

Annual report

on the activities of the PHA Slovakia for the year 2022

Pulmonary arterial hypertension is one form of increased blood pressure in the pulmonary arteries. It is a disabling, debilitating and fatal disease. It seriously affects a person's ability to perform most normal activities of daily living. The main task of the association is to help patients as much as possible by organizing joint meetings focused on educational and rehabilitation activities, psychological and socio-legal assistance as well as efforts to improve social and health conditions. Because of its rare occurrence, the public is still poorly informed about this disease, therefore an important goal of the Association of Patients with Pulmonary Hypertension is to spread awareness of pulmonary hypertension among the general public.

The Association of Patients with Pulmonary Hypertension was founded on March 5, 2010. For the purpose of greater awareness, we organize in the association not only patients, but also family members, doctors, paramedics and friends. We are an active member of the European Pulmonary Hypertension Association, Eurordis, the Slovak Alliance of Rare Diseases, the Association for the Protection of Patients' Rights of Slovakia, we support the Rare Disease Association. We cooperate with several patient associations in Slovakia and abroad.

Association board:

- Iveta Makovníková – president
- Jana Guráňová - vice president
- Katarína Hrbáčiková – member
- Lukáš Gondáš – member
- Marta Čerepkaiová - member

Members of the control committee:

- Pavol Marko – chairman
- Anna Babková - member
- Ján Ďuriš - member

Currently, the association has 84 members.

Activities carried out in 2022:

1. PH awareness events

Rare Disease Day

On the occasion of Rare Disease Day, we ran a campaign on Facebook and Twitter to raise awareness about rare diseases, which was launched by Eurordis. On this occasion, a digital book translated into 28 languages, including Slovak, was created in cooperation with the Rare Disease Day platform. It was [a story about friendship](#), which brings children closer to how children with rare diseases feel in the collective and how they can help them.

PAH discussion forum

Since 2017, we regularly meet with students of the third year of the Secondary Health School in Lučenec. For the last two years, we have been forced to conduct the meeting via webinar. Topics about PAH and everything related to it (I. Makovníková) as well as about transplants and organ donation (J. Guráňová) were supplemented with short patient stories. Jana Guráňová also talked about adoption options and introduced her 14-month-old son. The whole webinar was compiled for two teaching hours. Two classes participated. We believe that next year the discussion forum will take place in person, because contact is important.

They wrote about us: <https://szslucnalc.sk/?p=14983>

World Pulmonary Hypertension Day

We commemorated the 10th anniversary of World Pulmonary Hypertension Day with several events within the European campaign "Get breathless for PH". In mid-April, we launched [a campaign on social networks](#). We requested that [important buildings](#) in the capital be illuminated blue. On May 5, the Presidential Palace was lit up in the color of PH. MR Štefánik at OC Eurovea.

The main event was [the ascent to Chmeľová](#). On the eve of the ascent on May 6, [an informational seminar](#) on PAHs and the significance of the ascent was held at the Vršatec Hotel. It was called Miracles sometimes happen. The main lecturer was MUDr. Milan Luknár, who focused on a new treatment for PH. On Saturday, May 7, accompanied by the RTVS staff, 45 participants took photos of patients to Chmeľová. The number of tourists was a reflection of previous pandemic years, during which events did not take place. The general partner of the event was Janssen. Other partners Bayer HealthCare, MSD, AOP Healt, Hotel Vršatec.

Another support in informing about PH was our running team, which this year decided to show its support abroad. [The Vltava Run](#) was a 360 km relay race from Šumava to Prague. It took place on the 14th-15th. May. After the competition, the team members visited our association member Tomáš Falb in Prague after a lung transplant.

www.rtvs.sk/televizia/archiv/14048/328286#1171

Video:

<https://www.youtube.com/watch?v=cE4uhgYTKsM&t=10s>

Sport events

For several years now, we have been favored by athletes who represent our association in Get breathless for PH campaign t-shirts at various running competitions. Their number, activity and willingness is constantly growing. They understood the need to spread information and made PH visible through running competitions not only in Slovakia, but also in neighboring countries (Czech Republic, Hungary). This year they ran more than 30 competitions as teams or individuals. Long-distance relay races and marathons have the greatest response.

