

GRAVESEND EPILEPSY NETWORK

Registered Charity Number 802373

January 2013 Newsletter No 31

CONTACT TEL: 01474 351673

Chairman's Message

Happy New Year!!

Maybe it's not so new, it's already the 10th January and I have only just got myself psyched up to sit down and write this year's message.

What can we say about 2012?

It was a good year financially; we received several donations throughout the year giving rise to a situation where our income was higher than our outgoings. This hasn't happened for quite a few years now.

We have welcomed a number of new Members to the Group meetings. Two of these are raring to go and are bringing new ideas to the table. Welcome to Lee Shiret who is to take on Fundraising and Scott Kidd who is keen on boosting Membership.

Our services continue to be needed and called upon by people to help them deal with the everyday problems of living with epilepsy, and our members are there to provide that support.

During the year training courses were arranged for 2 support workers. Sam Broadhurst attended a 2 Benefits courses and Dave Hall a Grant Application course. Sam in particular is very busy helping people apply and appeal for benefit support, and thanks to the training has a 100% success rate. Just for interest Dave Hall has taken back the Treasurers role as well as doing Funding Applications.

Thank you to everyone that helped to shake a tin during Epilepsy Week in May. Special thanks to Chris Ryan for organising and running everyone around, Lee Shiret and Dave Hall who not only shook a tin in Town, but were also in attendance every day for the stores collections. Absolute heroes. It is this sort of attitude that helps the charity survive financially year on year.

Requests for contributions to the Newsletter have not been widely taken up, so you will find it a bit less demanding to read this year. Hopefully we will get a better response next year! If *anyone* would like to contribute an article at any time they are welcome to do so.

One highlight of 2012 was 3 members of GEN being invited to Downing Street in January by Epilepsy Society to help them celebrate their 120th Anniversary. This was one of a number of events that ES staged throughout the year. Downing Street was a fantastic experience, which was hosted by Samantha Cameron who spoke about the importance of helping people live with epilepsy. This was after her and David's son died with it a few years ago. Towards the end of the reception David Cameron arrived back from Brussels and came straight into the room to talk to many people and express his support of the Society and the work it carries out. As we left, we took the opportunity for photos in front of the door at No. 10. We were not alone, eminent Professors, Neurologists, Doctors and ES Governors, were all standing around like school kids wanting their photos taken. So we obliged and forwarded the photos to them!

Our membership of the Joint Epilepsy Council required our participation in completing a survey on how the JEC should plan for the future. This was after several high profile Epilepsy charities cancelled their memberships. After several meetings in London an agreement was reached on funding and activities which we hope will enable JEC to continue lobbying Parliament and instigate new projects and initiatives.

I have just heard that the 1st coffee morning of 2013 saw 23 people attending. I hope this kind of support continues throughout the year. Without you, things could get pretty lonely!

I and all the Committee wish you a happy, healthy 2013 and we hope to see you and enjoy your company at one of the coffee mornings or at the many events that we are planning during the year.

Fred Savill
Chairman

Susan Griffin

This year we decided to change the venue of our coffee mornings. They are now held at JK's Cafe on Riverview Park and since we have been going there the coffee mornings have been a great success. The coffee and snacks are an excellent price and delicious and the staff are friendly and always ready to help you if they can. The group were so impressed with it we asked if we could have one of our meals there; to our delight the owner agreed to open up in the evening just for the Epilepsy group. A great time was had by all and it's so good, we are having our Christmas meal there! So a big thank you to all the staff at JK's for making our coffee mornings a great success. **SG**

As some of you know Lynn and I man an Epilepsy Information Desk at the Paediatric clinic at Darent Valley Hospital. We work with Dr Kulkarni the Paediatrician who has taken a special interest in children with epilepsy. We have been going along for roughly 2 years now. The clinic is twice a month. But last year the doctor approached us and told us that there were many more children are being diagnosed, and because of this, as from the 16th January, the epilepsy clinics will be every week.

