

# REPORT 2021

## ACADEMY OF PATIENT ORGANIZATIONS

Zuzana Komárková  
APO Project Manager, AIFP



# THE ACADEMY OF PATIENT ORGANIZATIONS (APO)

is an educational and capacity building project of the Association of Innovative Pharmaceutical Industry (AIFP) intended for Czech patient organizations with the following main pillars:

- Education
- Multi-source funding
- Networking
- Transparency

## THE GOALS OF THE APO ARE PRIMARILY:

- To support the independence of Czech patient organizations
- To enable their long-term development
- To improve the quality of internal processes and transparency in financing
- To obtain funds from Czech and European sources
- To improve the quality of their negotiation and communication skills
- To use the Internet and social media effectively
- To explain legal processes, rights and duties of patients

## 2012

**The APO started its activities in 2012.** The kick-off meeting was held in the Parliament of the Czech Republic. It was attended by Mary Baker, President of the European Brain Council at that time, as a special guest, by representatives of the Committee on Health Care of the Parliament of the CR and more than 40 representatives of patient organizations. **30 patient organizations** represented by 44 individual participants were involved in the APO in 2012–2013.

## 2013

In 2013, the APO continued its activities with a follow-up retraining course **“NGO Effective Manager” – accredited by the Ministry of Labour and Social Affairs**. The course was attended by a total of 18 individual representatives of patient organizations. The course consisted of 16 all-day lectures with attendance check and one exam day. Successful participants received an official certificate. Official patronage of the Academy was taken by the Minister of Health of the Czech Republic at that time, MUDr. Martin Holcát, MBA.

## 2014

The APO entered 2014 with **27 newly registered patient organizations** and hence continued its activities with a total of **57 patient organisations**. During the year it organised **25 all-day educational seminars**.

In October 2014, in the residence of the U.S. Ambassador in Prague, **APO Alumni**, the first annual informal meeting of representatives of patient organizations involved in the APO and representatives of various healthcare institutions of the CR was held. The event was opened by His Excellency Mr. Andrew Shapiro, the U.S. Ambassador in the Czech Republic at that time. The **second patronage** was granted to the APO by the Deputy Minister of Health of the Czech Republic.

In June 2014, a **sub-project** called **“Know Your Medicines”** was launched. It is an online counselling service helping patients get information about the medicines they are taking, identify possible interactions and multiple uses of the same substance, as well as identify which specific foods and herbs they should avoid. By the end of 2019, we had received more than 50,000 queries.

## 2015

In 2015, the APO continued its activities with the participation of **71 Czech patient organisations** and organized **24 all-day lectures**. In June 2015, a nine-member **APO Advisory Board** was appointed. At the end of summer 2015, the first **APO Summer School**, an all-day patient conference organized in cooperation with the Czech Medical Association of J. E. Purkyně, took place. The aim of the conference was to achieve closer cooperation between representatives of patient organizations and representatives of the Czech Medical Association of J. E. Purkyně.

**APO Alumni II** was held at the British Embassy in Prague. The participants received a warm welcome from Her Excellency Ms Jan Thompson. The meeting was attended by more than 60 representatives of patient organizations. The invitation was accepted by Ms Nicola Bedlington, European Patients' Forum (EPF), Ms Lenka Teska Arnoštová, I. Deputy to the Minister of Health of the Czech Republic, Ms Alena Šteflová, Head of the WHO Country Office in the Czech Republic, as well as by representatives of other interest groups of the Czech healthcare sector.

In summer 2015, **APO Facebook profile** was created.

## 2016

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

**The APO Advisory Board** met twice in 2016 and supported the organization of the second **APO Summer School II**, an all-day event in collaboration with the Czech Medical Association to continue in a dialogue and to enhance their cooperation. Both sides, representatives of patient organizations and the Czech Medical Association of J.E. Purkyně, met at roundtables within 11 different therapeutic areas. The agenda of the APO Summer School II also included an hour and a half long discussion with the I. Deputy to the Minister of Health of the Czech Republic.

In 2016, the **"APO Award"** was announced for the first time for the best ongoing project (the winner was the Mamma HELP project) and the best innovative project vision (the winner was the Parkinson-Help project).

The third annual **APO Alumni III** was held under the patronage of the French Ambassador at the French Embassy in Prague in November 2016. The event was attended by representatives of patient organizations and representatives of the Ministry of Health, the State Institute for Drug Control, the World Health Organization, the Czech Medical Association of J.E.P., industry, media and others.

## 2017

The APO continued its activities with the participation of more than **90 patient organizations**, which had a chance to attend **23 all-day seminars**.

