

PHA Slovakia 2018 Annual Activity report

Pulmonary arterial hypertension is a rare disease. The disease is characterized by increased pressure in the pulmonary stream, progressive right heart failure, significantly impaired quality of life, which often affects young people. The cause of the disease is often unknown, the symptoms are not specific and therefore the disease is difficult to diagnose. The goal of our civic association is to raise awareness of PAH among the general public as well as efforts to improve conditions for PH patients.

Association of patients with pulmonary hypertension, o.z. (PHA Slovakia) was founded on 5th of March 2010. For the sake of greater awareness, we organize not only patients but also family members, doctors, healthcare professionals and friends. We are an active member of the Pulmonary Hypertension Association Europe, Eurordis, the Slovak Alliance of Rare Diseases, the Association for the Protection of Patients' Rights of Slovakia, and we support Civic organization Rare Diseases. We cooperate with several patient associations in Slovakia and abroad.

[PHA Slovakia board members:](#)

- Mgr. Iveta Makovníková – president
- Ing. Jana Guráňová – vice-president
- Ing. Katarína Hrbáčiková – member
- Tomáš Falb – member
- Anna Kráľová - member

[Revisory committee:](#)

- Pavol Marko – chairman
- Ing. Július Greguš - member
- Ján Ďuriš - member

At the end of the year 2018 we had 83 members.

Activities carried out in 2018:

1. PH raise awareness events

Rare disease day

On the Rare Diseases Day we have run a campaign to raise awareness of rare diseases on Facebook, Twitter, launched by Eurordis. On this occasion Civic association “Rare diseases” launched a new specialized educational portal <http://www.zriedkavechoroby.sk>, which is unique in its content not only in Slovakia or the Czech Republic, but also in the whole Central Europe. The portal was presented at a press conference on February 5th at the Aston Hotel in Bratislava, which was also attended by PHA Slovakia president Iveta Makovníková as a representative of the supporting organization. 5 TV reports and 7 articles were published.

Discussion forum on PAH in schools

At the beginning of February 2018 we organized the second discussion forum on PAH for students of the Secondary Medical School in Lučenec. The seminar lasted two lessons and was attended by around 35 students. During the seminar, video spots on PAH and a three-part film “Daniel's Life with

PAH” were played for students. Patients with PAH told students how to live with this severe disease. They were mostly interested in how patients deal with social problems.

World Pulmonary Hypertension Day

World Pulmonary Hypertension Day was commemorated by several events within the European campaign “Get breathles for PH”. We have joined the event by launching campaign on social networks. The main event was a climb to [mountain Ostredok](#) from in the Great Fatra Highway. In the evening, before the day of the climb, an [information seminar](#) on PAH and the importance of the output was held. On Saturday, June 2nd, 142 participants climbed the Great Fatra peak with patient photos on their back. They included doctors, medical staff, family members, tourists, but also other participants from different parts of Slovakia and the Czech Republic. After return, we made an informal evaluation, where the regional activities were presented by the presidents of the associations from neighboring countries of Hungary and the Czech Republic. We enjoyed the stay with a rich raffle. The event continued on Sunday morning by planting a tree in the center of Banská Bystrica under the motto "[Plant your lungs](#)". With the support of ZAaRES, we have planted a rare occurrence of the Cercis tree in the Slovak National Uprising Class. Media coverage was made with the support of Regina radio. Two reports were broadcast.

Captain of the cross-country team Michal Gaplovský joined the unique relay called [D-one](#) in the ČSOB bank marathon dedicated to the support of rare diseases, which was initiated by association “Rare diseases” with ambassador Daniela Hantuchová (world famous Slovak tennis player). The runners supported the campaign by participating in two competitions of the ČSOB Marathon and the [National Run Devín - Bratislava](#). Patient's family members also contributed to the campaign.

The general partners of the event were Actelion Pharmaceuticals, Bayer HealthCare and MSD. Other partners GSK, ZAaRES and Cewe Fotolab. The whole event was held under the auspices of the Mayor of Banská Bystrica.