So if you want any Information leaflets or want a chat you will find Lynn or me every Wednesday afternoon at the Children's Resource Centre. **SG**

Our fish and chip supper proved once again to be a great success. The food was enjoyed by all that attended. We would like to thank Livingstone Fish Bar for not only the great food but also being kind enough to deliver it to us piping hot. **SG**

Unfortunately due to the weather our picnic at Woodlands Park had to be cancelled. After phoning everyone to cancel the picnic a while later the sun came out! This year we are hoping to have complete control of the weather and that we will be able to have our annual get together this year! We did speak at the AGM about having a trip to France or Belgium. We would be interested to know how people feel about this. Come and tell us at the coffee morning! **SG**

Our Indian meal at Delhi Kitchen was great, although some of our Members had English food! Although the restaurant hadn't had such a large party before, they were very helpful and attentive. A good time was had by all although Fred's son Paul had a bad seizure halfway through, but I can honestly say that I don't think it was the food that caused it! **SG**

David Hall

Although not as much as in previous years we are still grateful for contributions amounting to £120.00 that were raised through the Give As You Earn scheme and the Easyfunding.org schemes. **DH**

I was very disappointed to miss the AGM on the 1st November. This was due to the fact I was taken to Darent Valley Hospital having had quite a serious fit that morning. The complete story of my "visit" there can be read elsewhere in this newsletter. I hope that you appreciate funny stories, especially one about the hospital that has been nicknamed Death Valley. **DH**

We are again very much indebted to the many people that have donated money to GEN this year. The donations totalled nearly £6,000, and included a £1,000.00 grant from Kent County Council, £1,000.00 from Gravesham Council, £1200.00 from Mark and Shirley-Ann Crane and £1000.00 from Anthony Smith. **DH**

The Flag Day in May for National Epilepsy Week was a great success. The huge total of £1750.00 was collected by Members in the Town Centre, and at supermarkets Sainsburys and Morrisons.

I particularly enjoyed my time standing outside NatWest Bank, especially when a young boy and his mother got off of the 499 bus. She gave him three pound coins to put in the collection box. He looked up at me and asked if I had epilepsy, when I replied that I had, he said "So 'ave I, 'orrible ain't it"! Both his Mother and I just burst out laughing; what else could we possibly do! **DH**

Special mention here to Chris Ryan, who ran around each day armed with buckets, sashes etc and making sure all venues and times were covered; and to Dave Hall & Lee Shiret who collected on all 3 days. **SG**

Towards the end of the year following the very sad death of a popular member, Jamie McGrath who died of cancer, we had the amount of £5,000.00 sent to us by his solicitors. Jamie had very kindly left that amount to GEN as a donation for all the help that he has received over many years. He will be sadly missed by all of us, as he was one of the people who attended our coffee mornings at Sainsburys, always accompanied by his faithful trolley. GEN sent flowers and Lynn, Chris & Susan attended his funeral. **DH**

Chris Ryan

Flag Day this year wasn't just one day; it was spread over 3 days! This is because we had also had permission to collect in Sainsbury's and Morrison's this year.

The week previously, on the Saturday, we had a collection in Gravesend Town Centre with an Information Desk which was 'manned' by Susan Griffin and Linda Jadidi.

We had a rota for the Supermarkets so that there would be someone there all the time collecting and there were lots of volunteers. **Thank you to one and all who gave their time for this.**

So, loaded with our buckets with notices on them that David Griffin had designed and printed, our sashes on and our stickers, we were well armed to catch the public's eye- and we did!

From pennies to pounds to £20! Also a few foreign coins as usual! We made the grand total of £1750!

It was all good fun too, the wind blowing at Morrison's was a bit chilly but when the sun came out I managed to get a few 'rays'. We were all competing with each other and swapping places trying to collect the most!

A lot of us agreed that the Supermarkets were a good place to be and hopefully we will be able to repeat it again next year.

As a matter of interest, Asda refused our request to let us collect! **CR**

After trying a few different venues for our coffee morning I think we have found 'our niche'.

The library was a bit squashed and it always fell on someone to make tea and coffee for everyone else which wasn't the idea.

Next we tried Elite Venue at Kings Farm but some people found it awkward to get to so..... We tried JK's cafe at Riverview Park and everyone seems to be happy. The people are pleasant, the food is tasty, the price is good and most of all I love their coffee! **CR**

We also had one of our meal nights there. They usually close at 3pm but opened again just for us at 6.30pm and we had the place to ourselves. We had all pre-ordered our meals and it came up piping hot and delicious. We all enjoyed it so much we asked if we could have our Christmas meal there and they said yes! **CR**

It was on Friday 14th December 2012 and there were 37 of us all sitting with festive tablecloths and crackers at the tables. We had an excellent Christmas meal with a choice of Turkey or Roast Beef with Apple pie with cream, custard or ice cream to follow. When we had booked we were quoted the price of £9.50 each for the 2 courses. But they really did us proud by serving a delicious home made soup to start and coffee or tea to end. All for the same price! David Reely treated us all to individually wrapped Christmas cake and we had a lovely evening.

