

GRAVESEND EPILEPSY NETWORK

Registered Charity Number 802373

January 2010 Newsletter No 28

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Chairmans Message 2010

2010 is upon us with a New Year and new Decade. We have faced many changes and challenges over the years, and we look forward to whatever challenges the coming year has in store.

2009 saw a change in our group meeting arrangements, from formal monthly meetings to fortnightly social get togethers. We were unsure how this arrangement would work, but it has proved to be very popular and very well supported. Members seem to socialize more and keep in contact between gatherings.

We have been shocked by the deaths of 2 staunch supporters in 2009. Firstly Sarah Dowe died of cancer in July, after a very short illness, and then Jean Marshall in November from her epilepsy. We send our deepest condolences to both families.

JUST in case you have not heard, Lynn has been named in the New Years Honours List and been awarded an MBE for Services to people with epilepsy. She is very embarrassed, shocked, amazed and delighted about the award, but also mystified, as she does not think that she has done anything to deserve it. However, the many thousands of people that she has helped over the last 28 years think otherwise, and many of the telephone calls, letters, cards and emails congratulating and thanking her for her help are very moving. No one really understands how much Lynn has touched all these peoples' lives, as everything she does is in strictest confidence. Lynn has said that she will be using her new found celebrity status to promote better awareness, understanding and funding for epilepsy issues.

As is usual, at the last AGM held at the Day Centre in Clarence Row last November, the Committee and Members agreed a programme of activities for the coming year. We do our best to make it as varied and interesting as possible, but are always open to suggestions for other activities to add if you have any ideas.

I realize that I may be getting boring, but I would like to thank all the Committee for the work that they put in during the year, and also the Members for their support of our efforts. If it were not for you everything that we do would be meaningless.

Well I have run out of things to say (No, honest!), so I will stop here. Members of the Committee have submitted articles for this Newsletter. I hope you get time to read it as a lot of effort is put in by Lynn badgering us for our reports, editing and then putting it all together and finally publishing and posting to over 300 contacts, So you had better read it, 'cos we will be asking questions!

May I wish you all a happy, prosperous and above all, a healthy 2010.

Fred Savill

Our army of used stamp collectors is growing! Our thanks go to Bryan, Lizzie, Louise, Chris, Sandra, Paul & our friends at Blenheim Grove, Joan, Nigel, Dave, Fred and Jamie. (Apologies to anyone that I have missed out.) We donate the stamps to the National Society for Epilepsy who sell them by the ton. The money raised goes towards epilepsy research. **LS**

This time last year saw Louis Gauci in hospital. After many years of pain he was admitted to the world renowned Orthopaedic Hospital at Stanmore Middlesex. There, he had major surgery on his spine. It was a worrying time for the family but Louis astonished everyone, including staff, by making an amazing recovery. It is good to see him free from pain and back to his old self. **LS**

A dear friend and member for many years, Joyce McGrath, died in February. Although she couldn't attend meetings Joyce regularly sent me long, chatty letters, with all of the latest news of her and Jamie. I really miss her letters. Very often she would enclose a £5 note 'for help towards postage'. I'm sure that she would be so pleased that Jamie is now attending our coffee mornings. Jamie asked for people to give to various charities instead of buying flowers. He presented us with a cheque for £165 which was received with thanks. We will endeavor to put it 'towards postage'. **LS**

On Valentines Day (February 14th) Clare and Darren Davy were married. We drove the Bride to Dartford and I was very surprised to be asked to give the Bride away. It was a great venue and a lovely ceremony. The Bride looked beautiful and the Groom (who also scrubbed up well!) looked very proud. We understand that they are to have their marriage blessed in the Church on their 1st Anniversary. May they have a long and happy married life together. **FS**

Our good friend Bill Dean spent time in hospital last year. We were hoping that while he was there that the Doctors may have discovered why he is in so much pain. But no such luck. He was discharged with no change. We can only hope that there might be some improvement in 2010. **LS**

We welcomed a new member this year when Jean Shaw and her dog Tina, moved from Chatham to Gravesend. She has already made her mark on the Group with her chatter, and is very welcome. **LS**

