Guest Speaker – Cherie Binns from iConquerMS PPRN

“The Engagement Talk”

- Engagement Model in the Multiple Sclerosis Patient Powered Research Network
  - How does this PPRN do engagement research?
  - MS PPRN has been in business for 3 years now – new network, has 4,200 members today
- What does engagement look like?
  - Many members rely on their mobile apps, so PPRN created a mobile app for their members to complete surveys
    - Did not test app themselves
    - Survey participation started to drop off from nearly 100% to 17%
    - Answers were being deleted after answers, and had to scroll very far down to hit submit button
  - When issues were fixed, completion rate tripled
- iConquerMS started with a study on twins with MS
  - This led to the development of a biomedical data repository
  - Committed to finding a cure to MS
  - This was extremely important to patients so there was a lot of participation
    - They wanted to make sure researchers heard their voice
- This PPRN is an online community of people who live with MS and they communicate via dashboards and webpage
  - Very strong presence on smartpatients.com
    - Any sort of patients with illnesses or conditions can go talk to others for advice and support
  - Came to being as part of the national effort from PCORI
  - This is an initiative by and for people living with MS
- Created by the Accelerated Cure Process
  - Feinstein Kean Healthcare and Arizona State University jumped on board to collaborate
  - People with MS helped develop the concept and website
  - Cherie and others in the PPRN are very responsive to those contacting their network
  - Also supported by MS Coalition – some with very recognizable names
- Governance of iConquerMS
  - Many people in the governance structure are living with MS
    - All committees must be an odd number of people with the majority being MS patients – these are the people who show up at every meeting, whereas those without MS tend to not attend meetings
  - Started looking on LinkedIn for people to add to their community
    - If you are looking for people to add to your group, and find keywords to search in LinkedIn which will lead you to people who are committed to research and alleviating those problems
- Patient and Family Care Coordinators
  - Committed to helping start patient advisory boards or committees who need them
They hold monthly webinars that anyone can attend – it is great help for finding patients to add their voice

Link into any organizations who are part of PCORI or PCORnet
- There are lists of all networks of all different kinds on their website that we can draw from

People with a condition are the best source of information on the research topics that are most important to them
- This gives us the opportunity to reach out to members and say their voices are heard and we are taking a cluster of similar questions and answering them in a one page format that will be posted on website with links to research that has been conducted
- Many people use complementary or natural solutions
- Patients have other ideas of what they want in research and physicians tend to believe they need to have the most information when often patients do partake in a lot of research and are very empowered and their thoughts and opinions need to be considered

People with MS want to know more
- Can they work if they had a relapse where they couldn’t work and applied for SSDI?
- What is going to happen next?
- Can they ever have babies?
  - One of 14 approved medicines for MS is safe for pregnancy and breastfeeding, but some are very toxic whether taken by the male or the female – this information needs to be more widely available
- Will I need a wheelchair or cane to walk?
  - Diagnoses can take a very long time – Cherie was not diagnosed for 14 years even though the doctors knew
    - They did not want to tell her because she was very busy and had a lot of responsibility and they didn’t want the diagnosis to crumble her
    - This is not their decision to make, it is the decision of the patient to determine what they will do with their diagnosis. The doctor has a responsibility to tell the patient
  - People can end up wheelchair bound but this can be prevented by early administration of medicine which cannot be done as easily if doctors are not being honest about diagnoses
  - People who stay on medication can stay active and healthy much longer
- Where can I get answers to my questions?
  - IConquerMS has a lot of resources they can direct people to for answers to their questions

Anyone can join this PPRN even if they do not have MS
- Parents, children, and caregivers can join and be part of the healthy controls

The goals of future research care determined by experience, opinions and knowledge of people with MS in charting a course for future research
- People who will most benefit should be given great consideration for their feedback

Some doctors are not aware of current research and new medications that are effective and are hesitant to consider patients who wish to try these new methods
Patients need to advocate for themselves and insist that their doctors keep up with current research.

- Now that we have the ability to treat MS people are living longer, but there are not any research projects currently, especially regarding medications, for people over the age of 55.
  - Sometimes these older patients can be some of the best resources.
  - Patients are always asked which medications they are on, what they have taken in the past, or if they have never taken it.
  - Not many people right now are consistently taking medication for their MS.
    - This is because doctors quit prescribing these to older patients because they can cost 9k per month for older people.

- On website, once a survey is completed they can view how their responses compare to others who have also filled out the survey.

- PPRN makes themselves available to researchers to review the documents that are provided to potential subjects regarding recruitment and participation.
  - This helps them get in touch with the best group of people for their study.
  - Wording of research project can get people involved very quickly or can turn them away very quickly.

- People are like emeralds – we are all flawed but sometimes these flaws make us even more valuable.
  - Everyone is different and has many different things to contribute that are valuable for all of us.