



Annual Report of
Epilepsy HERE (Help, Education and Research for Epilepsy)
for year ended 31st March 2017

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 2015 have served as
trustees**

Monica Elizabeth Kendall — Chairperson

Colin Robert Barnes— Secretary
Elfrieda (Freda) Chapman

Roger Kendall A.C.I.B. — Treasurer

Melinda Barker

Patricia Dickson

William Gower

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: National Westminster Bank Whitstable 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
Ronald Cruickshanks Foundation



Epilepsy HERE

Notice of Annual General Meeting to be held at Canterbury Umbrella Centre on Tuesday 4th July 2017

AGENDA

- 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 Lord Mayor Councillor Rosemary Doyle and Lady Mayoress of Canterbury Jenny Yonge and Ruth Hulbert, Lead Research Nurse, East Kent Hospitals University Foundation NHS Trust
- 7.35 p.m. Talk by Ruth Hulbert
- 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 2016
- . 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. Raffle and Refreshments.
- 9.00 p.m. Close

Epilepsy HERE (Help Education and Research for Epilepsy)
Charity No 1079172

Annual General Meeting 2016

Present :	The Lord Mayor of Canterbury – Mr George Metcalfe	
	The Lady Mayoress	Lillian Metcalfe
	Epilepsy Nurse in Charge in area	Denise Wilkes
	Colleague	Julie
	Treasurer	Roger Kendall
	Chair	Monica Kendall
	Julian Gower	
	William Gower	Secretary
	Colin Barnes	Trustee
	Melinda Barker	Trustee
	Patricia Dickson	
	Lawrence Ward	
	Pamela Bramley	

The Lord Mayor Mr George Metcalf started his talk stating that there is an army of volunteers working on behalf of so many charities in the country around 3 million all doing necessary work which would cost the country a great deal of money. He admired our cause and the way we work. He talked about a special fund of the Lord Mayor and urged us to look this up on the internet soon as the date of its closure is soon to close it for the year.

Denise Wilkes went on the talk about her experiences which was limited in comparison to our own. She went on to say that they are interviewing for a replacement in Tracy's capacity? In the meantime Sean Seale is doing the coordinating which Tracy was doing.

The above mentioned Tracey Truscott's resignation as well as her numerous achievements for this area. That Sean Seale has taken over the administration until her successor has been appointed as there are still so many of the patients in need of specialist care. They also mentioned that they are not only in charge of epilepsy in this area but diabetes, dementia and lymphoedema.

Monica Kendall gave a report highlighting points made in the printed Annual Report

- Great strides have been achieved in this area and we sincerely hope that this will continue
- As a group in the Canterbury East Kent area covering most of Kent we are helping those with epilepsy and their carers, family members or paid workers in their homes and in care homes to know more about epilepsy
- We managed to sell Christmas cards for research in epilepsy totalling £980.00 at the end of last year
- We started the 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 each month at the United Reformed Church in Whitstable where our office is. The times we are manning the office are from 10.30 to midday then from 2.00 – 4.00 pm not Thursday because of the Help Desk at Ashford in the morning
- We continue to hold a helpdesk at Kent & Canterbury Hospital and the William Harvey Hospital in Ashford as well as brochures at Queen Victoria Memorial Hospital, Herne Bay and the Cottage Hospital at Faversham where some racks have been set aside for our use where 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 websites direct individuals and their carers

if they are able to access the internet if they are able to access the internet continuously advancing our own knowledge on the websites

- A team of specialist nurses are well established in this area enabling people with problems to make appointments to see them. We are still members of other organisations who are a source for information. The help desks are funded by National Society for Epilepsy which is undergoing a re-naming now known as epilepsy society. This is the largest research organisation into the epilepsies in the UK. Help Desks are manned by members of this group

Chairman's Report

It has been quite a turbulent year for many charities ourselves included not knowing what future charities will be presented with this after the difficulties that many charities including those set up as Trust funds to enable many charities to survive the road railing of funds with an interest rate so low how can we expect to survive. With the JEC Joint Epilepsy Council not continuing as it became too expensive to maintain. Funds were freely available to enable us to attend venues to explain about newer treatment but now the pot appears to be drying up.

We continue as members of the All Party Parliamentary Committee set up for those with an interest and focus of the needs of those with epilepsy, originally set up with Earl Howe he has since become a member of the cabinet barring him from service in this capacity then Laura Sandys MP for Thanet East in the Chair and now Valerie Vaz MP for Walsall West. It enables us to meet and become known to other members and them to us and members and delegates from all around the country with concerns for those with epilepsy as well as speakers in their field of expertise in epilepsy. The last meeting was called together with the All Part Parliamentary Committee for Diabetes, Sickle Cell Anaemia, Coeliac Disease chaired by Keith Vaz discussing the non implementation of schools of special needs such as dietary needs of the children in their care schools argue this is owing to the lack of funding to enable this to be practiced.

Throughout the year with the cuts in the epilepsy field we lost our original Epilepsy Nurse who nurtured the services to epilepsy. Originally the first Sapphire Nurse in this area who was paid for initially by Epilepsy Action. The monies were raised by them after which monies were raised for 5 other nurses to the East area during the time Tracey who was instrumental in the Epilepsy Services in East Kent which now includes West Kent and we are 1 nurse down. We were able to work with Tracey and the neurologists to build up this service as a team. We attended some conferences regarding epilepsy and were taught about the new drugs and about cell formation for those without the essential cells to help them overcome their seizures, how they are able to assist in their formation and know some of the reasons why certain drugs work for some people and not in others. We were invited to an evening at Leeds Castle with our host Perry's Chartered Accountants where many other leading charities all over Kent were invited too and getting to know other charities in the area was most useful.

