



REPORT 2018

ACADEMY OF PATIENT ORGANIZATIONS



Zuzana Komárková
APO Project Manager, AIFP

THE ACADEMY OF PATIENT ORGANIZATION (APO)

is an AIFP educational and capacity building project intended for the Czech patient organizations with the main pillars:

- Education
- Multi-source funding
- Networking
- Transparency

The goals of APO are primarily:

- To promote the independence of the Czech patient organizations
- To support their long-term development
- To improve quality of internal processes and transparency in financing
- To get funding from the Czech and EU sources
- To improve the quality of their negotiation and communication skills
- To use the internet and Social media effectively
- To explain Legal process, rights and duties of patients

2012

APO has started in 2012. The Kick off meeting was held in the Parliament of the Czech Republic. The special guest Mary Baker, President of the European Brain Council, the deputies of the Health Committee and more than 40 representatives of patient organizations participated at the Kick off meeting. **30 patient organizations** were involved in APO 2012–2013 and were represented by 44 individual attendees.

2013

APO followed in 2013 by **Advanced Retraining course “NGO Effective Manager” – accredited by the Ministry of Labor and Social Affairs.** Number of 18 individual representatives of patient organizations participated the course. It included 16 all-days of education with screened presence and one examination day. Successful attendees received an official certificate.

2014

APO in 2014 began by the Kick off meeting in the Senate of the Czech Republic in October 2013 and Mr. Martin Holcát, the Minister of Health of the Czech Republic granted the **first auspices to the APO project.** With 27 newly registered patient organizations APO continued with **57 patient organizations** and **25 full-day lectures. APO Alumni,** the first annual informal meeting of representatives of patient organizations and deputies of the health care system, was initiated in October 2014 and was held in the U.S. Residence in Prague. His excellence Mr. Andrew Shapiro, US Ambassador in the Czech Republic opened the event. APO received the **second auspices** from the deputy of the Minister of Health of the Czech Republic.

Anonymous Online advisory center “I Know My Medications”, a sub-project of APO was launched in June 2014. It helps patients to understand the medications they are taking and to identify potential interactions and multiple use of the same molecule and also to recognize specific food and herbs that should be avoided. We have received more than 40 000 queries until the end of October 2017. For more [information](#).

2015

APO continued in 2015 with **71 involved Czech patient organizations** and **24 all-day lectures** took place. **APO Advisory Board** with 9 members was established in June 2015. The next sub-project **APO Summer School**, all-day event in cooperation with the Czech Medical Association of J. E. Purkyně was held in the end of summer 2015. Its task to achieve closer collaboration between representatives of patient organizations and deputies of Medical Professionals.

APO Alumni II was held in the British Embassy in Prague. Her excellence Mrs. Jan Thompson warmly welcomed the participants. The invitation accepted Mrs. Nicola Bedlington, European Patients' Forum (EPF), Mrs. Lenka Teska Arnoštová, the first deputy of the Minister of Health in the Czech Republic, Mrs. Alena Šteflová, Head of WHO Country Office in the Czech Republic, more than 60 representatives of patient organizations and other interest groups in the Czech healthcare system. In summer 2015 **APO Facebook profile** was created.



Akademie pacientských organizací

2016

More than **80 Czech patient organizations** were involved in APO 2016 and their representatives attended **24 all-day APO lectures**. Two of these workshops were organized in cooperation with the Ministry of Health of the Czech Republic.

APO Advisory Board met two times in 2016 and supported to organize the second Annual **APO Summer School II**, all-day event in cooperation with the Czech Medical Society to continue in dialogue and deeper cooperation. Both sides, representatives of patient organizations and medical professionals met at the Round tables on 11 different therapeutic areas. One and half long discussion with the first deputy to the Minister of Health of the Czech Republic was on the program of the APO Summer School II.

