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

Newsletter 6 April 2015

KLS Support UK Meeting 6 September 2015

KLS Support UK are pleased to invite you to the Fourth KLS Support UK meeting to be held on Sunday 6 September 2015 in London.

Following feedback from the last meeting there will be a talk by Mina Abedian, a psychologist at Guy's Hospital who is experienced in dealing with adolescent illnesses. Mina will also be running a break out session for the young people with KLS so that they can discuss together life with KLS. We hope to also be joined by one of our medical advisers who will talk about KLS. There will also be lots of time to meet other families over tea and to share experiences.

This is your meeting so please get in touch if you have any suggestions or questions. There is no charge for this meeting. The costs of this meeting will be funded by KLS Support UK.

Register If you would like to attend please register by clicking the register button. It would be helpful if you could register and let us have any suggestions before 11 May.

Fundraising

We would like to thank all those who have been involved in fundraising or who have donated to KLS Support UK.

We are excited to report on the first fundraising event organised by KLS Support UK which was a 10k run at the Queen Elizabeth Olympic Park in London. The sun shone and there were 22 runners, wearing KLS Support UK T shirts to raise awareness, including the Clarke, Stanley, Farden, Ball and Berahnegard families and friends. Thank you to all the runners and to the Robinson family for their support and fabulous photos. Thank you to all who donated. A fantastic sum of £3500 was raised and great fun was had by all.

The same weekend on International Women's Day Karen Stylianides ran the 261 women's marathon in Palma, Mallorca. Congratulations on running your personal best and thank you so much for raising funds for KLS Support UK.

Details of the next fundraising events, including various runs by the Renouf family and how to donate can be found here .

If anyone would like to organise another event such as running, cycling, swimming or walking we are happy to assist and organise T shirts and help set up a mydonate fundraising page.

Funds raised are used to help KLS Support UK carry out its objectives of support, raising awareness and supporting research. To date funds have been used for providing annual meetings, taking stands at medical conferences to raise awareness of KLS, producing leaflets and posters to provide information and T shirts to raise awareness.

We also support research. We are particularly interested in what we regard as the most important research area – the one that will allow us to unlock preventing KLS episodes- finding the cause of KLS. As a small group, KLS Support UK have limited ability to raise funds and are not in a position to fund fully a research project at this stage (which would cost an estimated £100,00 pa for 3 years). However, to date we have been able to support research without being required to fund the research and we will continue to look at ways in which we can support and encourage research into KLS.

Research

We continue to collaborate on research with other worldwide groups particularly the KLS Foundation. Thank you to all those who have participated in research in the UK and the US. If you are still interested in participating in the Genomics England research under Professor Houlden contact us or under Dr Breen and for the NIHR BioResource please contact Dr Breen and for the Stanford Research Mali Einen. This research is carried out independently of KLS Support UK.

In March a KLS Symposium was held as part of the World Association of Sleep Medicine Conference in Korea. Dr Isabelle Arnulf, who spoke at the KLS Support UK Meeting in Manchester, chaired the symposium which was attended by 80 sleep specialists. A report on the symposium can be found here.

An update on the symposium and any other research news will be given at the September meeting.

Kids Sleep Dr App

For those of you who were at last year's meeting you may recall Professor Paul Gringras discussing the development of a Sleep App. We are pleased to report that The Kids Sleep App was launched at the Evelina on 2 April and can be downloaded for free. This is not tailored specifically for KLS but for under 16s with KLS or suspected KLS this will be useful to record or diarise episodes which can then be e-mailed to a person's sleep specialist. Any feedback on the app is welcomed.

Raising Awareness

Thanks to those who have shared their KLS experience in the media. It helps other families who are experiencing KLS and undiagnosed people in obtaining diagnosis as well as raising awareness and understanding amongst family, friends, schools, work, the general public and medical profession.

We continue to receive media requests so please let us know if you would be interested in taking part in future media projects either by e-mail or through the contact page of the website. We will put the journalist in touch with you directly and we are happy to help you with the process or to be interviewed with you.

We would particularly like to thank Beth and her mum Janine for taking part in the BBC Inside Out Documentary and for all their newspaper and magazine interviews. To view the programme and see some of the articles click here.

Thank you also to Helen Waterson for talking about her experience of KLS on Wales This Week.

Support

We continue to provide support mainly by telephone, e-mail and messaging through the website. We direct undiagnosed families to doctors with KLS knowledge. We are also happy to put families in contact with one another if requested.

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 constantly updating the website and our Facebook page. If you have any relevant information you feel would help other KLS families please let us know. Recent articles on the website include DVLA changes and PIP information, the new diagnostic criteria for KLS and research papers that have been recently published including the paper by Dr Arnulf in the Annals of Neurology published in February 2015.

We are also happy to introduce you to other families affected by KLS through Facebook. The only group connected to KLS Support UK is kls-support.org.uk Helping families affected by Kleine-Levin Syndrome. This is a closed group predominantly for people in the UK. We try to check that people we add to the group have KLS or are close friends or family of people with KLS. In this way we hope that journalists and other people with no connection to KLS will be unable to join the Group. For this reason we would ask members of the Group not to add people directly. If you know someone who would like to be added please ask them to contact us through the website. Please note we are not responsible for monitoring the content on the Facebook group.

There are many other KLS Facebook groups including the worldwide group Kleine-Levin Syndrome (KLS) Foundation .

Please also follow us on Twitter to increase awareness of KLS.

We are always interested in hearing your comments, suggestions and concerns. If you would like to speak to us please contact us and we will call you.

If you do not wish to continue to receive e-mails and newsletters from KLS Support UK please click here to remove your contact details.

We look forward to seeing as many of you as possible at the meeting on 6 September.

Best Wishes

Adele Clarke, Beverley Hunt, Caron Krieger, Annette Robinson
KLS Support UK