The Independent

MEDICINES & MEDICAL DEVICES

Safety Review

Attending the Review team's meeting in your area?

Here is what you can expect on the day

A message from Baroness Julia Cumberlege, Chair of the Review



I and my team would like to thank you for coming to our meeting. We look forward very much to talking with you there. This meeting and the others we are holding up and down the country, are a vitally important part of the Review's work.

We want to listen to you and understand how you have been affected, and what you think we need to know or do. The Review was set up because of concerns that your voices have not been properly heard. It is our job to make sure you are heard, that lessons are learned, actions are taken and changes are made.

I know it can be stressful and difficult talking about harm and suffering, especially when it affects you and your family. At the meeting we want you to feel under no pressure to speak. But if you do feel able to talk to us, we promise to listen carefully.

I look forward to seeing you on the day.

Yours ever

Julia

Baroness Cumberlege CBE DL Chair, Independent Medicines and Medical Devices Safety Review

Who will be there from the Review?

The Review's leadership team will be there:

- Baroness Julia Cumberlege
- Sir Cyril Chantler, the Vice-Chair of the Review
- Valerie Brasse, the Review's Secretary
- Simon Whale, the Review's Communication Lead

Who else will be there?

When you come to the meeting, everyone else present will have been affected by the same issue as you.

So, for example, if you have suffered problems related to pelvic mesh, when you come to the meeting the other people present will also be people who have suffered pelvic mesh problems. The same is the case for families affected by sodium valproate, and for families affected by Primodos. We are not holding any meetings where people affected by different medical interventions are in the same room at the same time

Where is the meeting happening?

The location and date of this meeting have been selected after discussions with patient groups, and with your needs in mind. This means that the venue itself is accessible and so is the meeting room we will use inside. Toilet facilities are close to the meeting room. Refreshments (tea, coffee and cold drinks and snacks) will be available, but please note we are not able to provide a meal. For up-to-date information on your meeting's location visit the link below:

immdsreview.org.uk/visits.html

What will happen in the meeting?

This meeting is not formal, nor is it an evidence-gathering hearing. It is our opportunity to listen to you and have informal conversations with you. We hope it also gives you the opportunity to meet and talk with others who have suffered similar problems and share your experiences together.

When you arrive, there will be drinks and snacks available. The meeting room will have seating for everyone, spread across a number of tables. Our intention is that between 6 and 10 people sit at each table, depending on how many people altogether are coming. You can sit wherever you like. If there are tables with very few people we may suggest that they combine together at one table, but no one needs to move if they would prefer not to.

When everyone has arrived and is seated, Baroness Julia Cumberlege will start by welcoming everyone and explaining what the Review is doing and what it is seeking to achieve. She will talk for 5 to 10 minutes. If you would like to ask a question at that point, you are welcome to do so, and the Review team will do their best to answer.

Julia will also ask everyone to think about one or more questions, for further discussion during the session. These will be about what the Review needs to focus on or do, and what you think is most important for the Review to be aware of.

After that, members of the Review team (in pairs) will come to each table in turn and sit with you to have an informal conversation. At this time, it is

for you to decide what we should talk about and what we need to know. We will give everyone the opportunity to speak.

If your table is waiting for a member of the Review team to arrive, you are free to talk together about the questions that Julia asked in her introduction.

The Review team will spend as much time at your table as they can, but this depends on how many people are present. We hope to be with you at your table for at least 20 minutes.

Review team members will probably wish to take notes when they are with you. These are for the use of the Review team members only. If we were to consider publishing notes of conversations we would only do so with your permission. If you would prefer that they did not take notes of what you say while they are with you, please feel free to say so when they arrive at your table.

After conversations at the tables, Baroness Julia Cumberlege will make some closing remarks, reflecting on what the team has heard during the meeting. If anyone has further questions, time permitting, the team will be happy to respond.

After that, the meeting will finish.

What do I need to bring?

We don't expect you to bring anything, other than what you need to make yourself comfortable for the meeting.

Can I bring anyone with me?

Yes, of course. You may want to bring a carer or family member with you and they are welcome. If possible, we ask that you don't bring more than one person with you, so that we have room for everyone who wishes to attend. Please contact the Review team if that is likely to cause a problem for you. Our contact details are at the end of this leaflet.

Can I claim travel expenses for coming to the meeting?

Yes, we are able to pay the costs of your (and your carer's or family member's) travel to the meeting and back home again. There will be a form available on the day which we'll ask you to fill out (you can take it home and fill it out, there's no need to do it on the day unless you want to). This form will also be available on our website, so if you have internet access you can download it, fill it in and email it to us.

What if I have other questions?

If there's anything else you'd like to ask before the meeting, please feel free to contact us by email at reviewteam@kcl.ac.uk or by phone on 020 7848 6386.

You can also visit the website at:

immdsreview.org.uk

