Invest in ME Research

LETTER TO CMO of Wales

UK Registered Charity Nr. 1153730
PO BOX 561, Eastleigh SO50 0GQ, UK

# One Simple Question

December 2018

Dear Dr. Atherton,

We wish you a Happy Christmas.

As you may remember, Invest in ME Research is a UK charity that funds and facilitates biomedical research into myalgic encephalomyelitis (ME).
We arrange international research colloquiums and conferences that have successfully built up a family of the best researchers in the world for ME.

We asked to meet with all of the UK's Chief Medical Officers in 2017 and eventually met with Deputy Chief Medical Officer of England in London.
You had all promised that your absence from the meeting would be mitigated by later discussion with the CMO of England following the meeting.

The result from that meeting demonstrated a severe lack of knowledge about ME and a continuing apathy for any actions that would lead to a positive change in the lives of patients who have this disease.

This Christmas we will not attempt correspondence that will be met with the normal denial of any problem, or platitudes that the disabling condition of ME is recognised, or empty words such as NICE are revising their flawed guidelines.
We can get this merely by asking our supporters to write to their MPs.

This Christmas we will simply ask you all one question -

**What message will you give this Christmas/New Year to all people in Wales who have Myalgic Encephalomyelitis, and to their carers and families and their friends, regarding the prospects for people with ME?**

A simple question and we will happily publicise your Christmas/New year messages to our supporters and to the estimated 250,000* in the UK who have

ME (* estimated because we do not know the precise figure and, far more worryingly, neither do you).

If you will consider answering our request then you might consider the following points that may guide your response -

- It would be helpful to address patients such as Caroline – who this Christmas "celebrates" her thirty-fifth year of having this disease – with no treatments, no support services, no sight of significant funding for research into this disease that you, and all governments, recognise as a chronic, disabling neurological disease.
- It would be useful to consider patients such as young Rosa – and tens of thousands like her – who have to endure this disease when her peers are living life with all that it has to give – university, friends, holidays, careers, social meetings, hobbies…
- A real and unacceptable situation exists for parents of young people with ME whose only objective is to care (mostly without any payment) for their children and yet are frequently subjected to outrageous allegations of Fabricated or Induced Illnesses (FII) from social services who fail to understand this disease.
- You may be able to offer some comment to families of people with ME - such as that of Anne Örtegren who suffered unimaginable pain and yet courageously battled on regardless, trying to educate, trying to encourage people to understand this disease, trying to interest researchers to study this disease – yet whose extreme situation and the suffering from severe ME caused her finally to decide that the only pathway for her was to take the route of assisted suicide?
  Or for those who may find themselves in the same situation as Robert Courtney who decided to terminate his life due to the completely inappropriate treatment that he was receiving that forced his sectioning by an ignorant and irresponsible healthcare service that lacks basic understanding of the true nature of this disease.
- It would be worthwhile also to explain the issues around myalgic encephalomyelitis in Wales where there are so many people living without any specialist services, where there are no effective treatments, where there is scarce funding for fundamental biomedical research other than the funds raised by supporters such as those of Invest in ME Research.

- You may have something to assure people with ME whilst NICE review guidelines for ME yet incomprehensibly continue to retain guidelines that recommend deleterious treatments such as CBT and GET despite knowing that they are harmful.

When little is being done to address the situation that patients find themselves in Wales - with scarce commitment to specialist services, no treatments, little valid research, poor medical education about the disease and no accurate knowledge by yourselves of how many even suffer from this disease - then it would serve a useful purpose for patients with ME and their families to know your thoughts on how this may change.

All invitations from the charity to CMOs in the UK to our annual International ME Conferences have been declined. Indeed, the CMO of England has the unique distinction of declining an invitation to all of the thirteen conferences since 2006, held just a couple of hundred metres from the office in London.

Therefore, for next year’s conference, we will not make that invitation. It saves time for all of us.
However, you may note that you are still most welcome to attend.

Instead, we ask you this one simple question.
One simple question, for 2019 and beyond, to a section of the population of Wales that has been ill served up to this point in time.

One simple question, not deserving of a template response, but demanding a considered and responsible reply from the Chief Medical Officer of Wales.
People with ME and their families should deserve no less.

We thank you in advance.

Meanwhile, while we continue to see inaction for ME from establishment organisations we invite you to support the Invest in ME Research Christmas / New Year Fund Appeal – demonstrating that we, at least, continue to choose not to accept the status quo - http://investinme.org/18CNYPR.shtml

Yours Sincerely,

The Chair and Board of Invest in ME Research

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***www.investinme.org***