

REPORT 2016

ACADEMY OF PATIENT ORGANIZATION



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The Academy of Patient Organization (APO)

is an AIFP educational project and capacity building intended for the Czech patient organizations. The goal of APO is primarily to promote the independence of the Czech patient organizations (PO) and support their long-term development, improve quality of internal processes and transparency in financing, get funding from the Czech and EU sources, improve the quality of their negotiation and communication skills, how to use the Internet and Social media effectively and 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 almost 29 000 queries until the end of 2015. More than 2650 serious interactions and more than 2780 multiple use of the same molecule were identified.

2015

APO continued in 2015 with **71 involved Czech patient organizations** and **24 all-day seminars and workshops** 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 Jana Evangelisty 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.

The second APO Alumni 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 www.facebook.com/akademiepacientskychorganizaci.

Recapitulation 2016

In numbers



83 Czech patient organizations involved in APO



24 full-day lectures

Seminars in 2016

Topic	Date (Friday and Saturday)	Speaker
NGO Management and Work with employees	29. - 30. 1. 2016	Pavel Němeček
Communication and Presentation Skills	12. - 13. 2. 2016	Olga Medlíková
Fundraising	1. - 2. 4. 2016	Marek Šedivý
EU Grants and Programmes, Structural Funds (under the auspices of the Ministry of Health)	22. - 23. 4. 2016	Olga Laaksonen Petra Bartáková
NGO Taxes and Accounting	13. - 14. 5. 2016	Anna Pelikánová
Project preparation, writing and submission of grants (included SF EU)	20. - 21. 5. 2016	Petr Machálek
Public Relations, How to interest the Media	20. - 21. 5. 2016	Štěpánka Duchková
Patients Rights and Duties (under the auspices of the Ministry of Health)	17. - 18. 6. 2016	Denisa Kopková
Internet and Social Media, How to prepare interesting documents	19. - 20. 8. 2016	Kateřina Švidrnochová
Labor-social and diplomatic occasion protocol	16. - 17. 9. 2016	Olga Medlíková
Effective Work with the Media with focus on Press Release	4. - 5. 11. 2016	Lukáš Novák
Difficulties at work in the Helping Professions	2. - 3. 12. 2016	Marta Boučková

Feedback & Evaluation

The active participants completed online Survey questionnaires with possibility to comment answers.

1. Would you continue in APO 2017?



2. Does seminars have practical benefits for everyday use in your organization?



Comments: *"perfectly chosen topics and speakers, new contacts, information etc."*

3. Do you find useful to continue with APO Summer School in 2017?



4. Topics in 2017?

- ✓ Fundraising (grant application, individual and corporate donations etc.)
- ✓ How to write the project documentation (practical workshop, consultation of prepared projects, financial processing etc.)
- ✓ Internet and Social Media
- ✓ Public Relation, Work with Media
- ✓ Effective Communication and Presentation Skills
- ✓ Taxes and Accounting NGO (news in legislation)
- ✓ Legislation, Patient Rights and Duties
- ✓ Personal development of leader of NGO (psychology topics, how to manage stress, Syndrome of burnout, Coaching etc.)
- ✓ Management of NGO: management of Human Resources (volunteers), financial budget)
- ✓ Professional topics: Clinical Trials, Information about the Medicaments, Interaction of medicines, etc.
- ✓ Others: sharing best practice between patient organizations, networking, Prevention and Rehabilitation System
- ✓ Seminar and Round table with deputies of the Ministry of Labour and Social Affairs: social benefits, projects, disability pensions, homecare of patients etc.

5. Do you use "Calls for proposal" on APO websites?



6. Would you welcome the seminars via WebEx?



- ✓ Most of the participants prefer to meet with the speaker and other representatives of patient organizations personally.
- ✓ Some of the patient organizations with more offices around the Czech Republic welcome some topic via WebEx.

7. Additional comments, ideas, suggestions, ...

- ✓ *"It would be great to share experiences among organizations. Presentations of their work, projects, progress and to hear the feedback from others."*
- ✓ *"You are great and we really appreciate your work and your enthusiastic approach in the process of "breaking ice" between patient organizations and Czech Ministry of Health. We keep our fingers crossed and we are looking forward to your new projects."*
- ✓ *"Thank you for your brilliant cooperation and for your excellent seminars. Each seminar is very helpful. I suggest to have more networking events and presentations."*
- ✓ *"I would like to thank you for all your seminars. The atmosphere is always very welcoming and forthcoming. What I appreciated the most is the fact that we don't have to be afraid to immediately react/ask during presentations."*
- ✓ *"Awesome job! Your seminars have great quality."*
- ✓ *"I would suggest seminars in Brno - since many patient organizations have their headquarters in Brno and I am sure that they would be very interested in attending all seminars."*
- ✓ *"Dear Zuzana, I would like to thank you for your care and information service during the whole year. You set the quality bar so high that it makes so difficult for me to stay in focus till the end of any other seminars except APOs seminars. I really appreciate the quality of seminars with great well prepared speakers with interesting topics. I am looking forward for 2017 collaboration."*
- ✓ *"Big thank you, especially to the project manager Zuzana."*
- ✓ *"Mutual experiences help us to continue."*
- ✓ *"Thank you for everything."*
- ✓ *"Seminars were awesome, thank you."*
- ✓ *"You are doing great!!"*