50 representatives of patient organizations participated in a **three-day programme in Brussels** under the auspices of Ms Kateřina Konečná, a member of the European Parliament. The main part of the Brussels programme was the conference "Why Europe", roundtables with European patient organizations and a networking event in the Czech House in Brussels. The event was attended by the Minister of Health, I. Deputy to the Minister, representatives of the European Parliament, European umbrella organizations, Permanent Representation of the Czech Republic to the EU, the EFPIA, pharmaceutical industry representatives and others.

In 2017, the third all-day **APO Summer School III** was held, the main topic being the Health Technology Assessment (HTA). Our invitation was accepted by leading European HTA experts and a representative of patients from Germany. In October 2017, the second **"APO Award"** for the best projects was announced.

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

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



## 2018

The APO continued its activities with the participation of **97 patient organizations**. These organizations attended another **APO educational programme**. The most attended lectures were "Fundraising and Marketing", "GDPR", "Accounting and Taxes of NGOs", "Conflict Resolution Prevention", "Personal Typology MBTI", "Burnout Syndrome" etc.

In 2018, the **APO Mentoring with two topics** ("The Internet and Social Media" and "Fundraising and Marketing") was launched. A total of 38 patient organizations took advantage of it.

At the end of the summer, the fourth annual all-day patient conference – the **APO Summer School IV** was held, the main topic being "Involvement of Patient Organizations, Medical Associations and the Public in the Process of Health Technology Assessment (HTA)". There were over 120 participants at the conference.

Based on the outputs of the conference APO Summer School, the Ministry of Health of the Czech Republic in collaboration with the AIFP prepared an **HTA intensive educational programme** for Czech patients. 18 representatives of patient organizations participated in the five-day programme. Ms Karen Facey, a British expert in the involvement of patients in the HTA, had prepared and gave an all-day practical lecture. At the end of the year, a certificate ceremony related to the certified HTA intensive programme was held. It was attended by the Minister of Health of the Czech Republic and his Deputies.

**The fifth annual APO Alumni** was held at the residence of the U.S. Ambassador in Prague. Our invitation was accepted by over 100 guests, most of whom were representatives of patient organizations.

The APO regularly updates its website in both Czech and English, and is active on social media.

as well as **in individual consultations** on the following topics: "How to Manage Non-Profit Organizations", "Strategic Planning", "Functioning of Non-Profit Organizations and their Bodies, Problem Solving", "Founding a Non-Profit Organization and Changes in Legal Standards, Labour Law, Civil Law (Contracts)", "How to Do the Right PR in a Non-Profit Organization" and, last but not least, "Fundraising".

In the summer, the fifth annual **APO Summer School** patient conference on the topic "Setting up Transparent Processes and the Participation of Patient Organizations in the Entry of New Technologies" was held in the premises of the Senate of the Parliament of the Czech Republic under the auspices of the President of the Senate. The conference featured distinguished guests from the Senate of the Parliament of the CR, the Ministry of Health of the CR, the State Institute for Drug Control, the European Parliament and, last but not least, representatives of patient organizations.

We consider the introduction of a regular **APO Bulletin** our major initiative of 2019. It consists of three main parts, the first being a current overview of the Czech legislation, the second part presenting information about upcoming APO activities, and the third part devoted to ongoing activities of patient organizations involved in the APO project. The APO Bulletin is distributed electronically to patient organizations, representatives of the Ministry of Health, the Czech Medical Association of J.E. Purkyně, the State Institute for Drug Control and other institutions. Regular reports show its large readership.

This year, in collaboration with the Ministry of Health, the APO project continued with the **HTA intensive programme** for representatives of Czech patient organizations. There were all-day advanced seminars and a new seminar for beginners.

At the end of November, the sixth **APO Alumni meeting** took place. During the meeting, the participants of the HTA intensive course received their certificates from the Deputy Minister Helena Rögnerová, on behalf of the Ministry of Health, and Director Jakub Dvořáček, on behalf of the Association of Innovative Pharmaceutical Industry.

## 2019

The year 2019 meant for the APO more than 100 involved patient organizations that could participate in **educational seminars**

## 2020

In 2020, the project actively involved **more than 100 patient organisations**. Due to the coronavirus pandemic, we were forced to adapt our activities and go online, especially with our educational seminars, which had become popular. Despite the unfavourable situation, we managed to implement **18 seminars**, attended by dozens of representatives of patient organizations. We also continued with **individual expert consultations** focused on four thematic areas: tax and accounting, fundraising, communication and law.

During the summer, while observing all epidemiological regulations, we organized the second **APO Networking**, a social event on the topic **“Benefitting from International Cooperation”**, aiming at sharing inspiring examples of cooperation between local and foreign patient organizations. As part of the successful meeting, the participants had a chance to hear presentations given by representatives of five Czech patient organizations about their successful projects of foreign cooperation.

