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16 February 2018

To Stanley Medical Research Institute (SMRI), formerly Theodore and Vada Stanley Foundation

**Re: the TIPS study, which was supported by your organisation**

I write to you to ask for your help in getting very important data out in the open about why so many young people with schizophrenia died in this study. We believe that the research community and the patients have a right to know how many people died in this study and why. Published accounts are not consistent: 49 deaths, 28 deaths and 31 deaths have been reported (see the two attached papers).

I have asked the primary author of the TIPS study, MSc Wenche ten Velden Hegelstad from Norway, about the deaths but have not received any documentation. I, and a colleague, Robert Whitaker from Boston, therefore submitted a letter to the editor of the journal (World Psychiatry) where Hegelstad et al. reported on the deaths in June 2017, asking for details about these deaths. The editor declined to publish our letter and to ask Hegelstad for details.

I have published an article (enclosed) on Whitaker's website, Mad in America, which has around 2 million visitors every year, explaining these various events and their disappointing outcome.

We believe funders have an ethical obligation to ensure that information, which is of great importance for public health, and which has been collected in the funded study, gets published. That would be a great service to psychiatry, the patients, and everyone else with an interest in this vitally important issue. When young people who are receiving antipsychotics die, we need to know why they died in order to reduce the risk of death in future.

You may consider this a Freedom of Information request, which means that if your organisation does not have detailed information on the deaths in the TIPS study, we expect your organisation to obtain this information from Hegelstad and to send it to us. Anything short of this would be unethical in our view, and we are convinced that patients with psychotic disorders agree with us (I am Protector for the Hearing Voices Network in Denmark).

Yours sincerely,



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