

Annual Report 2019

PH Austria - Initiative Lungenhochdruck

Frühe Diagnose • Beste Therapie • Lebensqualität • Heilung

PH  **AUSTRIA** *für
Patienten*
INITIATIVE LUNGENHOCHDRUCK

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Dear supporters, friends and members,

We would like to present to you our annual report from PH Austria - Initiative Lung Hypertension.

It was a very promising year for pulmonary hypertension patients. Not only in the medical sense, but also for the patient association. We were again able to organize a large number of patient events: patient meetings with scientific lectures, the aim of which is to provide our members with as much knowledge about the disease as possible and to keep them up to date in the social area and to make their everyday life easier with practical tips. Our 24-hour telephone hotline is also popular. We also hold chat meetings to strengthen the feeling of togetherness among the patients. With our meetings we were able to reach a large number of patients from Austria and also win many new members.

We were also able to achieve great success in the area of education / awareness-raising with the 8th Vienna Zoo Run, the 5th Vienna Ghost Run and many other events.

Pulmonary hypertension is currently not curable, which is why research is particularly important. With our lung children research association we strive to support them financially as best as possible. This year we were able to support three projects and invested a total of € 20,000 in pulmonary hypertension research. Although much progress has been made in research again in 2019, the goal of "healing" is still a long way off. We will therefore continue to strive to raise donations and strengthen the importance of the disease in public.

We would like to thank our sponsors and all supporters, without whom all of this would not be possible.

Gerald Fischer
Chairman

About the pulmonary hypertension self-help group

Our purpose:

We want to ensure the equality of all pulmonary hypertension patients in Austria so that all patients throughout Austria receive the best possible services. In addition, we strive to improve the quality of life and to provide our patients with advice and action and always have an open ear for them. It is important for us to give patients the feeling that they are heard and understood. We are the point of contact for all PH patients throughout Austria, no problem is too small for us! A study from the United States says:

PHA US study about patients and caregivers belonging to a Patient Association vs. not belonging to a PA

Patients belonging to a PA:

- 26% are feeling less worried
- 61% have more desire to socialize
- 54% have a higher self-esteem
- 40% are feeling less embarrassed



Caregivers active in a PA:

- 72% less do not think that the patient asks for more than they need
- 53% less feel that the relative is over dependant on them
- 58% less feel strained when around the relative
- 64% feel that they have more privacy

Executive board of the association:

Obmann	Gerald FISCHER geb. am 14.5.1959/Wien	An den Froschlacken 13 1120 Wien
Obmann Stv.	Eva OTTER geb. am 23.5.1960/St.Pölten	Neugebäudeplatz 3/3/6/26 3100 St.Pölten
Schriftführer	Monika Tschida geb. am 3.6.1982/Wien	Dürwaringstr. 45/2/9 1180 Wien
Schriftführer Stv.	Josefine TOMSICH geb. am 17.2.1954/Wien	Mittergasse 5 2484 Weigelsdorf
Kassier	Benita FISCHER geb. am 23.02.1967/Wien	An den Froschlacken 13 1120 Wien
Kassier Stellv.	Maleen FISCHER geb. am 24.05.1995/Wien	An den Froschlacken 13 1120 Wien
1. Rechnungsprüfer	Hiltrun SCHMIED geb. am 3.8.1942/Wien	Hoffingergasse 35/1/2 1120 Wien
2. Rechnungsprüfer 88/7/39	Manfred NEFFE geb. 2.10.1942/Wien	Kaiserebersdorferstr. 1110 Wien

Member

The PH Austria - Lung Hypertension Initiative currently consists of around 400 members from all over Austria.

Our operating range

Office pulmonary hypertension initiative

We operate an office at Wilhelmstrasse 21, which is open on weekdays from 8:00 a.m. to 4:30 p.m. through our employees. Our team consists of 2 employees and a volunteer (chairman). Tel.: 01/4023725, email: info@phaustria.org

Infodays

Four times a year we hold large information days with scientific lectures to keep our patients up to date. There are also chatmeetings several times a year, where our patients have the opportunity to exchange ideas and be among themselves.