In the second half of the summer, we co-organized an **expert roundtable** in the Senate of the Parliament of the CR **focusing on the future of patient organizations in the Czech Republic**. An analysis “The Role of Patient Organizations in the Czech Republic Including the Impact of the Covid-19 Pandemic” done by the consulting company of EY was presented at this event. Apart from representatives of patient organizations, the Minister of Health at that time, Adam Vojtěch, the Director of VZP, Zdeněk Kabátek, Senator Lumír Kantor and other experts participated in the meeting.

Due to the Covid-19 pandemic, digitalization of the Czech healthcare system became a pressing issue in 2020. Within the APO project, we therefore, in close collaboration with MUDr. Mgr. Jolana Kopsa Těšínová, Ph.D. from the 1st Faculty of Medicine, Charles University, organized an online conference on telemedicine, which kicked off a joint **project called “Digitalization of Medicine (not only) for patients”**. Representatives of patient organizations, the Ministry of Health of the CR, the Institute of Health Information and Statistics of the CR (ÚZIS), Faculty Hospital Olomouc as well as of other organizations and

authorities took an active part in it. There are going to be follow-up activities to this project next year.

Last but not least, the APO remained active on the social networking site of Facebook, it regularly updated its website and continued to publish its successful APO Bulletin.



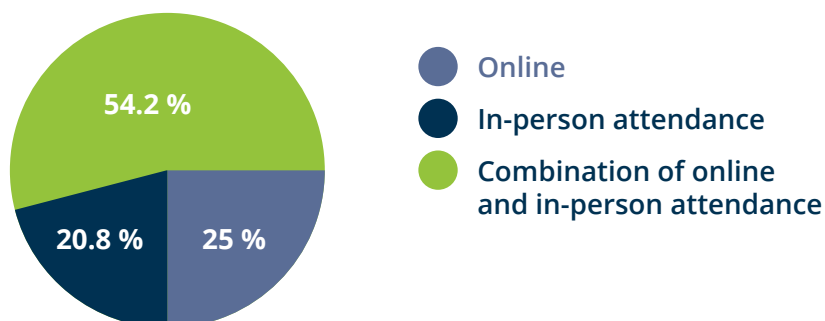
# Feedback from patient organizations

The APO team would like to thank to patient organizations involved in the APO project for regular feedback. We highly appreciate it. At the end of the year, we asked representatives of patient organizations to complete anonymous questionnaires, the results of which will help us prepare the 2022 schedule.

## RESULTS

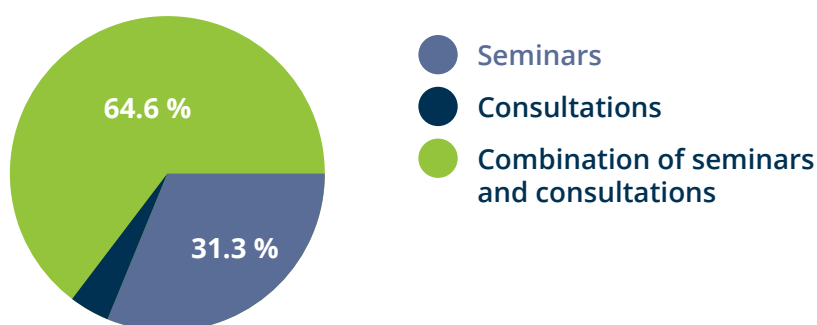
1.

**The participants prefer a combination of online and in-person meetings, but more likely online.**



2.

**The participants prefer a combination of online seminars and individual consultations, but more likely seminars.**



3.

**Most frequently requested topics:**

- a. Social networking sites: Twitter, LinkedIn, Instagram, Facebook
- b. Website administration
- c. How to work with Mailchimp and similar systems
- d. How to prepare an online/offline campaign
- e. Accounting and taxes
- f. Legal consultations
- g. HTA and patient involvement
- h. Advocacy
- i. Legislation, law – overview of the legislative process
- j. Soft skills:
  - i. Interpersonal relations
  - ii. Prevention and solution of conflicts
  - iii. Emotional self-defence
  - iv. The border between personal and professional communication and related relations
- k. Public-Relations topics:
  - i. How to write articles
  - ii. How to write an Annual Report
  - iii. Communication with media
  - iv. Online presentation of the organization
- l. Ethical aspects in cooperation with pharmaceutical companies (follow-up to the topic “Partnership – More than a Grant”)

Thank you also for your recommendations as regards the lecturers, the APO will certainly contact them.



