Sara Bostock's panel notes: Grief to Action

What brought you to advocacy work?

Death of my 25 year old daughter. Antidepressant induced suicide. From the moment she was sucked into the mental health system a few short months before her death something seemed drastically wrong. The emphasis on finding the "right" diagnosis, the aggressive treatment with pharmaceuticals, the "life sentence." In the days before she died she was reacting very adversely to medication – very agitated. So when her completely unexpected, out of character and violent death actually happened I was immediately propelled into an investigative mode. What had killed my daughter??

Didn't take long to discover a whole world of subterfuge (no other word for it). – world of victims and experts. Controversies raging in the field for decades really. Suppressed data about adverse effects of antidepressants and other psychiatric drugs. The effort to impose (artificially) a medical model on emotional problems etc.

Timing was perhaps fortuitous because publicity in the UK about Paxil, the very drug my daughter had been on, was bringing pressure to bear on the regulatory authority there, the MHRA, and they issued a warning about Paxil about a year after my daughter's death. The FDA followed with an announcement of an open public hearing regarding suicidality and a/ds in children.

I knew these FDA hearings provided a big opportunity to make my voice heard. Testifying at the hearings was a milestone moment to becoming an advocate.

What accomplishments are you most proud of?

My biggest achievement is probably my role in the creation of the website <u>www.SSRIStories.com</u>. As part of my investigative research I had connected with a woman in Texas, Rosie Meysenburg, collecting stories linked to SSRIs of violent and bizarre behavior from the media that she was sending out on a list serve. Every week I was receiving story after story in which themes and patterns were being repeated again and again. The cumulative power of the stories in demonstrating a signal of something seriously amiss was undeniable. I very much wanted to put the stories into an on line database that could actually be used for research and present it at a third FDA hearing (2006). With the help of a computer science student we created a database – a spreadsheet really – that could be sorted by drug, location, type of incident, date etc. A lay person's effort at an epidemiological study. An effort to track outcomes. At the time of the hearing there were at least 1K stories. I wanted to create some media hype over the site by introducing it as part of my testimony. Rosie loaded up over 4000 stories in the next 5-6 years before her untimely death. The website did become widely known and received many hits. It has helped many people realize they are not alone.

David Healy attributes the creation of his new site RXisk.org at least in part to the inspiration of SSRIStories.com and RXisk.org has now taken over the site and hopefully it will be updated in some new form and not lost to history forever because of Rosie's death. It has played a major role in raising awareness about the many diverse and

dangerous side effects of antidepressants. At some point the accumulation of "anecdotes" provides evidence of something clinical trials have been missing for decades. But aside from the site, I am also proud of having been able to raise my voice and engage in dialogue with important opinion leaders and experts to open their minds to something they didn't seem to want to acknowledge. I wrote many letters to editors and had at least 3 published in the New York Times and 1 in Time Magazine. I received acknowledgement from at least two medical journals as well when I wrote critiques of SSRI published research. I was quoted on many blogs and list serves and engaged in lively debate on line. I am in the process of trying to write a memoir that also includes some scholarly research regarding the mechanisms by which antidepressants are causing their harm.

I have been interviewed and appeared in a number of documentaries, including one that was aired in South Africa and received an overwhelming response from viewers.

I have connected with victims, including famous people like the mother of Iris Chang, who has gone on to write a book about her daughter in which she clearly attributes her untimely death to psychiatric drugs. I have helped many people understand better what happened to their loved ones.

I have taken part in demonstrations including in front of the annual American Psychiatric Association conference.

Challenges and Rewards

It's a challenge not to become discouraged. Deaths and iatrogenic harm still occurring on a massive scale. As I became more deeply involved I realized the scope of the problem extended far beyond psychiatry. And the problem is not so much a malicious conspiracy (although there are elements of that at times) but an insidious corruption of values that creeps up on doctors and clinicians and the pharmaceutical industry.

Challenge to be heard as a lay person at times, but on the other hand being a victim/survivor is a powerful voice.

Constant intellectual challenge – that is also one of the rewards. Explore the history of psychiatry and medicine and madness; explore neuroscience to see how it is being misappropriated in some cases in dealing with mental illness but it still is a field that has a lot to offer in terms of understanding how the medications are working, or more precisely not working.

The reward of engaging with other passionate advocates from all walks of life.

Vision for the future

That outcomes will be tracked and studied in a much more rigorous fashion. That doctors and patients both will report reactions and outcomes and use the information. That patients and the general public will be aware of the phenomenon of iatrogenesis and not be in denial about it. That there will be a real effort to avoid iatrogenesis. That healing rather than treating will be the objective. That patients and doctors will collaborate.