IRBs, Science, Public Advocacy and Compassion at ThinkWell

Tweeting for Public Advocacy

ThinkWell would like to invite all to participate in a @bioethx tweet chat on Monday August 4th 8:30 pm. The famous and most interesting Jean E Burns will also be a guest host. Her interview on participating in clinical trials as a Parkinson’s Disease patient is a must read. It is the same news patients, researchers and family members have shared with me in my work and for research on PLOT-IT my public led online trials
project. The story is elegantly and passionately communicated with dignity. Can we problem solve so everyone finds solutions that are win/win? This would be meaningful public advocacy. The chat will be on the role of IRBs, Science, Public Advocacy and Compassion. Use the hash tag #bioethx.

Some topics I hope will surface are:

- What are the rights in “Right to Try”
- Could FDA compassionate use be expanded and more compassionate
- Participant liability, who pays and for how long
- Is it ethical for a patient to pay for their own trials yes/no WHY
- How can participant treatment be improved
- What part can participants play in designing clinical trials and research priorities
- Improved patient choice and risk understanding, is it shared
- Can intervention be expanded beyond the trial and can it be expanded to those in control groups

Why Discuss Complex Issues on Social Media?

As a ThinkWell director, medical professional and as a patient, survivor, concerned family member, public advocate and member of the public I find social media liberating. My first opportunities to publish academic papers came through scientists doctors and public advocates I met online. I have learned much from patients and the public, things like they have all the skin in the game, they want to decide on risk
levels themselves and not have this dictated by others. As one person put it we last option patients are going to die, let us decide our own acceptable measure of risk.

I appreciate the initiative by BMJ where patients and the public can learn how to review and have their papers featured beside academic reviewers. BMJ is prepared to walk the talk! It is an excellent way we can make shared knowledge and decision-making a reality for better medical and scientific understanding. The patients and those who care for them at home can share insights and understanding that come from living with the condition and the intervention. I share in Let Them Review where public insights can well be a gateway to better research and care.

Tweet chat By F1000 on the Public and Scientific Information Gathering

I participated in a recent Tweet chat sponsored by #F1000talks along with the help of fellow guests of AnneMarie Ciccarella (@chemobrainfog), and David Gilbert (@DavidGilbert43), we discussed how patient advocates gather scientific information and expert advice. Public advocacy and building bridges to information sharing and relationships were key concerns. The topic was Patient and public advocacy: access to scientific information and expert advice in July for #F1000talks live chat to discuss how patient advocates find scientific information and expert advice. We had a great turnout of patients, patient advocates, research scientists and clinicians, and most importantly we learned from each other as we posted resources, ideas and concerns. You can read the collated Storify with selected comments here.
Got Research Papers Behind Paywall Silos?

The team and fellow contributors came up with some great resources for information sharing and public advocacy. @thecancergeek suggested we can always tweet using #Icanhazpdf to request papers. Even scientists use it to get papers. We can email authors by looking for the corresponding author on an abstract. PatientACCESS works too and is an initiative between six publishers: ASCO, the American Association for Cancer Research (AACR), Elsevier, SAGE, Wiley and Wolters Kluwer Health, as well as the Copyright Clearance Center (CCC) Conferences if you are mobile and can afford them or get sponsored were suggested by @chemobrainfog who shared she saw presentations in San Antonio in 2012 that just reached peer-reviewed journals now, 15-16 months later. Finally, the idea of patient-led journals, as a means of patients contributing to the research process, was mentioned. F1000Research discussed they might take up the idea for one of their collections.

Some websites and articles of interest mentioned on Twitter F1000 chat

- Reforming rheumatoid arthritis treatment: a step in the right direction
- Science be Inspired
- HealthTalk Online
- Subscription Journal Workarounds
- Cochrane Consumers and Communication Review Group

Got Questions? need help to participate? Maybe you would
prefer to communicate here please leave a reply. ThinkWell will offer a follow-up article the week following the bioethx chat.