



Newsletter 9

July 2017

We hope you and your family are well and episode free and for those in an episode we hope that the episode will end very soon.

## **KLS Support UK Family Day 14 October 2017 Brighton.**

KLS Support UK are excited to invite you to the 2017 KLS Support UK Family Day in Brighton on 14 October. This year we have the rare opportunity of all our medical advisers being able to attend as they will have been participating in the BSS Sleep Conference. You will have the chance to meet Professor Paul Gringras, Dr Mike Farquhar and Dr Guy Leschziner from the Guy's and St Thomas' Sleep Centre and Dr Cathy Hill from University Hospital, Southampton as well as sleep psychologist, Dr Rebecca Martyn and a sleep health visitor.

The event will take place at the [Metropole Hotel](#) from 1.00 to 4.00 pm. There will also be lots of opportunity to meet with other families and to ask questions.

So far 50 attendees have registered. To register [click here and then press on register button](#) which will create your tickets. Please complete a ticket for each person attending with their name. There will be no charge for attending.

## **Do you want to do an interview for the Guardian?**

We have been approached by the journalist Megan Carnegie who would like to feature KLS in the weekend Experience section of the Guardian this August. If

you would like to take part in this newspaper article please email Megan directly at [megan\\_c\\_brown@hotmail.com](mailto:megan_c_brown@hotmail.com) .

Thanks to all those families who have raised awareness in the media including Gemma Garfirth, Dr Heather Peto, Connor Prince, Jody Robson and Janine Goodier. Articles and programmes about KLS help new families find a diagnosis and help raise understanding of KLS amongst family, friends, teachers, work colleagues, the public and medical profession.

## Research

Research projects are continuing in the UK, USA and other parts of the world. For more information on how to take part in this research [please see the KLS Support UK website](#). An update on any research developments will be given at the Family Day and on the website.

## Fundraising

2017 has seen more fantastic fundraising feats. Congratulations and huge thanks to:

Tiffany Morris who ran the first Southampton Marathon and raised over £600



Lachlan Dunbar and his other Wasp2Wasps team members who cycled over 150kms raising over £4000



Jog on Buddy who completed yet another run for KLS of 50 miles through Cheshire and Shropshire raising over £300

Jake Renouf and his family who continue to raise funds through various fundraising initiatives and Easyfundraising

And to all of you who have fundraised, supported fundraisers or donated to KLS Support UK. If you would like to support any of the fundraisers or KLS Support UK, donations can be made through [Mydonate](#).

If you would like to do your own fundraising event we can help by providing a T Shirt or logo, helping set up a Mydonate fundraising page and publicising your event through our Facebook page or emails.

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 a KLS Support UK meeting for families each year, raising awareness at medical conferences and producing leaflets, posters and T Shirts to raise awareness.

## 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.

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 many of you in Brighton on 14 October.

Best Wishes

Adele Clarke, Danielle Harris, Beverley Hunt, Caron Krieger

## KLS Support UK

