



NMO survey

October 2014



METHODOLOGY

- Online questionnaire – July-October 2014

Many thanks
to the responders!



Introduction to our NMOs

31 Responders

- **Europe (19)**

- Austria
- Bosnia & Herzegovina
- Cyprus
- Denmark
- Finland
- France
- Germany
- Greece
- Italy
- The Netherlands
- Norway
- Poland
- Portugal
- Romania
- Russia
- Spain
- Sweden
- Switzerland
- Serbia

- **Asia (2)**

- India
- Turkey

- **Africa (2)**

- Morocco
- South Africa

- **North America (2)**

- Canada
- United States of America

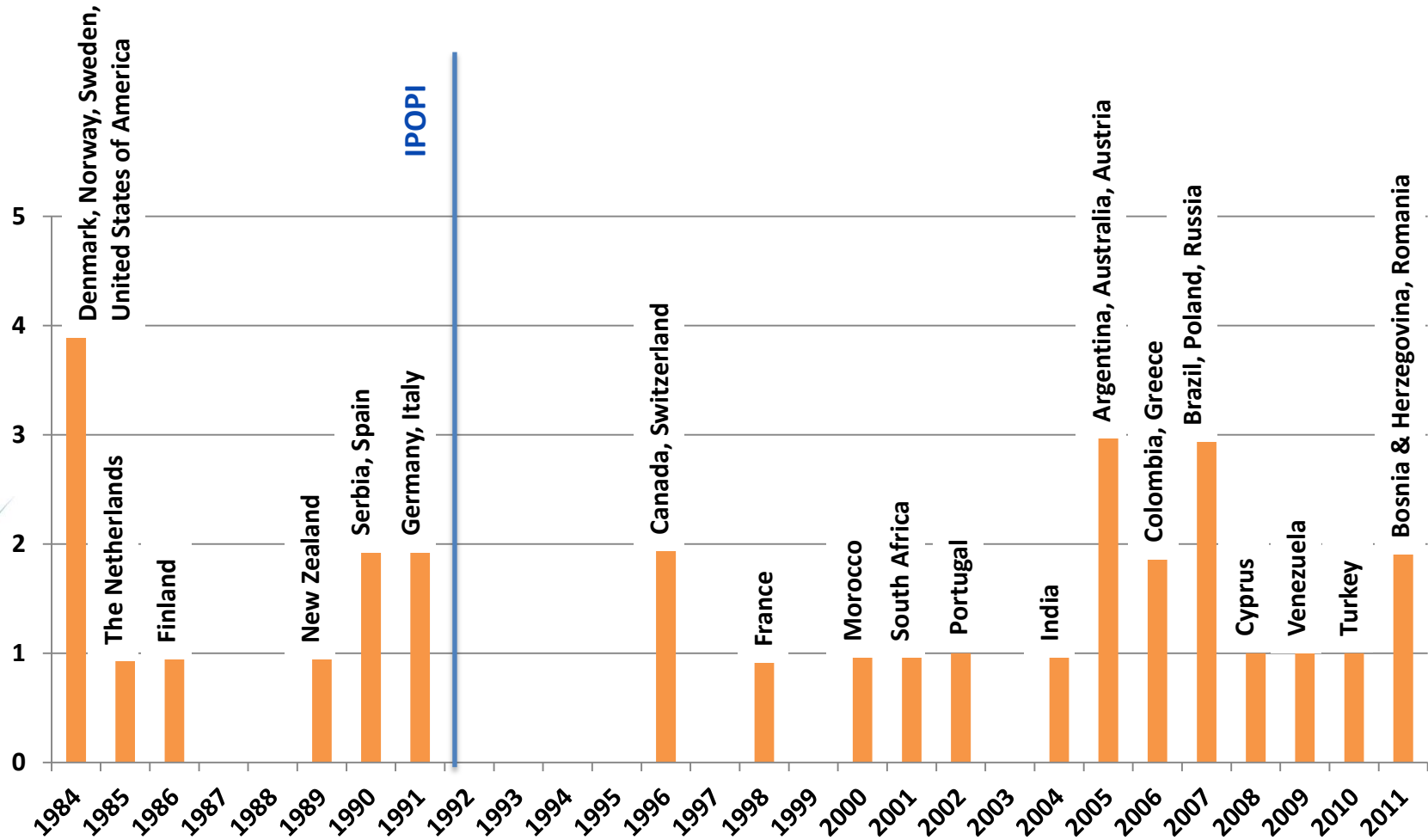
- **Latin América (4)**

- Argentina
- Brazil
- Colombia
- Venezuela

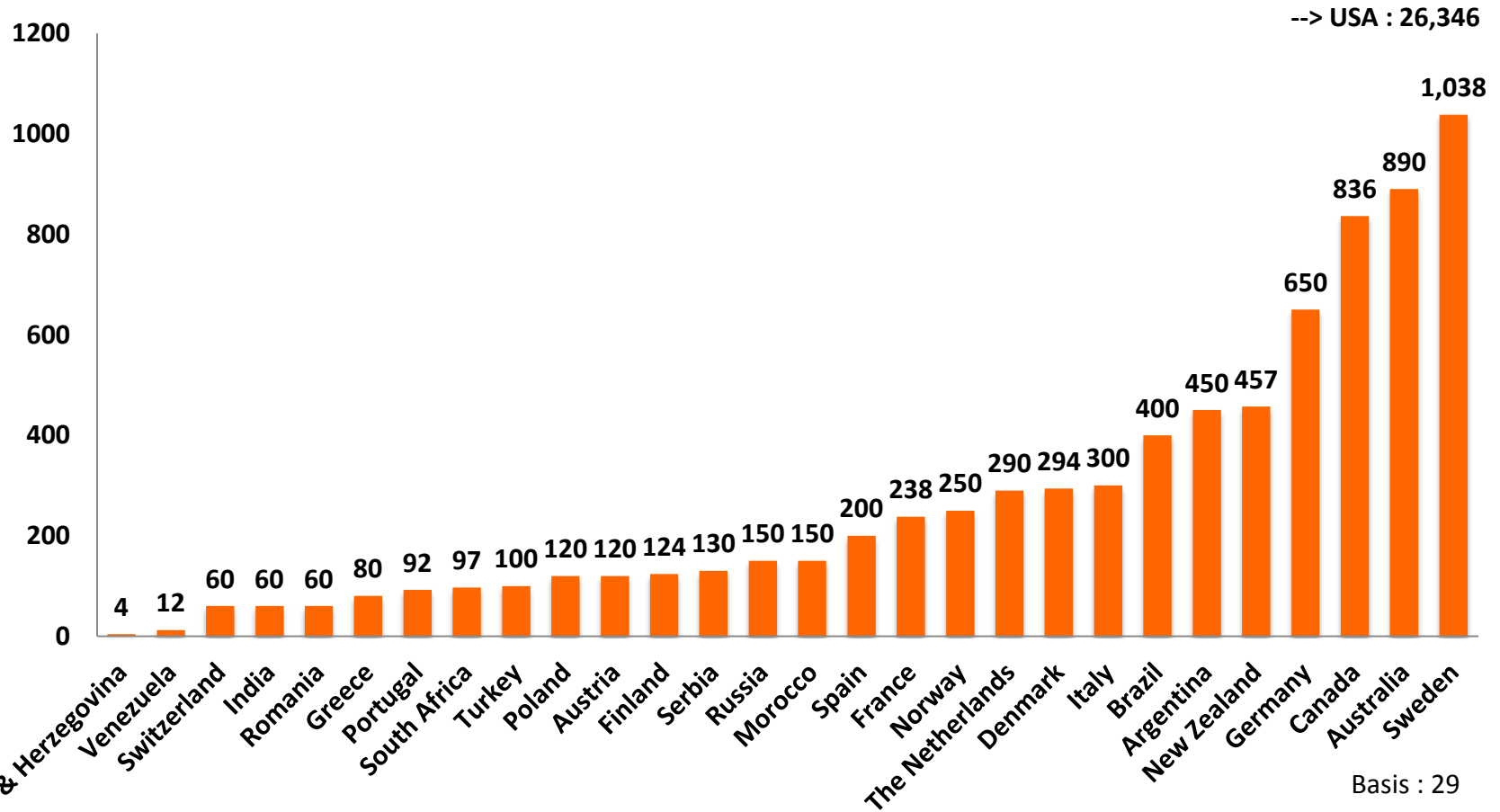
- **Oceania (2)**

- Australia
- New Zealand

When was your National Patient Organisation created?



How many members does your national Patient Organisation have?

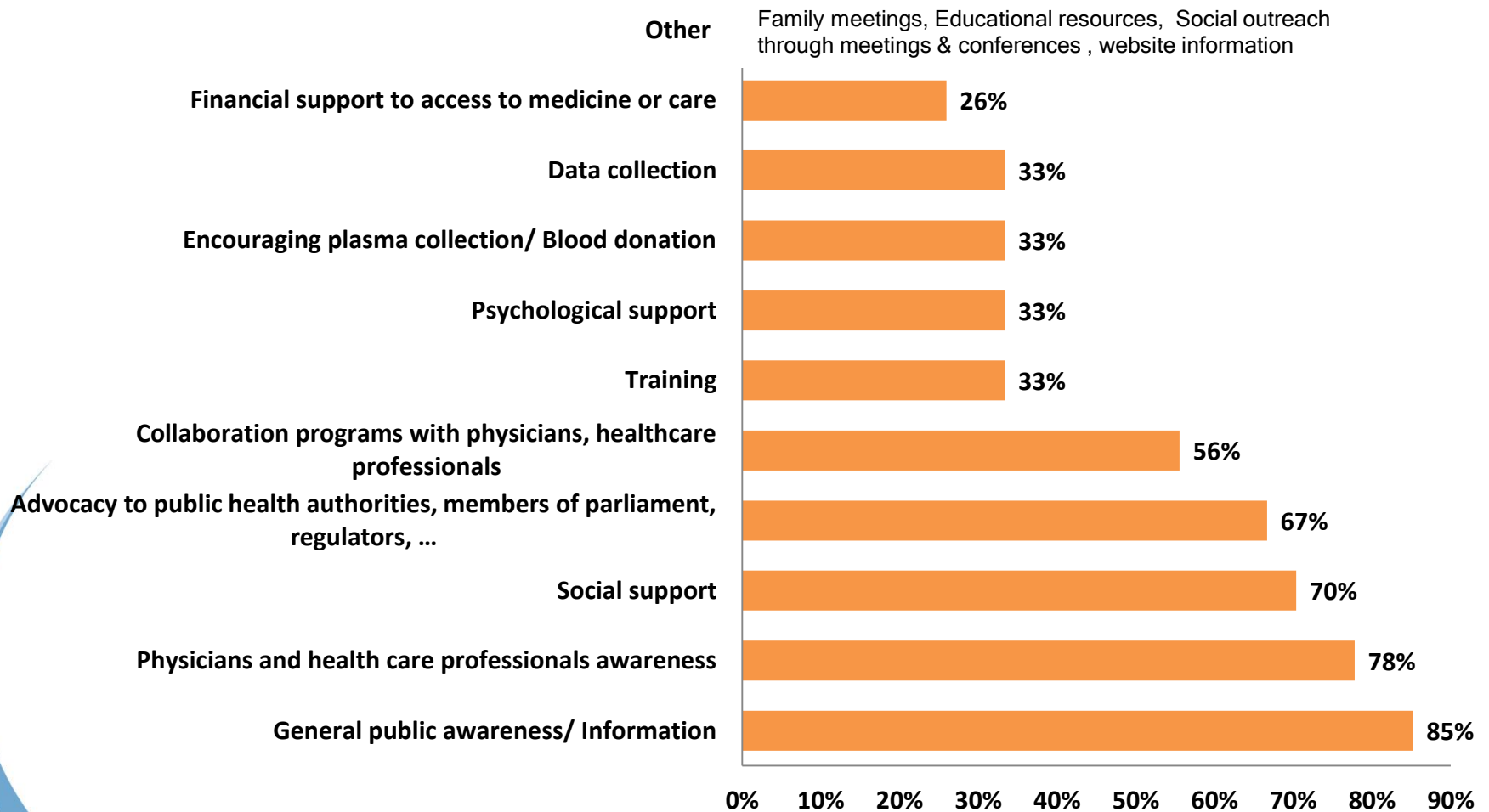


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**Which topics
for (of?) hard
work ...**

On which issues do you mainly work?





Key achievements

NMO Organisation Efficiency

Very Very Proud of !

New Zealand	Improved member services
Venezuela	Recruitment of new members, specially physicians
Finland	Member purchase, growth
Australia	increase in membership
Romania	Having new members
Italy	We grow number of our regional groups

Very Proud of !

France	Regionalisation: 10 local representatives trained & active
Finland	New web-site
Canada	APIQ - our Quebec Chapter's Growth
South Africa	Creation of three provincial groups
Brazil	Workshop with IPOPI

Still very proud !

New Zealand	Relationship building
Finland	Finance and funding growth
Australia	increase in fundraising volunteers
Brazil	Web site update

Patient support

Very Very Proud of !

Switzerland	Sponsoring (partly) of a BMT for a russian patient
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South Africa	Patient toolkit
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Very Proud of !

