

IGA travels to Jakarta, Indonesia to participate in 1st Rare Disease Educational Day

Tanya Collin-Histed, the IGA CEO writes...

The IGA works closely with external stakeholders to improve the lives of Gaucher patients globally and on Thursday 30th November 2019 I participated in an educational meeting led by Dr Damayanti at Universitas Indonesia.

The meeting was attended by around 30 persons including representatives from the hospital, regulatory agency, pharmacists, insurance company, the ministry of Health, doctors, medical students and the Rare Disease foundation.

The meeting was a collaborative event with the IGA working with FYMCA, Direct Relief and Shire to understand how we can work with the patients, clinicians and the Government in Indonesia to improve the lives of Gaucher patients and other LSD/Rare Disease patients.

Sometimes the journey to improve diagnostic, clinical care and access to treatment can seem like an impossible one, however visits like this enables those of us who have been down that road to support others to achieve this for themselves, step by step. Dr Damayanti and her team are already achieving these steps as in just 3 years, since Rare Disease Day 2016, together with the patient group they have been successful in getting exemption of importation tax on orphan drugs and reduced the process of important drugs for urgent cases from 1 month to a few days.

I also met two Gaucher patients on Sanofi, Genzyme's ICAP and by telling our stories and that of others to the ministry representatives they can see how early access to these drugs are lifesaving. During the meeting I was able to share my experiences as a parent to give testimony to the Minister of Health about how early access to treatment can save patients' lives and they in turn can contribute to society, as well as discuss how the department of health centralised funding in England to support the development of centres of excellence and the impact on patients quality of life being able to have home therapy.

Shire's Charitable Access Programme will be open in Indonesia next year and following this meeting we hope to receive some applications to help diagnosed untreated Gaucher patients.

The outcome of the meeting was that we will go back to Indonesia in 2019 and run an educational 3-day doctors meeting on rare and metabolic diseases, focusing on diagnostics, and how simple treatments can often improve patients' clinical outcomes and quality of life where there are challenges accessing high cost treatments.

Sometimes the journey to improve diagnostic, clinical care and access to treatment can seem like an impossible one, however the Shire CAP model enables those of us who have been down that road to support others to achieve this for themselves, step by step.