APO Award in two categories: The best ongoing project (winner was Mamma HELP) and the best innovative project vision (winner Parkinson-Help) was announced for the first time in 2016. The third **APO Alumni III** was held under the patronage of the French Ambassador in November 2016 at the French Embassy in Prague. The representatives of the patient organizations and the deputies of the Ministry of the Health, the State Institute for Drug Control, World Health Organization, Czech Medical Society JEP, Industry, media and others participated the event.

APO Alumni II 2015



APO Award 2016



2017

APO continued with more than **90 patient organizations** who had a chance to attend **23 all-day workshops**. The most useful topics were: fundraising, funds and project applications, networking, using the internet and social media, legal processes, rights and obligations of patients etc.

50 representatives of patient organizations participated in a **three-day programme in Brussels** under the auspices of Mrs. Kateřina Konečná, a member of the European Parliament. The main part of the Brussel programme was the conference "Why Europe".

Round tables, dedicated to different therapeutic areas, were an essential part of the conference. Czech representatives had a chance to meet representatives of European patient umbrella organizations and discuss closer cooperation. On a following day, the APO networking event was held in the Prague House in Brussels. The Minister of Health, the first Deputy to the Minister, representatives of the European Parliament, the European umbrella organizations, the Permanent Representation of the Czech Republic to the EU, the EFPIA, pharmaceutical industry representatives and others attended the event

and the representatives of Czech patient organizations had thus chance to meet and talk to them in person.

In 2017, an all-day patient conference the **APO Summer School** was held, the main topic being the Health Technology Assessment (HTA). Key European HTA experts and a representative of patients from Germany had accepted our invitation.

The second **APO Award** in two categories was announced in October 2017.

Based on APO members request, the **APO Networking meeting** was organized at the end of the year 2017. All the participants had prepared short presentation about activities of their patient organizations. They discussed hot topics and shared advice and best practice.

Since 2014, the **APO Alumni** has been organized. In 2017, it was for the fourth time and it was organized under the auspices of Senator Mrs. Milada Emmerová in the Senate CR.

APO is active on the APO website and in social media.

APO in Brussels 2017



Report 2018



more than **90** patient organizations involved in APO

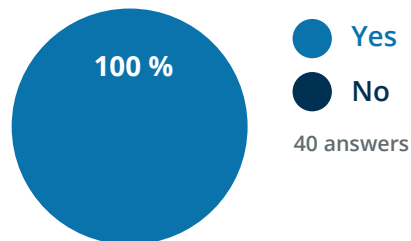


20 all-day workshops

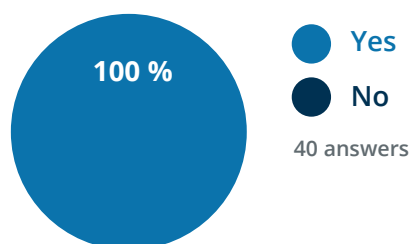
5 all-day HTA workshops

APO Survey

1. Will you continue in 2019?



2. Practical benefits from APO educational programme for management of your patient organization?



What topics were the most helpful?

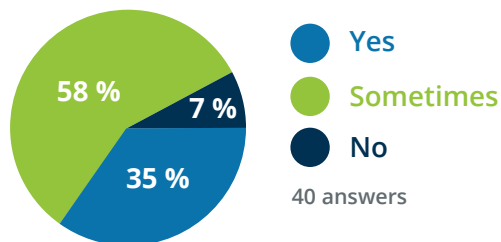
Fundraising and marketing
GDPR
Accounting and taxes NGO
Conflict resolution prevention
Personal Typology MBTI
Burnout
etc.

3. What educational topics would you welcome in 2019?

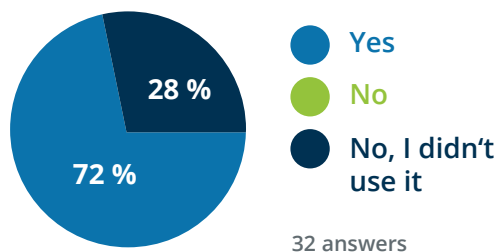
Fundraising and marketing
Legal aspects
Communication, PR
Accounting and taxes

Management of NGO
The Internet and social media
Project management
etc.