In April, Ian Hughes, who lives in Dartford with his wife and son, volunteered to run the London Marathon to raise money for GEN. His son has epilepsy and he wanted any sponsorship money raised to go towards helping other people who have the condition in the local area. He accomplished the course in 5 hours & 46 minutes, and raised £1,251! For this we are really grateful, and send our heartfelt thanks to Ian and everyone who sponsored him. **DH**

In May the Freemasons Cobham Lodge Ladies held a Dinner Dance which made £250. The Gentlemen in the Lodge then made this up to £400 and it was donated to us. We are so grateful for these donations and not a penny is wasted. We sent our sincere thanks to them, and informed them that we would use the money to help families in the local area. **DH**

Each yearly newsletter I seem to report a new drug being licensed for epilepsy (not that I'm complaining!) The name of the new drug this year is Eslicarbazepine Acetate (Zebinex).

Just for interest, it costs £400 million to develop a new drug!

Last years 'new' drug Lacosamide, is now being prescribed as an add on drug by Consultants across the country. They are achieving good results. **LS**

At the beginning of May, Stewart & Jean, Dave, Bryan and I went to the Woodville Halls and enjoyed '*Home Grown*'. A show compered by Paul James and Paul Harris. The 'Amelia Appleby Dancers' did renditions from the musicals and Billy Knutt sang '*I want to go to heaven*'. During the interval Bryan bought ice creams and showed me how to open the tub and find the spatula, useful information I was able to impart to others in our party! In the second part Billy Knutt joined Paul James to sing as '*The Two of Us*'. There were various performances from Paul James son's group, 'The Soundcasters', 'Simons & Simons', the father and son comedians and 'Fake-That'. Sarah Barker, the former BBC employee turned singer then sang some 1940's numbers. **AP**

The Network's funds were increased this year by regular donations totalling £200.00. This was accomplished through the Give As You Earn scheme. The amounts were sent direct to us by Julie Sheldon £60.00, and S Hayes £140.00.

We would like to thank them both for this regular donation. It is greatly appreciated. **DH**

It was Fred's 60th in May and all of the Group were invited.

With Fred's relatives, friends and GEN it was a great turn-out. A good time was had by one and all. There was good food, good drink and very good company!

The photographs of Fred 'through the ages' had us all enthralled and many people didn't know he was such an experienced pilot.

The disco had lots of people up onto the floor, dancing about trying to get rid of the many calories they had consumed!!

Everyone was in agreement about how lovely it was to all get together. Hopefully there will soon be another occasion (or an excuse) to repeat a great evening. **CR**

Also in May, a dozen of us went to the Day Centre in Clarence Row for a meal. Two tables at the back of the hall had been reserved. There was time to check out items for sale from a goodies stall and some of us made purchases. We sat down to Shepherds pie, carrots and Brussels, followed by fruit on pastry and custard. After each course we were offered seconds and later the ladies came round with ice cream! They really spoilt us. We bought raffle tickets and won a number of prizes. Bryan had been shopping and passed around cherry chocolates. What he didn't realise was they were cherry liqueurs and having eaten one, the drivers in our party wondered what would happen if they were stopped by the police on the way home! Everyone said that it had been a good afternoon. **AP**

There is a change to the Driving Regulations for people that have had *a first and single seizure*. The person must initially stop driving, but can start again after 6 months if 1) You have been assessed by a specialist who agrees that it is reasonable to drive, and 2) No abnormality has been found after EEG and/or brain scan.

As long as you have no further seizures, and you meet all the standard regulations to drive, you will get a full licence returned, which lasts until you're 70 years old. **LS**

If you are coming up to being seizure free for 1 year you can reapply for your driving licence. You can do this up to 8 weeks before. **LS**

Don't forget that if your epilepsy means that you cannot drive, I can write a letter for you to take to the local Council enabling you to obtain a bus pass. Let me know if you'd like this. **LS**

In August we had booked a trip on the riverboat 'Princess Pocohontas'. Unfortunately the Captain informed us 2 days before the trip that the boat had broken down! I phoned around to Members to inform them, and also for ideas on what we should do instead. We decided on a picnic on Gravesend Promenade. And what a great day we had! The sun was shining, the Regatta was taking place and everyone had fun. There was a really good turnout of Members, Joan came with her nephew, and Chris and Jim came with their son and daughter in law and four of the grandchildren. It was also Lynn's birthday, so we had the group singing to her and Chris kindly provided a birthday cake.

