



Epilepsy HERE

Registered as a Charity No. 1079172

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Meetings held Monday monthly (except January & August) at Headway House, Kent and Canterbury Hospital, Ethelbert Rosd, Canterbury CT1 3NG at 6.30 p.m.

"Coffee Break" at Whitstable United Reformed Church every third Tuesday each month 10.00 a.m. to 11.30 a.m.

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Funeral of Dr. L Kanagasooriam

Members of Epilepsy HERE joined hundreds of patients, family and friends gathered at Canterbury Cathedral on 18th January for the funeral of a "kind" and "hard-working" Whitstable GP who had worked at Whitstable Medical Practice since 1997 as a GP with Special interest in Mental Health and Epilepsy. They packed out the Quire to pay their respects to father-of-three Dr Lakshman 'David' Kanagasooriam, who died suddenly on December 19 at the age of 61. Speaking at the service, surgery partner Dr John Ribchester said: "He had a sense of vocation. He was never just doing his job, and he was a very thorough "He never lost his enthusiasm. And through his teaching I know that many GPs in training were motivated to adopt his conscientious and caring approach. "He will not be forgotten" Originally from Sri Lanka, Dr Kanagasooriam arrived in the UK at the age of 11 His sons James, 30, and Jonathan, 32, made heartfelt tributes to their father, a devout Christian who had served with his wife and "soulmate" Angeline as a steward at the Cathedral every Sunday for almost 20 years.

There were readings from the old and new testaments by his wife Angeline and daughter Evangeline and tributes from his sons James and Jonathan who said "He would take calls [from patients] in the middle of the night, and drive for hours down Kent's back roads. It wore him out, but it also gave him purpose, and more importantly, was the right thing to do."

The service included hymns sung by the Cathedral Choir, who were joined by ex-choral scholars from Eton and King's College, Cambridge, and an address by the Very Reverend Dr Robert Willis, Dean of Canterbury.

He had been a good friend of our charity will be greatly missed by all those patients with epilepsy who will remember his kindly manner and attention to detail.

February Meeting

Monthly meetings will resume at Headway House Ethelbert Road, Canterbury CT1 3NG at 6.30 p.m. on Monday 4th February 2019 when all will be welcome to join us.

A visit to the House of Commons

Monica had an invitation to a reception celebrating volunteers at the same time thanking them for all the work that they do from the National Council for Voluntary Organisations which was held at the Houses of Parliament on 12th December. Monica attended the party at the terraces of the House they asked charities to talk about what they do and why they do it in order that they are more able to put a face to the name and what they give to the community. Many other organisations were invited and it was not their first time of attending and recognising others from previous meetings talked to those they had previously met. As it was Monica's first invitations she decided to mingle and talk to others not knowing who they were or why they were invited so that was a starting question and went on to what Epilepsy HERE do. Many other individuals had epilepsy in their family and did not hesitate to say so and ask questions. It was a very good opportunity for networking. There were some members at the function with one eye on the screen telling them when they were needed for voting.

Many attending went for charities that they had a link with so she went around talking to those who may have an interest. The evening went quickly. It was a good way to learn about the needs of others and if links with others might be achieved it was a good way to learn about their requirements and the needs of them. She talked giving ideas of links with other charities and the details of other charities known to us, distributing leaflets of our own. In the crowd there were members of NCVS and the opportunity arose to talk with them. To those with family members of friends with epilepsy she was able to give information and re- assurance..

A HAPPY NEW YEAR TO ALL OUR READERS

Financially supported by



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Healthwatch Neurology Meeting

Melinda Barker attended the Healthwatch Kent meeting and has sent the following report.

"I went to the second neurological services which was run by Healthwatch Kent at Strode Park, Herne on the 29 November.

Due to the weather only six people, from Epilepsy Here, Independent Living, Headway, Rehab Occupational Therapist came back to discuss what progress had been made and what else could be done since our last meeting in July. We were joined by Jane Mills a Clinical Specialist Nurse who had recently moved from West Kent.

There was a feeling amongst everyone that once patients have been discharged from their doctor new patient referrals to voluntary services in the area was not as good as it could be, letters either go out but no follow up and sometimes no letters sent out and sometimes the patient is left to defend for themselves. Healthwatch Kent will seek clarity on what the patient pathway is from the commission and understand how the Community Health Trust refers patients to voluntary services.

For an update on the last meeting in July we heard strongly from the patients and professionals about the long delays for wheelchairs and repairs to wheelchairs, with the support from Healthwatch who raised the issue and this has resulted in a lot of activity and service users are now directly involved in improving this service.

We agreed to meet together again in March 2019."

Canterbury Music Makers

Canterbury Music Makers is a charitable society constituted in February 2004 to promote education in and the appreciation of music through the preparation and presentation of public orchestral concerts. The Society meets weekly on Monday evenings from 7.30 to 9.30 following the three annual school terms and normally presents an invited concert at the end of each term. The orchestra currently comprises over 50 members of diverse ability including our Secretary Colin Barnes who plays second violin. We are hoping that their planned concert on 30th March 2019 will be held at Whitstable United Reformed Church where we have our office and that any profits will be divided between the church and Epilepsy Research UK who are a charity set up to raise funds for research into epilepsy. Keep the date free and watch our website

The Kent & Medway Care Record

Recent changes in the law means that all NHS organisations must now legally share information about your care with other professionals to enable this joined up care to happen. The complex picture in Kent & Medway means there are 4 x hospital trusts, 3 x provider of core community services, 2 x providers of community based mental health services Also there are 249 GP practices around 466 social care providers. 394 dentists, 157 opticians more than 335 pharmacies in primary care 2 x Out-of-hours primary care services and 303 privately run residential and nursing care homes In addition a number of people travel from outside Kent and Medway to use services in Kent and Medway hospitals. The plan is

for the KMCR "Regardless of who employs them, health and care professionals will be able to quickly and easily view their patient's digital records (or relevant components of them) from wherever they are, and without the need to navigate multiple systems, regardless of the local health or care provider who holds them."

How will this happen?

The way in which this is going to be done is via the Kent & Medway Care Record which is a computer system that NHS organisations can view and read on a range of devices to help them plan and deliver the health care that you need. Only registered health and social care professionals can read your records and they can only see the elements that are relevant to their role For example, a Care worker visiting someone at home might be able to see that they have recently been discharged from A&E without having full access to that person's entire medical history. But they would be able to see who to contact to find out more if needed.

What are the planned benefits?

For patients:

- Improved outcomes because care professionals have better data about their condition, needs and wishes.
- Reduced delays in receiving the right care in the right place at the right time, and where applicable quicker discharge because care professionals do not have to wait for information to be received from another care setting
- Improved transitions of care that should avoid having to give their details and history each time.
- Assurance that all care professionals involved are aware of their needs and care plans.