The most important event for us was the relay race ["From the Tatras to the Danube"](#), which took place in mid-August. A 12-member team ran the 345 km route from Jasná to Bratislava in less than 33 hours wearing Get breathless for PH campaign t-shirts, under the name Patients with pulmonary hypertension. They carried our PH patients on their backs as mutual support. We came to welcome them to the finish line, thank them for their great work and encourage them.

In addition to running competitions, other fans, family members and members of the association made PH more visible during various hiking trips and other sports activities. Information on Orava was spontaneously launched in the form of [tourism](#) in the Western Tatras and [spinning](#) .

2. Activities for ZPPH members

Educational and rehabilitation stay

The [educational and rehabilitation stay](#) was traditionally held in the Spa Sliač on 21-26. August. 16 members of the association took part in the stay. The program consisted of an educational and rehabilitation part as usual. Nevertheless, the stay was a little different from other years. We had two treatments a day plus our activities, so the program was varied and we enjoyed it to the fullest.

On the day of arrival, we took part in an excellent music-recitation treat performed by the actress Eva Pavlíková, from which we had a wonderful cultural experience. A valuable lecture by the head of the nephrology transplant department of Roosevelt Hospital in Banská Bystrica MUDr. Nobody missed Eva Lacková. We have expanded our knowledge about organ transplantation. We were surprised by the news about the preparation for the pregnancy of the patients before the transplant and the successful postpartum conditions of the pregnancy after the transplant. We were surprised that young patients are already being prepared in Banská Bystrica. The presentation was very interesting and the participants had many questions. At the end, Mrs. Oľga Štefanická (Sanca pre pečen) asked to speak. In August, the Roosevelt Hospital in Banská Bystrica, in cooperation with the Slovak Hepatological Society, launched a preventive liver screening under the name Sirius, the aim of which is to detect liver disease at an early stage, when it is still treatable. Because Slovakia ranks 1st in the world in the incidence of liver cirrhosis, she invited us to participate in this event. And to make our ladies happy, we prepared two beauty hours for them with Mary Kay under the guidance of Mgr. Eva Koperová on the subject of lifting the eye area. Under expert supervision, the women learned how to take care of slowing down aging.

We only used the gym twice, as the program was really busy. And despite the fact that they practiced without a professional lecturer this year, it went very well for us. The combination of pilates and yoga was very pleasant. We supplemented it with walks in the spa park, each according to their possibilities. So that we don't lack and get educated not only in the field of medicine, we took a trip with a historical theme. We visited the articular church in Hronsek and the exhibition about the Copper Hammer in Banská Bystrica. Both places were truly exceptional. There was also a walk in the center of Bystrica, and at the end we enjoyed an excellent dinner with refreshments at Pizzeria Evijo. During our stay, we had evening barbecues, dance nights and sit-downs.

General assembly, working sessions

After the ascent to Chmeľová, a general assembly was held on May 8 in Hotel Vršatec. The general meeting was led by Anna Kráľová, the president Iveta Makovníková informed about the activities of the association during the election period and presented the work plan for the next year. During the general meeting, the ZPPH Council members were elected. New members Marta Čerepkaiová and Lukáš Gondáš were elected to the council. Subsequently, the members of the council re-elected I. Makovníková as chairwoman and J. Guráňová as vice-chairwoman.

During the year, 4 ZPPH Council meetings and 16 working meetings were held. At the end of the year, we renewed the meeting with partners. During the working dinner, we evaluated the whole year's activities and presented them with the work plan for the following year. We thanked them for their

support in the form of a small gift. After a pleasant discussion, everyone accepted the invitation to dinner.

A total of 15 consultations were provided to patients during the year.

