

**Dr Guy Leschziner opened.**

No consultants in this country see enough patients to know for sure what the exact symptoms of KLS are. France has a better way of centralising and diagnosing KLS patients so they have more of an idea. We will be able to refine our view of KLS by seeing more cases. We have made some inroads this year. We do not have a specific KLS clinic but it is the only sleep centre with a transitional clinic taking children through to the adult service. We meet three times annually to look after those transitioning.

Our standards of care include making sure not to miss an alternative diagnosis. A clear case of KLS may be easily diagnosed, however sometimes there may be an alternative or associated diagnosis. We collect information with the aim to define the clinical picture of KLS. We need to refine what KLS is and find the relevant tests to the point of a virtual KLS clinic where standard blood tests would be taken, sleep tests would be done between and during bouts to capture the sleep information. This would all be reviewed by psychiatrists so as to not miss a psychiatric diagnosis. We need the broadest picture possible on every case. And this information would follow from paediatric to adult.

Dr Gerome Breen will talk about research and thanked all those who have consented to Genomics research so far.

There are alternative avenues of research into migraine and KLS into which we are looking, as headaches seem to be very common in KLS patients.

This was followed by a Q & A session.

**Q** Can anyone with KLS register with Guy's and St Thomas' Hospital?

**A** In England any patient can ask their doctor to refer them to the sleep disorders clinic.

**Prof Paul Gringras then spoke.**

Evelina London paediatric services' website is being re-done and will be up and running in the next 4-5 months. We have added KLS into the page about a specialist clinic which KLS will share with narcolepsy because KLS numbers are too small to stand alone. On Tuesdays the under 16s excess daytime sleepiness clinic will be held for KLS, Narcolepsy and other similar conditions. Psychologists and psychiatrists will be available for faster feedback.

Although we did not get the grant to form a centre of excellence for KLS we can effectively operate along these lines. We wanted to look at a better way to capture the natural history, quality of life and treatments.

We have discussed developing an app which would help us and patients. An episode could be caught on the app and the patient's experience as they come out of an episode could be recorded maybe even using video. All information could be recorded on it; contact information, treatment information etc. This could eventually provide more accurate information on whether treatments work. The cost would be between £10k - £30k. The app could be produced anywhere. There is an app for epilepsy but it assumes seizures of no longer than 4-5 hours so could not cope with the length of KLS episodes.

A sleep app is being developed for the hospital and will be available in the next month or so, it will be free. It will register daytime and nighttime sleep. Some KLS information has been included to get us started. If anyone is interested in the app or would like to make suggestions,

please contact us on [sleepapp@outlook.com](mailto:sleepapp@outlook.com) The long-term goal would be for KLS patients to have their own app. There would need to be discussion on Android vs iPhone, how video would be captured and how information would be shared from patient to centre and vice-versa. Video would need to be transferred in a secure way to avoid mis-use. There was discussion about funding.

In the Q & A session the idea of applying for National Lottery Funding was brought up and that there are trusts and other organisations looking for small niche projects.

**Q** Do you keep the sleep diaries that KLS patients provide?

**A** Yes, we keep photocopies. The problem is that everyone keeps different information so it would not be possible to use the information collectively but keeping a diary is essential.

### **The floor returned to Dr Guy Leschziner.**

We need to see more patients so that KLS can be described more accurately and to have more information on how long it takes for diagnosis so we can build up a picture of what is going on in this country. Or do we define KLS in the same way as for example France?

**Q** Can we send information on our KLS to the clinic if we are not registered?

**A** The information needs to be used in a scientifically rigorous manner. Only patients who are registered will have their information kept. The centre would need to determine if the case is KLS and not an associated illness. That is why it is essential for KLS Support UK to guide patients to the centre.

**Q** Could there be a questionnaire?  
There are existing technologies which could be used for analysing data.

**A** In the last month Drs and consulting managers have been discussing online questionnaires with minimum procedures to databases. There could be tablets in clinics linked with hospital systems. When people move from paediatrics to adult services their notes would need to be transferred over.

**Q** How many patients with KLS do you have in your clinics?

**A** 15 adults, 7 paediatric.

**Q** Would it help if everyone transferred to you?

**A** We would like to make sure that other clinicians recognise KLS so in that respect it doesn't help if everyone comes to us. Adult neurologists have a slightly higher interest in sleep disorders now. We need to maintain interest outside London but there is strength in



numbers too. It would be helpful to maintain the centre and work with local specialists. One patient travels to London but they still see someone locally. We in London will ask if a certain test can be organised locally with someone with sleep expertise. So ideally a neurologist, psychologist and psychiatrist would work together locally and the centre would have access to investigations. Paediatric neurologists are more attuned to working this way. This is a great opportunity to maintain doctors interest and ability to diagnose and manage KLS.

