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The guardians of opinion

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Editor

Chronic fatigue syndrome is serious and exhausting for all concerned because it takes such different forms and because we do not yet know what causes it. But we will not get there any faster by holding a one-sided debate.

«I fell down on the floor and cried for two hours», Robert Miller of Reno told *ScienceInsider's* reporter Jon Cohen in September 2011 (1). He described the enormous relief he felt in 2009 when *Science* published an article that linked the retrovirus XMRV to chronic fatigue syndrome (CFS/ME) (2). According to him, this is the way the discovery was presented: «We found it; it's the causative agent, and we're going to figure out how to fight it and cure it!» Hardly surprising that he was optimistic.

The problem was, it wasn't true. In September 2011, it became clear that the finding could not be replicated in other laboratories (3). In December *Science* retracted the article (4). It was in many ways quite a normal event in scientific publishing, because research findings are not worth much before they are replicated. Scientists are often wrong, even when they publish in prestigious journals. There may be many reasons for this: they have over-interpreted their findings, made some methodological errors, included or excluded the wrong patients, used the statistics incorrectly. The real test of whether a new finding stands up will always be that other, independent scientists reach the same results. There was also dishonesty and fraud in the XMRV case. That's why *Science* retracted the article.

The most singular aspect of the discussion of possible causes and treatment of chronic fatigue syndrome are the intense emotions and the polarised debate – along with an impression that some patient organisations are willing to go a long way in order to promote research results that point in one particular direction and to suppress others. «The battle of CFS/ME has features of a religious war. Aspects of the debate are more reminiscent of a battle than an exchange of opinions», Bjarte Stubhaug remarked to Norwegian financial daily *Finansavisen* in December 2011 (5). Stubhaug is a psychiatrist with a doctorate in this field. Another psychiatrist, Professor Simon Wessely at King's College, London, receives such explicit threats that his post is routinely X-rayed. According to the *BMJ* he is not alone (6).

In *Tidsskriftet* no. 2/2012, development editor Stine Bjerkestrand wrote an editorial on how new media are causing a power shift (7). Her main point was to show how bloggers and tweeters influence opinion and the authorities, especially in combination with the traditional media. She also pointed out the problem that the social media are not bound by the same professional ethics or tradition of promoting a nuanced debate as do agents in established media, and that their presentation may therefore be one-sided. She used as an example the massive media pressure that developed in autumn 2011 in the wake of the publication of a Norwegian article on a possible new treatment for chronic fatigue syndrome (7, 8). In the editorial office we were naturally aware that the topic she had chosen as an example was controversial. But the example was good and illustrative, and there was of course no question of not using it for fear that it might be followed by a difficult debate.

And debate there has been – not least in the social media. Bjerkestrand and *Tidsskriftet*, for example, have been accused of «taking sides» and not acknowledging the research of Fluge et al. This is not true. The research findings that were presented in PlosONE are interesting, but have their limits, as all early stage research has. The researchers themselves have pointed this out, and it has been discussed in more detail in the article's comments field (8). More and broader-based research is required here, preferably conducted by an independent group. In other words, quite the normal situation. It is not until you check the link for «media response» that you find something out of the way. It becomes clear that Norwegian media went much further than others in describing the findings – «breakthrough» and «promising» mean different things.

The Norwegian health authorities also behaved in an unusual way. A bare month after the article by Fluge et al. was published, the Ministry of Health granted them an extra allocation. Why? «It's because they have done this work over and above their job at Haukeland University Hospital. And then we have to have this research continued on a somewhat larger scale, and we have granted [NOK] two million for this purpose», said the Minister of Health on Norwegian TV2 (9). Certainly getting such a rapid response from the funding authorities is a dream for many researchers. The Norwegian Directorate of Public Health, for its part, first rejected the Knowledge Centre's report on treatment of chronic fatigue syndrome and then recommended diagnostic criteria from an international group of medical professionals (10, 11). The report is controversial (12). The Directorate's approach is not exactly in line with its own *Retningslinjer for retningslinjer* [Guidelines for guidelines].

In the article I mentioned in the introduction (1), Marly Silverman also said that she was initially «ecstatic» at the idea that XMRV could be linked to the disease and regarded the findings as a «gift to the community and patients». She was very disappointed that the findings were not correct, but hoped the exciting theories would attract more researchers to this field: «I don't have the real answer, but I just hope science continues to look and figure it out». And that is just what may be the problem: the fact that scientists and clinicians fight shy of dealing with this patient group.

Chronic fatigue syndrome is a serious illness and exhausting for all concerned because it takes such different forms and because we do not yet know what causes it. It is understandable that patients and patient organisations are impatient and want effective treatment. We need the broadest and most unbiased approach possible to bring us closer to our goal. We will not get there any faster by holding a one-sided debate.

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