



Patients Organizations Development Academy





PATIENTS.PRO

The project is being carried out in partnership between **the Faculty of Health Sciences of the Warsaw Medical University** and **the Employers' Union of Innovative Pharmaceutical Companies INFARMA** under the honorary patronage of **the Ombudsman for Patients' Rights**.



Patients Organizations Development Academy PATIENTS.PRO Program Council

PATIENTS.PRO Program Council is a social advisory body whose role is to provide opinions on the main directions of the Academy's activities.

It is formed by **21 experts on the healthcare system** – representatives of leading institutions, patients' organizations, academic experts, and healthcare professionals. The role of the Program Council is to initiate actions and give opinions on the main directions of the Academy's activities, thereby ensuring the best understanding of the needs of organizations by offering them the most effective educational program.



Marzanna Bieńkowska
Zastępca dyrektora Departamentu Współpracy w Biurze Szczelnika Praw Pacjenta i opiekun Rady Organizacji Pacjentów przy RPP



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Prezes Fundacji Razem w Chorobie
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dr n. med. Eżbieta Bylina
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Prezes Zarządu Głównego Polskiego Stowarzyszenia Diabetyków



Magdalena Kołodziej
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Dorota Korycińska
Prezes Zarządu Ogólnopolskiej Federacji Onkologicznej



Anna Kupiecka
Prezes Fundacji OnkoCafe – Razem Lepiej



Beata Malecka-Libera
Senator RP



Marzena Nelken
Dyrektor Krajowego Forum na Rzecz Terapii Chorób Rzadkich ORPHAN



Joanna Parkitna
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Grzegorz Perzyński
Prezes Fundacji Transplantacja LIVERstrong



Dagmara Samselska
Przewodnicząca Unii Stowarzyszeń Chorych na Łuszczycę



Malina Wieczorek
Prezes Fundacji SM-Walcz o Siebie
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Agnieszka Wołczyńska
Prezes Ogólnopolskiego Stowarzyszenia Pacjentów Pacjentów ze Schorzeniami Serca i Naczyn EcoSerce



Violetta Zajk
Prezes Ogólnopolskiego Stowarzyszenia „zmajmy się razem”
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dr n. med. i n. o zdr. Monika Zamarlik
Prezes Ogólnopolskiej Federacji Organizacji Pomocy Dzieciom i Młodzieży Chorym na Cukrzycę



Dariusz Żebrowski
Prezes Fundacji StopDuchenne
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Patients Organizations Development Academy PATIENTS.PRO

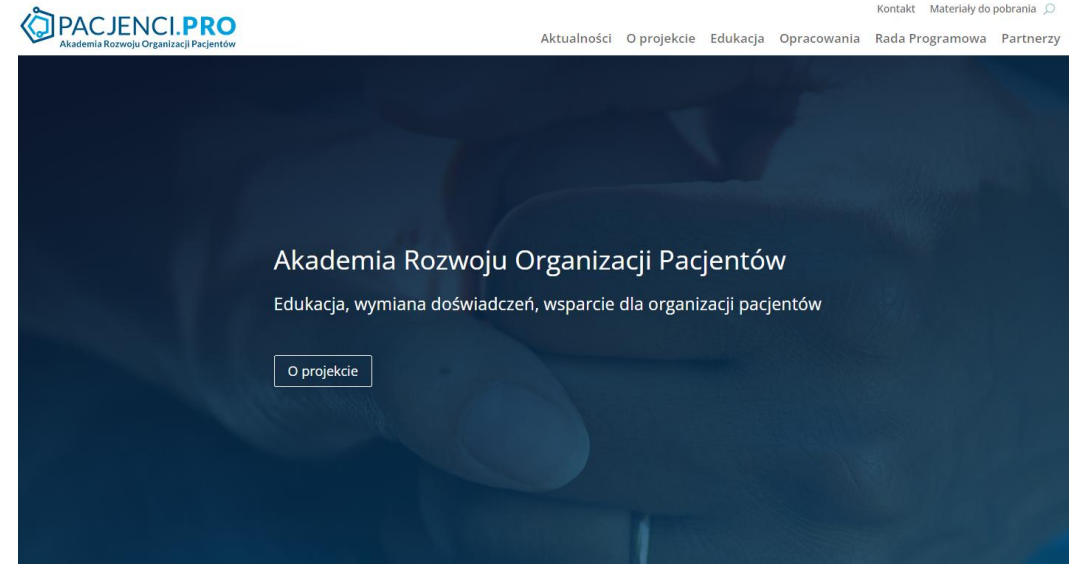
Patients Organizations Development Academy PATIENTS.PRO is **a nationwide program aimed at education, sharing experiences, and supporting patients' organizations.**

We want to provide ongoing support for the professionalization and empowerment of patient' organizations.

