

## **International Survey on PMR - GCA**

### **Introducing Elliott Greene**



Elliott Greene, Ph.D. in Microbiology (specialty in immunology), whose original background was as a research scientist, has been a software engineer for the last 20+ years. He now co-owns a small software company that specializes in conducting on-line surveys for other companies. Elliott is located in the USA and has PMR.

Elliott contacted PMRFighters after visiting the Tayside PMR-GCA Support website.

Elliott does not have any official links with the medical community and had no desire to try and get a study of this type (PMR survey) recognized by the medical officialdom. He just thought that it might be of interest and/or useful to the PMR patient community. We thought otherwise.

We informed Professor Dasgupta that we had been approached by a PMR sufferer from the USA who jointly owns a software company specializing in on-line questionnaires (surveys). He had devised an interesting online PMR questionnaire for global use and was soliciting our input. Professor Dasgupta's response was that he thought this is a great idea.

We contacted Dr. Sarah Mackie (Research into the cause and cure of GCA - based in Leeds) and Dr. Saravanan Vadivelu (Consultant Rheumatologist, Gateshead Health Authority) on the matter and asked them for comments and additions to Elliott's questionnaire. We also sent Elliott the questionnaire which we had devised. They all had additions and/or changes they felt were needed. We also asked some contacts for their comments as well.

We contacted Joan Reiter, founder of the NMR Foundation in the USA ([www.nmrfoundation.com](http://www.nmrfoundation.com)), to make her aware of Elliott's activities, and also told Elliott about Joan. They have since met up and are also working closely together. The NMR Foundation has very similar goals to what we are trying to set up nationally: patient driven, but absolutely committed to research first and foremost.

Elliott assured us that this survey is not meant to be a marketing ploy for his company, but rather that he was using his company's resources (website) and expertise to try to improve the situation regarding PMR information. As indicated earlier, his original background is as a research scientist, and he was appalled at the lack of useful systematic and statistically valid data regarding PMR. And so were we.

One advantage of using the on-line survey is that his company has developed software for automatic extraction of responses into a database and for the generation of detailed, useful, and easy-to-understand reports from this database. If, between us, we generated a common version of the questionnaire, then we could use both responses submitted directly on-line and responses we keyed in to the survey from those individuals who preferred to submit their response through the paper questionnaire, either because they prefer paper or do not have Internet access.

Elliott's company uses this approach when performing surveys for companies where not all of their employees have Internet access. Such employees receive a paper version which they mail to his company, and it then is transcribed by using the on-line survey. We sent to Elliott Professor Dasgupta's background and papers he has had published, in particular the paper Professor Dasgupta had written jointly with the Mayo Clinic. Interestingly enough, Elliott had already heard of Professor Dasgupta.

The final clincher with PMRFighters was Elliott's statement as follows:

"One of my main goals is to attempt to determine if there are any significant differences within various subgroups of PMR sufferers. For example, is there a difference between men and women in terms of age of onset, duration, response to Prednisone, etc? Does the disease resolve slower/faster in younger vs. older patients? There are a couple of articles out there that followed a small group of patients, but the sample size was so small as to make it difficult to come to any real conclusions. This is often the problem with clinical studies because the set of patients is often limited to the practice of the doctors involved. I am hoping that a survey filled out by actual PMR patients who can provide details of their experiences will yield a large enough response population to be able to extract some meaningful answers. I think it might also be useful to get some rheumatologists involved in terms of asking their patients to fill out the survey. This may be difficult as this might be construed as "stepping on the toes" of the medical establishment, but it wouldn't hurt to try.

An on-line survey with an appropriate set of questions would be perfect for collecting such information, with responses being collected into a database from which a variety of useful reports and graphs could be created."

This is exactly what Elliott's company does. He is willing to host such a survey on his company's website, and assuming a sufficient amount of data can be collected, start publishing the results for all to see.

PMRFighters are pleased we met Elliott and are looking forward to years of collaboration to find A CAUSE and CURE for PMR and GCA.