Media coverage:

<https://vzdravotnictve.sk/pacienti-s-plucnou-hypertenziou-symbolicky-vystupia-na-ostredok/>

<https://mybystrica.sme.sk/c/20838716/pacienti-s-plucnou-hypertenziou-symbolicky-vystupia-na-ostredok.html>

<http://www.phaslovakia.org/aktivita>

<http://aopp.sk/event/v%C3%BDstupom-na-ostredok-podpor%C3%ADte-pacientov-s-p%C4%BE%C3%BAcnou-hypertenziou/11/default/actual/>

<https://vzdravotnictve.sk/kalendar-udalosti-zdravotnictvo/vystupim-za-teba-ostredok-2018/>

<https://www.zriedkavechoroby.sk/zaujalo-nas/vystupme-na-vrchol-hory-za-pacientov-s-plucnou-hypertenziou/>

<https://www.zriedkavechoroby.sk/spravy/zadychaju-sa-uz-pri-malej-namahe-dnes-maju-svoj-den/>

<http://www.aopp.sk/clanok/za-pacientov-s-pucnou-hypertenziou-vystupilo-na-ostredok-142-ucastnikov>

<https://www.zriedkavechoroby.sk/spravy/142-ludi-vystupilo-na-vrchol-za-pacientov-s-plucnou-hypertenziou/>

Farmaceutický laborant

Video:

<https://www.youtube.com/watch?v=LK0v-wCQH04>

Sports events

For many years, we have been favored by athletes who represent our association in the Get Breathless T-shirt for PH at various cross-country running competitions. Their number, activity and willingness is constantly growing. They understand the need to disseminate information and raise awareness of PH through running competitions.

- 13.1. ČSOB winter series
- 10.2. ČSOB Draždiak
- 18.2. Rača cross Bratislava
- 25.3. Run at Železná studnička
- 15.4. National run Devín - Bratislava
- 8.4. ČSOB marathon
- 18.-19.8. OTKD
- 8.9. Nightrun
- 29.9. Mariantalský štvaneč
- 22.10. Dračí kros
- 7.10. MMM
- 4.11. Šamorin runner's league
- 25.11. Čachtický krvák
- 24.12. Bratislava Christmas run
- 31.12. Silvester run

The most important sport event was the relay race "From the Tatras to the Danube", which took place in August. The 12-member team ran the Get Breathless for PH T-shirts for the fifth year under the title "Patients with pulmonary hypertension" 345 km long race from Jasná to Bratislava in difficult conditions.

In addition to cross-country skiing competitions, our fans, family members and members of the association also made themselves known during various hiking events and other sporting activities. There were 8 of them. They spread awareness of PH not only in Slovakia but also abroad (Madeira, Croatia, Italy).

XXXIX. Annual conference of Slovak society of general practitioners

This year we appealed to doctors of first contact at the SSGP Annual Conference. In the one hour block "From Dyspnea to Pulmonary Hypertension" MD Milan Luknár entered with a thirty-minute professional presentation, preceded by a film with patients' statements about PAH problems and the changes in life after the disease (after transplant surgery). Iveta Makovníková brought the audience closer to her own problems with diagnosis of the disease. At the end of the block a short video spot called Zebra was played. The aim was to call for timely assistance and correct diagnosis. The block was chaired by MD. Marta Hájková, head physician of Lung department at the University Bratislava hospital in Ružinov. At the entrance to the hall the participants were given reprints from the magazine Causa subita 3/2018 with an apt article by M. M. Luknar "How to recognize a patient with suspected PAH". During the conference we had an information stand with press materials available for the participants. The event was supported by Actelion, AOP Orphan and MSD.

2. Activities for PHA Slovakia patients

Rehabilitation stay

In May, a 5-day rehabilitation stay was held for patients. The aim was to get acquainted with the principles of physical therapy and relaxation for a selected group of patients. Physiotherapist Mgr. Pavla Mizerová and clinical psychologist PhDr. Pavla Nôtová led exercises. Nine patients participated in the stay. The physical training program will continue for other patients next year.

Educational-recondition stay

This year we have included an educational and reconditioning stay for patients with PH in the program, from 5th – 10th of August 24 members of the association took part in the stay. The program was focused on education, which took place in the morning and the afternoon was devoted to yoga exercises. The main topics of education lectures were ethicotherapy (Mgr. Beata Hlohovská, University of Conscious Life) and forming of educated patient through the EUPATI project (Mgr. Petra Balážová, Association for the Protection of Patients' Rights). Yoga exercises (Robert Urgela, a therapist of traditional healing practices) focused on breathing, strengthening meridian pathways, warming up the joints, and acoustic-resonant relaxation and yoga nidra. We deepened the joy and self-confidence of the participants in creative workshops - painting their own motifs on T-shirts. The participants had the opportunity to use various spa procedures, free access to the swimming pool, pleasant walks in the spa park in the evenings, but the biggest asset was the meeting of patients itself.

