

KLS Support UK

Helping families affected by Kleine-Levin Syndrome

www.kls-support.org.uk



Newsletter 3 - June 2013

Following KLS Support UK's first meeting in Manchester last year

(in association with IPSA),

we are pleased to be hosting a second UK meeting in London

KLS Support UK Meeting - LONDON

Sunday 1st September 2013, 2-5 pm

The Governor's Hall, St Thomas' Hospital, SE1 7EH.

Based on feedback from the Manchester meeting, the programme will allow more time for families to chat with each other. There will be a presentation and question/answer session by one of our Medical Advisers, Dr. Mike Farquhar, Consultant in Paediatric Sleep Medicine. We are also hoping to have a presentation by an Education Adviser. Finally, there will be an opportunity to put questions to our panel which will include Dr. Mike Farquhar, KLS Support UK Trustees and KLS patients.

We hope you will be able to join us, so please ensure you [register](#) the names of attendees if you have not already done so.

If you would like to meet for lunch prior to the meeting we are happy to book somewhere if there is sufficient interest, but please [let us know](#) by 28th June. Alternatively if you would rather explore this wonderful part of London and make your own arrangements there are many restaurants/cafes on the South Bank close to St. Thomas' Hospital.

Research

We have been working with our Medical Advisers Professor Paul Gringras and Dr. Mike Farquhar from Guy's and St Thomas' Hospitals who earlier this year applied for funding to start UK research into KLS. We recently learned that unfortunately this application was unsuccessful. However, the drive and ideas behind the funding application are not lost and there is ongoing collaboration amongst researchers and doctors, both in terms of research and in setting up a multi-disciplinary KLS Clinic.

We would like to take this opportunity of thanking all the doctors and researchers involved for their commitment to finding the cause and treatment of KLS. We will of course update you with any progress.

This week we met with Professor Paul Gringras and Dr. Mike Farquhar who showed us around the impressive “Newcomen Centre”, the Children’s Neuroscience Centre, and the new Sleep Clinic at St Thomas’s which have been custom designed to provide a wonderfully friendly and calm environment. During our meeting they agreed to help us produce a Frequently Asked Questions section on the KLS Support UK website. Please send us your [questions](#) and we will compile a list of the most frequently asked to forward to the doctors.

Raising Awareness

Raising awareness of Kleine-Levin Syndrome is one of KLS Support UK’s aims. We are regularly approached by journalists who ask to be put in contact with families who are willing to be interviewed. If you are interested in speaking to the media please [contact us](#). We are happy to be involved with any part of the process and we always request that journalists include information about KLS Support UK so that KLS families or people who are looking for a diagnosis can find support.

Earlier this year we were very pleased to be able to set up an interview with BBC Radio Manchester about living with KLS. The programme which aired on 1st February included KLS Support UK and featured Beth and Janine Goodier and we would like to thank them very much for their participation in a highly factual and honest interview.

We also recently arranged an interview for The Guardian newspaper and we would like to thank Gemma and Mandy Garfirth who agreed to participate. The article in which they are featured will be published in **the Guardian Supplement this Saturday 8th June** and we look forward to reading it!

We would also like to take this opportunity to thank any other KLS families who have taken part in raising awareness via the media.

Support

Website

The updating of our website is a continual process and we hope you have had the chance to see all of the new information including sections on [School and Further Education](#), and [Benefits](#). We have been informed that one of our families has recently been successful in being awarded Disability Living Allowance (DLA). If you have any queries or suggestions on the website please do not hesitate to let us know.

Facebook

Our Facebook site was set up to enable people to meet and talk with each other. We are aware that there are now many KLS Facebook sites enabling people to communicate worldwide but the Facebook site associated with KLS Support UK is [kls-support.org.uk](https://www.facebook.com/kls-support.org.uk) [Helping families affected by Kleine-Levin Syndrome](#). We are unable to give specific advice on Facebook but if you have any queries please contact us via email or the website. If you feel you need to chat or need support we are happy to talk on the phone if you let us know via the website.

Fundraising

We are delighted that people are starting to support KLS Support UK and we are trying to make this process easier. We have applied to HMRC to be recognised for Gift Aid purposes and once we have the HMRC number we will be able to set up one of the charity donation sites. In the meantime we have a [PayPal donate](#) button on our website.

We are very grateful to Jog'on Buddy who is a family friend of the Goodier's. He has been inspired by Beth's struggle with KLS to attempt the Cross Bay Challenge on 16th June in order to raise funds for KLS Support UK. We would like to encourage you to follow his progress on Facebook and sponsor him [Jog'on Buddy](#).

We would like to take this opportunity to again thank the Renouf family for initiating easyfundraising and for the money they have raised to date. Here is the [link](#) to our easyfundraising page. Please register so you can raise money for us whilst you are shopping!

To date KLS Support UK has been largely self-funded by the Trustees who are all volunteers and parents of KLS children.

We have funded a stand at medical conferences such as the British Sleep Society Conference in Cambridge and the International Paediatric Sleep Association Conference in Manchester. At these conferences we were able to speak directly with the medical profession and distribute KLS Support UK leaflets in order to raise awareness. Useful contacts have been made at these events.

We also used the funds to produce and print our medical leaflet which has been approved by worldwide KLS Specialists including our Medical Advisers. If you need a hard copy of our leaflet to give to your GP or Consultant please let us know via the website and we will be happy to post one to you. Alternatively you can print a copy directly from the PDF on the website.

The funds are also being used to host the KLS Support UK meeting in London this September. The Trustees individually cover their own expenses of attending meetings and any travel and accommodation at conferences.

We are grateful for your donations so that we can continue to raise awareness, support families and host KLS Support UK meetings.

Contact Database

If you do not wish to continue receiving our newsletters or e-mails and would like your name removed from our database, please inform us. Otherwise we will assume that you are still happy for us to contact you.

We hope you are all able to have a good summer and that you can join us in September. We look forward to seeing you.

Adele Clarke, Beverley Hunt, Caron Krieger, Annette Robinson

KLS Support UK

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