

Activities carried out in 2017:

1. Events aimed to raise awareness

Rare Disease Day

- Social networks campaign on Facebook, Twitter and Google led to increase of awareness, joining Eurordis campaign.
- Published patient stories and videospots.
- Recorded video reportage about PAH and its consequences with Iveta Makovníková and doctor Milano Luknár, broadcasted in TV Markiza TV Show called Reflex.

WPHD

As part of the Get breathless for PH Campaign, we have prepared the third climbing to the peaks of Slovak mountains entitled „I will climb for you“. The entire project was divided into two parts.

1. Phase

The first part of the project was focused on medialization. A press conference took place on 2nd of May with the participation of 28 journalists and TV editors. At the end of the press conference Slovak celebrities, popular singer Tomáš Bezdeda and the actor, singer and comedian René Štúr, planted two shrubs as a symbol of healthy lungs and invited the general public to the climbing event. On 5th of May we conducted an information campaign at the Slovak Philharmonic in Bratislava.

www.rtvsk.sk/televizia/archiv/11666/124760#989 in.16:28

2. Phase

The second part of the project was carried out on 26th-28th of May in the Low Tatra. The event was attended by 172 participants, including 14 patients. On the evening the day before climbing, an informative seminar was held at the Liptov Hotel in Jasna about the importance of the campaign and the illness, in which patients presented their life stories. The topic of the seminar were transplantations and PH in children. On 27th of May the climbing to mountain Siná (1560m above sea level) with the motto "I will climb for you" took place. 162 attendees, including 3 PH patients and one patient after transplant surgery climbed to the top of the mountain. They carried 21 tables with photos of patients with PH on their back. The output was attended not only by family members, doctors, health professionals, but also general public invited by Slovak Television. Meanwhile, the patients took short walks around the hotel.

As a symbol of health, clean air, but especially symbol of the lungs, which are essential for every living organism on earth, the participants of the meeting planted 25 spruce trees, each bearing the name of a patient with PH. The motto "Grow your lungs" was really appropriate, as the surrounding forests were significantly destroyed and devastating by the construction works taking place in the neighborhood.

The whole event was filmed by the Slovak television for the Televíkend TV show and the most popular commercial television Markíza for the „Reflex“ TV show, for which they have also recorded the story of a 5-year-old Maťka with PAH.

Medialization resulted in:

- 12 internet articles
- 2 articles in nation-wide sold magazines
- 1 reportage for the main news in Slovak television
- 3 reportages in TV shows Televikend and Reflex – currently in preparatio
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2. Sports events

For the past few years, we have gain the favor of numerous sportsmen, who represent our association in its typical Get breathless T-shirts, earning us a lot of awareness. Events are growing in number and size of sportsmen involved. Mostly in running disciplines:

- 26.3.2017 Run on Železna studnička
- 8.4.2017 Štiavnický trail
- 9.4.2017 National run Devín - Bratislava
- 1.5.2017 Cross country Baba - Kamzík
- 7.5.2017 World run on 100 km
- 8.6.2017 Bratislava Night Run
- 9.-10.6.2017 Štefánik Trail
- 18.6.2017 Carpathian triathlon
- 2.9.2017 Rýchlik Zoška – Bratislava
- 8.9.2017 Záchranárska súťaž
- 9.9.2017 Nightrun

Most important run of all was the relay run called From Tatras to Danube, which took place on 19th-20th of August, ranging of 345km from our highest mountains High Tatra to our capital city Bratislava. For the 4th year, our running team ran in Get Breathless for PH T-shirts with the team name Patients with PH, in difficult conditions. It was accompanied with 2 cars with logos of PHA Slovakia and signed by PH patients names for whom they ran for.

<https://www.youtube.com/watch?v=Un5v00Q3N9U>

3. XXXVIII. Annual SCS congress

We have attended the yearly congress of Slovak Cardiology Society, where we have focused on physicians of first contact (general physicians). We have been present with informational stand and were handing out brochures and also projected a video about discussions with physicians. We have been offered a dedicated hour block in next years professional presentations for all attending doctors.

