, the greater the amount of time between insults, the fewer cognitive and neurological side effects. Acute treatment calls for ECT to be given as often as three times a week—and if a seizure doesn't last at least 25 seconds, the APA recommends repeating the procedure at a higher electrical dose within moments of the first attempt.³ "Maintenance ECT" is recommended when patients relapse. There are is are no PMA or PDP on record to establish safety limits on "maintenance ECT," Research demonstrates that spacing treatments at least 38.6 days apart will avoid a "cumulative effect." ⁶⁶ Some psychiatrists give patients repeat, back-to-back "index courses" as evident by the woman in Connecticut with an active court case to end her ECT treatments after having received more than 500 in five years—which "likely happens more often than people realize." ⁶⁷
- ECT's "Therapeutic effect" is caused by a temporary Postictal Suppression or "electrical silence," the absence of brain activity. (a sign of severe damage and impending brain death) by forcing 2.5-6 times the body's seizure threshold worth of electricity through the brain. Electrical silence is documented to last up to more than six minutes in some patients given ECT at levels above the threshold. When/if spontaneously resolved, brain activity slowly resumes in bursts of sporadic coma (delta) waves until "silence" is completely replaced with delta waves and the patient later awakes from coma activity. 1,2,68-73 "The process always damages the brain, resulting each time in a temporary coma and often a flatlining of the brain waves, which is a sign of impending brain death. After one, two or three ECTs, the trauma causes typical symptoms of severe head trauma or injury including headache, nausea, memory loss, disorientation, confusion, impaired judgment, loss of personality, and emotional instability. These harmful effects worsen and some become permanent as routine treatment progresses."⁷⁴

- 55% of ECT recipients self-reported negative effects on memory. Tests which accurately capture the extent and type of memory loss and cognitive deficits reported by patients, are not routinely used on every ECT patient, though FDA guidelines recommend it. Consequently, ECT patients are rarely, referred for timely, comprehensive brain injury assessment or rehabilitation.
- The more ECT Treatments a patient has, the greater the likelihood they will suffer seizure, respiratory distress, syncope, paralysis, dizziness, Loss of consciousness and/or death with the introduction of lidocaine during subsequent, unrelated medical and dental procedures. 30,75

Manufacturer & APA recognized risks of "Permanent Memory Loss and Permanent Brain Damage"

Brain damage is defined by the American Heritage Medical Dictionary as "the physically subtle, but functionally serious, injury ... [including] repeated multiple small hemorrhages sustained in boxing. Brain damage often affects the areas of higher function in a patchy way with loss of certain functions and retention of others. ... A proportion of brain-damaged people end up in a state of almost complete loss of the higher mental functions (amentia).⁷⁶ The American Psychiatric Association [and Somatics, LLC (Thymatron ECT device manufacturer) recognizes [seven] treatment parameters are each independently associated with more intense cognitive side effects ... [including] permanent memory loss or permanent brain damage."^{2,3} (Patients can potentially be subjected to more than one risk at a time with each treatment.)

How many people receive ECT yearly?

In 2004, Dr. Harold Sackeim, America's leading researcher on ECT use in clinical settings, testified in court deposition that an estimated two million people receive ECT yearly worldwide.⁷⁷ American ECT use has never been routinely audited nationwide to confirm how many Americans receive ECT, how many treatments each patient receives, how closely spaces treatments are, and what form of ECT they receive.⁷⁸ Yet modern media routinely quotes an arbitrary 1970's statistic that estimated 100,000 Americans receive ECT yearly. Since the beginning of ECT use in the United States, no one has conducted a nationwide audit to confirm or refute that estimate.

Since the 2018 reclassification of ECT as a Class II device for treatment resistant depression and catatonia in children (13+ years old) and adults, the 2020 Substance Abuse and Mental Health Services Administration's National Directory of Mental Health Treatment Facilities shows a 34% increase in the number of facilities providing ECT across the nation when compared to the 2018 directory.^{79,80}

ECT and death

Deaths of ECT patients are rarely acknowledged publicly, investigated, or properly addressed to ensure future patient safety.

For example, on 21 February 2020, an outpatient ECT recipient and resident of *Stepping Stones for Living* "received electroconvulsive therapy from a specialized clinic and was told to expect to be groggy and sleepy. Upon returning to [*Stepping Stones for Living*], the person went to bed and never left it, and was declared dead almost 24 hours later. ⁸¹ Autopsy report given to newspaper reporter by family, stated medical examiner, Dr. A. Quinn Strobl, determined "Sudden Cardiac Death in Schizophrenia" as cause of death (Slater, B. personal communication, June 17, 2020). Though patient safety violations are now acknowledged by investigation, "due to the unprecedented public health challenges during Minnesota's peacetime state of emergency due to the COVID-19 pandemic, a correction order will not be issued." ⁸²

