

About the Guillain-Barré Syndrome Support Group



Early beginnings

Unable to find out anything about the illness that had afflicted her, Glennys Sanders founded the GBS Support group in 1985. The Group's initial aim was to provide both information and support to those affected by GBS. The first of many booklets was produced, a network of local 'contacts' who visited hospitals and homes was organised, and a newsletter was distributed to the Group's members.

The first two decades

In the two decades that followed, a great deal changed. Knowledge of the illness increased enormously. What was regarded as a single disease entity, with a chronic relation that became known as CIDP, evolved into two spectra of neuropathy, one acute and one chronic. These included several rarer but related conditions. A much greater understanding of these illnesses emerged and treatments were developed.

The Support Group changed markedly too, becoming a registered charity in 1986. Its original sphere of activity encompassed the United Kingdom though later this was extended to include the Republic of Ireland.

The charity today

Our charitable objects now include:

- The provision of care, information, non-medical advice and other assistance to sufferers and their families
- Promoting research into the causes, prevention and treatment of the illness; and
- Advancing the education of the public and of the medical professions concerning the illnesses, their causes, prevention and treatment.

In order to achieve these objects, the Charity:

- has a National Executive Committee, the members of which are the Trustees;
- has a headquarters in Sleaford, Lincolnshire with two part-time members of staff;
- publishes and produces information and a journal/newsletter;
- has a free 24-hour helpline;
- has a network of local contact persons;
- has several local branches;
- makes research and other grants;
- gives awareness presentations to universities and hospitals;
- maintains a comprehensive presence on the Internet;
- has an annual conference; and
- undertakes fund-raising activities.

Into the future

Although much more is now known about GBS and CIDP, the mechanisms that cause them remain elusive. Whilst treatment is effective for many, it is less so for the patients who are the most severely affected. Consequently GBS can still prove fatal and CIDP can result in a lifetime of chronic illness.

As a consequence, research into finding improved treatments and even a cure for these illnesses is desperately needed. These illnesses do not have a high profile and we have found that a most effective way of getting young scientists and doctors interested in these conditions is to fund their early years in research.

The Charity still hears of cases where late diagnosis has resulted in delayed and less-effective treatment. Though modern techniques have revolutionised the ways we disseminate our information, a commitment

to raising awareness of the illnesses is ongoing.

The incidences of GBS and CIDP have remained constant but with increased knowledge, some patients formerly diagnosed with an unspecified 'peripheral neuropathy' are diagnosed with one of the rarer conditions that we cover. Consequently it is necessary to keep our information continuously updated.

It was once considered that having been affected by GBS or CIDP was sufficient to be a volunteer. However, as more is known about these illnesses with their differing symptoms and treatments, personal experience needs supplementing. Mindful of new legislation designed to protect the vulnerable, our volunteers also require additional training to ensure the safety of those at risk.

How you can help us

As long as people continue to be taken ill by GBS and CIDP, the Charity's work will never be complete. We can only continue to provide our service with the continuing help of our generous supporters. There are several ways in which you can help us and make that extra difference.

Some people like to hold a fund-raising event which also has the advantage of spreading awareness. Others, prefer to make a financial donation. Additionally, many wish to become members of the Charity so that the mutual support between them, and the Charity and other members may continue.

If you would like to help the Charity, our contact details are on the reverse. You can use the form to either make a donation or request an application form to join the Group.

You can find out more about us and other ways you can help us on our Website at: www.gbs.org.uk