4. Presentations about PAH

- There were 2 videos broadcasted in TV Markíza, one about PAH in child in TV Show Reflex and one about PAH transplantation surgeries with Iveta Makovnikova and doctor Milan Luknar
- Iveta Makovníková was also been invited to filming new session of TV Show The Wonderful Wishes prepared by TV Markiza, where she presented on PAH

5. Medialization

We have published articles about PH, patients stories, presented the issues of patients with PH and about the importance of PH Association. Most of the media coverage was however related to WPHD:

<https://www.cas.sk/clanok/542899/ludmile-v-tehotenstve-diagnostikovali-zakernu-chorobu-zivot-mi-zachrania-nove-pluca/>
<http://egoodwill.sk/zdravie-2/29469/>
<http://x.vysetrenie.zoznam.sk/cl/1000663/1626355/Choroba--ktora-sa-da-lahko-pomylit-s-asmou--Unavi-vas-pri-beznom-obliekani->
<http://www.hlavnespravy.sk/plucnu-hypertenziu-maju-stovky-slovakov-skora-diagnostika-im-zachranuje-zivot/988570>
<https://zdravie.aktuality.sk/clanok/4043/plucna-hypertenzia-ma-rychly-postup-a-moze-viest-k-smrti-ako-s-nou-bojovat/>
www.netky.sk/clanok/plucnu-hypertenziu-maju-stovky-slovakov-nepodcenujte-diagnostiku-zachrani-vam-zivot
www.teraz.sk/magazin/plucnu-hypertenziu-maju-stovky-slova/257595-clanok.html
<http://tivi.cas.sk/video/2509737/ludmile-v-tehotenstve-diagnostikovali-zakernu-chorobu-zivot-mi-zachrania-nove-pluca/>
vzdravotnictve.sk/piatok-svetovy-den-plucnej-hypertenzie/
<http://www.nusch.sk/sk/806/podporovatelom-s-plucnou-arteriovou-hypertenziou-je-aj-spevak-tomas-bezdeda>
www.pluska.sk/izdravie/liecba/unavi-vas-obycajna-prechadzka-nezahravajte-so-zivotom.html
egoodwill.sk/filantropia-cr/170-turistov-vystupilo-na-vrch-sina-za-pacientov-s-plucnou-hypertenziou/

Articles in magazines:

Nový čas, Plus jeden deň, Pľúca Liek, Medical practice

TV Broadcasts:

<https://www.youtube.com/watch?v=1vf1zqSf6LM>
www.rtvs.sk/televizia/archiv/11666/124760#989 v min. 16:28
videoarchiv.markiza.sk/video/televizne-noviny/televizne-noviny/68091 televizne-noviny
www.rtvs.sk/televizia/archiv/11700/128069#936 v min. 15:36
<http://videoarchiv.markiza.sk/video/reflex/cele-epizody/67138> reflex

Campaign on Facebook, Twitter, Google+

- RDD Campaign
- Get breathless for PH
- Call to action to improve Organ Donation and Transplantation across the EU
- Campaign to European Transplant day

6. Short videos of Time Matters series

We have published on our social networks series of patient stories in months March – May 2017. Short videos of patients that were recorded by national associations in Serbia, Austria, Portugal, Israel etc. 15 movies were translated to Slovak subtitles.

7. Activities for PHA members

Educational-relaxation stay

We have continued in bringing our patients the stay for them to exchange experiences and find a mutual support. Each year we prepare a 6-day stays for PHA members in one of the Slovak SPAs. This year it happened in SPA Sliach. It took place on 3rd-8th of September and was focused on physiotherapy, relaxation, breathe excercises and education. Educational program included presentations on healthy life style and proper diet (Ing. Dáša Ballová, Academia vitae). Accompanied by rehabilitational excercises (Mgr. Pavla Mizerová), yoga (Robert Urgela), relaxation excercises (PhDr. Pavla Nôtová), and short walking tours.

Training program for PHA patients

In cooperation with Center for PAH and FRO NUSCH, there was created a video „Body Training for Patients with PH“. This video is targetet for patients and should improve their wellbeing by regular excercises in home environment. It is available also on our youtube page.

<https://www.youtube.com/watch?v=e6Y2FHHngF4>

Cultural events

As is our tradition already, we are attending the „Concert without barriers“ in Slovak Phylharmonic for handicapped people. This year we have attended the concert that took place on 3rd of December called Advent Organ Concert.

GAM, work meetings

GAM took place on 18th of November in Vrutky. 32 members of associations attended to it. Whole day event was dedicated to evaluation of years 2016 and 2017 and to present a plan of works for 2018. GAM included new elections, in the end patients received a DVD with rehabilitation training and PAHhuman diaries.

We also had 4 board meetings out of which, one with the advisory team and 14 work meetings. In the end of the year on 1st of December we had our work dinner that included evaluation of activities for the past year and presentation of a plan for the year 2018.