Aging after ECT

"A single mild traumatic brain injury (mTBI) typically causes only transient symptoms, but repeated mTBI (RmTBI) is associated with cumulative and chronic neurological abnormalities." In addition to all ECT recipients who died in all-cause mortality from ECT this year, every person with a history of ECT has increased morbidity proportionate to the number of treatments received, length of time between treatments, stimulus type, electrode placement, and whether they were taking psychiatric medication while undergoing treatment. The more ECT treatments a person has the more electricity must be used to cause a seizure because the body's natural defenses strive to protect it from seizures. Elderly people require higher doses of electricity to cause seizures.³ Doctors break through the body's defenses by using intravenous caffeine to push the body to the brink.^{85,86} There are no recognized safety limits or PDP for IV caffeine use with ECT. Augmenting ECT with caffeine causes neuronal loss in the hippocampus and striatum.⁸⁷ Animal and human ECT neuropathology studies and research specific to high-field strength electrical contact with human cells document the following evidence for brain, nerve and muscular damage in animals and humans. Consider quality of life while aging with the following microstructural damages caused by ECT:

- "increased gliosis; diffuse degeneration; petechial hemorrhages in the brain stem with fat embolism; and more commonly edema and subarachnoid hemorrhage"
- Reactive gliosis⁸⁸
- Neuronophagia and shadow cells ¹⁴
- An "edematous brain" with neuronal damage and increased lipofuscin pigmentation.
- Neuronal loss in the hippocampus and striatum⁸⁷
- neurovascular insults ^{8,9}
- petechial and capillary hemorrhages^{1,2,8–10,12,13}
- Frontal Lobe atrophy⁸⁹
- Severe and irreversible injury to the nervous system¹⁶
- Astrocytosis and its resulting effects on the Blood-Brain Barrier (BBB) integrity and motor neuron function subsequent neurodegeneration.^{9,14,35,90}
- Permanent changes in how the body regulates electrolytes (Acquired channelopathies). 26-34
- Long-term sequelae of low-voltage electrical injury^{40–42,53,58}
- Permanent EEG abnormalities after ECT^{73,89}
- Changes in Evoked Potential testing^{19,48}
- Doctor acknowledged and patient reported movement disorders and sleep disorders after ECT.
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- Repeated ECT causes hyper immune reactivity ^{17,92}
- ECT can potentially permanently change brain metabolism ^{16,18}
- Non-dominant Unilateral ECT uses "six times the seizure threshold to achieve therapeutic effect
 means confining most damage to the nonverbal side of the brain, usually the right hemisphere.
 This exploits the well-known neurological phenomenon of anosognosia, or denial, that is
 associated with right-hemisphere lesions." Patients cannot recognize something is wrong, nor
 can they express it. 1,15

How much electricity do doctors use to force a seizure compared to what is required?

ECT providers tell the public that treatment uses just enough electricity is used to cause a seizure. The APA and device manufacturers recognize "High electrical dosage relative to seizure threshold" as one of the seven independent risks associated with "permanent memory loss and permanent brain damage."^{3,4} But MECTA instruction manual states "when an ultra-brief stimulus is used, the traditional bilateral (bifrontotemporal) placement has reduced efficacy even when dosage is set at 2.5 times the initial seizure threshold. At a traditional pulse width of 1.0 ms or more, right unilateral ECT has been shown to match the efficacy of bilateral ECT, when dosage is 6.0 times the initial threshold." Some doctors do not adjust for electrical output based on electrode placement, nor are they mandated to do so.

Consequently, some patients receive bilateral ECT with six times the electricity required to cause a seizure. This likely causes extensive microstructural damage in their brain stem. Perhaps that's why bilateral electrode placement is listed as one of the risks associated with permanent brain damage?

Unstandardized Medical Devices

Psychiatric facilities give patients ECT using a variety of ECT machines with varying electrical outputs. Not only does the output differ by manufacturer, the same manufacturers sell machines which produce vastly different electrical output depending on the country in which its sold. This renders doctors unable to apply the research conducted on one machine in one country, to the same manufacturer's device sold in another country, nor can they apply outcomes to different ECT devices. None of the devices ever underwent the rigorous scrutiny of a premarket approval application (PMA) for safety testing using modern clinical parameters prior to use on humans. Devices were originally grandfathered into FDA approval when the FDA began giving approval because the devices were already in use. With the introduction of anesthesia, it requires more electricity to cause a seizure, so manufactures made new, stronger machines which also never underwent rigorous PMA testing.

Due to a lack of PMA, there are no universally recognized dosing protocols (Product Development Protocols (PDP)) to establish the limits of safe use in medical devices for people of varying ages or diagnoses. According to personal communication with Dr. Kenneth Castleman, retired NASA biomedical engineer and forensic expert, "On the Thymatron, the pulse width, pulse frequency, and output power can all be set independently ... Doctors set the pulse width, pulse frequency, and output power (0 - 100%), and the device figures out the duration of the treatment.

The current is always 0.9 amp, and the voltage goes up to whatever is required to force 0.9 amp through the patient's head. Some combinations of low frequency and narrow width can't produce 100% output in 8 seconds and it will tell you to increase one or the other."

