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A psychiatric research scandal and an accidental activist

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By Carl Elliott

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The University of Minnesota has turned me into an activist against it. Let me confess right away that this is not a role for which I am naturally suited. I have never staged a protest or addressed a rally. Nor have I ever marched with a sign. On the occasions when I am required to give public lectures, I sweat nervously and display an embarrassing tendency to pause in mid-sentence for uncomfortably long periods. But even I can work up a pretty good head of anger when I see cruelty or injustice, and this is especially true when the injustice is deliberately inflicted and the victim cannot fight back. As a white South Carolinian brought up in the 60s and 70s I have a pretty deep well of shame to draw on, but never in my life have I felt the kind of shame that I feel at the way my university has treated a woman named Mary Weiss.

The short version of the story goes like this. In late 2003, a psychiatric researcher at the University of Minnesota used the threat of involuntary commitment to coerce Dan Markingson, a delusional, mentally ill young man experiencing a psychotic episode, into a highly profitable, AstraZeneca-funded clinical trial of antipsychotic drugs, despite the objections of his mother, Mary Weiss. For months Mary tried desperately to get Dan out of the trial, warning that his condition was deteriorating and that he was in danger of committing suicide. The psychiatrists ignored her, and five months into the trial, Dan killed himself in the most violent way imaginable.

In the field of medical ethics, some cases represent moral dilemmas so intractable that you could argue about them for a lifetime. This is not one of those cases. The abuses of this vulnerable young man are so obvious, and the evidence for their occurrence so overwhelming, that it is virtually impossible to argue the other side in good faith. Dan had been repeatedly judged incapable of giving informed consent. He was under a commitment order that legally compelled him to abide by the treatment recommendations of his psychiatrist. That psychiatrist and his co-investigator had enormous financial conflicts of interest, plus monetary incentives to keep subjects in the trial as long as possible. I could go on

much longer about exclusion criteria and study design, but it would probably be easier for you simply to read what I wrote about the case in [Mother Jones magazine](#), or these [blog posts by Matt Lamkin](#) of Stanford Law School and [Dr. Judy Stone](#). (If you want to see the evidence for yourself, read this [summary of the case](#) with links to the relevant documents). So obvious was the coercion in this case that in response, the Minnesota legislature passed legislation – [“Dan’s Law”](#) – prohibiting researchers from enrolling subjects under an involuntary commitment order in psychiatric clinical trials.

When I first decided to look into Dan’s death several years ago, after a [report in the St. Paul Pioneer Press](#), I started by talking to university officials. One of the first officials I spoke to told me that Mary Weiss was crazy, and that if anyone was to blame for Dan’s suicide, it was Mary herself. At the time, this casually delivered comment struck me as a stunningly callous way to speak about a mother who had lost her only child to suicide. After I met Mary and began looking at the medical records, I concluded it was a smear aimed at discrediting her. In fact, the university’s behavior towards Mary Weiss has been uniformly and consistently disgraceful. University attorneys have bullied Mary and tried to [block her efforts](#) to get Dan’s medical records. After her lawsuit against the university was dismissed on a technicality in 2008, the university threatened to make her [pay \\$57,000](#) in legal costs, in order to intimidate her into giving up her right of appeal. Mary’s efforts to reach the university president have not gone any better. Her friend, Mike Howard, told me that when they tried to hand-deliver a copy of their 2009 complaint to the office of the president, Bob Bruininks, they were escorted out of the building by security guards. The president’s staff would not even accept the envelope. (“You’d have thought we were smuggling in anthrax,” Mike told me).

As the controversy over this study has grown louder, the university has tried to portray it as a dispute from the distant past. Nothing could be farther from the truth. We still do not know if Dan’s suicide was an isolated case. It is possible that other psychiatric research subjects at the university have been seriously harmed or mistreated. Last fall, the [Minnesota Board of Social Work found](#) that the study coordinator for the [CAFÉ study](#) (the AstraZeneca clinical trial in which Dan died) as well as the federally funded [CATIE study](#) had faked the initials of an investigator on study records, failed to inform Dan of new drug risks, failed to heed the warnings that Dan was in danger of killing himself, and had been given medical responsibilities far beyond her training. If University of Minnesota officials were truly concerned about the welfare of research subjects, would they not at least want to investigate?

For the better part of the past three years I have unsuccessfully tried to

convince an impartial oversight body look into the questions surrounding Dan's death and other problems with research subject protection. I've contacted just about every office imaginable, from the Office of Human Research Protection to the NIH Research Integrity Office to the HHS Office of the Inspector General. (I have also complained about an incompetently performed 2005 [FDA inspection report](#)). At the university itself, I've tried the Research Integrity Officer, the Research Subject Advocate, the [Research Ethics Consultation Service](#), and even the Board of Regents. I've had arguments with two successive deans, the General Counsel's office, the Academic Freedom and Tenure Committee, and most disappointing of all, my colleagues in the Center for Bioethics. The recently appointed president of the university refuses to meet with me, and has taken to cc-ing his replies to the Office of the General Counsel. Even my friends and allies are tired of hearing me talk about this case. Mike Palmieri, who [included Mary Weiss](#) in the documentary film, *Off Label*, says, "You're like the whistleblower who won't *stop* blowing, even when the neighbors are yelling, 'Dude, it's 3 am! Can't we get a little sleep here?'"

Last month, the time seemed right for a different strategy. Mary Weiss and Mike Howard started [an online petition to the governor of Minnesota](#), Mark Dayton, asking for an external investigation. As an accidental activist I know very little about online petitions, but as Patton once said, "An imperfect plan executed immediately and violently will always succeed better than a perfect plan." So I have supported this imperfect plan, immediately and violently. It seems to be succeeding. Our early signatories include Susan Reverby, the historian who uncovered the US government-led syphilis experiments in Guatemala; Marcia Angell, Arnold Relman and Jerome Kassirer, all former editors-in-chief of the *New England Journal of Medicine*; Richard Horton, the editor of *The Lancet*; Richard Smith, the former editor of *BMJ*; Ben Goldacre, the author of *Bad Pharma*; and Ron Paterson, the former Health and Disability Commissioner for New Zealand. MindFreedom International has endorsed the petition, and [over 170 scholars](#) in bioethics, medical humanities and social studies of medicine have signed on, including anthropologists such as Tanya Luhrmann, Lochlain Jainn, Karen-Sue Taussig, Michael Oldani and Paul Brodwin.

Of course, I am not asking anyone to sign the petition without looking at [the evidence](#). What I am saying is that if you look at the evidence, you will conclude that a serious injustice was inflicted on a vulnerable family at the worst possible moment. This is not a hard case. It is an easy case where ordinary people have looked the other way for too long. We can never make things right for Mary Weiss, but by signing [this petition](#), at least we can try to ensure that what happened to Dan does not happen to anyone else.

Carl Elliott MD PhD is Professor in the [Center for Bioethics](#) and affiliate faculty in the Department of Philosophy and School of Journalism and Mass Communications at the University of Minnesota. His books include *White Coat, Black Hat (Beacon)* and *Better than Well (Norton)*. He blogs [at Fear and Loathing in Bioethics](#).

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