We strongly believe that it will enable patients' organizations stability so that they can work even more effectively for the health of Polish patients.

MISSION → To educate and support patients' organizations in developing their competences and independence

VISION → To build a development program which supports patient organizations. Our goal is to strengthen their competence and role in the healthcare system



Patients Organizations Development Academy PATIENTS.PRO is:

➤ TAILOR-MADE TO THE PATIENTS' ORGANIZATIONS NEEDS

The team which carries out PATIENTS.PRO program listen carefully to the opinions of participants and reacts flexibly immediately. As a result, the program responds to the actual needs of patient's organizations, reported, among other things, in regularly held consultations.

➤ CREATED FOR AND WITH PATIENTS' ORGANIZATIONS

The topics of online workshops, on-site workshops, and the Academy program are updated regularly.

➤ UNIVERSAL

The project does not focus on specific therapeutic areas; it is addressed to all patients' organizations. For those working on their behalf: both small and large patient's organizations established in small local centers and those operating in large cities.

➤ LONG-TERM

The implementation of the Academy is scheduled for several years.



PATIENTS.PRO – the project's 3 main pillars

1st PILLAR:

EDUCATION: PATIENTS.PRO ACADEMY

- **A comprehensive training program to strengthen the skills of patients' organizations.**
- We address the training and workshop program to meet the needs of patients' organizations so that they benefit as much as possible from the training provided.
- The educational plan of the **ACADEMY.PRO** is being developed through consultations with the Program Council and conducted surveys.

2nd PILLAR:

REPORTS & RECOMMENDATIONS

- **As part of the project Reports on healthcare issues are being developed. The materials create valuable sources of knowledge for organizations, especially on the participation and role of the patients' organizations in the processes shaping the healthcare system both in Poland and abroad:**
 - „The role of patient organizations in the healthcare system in Poland and around the world”.
 - „Directions of change for increased participation of patient organizations in Poland”.
 - „Barometer of involvement of patient organizations in processes of shaping the healthcare system in Poland in 2021”.
 - „Patient organizations in the healthcare system. Growth in value and capacity over the years, prospects”.
 - „Barometer of involvement of patient organizations in processes of shaping the healthcare system in Poland in 2022-2023”.

3rd PILLAR:

PLATFORM FOR SHARING EXPERIENCES Meetings, workshops, conferences, exchange of international experiences and CONVERSATIONS.PRO

- **The tools that are being implemented as part of the project meet the expectations and the needs of patients' organizations. Representatives of institutions are also invited to take part in individual activities.**
- We organize workshops with experts on topics that are currently relevant to the patients' organizations including the healthcare system and clinical trials.
- We organize conferences that unleash the role and the potential of patient organizations internationally.
- As a part of the CONVERSATIONS.PRO, we have presented what barriers patients' organizations face. Moreover, we show their role in developing the healthcare system and the benefits of cooperation between patients' organizations and public administration.

STRENGTHENING THE SKILLS OF PATIENTS' ORGANIZATIONS

Comprehensive & and free training courses and workshops. The program aims to implement the knowledge and skills necessary for the operation of the patients' organization.

The training program of the PATIENTS.PRO Academy has been prepared so that everyone can choose the classes that will help them develop the most necessary skills.

There are more than **400 hours of workshops**, training, and consultations with **17 experts**.

3 educational levels:

- basic – group training,
- advanced – training and individual consultations,
- expert – a package of individual consultation.

WE INVITE YOU TO PARTICIPATE IN THE ACADEMY

PROGRAMME OF ACTIVITIES: <https://www.pacjenci.pro/edukacja/>

PATIENTS.PRO ACADEMY



WITHIN THE 6 SEMESTERS (2021-2024) OF THE PATIENTS.PRO ACADEMY, 6 THEMATIC BLOCKS WERE HELD:

During the academy, we worked on topics such as:

- leading an NGO (vision, mission, strategy, management),
- effective leadership in an NGO,
- paid and economic activities of non-governmental organizations,
- dissemination and promotion of the activities of NGOs; principles of methods of communication with the public,
- communication skills in the digital world - platforms, communicators, ways of working online,
- fundraising.

