



Annual Report
Of Epilepsy HERE (Help, Education and Research for Epilepsy)
for year ended 31st March 2018
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 7th July 2017 have served as trustees

Monica Elizabeth Kendall — Chairperson

Colin Barnes— Secretary

Roger Kendall A.C.I.B. — Treasurer

Elfrieda (Freda) Chapman (until October 2017)

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: NatiWest Bank Ltd. Herne Bay and 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



Epilepsy HERE

Notice of Annual General Meeting to be held at Headway House, Kent and Canterbury Hospital, Ethelbert Road, Canterbury on Monday 3rd September 2018 at 630 p.m

AGENDA

- 6.15 p.m. Assembly.
- 6.30 pm Introduction and welcome to the Sheriff of Canterbury Cllr. Jeanette Stockley & Cllr. Ian Stockley and to Dr Mo. Sakel Director of Rehabilitation
- 6.35 p.m. Talk by Dr. Sakel on Neurorehabilitation
- 7.15 p.m. Vote of thanks to our Guests.
- 7.20 p.m. Adoption of the Minutes of the General Meeting held on 6th November 2017Jul
- . Chairman's Report.
- Treasurer's Report and proposal for adoption of accounts.
- Election of Chairman. Election of Treasurer.
- Election of Secretary
- Election of Management Committee Member(s)
- Special Resolutions creating a position of Assistant Secretary
- 7.30 p.m. Refreshments and networking.
- 8.00 p.m. Close

Chairman's Report

We are pleased to welcome this year's Canterbury's Sheriff Cllr. Jeanette Stockley and her husband Councillor Ian Stockley and we look forward to hearing a talk about other aspects of their careers. We wish to give them the opportunity to talk before listening to the ups and downs of our Charity which many other charities are undergoing generally. Our special guest Dr Mo Sakel, who is in charge of the Neuro-rehabilitation Centre who will talk to us about his work at the hospital and the Trust.

Ever since the time of setting up a Charity Epilepsy HERE (Help Education & Research for Epilepsy) the object of the group has been to help individuals whether carers, patients or any person wishing to obtain information about epilepsy to make it easier for them to learn more about the condition. We felt that patients did not get enough information, support and guidance in this respect. We run a help line for those wishing to or have questions answered and to talk about their condition as well as a monthly meeting to bring together those with the condition and try to arrange speakers on a subject that may help individuals with epilepsy and to enable members to socialise. In 2018 it will be more difficult as changing the day to Monday we have come across a few Bank Holidays. We plan to hold the meetings where this happens to the second Monday of such months are now held at Headway House on the first Mondays where these are bank holidays we plan to have these on the second Monday otherwise on the first Monday 6.30 – 8.00pm when no bank holiday occurs

From our own experience without the intervention of the Consultant physician or Specialist Nurse dealing with epilepsy the everyday practicalities were not touched upon. Individuals distribute leaflets at Kent & Canterbury Hospital in Canterbury, Queen Elizabeth Queen Mother Hospital in Margate and at the William Harvey hospital in Ashford and other places acting as a signpost when required. When confronted with the diagnosis of epilepsy it is quite frightening to be told you may have the condition without being able to understand the implications both medically and socially not only for the patient but the whole family. It is a condition that may not leave you and you may suffer for the rest of your life with it. It can be quite traumatic and the whole of the family network may need support in this respect.

Meetings were attended regularly and encouragement was forthcoming from the professionals in this field still find it very important to continue to gain more and more knowledge for our members sake to continually update our knowledge the treatment of epilepsy and convey this to our members through the use of a Newsletter. There is always more knowledge to be obtained which is sent to about 150 patients and carers and other influential people every three months or as we find necessary. We take a full and active part in the work of those around us and national voluntary organisations concerned with health and wellbeing. We run a web site which has attracted individuals from many areas in the UK, Europe, Africa and USA. By our continuous learning which involves attending conferences where we are able to gain more knowledge which can be very expensive to maintain but in order to improve the quality of lives of the individuals who have turned to us. Over the years we have regularly used the knowledge gained to provide epilepsy awareness training to staff in care homes schools and colleges and will talk to families when requested.

We have had a major setback with our main donor as the interest rate is so very low that this trust has decided it cannot continue as it was set up to do as government has put in great hurdles as obstacles in the way of such trusts and consequently for the benefitting charities. As we continue with the APPG (All Party Parliamentary committees we went to the Disability Forum at the APPG's for epilepsy and other long term disabilities One of these meeting illustrated many of the disadvantages

of disabilities in the schools which are very necessary but being ignored so children with long term conditions who are dependent on assistance from school nurses do not receive it. Although money is being given to the schools it goes in other directions as many of them are said to have more pressing needs for other things. Kent was said to be one of the better authorities but many schools say they were underfunded to the extent they were unable to provide these services and the children with these long term condition are the ones who suffer by not having their needs attended to because of the needs of other students. In particular those who require to take medication at particular times of day, or to drink and have their medication at regular or irregular times of day need help. In particular those with diabetes whether they need glucose or insulin and for sickle cell anaemia, epilepsy or other conditions or the results of children eating too much for not choosing to have school meals. Sickle cell anaemia, epilepsy or a child who faints then the school nurse is to be called to take on board what is happening.