3. Awareness and expansion of the membership base

Annual European PH Conference, PHAE General Assembly

Due to the pandemic, [both the Annual European PH Conference](#) and [the PHAEurope General Assembly](#) have been moved from 2021 to March 2022, however, they were held online via ZOOM. We participated in the preparations for several weeks. During the week, 11 presentations preceded the entire conference. This also resulted in many tasks for obtaining a financial contribution for the association, preparing questions for lecturers, setting up a virtual stand with our brochures, leaflets and video recordings. Peter Makovník and Jana Guráňová participated in the conference on behalf of our association. During the 2-day conference, they listened to lecturers - top specialist doctors, industry representatives, but also patients who answered our questions on various topics (treatment of CTEPH and PH in the USA, about exercise, sex and contraception, children's PH, about nutrition, Ayurveda).

The General Assembly was held twice. In January, the election of members of the PHAE board was held. Next

the general assembly took place on March 16 after the end of the conference. In addition to the evaluation of the activity and work plan for 2022, [the TOP 10 associations](#) with the largest number of activities were evaluated. ZPPH was ranked 7th (among 22 countries). The revised Call to Action - renewal project was also presented, which they planned to present in April 2022 in the European Parliament.

Another conference was held in Barcelona in November, but we did not attend this one for health reasons for the first time.

Patient awareness

We are constantly trying to expand our membership base. In order to further motivate patients to join the association, we try to introduce them to our activities through printed and visual materials, through the website and social networks Facebook and Twitter. At the Center for PAH at NÚSCH, we take care of promotion through [the bulletin board](#) and the supply [of educational and informational material](#) in all centers in Slovakia .

We have renewed contact with the PAH Center at VÚSCH. We informed them about the activities that we repeatedly prepare for patients.

We published a summary of activities in the year-end issue [of PH magazine Fialka](#).

In 2022, we gained [8 new members](#) .

4. Improvement of conditions

European projects

ZPPH was actively involved in the creation of the following European projects coordinated by PHA Europe, in the form of questionnaires and comments.

Call to action

PHA Europe launched a call to action in the European Parliament in 2012. At the ZPPH meeting, MUDr. Milan Luknár . After 10 years, there was a need to submit a new revised call, as the conditions had changed. On April 26, 2022, at a round table in the European Parliament in Brussels, representatives of various patient associations, regulatory bodies and pharmaceutical companies gathered together with the medical review committee, chaired by prof. Marc Humbert to officially present [the new position paper](#) . The event was one of the first meetings organized in the European Parliament and was the very first and flagship event of the MEP Lung Health Group. PHA Europe is part of it and cooperates with other associations of patients with lung diseases - the European Respiratory Society (ERS). The participants justified the challenge and drew attention to the need for better diagnosis and treatment of PH.

New guidelines

The long-awaited new ESC/ERS guidelines for the diagnosis and treatment of pulmonary hypertension were presented this summer during the annual ESC Congress in Barcelona. The working group for the new guidelines has spent an enormous effort over the last two years to update the previous guidelines, which were published in 2015. It was the first time that patient representatives had participated in such a survey and PHA Europe was part of this work.

<https://europeanlung.org/wp-content/uploads/2022/09/Diagnosing-and-treating-PH-Understanding-the-professional-guidelines-EN.pdf>

Protest

On June 22, with our participation in front of the parliament, we supported the AOPP protest press against the reduction in the availability of common medicines, the use of cheaper and insufficiently effective medical devices and the exclusion of patients from advisory bodies.

The sixth all-Slovak patient conference

On the 25th-26th November, the 6th all-Slovak patient conference was held, the organizer of which was the Association for the Protection of Patient Rights (AOPP). The program was about patient management - the path from diagnosis to treatment. This issue was discussed by representatives of health institutions - insurance companies, outpatient and hospital doctors, pharmacists, spas, drug manufacturers. The second day of the conference was dedicated to management and the patient's journey within individual diagnoses, which was presented by representatives of patient organizations. Iveta Makovníková presented [the Call to Action](#) , which took place in April at the European Parliament. She highlighted the needs of patients and health professionals in the diagnosis and treatment of PH in Slovakia. We prepared [flyers and brochures](#) Call to Action , which we distributed to health policy makers.