Imagine having 900mA electricity flowing through the brain for up to eight seconds, repeatedly.

Consequences of using anecdotal evidence which cannot be replicated instead of Evidence-Based Medicine

Without safe PDP administration universally built into the standard of care for Electroconvulsive Therapy, every positive and negative research finding and patient experience is mere anecdotal evidence. More than seven independent administration variables make it impossible to replicate

outcomes universally in community settings. Sackeim et al inadvertently demonstrated how a lack of strictly regulated PDP impacted 347 patients living with depression who received ECT at seven facilities in the New York City metropolitan area. They concluded:

adverse cognitive effects were detected 6 months following the acute treatment course. Cognitive outcomes varied across treatment facilities and differences in ECT technique largely accounted for these differences. Sine wave stimulation and Bilateral electrode placement resulted in more severe and persistent deficits.⁹⁵

The public believes that because Electroconvulsive therapy's FDA approved, it met rigorous safety testing to establish safety limits using modern clinical parameters. It was not. They believe all ECT is created equal and that everyone who has it can reliably expect the "same safe and effective" results. They cannot. There is no specific product protocols for the devices' special controls (technical parameters, waveform, output mode, pulse duration, frequency, train delivery, maximum charge and energy, and the type of impedance monitoring. Consequently, there is a vast outcome dichotomy ranging from symptom improvement to death.

Problem is, without routine comprehensive assessment which measures recognized severe effects in every single recipient, after every procedure and the tracking of neurological symptoms after treatment, there is an absence of published evidence specific to life after ECT. Doctors, hospitals, manufacturers and other proponents of ECT, state severe effects rarely happen. In reality, "the absence of evidence is not evidence of absence."

Is memory loss the only side effect of ECT?

While 29-55% of ECT recipients state they have long-lasting or permanent memory problems, memory loss is but one aspect of negative outcomes associated with ECT. According to Somatics' user manual for Thymatron System IV, other lasting severe effects include:

cardiac complications, brain injury, stroke, deficits in cognition and executive functioning, dental/oral trauma, general motor dysfunction, physical trauma (including fractures, contusions, injury from falls, dental or oral injury), treatment emergent mania and postictal delirium, neurological symptoms (e.g., paresthesia, dyskinesias), tardive seizures; prolonged seizures; non-convulsive status epilepticus; pulmonary complications (e.g., aspiration/inhalation of foreign material, pneumonia, hypoxia, respiratory obstruction (laryngospasm, pulmonary embolism, prolonged apnea); visual disturbance; auditory complications; onset/exacerbation of psychiatric symptoms; completed suicide; homicidality; substance abuse; coma; and death.²

Given the lengthy detailed severe effects outlined in the Thymatron User Manual, it appears they acknowledge their device is "an imminent threat to the life or physical safety of an individual."

Pay attention to both the good and the bad ECT stories

While we acknowledge patients and doctors reporting mood improvement after ECT, we must also acknowledge "the lack of reports of movement disorders and dementia iatrogenic diseases generally go underreported." For that reason, every patient experience, positive and negative must be taken into consideration when weighing eminent threat to life or physical safety. We must error on the side of

caution. It's the patient and their family, not the doctor, who must endure treatments' lasting negative effects for the duration of their life.

Medical Device's Mechanism of Action

Contrary to CFR Section 882.5940 (E), medical device manufacturers must legally provide "Information on how the device operates and the typical course of treatment," ECT device manufacturers have never provided "a description of the principle of operation or mechanism of action for achieving the intended effect" as directed by the 510(k) checklist (non-binding) stipulations for medical device information.

Patients receiving ECT and doctors providing it do not know the devices' mechanism of action works. Consequently, in when severe adverse events occur, doctors are unprepared to provide routinely comprehensive neuropsychiatric, cardiopulmonary, optical, and auditory assessments to every patient receiving ECT. They have never studied the neuropathology of repetitive high field strength electricity to the brain with a focal point on the brainstem (in the case of bilateral treatment) and are simply at a loss as to how to provide follow-up care for the duration of a patient's life after ECT.

This letter requests the expedited release of ECT's PMA and PDP in an effort to "disseminate this information with urgency to inform the public" so that the public can understand how FDA approved ECT for human use is being conducted to reduce the life-altering risks of permanent brain damage and permanent memory loss. The public deserves to understand which safety testing has been conducted and what protocols are in place to ensure safety. The public also need to know what is being done to routinely assess for each of the severe effects outlined in user manuals and how patients will be cared for as they age after ECT's repetitive brain injury.

If at this time, you do not feel we have provided sufficient information to adequately demonstrate "imminent threat to the life or physical safety" or the need to provide information to the public, please consider this FOI request in light of the devices having been grandfathered into use without PMA or PDP and the reclassification as a Class II devices for use on children 13 and older. This request is but an echo of your own office's request in their final ruling of 1979. In which case, the request was first processed nearly 41 years ago.