4.

**Tips on what to add to the APO programme:**

- a. Continue APO networking – sharing good-practice (but maybe also bad-practice) examples on a certain topic,
- b. Expert roundtables (with representatives from the Ministry of Health, insurance companies and others).

# APO 2021

Similarly to last year, this year was also affected by the Covid-19 pandemic. Bigger part of our educational seminars, workshops and individual consultations was organized online or in so-called hybrid mode (i.e. online and in-person at the same time). Thanks to the more favourable epidemiological situation, some of the events could take place purely in person, e.g. the **APO Summer School** patient conference on **“Partnership – More than a Grant”** or the intensive training programme **“Involvement of Patient Organizations in Procedures on Pricing and Payment for Orphan Drugs”**, which is a joint project of the Ministry of Health and the AIFP.

## APO Individual Consultations



February–June 2021



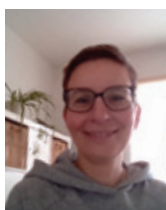
29

patient  
organizations



211

hours



### Bohdana Rambousková

Individual consultations with Bohdana Rambousková were focused on:

- PR principles and communication, communication strategy
- Presentation on social networking sites and various other materials
- Approaching current as well as future partners

“ I am honoured to have been able to be part of the capacity development of patient organizations and watch their progress. ”



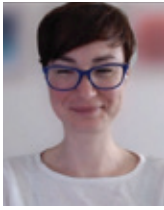
### Dan Zwieb

Within the consultations with Dan Zwieb, the participants were interested mainly in:

- Legal functioning of a patient organization
- Specific legal problems
- Solution to restrictions related to the Covid-19 pandemic

“ I was glad to work on this project, it was beneficial to me in many ways, I particularly gained experience in real operation of patient organizations. ”



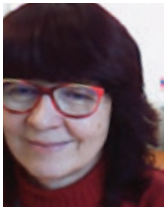


### Kateřina Švidrnochová

Within her consultations, lecturer Kateřina Švidrnochová focused mainly on the following topics:

- Digitalization, cloud systems and applications for online management of an organization
- Internal and external communication
- Creation of websites and presentation materials and/or newsletters

**“ I appreciate the preparedness of individual organizations for our online meetings, to-the-point questions as well as openness and ability to self-reflect.”**



### Marie Vtípilová

Within individual consultations with Marie Vtípilová, the participants discussed the following topics:

- Main accounting principles for non-profit organizations
- Accounting of funds, record of donations or tax returns
- Budgets and public collections organization

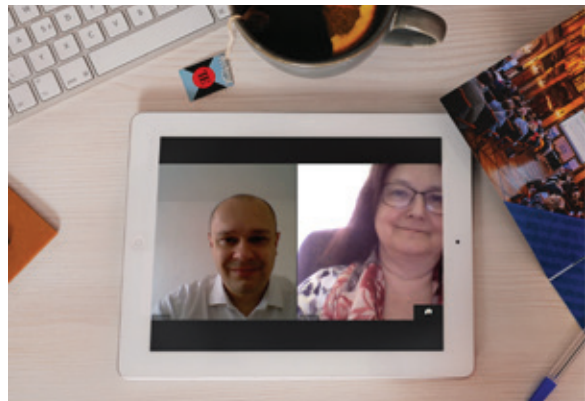
**“ All participants in the consultations were united by a sincere desire to manage their funds in the best possible way, to act in accordance with the law and to ensure the most efficient and effective use of resources for their organizations.”**



### Petr Freimann

The participants could consult Petr Freimann about the following topics:

- Fundraising
- Effective marketing communication
- Communication strategy



## // **Martina Michalová – ČAVO, z. s.**

Consultations with Kateřina Švidrnochová are always pleasant, lively and natural, she answered all my questions in a very clear and understandable way. I would like to thank for these consultation opportunities, which make my job for the association (and ours as organizations) much easier, and thus I am here fully available for our patients.

## **Vlastimil Milata – DIAKTIV CZECH REPUBLIC, z. s.**

Thank you for the consultation opportunities. It was pragmatic, understandable and very beneficial for us. Dan Zwieb was in the know and, in my subjective judgement, he had enough experience in this area. He fully met our expectations.

## **Monika Kaššaiová – Amelie, z. s.**

Many thanks for the opportunity to consult Bohdana Rambousková. I am excited about the consultation, the information and insight I got from her is really valuable for me. You are doing a great job and I will definitely recommend you elsewhere.