The men had a game of cricket (boys will be boys), with some missing the ball entirely, even though they had their glasses on (no names mentioned David Griffin!) The food that we all had was very enjoyable and I'm sure that everyone who came along would agree that it would be nice to do the same again sometime. **SG**

It is with great sadness that I have to tell of the death of Sarah Dowe. Sarah was an amazingly good friend and helped me a lot at school when my epilepsy was especially bad. She was a supporter of the epilepsy group, coming along to the dances we used to have, amongst other things. I never called her Sarah though, because of her red hair. She was fondly nicknamed by me as Carrots, and she always answered to it! We had many good times together and great holidays of which I shall always have wonderful memories. Tragically, she was diagnosed with cancer which had already progressed too far for any treatment. She will be sadly missed by everyone who knew her. **SG**

Purple is the International colour for epilepsy. Purple Day was started 2 years ago by a young Canadian girl to increase awareness about epilepsy. The date to wear purple (shall we get some ribbons?) is 26th March this year. If you have a computer you can find out more on www.purpleday.org **LS**

We had a theatre trip booked at the Woodville Halls; it was 'Songs from the Musicals'. When I went to pay for the tickets I was told that it had been cancelled. The group putting on the show had pulled out. A lot of people were disappointed as we were looking forward to it. As soon as something similar comes up I will let people know. **SG**

We were contacted in September by Pauline & Roger Amos. They are a couple that supported GEN over many years when we first started the Group. They told us of the devastating news that their dear son Steven had died after a very bad seizure. Steven attended the St Piers Hospital School at Lingfield for a number of years. When he reached 16 years of age, he was delighted to come home to Mum, Dad and Sister Lucy. Steven's epilepsy was always a problem. No drug seemed to help. But whenever I saw Steven at Darent Valley Hospital he was smiling. That is how I will remember him. Our thoughts and prayers are with all the Family.

Pauline and Roger asked for donations to GEN instead of flowers and gave us cheque for £550. Our sincere thanks go to them, their family and friends. **LS**

We have just been contacted by a friend of Pauline & Roger who says that he would like to run the 2010 London Marathon in memory of Steven. Stephen Dring is looking for sponsors and tells us that all money raised will be donated to Gravesend Epilepsy Network. We are enclosing a sponsorship form in with this Newsletter. **FS**

In October it was our Treasurer, David Hall's 60th Birthday (Is that 60 years old or 60 years young?!). He decided that 16 of us would go to the 'Reliance Fish Restaurant' for a fish & chip meal. A most enjoyable meal followed, with the usual bandying of words! My own, personal view though, is that the 'Reliance' is not as good as it used to be, and that they cannot really cope with a large number of people at the same time. Oh, for the days of 'Maxfields' of yesteryear (20 odd years ago?) when they used to be able to cope with a coach load of people. So, if there are any Members of GEN who can come up with ideas for alternative eating houses, please form an orderly queue in front of Susan! **SM**

Drug companies that manufacture anti-epileptic drugs have been told by the European Medicines Agency to include warnings in these products. This is that *some* of the drugs can cause *some* people, to have suicidal thoughts. The product information for Levetiracetam (Keppra) and Zonisamide (Zonigran) already carry this, but the problem is thought to be more widespread. If this is what is happening to you, if you have depression or changes in mood, do see your GP or mention it to your Consultant, who will have the experience to help you. **LS**

Eight of us from GEN attended the Mayors Fashion Show at the Woodville Halls in September, and I for one really enjoyed it. There were adults and children modelling. Clothes included bridal wear, Indian wear and yes girls the best was saved for last, men in kilts! The Mayor thanked everyone for coming along and said that a lot of money had been raised for her chosen charities. **SG**

September saw eight of us attend the 'Mayors Charity Fashion Show' at the Woodville Halls. It was to showcase local companies. Instead of the usual seating, the theatre had tables and chairs and a catwalk coming from the stage. Leaflets advertising the companies were on the tables together with peanuts and nibbles. We checked out various trade stands around the hall and obtained promotional items.

