A thick, light blue curved line that starts from the left edge and curves upwards and to the right, framing the text.

**Why is it good to
collaborate with
Rare Disease
organization**





This question was my concern
years ago
...and some of them are still
twinkling on my mental display

...





... will it soak our NMO?

... or decrease visibility of PID, after all efforts we've done to increase it?

... it's a "big issue"...are we just wasting our time?


How to avoid potential risk of loosing "safe position" (immunoglobulins vs. orphan drugs)?

Will donors support this "new"orientation ?

.....



What is the situation in country?

- **PID** is an rare disease !!!! (1 in 25.000)
- only **One** referral hospital + few experts in PID!
- **Dg** - not so good (adults/children ratio)
- **No** of patients - low increase in last few years
(comparing with diabetes, child cancer etc...)
- **Ig** – availability is constantly questionable – each year!
  we are “not in a priority”!
- **small No = week voice**
(not capable to change the situation!)



Do we need RD organization? What could we get?

- **international support** (EURORDIS)
- bigger number = stronger voice in advocating
- **proper attention of policy makers** (long term consequences of RDs)
- joint efforts
- more easy to reach activists & volunteers
- **increased visibility** in public – if playing clever
- National Plan for RDs (including PIDs) + National register of PIDs + budgeting based on data

What we've achieved in three years?



- **National fund** for RDs - established, patients represented
- **National Committee** for RDs – established, patients represented
- **The Law on health protection** - RDs included !
- **Law on patient's rights** – provides patient's participation
- **Law on medical data management** - to be changed (data and responsibilities)
- **Increased National budget** for RDs in 50%/year



What we've achieved? - 2

- **National drug lists** - extended with new orphan drugs
- **Abroad prenatal molecular diagnosis** - allowed
- **National Plan for RDs** - in progress
- **First National Conference** on RDs was with international representatives
- as well as:
 - 3 Round tables on RDs, two Panels on RDs, 4 Rare diseases Day (two video spots, several street actions, promotions)
 - many lectures and presentations for professionals
 - many media promotions, interviews, booklet on RDs....
 - web site, intensive social networking

OF COURSE, THERE IS SO MUCH TO BE DONE!



Collaboration between PID and RDs organizations in the SEE region?

In **Balkan region** there are joint actions among RD and PID organizations/patients' groups, exchange of knowledge among doctors, different initiatives by industry toward patients' support

In SEE region - good collaboration among PID and RD groups/organizations takes place in Romania, Bulgaria, Slovenia

In Russia and Belarus there are several organizations and groups and they are connected in helping patients, still struggling to make impact on policies...

In conclusion

The collaboration among PID and RD patients organizations/groups **could be useful**, because:

- the patients' voice is stronger
- the plans are covering bigger number of sick people
- the politicians are showing more respect when a large group is involved!

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Thanks for the attention!
www.pospid.org.rs