Switzerland	Sponsoring of the psychologist at the BMT station in Zurich Kinderspital
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Poland	Production of the full-lenght documentary in Polish and English - "It could be your story"
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Australia	increase in educational resources
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Sweden	The material on transition from child to adult care that we produced in 2012 together with PID nurses and doctors has been very well accepted and used.
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Poland	Publishing Polish editions of IDF's "Patients and Family Handbook", IPOPI's leaflets and printed patient's magazine "Immunoplus"
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Still very proud !

The Netherlands	Survival weekend for young adults
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Italy	We helped several families
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Awareness



Very Very Proud of !	
Austria	March of rare diseases
The Netherlands	awareness campaign
Very Proud of !	
Germany	TV appearances in different nationwide tv programs
Serbia	video material made by PID patient with recorded performance-public speech on PID issues
Greece	Participation at the 6th Conference on Rare Diseases in October of last year, held in Thessaloniki through from PESPA speech on PID, participation in events for rare diseases in February with a special campaign for PI.
Spain	General Assembly (April 2013 and 2014) with meetings to increase awareness between physicians
Romania	Talking to our doctors
Austria	Lectures in the Department of Health and Medical centers and major media
The Netherlands	Re-print and update from brochures
Morocco	2 WPIW

Awareness



Still very proud !

Germany	new homepage
France	WPIW. a serie of testimonies published on our website & Facebook that have deeply moved the patient community
Portugal	APDIP performed several initiatives within the WPIWeek 2014. On Saturday, 26, the children of APDIP visited the "Portugal for the Little Ones" a theme park in Coimbra. On Monday, 27, took place the "Walk for Health", 6 km in a historic area of Lisbon city. By this time, APDIP distributed the activities programme and commemorative poster of WPI Week 2014 by Hospitals and Health Centres from around the country.
Venezuela	Participation on speaks-conferences at public health centers
Serbia	awarenes raising on rare diseases in Serbia in collaboration with national RD organization
Greece	April (WpiW) - campaign, events, conference co Children's Hospital Agi
South Africa	Participation at two key medical events ASID and Africa PID school
Austria	Cooperation and public relations with plasma centers
Sweden	Our WPIW campaigns have had good media coverage and has helped spread awareness of PID.

Recognition of Patient & Patients' needs by State or Public Health Authorities

Very Very Proud of !

Argentina	Work with the Federation of Rare Diseases in a National Law
France	French parliamentary event
Greece	Constant struggle for immunoglobulin adequacy with the involment of the Greek parliament, Justice and Ombudsman.
Canada	Advocacy against Ban of Paid-for-Plasma Donation
Brazil	Governemente atention and meeting
Sweden	We are recognized as important advocates both for PID patients and for the Swedish disability movement as a whole, and are part of the steering group for the new PIDcare registry in Sweden and often invited to various governmental hearings etc.

Still very proud

United States of America	Passage of the Medicare IVIG ACT by U.S. Congress
Spain	Meetings with representatives of the Ministry of Health an with FEDER

Fundraising



Very Very Proud of !

Germany	new patron: actress Michaela Schaffrath
Portugal	In early 2013, several pictures of patients with rare diseases, shot in black and white, were exposed in the Assembly of the Portuguese Republic and the European Parliament. Among the various diseases was referenced the primary immunodeficiencies, with the photo of the president APDIP.
Morocco	2 Annual Gallas
United States of America	National Walks

Very Proud of !

New Zealand	Fundraising for strategic projects
Italy	We started a better found raising campaign

Access to treatment and care

Very Very Proud of !

Poland	Treatment programme for adult patients with PID
Russia	The IVIG maintenance in some regions has become regular

Very Proud of !

Venezuela	Detection and treatment of ill persons, children mostly
Argentina	Create with the support of the physician a network in the north of the country.

Still very proud !

Morocco	We convinced the hospital to purchase IVIG for inpatients.
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Patient social events

Very Very Proud of !

Serbia	Two summer camps for PID patients
Spain	Family weekend (Nov 2013)

Partnering with research

Very Proud of !

United States of America	PI Connect, award by PCORI to link IDF ePHR & USIDNET Registry
Portugal	In 2013, during the second meeting of Families with PID, APDIP organized a blood donor. The blood samples were collected by a Portuguese research institute (Instituto de Medicina Molecular – IMM) for preservation and future use in biomedical research.

Data collection



Very Proud of !	
Argentina	A survey about Q&L



Staff and organisation

Do you have professional staff?

- Only 9/28 National Org. have professional staff

No		Yes	Full time	Part time
Argentina	Romania	Australia	2	
Austria	Russia	France		2
Bosnia & Herzegovina	Serbia	Germany	1	4
Brazil	South Africa	Italy		1
Canada	Spain	Morocco		
Denmark	Switzerland	New-Zealand	1	2
Finland	The Netherlands	Poland		1
Greece	Turkey	Sweden		3
India	Venezuela	United States of America	27	2
Portugal				

Do you have regional representatives ?

No / 14	Coments	Yes / 14	Coments
Australia	Not formally. We try to have a patient or Board member in each state to co-ordinate member get togethers	Argentina	We have 5 groups along our country. They are from 5 provinces.
Austria		Brazil	We have regional directory in each state to make easier to contact patients
Bosnia & Herz.		Canada	As Canada is a very large country, it is important to have regional groups in order for patients to have access to Educational materials and peer to peer support.
Denmark		Finland	Peer support groups
Greece		France	10 regional delegates
India		Germany	regional groups/representatives all over Germany - Berlin, Düsseldorf, Frankfurt, Hamburg/Hannover, Heidelberg, Kaiserslautern, Leipzig, Münster, Nürnberg, Lahn/Sieg, Stuttgart
New Zealand	We select Board representation from national membership and host regional events using staff	Italy	In serveral regions of Italy we started regional groups, and new ones are still growing
Portugal		Morocco	in cities where there is a university hospital.
Romania		Poland	In almost every region of Poland we have our volunteers called regional coordinators
Serbia		Russia	Chelyabinsk, Samara, Ekaterinbourg, Saint Peterbourg, Tatarstan, Moscow etc.
Switzerland		South Africa	KwaZulu-Natal, Western Cape, Northern Cape and shortly Gauteng.
The Netherlands		Spain	Catalunya and Balearic islands have a Delegation linked to AEDIP
Turkey		Sweden	We currently have 6 regional groups that cover 78 % of our members. In addition, we also have two contact persons in other regions.
USA	We have volunteers throughout the country.	Venezuela	Actually we are linked to other medical groups that are involved in immune system's health issues

Is your National Patient Organisation a member of another patient representative organisation?

