Dear Friend,

As we draw closer to the end of 2016, it is time to once again reflect on the year which has passed. For the first time, RLS is finally getting some traction, particularly in the field of neurology and organisations like the European Academy of Neurology (EAN) who are taking an active interest in our work and learning about patient experiences. Sadly this does not yet mean that every GP in the UK knows about RLS or how best to treat it. However, in this newsletter you will read about the work we are doing to address this gap.

Our Annual General Meeting in September saw some new speakers joining us, all of whom were very well received. We have invited one of these speakers, Dr. Kirstie Anderson, to provide occasional articles for our newsletter, such was the reception she received from our guests. I am very pleased to say that she has kindly obliged. The first of her articles can be found in this newsletter. We are very pleased to announce that we also welcomed a new trustee to our fold, Mr. Tony Blackwell.

Last year’s RLS-UK Christmas Card was extremely successful and we have therefore produced another for 2016. As before, the selling of this card is not a profit-making exercise for RLS-UK but is a cost-effective way to raise awareness of RLS. If you are thinking of sending cards this year, please do keep us in mind. Details of how you can order can be found on page three.

Sarah Blanksby, who previously completed a fundraising parachute jump for RLS-UK, has recently put on her boots and hiked Mount Snowdon, again fundraising for us. You can read more about Sarah’s story in this newsletter but suffice to say she has taken grief and turned it into something positive, for which we are extremely grateful.

As you can see in the panel on the right, our 2017 AGM will take place on Saturday 2nd September. We are looking at venues for this meeting but also for regional coffee mornings, particularly cities in the north of England. If you happen to know anyone who could provide a free or discounted venue (and accommodation), please let me know. Perhaps one of our members has a daughter/son who owns a hotel!

For now, on behalf of all of the RLS-UK volunteers, I wish you and yours a peaceful, restful Christmas and a very Happy New Year.

Daragh Bogan | Chair, RLS-UK

Don't forget to visit www.rls-uk.org to order your Christmas cards!
RLS-UK Annual General Meeting 2016

Our 2016 Annual General Meeting took place on 6th September at the Royal College of Surgeons and what was expected to be our largest meeting to date was indeed that. In our annual report, we highlighted some of our key successes over the past year, many of which you will have read about in previous newsletters.

In the afternoon session, we welcomed our guest speakers, the first of whom was Dr. Kirstie Anderson, a Consultant Neurologist. Dr. Anderson was followed by Dr. Anna Sauerbier, a Clinical Research Fellow from King’s College Hospital in London and our final speaker was our dear friend, Dr. Julian Spinks. Some of the key points which emerged from the various presentations were as follows:

- It can be hard to separate insomnia from RLS (although RLS can be a trigger for insomnia) and it is therefore important to try to keep a good sleep schedule. Make a sleep diary.
- Do not participate in any significant exercise in the last 2-3 hours of the day.
- Nicotine can have a noted impact on RLS and there have been many cases where a person stopped smoking and their RLS disappeared.
- Obstructive Sleep Apnoea is often missed and people living with RLS or PLMD (Periodic Limb Movement Disorder) should be checked.
- Treatments: There have been problems of gambling, agitated wandering and hyper-sexuality linked with dopamine agonists. Doctors and patients should be more aware of the side effects of some treatments but you should be aware of these side effects if you have addictive behaviour. Gabapentin, Pregabalin and Opiates can worsen snoring and breathing. Iron, Ropinirole, Pramipexole and Rotigotine can cause skin problems.
- Raising iron levels does not always help but your ferritin level should be between 50-75.
- If you also have PLMD, there is a gauge to assess its severity. If you kick 5-15 times per hour, it would be regarded as mild, 15-30 times is moderate and 30-60 is severe. PLMD can be violent but the majority are little flickers, bigger movement more likely to be sleep disruptive.
- The term ‘half life’ refers to the amount of time it takes your body to clear one half of a given drug. One to watch out for is caffeine. The half-life of caffeine in healthy adults is usually 5-6 hours, so if you consume 200mg of caffeine at 4pm, you would still have 100mg in you at around 10pm. Caffeine is cumulative, so those who drink more than one cup of coffee each day need to work out when to stop drinking caffeine during the day.

The day finished with many of the meeting attendees taking part in a group photo as part of the European Federation of Neurological Associations’ #UnderTheUmbrella campaign. We also used the photograph as part of our International RLS Awareness Day campaign on 23rd September, where it was used on our Facebook and Twitter accounts. Our thanks to all who participated.
RLS-UK 2016 Christmas Card – The Sleep Thief

After the success of last year’s RLS-UK Christmas Card, we have decided to produce a new card for 2016, this time symbolising the solitude which many of those living with RLS go through night after night.

The text inside the card reads ‘A wish for peace and happiness at Christmas and throughout the New Year’ while the back of the card reads ‘The Sleep Thief - Restless Legs Syndrome (RLS) is a neurological disorder characterised by an irresistible urge to move, to stop uncomfortable or odd sensations, usually in the legs. As it mostly interferes with sleep, RLS is considered a sleep disorder and those living with RLS often find themselves sitting or pacing alone in the middle of the night while all around them sleep. Because of this, RLS can severely impact on quality of life.’

