



**Annual Report**  
**of Epilepsy HERE (Help, Education and Research for Epilepsy)**  
**for year ended 31<sup>st</sup> March 2016**  
**Charity 1079172**

**The charity uses the working name of Epilepsy HERE in its day to day activities**

**It is an unincorporated association governed by a constitution adopted on 7th  
December 1999**

**Entered on the Charity Commission of England & Wales register on 29 January 2000  
The registered Number of the Charity is 1079172**

**The principal address of the charity is**

**Whitstable United Reformed Church, Middle Wall, Whitstable CT5 1BW**

**During the year the following persons appointed at the  
Annual General Meeting on 7<sup>th</sup> July 2015 have served as  
trustees**

Monica Elizabeth Kendall — Chairperson

William Gower — Secretary

Roger Kendall A.C.I.B. — Treasurer

Elfrieda (Freda) Chapman

Melinda Barker

Patricia Dickson

No other person has acted as a Trustee or Custodian Trustee The recruitment of all trustees is by nomination to the Annual General Meeting. Calls for nominations are sent to all members together with the notice of the meeting. A Management Committee consisting of a Chair, Secretary and Treasurer and up to four other members governs the charity. The charity is completely run by volunteers with an interest in epilepsy and has no paid staff.

Bankers: Co-operative Bank PLC Skelmersdale Merseyside.

The charity has extensive powers of ownership and investment in accordance with the constitution. The objects of the charity are to advance the education of the public within the area of East Kent (being the local authority areas of Swale, Canterbury, Thanet, Dover, Ashford and Shepway) on all matters relating to epilepsy and related neurological conditions and to relieve those persons who have epilepsy and their families and carers so that their condition may be improved.

Supported by  
Ronald Cruickshanks Foundation



Notice of Annual General Meeting to be held at Canterbury Umbrella Centre on Tuesday 5th July  
2016

- 7.15 p.m. Assembly
- 7.25 p.m. Introduction and welcome to members and guests by Chairperson Monica Kendall.
- 7.30 pm Introduction and welcome to Cllr George Metcalfe and Mrs Lillian Metcalfe the Lord Mayor and Lady Mayoress of Canterbury and Denise Wilkes the Head of Clinical Services for Kent Community NHS Trust
- 7.35 p.m. Talk by Denise Wilkes on Specialist Nursing Services in Kent
- 8.15 p.m. Vote of thanks to our Guests.
- 8.20 p.m. Adoption of the Minutes of the General Meeting held on 7th July 2015
- . Chairman's Report.
- Treasurer's Report and proposal for adoption of accounts.
- Election of Chairman. Election of Treasurer.
- Election of Secretary
- Special Resolutions as advised
- Election of Management Committee Member(s)
- 8.30 p.m. Refreshments.
- 9.00 p.m. Close

## **Chairperson's Report**

### **Annual General Meeting 2016**

I would like to welcome all of you all to our 16<sup>th</sup> Annual General Meeting of Epilepsy HERE, our guests The Lord Mayor of Canterbury Mr. George Metcalf and his wife Lillian Metcalf. George I hope will be able to expand and talk about his many achievements throughout his working life. Denise Wilkes the Head of Specialist Clinical Services of Kent Community NHS Trust who is in charge of all the Epilepsy Nurses not only in our area but all other areas throughout the county. The Epilepsy Nurses are specialist nurses dedicated nurses who have studied, and qualified in the field of epilepsy offering their services and much hope to many patients needing specialist care. The lead Nurse Manager Tracey Truscott who started and developed the nursing scheme in this area left earlier this year as she felt the need to get back to Lincolnshire.

As a group in the Canterbury East Kent covering most of Kent we are helping those with epilepsy and their carers, family members or paid workers in the their homes and in care homes to know more about epilepsy. We managed to sell Christmas card for research into epilepsy totaling £980.00 by the end of last year.

We started this year with a move from our offices in Herne Bay to Whitstable which although in our area is venturing on new territory at Whitstable. As well as our meetings here at the Umbrella Centre we now have a morning coffee break on the third Tuesday of each month at the United Reformed Church in Whitstable where our office is. The times we are manning the office are from 10.00 until 12.30 p.m. then from 2.00 – 4.00 pm on Tuesday Wednesday and Friday. On Thursday we are at William Harvey Hospital in the morning and at Kent & Canterbury Hospital in the afternoon.

