



Newsletter 13

December 2019

We wish you Season's Greetings and a Happy New Year. We hope you and your family are well and episode free and for those in episode we hope that it ends very soon.

We would like to take this opportunity to thank all those who have supported KLS Support UK this year through fundraising, donating and raising awareness of KLS.

Save the Date 13 September 2020

We are planning the KLS Support UK Family Day 2020 which will be held in London on 13 September 2019.

Report on 8th KLS Support UK Family Day 2019

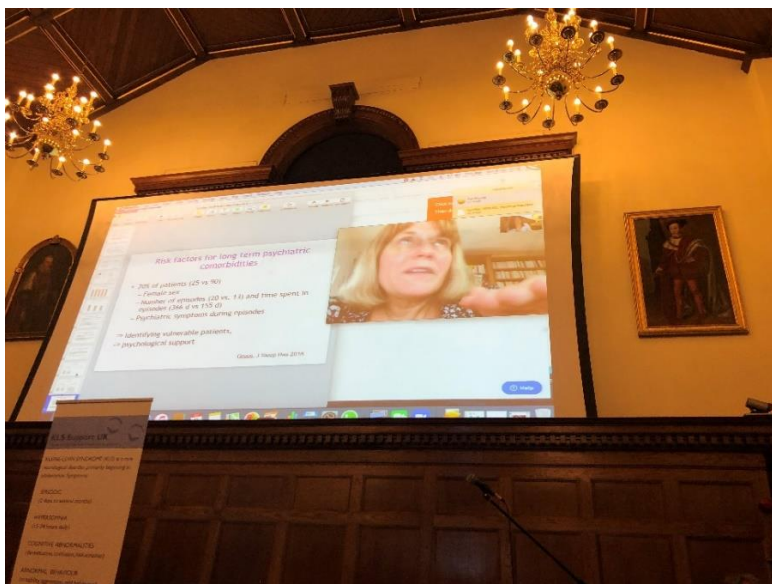
Thank you to all those KLS families who attended this year's Family Day. Around 40 people came from all over the UK and the day started with an informal lunch and time to get to know one another.



We would very much like to thank our speaker, Professor Isabelle Arnulf, one of the world's leading experts on KLS. Dr Arnulf is Head of the Sleep Disorder Service at the Pitié-Salpêtrière University Hospital in Paris, France which is the largest KLS Clinic in the world.

Although Dr Arnulf could not be with us in person on the day, she was able to deliver her talk over Skype and everyone in the room appreciated her empathy and expertise. Dr Arnulf gave a comprehensive talk on the symptoms, management, treatments and current research on KLS and answered questions.

Dr Arnulf's [slides of her talk](#) are on the KLS Support UK website together with the questions and answers.



Over tea there was a further opportunity for families to exchange experiences. This was followed by a breakout session for the young people with KLS and an informal discussion for the families. The afternoon finished with an uplifting presentation by Connor Walker.

Website updating – we would like to hear your views.

We are currently working on updating the KLS Support UK website. We would like to hear what you would like to see on the website so [please let us know](#).

Research

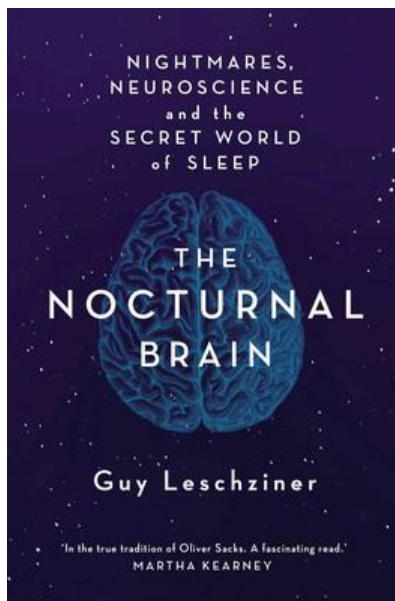
KLS research is continuing in the UK and around the world. For information on current research projects [in the UK](#).

Raising Awareness

For the second year running, KLS Support UK was invited to talk about KLS to medical students studying sleep at Warwick University.

Following the [Science Focus](#) article on Megan Firth, Professor Beverley Hunt was interviewed about KLS on [Talk Radio Europe](#).

Thank you to our medical adviser, Dr Guy Leschziner, for including an incisive chapter on KLS in his book *The Nocturnal Brain* and for talking about KLS in the media.



We would like to thank all those who have raised awareness of KLS in the media this year. Raising awareness in the media helps others with KLS find a diagnosis and helps family, friends, teachers, work colleagues, the public and medical profession understand KLS.

Fundraising

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

Congratulations and thanks to Jake Renouf on completing the incredible Man v Mountain Challenge, running 22 miles up Snowden and raising £400. Thanks to the Renouf family for their continued fundraising for KLS Support UK through Easyfundraising.

Thank you to Danielle Harris for running the 2019 Royal Parks Half Marathon and raising over £1300 for KLS Support UK.



Thank you to Debbie Cunningham for running the Great South Run and raising £360 and raising awareness.

We also would like to thank Sophie Hulme and Outnet for agreeing to donate a percentage of sales of Sophie Hulme's bags 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 Virgin Money Giving please let us know.

If you would like to donate to KLS Support UK we have a fundraising page on [Virgin Money Giving](#)

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

Support

We continue to provide support by telephone, email and messaging through the website. If you would like to talk to one of us please send us a message through the website or an email and we will call you.

We are also happy to put families in contact with one another if requested either personally or through our closed Facebook group.

You are receiving this Newsletter as you have agreed to receive emails from us. If you do not wish to continue to receive emails and newsletters from KLS Support UK you can [UNSUBSCRIBE](#) to remove your contact details.

Best Wishes and Season's Greetings

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

KLS Support UK