Patients were provided with 19 consultations.

8. Gathering informations and broadening of membership

PHA Europe GAM

PHA Slovakia attended to PHA Europe GAM in Barcelona as each year. Common cooperation of European countries leads to significant awareness raise in EU scale and improvement of conditions on national levels.

Informing patients

We are trying to continuously widen our number of members. To motivate our patients to enter association, we are trying to bring our activities closer to them, by printed and image materials. In PH center's waiting rooms, we maintain bulletin board. We post there educational and informational

materials, but lately we are in short of those. Summary of activities is always included in our yearly published magazine Fialka.

In Januar 2017, the new website, on which Peter and Iveta Makovnikova had worked for few months, has been released. Main reason was improvement of its design, UX and easier administration, as well as the need to change hosting, as our former partner was no longer interested in cooperation

We have gained 8 members in 2017, which makes for 10% of the membership.

9. Conditions improvement

Legislation

Our president and Roman Krivanek had attended workshop of a Ministry of Health to ammendment of law 363/2011 on the scope and terms of reimbursement of medicines, medical devices and dietetic food on the basis of public health insurance, and supported SAZCH and AOPP's comments on the planned change.

We have supported the protest of civic associations with cystic fibrosis against the planned relocation of Lung department in Bratislava University Hospital in Ružinov to significantly worse conditions. We participated in creation of a protest letter of the Ministry of Health of the Slovak Republic, and on the social network Facebook we launched a paid advertisement of an article on the issues regarding this matter.

2% of taxes

At the beginning of autumn, we have registered as beneficiaries of 2% of taxes. Profit from last year was used for Educational-recondition stay for members of PHA Slovakia in Spa Sliač. We also helped 5-year-old Matko Pončák, a child patient with PH who, after surgery, stayed in a wake coma by purchasing medical aids to improve his life.

Projects

We are tackling the fund for PHA Slovakia activities, we are trying to cover our expenses from other projects. Roman Krivanek has submitted 3 projects for grants. Only one was succesful. GSK's „When you are running out of breath“ project supported us with 1000€ for presentations of PAH – discussion forum for students.

10. Cooperation

European campaign to increase donor organ donations and transplants

We have addressed multiple associations and orgranizations in Slovakia to support this campaign. It has been endorsed by NTO, STS, SPFS and patient associations OZTP, Gift of Life, Chance for liver, SDaT. We have informed public through social networks and we also joined Thunderclap campaign. We appealed all Slovak MEPs to support Declaration, which was presented to EP, European Commission and other European Union institutes.

In summer of 2017 we have joined the project EUDONORGAN, which consists of educations of physicians, patient representatives and media, which happened in 2 phases. In form of online tests which was followed by 5 day training in person in Barcelona. Jana Guranova attended to it and she

completed it earning a certificate of Council of Europe. Her job is to conduct activities in cooperation with National Transplant Organization and Slovak Transplant Society to increase numbers of donors in Slovakia.

Days of organ donation and transplantation

The Slovak Transplant Society has prepared a traveling exhibition of post-transplant patient pictures at occasion of the World Organ Transplant Day. Jana Guráňová participated in this activity. Her photo was published and she also participated in the opening of the exhibition at Mall Eurovea in Bratislava, which took place on June 6, 2017.

We sponsored the European Organ Donation Day with the online Thunderclap campaign launched by the Council of Europe to inform the public about numbers in the transplantation process.

Cooperation with Czech PHA

Regular cooperation with PHA Czech republic goes on. Mutual visits on GAMs promise closer cooperation, information exchanges and advisory. On 21st of October Iveta Makovnikova with Pavla Notova attended the GAM of PHA Czech republic in Prague. We have also agreed on translation of new brochure of Czech association called Practical Guide (not only) for patients with PH in exchange of PHA Slovakia offered it's brochure „Psychosocial support for PH Patients“.

Other activities

- Social networks campaigns on Facebook, Twitter, Google+
- Maintenance of web site
- Rare disease survey - Eurordis
- Surveys for EPF and ERN
- Contributions to Mariposa News
- Cooperation with other civic associations
- Cooperation with centers for PAH and Lung department of University Hospital in Bratislava
- Education
- Working dinner with evaluation of activities for 2017

Donors contributions	
PHA Europe	41,3 %
Actelion	28,1 %
GSK	8,5 %
MSD	8,5 %
AOP Orphan	8,5 %
patients, other	5,1 %