

Equitable Access for All Persons with Rare Disease (Session 0605, 12 May)

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Points of discussion:

- What is your **vision** for optimal rare disease **diagnosis** and **care** in your region or locale?
- What is your organization **doing** to contribute to this vision and what are your short-term **goals**?



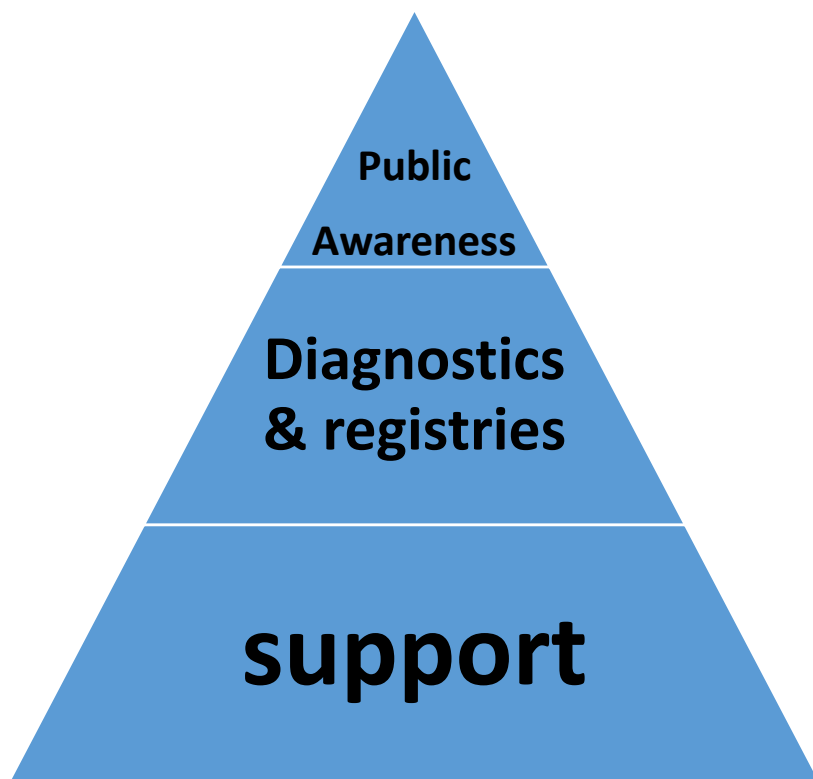
Super-trees: vertical gardens
resembling towering trees



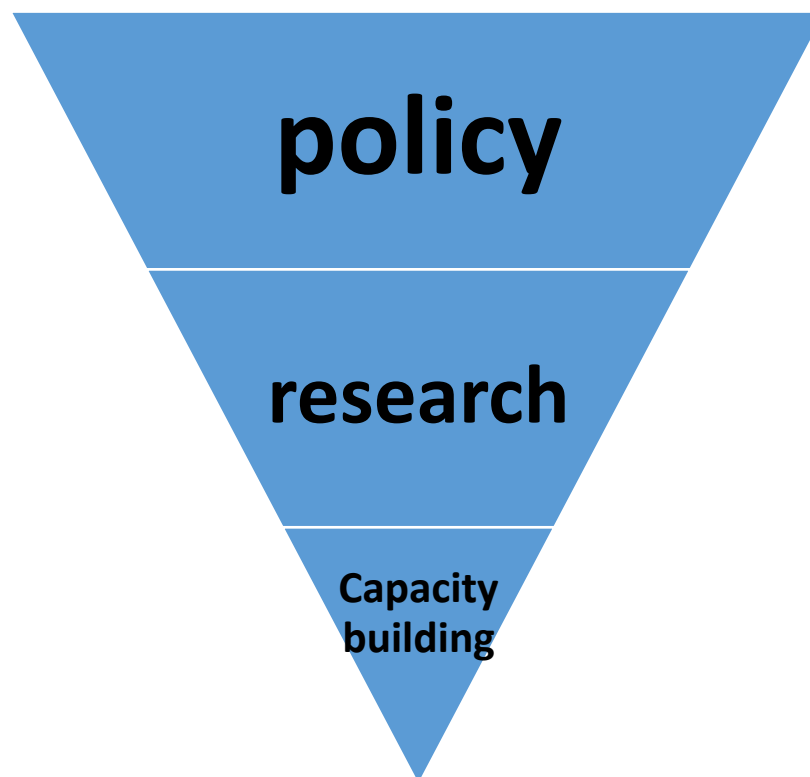
Singapore's national butterfly and
Debra's logo: the Common Rose

