



Newsletter 8

November 2016

We hope you and your family are well and episode free and for those in an episode we hope that the episode will end very soon.

Tuesday 29 November 10pm Channel 5 Medical Mysteries - The Boy Who Can't Stay Awake

A documentary following the Harris family in the challenging search for a diagnosis of KLS is being shown on 29 November at 10pm on Channel 5 Medical Mysteries. We would like to thank the Harris family for being involved in the filming and raising awareness of KLS.

Other Raising Awareness

There will also be a health feature on KLS in the Daily Mail early next week. Thank you to all those who have been involved in this.

Thank you also to Janine and Beth Goodier who have taken part in a forthcoming BBC 2 Series to be broadcast in early 2017. We will let you know the broadcast date when it is available.

An article about KLS was submitted to Patient UK, a major online medical resource for patients and health professionals. To read this article [click here](#)

Thanks to everyone who continues to raise awareness. We are often told by new families that they have obtained a diagnosis after seeing an article or TV programme about KLS. Keeping KLS in the media also helps family, friends, teachers, work colleagues, the public and medical profession understand KLS.

We are regularly contacted by journalists and producers interested in KLS. If you would like to be involved in future media projects, [please let us know](#). We will be happy to support you through the process.

Report on Fifth KLS Support UK Meeting 18 September 2016

2016 marks 5 years since KLS Support UK was set up to support families with KLS. Each year KLS Support UK has held an event to support families with KLS.

Over 40 people attended the Fifth KLS Support UK Meeting held in the Governors' Hall at St Thomas' Hospital in London. Thank you to everyone who came from across England including Middlesbrough, Lancashire, Cheshire, Oxfordshire, Surrey, Hertfordshire, London, Essex, Hampshire and Cornwall.

We would particularly like to thank our speaker and medical adviser, Dr Guy Leschziner, Consultant Neurologist and Sleep Specialist. Dr Leschziner spoke about the exciting expansion of the sleep clinic, research and treatments.



Sleep Clinic - The Complex Sleep Disorder Clinic at Guy's Hospital is expanding and will provide increased support to people with sleep disorders including KLS. The clinic has neurologists, a psychiatrist, psychologists, sleep technicians, a sleep pharmacist and a clinical trials co-ordinator to provide integrated support to patients and enable formalised clinical trials. Dr Leschziner spoke about the use of group and individual CBT in treating insomnia and other sleep problems. The NHS have agreed that KLS patients will have longer appointments than the standard 15/20 minutes.

The clinic will take referrals from anywhere in England and, for those unable to get to London, will liaise with local neurologists/GPs

and pharmacists to enable patients to get specialist support and treatments. The clinic works with the sleep clinic at the Evelina London to provide a smooth transition from children to adult service.

Research - Dr Leschziner spoke about his research on migraine and KLS. He had been struck by seeing a number of patients where headaches were a symptom of a KLS bout or where patients had headaches in between bouts or where patients were referred for KLS but were subsequently shown to have migraine with brainstem aura dysfunction and not KLS. Migraine treatment stopped the bouts of sleepiness in the case of patients with migraine with brainstem aura who had been misdiagnosed as having KLS. Dr Leschziner is keen to further research the overlap between KLS and migraine. To read more on this research [click here](#).

Treatments –KLS is currently extremely difficult to treat.

Clarithromycin – Dr David Rye in the United States is looking at the use of clarithromycin to treat hypersomnia. Dr Leschziner said it had not been proven to work for KLS and has some side effects such as abdominal pain.

Lithium- this is a treatment being used and researched in France by Professor Arnulf for severe, long or frequent bouts. It is not generally prescribed in the US. Dr Leschziner says it is an individual decision as to whether to start treatment with lithium. It is relatively safe if prescribed properly but has an impact on day to day life as, for example, regular blood tests are needed. In addition, it is a toxic drug and there is no guarantee it will work.

Triggers -There are huge grey areas around KLS. Not everybody has the same features. The triggers also vary and have only been looked at retrospectively. The ones most frequently documented are alcohol, sleep deprivation, concurrent infection, and for some flights and stress.