Service for patients

In addition to social care and counseling, we offer our patients counseling hours at the AKH. We also run 24-hour patient phones and provide our patients with oxygen concentrators for travel free of charge. In 2018 we were also able to continue our projects to offer psychological and nutritional support to all PH patients.

Awareness

In order to make the rare disease of pulmonary hypertension better known, we organized the Vienna Zoolauf for the 8th time this year, in addition there were major events such as the 5th Vienna Ghost Run in the Vienna Prater, an interview with Reinhold Messner on World PH Day, the Silent Run as well as a diver in our t-shirt in the Haus des Meeres and much more.

Information

We publish a newsletter four times a year for all of our patients and supporters. In addition, we operate an always up-to-date and informative homepage and a Facebook account, which keeps our patients and members up to date.

Member events 2019

17. January	Kellertheater Linz
2. March	Information day in Vienna
12. April	Information day Linz
30. April	Information day Innsbruck
7. June	Chatmeeting Graz
26. September	Chatmeeting Innsbruck
7. October	Information day Graz
5.+ 6. October	Nurse Forum for professional health care

Kellertheater in Linz

The evening was all about laughter is healthy again! This year attracted many patients from Upper Austria and their relatives to the Kellertheater in Linz. For 65 years the theater has been known for the best entertainment in the field of boulevard comedy. This is followed by the anniversary production, the performance, written by Michael Niavarani and Roman Frankl "Reset - Everything at the beginning". The focus is on Herbert, he is a businessman, married and has a mistress. Then it gets niavaranian: Herbert's wife is fed up with her husband too, the half-brother is chronically broke and gay. Herbert's best friend Martin comes with a suitcase, filled with two million euros, and asks him to hide his suitcase



from the finance a few days. Then Herbert has an accident and loses his memory. Everyone plays their game and it comes to normal madness. An evening the laughing muscles had a lot to do!

Information day in Vienna

How time flies! Once again the time had come, the Vienna Information Day was on the program. This time our info day took place on March 2nd. Around 90 people used the information day to learn a lot of news, but also to exchange ideas with other people affected. After the previous general assembly, which takes place every 2 years, we started with a great range of programs. The top-class speakers included Ms. Univ. Prof. Dr. Irene Lang and Dr. Ioanna Campean, both AKH Vienna, cardiology. Prof. Lang brought us up to date in her first part of the lecture on the objectives at the 6th World Congress in Nice. The second part dealt with the genetic aspects in the development of LH drugs. In the treatment of pulmonary hypertension, there is a direction in which the administration of medication is very tailored to the individual. Prof. Lang described this very clearly, each patient is not the same, tolerates the different medications differently, so a better effectiveness in therapy can also be achieved. The so-called genomics play a special role here, where the functional aspects of the interplay between genes are examined. Prof. Dr. Long, thank you very much for this interesting insight into the future! Furthermore, Ms. Lisa Kohlbacher, “the new one” in the team of Prof. Dr. Long, imagine. She takes over the tasks from Ms. Freistetter, who changed to another area of responsibility last autumn. Dear Sr. Lisa, we warmly welcome you and are glad that you are here! The presentation of Mr. Christian Demel from Generali Versicherung was new to the program. He explained how insurance can be used effectively. The crowning glory was the workshop of Mr. Norbert Faller, respiratory educator and physical physiotherapist. He showed us effective breathing techniques that can be easily incorporated into everyday life. This year we were again able to welcome many representatives of the industry, such as from Actelion, AOP Orphan, MSD and OrphaCare, with whom we would like to thank you very much, because without our sponsors such a great meeting would not be possible. We ended this informative day, which also brought a lot of emotions, with a very good buffet and lively discussions.



