

Dear Friends and Colleagues,

We hope our newsletter finds you all well.

As stated in our May Newsletter, we are **going global** to establish an international society- **IWGGD**. We are still working on the relevant procedures to formalize this name change, but this should not keep our international colleagues joining as members, joining the working groups, and being active members of all IWGGD activities. For more information, please contact the board members or through the [website](#).



**Working groups updates- Currently, there are six active working groups:**

**I. The laboratory working group** - The working group discusses GD's laboratory aspects, including (but not exclusively): biomarkers, biological materials, NGS technics, abnormalities other than those of the GBA gene, etc. The working group will develop standardization, protocols, and research activities, with periodic interaction with clinical WGs.

Chairs: Marc Berger, and Johannes Aerts.

**II. GD diagnostic working group-** The group discusses technical and ethical issues associated with the diagnostic process of Gaucher disease, including biochemical and molecular diagnosis, newborn screening, IA, and other diagnostic techniques (imaging, molecular diagnosis, biomarkers, etc.). The aim is to develop protocols and evidence-based

Chair: Andrea Dardis.

- III. Management and monitoring working group-** The group will create guidelines for the management and monitoring of GD, which can be used internationally to improve experience and outcomes for Gaucher patients. The group will understand the need for guidelines to specific problems in the management of Gaucher Disease through surveying our members and affiliated stakeholders.

Chair: Derralynn Hughes.

- IV. GD additional morbidities working group-** The 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". Next, different topics were discussed that could be prioritized. These include, amongst others, malignancies, bone disease, Parkinson's disease, metabolic syndrome, and fatigue.

Chairs: Carla Hollak, and Uma Ramaswami.

- V. Supportive care working group-** The supportive care working group works on projects related to patient care that do not fall under the category of the other working groups, including supportive and symptomatic care, focusing on adults, children, and women-related issues for type 1 and neuronopathic GD, the transition of care from childhood to adulthood and care coordination, patients reported measurement outcomes (PROMs), self-management and home therapy.

Chair: Shoshana Revel-Vilk.

- VI. Ethics working group (joined with IGA)-** The ethics working group discusses matters related to the research and care of patients with GD.

Chairs: Derralynn Hughes, and Tanya Collin-Histed.

**All guidelines developed by the WGs will be peer-reviewed and presented on the IWGGD website.**

**Members are welcome to contact the working groups chairs for more information.**

# ***SAVE THE DATE***

## ***Gaucher Disease in the Arab Population***

Thur day July 15 2021

10:00 AM – 15:30 PM (Jeru alem time)

Language : English with simultaneous translation  
to Arabic and vice versa.



**We are delighted to announce that the Shaare Zedek Medical Center will be hosting a virtual meeting in collaboration with the IWGGD and the IGA.**

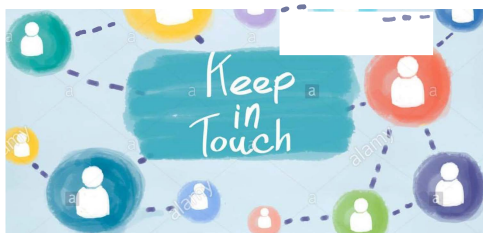
**This meeting will be focused on Gaucher Disease in the Arab Population.**

[Click here](#) for full agenda and more information.

**Register in advance for the meeting by [clicking here](#).**

The WEBSITE interface is currently undergoing some changes and we hope you will appreciate the changes once ready.

We are happy to announce that volunteers from the young investigators group are helping us with timely updates of the website and other digital connections.



Log into the IWGGD forum on our [website](#) and share your experiences, projects, and ideas with other members within our community.

## **New Memberships and Membership Renewals**

It is the time of the year where you get the opportunity to support the IWGGD by renewing your memberships.

link: <https://www.ewggd.com/members/>

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