

Patient organizations in Latvia

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Baiba Ziemele - disclosures



- **Latvia Hemophilia Society** (president since 2009*)
- **World Federation of Hemophilia** (board member since 2020)
- **Latvian Alliance of Rare Diseases** (president since 2016*)
- **Network of Patient Organizations in Latvia** (since 2018)

also

- Member of **Women's Committee** at World Federation of Hemophilia
- Member of **von Willebrand disease Global Group** and member of **von Willebrand and Rare Bleeding Disorders committee** at World Federation of Hemophilia
- Member of **von Willebrand disease Committee** at European Haemophilia Consortium
- Member of **Strategic Council of Healthcare** of Ministry of Health in Latvia (since 2020)
- Member of **Council of National Health Service** in Latvia (with Prime Minister delegation 18.08.2018., to be renewed in 2022)
- ePAG at **EuroBloodNet** (2019-2021)

All is unpaid voluntary work, except *, where received salary for project management and patient advocacy from Latvia NGO fund (www.sif.gov.lv) during April-October 2020 and January-October 2022

NGO sector in Latvia

- 26 576 – total number of non-profit organizations
- 18 712 – filed annual reports to State Revenue Service
- 12 189 – with annual income <0
- 34% have at least one employee
- 15% have paid salaries
- Apr 1 thousand organizations are in advocacy
- 720 organizations participated in consultations with Parliament or Ministries

5.1	6.2.	Sociālā aizsardzība	<i>Sociālā aizsardzība</i> Biedrības un nodibinājumi, kuru mērķis ir noteiktu iedzīvotāju grupu vai personu sociālās aizsardzības nodrošināšana, lai sekmētu cilvēku spēju pašiem nodrošināt savu pietiekamu dzīves kvalitāti konkrētā	88.99	19
	9. Tiesiskums un interešu aizstāvība				
	9.1.	Pilsonisko tiesību un cilvēktiesību aizsardzība	<i>Pilsonisko tiesību un cilvēktiesību aizsardzība</i> Biedrības un nodibinājumi, kas nodrošina pilsonisko tiesību un cilvēktiesību aizsardzību, jebkura veida diskriminācijas novēršanu saistībā ar dzimumu, rasi vai etnisko izcelsmi, reliģiju vai pārliecību, invaliditāti	94.99	
6.4	10. Filantropijas starpniecība un brīvprātīgā darba veicināšana				19
14.2.	Attīstības sadarbība	<i>Attīstības sadarbība</i> Biedrības un nodibinājumi, kas īsteno programmas un projektus, kas veicina sociālo un ekonomisko attīstību ārvalstīs, kā arī informē un izglīto vietējo sabiedrību par globālām problēmām un to risinājumiem	94.99		
		darba attīstību, tai skaitā piesaista un apmāca brīvprātīgā darba veicējus			
		domstarpību risināšana un ar tiesu saistītos jautājumos			
	9.4.	Patērētāju tiesību aizsardzība	<i>Patērētāju tiesību aizsardzība</i> Biedrības un nodibinājumi, kas nodrošina patērētāju tiesību aizsardzību un produktu kontroli, tai skaitā sniedz konsultācijas un atbalstu domstarpību risināšanā	94.99	

What is a patient organization?

- a nonprofit organization
- **Represents people with particular diagnosis or similar diseases according to their statutes**
- **Real patients or their relatives in the board or council**
- Works in at least 2 of 3 directions:
- Advocacy of patient interests,
- Education and awareness building about the disease and health,
- Ensures exchange of experience among patients and their relatives
- Can be regional, national, international

Source:

European Medicines Agency: https://www.ema.europa.eu/en/documents/regulatory-procedural-guideline/criteria-be-fulfilled-patient-consumer-healthcare-professional-organisations-involved-european_en.pdf

European Patients' Forum: <http://www.eu-patient.eu/About-EPF/whoweare/what-is-a-patient-organisation/>