Hope to see you there for coffee in 2013 on every other Thursday morning. **CR**

I for one really enjoyed the talk on Gravesham and Chalk. There were lots of things I learnt about the areas that I had never realised, even though I've lived here for 36 years!

Christoph Bull the historian made it very interesting and as he was born locally was very interested himself and it showed. He gives talks on lots of different areas and I hope we can have him back another time. Don't miss it if he does. **CR**

Stewart Marshall

On the evening of Wednesday July 12th 2012 fourteen of us, attended a Charity Dinner at the Upchurch Golf Club. Two charities were nominated this year, one being Gravesend Epilepsy Network (thank you Bryan!). The Dinner is the brainchild of Mark Crane (Matthew's father) who runs this event annually for charity.

As usual the event was very well attended. The dinner was delicious, especially the lamb shank!

A number of star guests were on hand to entertain us, they included PAUL WHEY the golfer, NEIL (RAZOR) RUDDOCK one time footballer who bought along his glamorous page 3 wife, JOHN ALTMAN (Nick Cotton) the actor from 'Eastenders' and BI-GEORGE, a Boy George lookalike, who fooled quite a few people! The star turn was BOBBY DAVRO, who brought the house down! He was brilliant!

There were over 80 prizes in the raffle, and the evening was rounded off with a charity auction of sports memorabilia.

Like last year, with so much going on, things were running behind time at this point. Nonetheless, having said that, I think everyone left the venue feeling that it had been a jolly good evening, and two charities had benefited from the occasion.

Two days later Fred & Lynn received visits from Mark & Shirley-Ann Crane who presented them with the magnificent sum of £1,300! So a big thank you to them.

Here's to the next one! **SM**

Lynn Savill

Huge thanks this year to our generous benefactors who include Gwen & Fred Savill Snr, Elaine & Richard Taylor, Chris & Jim Ryan, Joan Silverton, Lillian & Alan Gipson, North Downs Rotary, The Sisters at the Methodist Church, Peggy & Sharon Howland, Veran, Georgia, John & George Heaver and the Residents of St Gregory's Court who sent us a donation at Veran's suggestion. These donations make such a huge difference to us. We can help so many people, however small a donation. It means that we can send out literature free of charge to someone at the end of the Helpline, who are perhaps distressed at a diagnosis of epilepsy. The last thing on their minds would be postage and packing costs as well as the cost of literature. And thanks to these donations we don't have to bother them with this. Heartfelt thanks for this. Each one of you have helped a huge number of people to realise that they are not alone. **LS**

Thanks to our dedicated stamp collectors who include Gwen Savill, Chris Ryan, Joan Silverton, Bryan Dann, Janet Berrie, Sheila Marshall, Liz Allen, Sandra Avis, Maggie Lendrum (and friends) and Louise Sheldon. Susan & I are taking 3 large bags to the National Hospital for Neurology at the beginning of February. They will be sent free of charge to the Chalfont Centre for Epilepsy where they will be sold in bulk to collectors all over the world. The money raised is used for research into Epilepsy. SO important. Did you save YOUR used stamps at Christmas? Still time to add to them! **LS**

I have included a letter that you may like to give to your GP or Pharmacist. Professor Ley Sander, Medical Director at the Epilepsy Society has written it. It is about how some people can have breakthrough seizures if their medication is changed from one Drug Company's product to another. It is important that you are kept on the same make up of medication. Your GP or Pharmacist will deal with this for you if they are not aware of the ruling already. **LS**

There are a number of drugs that have come off patent. This means that the licence has run out for the company that originally made them. Once off patent any Pharmaceutical Company can manufacture the drug. This is why the above is so important. The drugs off patent are Keppra, Topamax and Epanutin. **LS**

Latest figures for the amount of children under 18 with epilepsy are 60,000! Enough to fill a football stadium. **LS**

People who take Epanutin will have noticed a change in the packaging. This is because it has been taken over by a different drug company. The name 'Epanutin' will gradually disappear and the new name will be 'Phenytoin Sodium Flynn Hard Capsules'. Rather a mouthful! If you are worried and have any questions about the changeover call Flynn Pharma's Helpline on 0800 0778566. **LS**