We continue to hold helpdesks at Kent & Canterbury Hospital and the William Harvey Hospital in Ashford as well as brochures at Faversham at the Cottage Hospital .where some racks have been set aside for our use when there is an epilepsy clinic being held where there are brochures on many different aspects of epilepsy on show and for people to take away. These are regularly updated. Our website provides information on aspects of epilepsy and directs individuals to other websites if they are able to access the internet continuously advancing our own knowledge on the subject. We encourage individuals and their carers to learn more about epilepsy.

A team of specialist nurses are well established in this area enabling people with problems to make appointments to see them. There is a new team of doctors becoming qualified in this field. We are still members of other organisations who are a source for information. The help desks are funded by the National Society for Epilepsy now known as Epilepsy Society This is one of the largest research organisations into the epilepsies in the world. Help Desks are manned by members of this group.

Throughout the year Government legislation has been adapted to help individuals get back into the work place as some of you may already be aware. Ourselves as with other organisations have been very active in the pursuit of what is right for the patient. Campaigning groups were able to show their feelings on the matter on a website especially

The Joint Epilepsy Council is not receiving enough donations to continue with paid staff to man the All Party Parliamentary Group meetings of which Laura Sandys was chair, is now chaired by Valerie Vaz MP for Walsall and we continue to be invited with Young Epilepsy providing administrative support. We attend the All-Party Parliamentary Group on Epilepsy in Committee Rooms of the House of Commons, Lords or in Portcullis House.

The Medical and Health Regulatory Agency proposed changes to generic prescribing but so far been avoided for people with epilepsy. Young Epilepsy at Lingfield is developing more services for children and young people. There is a Children's Assessment Centre at Kent & Canterbury Hospital and other Paediatric support throughout East Kent.

We attended the International Alliance for Patients Organizations and we were the only group representing epilepsy. However this cannot be relied upon for us to continue as funding is becoming very difficult to secure as the Treasurer will discuss in his report. We are still trying hard to live within our means as society in general is less generous the donations have become smaller and we do not ask for more than we need to keep afloat. We were unable to apply to Canterbury City Council last year as we were unable to know where our office would be. I will let Roger give a resume of the accounts and thank those who throughout the last year have given grants and donations to the Charity. We also wish to thank those members and friends who have helped the Charity in other ways.

### **Performance review**

The hospital helpdesks at Canterbury and Ashford generate around 6 direct enquiries a week some 300 per year and a large number of leaflets are distributed. The telephone helpline is available daily and the website is accessed numerous times. The home page has had some 15000 hits in the last 5 years and most pages are frequently visited with the link to Epilepsy charities and other useful sites being particularly popular.

We are active in social media especially on Twitter where we have nearly 600 followers. We visit our page on most days some 430 followers and make tweets and retweets where we consider it appropriate. We maintain a Facebook page so that our services are accessible digitally 24/7. The telephone line is available at any reasonable hour with an answering service maintained on 01227 360207

Our links with the larger national charities many of whom are co-members of the Joint Epilepsy Council enable us to keep up to date with advances in research and treatment. Membership of Red Zebra allows us to keep abreast of changes in the field of benefits and disability assistance. We have recently taken part in fairs in Whitstable, Canterbury and Faversham to introduce the new Connect Well service where we have registered to receive referrals from GP surgeries and other agencies.

Our attendances to sell Christmas Cards at charity fairs throughout East Kent between October and December have enabled us to raise several thousand pounds in recent years and have also helped to raise awareness about the work being done in epilepsy research. Since all cards have been supplied on a sale or return basis and are sold by volunteers we are able to remit the full costs to those charities who supply the cards a sum in the last year of nearly £1000.

## **Treasurer's Report**

A current account is held at Co-operative Bank PLC Skelmersdale Merseyside .The account requires the signature of two unrelated officers for withdrawals and all major expenditure is sanctioned prior to disbursement by the Management Committee. The transfer of this account to NatWest Whitstable has been agreed due to some difficulties encountered due to a lack of local contact.

During the year important grants were received from Ronald Cruickshank's Foundation of £1000 and Canterbury City Council of £500. Canterbury City Council gave us a valuable contribution in the form of free parking for our volunteers and remission of uniform business rate for which we are most grateful. The value of this diminished with the loss of our office at Christ Church Herne Bay. We were also unable to apply for funding from the city council for 2016-2017 due to uncertainty in regard to our office premises in the autumn of 2015.

