

KLS Support UK

Helping families affected by Kleine-Levin Syndrome

www.kls-support.org.uk



Newsletter 7

April 2016

We hope that this newsletter finds you and your family well and episode free.

SAVE THE DATE Sunday 18 September 2015

Fifth KLS Support UK Meeting

This summer will be 5 years since KLS Support UK was set up by parents of children with Kleine-Levin Syndrome. We have held a meeting for parents each year in either London, Manchester or the South of England based on feedback from families. We would like your view as to where you would like this year's meeting to be held. Please [complete the Survey](#) by following this link. It would be helpful if you could complete the survey by 1st June.

As in previous years there will be no charge for this meeting. The costs of this meeting will be funded by KLS Support UK.

Report on 4th Meeting September 2015 in Surrey

Thank you to everyone who made the journey to spend the afternoon in Surrey at the Fourth KLS Support UK Family meeting. People came from as far as Manchester, Essex, Lymington, Oxford, Reading, London and Basingstoke. We had a very relaxed afternoon enjoying afternoon tea and chatting. There was a report on the KLS Foundation Conference which was held in America in the summer. To listen to Professor Isabelle Arnulf's highly informative presentation on recent developments in Kleine-Levin Syndrome including diagnostic criteria and treatment [Click here](#).



We had an informal Q and A session which resulted in frank discussion and even laughter about triggers, coping mechanisms and symptoms. It was reassuring to hear how everyone copes and once again it was obvious that although some symptoms are common to all,

everyone seems to experience KLS differently. We all agreed that it is so reassuring to be able to share our KLS experience with people who really truly understand.

Raising Awareness

Watch this Programme May 12 8pm Channel 5 Medical Mysteries

This documentary follows Carew Harris and his family as they struggle to obtain a diagnosis of KLS. Enormous thanks to all of the Harris family for sharing their KLS experience in the media.

Thanks also to Jody Robson for sharing her story in newspapers and magazines.

Special thanks to Beth and Janine Goodier who continue to raise awareness in the media and are currently filming with a Japanese production company. We will keep you updated as to the broadcast date.

Thanks to everyone else who continues to raise awareness. Keeping KLS in the media helps other families with KLS to obtain a diagnosis. It also promotes understanding amongst family, friends, schools, work, the general public and medical profession.

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.

Fundraising

London Marathon

This weekend Rachael Fox-Jackson is running the London Marathon to raise awareness of KLS and funds for KLS Support UK. We thank her and wish her the best of luck. If you would like to support Rachael and donate to KLS Support UK it is easy to do so through [MyDonate](#).

Thanks to all of you who have been involved in fundraising or donated to KLS Support UK. We do not receive grants. Funds raised are used by KLS Support UK to carry out its objectives of support, raising awareness and supporting research. 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.

Special thanks to Jake and the whole Renouf family for their continued fundraising which includes numerous runs and Easyfundraising. To date they have raised an amazing sum of £2500.

Thanks also to Jog on Buddy for his continued fundraising runs for KLS Support UK.



Research

In the UK

KLS has been selected as one of the rare diseases to be researched by Genomics England. If you would like to take part in this important research, please let us know and we will put you in touch with the researchers. KLS is also part of the NIHR Bioresource and to take part in this please contact [Dr Gerome Breen](#).

In the US

The KLS Foundation have provided an additional grant to Professor Emmanuel Mignot at Stanford University for their research into the genetics of KLS. To take part in this research [please contact](#) Stanford.

A further grant has been made to Professor Isabelle Arnulf who is looking at MRIs of patients with KLS.

All new papers published on KLS can be found on [the KLS Support UK Website](#).

Support

We provide support by telephone, email and messaging through the website. We are also happy to put families in contact with one another if requested either personally or through our [closed Facebook group](#). We direct undiagnosed families to doctors with KLS knowledge.

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 always interested in receiving your feedback. Please [contact us](#) and we will call you back. If you do not wish to receive emails from KLS Support UK, please [click here](#) to remove your details.

We look forward to seeing as many of you as possible at the meeting on 18 September.

Best Wishes

Adele Clarke, Beverley Hunt, Caron Krieger

KLS Support UK