Information day in Linz

On April 12, we met with patients and their relatives from Upper Austria for a common information day. The venue was again the Radisson Park Inn hotel in Linz. Eva and Monika from PH Austria were happy about how many patients used the information day to learn new things, but also to be able to exchange ideas with other affected people. Eva presented the new projects and services from PH Austria in her lecture. MS. OÄ Dr. Steringer - Mascherbauer spoke about the development of therapeutic approaches for pulmonary hypertension. She also mentioned that the genetic aspects will play a major role in the future. She also reported that the therapy is more tailored than ever to the individual. On this information day there was a lecture for the first time, which focused on the all-round care of LH patients. DGKS Sandra Daxberger from the Elisabethinen in Linz and Eva Otter from PH Austria reported how important the cooperation between the nursing service and a non-profit initiative is for the patients after diagnosis or after a hospital stay. Eva reported how important these information days or the chatmeetings are to her as the person concerned. On the one hand, it is important in order to be able to help in various non-medical areas, and on the other hand, she needs to exchange ideas with other people affected, says Eva. Mr. Endfellner from Vivisol left no questions unanswered when it came to the administration of oxygen. He explained the difference between liquid oxygen and oxygen concentrators. He also showed us how to handle the individual devices that are currently on the market. We ended the interesting afternoon with an excellent buffet and a good mood, accompanied by great emotions.



Information day Innsbruck

An exciting and interesting afternoon took place on April 30th in Innsbruck on the information day. In addition, the participants of this meeting were the very first to be able to learn about our contribution to WorldPHDay. First there were high-profile speakers, such as Ms. Univ. - Prof. Dr. Löffler - Ragg and Dr Sonnweber, both University Hospital Innsbruck and Prim. Dr. Puchner, REHA - Klinik Münster, Tirol, scientifically valuable



topics on the program. Ms. Univ. Prof. Dr. Löffler - Ragg showed us a look into the future about the treatment options for pulmonary hypertension. Dr. Sonnweber explained the exact procedure and the available examination options in the LH - ambulance of the University Hospital Innsbruck. Prim.Dr. Puchner vividly described which therapies and medical areas are available to patients during a REHA stay. Our participants noticed that Prof. Löffler - Ragg and Eva wore "Get breathless for PH" T-shirts. For good reason! Chairman Gerry Fischer and his daughter Maleen, Prof. Löffler - Ragg, Mr. Yilmaz and Eva were on the day before the meeting in Bolzano in the MMM - Firmian, i.e. in the Messner Mountain Museum, and were allowed to meet with Reinhold Messner for an interview. It was about the parallel between Messner's ascent to Mt Everest without oxygen at an altitude of 8848 m and how a pulmonary hypertension patient feels in everyday life. Eva gave a picture of herself in her lecture, Prof. Löffler - Ragg and R. Messner and thus triggered great applause among the participants. You can read more about the interview with Reinhold Messner on pages 16 and 17. We ended the successful meeting with good food and lively discussions. Many thanks also to our sponsors! With their support they helped us to organize a great information day again.

Chatmeeting Graz

On June 7th, for the first time, patients with pulmonary hypertension had a chatmeeting in Styria. The place to exchange ideas was chosen very carefully. After many considerations it was clear - it is the Schlossberg restaurant, right on the Schlossberg in Graz. We met with Dr. Kleinschek in the arrival hall of the Schlossbergbahn. The ascent of 3 minutes was a lot of fun. Lots of sunshine,



cold drinks, coffee with pastries and entertaining conversations supported the good mood. Some participants took the opportunity to have a four-eye conversation with Eva and to ask them for advice on social matters. New members were also involved. A big thank you goes to Mr. Prim. Dr. Dorr and to Dr. Strong from the REHA Center St. Radegund. They enabled the 6 patients who are currently undergoing REHA to take part in this chat meeting. Statement by one participant: "We all really enjoyed the afternoon and did it well!" This meeting was a complete success and requires repetition! Plans for this were made the same day.

Chatmeeting Innsbruck

We had planned a very special chat meeting for our members from western Austria. Our guest, an employee of Prof. Löffler-Ragg, University Hospital Innsbruck, Pulmologie, Ms. Graziella Plank, performed Latin American dances with her colleagues. Whoever wanted to could dance along. In addition to her work as a study nurse by Prof. Löffler-Ragg at Innsbruck University Hospital, Ms. Plank is also a certified dance teacher for Latin American dances. So salsa, zumba and bachata were given to the best.



This meeting was characterized by a good mood, fun and cosiness. On this occasion there will be a repeat next year! Of course there was also buffet-style refreshment! The spectacle took place on September 26th in the Hotel Innsbruck.