## **Petr Ilčík – Popálky, o. p. s.**

The consultation was beneficial. Individual consultations suit me. Thanks to the workshops, which you also provide, I have been exposed to applications that have advanced our organization forward :-). Individual consultations are an excellent form of continuing education and I thank you for them. It is an opportunity for me to get specific information I am interested in. Ms Švidrnochová is an excellent lecturer and her advice is beneficial. I would like to thank you once again for your work and the opportunity to learn for free.

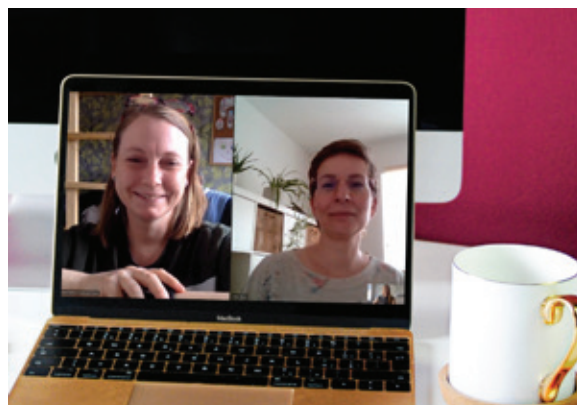
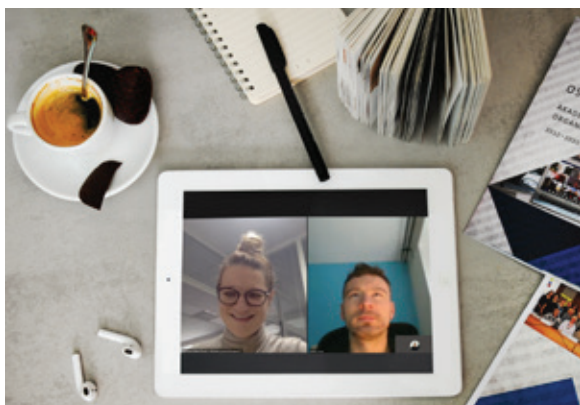
## **Jitka Svobodová – České ILCO, z. s.**

Thank you very much for arranging the consultation with Marie Vtípilová. We discussed in particular the way of entering into accounting the contributions from the Labour Office and what to look out for when doing accounting for non-profit organizations. We solved all I needed.

## **Miriam Svatá – Unie Roska, z. s.**

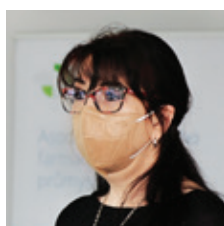
The consultation was again very beneficial for me. I always learn something new, interesting and get an independent opinion of a certain thing, which really suits me. I would like to thank to Petr Freimann and the APO for having been given the opportunity to participate.

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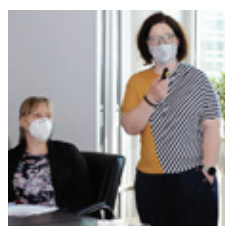


## APO Networking III. “Effective Management of a Patient Organization”

On Friday 4 June 2021, the third APO Networking meeting of patient organizations took place. Five organizations shared their experience on how to become a professional organization, how to manage the organization effectively, how to work in a team, share work etc. The meeting was held with the participation of nearly 50 representatives of patient organizations, both in person and online. The programme was guided by Vanda Kofroňová, an experienced presenter from Czech Television.



**Simona Zábranská,**  
Chairperson of Klub  
cystické fibrózy

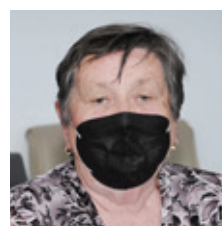


**Jana Lacinová,**  
Chairperson of Popálky  
(on the right),

**Jana Tlustá,** Popálky,  
Office Head



**Edita Müllerová,**  
Chairperson of Revma  
liga Česká republika



**Olga Slachová,**  
Chairperson of Svaz  
diabetiků Slatiňany,  
Chairperson of Svaz  
Diabetiků ČR



**Vlastimil Milata,**  
Chairperson of Diaktiv  
Czech Republic

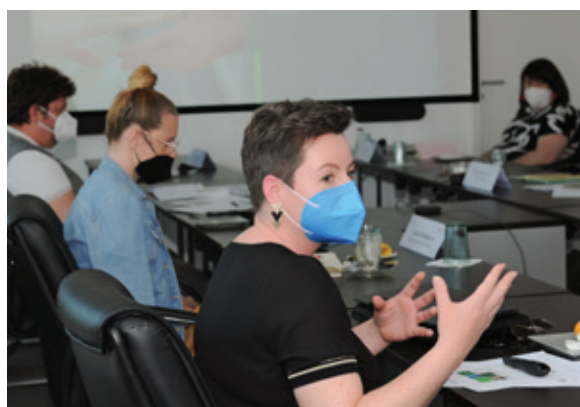
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### The main outputs and recommendations of the meeting are as follows:

- Strategic meetings of organizations where patients who are not part of the managing bodies are invited as well in order to get different, often even innovative views
- Monitor patients' opinions on social networking sites, do not be afraid to contact the most active ones and invite them to collaborate
- Search for slightly burnt-out managers in the commercial area
- Have your right-hand person and share competencies with them
- Have the main points of the lead written down to allow for handover to a new management if necessary
- Let your colleagues do their jobs and accept the fact that they will do it their way
- Hire a fundraiser and involve them in the organization as much as possible so that they then could inspire and involve others
- It is important to think seriously about whether I really want to pursue NGO leadership professionally (and thus leave job security)
- Make the most of local resources
- Delegate as much authority as possible



### APO Networking III. “Effective Management of a Patient Organization”





## APO Summer School VI. “Partnership – More than a Grant”

After a one-year hiatus caused by the coronavirus pandemic, the summer of 2021 could again see the patient conference **APO Summer School VI.**, entitled “Partnership – More than a Grant”. The aim of this meeting was to share inspiring examples of strategic cooperation between patient organizations, pharmaceutical companies and other “players” in the health system in the Czech Republic.

During the conference, three successful foreign projects on partnership between patient organizations, the pharmaceutical industry, doctors and other representatives of health institutions were presented. There were also presentations of four successful projects of Czech patient organizations and their cooperation with AIFP member companies and others.

- “IBD Under Control”, application for patients – IBD patients and Takeda
- “My Time Our Time – Invisible Women” – Breast Cancer Alliance and Novartis
- “My Frailty is not my Weak Point” – SMÁci and Roche
- “I’m not Written off yet” – ONKO Union and Pfizer

### We were also honoured by the visit and contributions of:

- **Mgr. et Mgr. Adam Vojtěch, MHA**, Minister of Health,
- **Ing. Zdeněk Kabátek**, Director of VZP,
- **prof. MUDr. Štěpán Svačina, Dr.Sc., MBA**, Chairperson of the Czech Medical Association of J. E. Purkyně,
- **Mgr. Irena Storová, MHA**, Director of the State Institute for Drug Control,
- **Ing. Bc. Kateřina Konečná**, Member of the European Parliament,
- **Mgr. Patrik Kastner**, Chairperson of the AIFP Ethics Committee.

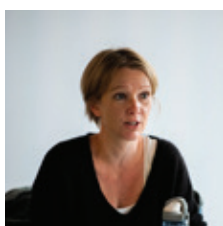
A big “thank you” belongs to the representatives of patient organizations who actively participated in the conference this year. Thanks to their unwavering support and willingness to share their experience and success, it was possible to demonstrate that true partnership is the basis for successful and meaningful cooperation.

## APO Summer School VI. "Partnership – More than a Grant"

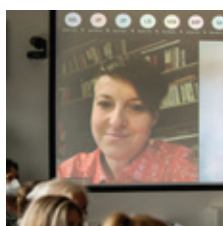


## APO Networking IV. “Smart Fundraising”

On Friday 15<sup>th</sup> November, the fourth APO Networking for the patient organizations involved in APO was held. The topic was “Smart fundraising”. Four representatives of patient organizations had prepared presentations and shared their experience of fundraising activities with us, demonstrating that it can be done even without the fundraiser. The participation in the session was in person as well as online (because of covid-19 restrictions at that time). The participants were taken through the whole event by an experienced moderator Mrs. Vanda Kofroňová.



*Magda Hrudková,  
Debra*



*Micha Lebeda,  
Endo Talks*



*Camelia Isaic,  
HAE Junior*



*Petra Němcová, Tereza Koucká,  
Alsa*

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### Recommendations from the presentations and following discussion:

**Strategic and financial planning** – first plan activities and development of the organization and then determine the financial plan, i.e. know what I will do, what personnel or material resources I will have to use and how much money I will need for it.

**Credibility** – do not distort facts, always keep your promise. Rely on your intuition and learn from your mistakes. Networking and collaboration represent a half of fundraising.