Protecting children, adults and elderly adults protected as a marginalized demographic by the Americans with Disabilities Act should be a priority for the FDA. The continued use of unstandardized medical devices used in delivering ECT without product development protocols causes imminent danger to uncalculated number of American and international ECT patients whose countries rely on FDA data to develop safety standards.

Recently, the associate director of placebo studies at Harvard Medical School, Dr. Irving Kirsch coauthored an analysis of all ECT's randomized control trials (ECT vs Sham-ECT) with Dr. John Read (University East London) and Dr. Laura McGrath. Their recent publication peer-reviewed article entitled "Electroconvulsive Therapy for Depression: A Review of the Quality of ECT versus Sham ECT Trials and Meta-Analyses" concluded:

"The quality of most SECT–ECT studies is so poor that the meta-analyses were wrong to conclude anything about efficacy, either during or beyond the treatment period. There is no evidence that ECT is effective for its target demographic—older women, or its target diagnostic group—severely depressed people, or for suicidal people, people who

have unsuccessfully tried other treatments first, involuntary patients, or adolescents. Given the high risk of permanent memory loss and the small mortality risk, this longstanding failure to determine whether or not ECT works means that its use should be immediately suspended until a series of well designed, randomized, placebo-controlled studies have investigated whether there really are any significant benefits against which the proven significant risks can be weighed" (italics added for emphasis). ⁹⁷

Below are the signatures of people who would like access to the PMA and PDP of a treatment which carries significant risks. I invited people to share their name, and up to eight words on how ECT impacted them, their families or people with whom they work who have a history of ECT. Since other countries look to the United States FDA as the gold standard upon which to base their own guidelines for ECT use, I included international signatories below those living in the United States. Research citations follow the signatories.

The significant risks detailed in this open letter is echoed in the graphic adjectives used to describe ECT's after-effects by ECT recipients, family members or someone who cares for an ECT recipient or people who work ECT recipients. We look forward to receiving an expedited response to request number: 2020-7319.

Respectfully,

Sarah Price Hancock, MS, CRC

Former Professor of Psychiatric Rehabilitation & ECT Recipient: Profound memory loss, general motor dysfunction, acquired channelopathies, BBB Dysfunction

Organizations-United States & International

Connecticut Legal Rights Project
Law Project for Psychiatric Rights
Disability Rights—Vermont, USA
National Association for Rights Protection and Advocacy
MindFreedom International
Mental Patients Liberation Alliance
MadFreedom, Inc.
Legal Guidance
Global Wellness Warriors
Ruh Global Impact
Hopeworx, Inc.
Progressive Voices
Consumers Health Freedom Coalition
OCSC

Signatories—United States

(A=ECT Recipient, B=Family member or someone I care for is an ECT recipient, C= Family or someone I care for <u>may</u> be an ECT recipient, D=Works with ECT recipient(s), E=May work with ECT recipient(s), F=No direct connection to ECT recipient(s), but value transparency in FDA safety testing & support releasing ECT's PMA & PDP)

- David J Hancock (La Mesa, CA)^B: Inhumane Human Torture with Ever Increasing Repercussions
- John A Price (La Mesa, CA)^B: insufficient informed consent on terrible long-term consequences
- Janet Price (La Mesa, CA)^B: not enough information to make a conformed consent
- Klint Price (Aurora, IL)^{B, D}: devastating disability and memory-loss
- Jeff Price (Powder Springs, GA)^{B, E}
- Michelle Price (Powder Springs, GA)^C: Life-altering, awful
- Amy S. Palmer (Oakton, VA)^C: detrimental, life-altering effects every aspect of life
- Dr. Kyle Kamran Jahangiri, DC (San Diego, CA) C, D: Sad, frustrating, excessive, a complex mess
- Dr. John Humiston, MD (Carmel, IN)^{C, D}: Serious lasting injury not seen in other patients
- Alma Rosa Parker (La Mesa, CA)^B: Challenges with everyday activities emotionally and physically
- *Margaret King* (Hamburg, NY)^A: Barbaric, torture, crippling, misinformed, frightful, sickening, dehumanizing, heartbreak
- Christina Delfino (Peekskill, NY)^A: Misleading, Traumatic, Unprepared, Ill-Informed, Under-Researched, Damaging
- *Deborah Schwartzkopff (McMinnville, OR)* ^A: battery, abuse, deceptive, malpractice, unethical, destructive & inhumane
- Dana Johnson (Winona) A, B: Horrific, unjust, damaging, harmful, abusive, isolating, violent, & hell
- Heike Kessler-Heiberg, Acquired Brain Injury Rehabilitation Professional (San Diego, CA)^D:
 Needing more protocol uniformity; significant memory impairment risk
- Allison Stiles (Downingtown, PA)^{B, D}
- Caren L Sax (San Diego, CA)^{B,D}: Horrific, life changing for the worst
- Colleen Whitley (Salt Lake City, UT)^B
- Julie Plunkette (Paducah, KY)^A: Not fully informed Torture terrifying damaging negative abusive
- Colleen Murphy (Apalachin, NY) A,B: Causes irreparable brain damage that lasts forever
- Jocelyn Pedersen (American, UT)^B: Barbaric, inhumane, cruel, unethical, unconscionable, & horrific
- Amy Peltekian, CEO, Global Wellness Warriors (Escondido, CA)^B: Horrific and life-changing not in a good way
- Amber DeRosear (Springfield, IL) A, B: Torture, Permanent memory loss, Traumatizing, Barbaric, brain damage
- Jason DeRosear (Springfield, IL) ^C: Took away her memory and cognitive thinking!
- Sallie Snyder (Lincoln, CA) A: Horrifying, life-altering, damaging, devastating, worse than death
- Lesley A Safer (Pigeon Forge, TN)^A
- Samantha Moreno (Ypsilanti, MI) ^A: Brain Damage, Disability, devastating, permanent memory loss debilitating
- John Breeding, PhD (Austin, TX)^{B, D}: horrific experience, terrible fear, and severe memory loss
- April Ricks (Draper, UT)^D: Delayed, Incalculable neurological damage, Unmeasured damage without oversight
- Makenna Bell (Addison, TX) ^B: Mom forgot who I was at 12 years.
- Amanda Wilson (Springfield, IL) ^B: Mom is not the same after ECT torture.
- Kathy Flaherty, Executive Director, Connecticut Legal Rights Project (Newington, CT) A, D: Used as last resort because desperate; didn't work.

