KLS Support UK

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

Newsletter 12 July 2019

KLS Family Day Sunday 8 September 2019

12:30 – 16:30pm
Governors' Hall
St Thomas' Hospital
Westminster Bridge Rd
London SE1 7EH

REGISTER NOW FOR FAMILY DAY

We are delighted that Professor Isabelle Arnulf, one of the world's leading experts on Kleine -Levin Syndrome, will be at this year's Family Day. Dr Arnulf is Head of the Sleep Disorder Service at the Pitié-Salpêtrière University Hospital in Paris, France and medical adviser to the KLS Foundation and Hypersomnia Foundation. She will be speaking and answering your questions on current research and treatments for KLS.

Dr Rebecca Martyn, lead clinical psychologist in the Sleep Medicine Department at the Evelina Hospital, will talk to parents whilst the break out session for those with KLS is taking place.

This year there will be even more time for families to talk together informally and share their KLS experiences over a sandwich lunch and afternoon tea. There will be no charge for attending.

So far over 40 people have registered. If you would like to come along please CLICK HERE TO REGISTER. We look forward to seeing many of you there.

Fundraising

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

Rival Ride

On 17 and 18 May Mark Rigby, Olivier Garrigue, Paul Volley and Jimmy Harvey cycled from the Harlequins Stoop in Twickenham to the Wasps Ricoh in Coventry, nearly 200km, in the Rival Ride. They raised over £1000 for KLS Support UK. Thank you so much Wasps Legends for your ongoing support!

Sophie Hulme

We would like to express our enormous thanks to Sophie Hulme, the designer famous for her handbags. Sadly, Sophie is suffering from both KLS and Ehlers Danlos Syndrome and has decided to close her business after 10 years and take a break to be with her family and young son. Sophie has most generously said she will support KLS Support UK and Ehlers -Danlos Support UK with some of the proceeds from the sales in the company's last period of trading.

Virgin Money Giving

KLS Support UK are now using Virgin Money Giving instead of mydonate.

If you would like to donate to or fundraise for KLS Support UK it is easy to do so through Virgin Money Giving. 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 get in touch.

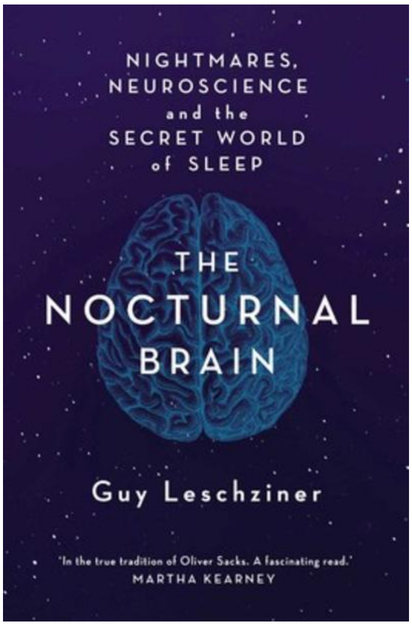
If you would like to donate whilst shopping, it is possible to support us through Easyfundraising.

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.

Raising Awareness

The Nocturnal Brain

We would like to thank Dr Guy Leschziner for his excellent chapter on KLS in his new book The Nocturnal Brain. Thanks also to Jamie Dunbar and his family for taking part in this project. The book is easily accessible to everyone but should also be required reading for all those working in sleep medicine.



We would like to thank all those who have raised awareness of KLS in the media this year.

Thank you to Megan Firth for getting involved in the well written article on KLS in the BBC Science Focus magazine.

Thank you to Sophie Hulme for raising awareness of KLS in the Telegraph, trade journals and through her company.

Thank you to the Howe family for their article in the Daily Mail and Rhoda Rodriguez-Diaz also in the Daily Mail.

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

KLS was selected as one of the rare diseases to be researched by Genomics England. Genomics England have completed recruiting participants to the 100,000 Genomes Project and will be returning results to the NHS Clinics involved in the project throughout 2019.

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.

Other News

We would like to take this opportunity to congratulate our KLS Support UK Trustee, Professor Beverley Hunt, who was awarded an OBE in the Queen's Birthday Honours for her services to medicine.

We hope you and your families are episode free and able to enjoy the summer. We look forward to seeing you at the Family Day on 8 September.

Best Wishes

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

KLS Support UK

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