

**Interview with Dr Ian Gibson MP**  
**5<sup>th</sup> December 2006**

In order to mark the launch of the GSRME Inquiry News Page, Dr Ian Gibson MP has agreed to give an interview to answer a few questions and look back over the process of the report, the responses to the report, and where we go from here.

**So why has the Group decided to launch a News Page?**

We realised we were doing a lot of hard work and had lots of plans, but there was no real way to communicate information to patients. The whole point of this Inquiry was to listen to the patients and ensure their voice was heard. While we are regularly in contact with individual patients and patient groups we recognise a lot of information was being passed round unofficially and we decided it was time things changed. I admit we should have had something like this from the start, but with limited resources it hasn't been easy. I'm hoping that the News page will serve as a vital link between patients and the Group. We will not be using it as frequently as some ME Groups use their sites, but we will be announcing important events, meetings and such like.

**How did the Group on Scientific Research into ME and the Inquiry come about?**

We were formed in the middle of 2005 following a meeting I had with Professor Malcolm Hooper, local constituents and ME sufferers. I realised that there was a real issue that needed to be tackled, it seemed no MP was willing to get too involved, but I'm a sucker for a bit of controversy and a good cause! I consulted with Des Turner MP, as he had experience with the APPG on ME, and he warned me it would be a hard task, but then agreed to sit on the Group anyway. The Inquiry is not an official inquiry but we approached several people and managed to persuade a number of MPs and Lords to give up their spare time voluntarily to the Inquiry, and they have worked very hard for the ME community since then.

**You say the Inquiry is not official, what does that mean?**

Well the GSRME is on the register of All-Party Groups, however we are not a Select Committee or government commissioned inquiry. We are doing this voluntarily because we believe in the cause. The only hurdle to us is that we have no funding. Therefore, resources are limited, and we rely on voluntary work from the Group and support staff. All work is done on top of existing duties. It was because we could not actually employ someone that we lost our administrative staff half way through. I know there have been accusations that the Inquiry will not have any teeth. However, we have not let our status affect the process so far and we will not start now. As MPs and Lords we have unique access to Parliament and to Ministers, we intend to make the inquiry have teeth. It won't be an instantaneous process and we can't respond to everybody straight away as we all have other commitments to constituents and other patient groups we cannot neglect. However, we will keep fighting on behalf of the ME community.

**You say you had limited resources, and you lost your administrator half way through the Inquiry, how do you think this affected the process?**

Well one affected the other. We lost two administrators in a row because they were not employed by the Inquiry directly. It was a great shame to lose our administrative support half way through. It is hard task organising 12 MPs to have a cup of coffee let

alone to conduct an Inquiry on this scale. We had hoped to have one administrator all the way through who could really take charge of the issue and know it inside out. The Inquiry definitely suffered from staffing difficulties half way through. However, that was beyond our control and while it means the Inquiry may not have run as smoothly as we might have liked I do not think it had any impact on the final report. We had sorted out our staffing issues by the time we came to actually writing it.

**For those who are new to the Inquiry can you describe the process of the Inquiry?**

First we had a consultation process during which we received evidence from patients, patient groups and experts from all over the world. Well actually, I say we had a consultation process first, although to be honest it was all the way through! We received letters, emails, phone calls and reports for a whole year. Every piece of evidence was seen or heard by at least one member of the Group, even if it was after the deadline for consultation, and its all stored in filing cabinets in my office! We then held five oral hearings where we met with patient groups, scientists, physicians and psychiatrists, so all sides of the argument were put directly to the members. We had a break over recess 2006 during which time we all went back to our constituencies to get on with our local issues and I put together a skeleton report. When we got back to Parliament in October we were able to get new administration sorted and then we had to go all hands on deck to get the report done especially with the NICE deadline approaching.

**How was the report written?**

Well as I said, I wrote the skeleton report and then we developed it together. It was a hard task to include everyone's opinion. Getting the language and terminology right was a negotiating process. Often the member who had a specific knowledge of a certain area wrote the concurrent section and then the rest would approve or amend it. We sent emails back and forth constantly and inevitably, some sections were a compromise. It was hard work, but it was worth it because, at the end, we have a report that everyone in the Group is happy with.

**You submitted the report to NICE by the deadline, but why didn't you use the proforma?**

Well I'm a bit fed up about that. I had a conversation with NICE at the start of the summer and was told it would be accepted as a report. It was not made clear to me at that point that this meant it would not get a formal response. On the 23<sup>rd</sup> Nov - the day before the deadline - several groups contacted us asking for help as they too had prepared a report not in proforma and they were concerned it would not be considered fully. It was a crazy day I can tell you. We agreed to help these groups and contacted the Chairman of NICE. We were assured that although evidence not on the proforma would not receive a line by line response, all submissions would be given full consideration as equal evidence, irrespective of format. Due to our limited resources, we were not able to submit on the pro forma with one day's notice as we were still putting the final version of the report together.