- Maren Klawiter (Quaker Hill, CT) B,D: Inhumane and harmful if not voluntary; lacking transparency.
- Sara Elizabeth Liss (Middletown, CT) B, D: Awful; caused severe, permanent amnesia
- Sharil Follman (Sedro Woolley, WA) A: Most horrific, physically, mentally damaging experiences of my life.
- Lauren J. Tenney, PhD, MPhil, MPA, BPS (West Palm Beach, FL)^D
- Virginia M. Teixeira, Esq (Middletown, CT) B, D: Involuntary, Frightening, Unconstitutional, loss, lonely, nonmedical, torture, experimental
- Jim Gottstein (Anchorage, AK)^{B, D}: horrific, damaging, fraudulent, memory-loss
- Kirk W. Lowry, Legal Director, Connecticut Legal Rights Project (Middletown, CT)^D
- Colleen K. Whitley (Millcreek, UT)
- Laura Ziegler (Plainfield, VT) B, E: closed head injury in the guise of medicine
- John Breeding, PhD, Psychologist (Austin, TX) B, D: Terrible fear, brain damage and profound memory loss
- Michael Sabourin, formerly VPS psychiatric resident representative (Marshfield, VT) ^{B, D}: short-term memory loss with negligible long-term benefits without maintenance
- Wilda L. White (Poultney, VT) B,D: Unsettling memory loss that was not adequately revealed before treatment
- Ed Paquin, Executive Director, Disability Rights-Vermont (Montpelier, VT) B, D
- Nicole Calhoun (Houlton, USA)^A: Permanently disabling and not effective
- Judith Shalitt (Lakewood, NJ) ^B: Never worked again, cognitively damaged, remained depressed, later suicided
- Kerry M., Peer Support Specialist (Santa Clara, CA) A,D: Frustrating, terrifying, painful, lifedestroying, infantilizing, isolating.
- Madelyn Jean Jones (Roseville, CA) ^A: Terror, Death, Anxiety, Helpless, Violated, Triggers, Ignored, & Emergency.
- Jacob Z Hess (Paradise, UT) B, D: Long-term impacts on memory and capacity
- Bridget Youngdale, Family Support Specialist (Vista, CA)^B: Effective in treating depression but traumatic side effects
- Christine P. Sharp (La Mesa, CA) ^B: Horrific, resulting in extreme life-long disability
- Autumn Johnson (Royse City, TX)^B
- Melinda James (McKinney, TX)^B: One of the worst experiences ever
- Burgandy Brittain, Medical Laboratory Scientist (Orem, UT)^{B, D}: Understudied and potentially dangerous
- Karen D. Canfield (Orem, UT) ^B: Devastation, memory loss, dysfunction, altered, personality change, unsafe
- Hallam May, Family Support Specialist (San Diego, CA)^B: Scary, uninformed, confusing, lack of alternatives explained
- Marla Foulger (Potomac, MD)^B: ECT has caused multiple severally negative effects
- Savio Chan (Hayward, CA)^B: Horrifying seeing ECT still in practice ignoring long-term impacts.
- Melissa Gomez (San Diego, CA)^E
- Nancy Alisberg, Chair of the Public Policy Committee, National Association for Rights Protection and Advocacy (West Hartford, CT)