Drinks were purchased from the adjacent bar. 'Bustles and Breeches' (Fancy Dress Hire) began with a humorous look at fashion through the ages from cave men to the future; 'Debenhams' showed off a selection of their clothing; 'For the girlys-from Tracy Baker' presented a range of gowns and evening wear. There were then songs from Maxine. Then 'Eastern Vibes' showed a collection of eastern style garments and fashion accessories. Lastly 'Bridal Wardrobes' presented a selection of dresses and suits. We bought raffle tickets and were fortunate to win a number of prizes. **AP**

In October we had another meal at the Day Centre in Clarence Row. Again two tables at the back of the hall were reserved. We thought as it was a Friday, that we would be getting fish and chips, but we were served up with pork loin steak, baked beans and chips followed by spotted dick and custard! The pork steak was succulent and some in our party eagerly accepted seconds when asked. Later several of us had ice cream. We bought raffle tickets and won a number of prizes, including a bakewell tart that I consumed at home as a dessert after my tea! We all agreed it had been a good social occasion. **AP**

We tried the Carvery at 'The Old Prince of Orange' during the year. They have a small function room which they let us use which was very bright and pleasant. Mixed reactions about the food but well worth the price they charged. And the company was great! **FS**

In October the Group were asked if they would like an exhibition stand at a major Rotary Club Conference. Kevin Bampton, who is one of the leading lights in Rotary and a long time supporter of GEN, invited us to apply for a stand for their 2009 Conference being held at Brighton. The idea was to bring GEN to the attention of all the Rotary Clubs in the South East, in the hope that they would include us in their list of beneficiaries when they distribute the funds they have raised over the past year. The Conference ran over a Friday, Saturday and Sunday. Lynn, Susan, David and I drove down to Brighton on the Thursday afternoon, with a hired minibus full of literature, badges, pens, diaries and anything else that we thought we may be able to sell, in an attempt to get our stand ready. We also had a big tin of 'Quality Street' to entice people onto our stand! As well as these goods I had arranged for 200 of the Epilepsy board games to be delivered by a haulage company directly to the Conference Centre. The games have been stored by the company that I work for in Thamesmead.

We were expecting to have to fill an exhibition stand 9 foot by 12 foot and had the huge poster that David painted for our Anniversary year. We also had an enormous amount of items to display. However, when we were finally allowed into the Hall, we found that it was only 3 foot by 6 foot! So a major re-think had to take place and our 4 brains went into overdrive!

The stand was finally dressed and, even if I do say so myself, it was the best one of all of those exhibiting. And boy, did we make an impact on the delegates! We pushed those games like there was no tomorrow (there wasn't, we had no means of getting any leftover games shipped back for storage!) We hounded anyone that came anywhere near our stand, and ended up being the talk of the conference! We were told that Delegates even spoke about us over their evening meals. At the end of the first day, as we drove along Brighton seafront on the way back to our little B&B, Lynn and I played 'spot the board game'. It seemed that almost everyone had one under their arm as they walked back to their hotels!

All of the exhibitors had to vacate their stands by 3pm on Saturday, although the conference continued 'til Sunday. About 2.30 we gave away the last board game and heaved a sigh of relief knowing that we had taken the place by storm! We not only gave away games about epilepsy, we educated an awful lot of people to the condition at

the same time. We now sit back and wait to see if all our efforts will be rewarded. **FS**

At the end of October the Group was represented at the Brighton Rotary Conference and during that time raised £155.00 in donations. Will and Shirley McGrandles then donated £30.00 to cover the cost of the stall and for this we are truly grateful. **DH**

Fred & I were invited in November to a London art gallery where The National Centre for Young People with Epilepsy (NCYPE) were launching an epilepsy diary for children. This has been needed for a long time in an effort to involve children in their day to day lives coping with epilepsy.

The diary is amazing! It's bright, colourful and eye-catching. Children will love it! There are illustrations on each page and 50 well known illustrators each gave one page free of charge. This included Aardman Animations who produced a 'Wallace & Gromit' illustration. The diary contains lots of interesting facts (did you know that reindeers like to eat bananas?) and funny anecdotes for the children, although there were many adults quoting items too! It also contains easy to understand text, for the children to learn what epilepsy is. The NCYPE Team should be congratulated on an excellent tool and a further way of quashing the stigma of epilepsy.

