

Annual Report 2008-09



Multiple Sclerosis Society
Cymru

MS Society Cymru

Temple Court
Cathedral Road
Cardiff
CF11 9HA

Tel: 029 2078 6676

Fax: 029 2078 6677

Email: mscymru@mssociety.org.uk

Web: www.mssociety.org.uk/wales

Helpline: 0808 800 8000

The Multiple Sclerosis Society of Great Britain and Northern Ireland
is a charity registered in England and Wales (207495) and Scotland (SCO16433)

Annual Report 2008-09

MS Cymru continues to go from strength to strength as the staff, Council members, Branch members and volunteers develop positive partnerships to improve the services, information and support for people affected by MS in Wales.

Following the appointment of the first ever Director of MS Cymru at the beginning of 2008, there have been a number of important appointments and role changes within the staff team. Sian Hughes' role as part time Administrative Assistant was upgraded to that of Project Officer in April 2008. Joseph Carter was appointed to the post of Policy, Press and Campaigns Manager in September 2008, while Li Ang took up post as Executive Assistant in November 2008. Cheryl Ewen replaced Sue Lloyd as Service Development Officer in January 2009; we said goodbye and a heartfelt thank you to Sue as she retired after nearly nine years with the Society in April 2009.

David Griffiths stepped down from his role as Treasurer of the MS Cymru Council at the 2008 AGM, while Allan Young, our UK Trustee and MS Cymru Council member, also completed his term of office in 2008. We welcomed Marion Davies, Keith Rollinson and Mark Williams as new Council members in 2008, and Paul Pavia was also elected to serve on the UK Board of Trustees.

The MS Cymru Council met throughout 2008 at locations around Wales, including Wrexham, Cardiff, Swansea, Llandrindod Wells and Llandudno. The minutes of these meetings were circulated to all branches in Wales.

Members will know that the planned office move did not materialise. This was due to problems in agreeing the terms of the lease and the spiralling costs of dilapidations – work required to make the office fit for purpose. A decision has been made to remain at Temple Court for the time being, and this will be reviewed later in 2009. In the current economic climate, MS Cymru is mindful not to commit resources unnecessarily, and to use income to improve services and support for people affected by MS in Wales.

We have made some important improvements to our IT systems. This includes trialling 'virtual desktops', which includes access to some key applications, such as Raiser's Edge. This will significantly improve the management of our fundraising. We have also worked with our Finance Department to produce new

budget codes which allow us to produce more meaningful financial reports. The Society-wide intranet project has also helped to improve internal communications across the organisation.

MS Cymru continues to develop valuable links and partnerships with key people and organisations around Wales. Our profile at the Welsh Assembly and with the media in Wales has increased substantially throughout the year, with wide press coverage of a number of stories and interviews on national radio and TV. We have developed a bank of case studies across Wales, which can be used on a number of pertinent issues – grateful thanks to all of our members who have agreed to represent the Society and people affected by MS in this way.

MS Cymru has taken a lead role within the Wales Neurological Alliance, with the election of Judi Rhys as Chair, while Joseph Carter has also been elected to the Executive Committee. We continue to make an active contribution to the Wales Carers Alliance and the Disability Pride planning group, and we have met with many key Assembly Members to brief them on issues affecting people with MS and to lobby on your behalf.

MS Cymru has been instrumental in setting up and servicing the Cross Party Group for Neurosciences and, through the Wales Neurological Alliance, we are represented on the Implementation Boards and the workstreams for both the north and the

mid/south Wales Neurosciences Review. We have campaigned on issues ranging from wheelchair waiting lists to disabled access to public transport. Our fight to improve services for people with MS in the more rural areas of Wales continues unabated. We have responded to a number of important consultation documents, and encouraged our membership to also put forward their views on such issues as Paying for Care, the reorganisation of the NHS in Wales and the review of Health Commission Wales.

Throughout 2008, MS Cymru participated in a number of events, which included the UK wide MS Life, held in Manchester, the first UK Disability pride event held in Cardiff, the National Eisteddfod, held in Cardiff, and the Family Fun Day held in Welshpool, in partnership with the West Midlands region of the MS Society. We delivered Welcome Aboard and Providing Support training for volunteers at various locations in Wales throughout the year, including a joint event with West Midlands. Newly Diagnosed Days were held, in partnership with MS Specialist teams across Wales, and we were able to offer more days than in previous years, due to successfully receiving trust funding. We have also delivered training to health and social care professionals, designed to help increase their awareness of MS. For 2009, we are planning both an Evolving Services conference and a Living with MS event in north Wales, for 20 and 21 November 2009 respectively.

We have made significant progress with improving our MS Cymru website, and while the site is still under development, the changes to date will be noticeable to users. For example, we are now able to update our news and events section regularly, so that visitors to the site can be kept informed of our work. We are also delighted that we now have our own online donations page. MS Linc has had a makeover, and we have increased the circulation to include Assembly Members, health and social care professionals, as well as other relevant charities. We continue to work closely with the Publications team to keep our core titles up to date and available in both Welsh and English. MS Cymru has also produced a press pack during the year, to inform the media in Wales of our work, and we have also provided publicity banners for all the branches in Wales.

The four Area Networks met in April and October 2008, and again in April 2009. There are now 17 branches in Wales, and the Area Network structure has provided a useful forum for collaboration between branches, and for sharing information.

An innovative Telephone Buddy Project was developed by staff at MS Cymru during the year, following an initial idea floated at an Area Network Meeting. This is a volunteer-led project, which will allow people newly affected by MS in Wales to be matched with a trained volunteer who will provide telephone support

as required. This project has attracted external funding, and we will be providing further volunteer training later in 2009.

During 2008, following strong representations from MS Cymru and the Newport and Cwmbran branches, we were able to secure a commitment from Gwent NHS Trust to continuing funding for a second specialist MS nurse. They have also employed a full time specialist Occupational Therapist, whose post has been funded by contributions from the MS Society and Newport Branch. We continue to be closely involved in the negotiations to secure a multi-disciplinary clinic for people with MS in north Powys, and to strengthen the MS team operating out of Morrison Hospital in Swansea. MS Cymru is continuing to campaign for services for people with MS in rural communities, particularly Powys, where provision remains extremely poor. We are also continuing to support the local neurological alliances around Wales, and most recently have been instrumental in establishing a local neurological alliance in Neath and Port Talbot. The neurology discussion days, which have been held in north Wales, as a joint venture between the Wales Neurological Alliance and the Walton Centre, have been particularly well supported by both service users and health professionals.

Following the appointment of Iestyn Evans as National Fundraiser, MS Cymru was able to exceed the fundraising target set for 2008. We were successful in gaining funds from a number of charitable trusts, and our community fundraisers throughout the country did a marvellous job, both in raising money and achieving their own personal goals. We received a legacy gift of £10,000 and a significant donation of £10,000 from Ifor Williams Trailers. Branches from around Wales have generously supported the research project in Cardiff University which is being funded by the MS Society, contributing over £10,000 in total. These much needed funds help to support the work that MS Cymru does on behalf of those affected by MS in Wales.

Finally, we wish to thank everyone who has supported our work in so many ways throughout the year. At a time of economic and political uncertainty, with so much change occurring in the way our health services are structured, it is good to know that the MS community in Wales stands united in the quest to improve services, support and information for people affected by MS. Through our joint efforts, we have already achieved a great deal, and with your continuing support, we can achieve much more. We look forward to reporting on and celebrating those achievements with you.

Judi Rhys

Director, MS Society Cymru

Ann Hodgson

Chair, MS Society Cymru Council