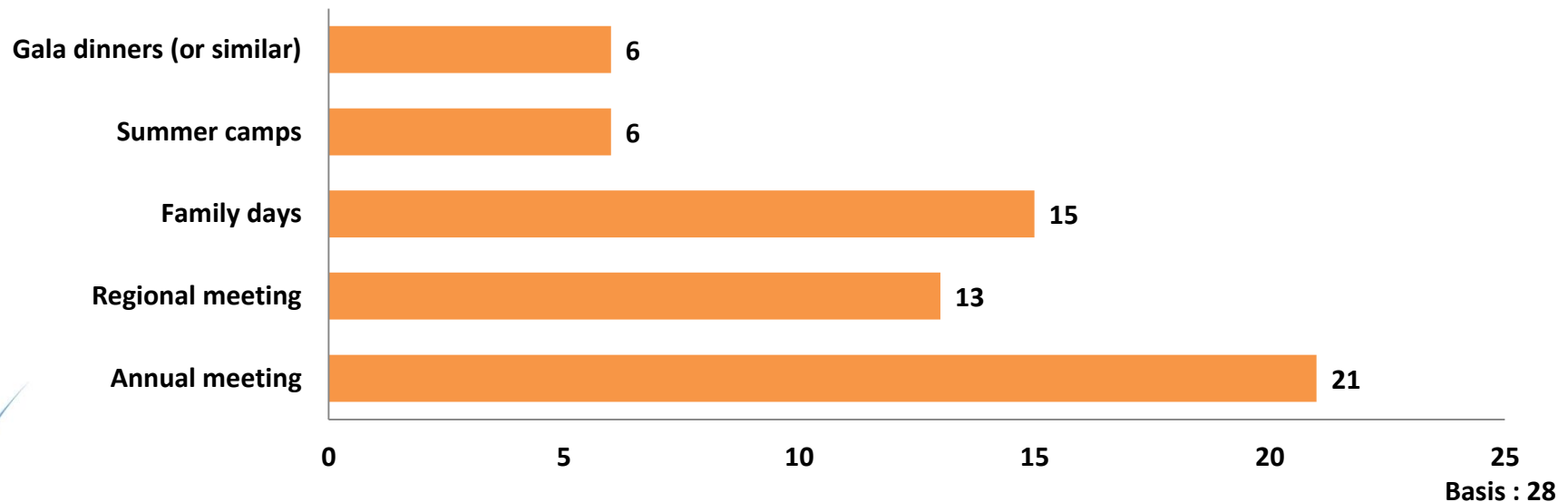
- National Rare Diseases Association
 - 19 are members
- Eurordis (European Organisation for Rare Diseases)
 - 10 European Countries
 - Germany, Finland, Serbia, Greece, Spain, Sweden, The Netherlands, Italy
 - 2 non European Countries
 - Russia, South Africa
- IAPO (International Alliance of Patients' Organizations)
 - 1
 - South Africa

Is your Patient Organisation a member of another patient representative organisation?

- EPF (European Patients Forum)
 - None
- Other
 - Organisations linked to
 - Plasma users
 - Rare Blood disorders
 - Disability
 - Other rare diseases groups

How do you involve patients, families, volunteers, to commit to your organisation on a regular basis?

Annual meetings, family days, regional meeting are the most frequent means to involve patients, families, ...



- Other means

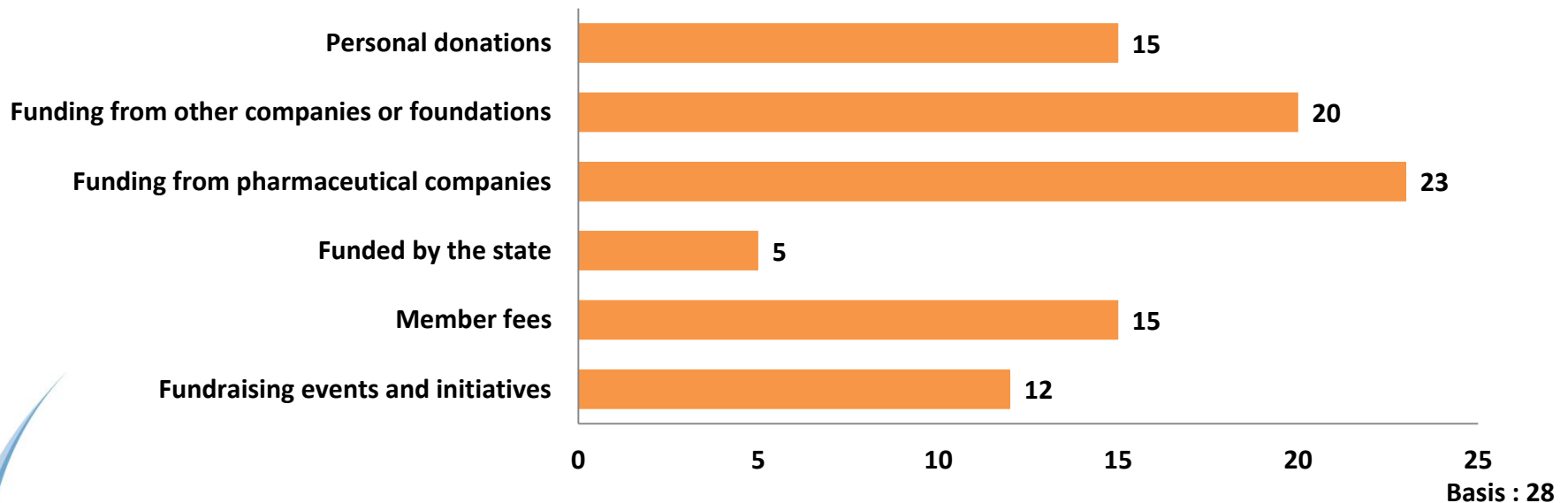
- Biennial National Patient Conference
- Weekend retreats
- Walk events.
- Newsletters

- Comment

- It is hard to get them involved

How do you get the resources to run your organisation?

Funding from Pharma...



- Other source

- We also sell advertisements in our members magazine.

- Comment

- For us it is a hard work!!
- Funding from pharmaceutical companies = in the past (before the financial crisis), occasionally

Three interlocking gears of different sizes and colors: a large yellow gear on the left, a medium blue gear in the middle, and a small red gear on the right. They are arranged in a diagonal line from bottom-left to top-right. Below the gears is a faint, light blue curved line that starts from the bottom left and curves upwards towards the right.

Running the organisation

What are the main problems in running the organisation ?