Information day Graz

The annual information day was on the program on October 7th. The purpose of this event is to make people suffering from pulmonary hypertension, but also their relatives understand the disease and to inform about news about the disease. Even the flu epidemic in Graz could not stop many of our members from attending the information day. A particularly exciting program was waiting for them this year. This time there were lectures by

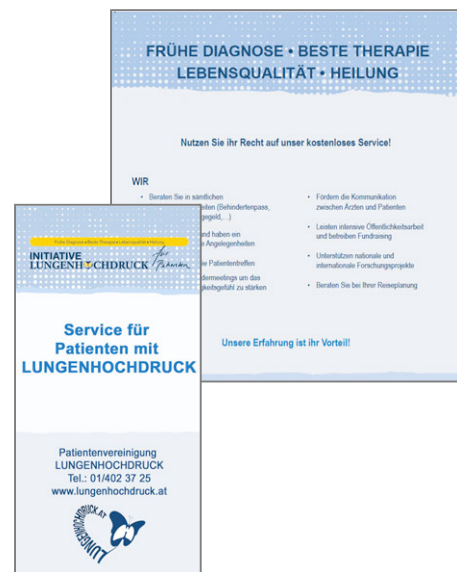


pulmonologists AND cardiologists about lung hypertension and its effects. Priv. - Doz.Dr. Kovacs, Pulmologie Graz. Since Prof. Dr. Priv had to take care of the bed for Olschewski. - Doz.Dr. Kovacs is responsible to report to participants on the new recommendations resolved at the 6th PH World Congress. He paid particular attention to the points that play an important role for patients, such as the classification of the classifications and the resulting choice of therapy. In modern times, the trend is towards personalized medicine. This means that the choice of therapy takes into account the age, the genetic disposition of the individual and the presence of any comorbidities. The contribution of Ass. Dr. Douschan dealt with such comorbidities, i.e. diseases that can occur in addition to the underlying disease, such as Diabetes mellitus, osteoarthritis, neurological diseases, to name but a few. Univ. - Prof. Dr. Zirlik, head of the cardiology department at the University Hospital Graz. There was an interesting contribution to the topic of cardiac ultrasound examinations, very good and understandable and explained with a lot of pictures by Prof. Dr. Robert Maier. Dr. Clemens Ablasser, also a cardiologist at the University Hospital Graz, took over the sensitive topic of pulmonary hypertension in left heart diseases. A lecture that dealt with the current recommendations on this clinical picture. Since this form of pulmonary hypertension exists in some participants, there were many questions about it. After the heads were full of information it went to the cozy part of the meeting. We ended the informative day with an excellent buffet and good discussions in a pleasant atmosphere. Information events are very important for patients, but also for relatives. On the one hand, they serve to better understand the disease, but on the other hand, those affected can exchange ideas with each other, sometimes friendships develop. At this point, a big thank you to our sponsors, without whom we would not be able to organize such meetings, but also to all speakers who hold their lectures free of charge.

Service for patients

Info brochure

We designed a brochure to give patients, relatives and supporters an overview of our work. This brochure is available in all PH clinics across Austria.



Ambulace day at the AKH

Every 1st Tuesday of the month we offer counseling hours in the "Cafe Clinicum" of the AKH. For this we have created new posters and service brochures.

Oxygene devices

This year we were able to provide our patients with two oxygen devices free of charge. In addition to two portable devices that are also suitable for flights, we also offer an oxygen device for the night. In 2020 we will discontinue this service for liability reasons, but we will continue to help our members to borrow a concentrator directly.

Telephone service for patients

We operate 3 patient telephones, through which our patients can reach us at any time. No problem is too small for us.