In the evening hours of the first day of the conference, a gala evening was held, where the awards "My doctor", "My sister" were presented. Based on nominations from patients and the general public, a 5-member jury appointed by the AOPP presidency decided to award 10 doctors and 10 nurses for their dedicated work and contribution to patients. The "My doctor" award was also

received by MUDr. Milan Luknár, PhD, to whom we have come to wish a lot of patience and vigor in his further excellent work for patients with PH. At the end, we gave an interview to Radio Regina.

<https://aopp.sk/clanky/default/zlepsenie-manazmentu-cesty-pacienta-pomoze-skratit-cas-od-diagnostiky-k-liecb>

<https://aopp.sk/clanky/default/pacienti-uz-po-siestykrat-ocenili-pracu-lekarov-sestier-cenu-verejnosti-si-odniesli-kosicke-zdravotnicky>

<https://www.zriedkavechoroby.sk/spravy/ocenenie-moj-lekar-ziskali-aj-dvaja-lekari-z-pracovisk-pre-rizedkave-choroby/?fbclid=IwAR2Xtx4b9uluhsUT7s3NBtY43Zza6qKN1KT8CJwaHkd7v4Xvkv0xldMxjL4>

Projects

We obtain funds for the association's activities mostly from projects, partly from 2% of taxes, or from donations. This year we submitted [4 projects](#) for World PH Day activities, information campaigns and patient education. All projects were successful.

We provided members with a job offer in the [Active.me project](#) from Norwegian funds for the position of a so-called "health coach" for over 60-year-old patients with high blood pressure and sugar levels. The offer also applies to the certification of this work. One member joined the project as a patient.

2% of taxes

We published the use of the profit of 2% from the tax [in the Obchodný vestník](#) . At the beginning of autumn, we registered as [recipients of 2% of taxes](#) . We used the profit from last year for an educational and rehabilitation stay for ZPPH members in the Sliáč Spa. We plan to use the contribution for the same purpose next year as well.

In Velky Krtíš on December 31, 2022

The report was compiled by: Mgr. Iveta Makovníková

Drawing of financial resources PHA Slovakia

for the year 2022

Income	Amount in €
Membership fee	690.00
2% of taxes	4,879.04
Refund of the protected workplace from UPSVaR	7,784.06
Gifts	6,595.00
Contract with PHAE - translations, web	5,250.00
The rest	2,358.84
Total revenue	27,556.94
Expenses	Amount in €
Services	
PH magazine Fialka, photo documentation	333.08
Web page	179.29
Antivirus license	17.45
Advertising on social networks	200.51
Leaflets and brochures	109.33
Advertising T-shirts	221.00
Together	1060.66
Operating costs	
Rent	1,274.06
Telephone, internet	447.08
Postage	153.85
Office supplies	52.26
Bank and other fees	225.16
Together	2,152.41
Wages, contributions	
Wages of workers, remuneration of lecturers	6475.89

Levy	3,533.83
Translations, web	4,200.00
Together	14,209.72
Travel expenses, per diems	
Working meetings, Council meetings, trainings	370.69
Campaigns, seminars, congresses, conferences	558.92
Together	929.61
Events	
World PH Day, General Assembly	5,532.86
Educational and rehabilitation stay	3,210.10
From the Tatras to the Danube - relay race	1,300.00
All-Slovak patient conference	220.96
Activity evaluation - working dinner	1,285.78
Together	11,549.70
The rest	
Membership fees	100.00
Together	100.00
Total expenses	
	30,002.10
Balance	
	-2,445.16
Contributions in %	
UPSVaR	31%
PHA Europe	28%
2% of the tax	19%
Janssen	9%
proceeds from WPHD	6%
AOP Orphan	4%
members of ZPPH	3%

Prepared by: Mgr. Iveta Makovníková
In Velký Krtíš on January 3, 2023