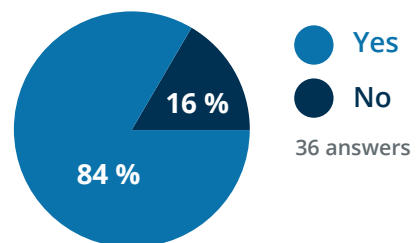
4. Do you use the APO Calls for proposal focused on patient organization needs at <https://patientskaakademie.cz/cs/monitoring-vyzev/> ?



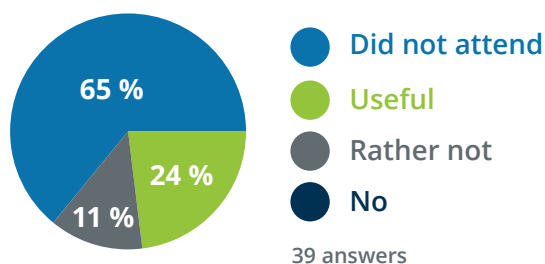
5. Was the APO mentoring in 2018 helpful for you?



Do you wish to continue with mentoring in 2019?



6. Was the HTA educational programme in cooperation with the Ministry of health beneficial for you?



Would you like to attend the HTA programme in 2019?



APO Overview 2018

APO Mentoring

APO has started with mentoring in 2018 within two areas.



Dates
March – June 2018



85 hours



38 patient organizations

1. The Internet and Social media (lectured by Mrs. Kateřina Švidrnochová)

Topics:

- The website and Social media
- iCloud systems for internal data management
- Internal effective communication within patient organization
- GDPR

2. Fundraising and marketing (lectured by Mr. Petr Freimann)

Topics:

- Fundraising
- Marketing
- Effective communication
- Campaign
- Motivation
- Arguments

More info at <https://pacientskaakademie.cz/cs/individualni-konzultace/>



APO Summer School IV.

The fourth annual APO Summer School conference, held on 30 August 2018 in Prague, intended for representatives of Czech patient organisations and other interested parties from the area of Czech Healthcare.

The main topic of this year's APO Summer School was: Involvement of patient organisations, medical societies and the public in the process of Health Technology Assessment (HTA).

Over 120 people participated in this year's APO summer school, representing patient organisations, the Czech Medical Association of J. E. Purkyně, the Czech Ministry of Health, the State Institute for Drug Control, the Czech Pharmacoeconomic Society, the European Parliament, industry, media and others.

Mr. Jakub Dvořáček, the Executive Director of AIFP, and Ms. Lenka Teska Arnoštová,, chairperson of Company medical law at Czech Medical Association JEP, opened the conference.

We were pleased to welcome three experts on involving patient organisations in the HTA process from Great Britain, France and Scotland.

The first speaker was **Karen Facey, PhD.** from Great Britain, co-author of the professional publication "Patient Involvement in Health Technology Assessment", discussing the following topic: **How and why can patients and patient organisations be included in the HTA process?**

This was followed by a presentation from **Heidi Livingstone, BA** from the British NICE (National Institute for Health and Care, Excellence) focussing on the topic: **How to help patient organisations take part more effectively.**

And our last foreign expert was **Hervé Nabarette, PhD.,** from AFM-Téléthon, representing patients involved in HTA in France. Hervé's speech was on the topic: **A new approach to patient involvement in HTA, the pricing and coverage determination process in France.**



An important part of the programme was the **roundtable on the topic of patient involvement in the HTA process**, which included representatives from:

- The Patient's Council of the Czech Minister of Health of the Czech Republic
- The Czech Ministry of Health of the Czech Republic
- The Czech Medical Association of J. E. Purkyně
- The State Institute for Drug Control

Part of the roundtable included a discussion with the audience and foreign experts.

