

WAMES is a campaigning organisation, seeking to influence the development of health, social care and education policy in Wales to improve the lives of all people with ME & CFS and their carers. We also campaign outside Wales on issues directly affecting Welsh residents.

We consult with people with ME & CFS and their carers to establish key concerns and determine priorities.

### **Other activities:**

- We respond to selected consultations which have implications for people with ME & CFS and their carers.
- We take part in occasional surveys on issues relevant to the voluntary sector.
- We provide support to young people with ME & CFS (up to the age of 26) and their families and carers by phone, email, post and newsletter
- WAMES does not offer advice about specific issues but can give information about a wide range of topics of interest to people affected by ME & CFS. We can also signpost to other organisations who can offer information and/or advice. Helpline contact details: [helpline@wames.org.uk](mailto:helpline@wames.org.uk) Tel: 029 2051 5061
- The WAMES Yahoo Group gives people over the age of 18 living in Wales the opportunity to meet and discuss others with an interest in ME & CFS through an electronic mailing list.
- WAMES looks for ways to raise awareness of ME & CFS and the work of WAMES. In May 2011 we launched an *ME Information for all* campaign
- WAMES is developing a range of bilingual Info sheets about a wide range of topics, which will be available for download from this website as they become available.

WAMES is a fully constituted voluntary organisation run according to the guidelines laid down by the Charity Commission. We will be registering with the Charity Commission during 2011. Our work is governed by written policies about confidentiality, equal opportunities, volunteering, protection, trustees and grievance procedures.

The governing committee consists mainly of people with ME and carers, and is elected by members at the AGM every March. They are responsible for implementing the WAMES strategy and carrying out the day to day operation of the Association.

Membership is open to residents in Wales aged 18+ and to organisations based in Wales who support the aims of WAMES. Members join in order to take part in the work but we also welcome volunteers and supporters who are in agreement with our aims, but do not wish to become members.

We are funded by donations from individuals, ME support groups and professional organisations. In September 2010 we were awarded an *Awards for all Wales* grant of £5,000 from the Big Lottery Fund for an awareness campaign.

## **Our History**

WAMES was set up in 2001 by local support groups to address the issues caused by devolution and a bilingual society i.e. campaigns held in England did not affect services in Wales and many people could not access information about ME in their native language. We launched the organisation with an awareness raising event in the National Assembly consisting of an exhibition, information and talks by our Medical Adviser Dr Betty Dowsett (originally from Newport, Gwent), Chris Clarke (Action for ME) and a young person with severe ME. This was the start of our political campaign for recognition of ME and services. Hedd Gwynfor kindly adapted his bilingual website to become the WAMES website and in 2005 we produced our first bilingual leaflet: *Pacing for ME & CFS: a guide for patients*, by Dr Ellen Goudsmit.

In 2006 we decided it was time to widen our support base in order to fully meet the challenges of the future and so we changed the way we were governed. A new constitution was adopted which made us independent of the local groups. From that point on people with ME and carers, as well as support groups, from all parts of Wales were invited to join our work as trustees, supporters or volunteers.

## **Our Publications**

WAMES publications include:

- Documents about WAMES: reviews, updates, leaflets, posters etc
- Consultation responses and statements
- Info sheets for patients, carers and professionals
- Surveys and reports
- Young people's newsletter

**Website:** [www.wames.org.uk](http://www.wames.org.uk)

## **Contact Us**

**Secretary:** Jan Russell [enquiries@wames.org.uk](mailto:enquiries@wames.org.uk) Tel: 01970 636515

Please contact Jan re:

- information about WAMES
- to be added to the campaign newsletter mailing list
- to donate money to our campaigns
- health services campaign
- to donate money to our campaigns

**Youth & Care Officer, Media Contact** [Sylvia@wames.org.uk](mailto:Sylvia@wames.org.uk) 029 2051 5061

Please contact Sylvia with enquiries about:

- ME in Wales
- young people (under 26) & the WAMES support service
- education and social care
- publicity and the media

**Medical advisers:** Dr Betty Dowsett, Dr Nigel Speight

**Patron:** Lord Barry Jones