#### Income diversification

- Seek support also outside the usual scope of donors / supporters of patient organizations
- Use pro bono services (e.g. translators, lawyers, IT specialists, PR agencies, small manufacturers etc.)
- Search supporters through organization members as well

#### Strengthen long-term relationship with partners and donors

**Don't forget to thank the donors**



## APO Networking IV. "Smart Fundraising"



“ I wanted to thank you for the fantastic event. Despite the fact that I had to leave earlier, it was really inspiring for me and I appreciate the openness of all of those who shared their experience. Thanks again. ”

“ It was extremely informative and meritorious. The fact that organizations can consult each other these days instead of considering each other competitors is a great progress. ”

“ Thank you for inviting me today, the event was a great success :) ”

“ This time it was really so interesting, and of such high quality presentations... ”



# Digitalization of Medicine (not only) for Patients

At the first APO online conference “Telemedicine”, which was held at the end of 2020, we established active collaboration with the team of MUDr. Mgr. Jolana Kopsa Těšinová Ph.D., chief physician, 1st Faculty of Medicine, Charles University, on the project of digitalization. We were joined by representatives of young doctors, pharmacists and general practitioners, students of medical, law and pharmaceutical faculties. Also playing an important role were members of the newly established umbrella organization for Czech patients, the National Association of Patient Organizations (NAPO). The project is mainly funded by a grant from the Technology Agency of the CR.

In order to obtain an in-depth understanding of patients’ telemedicine awareness and needs, we helped to **conduct a quantitative and qualitative public opinion survey among representatives of patient organizations involved in the APO**. Its outputs were discussed with leading lawyers specialized in distance care and subsequently presented to experts at three roundtables in the second half of the summer.

Topics of individual events:

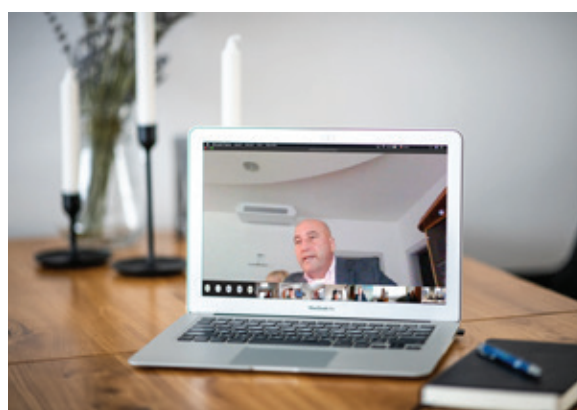
- **4 August 2021 – expert roundtable on health aspects,**
- **11 August 2021 – expert roundtable on pharmaceutical aspects,**
- **18 August 2021 – expert roundtable on legislative and financial aspects.**

The roundtables were held with the participation of representatives of patient organizations, the Ministry of Health of the CR, the General Health Insurance Company, the Association of Health Insurance Companies of the CR, the State Institute for Drug Control (SÚKL), the Czech Medical Association of J.E.P., the Czech Chamber of Pharmacists, the IT department of the Faculty Hospital of Olomouc, the Association of Hospitals of the CR and others.

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The outputs of these expert discussions were processed by the team of doctor Těšinová and, at the same time, they became the basis for the **annual conference “Digitalization of Medicine (not only) for Patients”, which took place on 30 November 2021 at the Academy of Sciences of the CR** (the recording is available on the YouTube channel of the Academy of Sciences of the CR). The aim of the conference was to make a wide range of experts acquainted with the outputs of the investigation of Dr. Těšinová’s team, the outputs of the summer roundtables, and in particular with 11 key points that came out of them and are crucial from the patients’ perspective in the context of the digitalization of medicine. The conference and individual discussion sessions were attended online or in person by representatives of all concerned parties, including media representatives. These activities were supported by the representatives of the Ministry of Health of the CR. The project will be further developed in 2022.

**“Digitalization of Medicine (not only) for Patients” – summer roundtables online**





## “Digitalization of Medicine (not only) for Patients” – 30 November 2021 conference



Mgr. Jakub Dvořáček, MHA, LLM, AIFP

MUDr., Mgr. Jolana Kopsa Teštinová,  
1<sup>st</sup> Faculty of Medicine, Charles University

# HTA Education for Representatives of Patient Organizations

Joint project of the Ministry of Health of the CR and the AIFP

At the beginning of 2021, we organized **another training for representatives of patient organizations on HTA** and their involvement in decision-making procedures on payment for health care.

The morning session focused on the challenges of legislative changes for patient representatives.

In the first part of the workshop, the speaker, MUDr. Jana Skoupá, MBA, member of the Committee of the Czech Pharmacoeconomic Society, focused on the following areas:

- Legislative requirements and the role of patients,
- Measuring the quality of life and the importance of this parameter in the HTA.

In the second part, MUDr. Tomáš Doležal, PhD., President of the Czech Pharmacoeconomic Society, presented the following topics:

- All-society view of a disease (indirect and social costs, impacts on the family and carers),
- Methodologically correct organisation of data collection.