Ms. Kateřina Konečná, member of European Parliament also accepted our invitation and relayed the current position of the European Parliament on patient involvement in HTA within Europe.

The last part of this conference was a presentation of the forthcoming HTA educational programme for patient organisations, which will take place during the autumn of 2018, under the auspices of the Ministry of Health CR. This programme is being prepared together with the Ministry of Health CR in cooperation with the Association of Innovative Pharmaceutical Industry, the Czech Medical Association of JEP, the Czech Pharmacoeconomic Society and foreign HTA experts.



HTA intensive programme for Czech patient organizations

Under the auspices of the Ministry of Health of the Czech Republic



5 all-day workshops with Czech and foreign HTA experts



18–20 October and 2–3 November 2018
9.00 am – 4.00 pm



19 participants



Venue
Ministry of Health of the Czech Republic

In cooperation with the Association of Innovative Pharmaceutical Industry and the Czech Medical Association of J. E. Purkyně.

The fourth annual all-day conference APO Summer School was held by the end of August 2018. The main topic was Health Technology Assessment and involvement of Czech patients. Round table with deputies of the Ministry of Health of the Czech Republic, the State Institute for Drug Control, the European Parliament, the Czech Medical Association, the Patient Council and HTA experts from abroad, was a vital part of the conference.

All the participants agreed about patient's involvement in the new Czech pricing and reimbursement processes. Based on outcomes of the conference, the Ministry of Health of the Czech Republic (MoH) in cooperation with the Association of Innovative Pharmaceutical Industry and the Czech Medical Association prepared the HTA Intensive Educational Programme for the representatives of Czech patient organizations.

Certificate Ceremony was held on 13th of December at the Lichtenštejnský Palace in Prague with the participation of the Minister of the Czech Republic, all his deputies, Mr. Jakub Dvořáček, executive director of AIFP and prof. Jan Švihovec, member of the Board of the Czech Medical Association and others.



APO Alumni V

On the 4th of December 2018, the fifth annual APO Alumni took place in the Petschek Villa – the Residence of the U.S. Ambassador in Prague. It was held under the auspices of **the Ambassador Mr. Stephen B. King**.

Over 100 guests accepted the invitation and more than 70 guests were representatives of member organizations of the Academy of Patient Organisations (APO). Among other guests were deputies of the Senate of the Parliament of the Czech Republic, the Ministry of Health of the Czech Republic, the State Institute for Drug Control, the Czech Medical Association of J. E. Purkyně, the Commercial Counsellor of the USA in Prague, industry and media.

At the event, speeches were delivered by the following guests:

- Stephen B. King, the U.S. Ambassador of the Czech Republic
- Christina Sharkey, Commercial Counselor of the USA in Prague
- Jakub Dvořáček, Executive Director of Association of Innovative Pharmaceutical Industry
- Helena Rögnerová, Deputy Minister of Health of Czech Republic
- Irena Storová, Director of State Institute for Drug Control
- prof. Jan Švihovec, the Czech Medical Association of J. E. Purkyně
- Lumír Kantor, Head of the Committee for Health Care and Social Politics of the Senate of the Parliament of Czech Republic
- Simona Zábranská, Director of the Club of Patients with Cystic Fibrosis

In their great speeches our guests emphasised mainly the significant growth in activities in different areas of patient organization involvement, better management of these organisations and, in particular, their increasing involvement in decision making processes in important issues of the Czech healthcare system. The event continued with a reception in the beautiful premises of the Residence.



APO Initiatives

Member patient organizations organize a lot of interesting activities. Via APO initiatives (apo@aifp.cz) they have chance to share it with all the patient organizations involved in APO.