APO 2016 - OVERVIEW

APO Advisory Board members in 2016

The members are:

- ✓ **Prof. MUDr. Štěpán Svačina DrSc., MBA**, Chairperson of the Czech Medical Association of J. E. Purkyně
- ✓ **JUDr. Lenka Teska Arnoštová, Ph.D.**, the First Deputy of the Minister of Health of the Czech Republic
- ✓ **MUDr. Martin Holcát, MBA**, Deputy of director for Treatment and Preventive Care in the biggest Czech hospital
- ✓ **Ing. Kateřina Konečná**, Member of the European Parliament
- ✓ **Mgr. Jakub Dvořáček, MHA**, Executive director AIFP
- ✓ **Mgr. Vlastimil Milata**, chairman of DiAktiv patient organization
- ✓ **Mgr. Jana Drexlerová**, director of Mamma HELP patient organization
- ✓ **Edita Müllerová**, President of the League of Rheumatism patient organization
- ✓ **Mgr. Jana Hlaváčová**, President of the Association of Young multiple sclerosis patients (member until the summer 2016)

Main discussed areas and competences of APO Advisory Board are Development of APO, Curriculum APO, Sustainable financing, APO Summer School, APO Award, Support patient organizations and their involvement in the healthcare and social system of the Czech Republic.

APO Summer School II

The second annual all-day event in cooperation with the Czech Medical Association of Jan Evangelista Purkyně was held in the end of the summer. More than 120 participants from patient organizations, medical professionals, Ministry of Health, European Parliament, industry, media and other institution attended. Mr. Nikos Dedes, president and a founding member of 'Positive Voice', Association of People Living with HIV in Greece accepted the invitation to join us. He introduced advantages of collaboration between patient organizations and Medical Societies. A discussion on mentioned issue followed. The participant compare situation in the Czech Republic and in Greece.

The main goal of the meeting was to continue in closer collaboration between patients and medical professionals, to elevate the erudition of patients, so they could be an equal partner in communication with the state authorities.

The main focus were roundtables based on 11 different therapeutic areas. At each roundtable the patient organizations and medical professionals discussed the possibilities to cooperate at the therapeutic areas. Moderators facilitated roundtables. The outcomes were published and showed differences of collaboration in the therapeutic areas.

The part of all day event was 1 hour long roundtable with the deputies of the Ministry of Health in the Czech Republic.



APO Award

The first year of APO Awards in two categories:

- ✓ **The best ongoing projects.** 12 projects registered for the competition in the first category. **The winner was Mamma Help** with the project **"Say it to the Kids"**. They won the PR service worth 45.000,00 CZK for this project.
- ✓ **The best innovative project vision.** 10 projects registered for the competition in the second category. The winner was **Parkinson-Help** with the project plan/vision **"Educational videos"** for patients and their families. They won the financial grant 45.000,00 CZK for this project.



APO Alumni III at the French Embassy in Prague

The third APO Alumni, networking meeting, was held under the patronage of his excellence Mr. Charles Malinas, new French Ambassador in the Czech Republic who personally welcomed all the participants at the Embassy.

The meeting hall was build to capacity of 90 attendant was filled. The representatives of Patient organizations, Ministry of Health, State Institute for Drug Control, World Health Organization, Czech Medical Association, Media, Industry and others attended.



Monitoring – Open Calls and Funding Sources

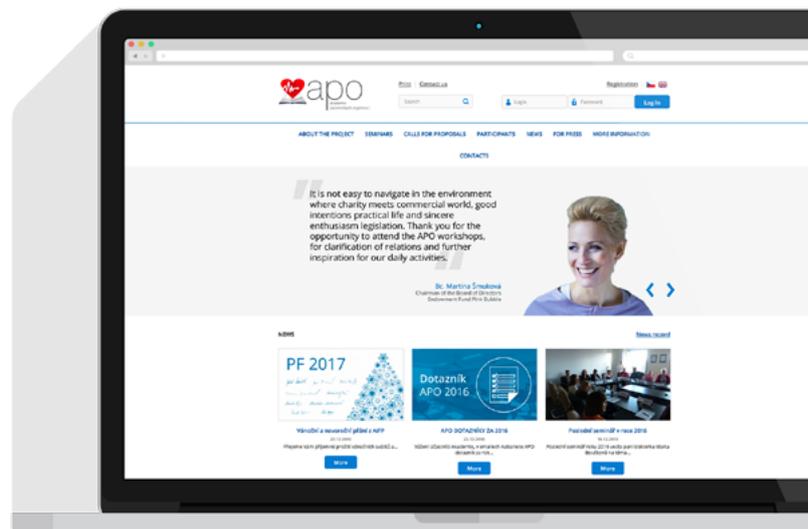


More than 400 calls of proposal targeted on patient organizations have been sorted out till the end of 2016. Free of charge for APO participants.

