

Kingston Haematology Patient Support Group

Newsletter No 7

2 November 2021

Hi everyone.

Please read to the end of this newsletter. It contains important advice about vaccinations.

New members

Welcome to our latest new members, Fernando and Ed.

Fernando has an uncommon condition linked to Leukaemia: Myelofibrosis. He was 70 on 30 October which he celebrated with his family. Hope you had a lovely time, Fernando.

Ed has been newly diagnosed with Myeloma. He lives in Surbiton Hill. Aged 62, he worked in corporate hospitality until lockdown. Cheltenham Festival was his last event.

Both have joined the WhatsApp group. The group has proved very helpful, particularly for members going in for stem cell transplants. They have welcomed timely advice on practical issues such as what to pack. Lorraine is currently going through the gruelling process and we are thinking of her and sending positive messages. We hope it helps to ease the feeling of isolation.

Government letter

You should have received the Government letter of 27 September sent by email and post. It contains the latest advice for those in the extremely vulnerable group. If anyone hasn't seen it, let me know, and I will forward it to you. Its main message is that we are no longer getting official advice to shield but we should still be taking extra precautions as follows:

- considering whether you and those you are meeting have been vaccinated – you might want to wait until 14 days after everyone's second dose of a COVID -19 vaccine before being in close contact with others
- considering continuing to practise social distancing if that feels right for you and your friends
- asking friends and family to take a rapid lateral flow antigen test before visiting you
- asking home visitors to wear face coverings
- avoiding crowded spaces.

“Although cases have gone up, there has not been the same increase in people becoming seriously ill and needing to go to hospital or dying. This is mostly because the vaccination programme has been so successful. Being vaccinated is the best way to protect yourself and other people. Vaccines are very effective at stopping people from getting seriously ill from COVID-19 so I would strongly encourage you to get all recommended doses of the vaccine.”

I am visiting friends in Somerset this week, being driven down this morning. They too are in the extremely vulnerable group. To ensure I bring no nasties from London, I took a home Covid test last night. Home tests are readily available - you order online - and they arrive very quickly by post.

Shingles

One of our group has recently contracted Shingles and has had to isolate. However, although a vaccine is routinely offered to over 70s, people who have weakened immune systems, for example due to blood cancer, should **not** have this vaccine. This is because, unlike the Covid vaccine, it is a **live** vaccine.

There is an alternative which you can ask your GP to obtain, which is not live and is suitable for our group. It is called **Shringrix**. I have double checked this with the Unit.

Third primary jab - please read

The most current advice on vaccinations is as follows:

It is the case that there is some uncertainty as to whether the two jabs we have had already are effective for blood cancer patients and others with low immunity. A **booster** jab therefore may not be the answer.

We are being urged to get what they are calling a **'third primary'** jab.

Myeloma UK has a long FAQ about the latest Covid vaccination advice about third primary jabs. This government advice was issued on 1 September. However, GPs may not be up to speed as yet.

The Haematology Unit are in the process of identifying their patients who are eligible for the third vaccine and you will receive a letter.

You are advised to contact your GP if you have not heard from them about a third primary jab.

I have also looked at the Lymphoma website. They have this to say:

"What if I'm offered a booster instead of a third dose?"

Many people are having difficulty accessing a third primary dose of COVID-19 vaccine. If you are eligible for a third dose but you are invited for a booster instead, a consensus of UK lymphoma specialists recommends that you have the booster dose. This helps you get additional protection against COVID-19 as soon as possible.

If you book a booster dose, try to find out which vaccine you are having.

- **Most boosters will be the Pfizer/BioNTech vaccine (Comirnaty®). The booster dose for this vaccine is exactly the same as the third primary dose.**
- **Some centres might be offering the Moderna vaccine (Spikevax®). The booster for this vaccine is a half dose but the third primary dose is a full dose. If possible, try to arrange your appointment to a clinic that is offering the Pfizer/BioNTech vaccine instead.**

- **The Oxford/AstraZeneca vaccine (Vaxzevria®) is not routinely being offered as a booster dose. When it is used, it is exactly the same as the third primary dose. Your dose will be recorded as a booster dose initially, while the NHS system is being updated. Your record should be updated at a later date to show that you had a third primary dose. This is important so you can be invited for any booster you might be eligible for in the future.**

30 September 2021

Updated 8 October”

Antibody test

You do not need an antibody test to get the third primary jab but, out of interest, I have recently applied for an antibody test through the NHS. It will be sent in the post for a finger prick blood test.

Patient Advocacy Panel

As you know, I am a member of Myeloma UK's National Advocacy Panel, which seeks to place the patient's voice at the centre of policy-making. On 30 July, following a patient survey, they submitted a strongly worded report to the Joint Inquiry into the Impact of Covid on blood cancer services. This included quotations from individual patients. It is 9 pages. Let me know if you would like a copy.

I have also responded to the survey by the Expert Panel for the Myeloma UK Delayed Diagnosis project. I am the patient representative on the Panel.

They are pleased to say they have had a good response to the patient survey so far, with over 1,000 participants in just a few days, so they hope to have some really meaningful data on the impact of late diagnosis for their final report. The results and issues raised and possible policy recommendations will be reported to the Panel at a Zoom meeting on 19 November, which I will attend.

Conclusion

This has been a bit of a dry and technical newsletter, so let's end on a brighter note.

The recent Japanese exhibition in the Temperate House at Kew Gardens was stunning.

And congratulations to Donald and Pamela who celebrated their 65th wedding anniversary at the end of August!

Regards

Dorothy

Dorothy Gonsalves
M: 07961 273528
Email: dorothygons@yahoo.co.uk

Kew Gardens