We launched the card at our AGM in September and received very positive feedback, with many packs sold on the day. Your purchase of our cards not only helps us raise vital funds to continue our work but also directly raises awareness of RLS due to the text on the back of the card. If you would like to purchase cards, which cost £5 for 10, please visit the shop on our website http://www.rls-uk.org

Sarah Blanksby once again raising funds for RLS-UK

Those of you who have been members for a few years will recall Sarah Blanksby, who completed a fundraising parachute jump for RLS-UK in memory of her brother, Andrew Wilson. Andrew had lived with RLS and had recently passed away, his death being both premature and unexpected. We were contacted by Sarah a few weeks back and she told us she was once again fundraising for us. Perhaps it’s better if Sarah explains why in her own words...

September was a difficult month for me. In mid-September I became older than my brother, Andrew, ever reached and the following week it was 1000 days since he died. He is on my mind every single day but these last few weeks had made me sad and it had been harder than usual. I really struggled with him not being around. My friends Serene and Hayley knew what I needed was another challenge and I’m not sure how but Snowdon came up. One moment we were talking about a zip-wire and the next we were saying ‘Let’s hike Snowdon’, the tallest mountain in England and Wales!

The journey up the mountain was tough, probably as we aren’t really walkers. Breathing was difficult but the views were breathtaking and every step we were thinking of our supporters. Coming down was hard on the legs and it really brought home to us why this climb was so important to us and the awareness and money it was raising for RLS-UK.

We are so proud of our 5 hour time completion time! We had expected it to be closer to 6-7 hours. The other walkers really inspired us to climb those tough parts. We were known as the three pink ladies as we were hiking in our pink rain macs!

I can’t emphasise enough how immense the support has been from the RLS-UK Facebook page and the emails I received have just meant so much to me. I was privileged to do it for the charity.

We simply cannot thank Sarah, Serene and Hayley enough for their efforts and for the money they raised for RLS-UK. If you would like to thank them, you can still do so on our Facebook page or you can still sponsor them at: www.justgiving.com/fundraising/SARAH-BLANKSBY1
RLS-UK in the Practice Managers’ Information Pack

Thanks to a generous donation from a member, we were once again able to place a leaflet in the Practice Managers’ Information Pack. Last year we included an A5 leaflet but this year we spent a little more and produced an A4 leaflet, which has now been sent to 30,000 practice managers across the UK.

The purpose of this is not only to raise awareness of RLS among medical practitioners but also, hopefully, that they will display our A4 poster in their respective medical centres, thereby helping us raise awareness of RLS among the general public. In addition to this, we will be sending an email to thousands of practice managers over the coming fortnight to offer them our tri-fold leaflets and other RLS-UK materials.

Bad bedfellows by Dr Kirstie Anderson

Dr Anderson is a Consultant Neurologist working within the Regional Sleep Service in Newcastle and also an Honorary Senior Lecturer, Newcastle University.

Insomnia disorder by definition describes difficulty falling asleep and/or difficulty staying asleep and causing daytime problems as a result. Symptoms have to be chronic, at least 3 months but exclusion of secondary causes of disturbed sleep is important.

I teach our medical students and junior doctors that RLS is a common insomnia mimic. At least 20% of referrals to our sleep service with insomnia are restless in body rather than mind. They describe legs that need to move, an unpleasant feeling hard to put into words. The duvet does not stay on, burning feet are put onto the coolest surface in the house.

The 73 year old lady sitting in front of me was unconvinced. She had waited 13 weeks to see a sleep specialist but, like many, had visited her GP multiple times before the referral had been made. The letter said “Insomnia for many years”. She wasn’t certain why I was asking about her legs and whether she got up at night to stretch and move (she did).

However, trying to understand what part restless legs played in the disrupted night was important for treatment. Not all patients with RLS have bad sleep, symptoms can come early evening and then settle but most with moderate or severe symptoms will have disrupted nights. Also not all nights are the same, the symptoms can be infuriatingly episodic. This is recognised for the first time in the latest diagnostic criteria issued by the International RLS Study (IRLSS) in 2014.

So those with restless legs can develop exactly the same racing mind as those with insomnia triggered by other causes, the increased adrenaline, the same pattern of schedules that slip and slide due to daytime sleepiness and because legs are simply less irritable during the day compared to the night. Then, even on nights where legs do not kick, the insomnia can become fixed so hours awake become the norm.

Education about lifestyle factors can help both insomnia and RLS. In the largest study looking at RLS, nearly 19,000 subjects across Europe were surveyed with 5.5% reporting RLS (Ohayon and Roth 2002, J Psychosom Res). This also clearly showed an association with increasing age, more than 3 alcoholic drinks a day, more than 20 cigarettes a day, increasing age and obesity. All factors that also increase the risk of insomnia.

Back to my patient; slim and active in her garden, a non-smoker, last drank to see the New Year in - so no simple, lifestyle fixes for her. So I thought medication would be needed to settle her legs. We discussed either Gabapentin or Pregabalin, drugs that increase deep slow wave sleep and help restless legs, starting a low dose and allowing her to increase after a fortnight if needed. This was alongside instructions to keep wake time fixed at 7am every day and a sleep diary. Four weeks later she rang to say she was sleeping through the night and felt better than she had done for years!

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