Tegretol Prolonged Release which used to be called Tegretol Retard is also having a change to their packaging. They will now come in a square box with square blister packs. The medication remains unchanged. Any questions for the drug company that make them, Novartis, can be called on 01276 698370. **LS**

For a year now the DVLA has dragged their feet about new rules on driving for people with epilepsy. There have been a number of proposals regarding seizures which do not affect a person's consciousness. Also, isolated seizures that may occur because of a drug change. But we're still waiting. Government moves sooooo slowly.....**LS**

I know that I repeat it every year but.....if your epilepsy is not controlled you could qualify for a free bus pass. Get in touch with Susan and she will arrange a letter stating that you have epilepsy. You then take this to the local library or Civic Centre, with 2 passport photos and it is issued after a few days. **LS**

Sam Broadhurst is doing an amazing job claiming benefits for people with epilepsy. GEN paid for his training and he is using it to full effect! He has completed numerous DLA forms for people and has had excellent results. His last Course was regarding the Government ceasing DLA and going over to PIP (Personal Independence Payment). He fears that it will discriminate against people with epilepsy. Do give Sam a call if you'd like to know more. **LS**

There is a new epilepsy drug for adults called Fycompa/Perampanel. It is currently only to be used as an add-on drug for partial seizures. **LS**

If you have photosensitive epilepsy and are using Gatwick Airport it is advisable NOT to use the new DIY scanning machines. They work on facial recognition, but if not immediately recognised a light increases which may trigger a seizure in people with this type of epilepsy. **LS**

A new, emergency medication carrier bag has been launched by a mum whose daughter has been diagnosed with epilepsy. Go to www.medpac.co.uk to see the range that Jayne Tarrant has created. **LS**

If you have epilepsy and are looking for insurance Susan has a list of Insurers who do not load their premiums. This includes insurance for travel, accident, driving etc. Give her a call and she will send you a list. Or see us and collect the list at Darent Valley Hospital on Wednesdays. **LS**

Thanks to a welcome donation to Epilepsy Society, Elizabeth Allen was invited to Downing Street! This was to celebrate ES's 120th Anniversary year. Lizzie has had help from the Chalfont Centre for Epilepsy where ES is based in Buckinghamshire. She was a patient there during 2012 when Prof Ley Sander tried her on a new drug for her epilepsy. Lizzie had her hair and makeup specially done for the event with a new outfit. She looked lovely-and Ley Sander said so! She saw David & Samantha Cameron and ended the evening by having her photograph taken on the steps of 10 Downing St! **LS**

We wish David Reely all the very best as he goes into hospital for an operation on his knee. **LS**

Georgia, and John Heaver and their family hosted a stall at the Invicta Club in Gravesend Town Centre. Veran was bitterly disappointed not to have raised more. This was due to a really horrible, rainy day when not too many people were in the Town. We thank everyone of the Heaver family for continuing to fundraise for us. This year they raised £102! **LS**

To celebrate 'Purple Day' the Joint Epilepsy Council (JEC) arranged with 2 MP's who have epilepsy, for a climb to the top of Big Ben. People with epilepsy have always been banned from doing this. But the MP's Laura Sandys and Paul Maynard fought the ban and won! JEC arranged a photo opportunity to publicise the event and asked for volunteers. GEN put forward Kyran Broadhurst and he was chosen! He is a very fit young man after playing rugby for years-and he needed to be fit as there are 334 spiral stone stairs! He was then able to take in the views of London below. Well done Kyran! **LS**

Our longest and oldest Member, Dennis Allen, celebrated his 90th birthday in November. GEN bought him a cake to mark the occasion; and then Vav walked in with a beautiful hand made one! We had photos, drinks and cake after the business of the AGM was completed. Congratulations Den! **LS**

We have heard that a new drug 'Trobalt/Retigabine' has been banned in some areas because of its high cost. Please let us know if you have any problems obtaining it. **LS**

Do call anyone on the Committee with any ideas or events you might like planned. The more input the better! **LS**

Fred Savill

We have had a heavy year financially with equipment. Our Telephone Helpline service ceased for a couple of days when our 15 yr old answer machine gave up the ghost. Also Dave Hall had lots of trouble with his printer trying to print out grant forms. So we had to spend some money and buy new. I consider that we do very well equipment wise and are quite frugal in outlay. Lynn shopped around to get good deals and both Argos and Ryman's came up trumps. We were, as a charity, able to get 20% off at Ryman's. Let's hope these pieces of equipment last as long! **FS**

