

ME in Wales

2006-2007: the WAMES Review

Our vision is for a Wales where adults and children with ME and CFS and their carers, are taken seriously and treated with respect, where diagnosis, treatment and services are accessible without a battle.

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Cymdeithas Cefnogi
ME & CFS Cymru

Welsh Association of
ME & CFS Support

ME (Myalgic Encephalomyelitis) is a potentially disabling and chronic neurological condition which affects the brain at a physical, mental and emotional level. The major characteristic is that symptoms become worse after physical and mental exhaustion and can fluctuate, leaving patients and families alike confused and frustrated. The term Chronic Fatigue Syndrome (CFS) is sometimes used interchangeably with ME but is also sometimes used as an umbrella term for unexplained illnesses with a strong fatigue element. There is currently no cure and no treatment which helps all patients.

Introduction

In 2001 WAMES was set up by local support groups to campaign on their behalf for better services for Welsh residents with ME. Progress has been slow but with the publication of NICE medical guidelines for CFS/ME in August 2007 and important research discoveries in the fields of genetics, leading to trials of diagnostic tests and drug treatments, we feel we are now entering a new phase in campaigning.

In order to fully meet the challenges we foresee WAMES being faced with in the future, and to widen our support base, we have changed the way we are governed. A new constitution was adopted in November 2006 which made us independent of the local groups. Now patients and carers, as well as support groups from all parts of Wales are invited to join our work as supporters or volunteers.

Aim and objectives

Our goal remains the same as we aim to give a national voice to people with ME & CFS, and their carers and families, in order to improve services, awareness and support in Wales.

We will do this by:

- campaigning for recognition of ME as a neurological illness in line with the WHO classification and the results of biomedical research**
- campaigning for health, education, social care services, benefits and research.**
- raising awareness of ME**
- offering support to young people with ME**
- providing information in Welsh and English for patients & professionals**
- aiding local support groups**

The challenge

- There are an estimated 11,800 people in Wales with ME and CFS.
- Wales has no ME health specialists.
- Doctors & other health professionals receive little or no training in the illness.
- The neurological and chronic nature of ME is not widely recognised.
- It is difficult to find an accurate diagnosis.
- It is difficult to find help with devising a management plan.
- It is difficult to access benefits, social care and appropriate education.
- The treatments offered (e.g. some drugs, behavioural and exercise therapies) can be inappropriate.
- There is a need for good quality research into all aspects of ME in Wales, especially epidemiology and service provision.

Highlights of 2006 & 2007

PRIME workshop

In September 2006 WAMES hosted a successful workshop in Cardiff led by the PRIME project. (www.prime-cfs.org) PRIME is an independently funded project concerned with getting the experiences of people with ME/CFS and their carers to a wider research and clinical audience. The workshop, held at Cardiff City Hall, attracted 26 participants - a mixture of researchers, clinicians, patients and carers.

The day focused on how researchers into ME can use PRIME's patient experiences database and PROMs (Patient Reported Outcome Measures) i.e. questionnaires given to patients to determine their health status in ME. There was also an opportunity to speak to researchers about their ideas for future research into ME and CFS. A number of researchers and clinicians were unable to attend the workshop but asked to be kept in touch.



Healthcare Report

More tortoise than hare: a report on health services for adults and children with ME & CFS

This WAMES report was published in April 2007 and is based on a survey of services in Local Health Boards (LHBs) and Health Commission Wales (HCW). It found that there are no specialised services for children and only 5 rehabilitation services in Wales which are aimed at any adult patient with fatigue as a symptom.

Young People's support

Our bilingual newsletter was re-launched with a new name chosen by the young people: *Outlook*, and was well received. We continued to tackle subjects such as treatments, prognosis, careers, education and received messages of support from the Automatic and Iolo Williams.

