



Dear Friends and Colleagues,

I hope that you and your families and patients are all well. It seems hardly possible that it is now over a year since we entered the new world of coronavirus-focused medicine, restricted travel and virtual meetings. This has been a difficult and challenging time for all and whilst virtual meetings and digital communication has improved our connectivity in many ways, I personally have missed the personal interactions with you, both in individual and larger meetings.

During the pandemic, as previously, the EWGGD board has continued to meet virtually on a monthly basis and I am grateful to my colleagues for the support and wisdom during this time. We have a number of activities planned for 2021:

1. We are excited that the members forum on our website will go live this week. You will be able to contribute to discussions with colleagues; presenting work, thoughts and ideas and interacting with other EWGGD members. I hope that you find this opportunity useful to propagate ideas and collaborations. Please see more details below.

2. As many of you will be aware we would usually have had an AGM at our annual scientific meeting. Whilst meeting virtually last year we did not feel in a position to do this however we wish to arrange an annual meeting for **April 7th this year**. This will be held by zoom and all of those of you who are members will be able to attend. You will recall that membership is by department/institution. There is one vote per institution however we would encourage multiple participants per institution to attend the actual meeting. Please let us know if you're interested . The agenda and link will follow.

3. Once again we do not feel that it will be possible to hold a live scientific meeting this year due to the uncertainty around travel plans airline restrictions

and periods of self isolation imposed on return. However we will hold a full virtual Congress in the autumn. We will confirm the date shortly. We hope that we will be able to meet again in person next year and will keep you posted on those details. We also expect to have a live stream of that meeting since it and seems likely that some people will still not once will be able to travel next year.

4. Finally in this newsletter you will find an update of the activities of the working group and plans for a virtual working group session on the same day as the AGM. As a consequence of many of our discussions in relation to guidelines we have found ourselves pondering various ethical issues which are not related to the scientific or technical management of Gaucher disease. This has stimulated our aspirations to consider a new working group focusing on the ethical dimension of clinical management and research in Gaucher disease. Our first step will be to have a joint meeting with the IGA board to further consider the scope for this group and thereafter we will be launching an Gaucher Ethics working group. Please do not hesitate to let me know if you would like to participate.

I hope that you are finding interest and assistance in all the activities of the EWGDD. If if you have ideas or requests or would like to get in contact please are feel free to email me or any member of the board or to message me through our members forum on the website.

All best wishes

Derralynn Hughes

Chair EWGGD



New!

Member Forum

Now available on our [website](#)

A separate e-mail with login credentials will be sent to each member.

We look forward to connecting with you on a regular basis and continuing the sharing of high quality science and experience

SAVE THE DATE

7th of April (14:00 till 17:00 GMT)

Register in advance for the meeting using this [link](#).

After registering, you will receive a confirmation email containing information about joining the meeting.

The meeting agenda for the WG session [is available here](#).

the AGM detailed agenda to follow.



Updates from the working groups

- **Update on the Laboratory working group:**

The laboratory working group is aiming to standardise and quality control our use of materials relating to Gaucher diagnostics in our laboratories. To this end they are actively working on arrangements for sharing material between the groups

- **Update on the GD diagnostic working group:**

The EWGDD Gaucher diagnostic working group has been working on four topics; (i) clinical signs and symptoms leading to suspect GD diagnosis (ii) GD Biomarkers, (iii) enzymatic activity and (iv) genetic testing. Members have been divided in sub-groups and each one has been working on a specific topic: gathering evidence, formulating evidence-based recommendations, and drafting a document using a template recently adopted by the board. We look forward to presenting our work in progress at the guidelines meeting in April.

- **Update on the management and monitoring working group:**

The EWGDD Gaucher management and monitoring working group has been working on understanding what is most important from our members, colleagues and patients for a guideline. We have been considering the methodology for gathering evidence and creating evidence-based consensus for the various management issues. We look forward to meeting together again shortly to start to draw the work and to present our current work on the guidelines at the guidelines/ AGM meeting in April.

- **Update on the GD additional morbidities working group:**

The EWGDD Gaucher additional morbidities working group has first discussed extensively that we should move away from “complications’ or ‘co-morbidities’ and define the occurrence of disorders that can be related or unrelated to GD as “additional morbidities”. Different topics were discussed that could be prioritized. These include, amongst others, malignancies, bone disease, Parkinson's disease, metabolic syndrome and fatigue. All of these are of interest, but we will focus on the first one: “Hematological and other malignancies”. We hope to produce a first draft of the consensus document which describes the epidemiology with practical guidelines for surveillance, to be presented at the meeting in April.

- **Update on the supportive care and measuring outcomes working group:**

The EWGDD Gaucher management and monitoring working group have been working on four related topics; the first is supportive and symptomatic care, focusing on adults, children, and women-related issues, the second is the transition of care from childhood to adulthood and care coordination, the third is patients reported measurement outcomes (PROMs), and the fourth is self-management. Each subgroup is working on writing a guidelines document using a template recently adopted by the board. We look forward to presenting our work in progress at the guidelines meeting in April.