Funding

- Find resources
 - Sourcing funding (NZ)
 - Funds raising (India)
 - Financial support (Spain)
 - The resources (Argentina)
 - Low possibilities for fundraising in the field of health (Serbia)
 - Need more funding (Australia)
 - Funding (SA)
- Lack of resources
 - No funds for a professional team of project manager and fundraisers (Poland)
 - To collect enough funding for additional campaigns or materials beyond the core activities (Sweden)
 - We need more funding to get paid staff (Finland)
 - Lack of money (Romania)
 - Money for staff salary (Brazil)
- Diversify funding
 - Find new sponsors (companies) (Germany)
 - Find private donators (Germany)
 - Get grants from health insurances (Germany)
- Get continuous funding
 - Consistent funding (USA)
 - No visibility on the budget for the year to follow : hard work every year to get funds (France)

What are the main problems in running the organisation ?

Have members

- Get new members
 - To convince patients to be member (CH)
 - To attract new members (Sweden)
- Country network
 - Difficulties to establish a wider network in our country (Venezuela)

What are the main problems in running the organisation ?

Lack of professional staff

- No professional staff
 - Lack of professional staff (Turkey)
 - Non professional management due to the lack of financial resources (Serbia)
 - Without staff it is difficult day to day work (Argentina)
- Not enough professional staff
 - Too much work we want to do with doctors education and public administration and health insurance etc. / for 2 persons and could not receive enough money to one person for 20 hours (Austria)
 - We need more staff to grow better (Italy)

What are the main problems in running the organisation ?

Commitment

- **Commitment**

- The commitment of the people (Argentina)
- Mobilize patients to participate with the association (Portugal)
- Lack of volunteers (CND)
- Volunteer based (SA)
- Lack of personal involvement of the members (Romania)
- Commitment of the patients (Brazil)
- Finding volunteers (New Zealand)
- To compile statistics of PID patients in Austria and no involvement of the patient to a statistic (Austria)
- To find people willing to work for the organization, regionally and nationally (Sweden)
- We need more involved patients to grow more and better regional groups (Italy)

- **Patient state of mind**

- A lot of members show little interest/are passive (CH)
- Patients and members are not active enough to join the work (Finland)
- Inactivity of members due to the lack of knowledge and courage (Serbia)
- Our patients face the situations with pessimism and lack of creativity (Greece)
- Lack of motivation in families to be involved in the organization (Serbia)

- **Patient centered on their own needs**

- When the patients are diagnosed and medical treatment is not interested in the self-help group (Austria)

- **Patient Financial contribution**

- Non payment of dues by the members of APDIP (Portugal)

What are the main problems in running the organisation ?

Availability / ability (force) of board members

- Lack of time
 - People in charge (member of the board) nearly all have a full time job & family and face a lack of time
 - The problems we have is our work
 - Availability of officers. (Morocco)
 - The people who belongs to the board of APDIP work full time in their jobs (Portugal)
- Lack of good health condition
 - Organisation consist of patients who have less strenght to work (Finland)
- Find new board members
 - Renewal of the Board (DK)
- Working condition
 - Home office (Australia)

What are the main problems in running the organisation ?

Situation of the country

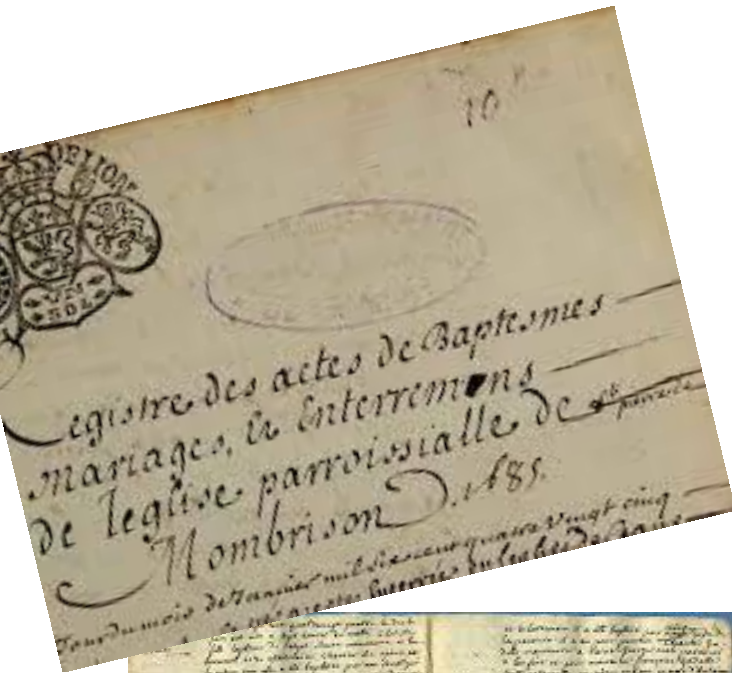
- **Political situation**
 - The cuts applied by the Ministry of Health causing same problems in communication with decision makers (Greece)
 - Government Agenda (India)
 - The Government reduces operational and administrative costs in healthcare (Portugal)
 - Lack of motivation on government offices for support (Venezuela)
 - State regulatory bodies (Australia)
 - "Poverty brings nagging" = Greek proverb (Greece)
 - Recognition by the state. (Morocco)
 - Government assistance (Brazil)
 - Partnership with government for projects (Brazil)
- **Size of the country**
 - Present situation of the country (Venezuela)
 - Country very large (Australia)
 - The long distances in our country (Sweden)
 - Distance (SA)
- **Population**
 - Large diversified population (USA)

What are the main problems in running the organisation?



