

IGA Volunteer Programme



Job title	<p>Patient consulting on hematological and other malignancies</p> <p>As part of a working group on Additional Morbidities/Complications and Life Events, represent the patient point of view in developing guidelines for the Gaucher community that are practical and in lay terms. The first topic to be examined concerns Hematological and other malignancies.</p>
Purpose	<p>Develop and implement activities to support accomplishment of IGA mission and goals in the 2021-2023 strategy.</p>
Key responsibilities	<p>The guidelines should follow the methodology: The Levels of Evidence and their role in Evidence-Based Medicine (nih.gov) and be relevant globally</p> <ul style="list-style-type: none">• Carry out detailed literature review• Describe the epidemiology with practical guidelines for surveillance• Ensure guidelines are patient centric and practical
Location	<p>Online meetings.</p> <p>Possibility of travel to conferences and meetings (mostly EU).</p>
Supervision/mentors	<p>Volunteer coordinator: Vesna Aleksovska</p> <p>Mentor: Margaret Giuliani</p>
Length of appointment	<p>One year (2021) with possibility to continue engagement on similar or other activities for the next year (Guidelines for other morbidities such as Parkinson's Disease)</p>
Time commitment	<p>Average 1-2 hours a week plus meetings</p>
Qualifications	<p>English language (speaking and writing), knowledge of working with Zoom meetings, Webex, e-mail, knowledge of office apps (word, excel, pdf)</p> <p>Knowledge of hematological and other malignancies, ideally based on personal experience as a Gaucher patient/family.</p>
Benefits	<p>Training, meeting important people in the Gaucher community, events to thank volunteers, travel grants for important conferences (for accomplished volunteers), opportunities to develop and lead projects. Certificate and reference letter from the IGA to acknowledge contribution.</p>
Support provided	<p>Volunteer handbook, orientation, zoom meetings, travel and accommodation reimbursement, if necessary, for the activity.</p>