- Debra Ruh (Rockville, VA)^{C,D}: They deserve the best treatments that do not make them worse.
- Deborah Abrams (Lakeside, CA)—Friend became wheelchair bound with cognitive and speech challenges
- Cassandra Casey (Lehi, UT)
- Joel Zwanziger (Carsbad, CA)^D
- Patricia Burke (Manchester, CT)^{B,D}: Lost part of his life
- Tiffany Sharp Broberg (Wichita, KS)^B
- Jennifer Mietus (Round Rock, TX) B,E: Latent significant problems
- Kasey Johnson (Austin, TX)^B
- Sarah Gardner (Portland, OR)^B: ECT caused numerous irreparable damages to their brain.
- Maria Wuthrich (Kaysville, UT)
- Toby B Csiszer (Las Vegas, NV): Horrifying, inhumane, malpractice, lacking scientific merit or validity.
- William Price (North Salt Lake, UT) B,D: Devastating
- Karen Michelle Welch, Andrologist (Orem, UT)^{B,D}: Hell. Evil. Satanic. Barbaric. Destructive. Damaging. Deceit. Unconscionable.
- Sharla W. Moyes (American Fork, UT) ^B: Devastating long-term effects, Insufficient informed consent
- Sarah Smith (Eugene, OR)^D: Barbaric, frightening, harmful, debilitating, outdated, medieval, torture, lack of informed consent
- Danny Plunkette (Paducah, KY)^B: Horrible, frightening, damaging, sad, angry, empathetic, wrong, unnecessary
- Janine Hardman (La Mesa, CA)^A: Permanent Long-term memory loss, continuing cognitive impairment, migraine
- Jacqueline Hall (Somerville, MA)^A
- Deanna Herrod (La Mesa, CA): Serious Regret
- Kathy Deane (La Mesa, CA)
- Nicole Calhoun (Houlton, USA) A: Traumatic, disabling, and ineffective
- Kurt Buske (San Diego, CA)
- George Ebert (Sterling, NY) A,E
- Anzania Carter, Vocational Counselor (Atlanta, GA)^E
- Dr. Jay Seitz, CEO, Neurocognitive Therapeutics, LLC (Boston, MA) We need up-to-date research on ECT, long-term outcomes, as well as newer alternatives
- Oliver Lu (Lancaster, PA)
- Anne Trudeau (Portland, OR)
- Cassandra Auerbach (Thousand Oaks, CA)
- Julia A. Sherman, PhD, clinical psychologist (ret.), (Tuscon, AZ) D
- Carolyn Barnes (Leander, TX)^B: predatory, abusive, and barbaric
- Robert E Nikkel (Wilsonville, OR)
- Paula Joan Caplan, Ph.D., Psychologist, Independent activist, writer, & filmmaker, (Rockville, MD)^D: Horrific
- Dean Myers (Strarford, NY)^{B, D}: They cried, as if they lost their minds!
- Cynthia Grier, Peer Support Specialist (Portland, MD)^{B, D}

- (Shelley) Robin Weiss, Peer Support Specialist (Lindenwold, NJ)^{B, D}: Treatments given for financial reasons nearly as much as therapeutic
- Dr. Lee Coleman, MD, Psychiatrist (Berkley, CA)^D
- Berta Britz (Newtown Square, PA) B, D: Life stealing
- Darlene Plumly (Houston, TX)^B: Life changing in a very good way
- Katharine Adams (New York City, NY) F
- Bonnie Jo Schell (Asheville, NC) Former Executive Director, Mental Health Client Action Network, Santa Cruz, CAB D: Lost memory, talked childlike, could no longer piece together their life story
- Jacqueline DiPillo (Johns Creek, GA)^B: Permanent memory loss. No mood improvement
- Susan Elkins^B
- James Nordlund, Mental Health Counseling Supervisor (Moorhead, MN) ^{B D}: Horrifying, they were lost, never the same person.
- Jonathan Post (Covington, GA)^F
- Howard Diamond, Certified Peer Specialist (Lynbrook, NY)^D: Horrific, Life-Destroying, Mindless, Destructive, Foolish
- Kelli Yvonne Hitsman (Ames, IA)^B: Causes brain damage
- Patricia Harrild (Vashon, VA)^B: It ruined my sister's life. Terrible experience!
- Cheryle Morgan (Hawthorne, FL)^F
- Elizabeth A. Richter (Canton, CT)^B: Horrific. He was conscious at the time.
- F Miller (Astoria, NY)^A: Horrific. Cruel very unpleasant
- Nadia Gomez (Brooklyn, NY)^F
- Ann Harrild (Pocatello, ID) —We weren't advised of the devastating side effects
- Kristina Yates (Oakland, CA) A, B & D: brain damaging, torturous, disorienting, terrifying, abusive, controlling, inhumane
- Pamela Green (Tulsa, OK)^B: Barbaric, torture, IQ-damaging, mind-erasing, depressing, hellish, traumatizing, fear-inflicting
- Andrea Tabbat (Towson, MD): Disorienting, Damaging
- Sarah Edmonds, PhD, Licensed Psychologist (Flagstaff, AZ) D: memory loss, did not work
- Natasha Crow, therapist (Eugene, OR)^E
- Anna H. (Pocatello, ID)^A: mind, body and soul murder
- Minnie Yee (Bronx, NY)^B: It was a very negative experience and not healing.
- Jason Hoobler (Cincinnati, OH)^F: Brutal, barbaric, intimidating, superstitious and ineffectually promoting escalations
- Mari Marks, PhD, Licensed psychologist (Los Angeles, CA)^{B, D}: No lasting benefit, long term heartbreaking memory loss
- Tipton McMahon (Katy, TX)^F
- Amy M Smith (Olney Springs, CO) B & D: torture
- Judith Brown (Seneca, NE) C, E
- William J Dowling, Jr (Lakewood, OH) A, B: Damaging. Inhumane. Torture. Cruel and unusual.
- Jared Crossland (Hot Springs, USA)^F
- Susanna Smith (Seattle, WA)^B: Painful, terrifying, and she had memory loss.
- Patricia A. Wolfe (Dumont, NJ)^D

