PoTS; my wish list

HRC 2018
My real wish list!
HOW DOES A DOCTOR USUALLY GO ABOUT WRITING A PRESENTATION?

PART 1
SEARCH THE TEXTBOOKS?
SEARCH THE INTERNET?
LET’S EXAMINE THE PATIENT PATHWAY

THE SUSCEPTIBLE PATIENT

AN ILLNESS

POTS
WHAT ON EARTH IS IT?

What is POTS?

- Why young women? Why does it happen when it does? Do we really understand normal human female physiology?
- Why do you get symptoms in so many areas?
- There are differences in physiology – different control issues in different areas. We need diseases not syndromes
Making a diagnosis!

- What is the best way of diagnosing it? – it isn’t just heart rate! Are there characteristic symptoms that we could use?

- How do we help non-experts consider the diagnosis?

- How can we get away from a purely psychological explanation? ‘functional illness’

- How can we get away from the fact that just because it doesn't kill you, that doesn’t minimise the symptoms
TESTING AND TREATMENTS

- What additional tests should you do?
- Can we stop relying just on the tilt?
- When should we refer for other assistance?
  - Bowels, bladder, headaches, sleep, joints, allergies, diet etc
  - Who can help and how can we make them help?
- What are the best treatments in the short and long-term?
  - Why do they sometimes not work?
  - What drugs are best and why?
  - What other drugs might there be?
  - Can we ever get a cure?
HEALTH CARE PROVISION

- How do we get more people interested in managing it?
- How do we better train health care professionals?
- How can we get more finance for management?
What is fatigue?

Is Lyme disease really a thing?

How do we draw together disparate interest groups? CFS, fibro’, etc etc.
Now you get some flack!

- Not everything on the internet is true!

- I don’t know everything and I certainly don’t have all of the answers

- Sometimes it does get worse and I have no idea why

- **BUT** is not in my vocabulary
HOW DOES A DOCTOR USUALLY GO ABOUT WRITING A PRESENTATION?

PART 2
They probably want the same as you:

- More awareness of POTS amongst healthcare professionals
- Longer appointments and shorter waiting lists
- More POTS doctors
- More multi-disciplinary management
- Better access to the treatments from co-operative GPs
- Simple therapies that work
- Simple tests for POTS
- Greater understanding of invisible illnesses by HCP but also family and friends, government agencies etc.
And the final conclusion: ‘RATHER YOU THAN ME’
THANKS A BUNCH!
As an alternative:
GET THE AUDIENCE TO DO THE WORK......
AND FINALLY
HOW DO WE CHANGE SOCIETY’S FOCUS FROM THIS?
TO THIS?
HOW DO WE FOCUS ON HYPERMOBILITY AS A POTENTIAL ISSUE?

I HAVE HYPERMOBILITY SYNDROME (HMS)

HMS means my joints move beyond the normal range you’d expect... basically I’m too bendy in places!

FOR INSTANCE:

- Sometimes my shoulders might pop out when I’m getting changed.
- My jaw can dislocate when I yawn or eat.
- It’s really easy for my shoulders to dislocate when lifting anything.
- My ankles sometimes roll over when walking.
- Walking long distances and up stairs might cause my hips to pop out.
- My fingers could dislocate when writing.
- Opening a bottle can cause my wrist to dislocate.
RATHER THAN THIS?
Why do we support one but not the other?
HOW DO WE ENCOURAGE THE MAIN DEMOGRAPHIC TO INFLUENCE THE PROCESS?
#POTSyTOO

#BENDyTOO
...AND ON THAT TERRIBLE DISAPPOINTMENT...

THANK YOU FOR YOUR ATTENTION