

# AIPM PATIENT ORGANIZATION STRATEGY

IN PARTNERSHIP FOR PATIENTS

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## Introduction

The Association of Innovative Pharmaceutical Manufacturers (AIPM) is committed to the long-term development, independence, and professional strengthening of domestic patient organizations. The AIPM is in a unique position: it is able to support and connect the worlds of patients, the industry, and healthcare decision-makers. Our goal is to create a partnership that ensures that patient organizations are active, competent, and recognized actors in the healthcare system – both in decision-making and in representing patients.

## Situation Analysis

### Current challenges

The domestic patient-organization ecosystem struggles with numerous systemic and operational difficulties that hinder the long-term development, stability, and policy influence of the organizations.

- **Small size, volunteer operation, and lack of resources**

Most organizations operate with a few members, often on a volunteer basis, which results in vulnerability regarding resources. This limits strategic planning, the ability to bear administrative burdens, and the sustainable implementation of projects. Due to a lack of resources, survival is often the goal rather than long-term development. There are few truly strong organizations with a long history.

One group of patient organizations consists of those whose members are typically patients and their relatives. These organizations provide advocacy for patients and, in many cases, also support them in meeting the most basic needs. The other type are patient education and health promotion organizations, which mainly deal with prevention, awareness-raising, and information campaigns, typically organized around a specific therapeutic area.

From a funding perspective, these organizations operate on a non-profit basis, most managing with small annual budgets, relying on a few sponsors. Organizations that operate with their own employees and larger budgets are rarer. State subsidies are rarely accessible. An important opportunity is the offering of 1% of income tax, which can be granted to organizations that have at least two closed financial years.

- **Isolation and lack of knowledge sharing**

Cooperation is rare, and patient organizations often work alone in their own field. There is no established practice of systematic sharing of knowledge and best practices,

which limits innovation and the possibility of collective advocacy. When developing its strategy, the AIPM mainly focuses on issues related to patient organizations. Experiences of recent years show that a few patient organizations and their leaders perform outstanding work and are known and recognized internationally. However, the vast majority of organizations still operate in isolation, are not active internationally, and often do not even share knowledge regularly at the national level across different therapeutic areas.

In 2020, the ABEP (AIPM and Patient Organizations Cooperation Platform) was launched, which plays the role of the EFPIA Patient Think Tank in Hungary. ABEP was relaunched in October 2022 after a one-and-a-half-year break, and from 2023 it has been operating regularly on a quarterly basis.

- **Hindered participation in decision-making**

The current legal and institutional frameworks do not support the meaningful involvement of patient organizations in healthcare policy decisions. Due to the lack of structured consultations, formal representation channels, and participation rights, the patients' voice often does not appear with appropriate weight in policy debates.

- **Missing feedback mechanisms**

There is no institutionalized system for measuring, evaluating, or integrating the impact of patient advocacy activities into professional decision-making. In the long term, this weakens the credibility and influence of patient representation.

## Strengths and opportunities

In addition to challenges, there are numerous resources and opportunities available that AIPM's strategic development can build on.

- **Already existing platforms (ABEP, Patient Organization Academy, Patient Organization Meetup)**

AIPM's earlier initiatives – such as ABEP, the Patient Organization Academy, and the Patient Organization Meetup – provide a stable foundation for further development. With these, not only structured dialogue and training can be realized, but the patient-organization ecosystem can also be strengthened.

- **Opportunity to integrate into decision-making**

Alongside the AIPM Patient Organization Academy program, the Expert Patient Representation training program will also start in 2025 under the care of AIPM, which specifically prepares patient organization representatives to participate in healthcare policy and professional decision-making processes in a meaningful and credible way. This training raises the quality and role of patient representation to a new level.

- **Motivated and open-to-learning organizations**

On the part of patient organizations, there is a clear demand for development, knowledge expansion, and professional networking. This openness is an important basis for the success of competence-building programs.

- **Institutional representation and structured advocacy channels**

In Hungary, a legal framework has already been created that would allow patient organizations to meaningfully join processes related to healthcare provision and therapeutic decisions. One of its key instruments is the National Patient Forum (NBF), which was established by law as a state advocacy platform (Decree 50/2012. (XII. 19.) of the Ministry of Human Resources on the National Patient Forum). However, in recent years, the Forum has become inactive, and its operation is not ensured. At the same time, the Hungarian Association of Patient Organizations (BEMOSZ) also exists, which, as a civil umbrella organization, seeks to integrate and represent the interests of patient organizations. BEMOSZ operates with active leadership and, with proper support, carries serious potential in strengthening the organizational network. The current environment creates an opportunity to encourage the revival and sustainable operation of the NBF as a state-level connecting point, building on the already existing legal foundations. Alternatively, or in parallel, the role of BEMOSZ can also be strengthened, which, from the civil side, can provide organized, credible, and structured representation. Strengthening both directions would promote patient organizations becoming genuine strategic partners in decision-making.