- Thomas O. (Chicago, IL)^{C, E}: Crippling, brutal, medieval, barbaric, inhumane, unscientific, immoral, unethical
- Arnold Gore (Brooklyn, NY)
- M. A. Malczewski (Philadelphia, PA)^A: Without a slightest degree of objective or subjective benefit
- Wenona Lee Gardner, Peer Support Specialist (West Allis, WI)^D: Grueling Torture, Devastating, Horrific, Tragic, Mind Raping, Memory Loss
- Loretta A. Wilson (Flushing, USA) A, C, E: brutal, castrated, barbaric, excruciating, debilitating, isolating, intimidating
- Shango Los, Patient Educator (Vashon, WA) B,D
- Amy Harlib (New York, NY)^F
- Tyler Markwart (Moses Lake, WA) F
- Bruce C. Faurot, Peer Support Specialist; Medical Services Worker; &/or Psych Tech (Santa Rosa, CA) B,D: Depends on the patient & year of treatment
- Nichole Oates (Seattle, WA)^F
- Maureen Schiener (Amherst, NY)^B: I don't believe this procedure is safe or effective.
- Gerald Lawrence Bliss (Blaine, TN)^B: You are stealing their lives.
- David Cohen (Los Angeles, CA)^F
- David Potter (Portland, OR)^B
- Angela Peacock, Community Organizer (Livingston, TX) B,D: They are brain damaged and traumatized
- Kathleen Labriola, Counselor & Nurse (Berkeley, CA)^{B & D}: torture, terror, memory loss, severe headaches, dizzy spells
- Kent Reedy (San Diego, CA)^A: Hours of total unconsciousness, years of fragmented memories.
- Luke Evans (Omaha, Nebraska) B,E: Torture, unconscionable, life destroying, identity theft, NDE-inducing
- Adrienne Lauby, volunteer (Cotati, CA) A,E: It took away too much of my life.
- Ian Ashton-Miller (Ann Arbor, MI)^E
- Julia Glanville (San Francisco, CA)^F
- Barnett J Weiss, Therapist LCSW (New York City, NY) B, D: The horror!
- Kimberly Doyle (Evergreen, CO)^A: Caused permanent memory-loss, cognitive damage, PTSD, BARBARIC
- Anna Rudzinski (Chicago, IL)^F
- Ariella Lee (Winston-Salem, USA)^F
- Diane M Rivas (Eugene, OR)^F
- John Peterson (South Jordan, UT)^B: It was a horrible experience!
- Crystal Yvonne Sweeney (Baltimore, MD)^F
- Rebecca Edens (Salem, OR) B,D: Shocking! Traumatic Brain Injury Brain & Spirit Damaging Experience
- David F. Zupan (Eugene, OR)^B: Unnecessary, intrusive, debilitating, disempowering, outrageous, inhumane, frightening, excessive
- Jamie Mack (Round Rock, TX)^{A, B}
- Jennifer Bangerter (West Valley City, UT)^B: Completely stole any chance of a normal life.

- David James (Pueblo, CO)^F
- Pamela Green (Tulsa, OK)^B: hellish, barbaric, torturous, mind-eraser, depressing, fear-creating, life-wreaking, family-wreaking
- Michael Myers (Seattle, WA)^C
- Kimberly Renninger, Director of Advocacy (Pennsburg, PA) D: Traumatic, Coerced
- Alan Podber (Battleboro, VT)^F
- Vicky Escoe (Muskogee, OK)^F
- Andrew Katsetos (Austin, TX)^B