AWARENESS

29. April	Interview with Reinhold Messner for the World PH Day
5. May	Diver in the Haus des Meeres World PH Day
25. May	Silent Run opening for the World PH Day
13. June	Wiener Zoolauf
3. October	TowerRun at the Haus des Meeres
30 October	GhostRun im Prater
18. +19. October	Nurse Forum Mondsee

World PH Day



Interview with Reinhold Messner – Message to the world

On April 29, 2019, we were able to achieve a very ambitious goal. For World Pulmonary Hypertension Day we were looking for a prominent personality who would give an explanation of pulmonary hypertension and who would be available for a photo with our T-shirt. Since, unfortunately, thank God, there are no prominent victims, we considered who could describe what life with low oxygen levels in the blood could feel like. So we came to the extreme mountain climber Reinhold Messner, the first person to climb Mount Everest and then all eight-thousanders without artificial oxygen. Who, if not him, can describe exactly how strenuous even the smallest of activities can be? Gerry phoned Reinhold Messner's personal assistant in Bolzano and then wrote him a personal letter. We also sent the book from Gerry's daughter Maleen. About a month later we received the good news that on April 29th in Bolzano at the MMM Firmian (Messner Mountain Museum) we were allowed to interview Mr. Messner for half an hour. We were overjoyed and at the same time outrageous and



begged for an hour. We prepared well and after Reinhold Messner for his Documentation "The last step" was awarded the ROMY on April 13th, we were able to record this documentation and study it carefully. Many statements in this documentation by Reinhold Messner and Peter Habeler could come 1: 1 from our patients. After much thought, we put the questions together for Mr. Messner. Eva, Maleen, Benita, Gerry and a two-man film team drove to Bolzano on April 28th. On April 29 in the morning, Prof. Löffler - Ragg from the University Hospital Innsbruck and our member Yilmaz Yahya joined. The atmosphere of the MMM Firmian was impressive. We felt like we were in Tibet and enjoyed the strength and tranquility of this unique place. Reinhold Messner came with the book from Maleen under his arm and answered our questions with great empathy.

Diver in the Haus des Meeres for World PH Day

Wolfgang H., diver in the Haus des Meeres in Vienna, would like to draw attention to the fact that there are many children and adults among us who rely on additional oxygen on the water surface on the occasion of World Pulmonary Hypertension Day, which takes place on May 5 . He also wore the white WorldPHDay T-shirt with the lungs, which made the sharks very curious. If you are also curious, please visit us at www.lungenhochdruck.at and help us to support patients with pulmonary hypertension on their difficult path. We would like to thank Wolfgang H. and the team of the Haus des Meeres in Vienna for the great support!



Silent Run

The World PH Day or World Lung Hypertension Day is a worldwide event to raise awareness of the disease. Around 80 organizations around the world took part in various activities this year to raise awareness of this disease. We at PH Austria had three very special ideas. A new running route was opened on May 25th at the Vienna Central Cemetery.



The reason for this was that the runners can pursue their hobby on the main paths, away from the small side paths where the graves are located. On the occasion of this opening there was a charity run event, the Silent Run, in aid of the Lung Children Research Association. Gerry, Eva and Monika were very grateful for the support. The little ones started their 1.25 km run first, followed by the amateur runners who had to cover a distance of 5 km. Finally, the professionals started the 10 km run. The winner of the 5 km and 10 km run said in his interview: "It's a great event, but it reminded me that we have to appreciate life!" Monika and Eva were able to look after a stand. Many interested participants and visitors came to find out about the illness and to buy one of our T-shirts for a voluntary donation. The mother of a little girl suffering from pulmonary hypertension also stopped by our exhibition stand.

"The Three" provided the musical highlights. They gave a concert after the run, in which the song "Long live the central cemetery" could not be missing. The net proceeds of this charity event went to the Lung Children Research Association. The donation check was presented by the managing director of the Friedhöfe Wien, Ms. Niklas, who was pleased about the numerous participants. It was nice to see how the participants completed this run with a lot of respect for the scenery and the occasion.

8. Wiener Zoolauf

Two thousand runners sprinted past tigers, trotted through Schönbrunn with zebras and competed with antelopes. The Schönbrunn Zoo and PH Austria - Lung Hypertension Initiative inspired the participants for the eighth time with a running event that is second to none. The Wiener Zoolauf has been an exciting fixture in the country's running