**How was the report launched and distributed?**

Well we got it into NICE for the Friday deadline and launched the report from the website Sunday 26<sup>th</sup> 10pm. The reason we embargoed it over the weekend is because we had been told by the press they would be more likely to make an issue of a health

story like ours on a Monday. We did not hold a press conference as these days it is nearly all done by email. The only advanced copies had gone to the press and the person who began the whole process, these were under strict embargo of course. There has been limited press interest so far, just a few articles in local press and a small one in the Guardian. I had better say thanks to Dr Greensmith of Bristol, who has been making the issue known in letters pages across the country. We will be sending copies to Ministers once the Group has had the chance to approve covering letters. It has already gone to the Department of Health as they requested a copy some time ago.

### **Why do you think there has been limited press interest?**

I'm really not sure, we sent it to all the major news sources. Many people thought it would be a big story, but I was never sure either way, it's impossible to tell with the media. It cannot be denied that in the past the media has been unsympathetic to those with ME. We are not doing it for press interest anyway. Our priority is getting the biomedical research done. You can argue what the best way to do that is, yes, raising the profile of an issue is important and can put pressure on government. But getting the message direct to actual decision makers is the only way to effect change. Looking at these options and making the Report count is our next task. This is something we are going to discuss at the next GSRME meeting, which is next week. It is also something I want to discuss with people in the ME community.

### **How has the Report been received by patients?**

The overwhelming response has been positive. We have received thank you emails from around the world. Most people say they are happy with the majority of the report but not with all of it, which is fair enough. However almost everybody has welcomed the recommendations and said it is a step forward. We are receiving responses all the time and are collecting them in a folder. It is not a formal consultation because I think it is important that the Report reflects the opinion of the Group, but we want to know what people think and what people want to happen next. There are of course a few dissenting voices who have contacted me with very harsh criticism of the Report, but they are a very small minority. I think that people can and should make their own minds up.

### **Speaking of criticism, how do you respond to criticism of the Inquiry itself?**

Lots of ridiculous things have been said about who has influenced the Group or that I am a liar or whatever, all from extremely vocal minorities. Personal attacks can never be justified, and there is no evidence that the Inquiry was anything less than independent. I would simply urge everybody to read the report for him or herself and make up their own minds. Don't rely on a synopsis from one group or another. I know many people with ME may find it a struggle to actually get through such a large document, this is why we are waiting until January to have the meeting, so most people will have had the chance to read it and decide for himself or herself what they think. We are aware that the lack of a hard copy is an issue and we are looking into it. I know that some individuals are criticising the structure of the Inquiry, it has not changed since the beginning, yet all of a sudden, it's not good enough. We are doing the best we can with the means available and I think our best is good enough. There is no point getting bogged down in negativity. I want to work together with people who are willing to build positive consensus and hopefully make some big changes in this field.

**It has been said that all you have done is called for another Inquiry, how do you respond to this accusation?**

As an MP, or group of MPs and Lords, we cannot pass final judgement on this. Personally, I think there simply must be a biomedical pathology, but my opinion is not good enough. Further research needs to be done and existing research needs to be assessed by the relevant medical professionals here in the UK. It would be irresponsible for MPs or Lords to pretend to have the medical knowledge to make definitive rulings in such an important and contentious area as this. I think our recommendations are really positive steps forward and as I've said I want to work with people to make our recommendations count.

**So how do you propose to make the report count?**

As I said, letters to Ministers are important, and pressuring NICE and the Dept of Health and the DWP (Dept for Work and Pensions). I know work is going on behind the scenes in many government departments but we need to keep the pressure up. I see the Report as a step in a wider process to effect change in this area. It is not a panacea, but every little bit helps. We are going to have a meeting with contributors and patient Groups in January to help take things forward.

**So what when and where is this meeting?**

We will discuss the Report, what people like, what they don't and how to take it forward. We want to include the ME community and we want them to help us, I said we have limited resources, so let's all really work together on this! We can use the Gibson Report as a starting point. I know there are many separate organisations doing a lot of good work. I think combined they have a lot of power. I will be discussing some proposals with the Group at our meeting next week, we will also look at setting a date for the wider meeting some time in January. The meeting will be held in Westminster, and there will inevitably be limited places at the meeting. We will let people know further details via the News page after the Group meeting next week.