- **Access to international examples and best practices**

International organizations such as the EPF (European Patients' Forum) or EFPIA (European Federation of Pharmaceutical Industries and Associations) already operate models and standards that show a clear development path. Adapting these makes it possible for Hungarian patient organizations to also become integrated actors in domestic and European healthcare systems.

## SWOT Analysis

<p><b>Strengths:</b></p> <ul style="list-style-type: none"> <li>○ Structured, long-term strategic commitment by AIPM to support patient organizations</li> <li>○ Well-established platforms: ABEP, Patient Organization Academy, Meetups</li> <li>○ Training-based capacity building</li> <li>○ Objective of integration into decision-making (e.g., HTA process)</li> <li>○ Communication support: publications, awards, opportunities to participate as exhibitors and speakers at conferences</li> </ul>	<p><b>Weaknesses:</b></p> <ul style="list-style-type: none"> <li>○ High dependency on AIPM as the main (non-financial) supporter</li> <li>○ Lack of diversification in funding</li> <li>○ Legal changes strongly dependent on political will</li> <li>○ Lack of bottom-up civil initiatives</li> <li>○ Lack of English language knowledge</li> </ul>
<p><b>Opportunities:</b></p> <ul style="list-style-type: none"> <li>○ Connection to EU HTA and other decision-preparation processes</li> <li>○ International connections (EPF, EFPIA)</li> <li>○ Definition of patient organizations and their roles in legislation</li> <li>○ Strengthening the role of NBF</li> <li>○ Increasing the advocacy power of the civil sector</li> <li>○ Presence of organizations motivated for development</li> <li>○ Increasing public trust in clinical trials through patient-side communication</li> </ul>	<p><b>Threats:</b></p> <ul style="list-style-type: none"> <li>○ Lack of political will for legal and institutional reforms</li> <li>○ Patient organizations being treated only as tools for representation</li> <li>○ Low level of public acceptance</li> <li>○ Increasing fragmentation and disintegration of the civil sector</li> </ul>

## Strategic Vision and Mission

### Our Vision

Our goal is to promote the creation of a sustainable and professional patient-organization ecosystem that not only exists on the periphery of the healthcare system but also actively shapes it. We aim to contribute to enabling these organizations to:

- operate independently and manage resources,
- form professionally well-founded opinions,
- participate meaningfully in decision-making,
- represent patients' interests both at national and international levels,
- take part in promoting clinical trials and encouraging participation.

This vision serves not only the strengthening of organizations but also the development of a patient-centered healthcare system.

### Our Mission

AIPM's role in this process is supportive: it connects patients, the pharmaceutical industry, and decision-makers. The goal is not merely to provide support, but to strengthen patient organizations so that they are also able to operate independently in the long run and become credible actors within the healthcare ecosystem.

Key tools for achieving these goals are the initiatives operated by AIPM:

- **ABEP** (AIPM and Patient Organizations Cooperation Platform), which provides structured dialogue between industry, patient organizations, and, where possible, decision-makers,
- **AIPM Patient Organization Academy**, which offers training and community-building aimed at strengthening organizations,
- **AIPM Expert Patient Representation Academy**, which prepares representatives for participation at decision-making levels,
- **Patient Organization Meetup**, which aims at knowledge expansion and community building.

Together, these tools form the professional and infrastructural foundation that enables the realization of the goals set out in our vision.

Our aim is for patient organizations to become strategic partners and to fulfil a socially recognized role.

## Strategic Goals

### 1. Structured Partnerships and Platforms - ABEP

AIPM's goal is to support dialogue and cooperation among the relevant stakeholders in a structured form. One of the main tools for this is **ABEP** (AIPM and Patient Organizations Cooperation Platform), which provides a forum for dialogue in the form of regular quarterly meetings. These meetings create opportunities to define common priorities, exchange experiences, and develop joint proposals.

At the forums, participants can discuss current issues, news, and topics relevant to patient and industry communities in a compliant manner. The events are complemented by professionally recognized, inspiring presentations – preferably at decision-maker level – that contribute to expanding participants' knowledge and reinforcing the foundations of long-term cooperation.

