



Letter to the editor

**Epilepsy health consumer groups and charities;
How representative of patients are they?
(Grinton M., et al. *Seizure J.* (2012))**

Dear Dr. Reuber,

Epilepsy Society would like to respond to the above article published in *Seizure* earlier this year.

Through our tertiary assessment and treatment centre, residential care and supported living services, as well as a long standing association with the National Hospital of Neurology, Epilepsy Society works directly with thousands of people with epilepsy each year. We are also doing more than ever before to engage and involve people beyond our medical and care service provision:

- Our most recent survey (on medicines adherence) attracted over 1000 responses from people with epilepsy across the UK. The results of this survey, as with previous surveys will be used to inform our campaigning priorities, information production, and the development of services for people with epilepsy.
- Many of the resources we provide to people with epilepsy such as seizure diaries and a new diagnosis pack, interactive iPhone and Android app, were developed with extensive input of people with epilepsy, as well as carers of people with epilepsy and medical professionals.
- We also analyse trends in the calls made to our confidential helpline and enquiries to our regional information clinics. This is so we can understand the current issues of importance and priorities for people with epilepsy. For example, one of our current policy priorities is responding to welfare reform; this is a direct result of calls to our helpline from people with epilepsy who are concerned about changes to their benefits.

Fee-paying members, of the sort referred to in the study undertaken for this article, make up only a small proportion of people with epilepsy that our charity engages with. Indeed we actively encourage people to engage in a way that suits them. Many people with epilepsy come to charities such as Epilepsy Society primarily for information. We produce this information in many different formats ranging from easy read versions of leaflets, to a confidential helpline, to conferences. Other people with

epilepsy pro-actively share their views with Epilepsy Society via our forum and facebook page, youtube and twitter accounts. Our own experience would support the findings of this study in relation to membership; those with most intractable epilepsy are more likely to become fee paying members. However, it is important that we are able to represent the full spectrum of people living with, and affected by, epilepsy. This is why we offer a range of ways to get in contact, share experiences and help develop priorities for our development work.

Epilepsy Society continues to develop new ways to engage with people with epilepsy; we are currently developing a policy area of our website so we can keep people up to date with the work we are doing to influence public policy development, which they themselves have helped to determine our priorities for. We also have plans to develop patient view forums in 2013 specifically to give a voice to people affected by epilepsy, and to harness their views and experiences. One finding from the study we find very encouraging is that people with epilepsy are feeling empowered to speak to their GP or consultant to bring about improvements in services. We can provide a voice for those who do not feel so empowered as, for example, many people on the helpline do not feel they can talk to their health practitioner.

We acknowledge the study was intended to be a pilot from which to ascertain whether a wider scale study is possible. It is worth noting that because the epilepsy charity world is a very crowded market we do not actively market our work in Scotland. If a wider scale study was undertaken we would welcome the opportunity to be involved to ensure the sector as a whole is operating in a way that is transparent and that good practice in representing service users is celebrated.

Yours Sincerely,

Graham Faulkner
*Epilepsy Society, Chesham Lane, Chalfont St Peter, Bucks SL9 0RJ,
United Kingdom*

*E-mail address: graham.faulkner@epilepsysociety.org.uk
(G. Faulkner)*