Synergistic approach, complementarity

Bottom up



Top down



What we do:

- For getting recognition for RD, work at the national level (both top down and bottom up) needs to be supplemented by that at the regional level
 - **Short term goals:** provision of high quality, optimal **dressings/products/care** for patients; **collaboration** with other Debra groups for better care
 - **Mid-term goals:** patient **registries** (*disease specific as well as those based on a similar phenotype. E.g., wound care for skin diseases*) to generate **data** for facilitating **diagnostics** and promoting clinical trials **tele-medicine**
 - **Long-term goals:** promoting and funding for **research** (e.g., IMB A*Star Lab, Singapore)

DEBRA: walking our talk

- local, regional, international
- support patients and groups to promote better delivery of EB care in the resource poor Asia-Pacific **region**
 - India, Pakistan, Indonesia, Cambodia, Philippines.
- Support **local** patients with wound-care products, access to experts, diagnostics, enrolment in clinical trials;
- Collate data from patient registries for clinical trials
- establish and strengthen tele-diagnostic panel

First EB meeting, India (Jan, 2018)

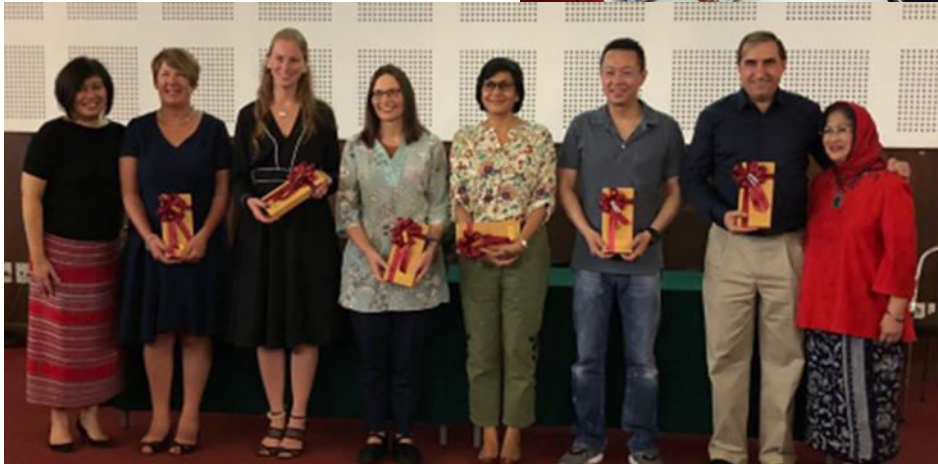


First EBWB meeting Bandung, Indonesia

May 2, 2018



Bandung, Indonesia



THANK YOU!



- What are challenges to equitable access within your own region or patient population?
 - Absence of policy, insurance, to subsidize cost of care
 - Prohibitive cost of RD products/medication, lack of infrastructure
 - Scattered, small numbers, immense heterogeneity
 - Lack of expertise, access to knowledge/products
- What are opportunities for addressing barriers, whether tangible or intangible?
 - National and regional umbrella organisations (APARDO, RDI)
 - Working with pharmas to establish APEC RD Expert Network (comprising patient organisation representatives and organisations and clinicians with a focus on RD)
- Within a jurisdiction, what are barriers to equity for rare diseases relative to other health priorities?
 - scarcity and inconsistency in rare disease information
 - Poor diagnosis of RD early, accurately, and systematically
 - Low quality healthcare
 - Burden on health givers
- Are there technological advances that can help us move toward global equity?
 - Cheaper and ubiquitous access to the internet makes tele-medicine possible and