KLS Support UK
Helping families affected by Kleine-Levin Syndrome
www.kls-support.org.uk

Newsletter 5 September 2014

Thank you to everyone who attended the meeting in London. We were delighted that over 30 people were able to come including from as far away as Holland and France. For some of those attending it was the first time they had met other KLS families and for others it was an opportunity to catch up with people they had met at previous meetings.

The meeting started with a short update by KLS Support UK trustee, Adele Clarke, on the recent activities of KLS Support UK. Then it was over to our medical advisers Dr Guy Lechsziner, Consultant Adult Neurologist and Sleep Physician and Professor Paul Gringras, Lead Consultant in Children's sleep medicine and neurodisability Together with Dr Mike Farquhar Consultant in paediatric sleep medicine who spoke at our last meeting, they provide a fully integrated child and adult sleep service as part of the Guy's and St Thomas' Lifespan Sleep Disorder Services. They were joined by Dr Gerome Breen Senior Lecturer at King's College London who is involved in both the Genomics England Project and the NIHR BioResource Project. We are extremely grateful to them for their interest in this rare condition and for giving up their Sunday afternoon to speak to us and answer questions.

What follows is KLS Support UK's report of their talks and the discussion that followed.

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 email us here 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.

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
Visit our website bioresource.nihr.ac.uk **or** slam.nhs.uk
Follow us on Twitter @bio_resource
Version 3/Date: 09/01/2014

KING'S HEALTH PARTNERS

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.

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.

Thank you to those who completed the feedback questionnaire. If you did not get a chance to complete it or you were unable to attend but would like to have an input into the next meeting we will be sending you the questionnaire by e-mail. Please complete and return it to us by e-mail. If you prefer to post it please contact us through the website for our address. We will soon start to organise the next meeting based entirely on your responses.

Fundraising

We would like to thank all those who have donated and fundraised this year to help us support families, raise awareness and assist in research. Special thanks to the Fox family who celebrated Silver and Golden Wedding anniversaries this year and very kindly requested donations to KLS Support UK instead of presents.

At the meeting we were delighted to accept a cheque from a very special young man Jake, who whilst struggling with frequent episodes and GCSEs, with his family has conducted the most extraordinary fundraising activity this year including running, easyfundraising and special birthday donations. Thank you so much Jake for all your efforts and for raising in total the amazing sum of £1,544.72.

It is now much simpler to donate to KLS Support UK online through mydonate and to set up your own fundraising page for your special fundraising event. We are happy to help you do this and to provide you with the KLS logo for your kit. All money donated through mydonate reaches us as mydonate does not charge a fee and it makes giftaid simple too.

Thank you to Jog on Buddy who continues to run for us. He ran the Delamere trail half marathon on 7 September and if you would like to support him please visit his mydonate page here.

Another excellent way to fundraise without cost to you is easyfundraising so while you are browsing and shopping on the internet it would be great if you could support KLS Support UK through easyfundraising. Details of fundraising and other ways to get involved are on our website.

Raising awareness

As part of our continuing aim to raise awareness of KLS amongst the medical profession, in January KLS Support UK took a stand at the BPNA (British Paediatric Neurology Association) Annual Conference. It was good to meet up with Dr Cathy Hill, one of our medical advisers, who was speaking on KLS.

Thank you very much to everyone who has shared their KLS experience in the media. It is very important to keep KLS in the media to raise awareness and so that undiagnosed families can find help in obtaining a diagnosis. Every time KLS is portrayed by the media it generates more media requests, some of which are an excellent opportunity to spread awareness of KLS in a factual and realistic manner. We would particularly like to thank Beth and Janine Goodier who have been involved in two BBC radio interviews this year. Currently they are filming the BBC Inside Out Documentary which will be broadcast early next year. We will let you know the broadcast date on the website and Facebook page as soon as we know it. Thank you also to Steve Chapman who was filmed by ITV for a local broadcast.

There are links to the media articles on our website.

If you are interested in being involved in future media projects please let us know via the “contact us” form on the website. We can direct the journalists to you and we are happy to help you through the process or to be interviewed with you.

If anyone wants to share their experience on the website, which helps doctors and other KLS families, please contact us.

Research

We continue to collaborate with other worldwide groups particularly the KLS Foundation and KLS France. Thank you to those who have participated in the research in the US and earlier this year for the Genomics England Project in the UK through Dr Henry Houlden. We will of course keep you informed of any results or other opportunities to participate in research. We are also looking at the possibility of contributing to the funding of research in the UK.

At the meeting Dr Gerome Breen spoke about the BioResource and Genomics England Projects and families were able to find out how to donate samples to both to help research into KLS. If you were unable to attend the meeting but are interested in taking part in this research please contact Dr Gerome Breen. If you have already taken part in the Genomics England research you can still contact him to be involved in the BioResource.

Support

We continue to provide support mainly by telephone, email and messaging through the website. We direct undiagnosed families to doctors with KLS knowledge. We are also happy to put families in contact with one another if requested. 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 constantly updating the website and our Facebook page. If you have any relevant information you feel would help other KLS families please let us know.

We are always interested in hearing your comments, suggestions and concerns. If you would like to speak to us please contact us through the website and we will call you.

If you do not wish to continue to receive e-mails and newsletters from KLS Support UK please click here to remove your contact details.

Adele Clarke, Beverley Hunt, Caron Krieger, Annette Robinson

KLS Support UK

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