Latvijas Pacientu
organizāciju tīkls



LATVIJAS RETO SLIMĪBU
ALIANSE



*14 patient
organizations in
rare diseases*



*31 patient
organization in
various disease
areas*



ONKOALIANSE



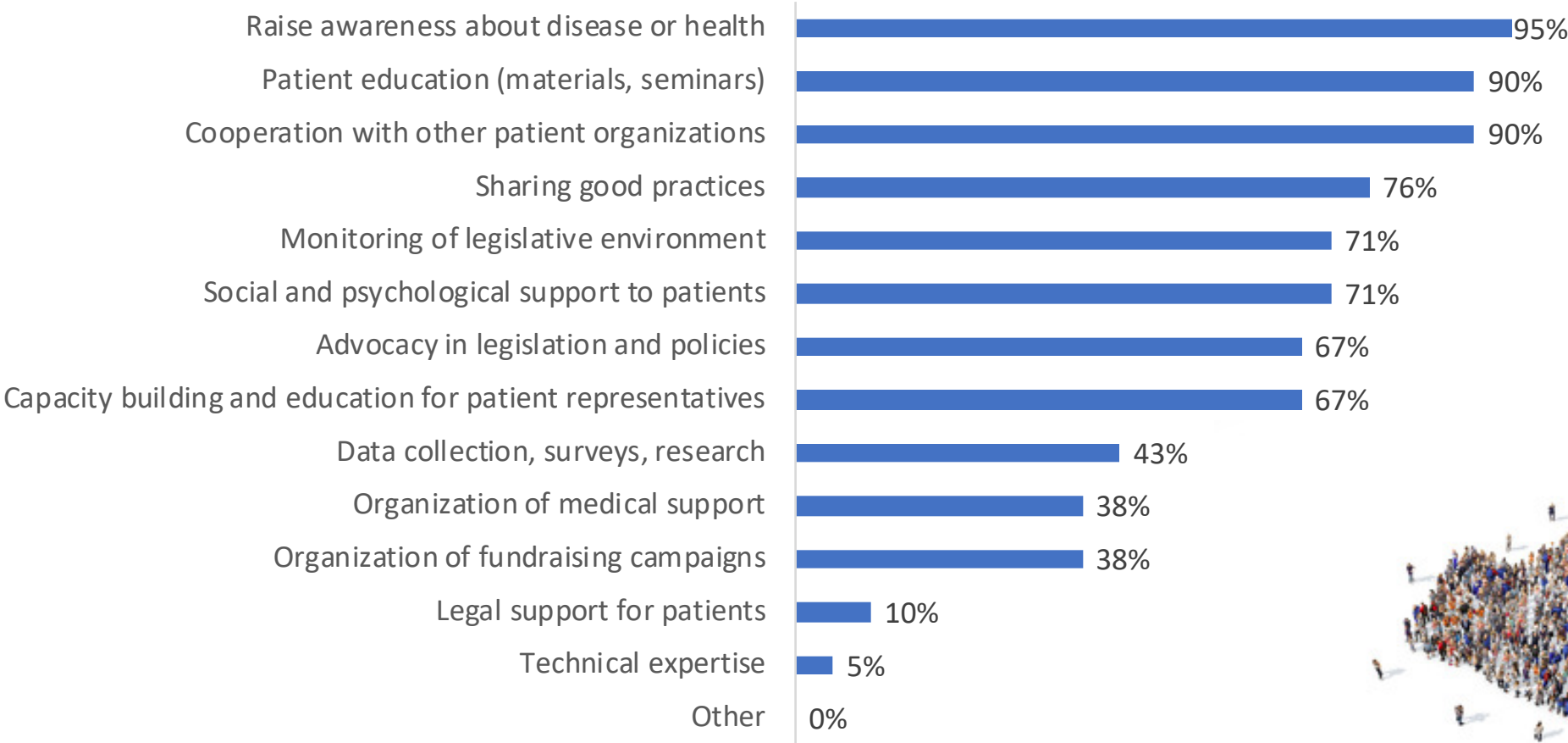
*7 patient
organizations
in cancer*



What is not a patient organization?

- Any nonprofit which is in health-care area
- Nonprofits focusing on social area
- Doctor organizations or professional associations
- Other associations
- Pharma companies
- Hospitals
- Government officials and employees of ministries and agencies

What we (POs) do?



Source: Survey of Patient organizations in Latvia, July 2019,
published in Abstracts of the 79th International Scientific Conference of the University of Latvia, Riga, Latvia
<http://medicina.lsmuni.lt/abstracts-of-the-international-scientific-conference-on-medicine-organized-within-the-frame-of-the-78th-international-scientific-conference-of-the-university-of-latvia/>

Network of Patient Organizations in Latvia

- Est. 2018
- 30+ leading patient organizations from various fields
 - Heart and coronary, endocrine, oncological, neuromuscular, various rare diseases, HIV and virus hepatitis, reumathological, autoimmune and other diseases
- With goal
 - **to improve quality of life and access to healthcare services for all patients, irrespective of their diseases,**
 - **to promote a legitimate, effective, transparent and inclusive healthcare system, and**
 - **to ensure the flow of information and cooperation among themselves and other players in the industry.**

In LPOT we

- Bring patient voice to decision makers
- Monitor everything in healthcare system
- Ensure communication and cooperation
- Share advocacy efforts and representation
- Build capacity for our members formally and informally
- Participate in research: data and evidence
- Grow member base



Patient organization involvement in research

- We validate survey design, questionnaires, UX
- We provide correct translations and adaptations
- We share invitations to participate
- We provide data collection to ensure privacy
- We explain data privacy and ethics
- We can summarize data
- We can validate or enrich conclusions



Patient engagement in Research

Before start

- Planned patient engagement across project
- Selection of appropriate engagement model
- Concept and hypothesis formulation together with appropriate patient partner
- Ensure budget and compensation for patient engagement

During project

- Together with patient reps assess TG needs and expectations
- Adapt research and procedures where necessary
- Assess impact of patient engagement already in middle and at end of project

Beyond project

- Communicate and disseminate project results
- Engage with community to implement results

Thank you!

Network of Patient Organizations in Latvia

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