



Kingston Haematology Patient Support Group

Newsletter No 8

21 December 2021

Hi everyone.

Welcome to the Xmas newsletter.

I will be at home Xmas Eve to Boxing Day and beyond. Please feel free to ring me on my mobile at any time during the Xmas period. And it would be lovely to see you if you would like to come round. There is plenty of food and drink!

Covid

It would be nice not to have to mention Covid but the new variant is spreading fast. Most people are being cautious in the run up to Xmas.

If I have been out and about, I take regular home flow tests to ensure I am not a risk to anyone.

I trust everyone has had their third jab.

New NHS treatments

You should all have had the email of 20 December to high risk patients. This provides details of two new treatments. It is important that you all have a PCR home test available if you think that you have symptoms of Covid. And one of the treatments should be started within **5 days** of symptoms starting. **Do let me know if this happens to you.**

Antibody test

Has anyone else had an antibody test? I am ashamed to admit that I was not successful in using the home antibody test. I couldn't get enough blood out.

Myeloma UK

The Myeloma UK website has detailed information about vaccinations.

I did not know previously that we need a booster **three months** after the third jab and that these can be pre-booked.

The website states that "people with weakened immune systems will be encouraged to have a **booster at a minimum of *three months* after their third primary dose**"

Peer to Peer Programme

Myeloma UK has also been active in providing further support for patients and carers. They have launched a ***Peer to Peer Programme***.

We are recruiting for volunteers who are willing to share their experiences of myeloma and related conditions with people seeking support. For further enquiries please contact Courtney on peer@myeloma.org.uk. Please note the new deadline is 6 January 2022.

Volunteers provide telephone support for other patients. There is also another role responding to posts on the online forum. There is an application process which includes a virtual interview and two days training is given. I have applied and have been accepted.

If anyone is interested, please look at the information about the programme on the website. There is still time to apply. The deadline is 6 January.

Group leaders. I attended a virtual training session where the speaker was a counsellor from Birmingham. She had some very sensible advice for us. I wish I had had something like that when I first started out.

One piece of advice that I will be following up is to draw up an **Agreement** on how the Patient Support Group is run.

We did establish some ground rules at our inaugural meeting in March 2019 but that was some time ago and we have new members now. **It would be useful to have an agreed document**

for the group and I will email round a first draft for any comments. Remember, this is *your* group, not mine. I just run it on your behalf. So it is important to check whether it is meeting your needs.

Living with Uncertainty

The Counsellor also provided advice on living with uncertainty. I will circulate this separately. **Let me know if you find this helpful or have any comments I can feed back to her.**

Patient Advocacy Panel

The Expert Panel for the Myeloma UK Delayed Diagnosis project on which I am the patient representative, has reported interim results and hopes to publish in the New Year. It will make for powerful reading.

Conclusion

Wishing you all a happy Xmas and New Year.

I always copy our newsletters to Lesley in the Unit and to Archana in Macmillan's.

So thank you so much for all the support you and all the staff at Kingston have given us over the past year. This is despite all the pressures and having to wear PPE all day long. I hope you get a well deserved enjoyable festive break.



Regards

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