

THE ENCEPHALITIS SOCIETY

- action for support, awareness and research -

The Encephalitis Society is a UK based charity.

- In 1994, it was established as the Encephalitis Support Group - in response to both the overwhelming lack of information on encephalitis for people affected by the condition and their need for mutual support in coming to terms with its consequences.
- In 2002, it resolved to formally extend the Society's membership and services to include the Republic of Ireland. Through its website, the Society's resources are accessed worldwide.
- In 2003, it adopted as its operating name, "The Encephalitis Society", and opened the Encephalitis Resource Centre.
- The Society is, as far as we know, the only resource of its kind in the world.

Encephalitis is an often life-threatening illness caused by infection, usually viral, or by autoimmune diseases affecting the brain. Subsequently many people are left with an acquired brain injury, the degree and severity of which will vary.

The Aim of the Society is to improve the quality of life of all people affected directly and indirectly by encephalitis. It fulfils this aim by -

- Supporting adults, children, families and carers of those affected by encephalitis.
- Raising awareness about the condition, its consequences and support for improved services
- Promoting and assisting with research into encephalitis.

Support

- offering a listening ear via a manned telephone information line
- providing direct support for adults, children and their families
- organising meetings, regionally and nationally, at which members can learn about the illness, its consequences and get together to share their experiences
- facilitating family weekends and retreat weekends for adults
- arranging conferences, workshops, and seminars for professionals.
- maintaining Link Up, a contact scheme for members
- signposting people to other organisations, where appropriate

Information Resources

- booklets, fact sheets, information packs and a DVD on encephalitis and its consequences
- the Society's Website: www.encephalitis.info
- Regular newsletters.
- Tailor-made training packages for health, education and social care professionals.
- Links to other organisations.

Raising Awareness

- amongst the general public and professionals through annual awareness weeks.
- amongst relevant professionals through workshops, training programmes and conferences.
- through representation on national fora and responding to government initiatives.
- Presenting information and research at national and international conferences and professional forums

Promoting Research

- appointing leading medical and health care professionals to the Society's Professional Advisory Panel.
- conducting research and working with in partnership with other researchers and research institutions
- putting researchers in the field, in touch with people affected.
- undertaking surveys and evaluations.
- raising funds for research projects.
- awarding grants for research.
- Working in partnership with other organisations on research and formulating guidelines for best practice and national standards in the UK

Governance

The Society is governed by a Board of Trustees, the majority of whom have been personally affected by encephalitis. Members to the Board of Trustees are appointed at the Annual General meeting.

Encephalitis Society Advisory Panel

An expert Professional Advisory Panel provides the Society with professional resources. Members of the Panel include highly regarded experts from neurological, psychological, paediatric, therapeutic and other relevant fields. The Panel meets annually to exchange information and progress research initiatives. Members of the panel also assist with enquiries of a clinical nature.

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The Encephalitis Society is the operating name of the Encephalitis Support Group, which is a Charitable Company Limited by Guarantee. Registered Charity No: 1087843. Company, registered in England and Wales No: 4189027. Registered Office, as above.

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