APO Website and APO Facebook

Both are regularly updated. All the information, invitations, recommendation, photos and others are shared on the website and Facebook.



www.pacientskaakademie.cz



Akademie patientských organizací



APO Plans in 2019



more
than

90

Patient organizations involved in APO



18

All-day APO workshops

3

All-day HTA **advanced** programme in cooperation with the Ministry of Health of the Czech Republic and the Czech Medical Association of J. E. Purkyně

6

All-day HTA **basic** programme in cooperation with the Ministry of Health of the Czech Republic and the Czech Medical Association of J. E. Purkyně



1

All-day networking session II



Mentoring



APO Summer School V – an all-day patient conference

APO Alumni VI

APO Advisory Board meetings



APO will continue in cooperation with

The Ministry of Health of the Czech Republic
The Czech Medical Association of J. E. Purkyně
The State Institute for Drug Control
The European Parliament
The Ministry of Labour and Social Affairs
Health insurance companies
and others

Participants APO 2018

- ALEN SDRUŽENÍ ŽEN POSTIŽENÝCH RAKOVINOU (ALEN – SDRUŽENÍ ŽEN)
- ALIANCE ŽEN S RAKOVINOU PRSU O. P. S.
- ALSA Z. S.
- AMA – SPOLEČNOST ONKOLOGICKÝCH PACIENTŮ, Z. S.
- ANDĚLSKÁ KŘÍDLA Z. S.
- ARCUS – ONKO CENTRUM, Z. S.
- ASOCIACE MUSKULÁRNÍCH DYSTROFIKŮ V ČR
- ASOCIACE PORADEN PRO OSOBY SE ZDRAVOTNÍM POSTIŽENÍM (APZP)
- AVMINORITY, Z. S.
- BENEŠOVSKÝ KLUB ONKOLOGICKY NEMOCNÝCH (BENKON)
- BORELIOZA CZ O. S.
- CENTRUM PRO DÍTĚ S DIABETEM, Z. S.
- CENTRUM SLUŽEB SPCCH V ČR, Z. S.
- CEREBRUM – SDRUŽENÍ OSOB PO PORANĚNÍ MOZKU A JEJICH RODIN, Z. S.
- ČESKÁ ASOCIACE PARAPLEGIKŮ – CZEPA, Z. S.
- ČESKÁ ASOCIACE PRO VZÁCNÁ ONEMOCNĚNÍ Z. S. ČAVO
- ČESKÁ SPOLEČNOST AIDS POMOC, Z. S.
- ČESKÁ SPOLEČNOST PRO DYSTONII
- ČESKÁ UNIE NESLYŠÍCÍCH
- ČESKÉ ILCO, Z. S.
- ČESKÝ OBČANSKÝ SPOLEK PROTI PLICNÍM NEMOCEM , ČOPN
- DEBRA ČR, Z. Ú.
- DIACENTRUM, O.S.
- DIAGNÓZA FH
- DIAGNOZA LEUKEMIE, Z. S.
- DIAKAR, Z. Ú.
- DIAKTIV CZECH REPUBLIC, Z. S.
- DIALOGOS Z. S.
- DOTYK II, O. P. S.
- DYSTONIE – RODINA SPOLU,Z. S.
- EPISTOP, O.S.
- FOKUS PRAHA, Z. Ú.