### **Dr Gerome Breen then spoke about the NIHR BioResource.**

They are aiming to collect samples and clinical information from 50,000 volunteers that can be used for scientific and medical research. They have already started biobanking KLS samples. Adewale Odesanye and Bonnie Segwagwe provided information packs to families that were interested. Their leaflet is available [here](#) if people are interested in being part of this research project.

### **Genomics England.**

Genomics England aim to sequence 100,000 whole genomes from NHS patients by 2017. The project will focus on patients with rare diseases, their families, and patients with common cancers.

It is not known if KLS is genetic but it is rare. The aim would be to look for genetic mutations which may be the cause as with other illnesses or it may just rule out a genetic link. The aim is for a diagnostic test which would be cost effective compared to the wait many patients have to be diagnosed.

This is the first large scale investigation but in the next decade as technology develops there will be more investigations working on various disorders which will enable research. With a bank of material it will be easier and cheaper to access material and apply for funding. Samples have gone to various places but this bioresource includes patients for later contact. This resource will be managed in an open and collaborative fashion.

**Q** Can samples be given from someone who has been KLS free for some years?

**A** Yes. Numbers are needed so it is important that those free of KLS donate samples but also give information on how many years they have been KLS free.



Biomedical Research Centre for Mental Health and Dementia Unit  
at South London and Maudsley NHS Foundation Trust  
the Institute of Psychiatry, King's College London

NHS  
National Institute for  
Health Research

## We need your help!

Develop

Discover

Deliver

**Volunteer for the NIHR BioResource for Mental Health and do something positive for the future of research and treatment.**

A BioResource is a library of biological (e.g. blood), clinical (e.g. medical records), and neuroimaging (e.g. brain scans) information that can be used for scientific and medical research purposes.

We hope this library will improve our understanding of different psychiatric and neurological illnesses. This will help us develop innovative treatments more quickly in the future.

**Contact us to find out more, or to volunteer:**  
**FREEPHONE**—0800 9951 9999 or 020 7848 5381 (Monday-Friday 9am-5pm)  
**Email** [bioresource@kcl.ac.uk](mailto:bioresource@kcl.ac.uk)  
**Visit our website** [bioresource.nihr.ac.uk](http://bioresource.nihr.ac.uk) or [slam.nhs.uk](http://slam.nhs.uk)  
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KING'S HEALTH PARTNERS

**The refreshment break gave an opportunity for a social get together for everyone present.**

**There was then a general Q&A/discussion session chaired by Professor Beverley Hunt, a trustee.**

There was a panel of parents and patients answering questions about KLS from their experience which resulted in an open and lively discussion.

**Q** It was pointed out that the KLS Support UK leaflet says avoid alcohol and infectious people. Why infectious people?

**A** KLS Support UK consulted Dr Arnulf and it was in her opinion wise to avoid infections when possible.

This question was also put to the panel and there was a mixed response. Some definitely had their first episode and sometimes subsequent episodes triggered by an infection e.g. flu, tonsillitis, chest infection others could not remember any trigger.

Fitness in general was discussed.

**Q** Were patients all very sporty before KLS struck?

**A** There was a mixed response to this too. Some had been promising sportsmen/women before KLS hit them.

**Q** Is it important/possible to maintain a good level of fitness with KLS.

**A** There was a mixed response. Some are able to maintain a very good level of fitness between episodes whereas some have a level of exercise intolerance.

**The general consensus on tips for coping were:**

- Listen to one's body and be aware of sleep needs and follow them.
- Be sensible and don't push the body and mind when tired.
- Plan carefully to avoid getting over tired.
- Compromise. Accept that one may not be able to do all that one wishes.
- Explain changes to people around you and let them know what you can and cannot do.
- Keep oneself as fit and healthy as possible between episodes because muscle tone is lost quickly when lying down and this can make recovery more difficult.

Something which did come up in discussion was that the longer the gaps between episodes the more you feel like your old self in between episodes.

There was a discussion on medications which had been tried. The consensus of opinion was that medication does not work and that stimulants make most KLS sufferers feel even more awful during an episode. One of the older KLSers does have medication which works for him though.

**There was a discussion on what KLS feels like.**

- Sleeping is not proper sleep but just the consciousness switched off. One patient does feel they slept well during episodes.
- A feeling that the world is moving around.
- An out of body experience.

- An inability to differentiate between dream and reality.
- Some people experienced weird dreams.
- Some had no concept of time.
- If one wills it reality will change.
- The need for the familiar. Films and TV programmes are popular. Most enjoy familiar films, usually aimed at children. Male patients often watch the same comedy programmes over and over.
- Some woke up and were raring to go, even having insomnia; others needed several days to recover.
- Those having clusters of episodes didn't seem to recover well between.
- As recovery sets in many enjoy being taken for a drive. This may only be for a few minutes to start with.

*Thank you to everyone that came to the meeting and especially to all of those who participated in the discussions. It was fascinating to hear how similar but so different everyones experience of KLS was.*