PATIENTS.PRO ACADEMY

135 participants

75 patients organizations



PACJENCI.PRO
Akademia Rozwoju Organizacji Pacjentów



COMPLETED WORKSHOPS

TRAINING BLOCK	1 ST SEMESTER: 104 hours	2 ND SEMESTER: 104 hours	3 RD SEMESTER: 80 hours	4 TH SEMESTER: 80 hours	5 TH SEMESTER: 32 hours	6 SEMESTER: 32 hours
I. Strategic management	Running an NGO (vision, mission, strategy, governance)	Design thinking in an NGO			Occupational hygiene in NGOs – work-life-balance and burnout prevention	
II. Operational management	Effective leadership in an NGOs	Systems and software supporting the organization		Crisis management – reductions and changes		
				Effective leadership in an NGO, individual mentoring		
				Professionalization of people management in the organization		
III. Funding and legal and formal issues in the organisation	Funds in a patient organisation – law and practice	Protection of personal data in the organization (along with the implementation of the GDPR)		Paid and economic activities of non-governmental organisations		
IV. Building and maintaining relationships with the environment	Dissemination and promotion the activities of the NGO; Principles of the public transport method	Image creation and activity in electronic media	Planning and implementation of social campaigns	Image creation and activity in electronic media	Graphic design – Practical aspects of communication and marketing	Image creation and activity in electronic media (website, social media) - social media in practice
			Self-presentation and public speaking			
			Relationships with recipients of your organization's activities			
V. Building and maintaining relations with the environment	Communication skills in the digital world – platforms, communicators, forms of on-line work	Communication competences in the digital world – platforms, communicators, forms of on-line work	Partnerships and cooperation with partners from three sectors – local government, business, NGOs	Negotiation and problem solving; Influencing and assertiveness as personal and organisational competences	Self-presentation – courage and partnership – repetition	Partnerships and cooperation with partners from three sectors: local government, business, ngo's - business communication
			Public Affairs – how to take care of dialogue, relationship and needs in relations with decision-makers	Cooperation with journalists and public figures – practice		
VI. Financing the activities of the organization	Sources of NGO funding – practical guide	Fundraising			Financing the organization's activities – repetitory	Projects and finances in practice
	Fundraising					



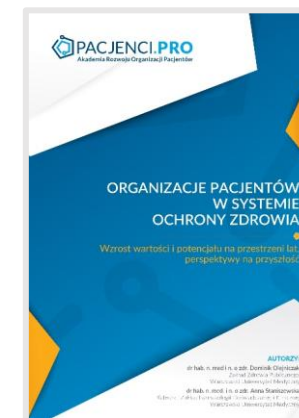
REPORT:
The role of patients' organizations in healthcare system in Poland and worldwide

This is a study, showing comprehensively the determinants and models of patients' involvement in shaping the healthcare system at all levels. The report aims to analyze patient organizations' involvement models in Poland and compare them with solutions used in other countries, such as the Czech Republic, Great Britain, the Netherlands, and Canada.



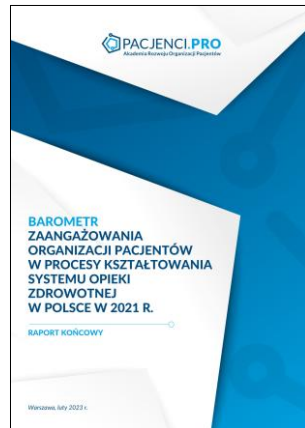
DOCUMENT:
Directions of change for increasing participation of patients' organizations in Poland

The study provides a starting point for discussion of the extent to which patients' organizations can be involved in selected areas of health policy.



REPORT:
Patient organizations in the health care system. Growth in value and capacity over the years, future prospects

The report includes, among others: an attempt to systematize current activities to involve patient organizations in creating solutions within the healthcare system, as well as to develop recommendations for further development in this area. The publication also describes international examples that can serve as models for cooperation between patient organizations and decision-makers in Poland - the Czech Republic and Great Britain. Unlike the first PATIENTS.PRO report, the document also touches on the activities of organizations from Greece.



REPORT:
Barometer of patients' organization involvement in processes of shaping the healthcare system in Poland in 2021

The report is based on a survey to determine fields in which patients' organizations have shaped the healthcare system in 2021. The survey also assessed cooperation with central institutions, including identifying barriers to cooperation.