International Signatories

- Diane Botterill (Nipawin, Saskatchewan, Canada)^A: Traumatizing, barbaric, memory destroying, soul-destroying, cruel, abusive, misrepresented
- Dr Sue Cunliffe (Worcester, UK)^{A, D}: Destroyed me. Not monitored nor honestly consented.
- Dr Lucy Johnstone (Bristol, Somerset, UK)^D: Terrifying, damaging, unjustified
- Dr Gareth Morgan (Leicester, Leicestershire, UK)^E:
- *Tamar Harris (Kiryat Tivon, Israel)* A,B: brain damaging, traumatic, disabling, destroyed life, identity, & trust
- Jo Watson, Mental health professional (Birmingham, UK)^D: Imposed, damaging, misleading, destructive, harmful, distressing & enraging
- Dunja Grisell (Stockholm, Sweden) A: Traumatic, debilitating, devastating.
- Una M. Parker (Leeds, West Yorkshire, UK) A: Undermining memory, confidence, ability to concentrate
- *Jill Davies, Counsellor (Hereford, Herefordshire, UK)* ^{B,E}: Disabling, violating, humiliating, devastating, life-limiting, distressing, sad
- Andy Luff (*Hereford, Herefordshire, UK*) ^A: Violated, lost, confused, humiliated, lonely, embarrassed, helpless, childlike
- Dr Rex Haigh, FRCPscyh (London, UK)^D: Variably amnesic
- Dr W Larkin (Chorley, Lancanshire, UK)^D
- Sami Timimi (Lincoln, Lincolnshire, UK)^D
- E. Miller (Winchester, UK) B: Violation, desperate, Rights removed, not fully informed
- *DMM (Winchester, UK)* A,B: Memory loss. Loss of rights, not fully informed.
- Jo McCarthy (Whitehorse, Yukon, Canada) A: Devastating consequences, dramatically debilitating, then zero rehabilitation/support
- *Jennie Williams, Clinical Psychologist (Faversham, Kent, UK)* ^{B,D}: Frightening, disempowering, primitive, damaging, ineffective, punitive
- Sue Irwin, Horticultural health & Wellbeing Officer (Worcester, Worcestershire, UK) A,B,D: ECT mirrored my experiences of childhood abuse
- Professor Rhiannon Corcoran (Liverpool, Merseyside, UK)^{B, E}: Traumatic, un-evidenced, debilitating, unethical, unjustified, unsuccessful
- Anne Guy, PsychD (Basingstoke, UK)^F
- Lucy Williams (Margate, Kent, UK)^B: Traumatic, damaging, harmful, unhelpful
- Professor Michelle McCarthy (Canterbury, UK)^F
- Nick Webb (Gold Coast, Australia)^B

- Danielle Egan, Journalist (Vancouver, BC, Canada) D: No benefit, numerous cognitive side effects, brain-disabling
- Cas Schneider (Newton Abbot, Devon, UK) B,D: Terrifying
- Don Weitz (Toronto, Canada)^B: My friend is Traumatized. It destroyed many memories.
- Pat Butterfield (Keighley, West Yorks, UK) A, B,C,D: Soul destroying. Many years of therapy to reverse.
- Ruth Dixon (Barton Upon Humber, North Lincolnshire, UK)^B: it caused brain damage
- Dr Steven Coles (Loughborough, Leicestershire, UK)^{B, D}: Horrifying, destructive, useless, controlling, ineffective treatment, devastating impact
- Professor John Read, Psychologist (London, UK)^F
- Hilla Komem (Kiriat Ono, Israel) B,E
- Andrew Gordon Towgood Bett (Forfar, Angu, UK)^A: Frightening, Dangerous, Useless, Harming, Criminal, Ignorant, Barbaric, & Abusive
- Lila Hefer, Social Worker (Pardes han, Israel) B,D
- Yossef Shoshan (Ilaniyaistarl, Israel)^B: Terrible, Barbaric & Cruel
- Fray Daniel Klementy, OFH (Olesh, Israel)^F
- Adi, Social Worker (Rosh Haayin, Tel Aviv, Israel)^{B,D}: Memory loss
- Yael Lindner (Modiin, Israel) ^B: An experience of irreversible damage
- Elizaberh Gilarowski (Toronto, Ontario, Canada)^F: awful unnecessary necessary memory loss
- Alana Didur, Community worker (Hamilton, Ontario, Canada)^{8, D}: Lacking information
- Tuba Yektaii (Ottawa, Ontario, Canada)^B: Savage memory-loss, barbaric
- Joy Dyck (Edmonton, AB, Canada)^A: Tragic. I lost all sense of identity.
- Rosalee Dubuc (Edmonton, AB, Canada)^B: Harmful, contributed to a downward spiral
- Diana Epperson (Vancouver, BC, Canada)^B: erased memories, frightening, brain damage
- Michael Woolard (Melbourne, Victoria, Australia)^D: Desperation, violation and anger
- *Irit Shimrat* (Vancouver, BC, Canada)^B: Life-wrecking, mind-destroying, horrific, debilitating. devastating, zombifying, cruel, torturous
- Brookes Bayfield, Outreach worker (Vancouver, BC, Canada)^D: Closed head injury, traumatizing, brain damage, memory loss
- Chris Chapman (Toronto, ON, Canada)^F
- Corinne Chepil, Program Coordinator, Adult Day Centre where some had ECT (ret.), (Vancouver, BC, Canada)^D: Memory-robbing, soul-sapping, immoral, torturous, unjust, archaic, cruel, primitive
- Marilena Stylianou (Larnaca, Cyprus): Inhumane insensitive cruel stupid dehumanizing harmful brain-damaging medically unethical

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