Other

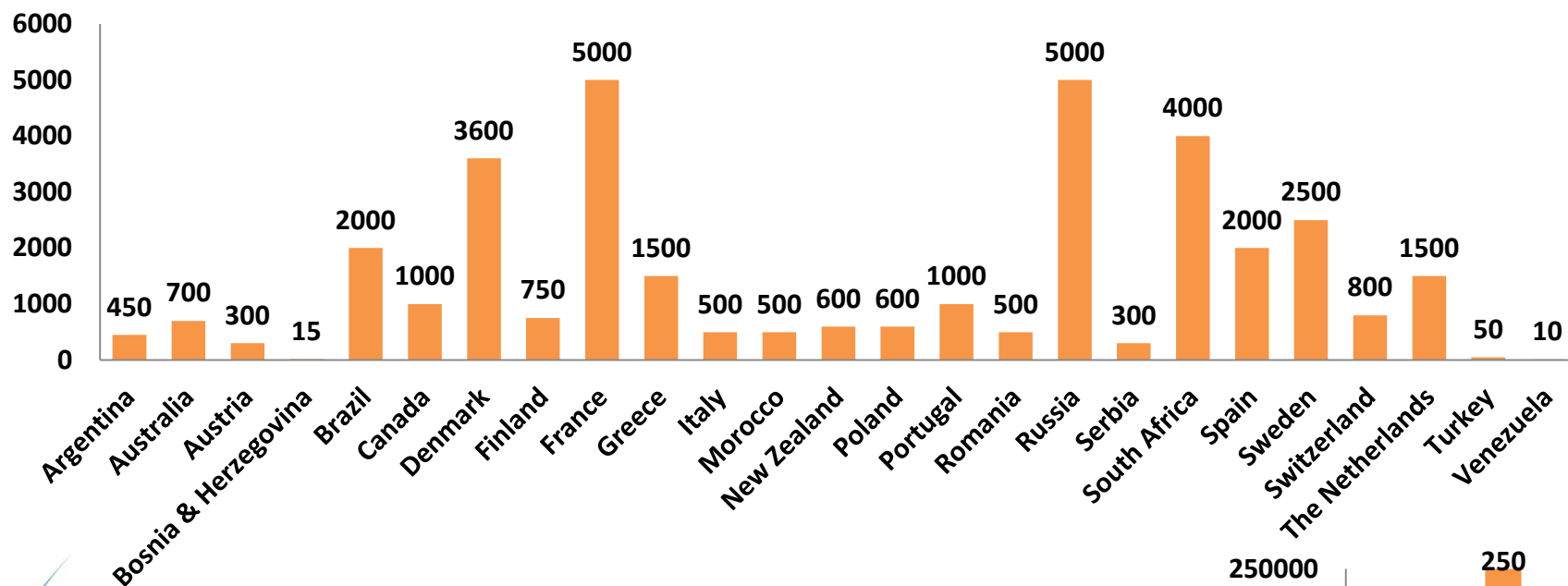
- Information
 - Dissemination of information (Spain)
- Lack of regional cooperation
 - There is no cooperation between organizations in southern Europe to address our common problems at EU level (Greece)
- Lack of Tools or skills
 - Advocacy tools/local medical documents (SA)
 - We need more awareness in political affairs (Italy)
- Relation with Doctors
 - Communication with doctors (no medical advisors) (DK)



Registries

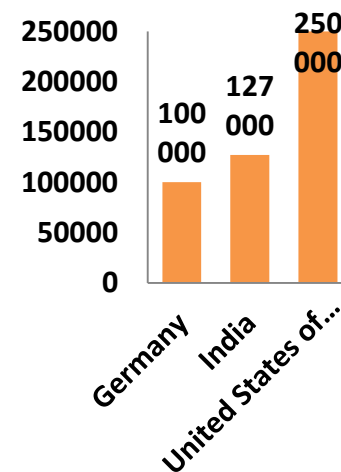


What is the estimated number of PID patients?



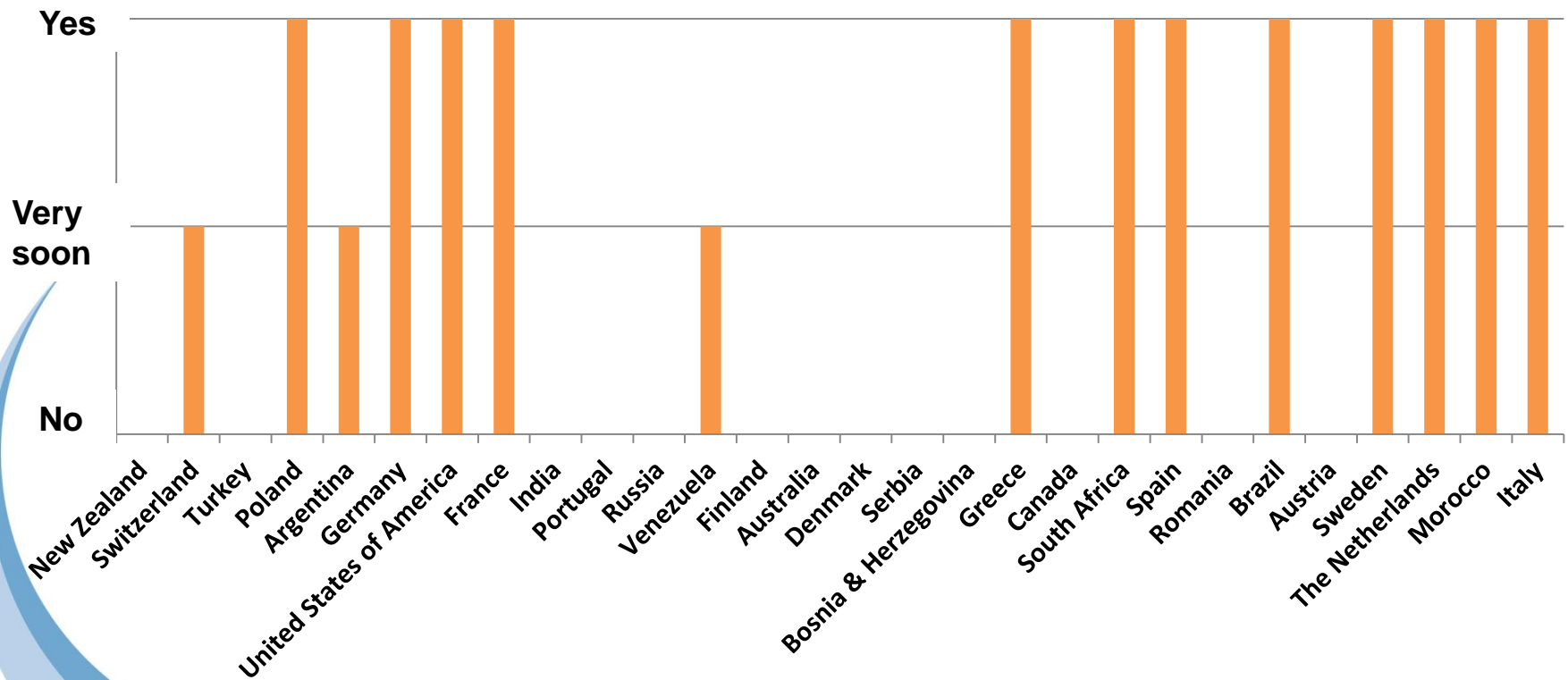
• Sources

- 7 from national registry
- 8 from numbers of members
- 12 estimated prevalence in the country
- 6 data from physicians or hospital registry



Is there a registry for PID patients in your country?