calendars since 2012. On June 13, 2019 it was time again! For a strictly limited number of 2,000 runners, the event offered the unique opportunity to walk through the oldest zoo in the world, past zebras, pandas and polar bears. In addition to the overwhelming backdrop and the spectacular feeling, they run here every year for a good cause. The net proceeds will go equally to the Lung Hypertension Initiative and the Schönbrunn Zoo. Top results were achieved Sabrina Schwaiger crossed the finish line on June 13, 2019 with the time of 24:35 minutes as the fastest woman, Roland Hinterhofer as the fastest man with 19:57 minutes, Leonie-Zoe Haller and Paul Louvar secured the titles of the fastest runner under 16 years. The Vienna zoo run also achieved a top result in 2019: a donation of 30,000 euros was achieved. This supports the work of the pulmonary hypertension initiative and contributes to the new construction of the aquarium in Schönbrunn Zoo. Great commitment from everyone involved There was plenty to do the day before the run. 2000 starter bags had to be filled, the route measured and start numbers issued. The day before the event started, we set up our inflatable lungs and bow with the LH logo at the start, installed beach flags and provided sponsors' banners along the running route. At the start, cheerleaders cheered on the runners and when they got there they were warmly welcomed. This year we were able to sponsor Apomedica - Dr. Böhm, CocaCola, Gatorade, Gärtner Gemüse LGV, Gesund in Schönbrunn, Hypo - NOE, Kattus, Manner, Mautner Markhof, MSD, Ottakringer, Ringana and Wien Energie count. A big thank you to all our sponsors, runners and employees! The team from PH Austria, employees of the Schönbrunn Zoo and many volunteers contributed to a great functioning event on both days.

Towerrun at the Haus des Meeres

The stair run, also known as tower running, is becoming increasingly popular worldwide. So also in Vienna. For the fifth time, the Haus des Meeres - Aqua Terra Zoo organized this run. 270 external steps had to be mastered as quickly as possible. Despite fresh temperatures and a lot of wind, 34 stair runners accepted the challenge on October 3. Our Monika also climbed the 270 steps. She reached 10th place. We congratulate her very much! Sports enthusiasts had to press a buzzer, a red button-shaped trigger, to start timing. Once at the top, the rubber button had to be pressed again to stop the time. The participants were rewarded with an impressive view from a height of 50 meters. There was also



ice cream, lemonade or mineral water, popcorn and liver cheese for strengthening. For women, first place went to Veronika Windisch with a time of 01: 13.24, who could not beat her record set in 2016 with a time of 01: 10.25. The winner of the men mastered the 270 steps in an incredible time of 00: 59.12 seconds. The PH Austria team worked diligently to help fill the starter bags and issue the start numbers. We also had the opportunity to look after an exhibition stand and were able to present our services and inform about the disease. Among the supporters of the run were Atlas Copco, Brau Union, Energy Cake, Eskimo, Fischer Schnapsmuseum, Gumprecht, Manner, Poppy Popcorn, Riviera and Römerquelle.

5. Vienna Ghostrun - Halloween

For the fifth time in line, our charity run took place in the Vienna Prater under the motto "We're running away the grim reaper" and has become an integral part of Halloween. Ambitious ghost hunters were able to observe more than 700 sporty zombies, skeletons, witches and ghosts at the GhostRun on October 30th in the Vienna Prater. There were two distances to choose. The family run, which ran over a distance of 1.5 km, and the main run. The main run took place in the evening and there we had to master 5 km. Together with Peter White, the two-time wrestling winner of the "Prater Catchen" event, young and old warmed up before the starting shot. It went straight directly on the Prater Hauptallee. Nordic Walking participants were also there again. The start numbers were handed over in a tent, PH Austria operated a very large stand, Gösseck took care of the thirsty and hungry among the runners and for a donation of 10 euros you could be transformed into a scary monster at the make-up station. The best masks were awarded this year. We would like to thank the sponsors who supported us to organize this event. For this we can AOP, Apomedica-Dr. Böhm, Energy Cake, Gewista, Gösseck, Heindl, Janssen Cilag, Lilliputbahn, Manner, MSD, Prater, Radio Wien, Schneekugelmuseum, Ströck, Vienna Comic Con and Wien Holding count. We at PH Austria are grateful to every participant, every accompanying family - they all ran for those who can no longer do it themselves. This year the revenues reached a record sum of 10,000 euros. This money raised makes an important contribution to the fight against the still incurable disease of pulmonary hypertension. In this way, we can advance research and provide those affected with even more targeted and intensive support. A successful event that is always fun.

!



Nurse Forum – focus on pulmonary hypertension – the dialog continues

"Doctor and nursing hand in hand" was the motto of the national workshop from October 18-19 in Mondsee. For the second time, MSD (Merck Sharp & Dohme) organized a seminar in which the focus was on the cooperation between doctor, nursing staff, study nurse and PH Austria, represented by Eva Otter. "In order to be able to optimally care for patients suffering from pulmonary hypertension, the specialist knowledge of various professional groups is required," says OÄ Dr. Steringer - Mascherbauer in her lecture. Right from the start, workshops on the management of PH-specific nursing, right-heart catheters and echocardiography were offered from the nursing staff's point of view. The supporting program included an excellent, extremely interesting lecture given by Prof. Dr. Johannes-Peter Stasch on the subject of relief for the heart and lungs - from nitroglycerin to innovative therapies. During their lecture, Dr. Daniela Kleinschek, University Hospital Graz, Pulmologie and Eva Otter from PH Austria how important it is for those affected to feel well looked after. An interesting and important conference ended with tips and exercises from respiratory physiotherapy. We at the Lung Hypertension Initiative know how difficult the life situation can be after a serious diagnosis. Our area of responsibility is, among other things, to show those affected a new way of life and to support them in social matters. With the help of chatting meetings, we promote the communication between the patients and help to better understand the disease and learn to accept it by holding information days. Such meetings are particularly important for all professional groups in order to establish contacts, gain experience and thus ensure optimal patient care. Our thanks go to MSD, who planned and supported this interesting seminar.

Lungkids Campaign

We have been working on a new Europe-wide awareness campaign under the name "Lung Children" since autumn 2015. In cooperation with a young advertising agency, posters have already been created and successfully published advertising films.



O2DYSSEY Broschüre



Self-help day

Unfortunately we did not make it this year, but in 2020 we will definitely be back in the town hall.

Milestone Campaign continues

We were again able to get a lot of attention and donations through our place of milestones in the Vienna Prater.

Lungen Kinder **PERSÖNLICHER MEILENSTEIN IM WIENER PRATER.**

Mit dem Erwerb dieses Meilensteines bereiten Sie jemandem Freude und helfen Kindern diese tödliche Krankheit leichter zu ertragen.

Verewigen Sie sich im Wiener Prater um nur € 29,-
Gleich nach der Bestellung erhalten Sie Ihre Urkunde.

PH AUSTRIA
INITIATIVE LUNGENHOCHDRUCK

Weitere Infos und Bestellungen unter
www.meilensteine.at oder telefonisch unter 01/402 37 25

URKUNDE
für Ihren persönlichen Meilenstein im Wiener Prater

IHR (YOUR) NAME
IHR (YOUR) SLOGAN!

Der persönliche Meilenstein wird im Wiener Prater vor dem Panorama auf dem Markt Obere Praterstraße, bei Station 100 oder 101A auf einem besonderen Areal, das alle Jahre für eine Lungenhochdruck, eine noch verlässliche Krankheit, die alle Jahre tritt, errichtet.

Für Ihre Unterstützung bedanken wir uns sehr herzlich!

Silvia
Silvia
Forschungsstelle Lungenhochdruck

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Top medical council

We represent patients with rare diseases in the OSR and are actively involved in an action plan of the European Commission for rare diseases.

PHA Europe

The pulmonary hypertension initiative is one of the most active members of the European umbrella organization PHA Europe. We always strive for a very intensive cooperation and are proud to be a role model within this umbrella organization as a national patient group.

early diagnosis • best treatment • better quality of life • finding a cure

PHA EUROPE *for the patients*

Information

Social folder

We have created a very detailed social folder for all of our members. The folder summarizes all social support options for pulmonary hypertension patients in Austria. In addition, patients will find information on how and where to submit applications and what conditions are necessary. The folder was presented at our patient meetings and published on our website in 2016 and has been continuously updated since then.

Newsletter

In 2019 the newsletter was published regularly every 3 months. The fixed content includes social tips, "From us for us" (a patient tells his personal story), preview and review of events, as well as guest contributions from specialists. The newsletter is sent to all patients and members by post and is also published in the outpatient clinics.

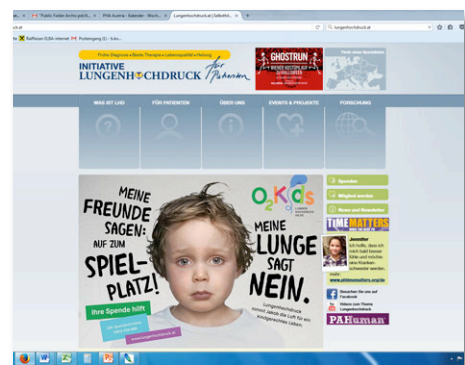


Continuation and improvement of our Website

See on www.phaustria.org

We are currently in the process of making our homepage even clearer and spreading more information in this way. We are working with a specialist on an even better SEO.

In addition, our Facebook page will be structured in a clearer and more interactive way to address even more people.



In 2019, we were delighted to receive 190 press articles reporting on pulmonary hypertension, the initiative and our activities.

Meine Fakten im Blick

1843 PH Austria Analysezeitraum: 2019



Meine Daten

Clippings	easyAPQ
250	€ 1.536.873,53
Druckauflage	Clipgröße
13.674.813	243.055 cm ²

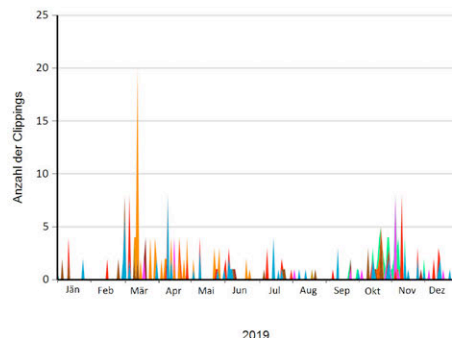
Meine Medien



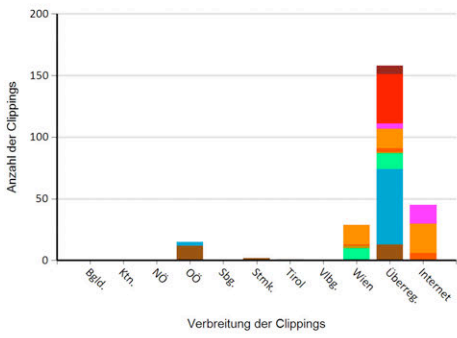
Meine Suchbegriffe*



Suchbegriffe-Chronologie*



Regionale Verbreitung*



Meine Medientypen



Bei den mit * gekennzeichneten Charts herrscht Farbkongruenz.

Einfach den Überblick behalten. >>>

Survey 2020

Schedule 2020

- **21.01.** **Linz Kellertheater**
- **07.02.** **1. Information day Klagenfurt**
- **29.02.** **Rare diseases day**
- **07.03.** **Information day Vienna**
- **28.04.** **Information day Innsbruck**
- **05.05.** **World PH Day**
- **28.05.** **Chatmeeting Graz**
- **13.06.** **Perchtoldsdorfer Vespatreffen**
- **17.06.** **Zoolauf**
- **27.06.** **Family information day Vienna**
- **30.09.** **Chatmeeting Innsbruck**
- **11.09.** **Information day Linz**
- **Oktober** **Information day Graz**
- **2.10. + 3.10.** **Nurseforum**
- **31.10.** **GhostRun**
- **06.11.** **Chatmeeting Wien**
- **Nov.** **Self-help day presentation Vienna city hall**

Further plans for 2020

- We will continue our hours of care in the AKH and will be on site every first Tuesday of the month to actively support our patients.
- Of course, our office is open on weekdays from 8 a.m. to 4.30 p.m.
- Intensification of cooperation with the Ministry of Social Services and the pension insurance institution in order to simplify access to disability ID and care allowance.
- We are planning to create a travel brochure especially for patients with pulmonary hypertension (barrier-free, PH centers nearby...).
- We plan to publish the lung children campaign in Austria and thus significantly improve fundraising for our association.

We would like to thank our supporters again on behalf of all our members and look forward to a successful cooperation in 2020.

CONTACT:

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