Lynn & I did a talk at North Downs Rotary during the year. What a lovely group of people! They showed interest in lots of different aspects of epilepsy and a short time after my MD, Ralph Smith, donated £250 to GEN! **FS**

Lynn typed out and printed small leaflets about GEN. We had an idea a number of years ago to ask Pharmacists to place these leaflets into the medication bags of anyone collecting anti-epileptic drugs. This was to let people know that there was an epilepsy support group in the area if they needed help, support or information. There has been a good take up on this with the pharmacists. However, we would be interested to hear if you have received a leaflet in with your prescription or if they were being nice just to get rid of us! **FS**

I know that many of our Members will want to send their congratulations to Professor Ley Sander on becoming the Medical Director of Epilepsy Society during their 120th Anniversary year. He takes over from Professor John Duncan who has held the post for the past 14 years and who is moving on to carry out equally important work at the National Hospital for Neurology. **FS**

I have recently had to complete a form for Kent County Council informing them of how we spent the £1000 grant they awarded us. This wasn't difficult to do as with the outgoings for printer, telephone answering machine, postage etc etc it is spent already! **FS**

Again, the Committee & I wish all Members and friends a happy, healthy 2013. **FS**

GRAVESEND EPILEPSY NETWORK
Dates for 2013

January

- 10th Coffee at JK's Riverview Park. Gravesend. 10.30
24th Coffee at Riverview Pk 10.30

February

- 7th Coffee at Riverview Pk 10.30
21st Coffee at Riverview Pk 10.30

March

- 7th Bring & Buy Sale 7.30 Day Centre. Clarence Row. Gravesend
21st Coffee at Riverview Pk 10.30
28th Meal at Delhi Kitchen 7pm

April

- 4th Coffee at Riverview Pk 10.30
18th Coffee at Riverview Pk 10.30

May

- 2nd Andy Smith Epilepsy Specialist Nurse. Clarence Row. Gravesend
13/14 Collection in Morrisons
16th Coffee at Riverview Pk 10.30
30th Coffee at Riverview Pk 10.30

June

- 6th Coffee at Riverview Pk 10.30
15th Flag Day in Gravesend Town Centre. Please help if you are able.
20th Coffee at Riverview Pk 10.30

July

- 4th Coffee at Riverview Park 10.30
18th Coffee at Riverview Park 10.30
20th Trip to France or Belgium?

August

- 1st History Talk Day Centre. 7.30
15th Coffee at Riverview Park 10.30
29th Trip on 'The Waverley' paddle steamer

September

- 12th Coffee at Riverview Park 10.30
27th Meal venue to be arranged

October

- 10th Coffee at Riverview Park 10.30
24th Coffee at Riverview Park 10.30

November

- 7th AGM at Day Centre. 7.30
21st Coffee at Riverview Park 10.30

December

- 5th Christmas Drinks & Eats. Day Centre. 7pm
20th Christmas Meal. Riverview Pk. 6pm

GRAVESEND EPILEPSY NETWORK
Registered Charity Number 802373

Membership Form

I/We the undersigned wish to become members of the **Gravesend Epilepsy Network** for the year of 2013.

Attached is one year's membership fee of £5.00 per family for the year.
(Cheques made payable to Gravesend Epilepsy Network)

I/We would like to be reminded of social events and agree that my/our name(s) and telephone number(s) be given to the Events Organiser for this purpose. (Tick/delete as required)

I/We consent to Scott Kidd being informed of our Membership of GEN. (Tick/delete as required)

Name/s _____

Address _____

_____ **Postcode** _____

Telephone Home _____ **Mobile** _____

The Data Protection Act 1998 requires us to inform you that information you have voluntarily given (ie. name, address & phone number) is stored in closed confidential paper files. There will be only limited access to these. The information held would not be sold or given to any other organisation.

Susan Griffin is our current Events Secretary. She will need to have your name & telephone number so that she can contact you about social events. Please mark above to give consent OR delete the sentence if you do not want that information given to her.

Scott Kidd is our new Membership Secretary. He would like names to know who has joined as a Member of Gravesend Epilepsy Network.

Please send completed form to:-
Lynn Savill MBE
13 St Georges Crescent
Gravesend Kent
DA12 4AR