- 12 countries have a registry
- 3 are in preparation



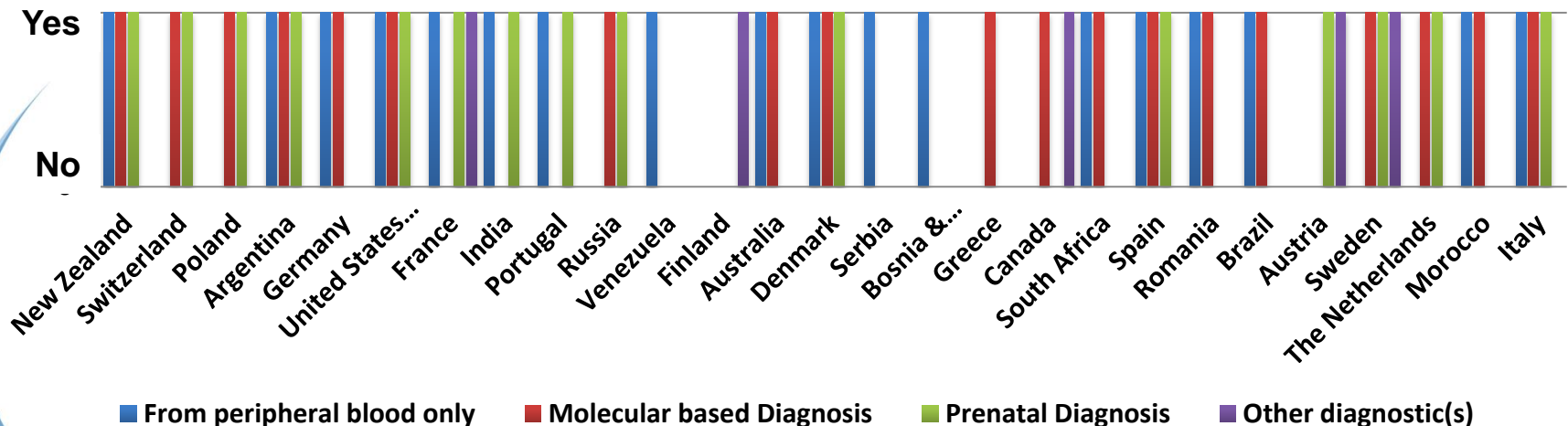


Diagnostics



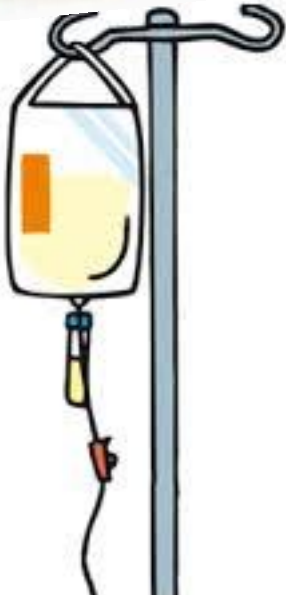
What kind of diagnostics are available in your country?

- From peripheral blood only : 18/26
- Molecular based Diagnosis : 19/26
- Prenatal Diagnosis : 15/26
- Other diagnostic(s) : genetic screening, Newborn screening



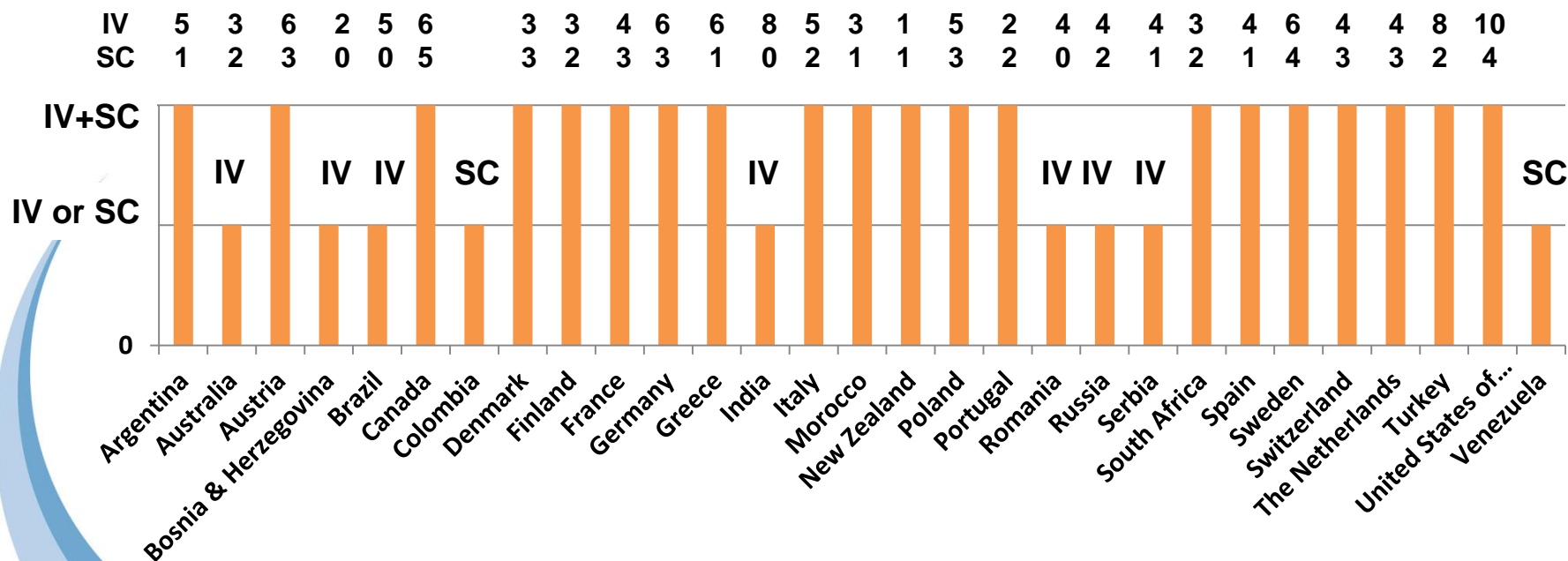


Treatments



How many different types of Immunoglobulin therapy are available in your country?

- Most countries (20/29) have access to both IVIg and SCIg
- 2 countries have access only to SCIg
- 7 only to IVIg

