

## Q&A with Prof Chris Ponting

*Chair of Medical Bioinformatics, University of Edinburgh and Deputy Chair, UK CFS/M.E. Research Collaborative (CMRC), May 2018*



### What inspired you to join the CMRC?

In a word: Simon. I've known [\[blogger and M.E. advocate\] Simon McGrath](#) more than a decade longer than the 20 years or so of his M.E. I have seen him on his better days, and have been unable to speak with him on his worst.

I have seen M.E. steal some of life's ordinary hope and future. Simon has so much more to give in life than M.E. allows. I started off my career as a physicist but then chose, instead, to try to use biomedical research to make a difference to people. It was a constant frustration that I couldn't help Simon, and other people with M.E. Now is my chance.

All that I have seen or heard tells me that change is desperately needed, and needed fast. Time will soon tell whether the Collaborative can help catalyse change. A window of opportunity is currently open, and we have to take advantage of it before it slams shut, before the attention of decision-makers and grant-funders naturally turns to other areas. This opportunity has been gained by the exceptional work of many people, but in my view most specifically [*Unrest* director] Jennifer Brea, in challenging how society perceives M.E./CFS.

Much work behind the scenes is pushing for change, or more precisely for the funds needed to deliver the robust, well-powered biomolecular research that might overturn prejudice and generate new hypotheses.

### What is your view on the PACE trial and behavioural treatments for M.E. and/or CFS?

There have been several questions that I thought worth asking of the PACE trial team. So early in May 2017 I sent through questions focused on the revised recovery criteria, and on the unblinded nature of the trial and its subjective outcome measures. Of course, I am disappointed not to have received any response. The [reanalysis of PACE data by Wilshire et al.](#) shows that effects of CBT and GET are more modest than previously claimed. I agree with them that even these modest effects could be an unintended consequence of the unblinded trial design

### What challenges are the CMRC facing right now?

To help to win a step change in M.E./CFS funding; to gather a team of scientists who work with people with M.E. across disciplines to produce world-class science; and to create the "intellectually generous community sharing data, best practice and technologies" (alongside the Collaborative's other [recently announced values](#)). Our research should be curious, inclusive, questioning and open-minded, and we need to celebrate well-reasoned and evidence-based views. We need to listen. When we don't know, we say so.

Prof Stephen Holgate is the right person to lead this: he founded the CMRC; he is he go-to person for funders; he is inclusive and generous; he is an internationally renowned clinician scientist. Yes, we do not agree on everything, which is to be expected among researchers: "Disagreement is something normal," the Dalai Lama said. It is not his fault that UK funders have not (yet!) funded M.E./CFS research adequately.