Tüdőér Egylet -Report for the year 2024

All data in THUF

ASSETS	2023	2024
A. FIXED (LONG-TERM) ASSETS		
II. Property, Plant, and Equipment	94	0
TOTAL FIXED (LONG-TERM) ASSETS	**94**	**0**
B. CURRENT ASSETS	**6 716**	**8 231**
IV. Cash and Bank	6 537	7 918
C. PREPAYMENTS		
Prepaid Expenses	179	313
TOTAL ASSETS	**6 810**	**8 231**

LIABILITIES AND EQUITY	2023	2024
D. OWNER'S EQUITY	**6 629**	**7 816**
II. Change in equity/ result	8 724	6 629
V. Current year's result from core (public benefit) activities	-2 095	1 187
F. LIABILITIES	**172**	**385**
Short-Term Liabilities	172	385
G. ACCRUALS	9	30
TOTAL LIABILITIES AND EQUITY	**181**	**415**

All data in THUF

PROFIT & LOSS ACCOUNT	**2023**		**2024**	
	Core activity	Business activity	Core activity	Business activity
3. Other income	8 059		10 691	
from this				
-Membership fees	96		83	
-Support	7 963		10 607	
from this: donations	6 370		9 255	
4. Financial income	0		246	
A. TOTAL INCOME	8 059		10 937	
from this public benefit activity income	8 059		10 937	
5. Material type expenses	5 089		5 134	
6. Personal related expenses	4 386		4 522	
7. Depreciation	163		94	
8. Other expenses	51		0	
9. Financial expenses	465		0	
B. TOTAL EXPENSES	10 154		9 750	
from this public benefit activity expenses	10 154		9 750	
C. RESULT BEFORE TAX	-2 095		1 187	
10. Tax expense	0		0	
D. PROFIT/ LOSS FOR THE YEAR	-2 095		1 187	

Activities of Tüdőér Egylet

For World PH Day 2024 we had a „Get breathless for PH” program at the Hungarian Dragonboat Championship

Luckily, our sports ambassadors did not let us down this year either. Last year, a team ran for us around Lake Balaton. In 2024 on April 20th, the ’Dunai Sárkányok’ (Danube Dragons) competed for us on the Danube at the 13th Long-distance Hungarian Dragonboat Championship. The president and members of the Hungarian Dragon Boat Association supported our initiative to draw attention to our rare disease on the site of the race. At the all-day event, the Dunai Sárkányok entered in 3 races, with about 20 people, a mix of women and men, rowing distances of 8 and 4 kilometers.

We had the opportunity to set up our stand in a wonderful environment, on the Petőfi island in Baja, on the banks of the Danube. Our colorful t-shirts quickly attracted attention. In addition to handing out leaflets and information materials, interested people blew up balloons, and we checked their blood oxygen level and pulse before and after to see how they reacted. The approximately 1,000 competitors and fans present listened with interest to our stories about what a PH patient experiences everyday and what exertion means to them. Many people took our information materials with them. After the competition, they came back to our stand and told us that they now became aware of the feeling of heavy breathing, as they too had pushed themselves almost to the point of total breathlessness while finishing the race. We discussed that, although they regenerate quickly, unfortunately, this feeling is constant for those living with PH. We saw the smile of sympathy on their faces and answered their many questions tirelessly.

During the break of the race, we had the opportunity to try the dragon boat. Our boat, completed with racers from Dunai Sárkányok, made a circuit on the Danube. I don't think we're going to compete in the world championships yet, but we did well and really enjoyed the “great speed” on the water. ☺

This event was also a pleasant break from the everyday environment for the members of the association. In the evening, we headed home recharged by the nice experiences.

Raising awareness to PH in campaigns

At the end of April, we launched 2 campaigns. We sent press releases to the media, as a result of which several online platforms reported on World PH Day and our association. In the meantime, we also joined the PHA Europe campaign. We posted the visual elements translated into Hungarian about PH, the symptoms, the challenges of people living with PH, etc.

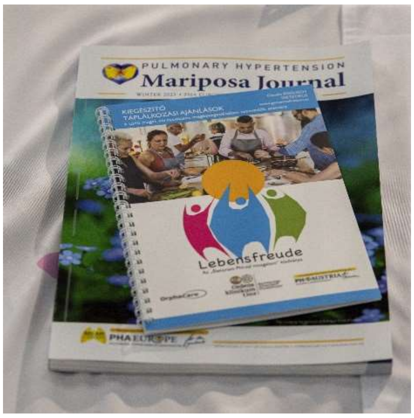
12th National meeting for PH patients

On May 25, 2024, we managed to hold our National PH Patient meeting for the 12th time. All PH patients in the country were invited to the meeting. Our fellow patients could gain new knowledge by listening to the educational lectures of PH specialists. Such empowered patient programs help fellow patients to cooperate better with the treating physicians and to consent to medical reccomendations more willingly. Education promotes positive thinking and thus contributes to the development of a healthy lifestyle. About 60 people participated in the event.

The doctor-patient meetings are the best forums for pulmonary hypertension patients to meet fellow patients and exchange experiences. Within an organized framework, they can tell how the symptoms of the disease and the various treatments affected them. Fellow patients can learn a lot from these and draw strength from the spiritual support. The meeting is also a good opportunity for doctors working in the field of PH to meet patients informally. In the framework of this, lectures are held on topics affecting the patients' everyday life. There is opportunity to ask questions and share concerns that affect the entire PH community.

Once again, we heard interesting and useful information on many topics.

We talked about blood thinners as an introduction. This was followed by useful diet tips. Once again, we distributed the Nutrition booklet that was supported by OrphaCare and PHA Europe.