In 2007 our young people's contact Michelle Penny was interviewed by BBC Interactive and the South Wales Echo leading to articles on the BBC website and in the South Wales Echo. These highlighted the difficulties of getting an education when you are a severely affected person with ME, and her successful exam passes.



Michelle

NICE medical guidelines

Guidelines from the National Institute for Clinical Excellence on CFS/ME were published in August 2007. WAMES had previously been involved in the consultation process but were disappointed with the final version. We published a statement highlighting the inadequacy of the diagnosis guidance and the inappropriateness of the treatment advice.

Campaigns

Don't forget ME During 2007 we launched a letter writing campaign asking adults and young people with ME across Wales to write to their LHBs asking what services were available following the publication of the Chronic Disease Management Framework, which the Health Minister had told WAMES would shape services for ME. We began to contact LHBs to discuss service development and will continue this campaign during 2008 as it was confirmed that in spite of the NICE guidelines and CDM Framework there are still many obstacles to the development of basic health services for people with ME and CFS.

Biomedical research awareness

Patients continued to report a widespread lack of understanding of the physical illness of ME with many health professionals still believing that it is a mental health condition. We therefore sent a copy of the MERGE DVD on biochemical research findings to GPs and other relevant people in May 2006.

Partnerships & Consultations

WAMES continued to support the WNA (Wales Neurological Alliance) and joined the newly formed LTCAC (Long Term Conditions Alliance Cymru). We also put forward the ME patients' viewpoint in a number of consultations connected to children's healthcare, carers, quality of life and medical guidelines.

Telephone and email enquiries

Following our mailing of info sheets to GPs in 2005 we received a number of requests for names of health specialists that GPs could refer their patients to. Unfortunately we were unable to provide names of any in Wales. Requests for information were also received from patients and parents on specialists, benefits, education and social care. There are still too many patients being refused benefits and experiencing no support or even hostility from professionals in health, education and social care.

Income and expenditure

Donors

- AJK Ltd via Lynne Williams
- Clwyd ME Group
- Glamorgan ME Group
- Mid & West Wales ME Group
- Gwent ME Group
- St Cyres School

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|-------------------------------------|---|
| Income 2006 | £ 996.60 |
| Income 2007 | £ 570.32 |
| Balance (31 st Dec 2007) | £6692.49 (General Account £1778.38 Young Persons Account £4914.11) |

Future plans

Training & research

WAMES wants to see ME included in research agendas and the education of health professionals (at all levels). Talks about this will continue with academic institutions.

Publication of bilingual information sheets

WAMES is committed to the distribution of information about ME to professionals, patients and carers in both Welsh and English.

Website & Message Board

We wish to redesign and update our website and promote the message board.

Young people's support

We will look for ways to develop the support service, especially the newsletter and bilingual literature.

Campaign for better services

We will continue to engage with The Welsh Assembly Government and professionals to find ways to improve services and will be seeking information from patients on their experiences of services in Wales.

Recruitment drive

In order to carry out all our plans over the next few years we need to attract more people to help.

- Volunteers to help in many ways both large and small
- Supporters can:-
 - Give us information about ME in Wales
 - Sign up for our campaign newsletter
 - Spread the word – ask us for posters and leaflets
- Fundraisers

Our Organisation

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| Secretary | Jan Russell | 01970 636515 | enquiries@wames.org.uk |
| Co-secretary & Parent /Carer Contact | Sylvia Penny | 0290 2051 4328 | sylvia@wames.org.uk |
| Treasurer | Elizabeth (Liz) Chandler | | liz@wames.org.uk |
| Young People's contact | Michelle Penny | | michelle@wames.org.uk |
| Other trustees: | Ann Thomas, Chris Davies (resigned March 2007), Tony Thompson | | |

It is the policy of WAMES that the majority of trustees are patients.

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| Patron | Lord Barry Jones |
| Adviser | Dr Betty Dowsett |

www.wames.org.uk

Message Board <http://health.groups.yahoo.com/group/WAMES/>