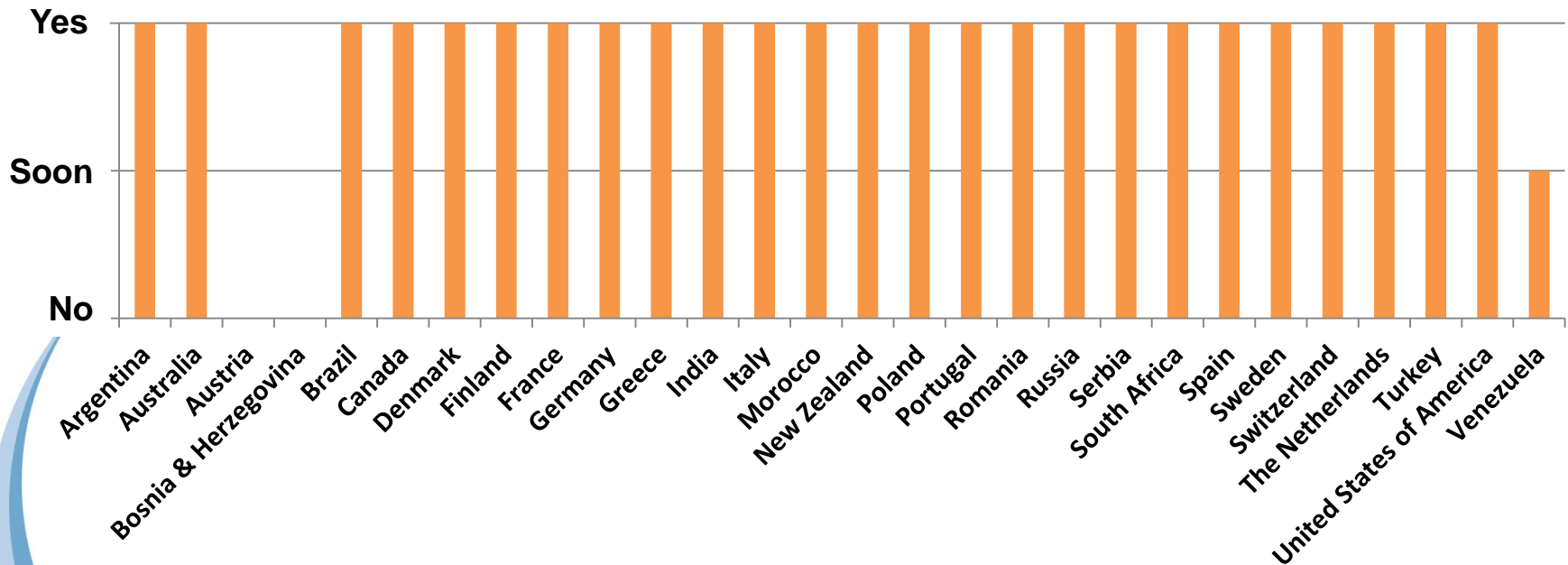


Is it possible to get home therapy for immunoglobulins?

Yes ScIg + IvIg 6 countries	Yes ScIg 14 countries	No, but it should be possible soon 3 countries	Not at all 5 countries
Argentina France New Zealand Sweden The Netherlands USA	Austria Canada Colombia Denmark Finland Germany Greece Italy Poland Portugal South Africa Spain Switzerland Turkey	Australia Bosnia & Herzegovina Morocco	India Romania Russia Serbia Venezuela

Are there Bone Marrow transplantation (or Hematopoietic stem cell transplantation) facilities in your country?

- Most countries (25/28) have



Who pays for PID treatment in your country?

The state in full	State partly + Private insurance	Private insurance	Personally covered
Australia Austria Bosnia & Herzegovina Brazil Denmark Finland France Greece Italy New Zealand Poland Romania Serbia Spain Sweden The Netherlands Turkey Russia	Argentina Canada Morocco Portugal	Germany Switzerland South Africa United States of America	India Venezuela

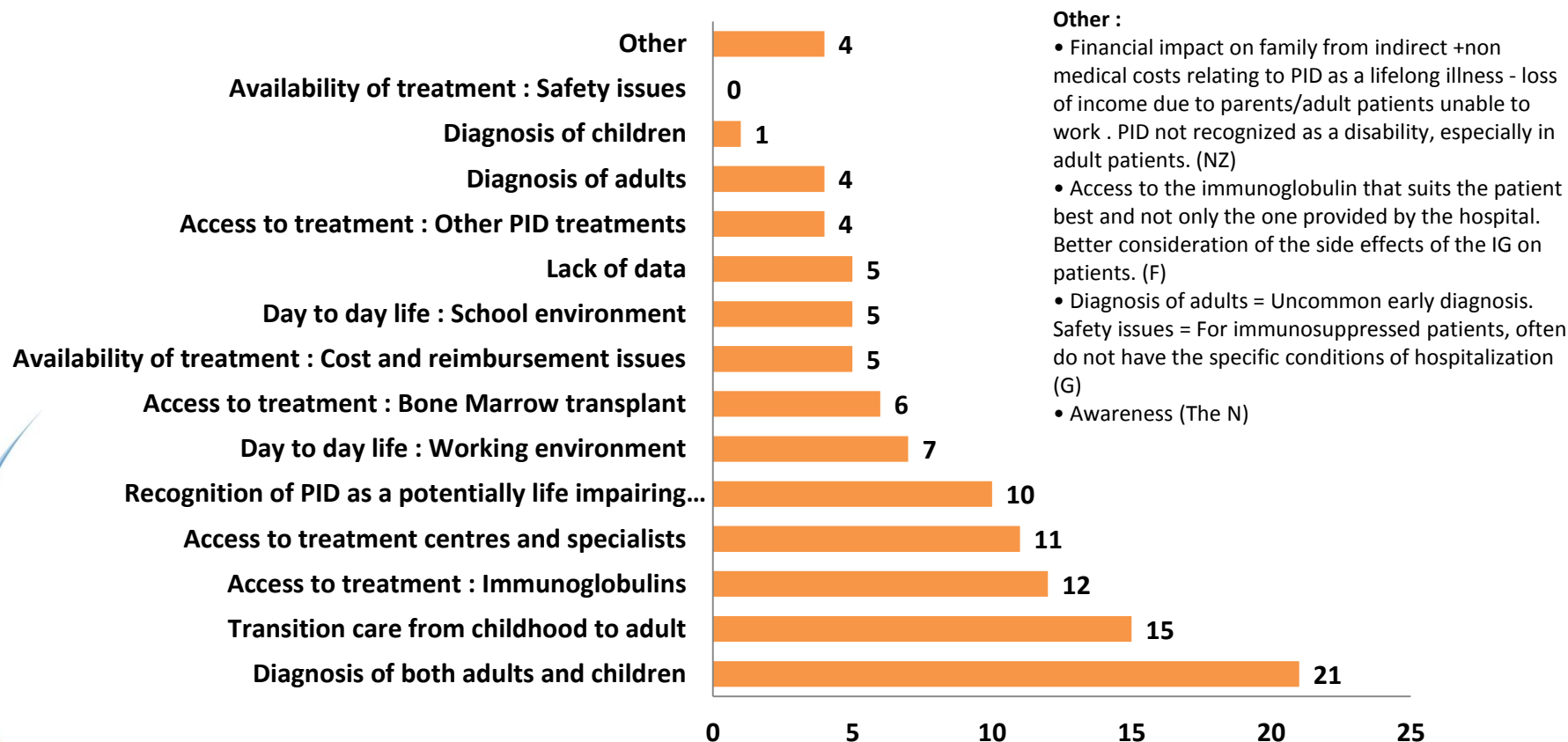
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3 main areas of concern

What are the 3 main areas of concern at the moment for PID Patients in your country?

- Diagnosis remains a concern globally



**Many thanks
for your attention**

