

# **Are Patients Being Given Objective Information On MS Drugs?**

By Ashton Embry

One of the hardest decisions for a person newly diagnosed with MS is to decide whether or not to use one of the available MS drugs (Copaxone, Avonex, Betaseron, Rebif) and if so, which one.

This dilemma is complicated by the fact that the main sources of information on the drugs (national MS societies, neurologists, MS nurses) usually supply only one-sided information on the drugs. This highly subjective information comes from published scientific articles on the results of the clinical trials that tested the drugs.

One might expect that such scientific articles would be very objective but unfortunately this is not the case. These articles are written by researchers who are funded by the drug companies that produce the drugs they are writing about.

## **Giving The Data Spin**

It is not hard to understand that the authors of such articles do not bite the hand that very generously feeds them and thus “spin” the data in such a way that it is concluded that the drugs are very helpful for persons with MS. The drug companies then take these published, very subjective conclusions and spin them some more so that the drugs look even better.

The information providers seem only too happy to go along with the very biased conclusions published in the articles and supplied by the drug companies. They simply repeat the tainted and highly suspect conclusions like a mantra.

Thus persons with MS have little hope of making good decisions when it comes to the drugs because they do not have any solid, reliable information to base them on.

This serious conflict of interest problem is well recognised by the medical profession and, to counter it, an international organisation, known as the Cochrane Collaboration (<http://www.cochrane.org>), was set up in 1992. The main aim of this organisation is to “help people make well-informed decisions about healthcare by preparing, maintaining and promoting the accessibility of up-to-date systematic reviews of the effects of healthcare interventions”.

The Collaboration encompasses an established network of 50 research groups worldwide that prepares and maintains Cochrane Reviews, covering a range of medical specialties and free from the influence of drug companies. Approximately 10,000 people are actively involved in the work of The Cochrane Collaboration, almost all on a voluntary basis.

## **An Objective Look At MS Drugs**

The good news is that the Cochrane Collaboration has taken an objective look at the MS drugs and produced Cochrane Reviews for them. The bad news is that the national MS societies and many

neurologists and MS nurses are ignoring the results of these objective reviews and most people with MS are not being given this unbiased information on the MS drugs.

One Cochrane Review panel looked at all the clinical trial data for Copaxone, also known as glatiramer acetate, and this report is available in the Cochrane Library (<http://www.nicsl.com.au/cochrane/index.asp>).

An article on the main conclusions of this important study was published in November 2004 in *The Lancet*\*, a very prestigious medical journal. The summary conclusion of the article is “Our systematic review of all randomised controlled trials of glatiramer acetate found little support for use of this drug in patients with MS”.

Other statements include “Whatever the disease course, glatiramer acetate is no better than placebo in preventing clinical progression at two years”, “When pooled estimates of treatment effect are adjusted for heterogeneity across studies, there is no difference between relapse rates for patients taking glatiramer acetate compared with those taking placebo up to two years” and “The median time to first relapse has also been studied, and no significant difference was shown between the treatment and control groups”.

I would emphasise that this review is based on a very objective analysis of the data and is not coloured by the financial influence of a drug company. The authors simply wanted to see if Copaxone helped or not and the available data clearly says it does not.

The Cochrane Collaboration has also undertaken an objective, systematic review of all the clinical trial data for the interferon drugs, Avonex, Betaseron and Rebif, for relapsing remitting MS. This review is also available at the Cochrane Library and a summary article was published in February 2003 in *The Lancet*.

The main conclusion of this study is “There is still a lack of solid evidence that recombinant interferons are effective after a year of treatment for patients with relapsing multiple sclerosis”.

Other conclusions include “Interferon seemed to reduce the number of patients who had exacerbations by about 25% during the first year of treatment but, at two years the results were not robust and were difficult to interpret because of the many dropouts” and “Doubts remain as to whether they can really prevent progression of the disease”.

Such conclusions are not exactly a glowing endorsement of the interferon drugs and are a far cry from the information that persons with MS most often receive. Finally the authors also note that “side-effects were common, and acute toxic effects adversely affected patients’ quality of life”.

Not surprisingly, this unbiased article on the interferon drugs drew heavy fire from the MS researchers who are well funded by the drug companies. In a series of discussions and replies published in *The Lancet*, the Cochrane Group, which included some very high profile and well respected MS researchers such as the chair of the Clinical Neurosciences Department at Oxford University, easily answered these desperate attempts to discredit the study.

The Cochrane Group was also able to make a few more damaging points such as the “unavailability of primary data”, “the sponsors’ analyses eliminate considerable patient experience from each calculation”, and “We had to extract key data, known to the investigators but not present in their

publications, in order to arrive at this conclusion, which we find an unwelcome development”. This last statement comes as close as they dared to calling the authors of the original papers unethical scientists.

### **MS Patients Given Erroneous Data on Drugs**

The bottom line is that a sober, objective look at the available data on the effectiveness of the MS drugs indicates that there is very little evidence that the interferons do much good and that there is no evidence at all that Copaxone has any value.

This is not to say that future proper studies and honest presentations of them may one day show these drugs have some value. It is just that right now such evidence does not exist.

To me it is a very sad situation that persons with MS continue to be given misleading and erroneous data on the drugs. It is quite possible that persons with MS are being sold worthless products that have nasty side effects.

It is difficult for persons with MS to obtain unbiased information on the MS drugs. However, it can be done and it is most important to do so. I invite anyone interested in objective information on the MS drugs to read the Cochrane Reviews and to draw their own conclusions.

Just like when one is buying a used car, there is no doubt it is “Caveat Emptor” (Buyer Beware) when deciding to use an MS drug or not.