NCYPE have kindly let us have 2 boxes of diaries. Fred & I collected these from Lingfield last week. These are to be given to the Paediatric Department at Darent Valley Hospital. Let's hope that the children in our area feel special because of it. **LS**

Are you worried about disco lights or flashing Christmas tree lights triggering a seizure? Both these things can be made 'safe' for people with epilepsy by having a slow flash in between. It's only when the flashing is more than 3 per second that the lights cause problems. Disco lights can be adjusted so this doesn't occur.

Someone has told me that they always have a seizure at discos, even though they have not got photosensitive epilepsy. In this case, I wonder whether the thought and the stress of expecting one is contributing, and thus causing, the seizure to happen? **LS**

Members Ray & Monica, Joan and Bill & Peggy go on lots of coach holidays throughout the year. If you would like to know about this kind of holiday or day trip do speak to them. They are a mine of information regarding this. As good as the travel agent anytime! **LS**

Seven of us went to the Woodville Halls in October together with members of other local organisations. We had an invitation to meet our British Army from the Army Presentation Team. GEN was sent identification badges and when we arrived these were logged by a soldier. We then went to the lobby area of the Civic Centre for the Reception where wine, water or juice was served. Soon after, a soldier barked an order inviting guests to 'go into the theatre for the presentation'. 'The British Army Today' is a short film covering aspects of army life. Brigadier IS James OBE, the commander of the army in the southeast region, then answered a number of questions put to him by the audience. A veteran wanted to know why we didn't have National Service. He replied that it takes regular soldiers away from other duties to look after these recruits; something other countries that still have compulsory military service are learning. He added a form of national service is only viable in a national emergency. Another man said his six-year-old grandson was interested in the army and asked when he becomes adult would the army be a good career choice. The Brigadier replied that it would be an excellent choice, the army of tomorrow, like the one today, would have openings in many different occupations and professions. Another person asked about the lack of equipment in Afghanistan and Iraq. The Brigadier said everyone wants more equipment and went on to point out that the army has a range of heavy armoured and tracked vehicles but these can damage village roads and underlying infrastructure, which alienates people who you need to keep on your side. If a threat is perceived as low, the lightly armoured snatch Land Rover is then a better patrol vehicle. This part of the evening came to a close and we returned to the lobby area where light refreshments had been laid out. Lynn spoke to a woman soldier and learned how roadside bombs are disguised and detonated. She also found out that in stamina tests females have slightly lighter packs than the men but to compensate have a longer distance to march! Later on Group Members got into conversation with Brigadier James. Vav told of life in London at the end of the last war and how she saw soldiers marching and how it's different now. The Brigadier said the Americans seemed to be closer to their military. He said when he visited the States, he went to see a baseball game and before the start of the match, the announcer asked Armed Forces personnel to stand for an ovation. He said the announcer then asked any Allied Personnel to stand and receive the same.

At the end of the evening we handed in our badges. The clip was removed, and they were handed back inside an information folder. We all thought the presentation had been extremely interesting. **AP**

It was a huge shock when our regular and long standing Member and good friend, Jean Marshall died in November. Jean has suffered so badly over the years, being in such pain. She was really tired of not feeling well. Thank God, she is now out of pain. Long standing friends and many from GEN were at her Funeral. Donations totalling £205 were given to the Gravesend Epilepsy Network and other charities. We thank family and friends for this. Our thoughts are with Stewart, Mark & Katy at this time. **LS**

Will & Shirley McGrandles are Great Grandparents! Our congratulations to them and their ever increasing family! They surely must be one of the youngest 'greats' couples around? **LS**

We were invited in December to the Community Evening at GlaxoSmithKline in Dartford. It was a bitter/sweet evening as this was the last at this site. GSK are closing in 2012 after 120 years in Dartford.

Members may recall that GSK supported our 25th Anniversary year by donating £5,500 to enable 54 members to have a long weekend away at Hayling Island in Hampshire. They have always been so good to Charities, and their Community Team have worked so hard over many years.

