





REPORT 2019

ACADEMY OF PATIENT ORGANIZATIONS

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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 50 000 queries until the end of year 2019.



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.



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 processionals met at the Round tables on 11 different therapeutic areas. One and half hour long discussion with the first deputy to the Minister of Health of the Czech Republic was on the programme of the APO Summer School II.

APO Award in two categories: The best ongoing project (winner was Mamma HELP) and the best innovative project vison (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 continued with more than **90 patient organizations** who had a chance to attend **23 all-day workshops.**

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 with the European patient organizations and networking event in the Czech 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.

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.

The **APO Networking meeting** was organized at the end of the year 2017.

APO Alumni IV was organized under the auspices of Senator Mrs. Milada Emmerová in the Senate CR.



APO continued with **97 involved patient** organizations. They attended another APO educational programme. The most visited lectures were Fundraising and Marketing, GDPR, Accounting and Taxes of NGO, Conflict Resolution Prevention, Personal Typology MBTI, Burnout etc.

The APO Mentoring with two topics

(The Internet and Social Media and Fundraising and Marketing) was established in 2018 and it was used on maximum by 38 patient organizations with 85 hours.

Patient conference APO Summer School IV was held at the end of the summer with the main topic: Involvement of patient organisations, medical societies and the public in the process of Health Technology Assessment (HTA). Over 120 people participated the conference.

Based on outcomes of the conference APO Summer School the Ministry of Health of the Czech Republic in cooperation with AIFP prepared the **HTA intensive programme** for the Czech patients. 18 representatives from patient organizations attended the 5 all-day programme. Mrs. Karen Facey, from Great Britain, expert on involvement of patients in the HTA prepared and lectured all-day practical lecture. Certificated ceremony of HTA intensive programme was held at the end of the year and the Minister of Health CR and his deputies participated.

The fifth annual APO Alumni was held at the Residence of the U.S. Ambassador in Prague. Over 100 guests accepted our invitation and more of them were representatives of patient organizations.

APO regularly updates website, both mutation Czech and English and is active on the Social media.

APO Summer School 2018





APO Alumni V 2018

APO Summer School 2018



Report 2019



more than 100 patient organizations involved in APO



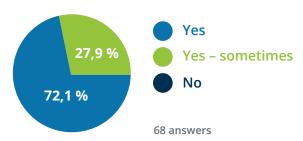
16 APO lectures

all-day HTA lectures advanced

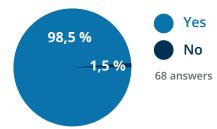
6 all-day HTA lectures basic



1.) Will you continue in 2020?



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





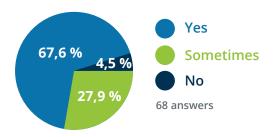
3. What educational topics would you welcome in 2020?

Legislation (Contracts, GDPR, etc.)
PR, marketing and communication with Media
Fundraising

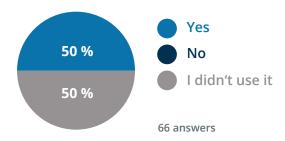
Social media and website Accounting and taxes of NGO Psychohygiene Project applications

(4.**)**

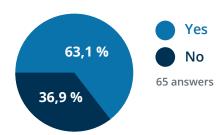
Do you use the APO Calls for proposal focused on patient organization needs at www.pacientskaakademie.cz/monitoring-vyzev/?



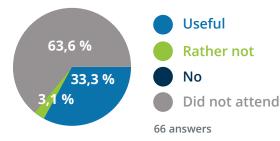
5. Was the APO mentoring in 2019 helpful for you?



Do you wish to continue with mentoring in 2020?



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











APO Overview 2019

APO Mentoring



Dates February – June 2019



44 hours



32 patient organizations

1. Mentoring with Mr. Marek Šedivý

Topics:

- Management of non-profit organizations, functioning of management boards, strategic planning
- Public Relations cooperation with journalists, event organization, brand building, networking, lobbing
- Fundraising

2. Mentoring with Mr. Petr Vít

Topics:

- Functioning of non-profit organizations and their bodies, problem solving
- Founding of non-profit organizations and changes in legal forms
- Labor law
- Civil law (contracts)
- Copyright law
- GDPR

More info at www.pacientskaakademie.cz/individualni-konzultace/

Mentoring with Mr. Petr Vít



Mentoring with Mr. Marek Šedivý



APO Summer School V

The fifth annual APO Summer School patient conference was held on 25th of September in the Main Hall of the Valdštejn Palace under the auspices of Mr. Jaroslav Kubera, chairperson of the Senate of the Parliament of the Czech Republic.

Topic of this year's APO Summer School was: Setting up transparent processes and the participation of patient organizations in the entry of new technologies. Over 160 people participated at the APO Summer School, representing patient organisations, the Senate of the Parliament of the Czech Republic, the Ministry of Health CR, the State Institute for Drug Control, the Czech Medical Association, the European Parliament, European Federation of Pharmaceutical Industries and Associations, pharma industry, media and others.