General assembly, working meetings

On December 1st, the General Assembly was held in Zavadka nad Hronom with the participation of 25 members of the association. The all - day program was devoted to the evaluation of PHA Slovakia's activities for 2018, the work plan for 2019 and elections to the PHA Audit Commission for 2019-2021. The General Assembly was led by vice-president Jana Guráňová. President of the association Iveta Makovníková informed about the activities of the association, presented the work plan for the next year, informed about the PHA Europe Annual Conference, legislative processes in drug policy. Guráňová spoke about participation in the campaign to raise awareness of organ donation and transplantation. During the introduction of the work plan for 2019, Tomáš Falb presented the route of climbing up to Zelená pleso, which will take place on the occasion of World PH Day. The General Meeting was closed by general discussion.

Five meetings of the PHA Slovakia board were held during the year, one with an expert advisory team and 13 working meetings. At the end of the year on 12th of December, we prepared an [evaluation of our activities for our partners'](#) and presented them our work plan for the following year.

Patients received a total of 13 counselings.

3. Information and enlargement of membership

General annual meeting of PHA Europe

Regular participation in the [annual PHA Europe conference](#) contributes to information and education, while actively participating in project development. Working together on European level leads to a significant visibility increase within the European Community and an improvement in the conditions at national levels. This year, the conference took place between 13th and 16th of September in Berlin, the president Iveta Makovníková and the translator Peter Makovník represented PHA Slovakia. The main points of the 4-day program were the General Assembly with a presentation of the activities for the previous parliamentary term and a work plan. In the training session, four workshops were prepared on various aspects that we considered necessary to strengthen patient uniting: patient training, membership expansion, cross-border cooperation and fundraising. Guest lectures on recent developments in PH were given by MD Henning Gall (Uniklinik Giessen, Germany), who spoke about role of biomarkers in PH diagnosis and the possibility of easier diagnosis. Prof. Dr. Marion Delcroix (University Hospitals Leuven, Belgium) dedicated his lecture to CTEPH webinars. This year we had the opportunity to meet representatives of Arena, Actelion, Bayer, MSD. During the gala evening the best activities of the Get breathless for PH campaign were evaluated.

Patients informing

We are constantly striving to expand our membership. In order to motivate patients to join the association, we strive to bring our activities closer to them through press and image materials, the website and the social networks Facebook and Twitter. At the PAH Center at National Institute of Cardiovascular diseases, we take care of promotion through an on-wall panel, where we supply educational and information materials for patients. In 2018 we have added new brochures [Practical Guide \(not only\) for patients with PH](#) and we released two issues of [PH magazine Fialka](#). We published a summary of activities in the year-end issue.

In 2018 we gained [9 new members](#).

Education

Iveta Makovníková participated in [two educational cycles](#) “Patient and Medicine” and “Successful Patient Organization = stronger voice of the patient”. The training focused on awareness raising, advocacy, clinical trials and online patient organization communication/media skills.

On 23rd-24th of November, 4 members of PHA Slovakia attended the [2nd National Patient Conference of Association for the Protection of Patients' Rights](#). The main topics of the conference were early intervention, biosimilar, clinical trials and rational pharmacotherapy. As part of the conference, the first prize “My Doctor, My Nurse”, was given by Minister of Health A. Kalavská.

4. Conditions improvement

Marking up

We strongly objected to the proposed increase in surcharges for medicines, and we submitted our disagreement with the increase in surcharges for medicines for PAH. Makovníková, Makovník V., Krivánek and Jánošíková participated in a discussion with politicians and key players on [the revision of changes in reimbursement of medicines](#), which took place on the occasion of the 2nd National Patient Conference of Association for the Protection of Patients' Rights.

2% of taxes

At the beginning of autumn, we registered as [2% tax recipients](#). Profit from last year was used for educational-recondition stay for association's members in Sliač Spa. We plan to use the contribution for the same purpose next year.

