

Addressing information needs on acquired brain injury

Stephen Tyrer and Elnaz Nesvaderani explain the aims and work of UKABIF, a charity which supports people with acquired brain injury and raises awareness of their needs

The United Kingdom Acquired Brain Injury Forum (UKABIF) is a charity set up in 1998 to improve awareness of the effects of acquired brain injury and related service needs including prevention, treatment, rehabilitation, health and social welfare, education, housing, work, financial factors, legal issues, civil rights, ethnic concerns and other issues affecting people with a brain injury arising from whatever cause.

UKABIF consists of professionals from many different disciplines involved in the rehabilitation and care of people who have had a brain injury that has arisen during childhood or adult life. The forum was developed because there was considered to be a need for a body to give informed professional advice to policy makers and provide educational support for those with brain damage. The first meeting of the group took place in November 1998. An executive committee was then formed and since then there have been regular meetings every quarter.

The organization hosts two conferences every year on a brain injury topic to which other professionals and relatives and sufferers from brain injury are invited. All the officers and members of the executive committee carry out their tasks in an honorary capacity and the only paid member is an administrator. UKABIF receives funding for this source from a number of charities that support educational initiatives in neuroscience. Although brain damage arising from trauma is a common cause of acquired brain injury, UKABIF does not confine itself to head injury; conditions such as stroke, encephalitis and metabolic

disorders also come under the attention of the organization.

All-party parliamentary group

Shortly after the inaugural meeting of the forum, an all-party parliamentary group

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(APPG) concerned with brain injury was formed under the Chairmanship of Jim Marshall, MP. UKABIF now has regular meetings with the APPG under its present Chairman, Bob Russell, MP. The aim of these meetings is to inform MPs about issues involving those with brain injury. Recent meetings have focussed on the very slow implementation of the National Service Framework (NSF) for Long-Term (neurological) Conditions (because no additional resources were allocated for this project, an absence of targets, and a lack of a single agency responsible for the programme). Previous meetings have covered topics as diverse as special educational needs for those with brain injury, cognitive impairment, ethics of withholding and withdrawing treatment, and disability legislation. Future meetings are proposed concerned with drinking and driving issues that lead to acquired brain injury, issues surrounding children and acquired brain injury, and the rehabilitation of those who have brain damage sustained in military conflicts.

The contact with MPs is an important part of the work of UKABIF and has led to questions posed by the organization being addressed in Parliament.

Other activities

However, UKABIF does not confine itself to lobbying MPs. It provides a service for those who contact the organization directly wanting advice on how to manage with a brain injury. It is responsible for the Directory of Rehabilitation Services for Acquired Brain Injuries, which can be accessed from the website (*Table 1*). This directory includes information on rehabilitation services throughout the UK. Regular conferences are arranged informing professionals and the general public about brain injury matters. Future topics being planned include the new Medical Capacity Act, the Long-Term Conditions NSF in March 2008 and a collaborative conference with the Scottish Head Injury Forum later in 2008. A regular newsletter is produced three or four times a year which can be downloaded from the website. This informs the membership of current events in the field including meetings of other similar organizations in the area. There are strong links between UKABIF and regional fora and an annual meeting involving these groups now takes place.

Membership

Any person and any organization can become a member of UKABIF. There are two types of membership, personal and organizational. All members receive a copy of the newsletter, and are entitled to vote at the annual general meeting.

Table 1. Further information

The United Kingdom Acquired Brain Injury Forum (UKABIF)

www.ukabif.org.uk

Further information about UKABIF can be obtained from the website or by writing to the Administrator at the Royal Hospital for Neurodisability, West Hill, Putney, LONDON SW15 3SW

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