The reduction in our funding and the requirement to pay Kent County Council meant we had to give up our monthly attendance at Thanet Gateway Plus. Fortunately we are not charged for helpdesks at William Harvey Hospital and Kent and Canterbury Hospitals and travel cost are paid by the hospital trust and the Epilepsy Society respectably. Epilepsy Society had considered withdrawing the supply of literature but in the outcome decided to continue. Despite all these generous grants and a number of other donations the financial position has required us to call on our very meagre reserves and if we are to continue as an independent charity we will need to replenish them if we are to remain beyond the next year.

The accounts reflect the cost of office space at Whitstable United Reformed Church, Middle Wall, Whitstable and we shall apply to Canterbury City Council to remit the total business rate.

We are members of Red Zebra Kent NCVO (National Council for Voluntary Organisations), and the International Alliance for Patient Organisations (IAPO).

The financial climate remains very challenging and although there are sufficient funds to continue at the present level of activity in the immediate future new funds will need to be secured in the year 2016 and beyond if the charity is to continue..

We are particularly grateful to personal donors and those who give their time. Their generosity is duly acknowledged. These enabled us to sell almost £1000 worth of Christmas Cards for epilepsy charities, which engage in research, during the later months of 2015.

The funds generated have enabled us to provide about 1400 hours of volunteer effort to provide information, advice and training on epilepsy throughout East Kent

## Income and Expenditure Report

	Total	Restricted	General	2015
Donations	551		551	1306
Gift Aid				72
Grant Canterbury City Council	500		500	1000
Grant Charities and Trusts	1000		1000	1000
Grant Lions Club				250
Fundraising	76		76	
Interest	2		2	6
Membership	70		70	32
Training income	127	127		
Miscellaneous	30		30	15
Xmas Card Sales	980		980	735
	3336	127	2229	4416
Expenses				
Annual Dinner				50
Expenses Travel	305	122	183	781
Fundraising expenses	61		61	36
Insurance	174		174	186
Membership	280		280	460
Miscellaneous	45		45	19
Printing	17		17	23
Rent Meeting Rooms	207		207	303
Rent office	820		820	1160
Stamps postage	162		162	473
Stationery	233		233	359
Telephone/internet	471		471	286
Relocation expenses	40		40	
Xmas card Purchases	980		980	710
Total	3795	122	3673	4846
Deficit	459		430	

Balance Sheet 31<sup>st</sup> March 2016

		2015
Balance at Co-operative Bank 1 April 2015	4732	5204
Received	2013	3985
Paid	2546	4430
Balance at Co-operative Bank 31st March 2016	3949	4732
Less Creditor	250	
Available bank funds	3949	4732
Plus debtor		
Less Contingent creditor		1232
Petty cash	135	36
Current Assets	4084	3536
Balance General Fund	2358	1752
Balance Restricted Training Fund	1696	1784
Awards for All restricted		
Total Funds	4054	3536
Movement in General Fund	518	739
Movement in restricted fund	-88	-1169
Movement in funds	518	-430

## Notes to the Accounts

- 1) Current funds are paid into a Community Direct Account at Co-operative Bank PLC, Skelmersdale and payments are made by cheques drawn on the bank requiring the signature of two officers either to the creditor or to the Treasurer for payments made by him as agent of the Charity.
- 2) The funding has been obtained by direct appeal to other charities, organizations or charitable trusts. The grant of £500 from Canterbury City Council and of £1000 from Ronald Cruickshanks Foundation has enabled us to meet our core expenses. The removal of the need for a contingency fund for electricity and gas and the reduction of the rental notice period is the reason for the increase in unrestricted funds despite the overall deficit.
- 3) The membership fees paid relate to the Joint Epilepsy Council and CASE Kent
- 4) Public Liability Insurance was provided by Markel International Insurance Co Ltd. and includes cover for Trustees Liability Insurance
- 5) All items of furniture or equipment have been either donated or purchased from current funds and no item with a value above £100 remains. No item was added in the year under review.
- 6) These statements have been prepared with care by the Treasurer and agree with the books and records of the charity. There is no requirement for audit in the constitution and the amounts are below the threshold for independent examination set by the Charity Commission. Nevertheless they will be subjected to examination and a certificate obtained once they have been adopted by the AGM.
- 7) A reserve policy is in place to enable the charity to meet its commitments during any period of financial stringency including payment of the occupancy charges during the required notice period of one month.
- 8) We are grateful to the Minister and Elders of Whitstable United Reformed Church for allowing us the use of the office on favorable terms