

**MERSEY REGION
EPILEPSY
ASSOCIATION**

59th ANNUAL REPORT

**FOR THE YEAR ENDED
30TH SEPTEMBER 2015**

MERSEY REGION EPILEPSY ASSOCIATION

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Registered as a charity: 504366

MERSEY REGION EPILEPSY ASSOCIATION

Mersey Region Epilepsy Association
is an independent charity providing support and
information to people with epilepsy across Merseyside and Cheshire.

President: Professor Tony Marson, MBChB, MD, FRCP

Vice Presidents: Ken Dodd OBE
Professor Gus Baker
Professor Michael Orme
Ricky Tomlinson

HONORARY OFFICERS

Chair: Peter Rogan MBE, MSc

Vice-Chair/Secretary: David Renison LLB

Treasurer: Derek Shanks ACIB

STAFF

Fieldworker/Administrator: Christine Seddon BA

VOLUNTEER ROLES

Group Liaison Officer: Jean Norton

EXECUTIVE COMMITTEE

Dr Richard Appleton	Consultant Paediatric Neurologist
Mr Bryan Cartwright	Service User Representative
Professor Paul Eldridge	Consultant Neurosurgeon
Mrs Anne Inman	Service User Representative
Mr Paul May	Consultant Neurosurgeon
Mr Tony McClure	Employment Specialist
Mrs Jean Norton	Service User Representative & Group Liaison Officer
Mr Leyland Preston	Service User Representative
Mrs Marian Preston	Service User Representative
Mrs Anne Sweeney	Epilepsy Specialist Nurse
Dr Udo Wiesmann	Consultant Neurologist
Dr Ian Williams	Consultant Neurologist
Mr Ron Williams	Service User Representative

**Supporting people with epilepsy
across Merseyside and Cheshire**

OUR ROLE

We provide support and information, free at source, to people with epilepsy and their families/friends on a localised basis. Our services take place across a variety of settings:

- Our telephone help line operates from our home based office. People can contact us for information or advice, and they can also access our other services.
- We have a comprehensive website giving information on all aspects of living with epilepsy.
- We travel across the region into people's houses for home visits. This service is particularly valuable when people find it difficult to get to us.
- Out in the community, we are proud of our affiliated support groups and clubs, which provide a social outlet and offer education and support for people with epilepsy.
- We are at the information desk at the Walton Centre every Tuesday from 1pm to 4pm.

CHAIRMAN'S REPORT

The year has been busy in so much as our activity has remained in demand with Chris Seddon doing an admirable job visiting people in their homes to help out with problems that have arisen as a direct result of having epilepsy. Not surprisingly a lot of her work revolved around advising on difficulties resulting from changes to Housing Benefit allowances referred to as 'bedroom tax'. Visiting the newly diagnosed has been another prominent feature of her work.

The MREA website has recorded an average of 14,000 hits per month. Records show that a significant number of visitors are from outside the UK, the majority of them being from the USA. A major task ahead is to update the website on a regular basis and maintain its accuracy.

I have been pleased to represent the Association in a major research initiative being undertaken by the University of Liverpool under the direction of our President, Professor Tony Marson. The research is focusing on services to epilepsy patients attending Accident and Emergency departments in hospitals about Merseyside. These were found to be less than adequate and the research will assess the services available and hopefully new pathways will develop to be adopted in our own area and possibly across the whole country.

The Treasurer's Report once again shows an excess of expenditure over income. Previous recent Annual Reports show that it is a trend that has become normal rather than exceptional and is cause of great concern. It is a problem that has to be addressed as a matter of urgency.

My thanks are offered to everyone who contributes to the life of the Association and on a personal note I have especially to thank David Renison, Derek Shanks and Tony Marson for the unfailing support they have given to me throughout the year. On a day to day basis I work very closely with Chris and find her to be tireless in her work and dedication. I offer her a very special vote of thanks.

Big challenges face all smaller charities as financial cuts are made at every level and MREA is no exception. The year was a difficult one in making ends meet and I anticipate the forthcoming year to be even more challenging. In spite of what may be ahead I look forward to leading the Association in providing a valuable service to all who are in need of what we have to offer.

Peter Rogan
Chairman

ACTIVITIES

Fieldwork

Christine Seddon has had another busy and successful year, making direct contact with people who have asked for varying degrees of help. In all she met 39 people on a one to one basis, usually in their own homes, to resolve difficulties ranging from housing problems to the completion of Disability Living Allowance forms. Chris delivered 5 epilepsy awareness talks to Carers' organisations and went to 3 support groups to inform them of our work. Chris attended the Brain Chairty Centre on the first Tuesday of every month between 2pm and 4pm for people to call in and discuss any concerns with her. She also started manning the information desk at the Walton Centre on a Tuesday afternoon between 1pm and 3pm to give out information and support to those attending clinics.

She has organised once more the annual sponsored walk around Sefton Park to which we add our grateful thanks to the South Liverpool group for providing refreshments to the walkers.

Telephone Help Line

Our Call Log for the year shows that we dealt with 399 enquiries to the office. 341 of these calls came in from the general public, of which 106 related to Disability Living Allowance (now called Personal Independence Payment). 41 calls were taken from professionals working in social care or education. In response to these calls 53 packs of literature were sent out from the office.

Talks and Courses

Our team of speakers were called on to deliver epilepsy awareness courses to a wide variety of organisations. The amount of work done in this sphere is somewhat limited by the number of authorised speakers we have at our disposal. Nevertheless, we will continue to deliver these courses as and when requested.

External Relationships

- We have an excellent relationship with Neurosupport, with whom we are able to exchange client referrals as and when required.
- MREA continue to be actively involved with the Joint Epilepsy Council of the UK and Ireland.
- Our contact with other epilepsy organisations, both here and abroad, continues.

Affiliated Groups

The Association maintains contact with affiliated groups and clubs. Full details of venues and times of meetings are available from the office.

MREA 200 Club

The 200 Club is in desperate need of new members to maintain the status quo and our grateful thanks go to Caroline Healey for all her hard work over the year. Application forms are available from the office. The winners were as follows:

Oct '14	No.156	Richard Harris	Apr '15	125	Mrs K Lindsay
Nov '14	90	Mrs J Healey	May '15	99	D Chadwick
Dec '14	132	Millie Charnley	Jun '15	37	Helen Cain
Jan '15	106	Julie Williams	Jul '15	141	Mr & Mrs McClure
Feb '15	52	Ms J Ralfs	Aug '15	154	Mr Ian Harris
Mar '15	04	Mr & Mrs Rogan	Sep '15	46	Miss C Healey