As well as the newly introduced coffee breaks in the daytime at the United Reformed Church at Middle Wall in Whitstable for those unable to come to the evening meetings owing to other members of the family who need to have the presence of the members we have had some very interesting speakers this year at these especially Dr Trudy Thomas from Medway School of Pharmacy about the interaction and side effects of drugs. Her talk was very well received. She talked about the revival of Cannabis with the part of the plant that gives the controversial 'highs' is extracted as it can be helpful to those whose epilepsy cannot be controlled by conventional prescribed drugs.

We attended Frinstead Village Hall at an Autumn Fair where we distributed information on what the group does. There were other stalls selling books, flowers, plants, tea coffee, cakes and cold drinks it was well attended by the surrounding villagers and I was asked to give a talk about epilepsy and what the group does. As the event drew to its close we were presented with the monies that they had made on that day. Although a

small village they regularly hold these events and donate the proceeds to worthy causes. It has been one of the venues where we have been selling Christmas cards each year.

The Personal Independence Payment PIP has taken over from The Department of Work & Pensions top ups to those with disabilities. Quite a controversial scheme as their attempts to hold back payments to claimants makes the claims almost impossible and is still controversial.

We did very well selling Christmas cards for the research institutes for epilepsy, but I will let Roger go into detail on this front.

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 25000 hits in the last 6 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 650 followers. We visit our page on most days 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 helpline 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 were co-members of the Joint Epilepsy Council enabled 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 Faversham and attended meetings to discuss the forthcoming recommendations in health services with the implementation of the STP for Kent. We are members of the 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 over 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 £900 in 2016 to 2017.

Treasurer's Report

Current accounts are held at National Westminster Bank as part of the Chatham Business area. The account is currently domiciled at Whitstable. Although not a matter for report in this year the branch is due to close on June 12th 2017. An account is also maintained at Co-operative Bank PLC Skelmersdale Merseyside with a sufficient balance to meet commitments for six months in the event of any unexpected commitments. The accounts require the signature of two unrelated officers for withdrawals and all major expenditure is sanctioned prior to disbursement by the Management Committee. The Treasurer has a debit card to enable him to review the statement and to make withdrawals or purchases up to £100 for day to day office expenditure.

During the year important grants were received from Ronald Cruickshank's Foundation of £1000 and sizable donations were received from Frinsted Village Hall and Yorkshire Building Society Community Fund the level of donations from other sources were maintained with valuable contributions from members and friends. 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. We continue to provide help desks at William Harvey Hospital and Kent and Canterbury Hospitals and travel cost are paid by the hospital trust. The Epilepsy Society now supplies the literature for these stands free of cost to us. Despite all these generous grants and a number of other donations the financial position has required us to call on our very meagre reserves although to a lesser extent than in the previous year.

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

We are members of Red Zebra, National Council for Voluntary Organisations (NCVO) 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 2017 and beyond if the charity is to continue and maintain the present level of activity. This will be particularly so after the current year since Ronald Cruickshank's Foundation have signalled their intention to close at the end of 2017.

We are particularly grateful to personal donors and those who give their time. Their generosity is duly acknowledged. These enabled us to sell some £900 worth of Christmas Cards for epilepsy charities, which engage in research, during the later months of 2016.

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

Income and Expenditure Report

	Total £	Restricted £	General £	2016 Total
Donations	557		557	551
Donation Frinstead Vge Hall	227		227	-
Grant Canterbury City Council	-		-	500
Donation Yorkshire BS	100		100	-
Fundraising	54		54	76
Grant Ronald Cruickshanks (Ronald CruickshanksFoundation)	1,000		1,000	1,000
Interest	-		-	2
Membership	55		55	70
Miscellaneous	-			28
Sale of Pens	-			
Training Fynvola	100		100	127
Sale of Xmas Cards	801		801	980
Training	121	100	21	2
	3,014	100	2,914	3,336
DBS checks	33			
Fees Conference	-			200
Fundraising exp	24			61
Health&Safety(PAT)	130			
Insurance liability	179			174
Membership	-			280
Miscellaneous	24			38
Printing	137			17
Promotional items	69			
Purchase of Christmas cards YE	809			980
Rent Meeting room	160			207
Rent Office	960			820
Stamps postage newsletter	56			162
Stationery(business cards)	70			235
Relocation expenses	-			40
telephone/internet(domain)	661			471
Travel expenses (bus)	52			305
	3,364			3,990
Deficit	350			654

Balance Sheet 31st March 2017

	31st March 2017	31st March 2016
Balance at Co-operative Bank	532	4,732
Less creditor		250
Balance at National Westminster Bank	3,268	
Available Bank Funds	3,800	3,949
Petty Cash	69	135
Total Funds	3,869	4,084
Balance General Fund	1,971	
Balance Restricted Training Fund	1,796	
Balance publicity fund	102	
	3,869	

Notes to the Accounts

- 1) Current funds are paid into a current account at National Westminster Bank Whitstable and we maintain a small balance at 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 £1000 from Ronald Cruickshanks Foundation and other donations 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) Public Liability Insurance was provided by Markel International Insurance Co Ltd. and includes Coverfor Trustees Liability Insurance
- 4) 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 valued at £80 was added in the year under review to replace an obsolete machine.
- 5) 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.
- 6) 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. And the required notice period of 12 months for internet and telephone services.
- 7) We are grateful to the Minister and Elders of Whitstable United Reformed Church for allowing us the continued use of the office on favorable terms