KLS Support UK

Helping families affected by Kleine-Levin Syndrome

www.kls-support.org.uk

Newsletter 10 March 2018

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.

SAVE THE DATE

16 September 2018 KLS Support UK Family Day at St Thomas' Hospital, London

Dr. Guy Leschziner will be speaking and will update us on the KLS Foundation Conference, which is being held in San Francisco on 23 - 24 June 2018. He will be taking part in the medical conference there with other KLS doctors and researchers from across the world.

This will also be an opportunity to meet up with other KLS families.

Would you like to help on research into diagnosis of KLS?

Jake Begley, a psychology student at The University of Kent, who is on a placement at Guy's and St Thomas Lifespan Sleep Group, is doing research on Exploring the Journey from Onset of Symptoms to Receiving a Diagnosis in KLS. If you have a NHS diagnosis of KLS and would like to find out more or take part in this important and confidential project, please contact him directly on jb917@kent.ac.uk. He would appreciate if you could contact him as soon as possible as he will need to complete telephone interviews by May.

Report on 6th KLS Support UK Family Day 14 October 2017

Thank you to all those KLS Families who attended the Family Day in Brighton.

Over 40 people came along from across the UK.

We would particularly like to thank our speakers and medical advisers, Dr Guy Leschziner, Consultant Neurologist and Sleep Specialist at Guy's Hospital and Dr Cathy Hill, Consultant in Paediatric Sleep Medicine at University Hospital Southampton. We would also like to thank Dr Rebecca Martyn, lead clinical psychologist and Theresa Ross, specialist health visitor, at the Evelina who led a breakout session for the young people with KLS.

Here is a summary of the day.

Cathy Hill

Cathy spoke empathetically about the difficult journey that KLS families have to diagnosis. Diagnosis should be made by experts in specialist centres. Professionals value the input from KLS families whom she recognised are the real experts on KLS.

Care for KLS requires a multi-disciplinary approach as it impacts a patient's whole life. A team is needed including doctors and clinical psychologists. The team can help with educational needs by educating schools/colleges about KLS and the support needed.

Cathy also spoke about the research she is involved in carrying out cognitive assessment in and out of episode to better understand how the condition is affecting patients.

Guy Leschziner

Guy also spoke empathetically about KLS. He explained that he is constantly learning from patients and that the definition and perception of KLS has been developing over the last 10 years. He agreed with Cathy that stories from patients gives a better understanding of KLS**.**

The doctors at the Guy's and St Thomas' Lifespan Sleep Group are collecting as much information as possible on KLS experience and triggers. They are working on setting up a UK database of KLS patients. They will also be producing a questionnaire to understand the British experience of KLS and how best to support UK patients.

The Lifespan Sleep Group manages the transition from paediatric to the adult side so there are familiar faces and continuity of care.

Guy confirmed the need for a multi- disciplinary setting including a dedicated in- house psychologist and psychiatric service which could help with any anxiety and mood disturbance which some KLS patients may experience.

On research, Guy spoke about the 100,000 Genome Project which is looking for a possible genetic origin of KLS. This is proving slower than anticipated but analysis is now being carried out at King's College London and he will keep us updated on any results.

Rebecca Martyn

Rebecca said she had only met 2 or 3 KLS patients. However, from her experience of dealing with many narcolepsy patients she considered there were some comparisons and similarities with narcolepsy which were helpful in looking after KLS patients. She referred to the impact on a patient's life and coping with any anxiety or depression that arises. She thought it was useful for KLS patients to meet other KLS patients.

Issues round diagnosis

Cathy and Guy were concerned about the time taken for families to get a diagnosis. They recognise that it can take too long and that the stress of not knowing is particularly unhelpful.

Questions to the doctors

How many KLS patients have EDS/POTS?

The doctors were aware of one or two but considered the condition unlikely to be linked.

What research is being done on those who develop KLS later in life?

The evidence from France is that if KLS is developed as a teenager, then it's more likely to go into remission. The evidence is that it's more difficult to recover if KLS emerges later in life. But evidence is somewhat limited as there are fewer adult cases.

Why is my sleep monitor so unreliable?

A sleep monitor only records movement, which isn't a measurement of sleep. Sleep can only really be measured in a Sleep Clinic. The best way to measure changing sleep patterns is to have the patient in a Sleep Clinic both in episode and out of episode. A Sleep Study is also recommended to check it's not sleep apnoea or another sleep related illness. A standard EEG test can sometimes give physiological backup to a KLS diagnosis. It's unusual to diagnose KLS just on sleep patterns.