Creation of projects

As the financial resources for PHA Slovakia's activities are lower from year to year, we try to cover our costs from the projects that Roman Krivánek worked on. We submitted 3 projects for World PH Day activities and patient education. All projects were successful.

5. Cooperation

European campaign to increase organ donation and transplantation

On 14th of September 2018, the first EUDONORGAN event took place in Warsaw, which was a follow-up for 2017 EUDONORGAN training program, also attended by Jana Guráňová. The event itself was preceded by a press conference. It had two main topics: organ and tissue donation in practice and the role of the media on organ and tissue donation. The program also included testimonies of kidney and heart transplant patients and one kidney donor. The event was attended

by Jana Guráňová and the main transplant coordinator from Slovakia, MD Ľuboslav Beňa, who gave a brief presentation on media campaigns related to organ donation in Slovakia (called Seven Lives).

Congress of transplantology

The Slovak Transplant Society organized the 2nd Congress in Bratislava between 18-20 of October. The program covered a wide range of topics and issues related to organ and tissue donation and transplantation. The congress was attended by Jana Guráňová, who, as a trainer of the EUDONORGAN program, enriched her existing knowledge with a lot of new useful information. <https://videoportal.joj.sk/noviny/epizoda/58760-noviny-tv-joj> (at 16:31)

Short Story Book "Live in Me"

On October the 9th 2018, a collection of short stories “Live in Me” was christened at the Martinus Bookstore in Bratislava. The initiator of this activity was Civic Association Gift of Life. Ambassador of the book became SND actress Táňa Pauhofová. The book contains 15 short stories based on the true stories of patients after organ transplantation. The book was preceded by a literary competition of patients after transplantation “My Story”, in which Jana Guráňová participated. Her story became a model for a short story written by Dana Podracká. The aim of the project is to raise awareness and improve public opinions in the field of transplantation and organ donation in Slovakia. <http://www.darzivota.sk/krst-knihy-zi-vo-mne/>

Cooperation with the Czech Association

Regular exchange of experience with members of the Czech Association continued in 2018. At the invitation of Czech PHA, PhDr. Pavla Nôtová attended a [rehabilitation stay](#) in Poděbrady, where she led relaxation techniques for three days, followed by a interview, education and counseling. Physiotherapist Pavla Mizerová joined in to exchange experiences. Pavla Nôtová also accepted an invitation to the [General Assembly of PHA Czech Republic](#), which was held on 23 November 2018 in the Želiv Monastery. Mutual visits to events promise closer cooperation, exchange of information, advice and mutual assistance.

Utilization of PHA Slovakia In year 2018	
Receipts	Total in €
Membership fees	800,00
2% of taxes	4 366,04
Refund of protected workplace by Office of Labour, Social Affairs and Family	6 187,00
Gifts	13 680,69
Other	1 929,69
Total receipts	26 963,42
Expenditures	Total in €
Material equipment	
Professional literature	37,96
Office armchair	253,21
PC mouse	6,90
Total	298,07

Services	
PH magazine Fialka, photographic works	884,60
Website	118,13
MS Office	28,00
Domain	13,14
ESET license	17,45
Total	1 061,32
Operational costs	
Rent	1 108,29
Phone, internet	543,87
Postal costs	183,60
Office supplies	54,63
Banking and other fees	248,13
Total	2 138,52
Salaries, funds contributions	
Employee salaries, lecture remunerations	4 925,45
Funds contributions	2 519,17
Total	7 444,62
Travel expenses	
Working meetings, council meetings, trainings	612,89
Campaigns, seminars, congresses, conferences	247,75
Total	860,64
Events	
PAH Discuss forums	225,54
Rehabilitation stay	1 799,60
WPHD Climbing Ostredok	4 553,78
Education-relaxation stay	3 421,05
From Tatras to Danube – relay run	681,37
Annual conference PHA Europe - Berlin	234,46
General practitioners conference	578,22
General assemblz meeting	633,88
Activities evaluation – working dinner	1 120,23

Christmas concert		48,00
Working meetings		84,35
Total		13 380,48
Other		
Membership fees		100,00
Other costs		25,80
Total		125,80
Total expenditures		25 309,45
Balance		1 653,97

Donors gifts		
Actelion	49,70	%
AOP Orphan	19,90	%
PHA Europe	13,50	%
GSK	9,50	%
MSD	6,80	%
Others	0,60	%

In Vefký Krtíš, 8th of January 2019

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