REPORT:
Barometer of patients' organization involvement in processes of shaping the healthcare system in Poland in 2023-2024

The main objective of the survey was to determine to what extent and in what form patient organizations were involved in selected processes related to the shaping of the healthcare system in 2022 and 2023, and how the level of this cooperation has changed in comparison with 2020-2021. The cooperation of patient organizations with the Agency for Health Technology Assessment and Tariff System, the Office of the Patient Ombudsman, the Headquarters of the National Health Fund, and the Ministry of Health was evaluated, and for the first time, the cooperation was examined with the Medical Research Agency and the Center for e-Health.

COOPERATION WITH POLISH AND INTERNATIONAL HEALTHCARE INSTITUTIONS

- As part of PATIENTS.PRO Academy tools to address the current needs and challenges of patients' organizations are being developed.
- We invite institutions that participate in shaping the healthcare system in Poland to join us and cooperate with PATIENTS.PRO Academy.
- The institutions are invited to organize or co-lead workshops (including healthcare system workshops) and conferences (international ones) and provide commentaries during PATIENTS.PRO conferences (documentary premieres) or to take part in videos (CONVERSATIONS.PRO).



INTERNATIONAL EXPERIENCE EXCHANGE

1st International Conference entitled "The healthcare system today and tomorrow. A perspective on the experience of patients' organizations", November 10th, 2021.

Esteemed & international guests:

- **René Břečťan**, Vice Chairman of the Czech Association of Rare Diseases (ČAVO) and Vice Chairman of the Executive Committee of Parent Project, Czech Republic,
- **Victoria Thomas**, National Institute for Health and Clinical Excellence (NICE), United Kingdom.

The conference was dedicated to the inclusion of patients' organizations in the shaping of the healthcare system and the major challenges they face in a post-pandemic world.


Public policy, patients' voices - NICE's public involvement work

Victoria Thomas
Head of Public Involvement

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NICE National Institute for Health and Care Excellence





René Břečťan
Wiceprzewodniczący czeskiego Stowarzyszenia Chorób Rzadkich (ČAVO)

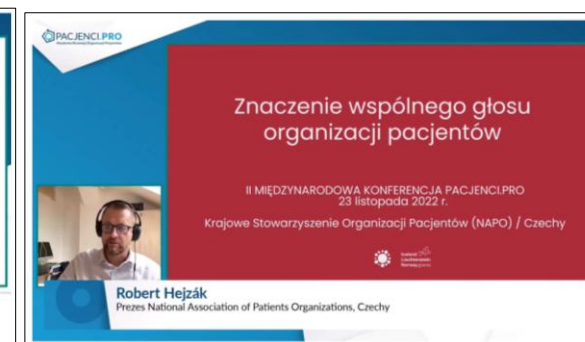
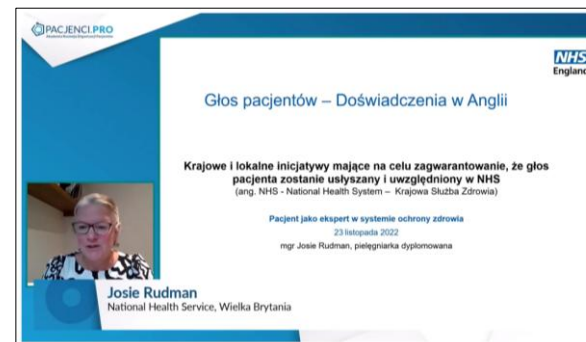
2nd International Conference PATIENTS.PRO "The patient as an expert in the healthcare system. Perspective and experiences of patients' organizations", November 23rd, 2022.

Cooperation with representatives of international health institutions and the British Embassy in Warsaw:

- **Josie Rudman**, representing the UK's National Health Service (NHS), head of New Hospitals Programme Transformation, NHS England and NHS Improvement,
- **Elena Marušáková**, Association for the Protection of Patients' Rights of the Slovak Republic "Vice President", Slovakia
- **Robert Hejzák**, head of the National Association of Patients Organizations,
- **Anna Arellanesová**, head of Rare Diseases Czech Republic.

During the conference, **topics on common areas and processes in which the experience of patients' organizations can contribute to improving the functioning of the healthcare system** in Poland and other European countries.

INTERNATIONAL EXPERIENCE EXCHANGE



INTERNATIONAL EXPERIENCE EXCHANGE

III International Conference PATIENTS.PRO "The patient as a co-creator of the health care system - experiences of patient organizations in Poland and around the world", March 21st, 2024.