Then a difficult topic followed: how to live with the medicine pump. A fellow patient told us about the difficulties of this through her personal experiences, and our treating doctor summarized the knowledge about the different devices and substances.

5 years after her previous presentation, the representative of NEAK (Hungarian National Health Fund) was able to come to present for us again and assured us that they will continue to strive for good cooperation despite the stressful circumstances.

To end the event, we had the opportunity to do breathing exercises led by our physiotherapist, exercises that are recommended for every day.

In May 2024, after many Saturdays that we have spent attending the lectures and workshops between November and May, we successfully graduated from the Patient Organization Academy organized by AIPM. We learned a lot of useful things, for example about communication and social media, but we also dealt with the legal environment and Health Technology Assessment.

EMLÉKLAP

Ezúton igazoljuk, hogy a

Tüdőér Egylet

betegszervezet képviselője elvégezte az Innovatív Gyógyszergyártók Egyesülete által szervezett Betegszervezeti Akadémiát a 2023/2024 évfolyam résztvevőjeként.

Szívből gratulálunk, sok sikert és örömet kívánunk a betegszervezeti munkához!

Budapest, 2024. május 4.

Dr. Szalóki Katalin
Igazgató

AIPM

Dr. Kocsis Janka
Főszervező

In 2024, we participated again in the event of RIROSZ (Hungarian Rare Disease Association), organized on the occasion of World Rare Disease Day. This year, it was held in the north-western part of the country on February 24th. The City of Sopron hosted it, which is in a region where there is not really a regional care/research network dealing with rare diseases, so it was important that the conference brought together health decision-makers, the region's professionals, and patient organizations. The enthusiastic association participants drew attention to the everyday problems of those suffering with PH, and the results achieved so far.

We had our General Assembly on April 25th, where our doctors talked about current issues with the participants, and those who joined could also receive a copy of a nutrition brochure.

During the year, we continuously monitored legislative changes, which require significant energy. We take advantage of every opportunity where a presentation is given.

We wrote grant applications and held discussions with several institutions on how we can ensure the financial background of the association's operation. We have published calls to offer 1% of the PIT, as well as the possibility of other forms of support. We also have a new method to collect donations: with the help of a QR code, people can donate money they received when they recycled packaging.

Egyedi azonosító

Kérjük, olvasd be az azonosító kódod, hogy közvetlenül a bankszámládra utalhassuk a visszaváltási díjat.

Tüdőér Egylet

We also took part in the general assembly of RIROSZ (Hungarian Rare Disease Association), the umbrella organization of which we are members.

We monitored the access to medicines for rare disease patients, as well as the innovations that promote a cure for PH. We also invited a representative of NEAK (National Health Insurance) to our National Conference to inform about the possibilities of state financing of drugs for PH patients.

We drew attention to the importance of patient organizations and the activities of our association at the HERA Info Days, META conference, and EESC conferences.

We also participated in the EgészségÉRTÉS - Women's Health Round Table events, where physicians and health decision-makers and representatives of patient organizations think together in the organization of the prestigious Semmelweis University (SOTE). We were also present at the AIPM meet-up event. These are good networking opportunities during which we can raise awareness for our association.

We introduced ourselves at the AIPM HEALTH. VALUE. MEDICINE event, where we informed those interested at our stand, and many took our materials with them.

In many cases, drug treatment of PH can slow the progression of the disease, but there is no cure yet. Fortunately, there are a variety of medicines available in our country, but there is a point where those no longer help. At that point, only lung transplantation can save patients' lives. That is why we cooperate with the MSZSZ and the Hungarian Heart and Lung Transplant Association. We took part in the Trapi days and the Lecsó festival in Szentes.

In October, we entered the SPAR Budapest Marathon. This time, it was not others that ran for us, but we signed up for the 2.3 km Gondosóra walk and the 500 meter FODISZ equal opportunities race together with fellow patients, family members, and friends. It doesn't seem like a long distance, but it was a great achievement for us to walk all the way. At our tent, we spoke to those interested about Pulmonary Hypertension and many people took our flyers and publications with them. The atmosphere captivated and inspired all participants. Out of breath, but happy, we reached the finish line. We also launched a fundraising campaign, as the association would need a portable oxygen concentrator, which the patients could receive for use as needed.

You can see our video at: https://www.youtube.com/watch?v=8sJcjxwWOSo

In November, we represented the association at the APHEC, where we could hear useful presentations. We participated in workshops and spent a pleasant time with fellow patients from many European countries.

In November, we had our PH Awareness Month FB campaign as well, where we could use the visuals of the common campaign done by PHA USA.

On November 29th, the high-level conference of our EU presidency and the EESC on rare diseases was held in Budapest, where we represented our association.

At the conference, the exploratory opinion "Leaving no one behind: a European commitment to the fight against rare diseases" adopted at the October plenary session of the EESC was presented, which calls for the creation of an integrated European health framework program that sets specific goals for the improvement of the care of rare diseases by 2030.

CONFERENCE / KONFERENCIA #RareDiseases

For an EU commitment to tackling rare diseases

EU kötelezettségvállalás a ritka betegségek elleni küzdelem mellett

29.11.2024 | 9:00-16:00 | [illegible] | #RareDiseases

The year 2024 was eventful in the life of the association.

With our activity, we also satisfied basic needs of the society, in addition to keeping in mind the interests of the community of patients living with PH, such as:

- Increasing the population's health awareness (education, awareness)
- Improving the quality of life: lifestyle advice, psychosocial support, community events
- Advocacy: participation in research, legislative opinions, innovative treatment options
- Community building: meetings, joint programs with other organizations