Survey - As there are so few patients with KLS in the UK and, therefore, very little UK data, Dr Leschziner thought it would be a good idea to carry out a survey. KLS Support UK will be working with him and our other medical advisers on this survey which we will send out in 2017.

There was then a chance to ask Dr Leschziner questions. It was his view that it was better to have flu and recommended travel vaccines than not to. Some malaria tablets were better than others for KLS patients. There was no

connection between POTS and KLS but sometimes POTS was the reason for the KLS like symptoms.

Tea and Q&A

After the talk, there was lots of time for families to meet and chat over tea before a general Q&A. There was an open and useful discussion about practical ways to deal with KLS.

Communication - One family notified a friend when their child went into episode so that friends knew they were not being ignored. Another got to know their child's friends so that the friends could tell them if their child went into episode at university. There was a suggestion of a what's app group for young people with KLS.

Medical - Medical ID bracelets were worn by some people with KLS. A legal Power of Attorney was useful for those over 16 so that parents could talk to doctors and, if necessary, sign consent forms.

Benefits –One recommendation was to ask your consultant to agree to be added to the application form for Disability Living Allowance. Carers' Allowance may also be available for those receiving middle or higher rate DLA.

Care during an episode – A predictable, familiar environment in episode was essential and many with KLS like to do the same activity over and over again such as watching children's films and listening to the same music. It was agreed that anxiety was increased being in hospital during an episode. Another family treated each episode as if it were the last to keep positive. There were also reassuring updates on people who no longer had KLS episodes and were back to leading a normal and full life, studying, working and having families.

Research

In the UK

KLS has been selected as one of the rare diseases to be researched by Genomics England. If you would like to take part in this important research, please let us know and we will put you in touch with the researchers. KLS is

also part of the NIHR Bioresource and to take part in this please contact [Dr Gerome Breen](#).

In the US

The KLS Foundation have provided an additional grant to Professor Emmanuel Mignot at Stanford University for their research into the genetics of KLS. To take part in this research, which is open to families throughout the world, [please contact](#) Stanford.

KLS Support UK New Trustee

We are delighted to introduce Danielle Harris who was appointed as a new trustee of KLS Support UK this summer. Danielle has a son who has KLS. If anyone else is interested in getting involved or becoming a trustee, [please get in touch](#).

Fundraising

Thanks to all of you who have been involved in fundraising or have donated to KLS Support UK.

We would like to congratulate Rachael Fox-Jackson on running her first London Marathon to raise awareness of KLS and raising over £700. We would also like to thank the Renouf family for all their running, Easyfundraising and other fundraising initiatives bringing their overall total over the years to an amazing £2750. Thanks also to Tina Dutton and Jog on Buddy for their fundraising runs.

If you would like us to help you in fundraising for KLS Support UK by providing a T shirt or setting up an online account through Mydonate or publishing your event through our Facebook page or emails, please get in touch.

If you would like to donate to KLS Support UK it is possible to donate through [Mydonate](#).

If you would like to donate whilst shopping, it is possible to support us through [Easyfundraising](#).

Funds raised are used by KLS Support UK to carry out its objectives of support, raising awareness and supporting research. We do not receive grants and the trustees are volunteers. Funds have been used to provide KLS Support UK meetings for families, raising awareness at medical conferences and producing leaflets, posters and T Shirts to raise awareness.

Support

We provide support by telephone, email and messaging through the website. We are also happy to put families in contact with one another if requested either personally or through our [closed Facebook group](#). We direct undiagnosed families to doctors with KLS knowledge.

Please make sure your details and doctors' information are current by completing the form on our contact page so that we can keep you updated and provide support. Even if you have completed your contact information elsewhere please also complete the contact form on the website.

We are always interested in receiving your feedback. Please [contact us](#) and we will call you back. If you do not wish to receive emails from KLS Support UK, please [click here](#) to remove your details.

Best Wishes

Adele Clarke, Danielle Harris, Beverley Hunt, Caron Krieger

KLS Support UK