Mr. Jaroslav Kubera, chairperson of the Senate of the Parliament of the Czech Republic, Mr. Lumír Kantor, chairperson of the Committee for Social Policy and Health Care of the Senate of the Parliament of the Czech Republic and Mrs. Alena Šteflová, Deputy to the Minister of Health of the Czech Republic opened the conference.







Active speakers were:

- Mr. Radek Policar, Deputy to the Minister of Health of the Czech Republic
- Mr. Filip Vrubel, Deputy to the Minister of Health of the Czech Republic
- Mr. Jakub Dvořáček, executive director of the Association of Innovative Pharmaceutical Industry
- Mrs. Irena Storová, director of the State Institute for Drug Control,
- Mrs. Jana Hlaváčová from the Department of Patients' Rights in the Ministry of Health of the Czech Republic,
- Mrs. Jitka Reineltová, member of the Patient Council and Chairperson of patient organization Parent Project, z.s.,
- Prof. Jan Žaloudík, Senator of the Senate of the Parliament of the Czech Republic and member of the Masaryk Memorial Cancer Institute in Brno city
- Prof. Štěpán Svačina, Chairperson of the Czech Medical Association of J. E. Purkyně
- Mrs. Kateřina Konečná, Member of the European Parliament, speech via Skype
- Mr. Andy Powrie-Smith, director of communication in EFPIA and a member of the Patient Think Tank EFPIA







HTA intensive programme for Czech patient organizations – advanced

Under the auspices of the Ministry of Health of the Czech Republic in cooperation with AIFP



2 all-day lectures



5-6 April 2019



18 participants



enue

Association of Innovative Pharmaceutical Industry

Based on basic course "Involvement of patients in the process of Health Technology Assessment – HTA1" that was held at the end of the year 2018, the Ministry of Health CR and the Association of Innovative Pharmaceutical Industry (AIFP) prepared advanced course for the same participants who received a certificate.

Advanced course focused on

- "Clinical Trials" lectured by doc. Dr. Regina Demlová, Ph.D.,
 Head of the Institute of Pharmacology, Masaryk University Brno.
- "Financing the Czech Health System Reimbursement of Health Care" lectured by Mgr. Tomáš Troch, Head of the Department of Reimbursement Mechanisms of the Department of Price Regulation and Reimbursement of the Ministry of Health of the Czech Republic.
- "Base of Pharmacoeconomics, HTA" and "Reimbursement of drugs for diseases with higher prevalence" lectured by MUDr. Jana Skoupa, MBA, member of the Committee of the Czech Pharmacoeconomic Society.





HTA intensive programme for Czech patient organizations – basic

Under the auspices of the Ministry of Health of the Czech Republic in cooperation with AIFP







31 October - 2 November 2019 14-16 November 2019



27 participants



VenueMinistry of Health of the Czech Republic

The basic intensive programme in the area of HTA (Health Technology Assesment) was held again in October and November this year for another 27 representatives of patient organizations. It was held at the Ministry of Health CR. The name of the programme was "Involvement of patients in health care decision-making processes" and was diveded in 6 modules:

- 1. **"The Czech Health System and its Financing"** lectured by PhDr. Helena Hnilicová, Ph.D. from the 1st Medical Faculty of Charles University and Ing. et Ing. Lenka Poliaková from the Health Insurance Supervision Department of the Ministry of Health of the Czech Republic.
- 2. **"Assessment of medical technologies"** lectured by Dr. Tomáš Dolezal, PhD. from the Czech Pharmacoeconomic Society.
- 3. **"Prices and reimbursement of drugs"** lectured by Dr. Jana Skoupa, MBA from the Czech Pharmacoeconomic Society.







- 4. "Clinical studies" lectured by Mgr. Renata Hejnova from the Department of Clinical Trials of the Masaryk Memorial Cancer Institute.
- 5. **"Principles of cost-effectiveness and budget impact"** lectured by Dr. Tomáš Dolezal, PhD. and Ing. Tomáš Mlčoch from the Institute for Health Economics and Ing. Milan Vocelka from the State Institute for Drug Control.
- 6. "Case studies" lectured by Mrs. Karen Facey, Ph.D., UK HTA expert.

The certificated ceremony took part at the sixth annual APO Alumni. Participants who fulfilled 80% participations received the certificate from Mrs. Helena Rögnerová, deputy to the Minister of Health CR for Economics and Health Insurance and Mr. Jakub Dvořáček, executive director of AIFP.













APO Bulletin

In the Autumn this year APO launched the first Bulletin with three main parts. The first part is focused on legal overview, the second part is focused on actual APO activities and the last part is intended for activities of patient organizations.



APO Alumni VI

The sixth annual APO Alumni was held on 27th November in the Velkoprevorsky palace in Prague. More than 90 representatives of patient organizations attended the networking event.