Are there any KLS specialists in North of England?

Dr Paul Redding at Middlesbrough Hospital.
Sheffield Children's Hospital and for adults Dr Gary Dennis at Sheffield Teaching Hospital.

Guy said he would be happy to talk to other doctors in the UK if that would help.

How rare is KLS?

One and a half per million.

Is there any medication that works?

Lithium
Cathy said that Dr Isobel Arnulf in France has seen 153 KLS patients. She has some evidence that Lithium reduces the intensity of episodes and/or reduces the frequency of episodes. However, the causal link is not proven, a "real and

placebo" trial has never been carried out. One person with KLS said that for her it resulted in "lighter" episodes.

Flumazenil
Guy said Flumazenil was only available by injection in the UK, although in the US it is available as a cream/lozenge, which we are hoping to get in the UK soon. It is an antidote to certain drugs, e.g. Valium. Guy said that Dr David Rye, who has been researching its use in the US, was not convinced by it, although it seemed to benefit some people with hypersomnia. It seems to be relatively well tolerated, although it has toxicity so isn't ideal for your average 18-year-old. It is still experimental but the side effects are not as bad as Lithium.

Amantadine
One mother said she used Amantadine to help her child fight off a cold/virus and sometimes felt it warded off an episode. Guy said the experience of KLS patients is extremely useful given lack of proper KLS medical testing.

Exercise
One person with KLS mentioned that exercise, especially in the sunshine, helped him. Some others said they had tried exercise, but it didn't help.

Late Nights/Alcohol
Cathy said the evidence was that late-night parties and alcohol, especially when combined by teenagers, were **Big Triggers** of episodes.

Other problems in assessing treatments
Guy noted that one complication was that just because a patient has KLS doesn't mean that they don't have other unrelated medical issues.

Do you know what causes KLS?

Guy said we don’t know. KLS might be an auto-immune attack on part of the brain causing the KLS sleep patterns. It could also be a genetic problem. The episodic nature of the illness, where symptoms come and go, can be caused by genetic problems.

Cathy explained that it appears that during episode some parts of the brain are underperfused, resulting in a lower blood supply to two parts of the brain: the thalamus, the sensory part of the brain (especially since outside stimuli seem to be dulled during episode) and the front part of the brain which deals with control and order.

In Stanford, Dr Emmanuel Mignot is investigating whether the problem is somewhere in the genome. He has obtained a grant from the KLS Foundation and is running further tests.

Tea and Discussion

There was then tea and an opportunity for families to get to know each other and exchange experiences. Following tea, the young people with KLS had a break out session led by Rebecca Martyn and Theresa Ross to talk about the effect of KLS on their lives. During this time families had the chance to talk informally in a session led by trustee Dr Beverley Hunt.

Some of the things discussed were: how to deal with social isolation, the sleep issues coming out of episodes, how to catch up with what had been missed at school and life generally, anxiety and depression and the impact not only on the person with KLS but the whole family.

One of the main concerns was how to help a KLS child in education. It was important to get the doctor to communicate directly with the school. Diagnosis can help with extra time for exams.

The Family Day ended with a presentation by Connor Walker, who has KLS, on his Project Raleigh trip to Nicaragua. Connor's message was: Don't let KLS rule your life.

Raising Awareness

KLS Support UK took a stand at Sleep 2017 run by the British Sleep Society Conference to raise awareness amongst sleep professionals in the UK. KLS Support UK's leaflet was distributed to 300 doctors and sleep specialists in their delegates' pack.

We would like to thank all those who have shared their KLS experience in the media. A particular thanks to Muireann Ould and her mother Sally for the article in The Guardian.

Thank you also to Emily Shepherd, journalist student at Bournemouth University, for raising awareness through her interesting radio documentary on

KLS. Thanks to Jake Renouf and his family and Meg Gibson for taking part in the programme.

Raising awareness helps others find a diagnosis. 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.

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 Jok (Lachlan) Dunbar who was appointed as a new trustee of KLS Support UK last autumn. Jok 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.

If you are doing a fundraising event for KLS Support UK, please let us know and we will be happy to publicise your event through our Facebook page or website. 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 please get in touch.

If you would like to donate to KLS Support UK we have a fundraising page on 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.

We are always interested in receiving your feedback. Please contact us and we will call you back. If you do not wish to continue to receive e-mails and newsletters from KLS Support UK click here to remove your contact details.

Best Wishes

Adele Clarke, Jok Dunbar, Danielle Harris, Beverley Hunt, Caron Krieger

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