



APPLICATION PROCEDURE TO MEDICAL ADVISORY GROUP

Children, who are Hong Kong residents and who suffer or may be suffering from a rare metabolic disease often face challenges in finding a diagnosis for their ailment, needing assistance at many levels of social care, and occasionally may not have access to the best possible treatment.

Paediatricians may apply, on behalf of their patients to the Joshua Hellmann Foundation for Orphan Disease (JHF) when support is needed which can not be received from other sources and the patient has no means to self support for medical assistance.

The application is not to offer patients a 'second opinion', nor will applications be acknowledged requesting sponsoring for experimental and unproven treatments, or to provide income support.

Applications will be received and discussed by the Medical Advisory Group (MAG) of the JHF, and other experts, social workers or laypersons may be invited to offer additional advice in regards to the application.

The JHF would like to receive the following information in support of an application:

- 1. Name, date of birth and sex of patient, preferably with a photo attached.*
- 2. A medical case summary prepared by a paediatrician. Additional information may be submitted by the patient and his/her family. This summary should detail all relevant medical interventions, including admissions and treatments that have occurred since birth as well as the impact of the illness on daily activities and future prospects*
- 3. An explanation why financial support from the JHF is requested. Patients who are under the care of the Hong Kong Hospital Association will be asked to submit a "means testing" by the HA Medical Social Worker.*

The MAG of the JHF may need more information and will contact the applicant if this is needed. Applications are discussed at each Board Meeting, and applicants will be kept informed of the status of their application.

Approval may be fully, partially, or may be declined. The MAG will provide arguments of its decision however, MAG conclusions are final and are not open to discussion or appeal.

Upon approval of an application, applicants will be asked to cooperate with the MAG of the JHF in obtaining regular updates of the benefits or outcome received after sponsorship. Such cooperation may mean the release of information by your doctor.

The JHF hopes to raise awareness for Orphan Diseases by assisting existing patients, educating doctors and the public, and where possible support and promote research.