During the evening they have a free raffle with prizes totalling approx £300. We have been extremely lucky over the years, winning our karaoke machine among others things. This year we were blessed again, and won a new camcorder. This is just what we needed as Consultants are asking more and more for video evidence of peoples seizures. We have an older machine which was difficult to copy onto DVD. There was also £50 in vouchers. Sadly, some charities didn't win. Until the end of the evening. The Community Team announced that as GSK had been in Dartford for 120 years, that every charity attending would receive £120 of Argos vouchers!

After buying a memory card for the camcorder, Chris, Stewart and Bryan bought the remaining vouchers. These totalled £135 which has gone into Group funds.

We wish all our friends at GSK best wishes for their future. We will miss them. **LS**

Our Sainsburys coffee mornings continue to be well supported. There were 16 people at the last one! We have a number of social events on the 2010 programme and I will call everyone as each date approaches to find out numbers. Watch this space! **SG**

We had our 'Christmas' meal at the Chinese Restaurant! The snow lay thick and there was a number of Members that sadly couldn't get there. Those who did manage it however, had a great time. We'll try and repeat it during the year, but we'll leave out the snow bit! **SG**

Our 'Christmas Drinks and Eats' saw a turnout of 36 people! It was lovely to see so many old friends coming along to catch up on news. Everyone bought goodies with them to share and a good time was had by all. **SG**

Our Christmas raffle made an all time record of £33. This was all profit as Members donated the prizes. Well done everyone! **DH**

Under new rules if you are over 60 years of age and have less than £16,000 in savings, you may qualify for Council Tax Benefit. If you already receive this Benefit you may be entitled to more help. Your local Council will be in touch. **LS**

There is a website where you can work out for yourself benefits you may be entitled to. Go to www.entitledto.co.uk **LS**

From January 2010 pharmacists have been asked by the Department of Health to substitute expensive branded drugs with cheaper versions. Although essentially the same, the various Pharmaceutical Companies manufacture their drugs in different ways. For people with epilepsy this can be serious. It doesn't matter if a person is already taking the cheaper version, it matters when pharmacists switch versions. So, when you collect medication please take along the box of the previous tablets given and make sure you get the same again.

Elizabeth Allen had her tablets changed to a different version and had 2 very bad seizures as a result. **LS**

Please keep the programme following (cut it out?) as it will act as a reminder of events planned for the rest of 2010. **SG**

May I thank my many dear (and devious!) friends who, I understand, wrote letters of support to my being named in the New Years Honours List and awarded an MBE. It was a big shock, a lovely surprise and I feel very honoured. *I also feel very honoured to have so many good friends.* I received THE letter asking me to attend Buckingham Palace on the 16th February 2010 to receive my award. We intend having a get together with friends later that week. I will let you know the date as soon as possible.

I have had so many lovely cards and letters from people that I have met over the years. It has been wonderful to hear from each and every one. **LS**

COMMITTEE FOR 2010

Chairman	Fred Savill	07936705068
Vice Chairman	Stewart Marshall	01474350901
Treasurer	David Hall	01474745434
Social Sec	Susan Griffin	07518346682
Minutes Sec	Anthony Pinder	01474355537
Hon Member	Lynn Savill	07864955614
Hon Member	Chris Ryan	01474567945

PROGRAMME FOR 2010

January

7th Sainsburys Pepper Hill
21st Sainsburys Pepper Hill

February

4th Sainsburys Pepper Hill
18th Theatre Trip

March

4th Sainsburys Pepper Hill
19th Lunch at Day Centre

April

1st Sainsburys Pepper Hill
15th Sainsburys Pepper Hill
25th St Georges Day Parade

May

14th Shorne Country Park 1.30
27th Sainsburys Pepper Hill

June

11th Promenade Café 1.30
24th Sainsburys Pepper Hill

July

8th Sainsburys Pepper Hill
23rd Fish & Chips at Day Centre

August

5th Sainsburys Pepper Hill
19th Sainsburys Pepper Hill

September

2nd Sainsburys Pepper Hill
18th Coach Trip
30th Sainsburys Pepper Hill

October

14th Sainsburys Pepper Hill
29th Bowling

November

4th AGM at Day Centre
18th Sainsburys Pepper Hill

December

2nd Christmas Drinks & Eats
17th Christmas Meal venue tba
30th Sainsburys Pepper Hill

**Please note that these dates fall on
different days of the week**