Through the years in the past our epilepsy nurses were such good support to many who only saw their consultants once a year. They were pressurised to such an extent that with all the extra duties given to the epilepsy nurses that one by one the nurses found other suitable positions. Now the service has to start from square one again. Which is the same problem of under funding for the epilepsy nurses which has given the trust here the additional problem of having to retrain a new recruitment of specialist nurse and then training these nurses. I think they realise that epilepsy is on the increase and the length of time it takes consultants and nurses being sure that what they are dealing with is a slow process along with those employed by the Department of Works and Pensions, whether they understand epilepsy at all. When the workload became unworkable the experienced staff leave their positions obviously creating further positions and further training is required. Was this the poor sightedness of the trust or the result of underfunding? Decisions have to be carefully thought through. With more than 600,000 people in the country with epilepsy and at least 68 people a day told that they have the condition how believing that too much which is spent beggars belief.

It was during the past year that one of the original members. Freda Chapman died. When we became an independent charity named for Kent at Epilepsy HERE. We are also available at Help Desks at 3 hospitals at the same time as our consultants or Epilepsy Nurses are running a clinic and Freda was there in the background helped at the Helpdesk in Canterbury from time to time. She was a signatory on cheques too. She is missed she was one of the founder members to support us in dealing in this part of the country.

The continuous sales of Christmas cards went on from the middle of September until Christmas at many venues though Kent. Most weekends we were involved as well as at Help Desks. We raised high funding and were invited to an evening with Epilepsy Research because of the number of their Christmas cards we sold. They talked about the new research projects awards and the subjects they will cover. It was most interesting.

We give training in Care Homes and Canterbury College who said our training was extremely good. Funding is never reliable for large voluntary institutions; everyone appears to be struggling with funding throughout Kent

Minutes of the re-convened Annual General Meeting held on Monday 6th November 2017
At Headway House, Kent & Canterbury Hospital

The Chairman's report having been previously circulated was adopted without comment

The accounts for the year ended 31st March 2017 having been independently examined were presented to the meeting and adopted

Monica Elizabeth Kendall was re-appointed Chair of the Charity

Colin Robert Barnes was re-appointed as Secretary

Roger Kendall was re-appointed as Treasurer

Melinda Barker and Patricia Dickson were re-appointed as trustees of the Charity

Julian Gower the Independent examiner was thanked for his services.

There being no other business the meeting then closed

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 enable us to keep up to date with advances in research and treatment. We have registered on Connect Well service 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 over £800

Treasurer's Report

A current account is held at NatWest Bank Herne Bay where all deposits are made a small residual account is held at Co-operative Bank PLC Skelmersdale Merseyside .The accounts requires the signature of two officers for withdrawals and all major expenditure is sanctioned prior to disbursement by the Management Committee. T

During the year a grant of £3000 was received from the dissolution of Ronald Cruickshank's Foundation and as sum of £422 was received from the closure of the Joint Epilepsy Council 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.

Whilst these amounts increased our level of reserves neither source will be available in future and new sources of funding will need to be found in the future. 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. The Epilepsy Society continues to provide us with a large number of information leaflets free of cost. For the first time in many years the accounts reflect a surplus of income over expenditure.

The accounts reflect the cost of office space at Whitstable United Reformed Church, Middle Wall, Whitstable and we again 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 2019 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 over £800 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 over a thousand hours of volunteer effort to give information, advice and training on epilepsy throughout East Kent

Income and Expenditure report

Income	Total	Restricted	2017
Donations	762		557
Donation Frinstead Village Hall			227
Grant Canterbury City Council	500		
Donation Yorkshire Building Society			100
Fundraising events	100		54
Grant Ronald Cruickshanks Foundation	3000		1000
Membership refunded	422		55
Miscellaneous	150		
Sales Epilepsy Society	65		
Training	250	250	221
	5249	250	2214
 Expenditure			
DBS checks			33
Fundraising expenses	62		24
Health and Safety			130
Insurance liability	180		179
Membership	40		
Miscellaneous	38		24
Printing	232	100	137
Promotional items	45		69
Rent meeting room	125		160
Rent Office	960		960
Stamps postage	56		56
Stationery	17		70
Telephone/Internet	3		661
Travel expenses			52
	2098		2555
Surplus/(deficit)	3131	100	-341
 Balance Sheet			
		31/3/18	31/3/2017
Balance at Co-operative Bank		601	532
Less creditor			
Balance at National Westminster Bank		6,366	3,268
Available Bank Funds		6,967	3,800
Petty Cash		33	69
Total Funds		7,000	3,869
 Balance General Fund			
		4,465	1,971
Balance Restricted Training Fund		2,388	1,796
Balance publicity fund		147	102
		7,000	3,869

Notes to the Accounts

- 1) Current funds are paid into an account at Natwest Bank Herne Bay and a small Reserve Account is held in a Community Direct Account at Co-operative Bank PLC, Skelmersdale All 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 £3,000 from Ronald Cruickshanks Foundation has enabled us to meet our core expenses and increase our reserves.
- 3) The membership fees paid relate to IAPO
- 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. A printer was added in the year under review to replace an item which had become unserviceable.
- 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