APO website

www.patientskaakademie.cz

- ✓ Updated version of APO website in Czech and also in English.



APO Facebook

APO has been successfully on Facebook since 2015. Published News, invitations, images, interesting information help to be in via touch with the patient organizations.

The screenshot shows the APO Facebook page. The profile picture is the APO logo, which includes a heart with a pulse line and the text 'apo akademie pacientů a zdravotníků'. The page name is 'APO' with the handle '@akademiepacientskychorganizaci'. The navigation menu includes Home, About, Photos, Reviews, Likes, and Posts. There is a 'Create a Page' button. The main content area shows several posts:

- A post from February 13, 2016, titled 'APO added 31 new photos — with Liba Žamborská and 10 others.' The text describes a workshop 'Komunikační a prezentační dovednosti' and lists participating organizations like ČAVO, SMA, and others. It includes a large photo of a workshop and a smaller photo with '+28'.
- A post from September 7, 2016, titled 'APO added 42 new photos — with Zuzana Komárková and 21 others.' The text mentions the 'Druhý ročník APO Letní školy 2016' with 120 participants. It includes a photo of a group of people and a smaller photo with '+39'.
- A post from October 25, 2016, titled 'APO' with the text 'Internetový portál Zdraví Euro píše o třetím ročníku APO Alumní a vyhlášení APO Cen.' It includes a photo of a man speaking at a podium.

Other APO actualities in 2016

Anonymous Online advisory center

On-line advisory "I know my Medications" continued in 2016. Until the end of the year we received more than 35,000 questions. Regularly updated information on [this link](#).

APO in cooperation with the Ministry of Health in the Czech Republic

AIFP is in collaboration with newly emerging project of the Ministry of Health "Cooperation of patient organizations and government" that is supported by funding of the Ministry of Labour and Social Affairs.

APO was part of EFPIA Health Collaboration Award II.

AIFP signed 2 sub-project "I know my Medications" and "APO Summer School" in the second Annual EFPIA Health Collaboration Award: A Healthier Future for Europe.

Curriculum 2017

Based on online survey and discussion

Lecture in 2017 - draft	Date
Management of Financial Planning NGO	February
Personal development of leaders NGO	March
Prevent Employee Burnout, Motivation of Employee and voluntaries	April
Fundraising - individual and corporate donations	April
Financial Grants, EU Programmes and Structural Funds	May
How to write the project documentation (grant application, practical workshop, consultation of prepared projects, financial processing etc.)	June
Taxes and Accounting NGO (news in legislation)	June
Public Relation: How to create an informative magazine and newsletter (content, distribution, etc.)	August
Planning of online campaign and Social Media	September
Legislation, Patient Rights and Duties	October
Managing Emotions in Crisis Situations	October
Prevention and Rehabilitation System in the Czech Republic (half day) and Sharing Best Practice (projects, ideas) between Patient Organizations (half day)	November

*Possible changes reserved.

Some of topics will be organized via WebEx

Round table with deputies of the Ministry of Labour and Social Affairs

Themes:

- ✓ Social Benefits
- ✓ Projects
- ✓ Disability Pensions
- ✓ Homecare of Patients etc.

APO in 2017

- ✓ More than 80 patient organizations involved in APO. This list is available on [APO website](#)
- ✓ 24 all-day educational seminars and workshops prepared based on need of representatives of patient organizations
- ✓ Continue with Calls of Proposals (more detailed, newly with Foundation Bohemica)
- ✓ APO Summer School III.
- ✓ APO Alumni IV.
- ✓ Cooperation with the Ministry of Health
- ✓ Regular APO Advisory Board meetings
- ✓ Round tables with deputies of the Ministry of Health and the Ministry of Labour and Social Affairs
- ✓ APO representatives will meet other European Patient Umbrellas Organizations in the European Parliament in Brussels. The event will be under the auspices of Mrs. Kateřina Konečná, member of European Parliament.
- ✓ Cooperation on EUPATI project in the Czech Republic and Memorandum between AIFP and the Ministry of Health in the Czech Republic



For more information, please, find in www.pacientskaakademie.cz/en/
and www.facebook.com/akademiepacientskychorganizaci/