The event was held **stationary** for the first time at Warsaw Medical University. Representatives of patient organizations, medical and system experts, and **international guests from Hungary, the Czech Republic, and Greece attended the conference.**

Representatives of public institutions present were:

- **Joanna Poźniak**, Counselor in the Department of Social Dialogue, Ministry of Health,
- **Jakub Gołąb**, Director of the Department of Cooperation in the Office of the Patient Ombudsman,
- **Elżbieta Bylina, PhD** Deputy Director of the Clinical Research Development Center at the Medical Research Agency,
- **Joanna Parkitna**, Medical Technology Assessment Department Director, Agency for Health Technology Assessment and Tariff System.

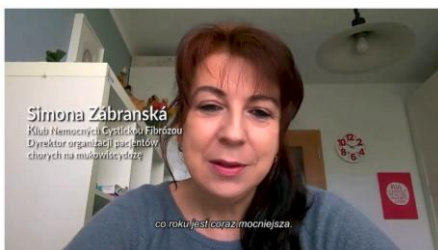
[A summary from the conference is available at PATIENTS.PRO.](#)



We invite leaders of patient organizations, MPs and senators, and representatives of public institutions to join the series.

So far, our invitation has been accepted by:

- **dr n. med. Beata Małecka-Libera**, senator of the Republic of Poland, chairwoman of the Senate Health Committee,
- **Barbara Dziuk**, member of the Polish Parliament and the Parliamentary Health Committee,
- **Anna Kupiecka**, President of the Onkocafe Foundation - Together Better,
- **Grzegorz Perzyński**, President of LIVER Strong Transplant Foundation,
- **Dagmara Samselska**, President of AMICUS Psoriasis and Psoriasis Foundation,
- **Magdalena Kołodziej**, President of WE Patients Foundation
- **Simona Záborská**, head of the Association of Cystic Fibrosis Patients, Czech Republic,
- **Paweł Kikosicki**, head of e-Health Center.



CONVERSATIONS.PRO



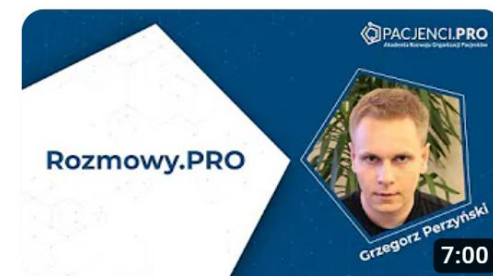
Rozmowy.PRO: Anna Kupiecka o tym, co daje jej siłę do działania



Rozmowy.PRO: Magdalena Kołodziej o zmianie lidera w...



Rozmowy.PRO: Dagmara Samselska o dialogu w ochronie zdrowia



Rozmowy.PRO: Grzegorz Perzyński – „raczkująca” organizacja...

WORKSHOPS AND WEBINARS ABOUT HEALTHCARE SYSTEM

Some workshops and webinars:

- 1st online meeting: „System ochrony zdrowia a rola organizacji pacjentów”, Maria Libura, PhD and Magdalena Władysiuk, vice president of HTA Consulting (10.06.2020 r.).
- „Kultura współpracy z pacjentami w Wielkiej Brytanii i w Polsce – warsztat wymiany doświadczeń pacjentów”, Josie Rudman, NHS, in cooperation with the British Embassy in Warsaw (21.09.2022 r.).
- „Rola organizacji pacjentów w badaniach klinicznych – ocena etyczna”, - in cooperation with the Medical Research Agency (17.10.2022 r.).
- „Jak wyrównać różnice we współpracy z instytucjami ochrony zdrowia?”, representatives of administration (MZ, RPP Office, NFZ) and patients' organizations, (13.04.2023 r.).
- „ROZMOWY.PRO: Organizacje parasolowe” Anna Kupiecka, President of the OnkoCafe Together-Better Foundation, and Marzena Nelken, Director of the ORPHAN National Forum (23.07.2024).
- „AOTMiT w pigułce...” – materiały edukacyjne dla organizacji pacjentów webinar organized in partnership with the Agency for Health Technology Assessment and Tariff System (05.11.2024 r.).
- „Wartość, jaką organizacje pacjentów mogą wnieść do systemu ochrony zdrowia...” – warsztat organizowany z Fundacją Rzecznicy Zdrowia (04.12.2024 r.).



We invite you to share information about the PATIENTS.PRO project with all patient organizations, which you meet on your way!



You are welcome to contact us by e-mail: kontakt@pacjenci.pro



Find out more on project: www.pacjenci.pro



We encourage you to follow the social media channels of PATIENTS.PRO:

