



## Information sheet: NOMINATE – call for participants in Patient/Parent Advisory Board

Dear parents,

EFCNI is partnering with Janssen (a pharmaceutical company of Johnson & Johnson) on a **research project**.

EFCNI is looking for parents/patients with experience of HDFN (Hemolytic disease of the fetus and newborn) to participate in a patient advisory board for this research project.

### What is HDFN?

HDFN (Hemolytic disease of the fetus and newborn) occurs when the fetal red blood cells are not compatible with those of the mother, thus, her immune system sees the baby's red blood cells as foreign and produces antibodies to fight these. When the mother's antibodies bind to the baby's red blood cells, these cells break down, leading to a potentially life-threatening condition of fetal anemia (anemia of the baby).

### Advisory board

#### *What is a Patient or Parent Advisory Board?*

This is an informal meeting where a representative group of patients provide insights on a topic based on their own experience. In this case, the meeting is a virtual one, hence, you will need a computer/iPad/tablet and an internet connection to participate.

#### *What are the objectives?*

The aim of the Patient/Parent Advisory Board is to better understand the impact of HDFN on the lives of affected families.

#### *Who can participate?*

We are currently looking for parents or patient representatives who fulfil the following criteria:

- **Over 18 years**
- Resident in Europe
- Experience with HDFN in a prior pregnancy



### *What is expected?*

We encourage active participation in the discussions, sharing honest opinions and perspectives, as well as exchange of personal experiences.

- Participation is completely **voluntary**.
- **No further background knowledge** is necessary.
- Participation in your **native language is possible**. In that case a translator will be provided.
- Participants will be compensated for their invested time.
- EFCNI supports the members of the Patient/Parent Advisory Board with a briefing call before the meeting and a debriefing call shortly afterwards, if desired.

### *When will it take place?*

The advisory board meeting is **virtual** and will take place either as a group or individually **towards the end of 2023 or beginning of 2024**. It will take up to 4 hours.

### *Please note*

Next to parents or patient representatives, there will be attendees from EFCNI and Janssen (the partner for this project) present in the virtual Advisory Board meetings. Protection of your data is of high importance! Your data will of course be treated confidentially.

### *Why is it important to participate?*

Your participation in the Advisory Board will help to better understand the impact of this disease on the lives of parents and newborns.

### **More about this research project:**

For more information about this research project, please visit our project page:

<https://www.efcni.org/nominate-project/>

### **We look forward to hearing from you**

If you are interested in participating, know someone who might be interested, or have questions about the research project, please contact us:

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