



In 2018-19 WAPO has performed a mapping project (phase I) as a step towards learning about the members to better serve them

**PROJECT DESIGN: A web research + a questionnaire + an interview with WAPO members to collect comparable information**

#### Project objectives :

- Get the big picture
- Learn about the differences
- Identify needs
- Plan activities

**The questionnaire**

**Country statistics including prevalence**

**Patient's problems in the country**

**Best practices of patient advocacy**

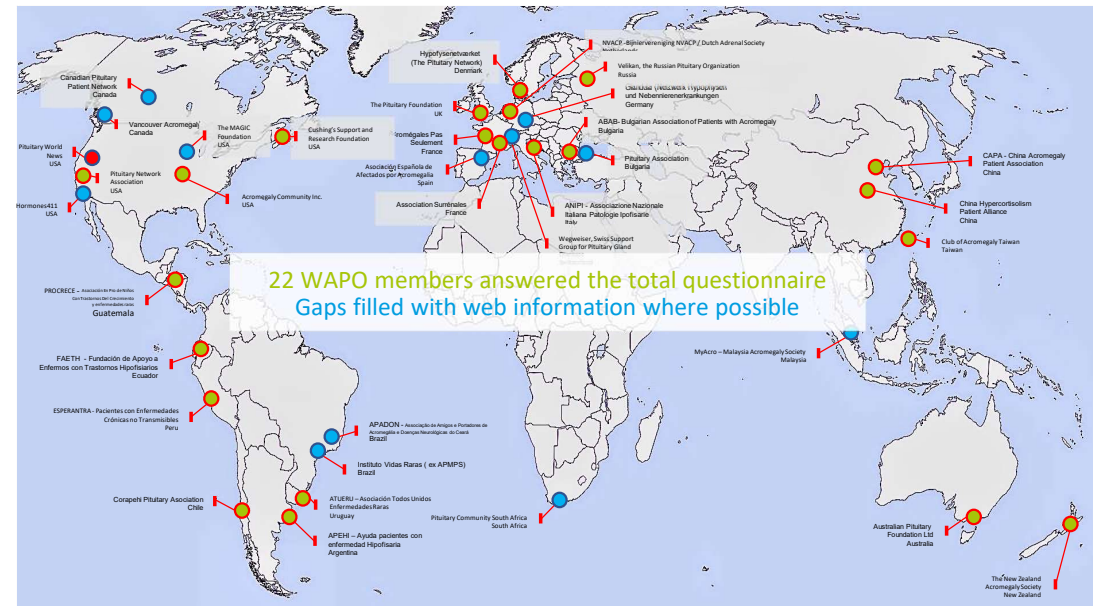
**Fundraising practices**

**Specific advocacy team expertise**

**Needs assessment**

**Drugs available in the country**

**Medical experts in the country**



## Key insights

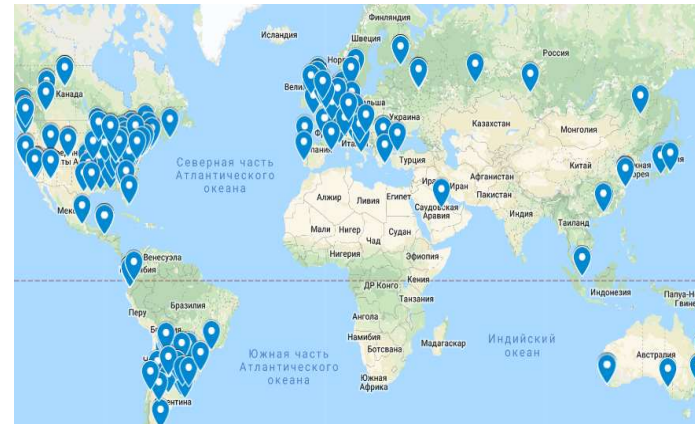
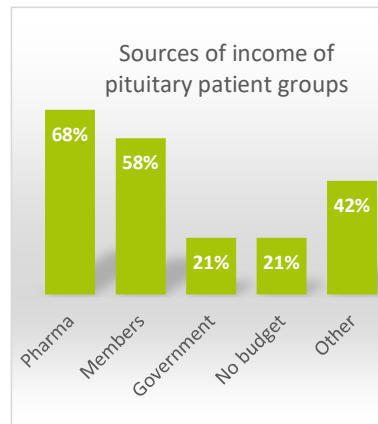
In some countries critical drugs are not available or even not certified.

Most patient groups are financed by pharmaceuticals and members, and current sources are insufficient.

There are specialists everywhere, but we still do not know about many of them. Patients can be a trusted source of information for other patients.

We know now the most acute needs of patient groups, and we know who suffers the most.

Disease	Medicine	Argentina	Russia	China	Bulgaria	Denmark	Spain	USA	France	New Zealand	China	Canada	Guatemala
Acromegaly													
Acromegaly													
Acromegaly													
Acromegaly													
Aggressive adenomas													
Cushing's													
Cushing's													
Hormone replacement													
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Hormone replacement													
Hormone replacement													
Hormone replacement													
Prolactinoma, NFA													



- Financial support (especially for emerging countries)
- Awareness information and networking resources
- Professional management / training in management / mentorship programs in:
  - Volunteers and community management
  - Fundraising
  - Database management
  - Legal issues and policy making
- Creation of international guidelines