In the first part the certificates were handed to the participants of HTA intensive programme who fulfilled 80 % of presence. The intensive programme was prepared by the Ministry of Health CR and the Association of Innovative Pharmaceutical Industry. Mrs. Helena Rögnerová, deputy to the Minister of Health and Mr. Jakub Dvořáček, executive director of AIFP and Mrs. Lenka Teska Arnoštová, chairperson of the Society of Medical Law of the Czech Medical Association of J. E. Purkyně had a speech. Networking part followed.











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

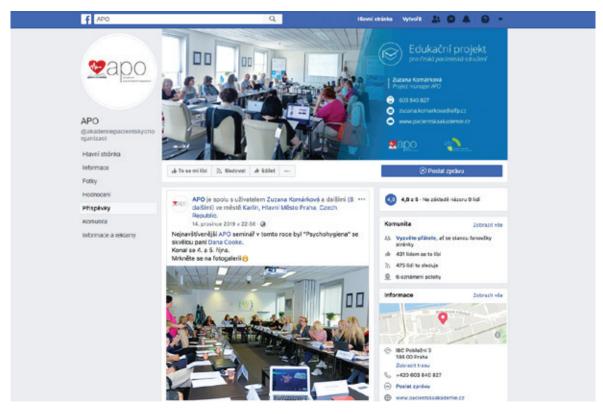
Both are regularly updated. All the information, invitations, recommendation, photos and others are shared on the website and Facebook.



www.pacientskaakademie.cz







APO Plans in 2020



more 100 Patient organizations involved in APO



Educational seminars



Mentoring on different topics



APO Summer School VI, all-day patient conference



APO Alumni VII



APO Advisory Board meetings



APO Award III



Networking activities



Continue on the programme of involvement patient in the HTA in cooperation with the Ministry of Health



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

Committee on Health Care – Chamber of Deputies Parliament of the Czech Republic

Committee on Health and Social Policy – Senate of the Parliament of the Czech Republic

and others

Participants APO 2019

- 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.
- ANGELMAN CZ, SPOLEK
- ARCUS ONKO CENTRUM, Z.S.
- ASOCIACE GENOVÉ TERAPIE, 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.
- 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
- DIAKTIV
- · DIALOGOS Z.S.
- DIAPOZITIV, 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.
- JELIMÁN, Z.S.
- KLUB NEMOCNÝCH CYSTICKOU FIBRÓZOU
- KLUB PACIENTŮ MNOHOČETNÝ MYELOM, Z.S.
- KLUB PARKINSON OSTRAVA
- KOLPINGOVA RODINA SMEČNO
- LASKAVÝ SPOLEK
- LIGA PROTI RAKOVINĚ
- LYMFOM HELP, Z.S.
- MAMMA HELP, Z. S.
- METODĚI Z.S.
- MIGRÉNA-HELP, SPOJENÉ HLAVY, Z.S.
- MYGRA-CZ, Z.S.
- NAHLAS, O. S.
- NÁRODNÍ SDRUŽENÍ PKU A JINÝCH DMP
- NAŠE SRDCE PRO BORELIÓZU A KOINFEKCE
- NEDOKLUBKO
- NEVYPUSŤ DUŠI, Z. S.
- ONKO KLUB SLUNEČNICE OLOMOUC, Z.S.
- ONKO UNIE, O. P. S.
- ONKO-AMAZONKY, O.S.
- 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
- SDRUŽENÍ MLADÝCH SKLEROTIKŮ (SMS)
- SDRUŽENÍ PACIENTŮ S METABOLICKÝM ONEMOCNĚNÍM KOSTNÍ TKÁNĚ PŘI OSTEOLOGICKÉ AKADEMII ZLÍN
- 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 CHOROBĚ, Z.S.
- SPOLEČNOST PSORIATIKŮ A ATOPICKÝCH EKZEMATIKŮ, O.S.
- SPOLEČNOST "E" / CZECH EPILEPSY ASSOCIATION Z.S.
- SPOLEK BESEDA, Z. S.
- SPOLEK DIAPOZITIV, Z. S.
- SPOLEK KOLUMBUS
- SPOLEK LUPUS ČR
- SPOLEK NUDZ, Z.S.
- SPOLEK PRO ATYPICKÉ PARKINSONSKÉ SYNDROMY
- SVAZ DIABETIKŮ ČR, ÚZEMNÍ ORGANIZACE PLZEŇ
- SVAZ NESLYŠÍCÍCH A NEDOSLÝCHAVÝCH OSOB V ČESKÉ REPUBLICE, Z.S.
- SVAZ PACIENTŮ ČR, Z.S.
- TYFLOSERVIS, O.P.S.
- UNIE ROSKA ČESKÁ MS SPOLEČNOST
- ÚSMĚV=ZDRAVÍ, Z.S.
- ÚSTECKÝ ARCUS, Z.S.
- 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