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Dear friends,

Rituximab/Chronic Fatigue Syndrome Study – Crowd-funding Campaign

Firstly, apologies for having been out of touch for so long and then only getting in touch with a group letter about medical research.

A brief update on my situation

Having had a relapse of CFS over two years ago, I am making very slow progress. I can now walk about the house a tiny bit (which is an improvement). I have had to be out of touch with many of my friends, as I usually lack the energy to be sociable. I require daily home help and am unable to play more than an occasional scale or two on the guitar. I'm unable to take photos, but have made an occasional print (two of which are in a show at The Vivian Gallery during the Auckland Photography Festival). In January, I started a new blog called [Unintended Masterpieces](#), which I haven't yet publicised. Over the last week I have recommenced updating my other blogs when possible, which is a good sign.

I'm doing all the things that got me better in the '90's, but that hasn't been enough to get me back on the road to recovery yet. (I wrote an account of my illness for anyone who is interested, which is on my website, entitled [My Journey Through Illness](#).)

Some new research is proposed, however, which may be a game-changer for me and for many others, the world over.

Research

A very interesting piece of research into Chronic Fatigue Syndrome was conducted in Norway in 2011 and a follow-up study is being planned.

The proposal is to conduct a 140-patient double-blind placebo-controlled study of the effectiveness of the B Cell suppressing drug Rituximab in CFS, after the initial 30-patient double-blind placebo-controlled study in 2011 produced significant results: two thirds of patients on the drug responded to the treatment, as opposed to only 12% of placebo patients.

Over the years, there have been several supposed breakthroughs in CFS research (such as XMRV), but I've correctly been cynical about them and they've not been replicated. However, this time I'm not cynical: this project was founded upon an unexpected improvement in CFS symptoms in a cancer patient receiving Rituximab. A 3-patient study and then a 30-patient study gave the same results, so it's time for a larger study. This 140-patient study is the most hopeful piece of research that has yet been proposed for CFS. It is important not only for the patient community as a whole, owing to the results of the pilot study and the established findings of immune activation in CFS patients, but also for me, because it ties in with my allergic history.

Sadly, the Norwegian government is only partly funding this study, so the doctor initiating it is seeking crowd-funding.

Below are links regarding this project. I appreciate that not everyone is able to make a donation, but if you can think of anyone who might be able to do so, please forward this letter to them.

Rituximab research links

Summary: [CortJohnson.org]

The crowd-funding project: [MEandYou]

The 2011 Study: [[New Scientist](http://NewScientist)] [[Research 1st](http://Research1st)]

Please don't feel you can't help if you are unable to donate, because forwarding this letter to friends is just as important. For this research to proceed, knowledge of this crowd-funding campaign must reach a lot of people with deep pockets. The more people who know about it, the greater the chances are of the research going ahead.

Thanks for taking the time to read this. The URLs are repeated below, along with a poem from thirteen years ago, which provides an insight into life with this illness.

Thanks again and best wishes,

Richard Smallfield

URLS (from the links above)

<http://www.cortjohnson.org/blog/2013/03/26/redefining-me-cfs-crowdsourciing-effort-fund-rituximab-trial-begin/>

<http://www.meyou.no/this-is/>

<http://www.newscientist.com/article/dn21065-chronic-fatigue-syndrome-eased-by-cancer-drug.html>

<http://www.research1st.com/2011/10/19/rituximab-trial/>

http://richardsmallfield.com/writing/RSmallfield_Journey.pdf

Rooms

I have known rooms – yes, I have known them – with towering walls that will not move; that care not that I cannot leave.

I have known rooms which, in contempt, have left a door open – knowing that, should I leave, I would only return broken.

Rooms with clocks: a bed and a clock (and the usual clutter – but essentially, a bed and a clock). I have watched for hours, the minute hand circle (with tedious lethargy) both the dial and me, as every thought stretched out to span every second and minute and hour, craving the hand's progress to another of sixty marks upon its face – and I would remain, awaiting its return to that place.

I have known rooms: I have known them with a bed, a window, a winter sky. I have smelt fresh lawn clippings that arrive one day each spring; watched crab-apple blossom return to my infinite now – as the minute hand edged imperceptibly on ...

I have known winter-night air breathe upon me through an open window – to be fouled by the march of morning traffic.

I've known a room with walls of beige, ceiling beige, carpet beige – linked only to the world (a kitchen) by intercom. 'Hello,' I once said, just to break the pain, to know that humanity still walked beyond the door. A friend walked in – 'They're not impressed: don't use the intercom just to say hello' – and happily sat down with another and chatted. Tears, throbbing inside, drowned out their words: *Don't let it show; keep the pain in ...* and they talked on ... Yes, I have known beige rooms, too.

Rooms lined up like lockers with sliding doors, polished floors and staff: old folk in pigeon-holes. A week in one of those, with the bed moved under the window so I could breathe the fresh air. So – I have lain behind glass, stared up at the hill (while still, the clock watched); stared through glass while the moon sprinkled iced light about the courtyard; looked out upon a garden encircled by windows (behind each, a soul older than mine) and seen a shadowy cat on patrol, pass beneath my own.

More rooms I have known: home, my photos on the walls, all needs within reach, the window before me; the sea's grey roar tearing through branches; jazz, books – contentment.

A room of light: sun streaming onto walls glowing white, above our glowing bed: room of warmth, room of love.

I have lain above the city in a spare room of friends, free – above city lights, while stars guarded the night.

Rooms, I have known; rooms have known me.

Walls have watched – though why did they bother? I could not leave these limbs: this bodily cell is locked. In this confine I have seen dreams turn yellow in decay; anger at all that led me here and at those who see only what they deem true, without appraisal.

I have seen ignorance from the esteemed, bigotry from the ignorant; incomprehension from the learned, complacency from the comfortable; I have seen wisdom from the scarred; understanding from the broken; love from those who listen.

After many rooms, am I still here? The clock watches this afternoon creep pallidly on – too laborious for comfort.

Maybe I will squirm; maybe I will sleep.

August 2000

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