In the afternoon, practically oriented session, the participants were divided into two groups, which together with MUDr. Skoupá and MUDr. Doležal discussed the following topics:

- **Drugs in oncology**
- **Orphan drugs**

With respect to the approval of the Amendment to Act no. 48/1997 Coll., on Public Health Insurance, we prepared another thematic training programme **“Involvement of Patient Organizations in Procedures on Pricing and Payment for Orphan Drugs”**.

The meetings were held on 2 and 3 November and 10 December at the premises of the Ministry of Health of the CR. Individual lectures and workshops were given by experts from the Ministry of Health of the CR, the State Institute for Drug Control and the Czech Pharmacoeconomic Society. The main topics were as follows:

- Principles for the reimbursement of medicinal products for the treatment of rare diseases – presentation of the intent,
- Assessment of criteria within the procedures on pricing and payment for medicinal products for the treatment of rare diseases,
- Opinion of the patient organization,
- Case study assignment,
- Procedure at the State Institute for Drug Control and statement of the patient organization,
- Workshop – working with the case study,
- Working with the case study – evaluation / recommendations.

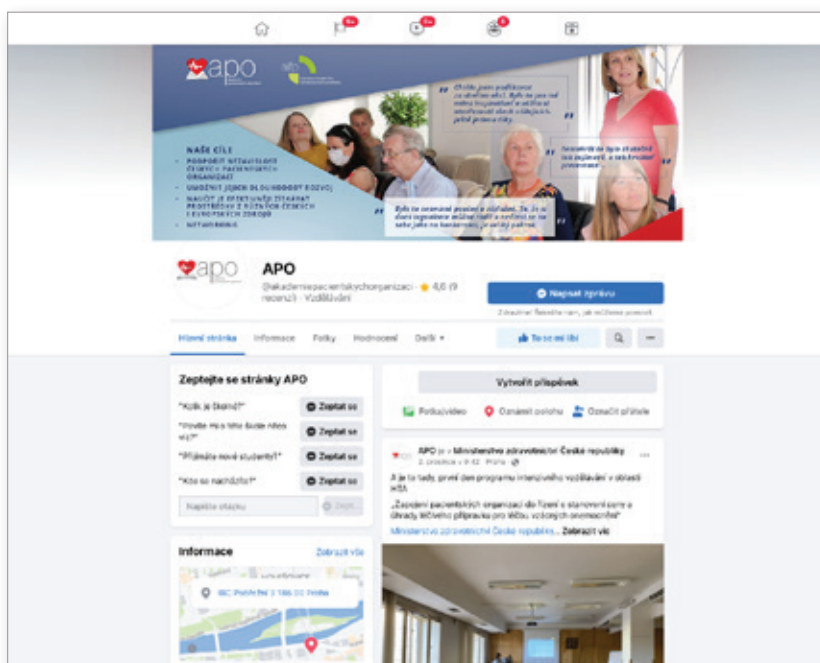


## HTA education for representatives of patient organizations



## The APO on Facebook

The APO continues to be an integral part of the patient community on the social networking site of Facebook. It actively posts an overview of its activities, interesting links, articles, invitations to meetings, etc.



## APO Bulletin

We also continue with the APO Bulletin, which enjoys a large readership. It is divided into three main parts:

1. Legislative overview,
2. APO activities,
3. Activities of patient organizations involved in the APO.

## APO Website

In March 2021, we completed the content and graphic update of the website. The website is now clearer and better structured.



# APO Plans for 2022



More  
than

**100** patient organizations involved in the APO



**Educational seminars**



**Mentoring**



**Networking events**



**APO Summer School VII, patient conference**



**APO Alumni VII**



**Another part of the intensive educational programme of the engagement of patient organizations in the HTA process and specific part called “Involvement of Patient Organizations in Procedures on Pricing and Payment for Orphan Drugs”**



**APO Board meeting**



**AIFP projects within the Czech Presidency**

## **The APO is going to continue its intensive cooperation with:**

- National Association of Patient Organizations (NAPO),
- Ministry of Health of the Czech Republic,
- Patient Hub,
- Czech Medical Association of J. E. Purkyně,
- National Institute for Drug Control,
- European Parliament,
- 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,
- 1<sup>st</sup> Faculty of Medicine, Charles University

We are going to continue our cooperation with organizations abroad, such as the EFPIA, the EPF, the Polish APO (modelled on the Czech APO) and others.



## OUR GOALS

- TO SUPPORT THE INDEPENDENCE OF CZECH PATIENT ORGANIZATIONS
- TO ENABLE THEIR LONG-TERM DEVELOPMENT
- TO TEACH THEM HOW TO RAISE FUNDS MORE EFFECTIVELY FROM VARIOUS CZECH AND EUROPEAN SOURCES
- NETWORKING



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