### 2. Patient Organization Academy and Expert Patient Advocacy Academy

AIPM supports the capacity building of patient organizations with two distinct but complementary training programs:

#### *a) AIPM Patient Organization Academy*

Launched in 2023, this training program aims to develop the leadership skills of patient-organization leaders so they can manage their organizations effectively with a strategic perspective.

#### **Curriculum:**

- Leadership skills: strategic planning, organizational development, volunteer recruitment
- Communication and advocacy techniques: effective message shaping, maintaining relations with different target groups
- Legal awareness and regulatory knowledge: operational frameworks, civil law, healthcare regulation

This knowledge ensures that participants can consciously and successfully lead their organizations.

#### *b) AIPM Expert Patient Advocacy Academy – program starting in 2026*

This advanced-level training program builds specifically on participants who have completed the Patient Organization Academy. Its goal is to enable committed patient representatives, who already possess solid knowledge, to move forward and credibly represent patients' interests at healthcare policy and decision-making levels.

Within the program, emphasis is also placed on understanding the role of clinical trials and promoting participation and education.

#### **Curriculum:**

- The changed role of the Expert Patient: acting as a strategic partner
- Negotiation skills: developing negotiation techniques for discussions with NEAK (National Health Insurance Fund of Hungary), professional boards, and healthcare policymakers
- Political environment and advocacy: understanding the healthcare system and decision-making mechanisms
- Professional communication: reaching different professional target groups (e.g., professors, hospital directors) and communicating messages appropriately
- Health economics perspective, data-based reasoning: using relevant data to support arguments for decision-makers

This program not only provides knowledge but also active preparation for participation in healthcare policy and professional forums.

### **3. Participation is Decision-Making**

AIPM's goal is for patient organizations not merely to observe but to actively shape healthcare policy decisions. To this end, AIPM sets itself the following tasks:

- encourage and support the revival of the **National Patient Forum (NBF)** as a functioning state representative body for patient organizations,
- aim for the legal definition of the concept of a patient organization,
- consider it necessary to review the legal and institutional environment to ensure that patient organizations have real opportunities to provide input into HTA and other decision-making processes.

This approach ensures that patients' opinions are genuinely incorporated into healthcare policy decisions.

### **4. Communication and Visibility**

The work of patient organizations achieves its purpose only if it becomes visible to society and decision-makers. AIPM supports this in the following ways:

- preparing a **Patient Organization Publication** that informs doctors about domestic patient organizations, so they can provide their patients with credible information for accessing support and community connections,
- presenting exemplary civil initiatives through the **Health Literacy Award** and other recognitions,
- providing opportunities for graduates of the Expert Patient Representation Academy to participate in AIPM-organized professional forums.

All this contributes to increasing the social acceptance of organizations.

## 5. Participation in Clinical Trials

Among the strategic objectives, strengthening the role of patient organizations in social communication and participation related to clinical trials is a high priority, considering that they can be key players in increasing public trust and awareness.

- Encouraging patient organizations to use their communication and educational tools to improve access to clinical trials and increase public awareness.
- Disseminating knowledge about clinical trials within training programs.
- Establishing partnerships with professional actors conducting or coordinating clinical research in order to improve patient involvement.

## Implementation Roadmap (2025–2027)

- **Development and operation of training programs:**
  - Continuation of the Patient Organization Academy with the following schedule: after 2 Academy cohorts, one Expert Patient Representation Academy cohort will follow.
  - Launch of the Expert Patient Representation Academy, followed by the organization of its second cohort.
  - Integration of knowledge related to clinical trials into the training programs.
- **Strengthening professional and decision-making connections:**
  - Developing a strategy for patient-organization participation in EU HTA processes, in cooperation with certain patient-organization representatives, the NNGYK (National Public Health Center) Department of Health Technology Assessment, and members of the AIPM Patient Engagement Task Force.
  - Strategic proposals and awareness-raising programs aimed at involving patient organizations in decision-making.
  - Establishing the legal definition of patient organizations.
- **Networking, visibility, and community:**
  - Preparation and distribution of a Patient Organization publication.
  - Organization of regular patient-organization meetups for knowledge sharing and community building.
  - Expanding the circle of patient organizations connected to AIPM.
  - Encouraging patient organizations to engage in communication activities related to clinical trials.
- **Ongoing activities:**
  - Providing opportunities for graduates of the Expert Patient Representation Academy to participate in professional forums.
  - Strategic fine-tuning based on annual evaluations and feedback.

## Monitoring and Sustainability

- After each training cycle, corrections will be made based on evaluations and feedback.
- Monitoring and updating of the strategy within the framework of the **Patient Engagement Task Force**.