

The Charity Shop 2 – a partial answer.

A few months ago, I wrote a blog article (['The Charity Shop'](#)) about the experience of meeting, just as an anonymous visitor to their shop, some of the volunteers who work so hard to fund a medical charity that supports my research (and the research of many other labs in this same general medical field). The blog reflected a worry about whether we scientists, with our all too fallible probing in the dark for morsels of new knowledge, can ever come near the expectations of those hard-working and dedicated volunteers who seem to put so much faith in us. How horrified would they be by the reality of all of the wrong directions we take, and of the tiny ratio of what we gain compared to the number of experiments, paid for by their dogged labour, that lie in the lab waste bin at the end of the evening?

Earlier today, I had the opportunity to speak with a patient and trustee of that same charity, at a major medical conference that he was attending. Over lunch, I asked D (as I will call him in this blog) what the charity's volunteers wanted and expected from the scientists they support. I was expecting to hear some obvious answer such as 'a cure', but the actual reply was much more subtle than that: 'hope'.

The word 'hope' on its own would only have added to my general feeling of personal and communal inadequacy, but it was followed by an illuminating explanation. 'Hope', it turns out, is not as simple as hoping that hard work and money will be translated by someone into a cure. Obviously there is that, but D made clear that he was perfectly well aware of the nature of the research process – of the wrong turnings and failed ideas, and of the vast gap that lies between a lab-based 'cure' of a cultured organoid or a mouse and the application of the idea to real people. What he said is that significant hope and comfort to patients comes simply from the knowledge that someone is there, white-coated and seriously trying to make a difference. Even when it is understood that most of us, most of the time, will be on paths that will turn out to be dead ends in terms of practical medical application (because that is the nature of research), the fact that we are willing to dedicate our own working lives to exploring these paths means a great deal to people under the cloud of the disease.

In the conversation, it was obvious that D was not thinking in terms of current research making a difference to his own condition, here and now: rather, the point was to try to do good for the generations to come. And, he reminded me, the choice is not between funding an unpredictable

research process and funding something better: the choice is between funding an unpredictable research process or doing nothing at all.

I realize that D is an extremely knowledgeable campaigner: while not a scientist himself, he follows research closely and understands it in close detail (if he had not identified himself as a patient and trustee and told me about his background, I would have assumed he was a physician). He is also a very high-achiever in his own profession. Nevertheless, he was sure that he was speaking for the majority of other patients and carers who support the charity, others of whom also happen to be conspicuous high-achievers (and many more achieving in areas of life where success is not as conspicuous but is just as important; caring, for example). His words were, therefore, reassuring. In the lab, we never deliberately waste money in trying new ideas, but in retrospect, when the idea turns out to be wrong, that use of the money can seem awfully like a waste. The discussion with D made clear that, from his point of view, the real waste would be to have the idea and *not* to take the risk in using resources to explore it properly.

This conversation went a long way to answer the questions in my earlier blog, and gave me an encouraging message to take back to the hard-working folks in the lab (when the much-delayed train on which I am writing this finally gets to Edinburgh). I will be meeting many more of the charity's supporters at a sports event (The British Transplant Games) next month: the prospect is a little less scary than it had been.

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Links:

- British Transplant Games: <https://www.britishtransplantgames.co.uk/>
- Train complaints website: <http://www.nationalrail.co.uk/contact/feedback/77662.aspx>