- HAIMA CZ, Z. S.
- ICTUS O. P. S.
- KLUB NEMOCNÝCH CYSTICKOU FIBRÓZOU
- KLUB PACIENTŮ MNOHOČETNÝ MYELOM, Z. S.
- KLUB PARKINSON OSTRAVA
- KOLPINGOVA RODINA SMEČNO
- LASKAVÝ SPOLEK
- LIGA PROTI RAKOVINĚ PRAHA Z. S.
- LYMFOM HELP, Z. S.
- MAMMA HELP, Z. S.
- MYGRA-CZ, Z. S.
- NAHLAS, O. S.
- NÁRODNÍ SDRUŽENÍ PKU A JINÝCH DMP
- NEDOKLUBKO
- NEVYPUŠŤ DUŠI, Z. S.
- ONKO KLUB SLUNEČNICE OLOMOUC, Z. S.
- ONKO UNIE, O. P. S.
- ONKO-AMAZONKY, O.S.
- OSTEOLOGICKÁ AKADEMIE ZLÍN
- PACIENTI IBD, Z. S.
- PARENT PROJECT
- PARKINSON-HELP Z. S.
- PINK BUBBLE, NADAČNÍ FOND
- PLATFORMA ZDRAVOTNÍCH POJIŠTĚNCŮ, O.S.
- POLOVINA NEBE O. P. S.
- POPÁLKY O. P. S.
- PROJEKT SPOLU
- PROSTAK (KARCINOM PROSTATY)
- RED RIBBON, Z. S.
- RETT COMMUNITY, Z. S.
- REVMA LIGA ČESKÁ REPUBLIKA, Z. S.
- RODINNÁ PÉČE
- ROSKA BRNO (REGIONÁLNÍ ORGANIZACE UNIE ROSKA V ČR)
- RYTMUS SRDCE, SDRUŽENÍ PACIENTŮ
- SDMO – SDRUŽENÍ PRO KOMPLEXNÍ PÉČI PŘI DĚTSKÉ MOZKOVÉ OBRNĚ, Z. S.
- SDRUŽENÍ CELIAKŮ ČR, Z. S.
- SDRUŽENÍ MLADÝCH SKLEROTIKŮ (SMS)

- SDRUŽENÍ PACIENTŮ S PLICNÍ HYPERTENZÍ, O.S.
- SDRUŽENÍ PACIENTŮ SE STŘÁDAVÝMI ONEMOCNĚNÍMI, O.S. (META)
- SDRUŽENÍ PRO REHABILITACI OSOB PO CÉVNÍCH MOZKOVÝCH PŘÍHODÁCH, O.S.
- SMÁCI, Z. S.
- SPOLEČNĚ K ÚSMĚVU, Z. S.
- SPOLEČNOST DIALYZOVANÝCH A TRANSPLANTOVANÝCH, Z. S.
- SPOLEČNOST PARKINSON, Z. S.
- SPOLEČNOST PRO BEZLEPKOVOU DIETU, Z. S. (CELIAK)
- SPOLEČNOST PRO MUKOPOLYSACHARIDOSU
- SPOLEČNOST PRO POMOC PŘI HUNTINGTONOVĚ CHOROBE, Z. S.
- SPOLEČNOST PS-ORIATIKŮ A ATOPICKÝCH EKZEMATIKŮ, O.S.
- SPOLEČNOST „E“ / CZECH EPILEPSY ASSOCIATION Z. S.
- SPOLEK BESEDA, Z. S.
- SPOLEK KOLUMBUS
- SPOLEK LUPUS ČR
- SPOLEK NUDZ, Z. S.
- SPOLEK PRO ATYPICKÉ PARKINSONSKÉ SYNDROMY
- STK PRO CHLAPY
- SVAZ DIABETIKŮ ČR, ÚZEMNÍ ORGANIZACE PLZEŇ
- SVAZ NESLYŠÍCÍCH A NEDOSLYCHAVÝCH OSOB V ČESKÉ REPUBLICE, Z. S.
- SVAZ PACIENTŮ ČR, Z. S.
- TYFLOSERVIS, O. P. S.
- UNIE ROSKA – ČESKÁ MS SPOLEČNOST, Z. S.
- ÚSMĚV=ZDRAVÍ, Z. S.
- ÚSTECKÝ ARCUS, Z. S. – SPOLEK ONKOLOGICKÝCH PACIENTŮ, JEJICH RODINNÝCH PŘÍSLUŠNÍKŮ A PŘÁTEL
- VICTORIA, LIGA PROTI RAKOVINĚ, ONKO KLUB LITOMĚŘICE
- WILLÍK – SPOLEK PRO WILLIAMSŮV SYNDROM, Z. S.
- ZAJÍČEK NA KONI, O. P. S.
- ŽIVOT BEZ STŘEVA, Z. S.
- ZNOVU DO ŽIVOTA