

# Annual Report 2018

## PH Austria - Initiative Lungenhochdruck

Frühe Diagnose • Beste Therapie • Lebensqualität • Heilung

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

## Content

About the pulmonary hypertension self-help group .....	4
Our purpose .....	4
Executive board .....	5
Members .....	5
Our operating range .....	6
Member events 2018 .....	7
Service for patients.....	13
Education/awareness .....	14
Information .....	19
Preview 2019 .....	19
Survey 2019 .....	21
Contact .....	22



Dear supporters, friends and members,

we would like to present you our annual report from PH Austria – pulmonary hypertension initiative.

It was a very promising year for pulmonary hypertension patients. Not only in medical sense, also in the patient association. We were able to organize a lot of patient events again: patient meetings with scientific lectures, for the aim to provide our members with as much knowledge as possible about the disease and to keep them up to date in the social field and to make their daily routine easier with practical tips. Also our 24-hour telephone hotline is gladly used. In addition, we organize chatting meetings for a stronger feeling of togetherness among 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 with the 7. Wiener Zoolauf, the 4. Vienna GhostRun and many other events in the area of education / awareness.

Pulmonary hypertension is currently not curable, so research is particularly important. With our lung children research association, we strive to support research as well as possible. This year we were able to support a project by Dr. Charlotte Huber, genetics department JKU Linz with € 15.000,--. Although much progress has been made in research again in 2018, the goal of healing is still a long way off. So we will 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	<b>Gerald FISCHER</b> geb. am 14.5.1959/Wien	An den Froschlacken 13 1120 Wien
Obmann Stv.	<b>Eva OTTER</b> geb. am 23.5.1960 /Wien	Neugebäudeplatz 3/3/6/26 3100 St.Pölten
Schriftführer	<b>Monika Tschida</b> geb. am 3.6.1982/Wien	Dürwaringstr. 45/2/9 1180 Wien
Schriftführer Stv.	<b>Josefine TOMSICH</b> geb. am 17.2.1954/Wien	Mittergasse 5 2484 Weigelsdorf
Kassier	<b>Barbara TITZE</b> geb. am 21.2.1967/Wien	Rebschulgasse 3B/3 2103 Langenzersdorf
Kassier Stellv.	<b>Benita FISCHER</b> geb. am 23.02.1967/Wien	An den Froschlacken 13 1120 Wien
1. Rechnungsprüfer	<b>Hildrun SCHMIED</b> geb. am 3.8.1942/Wien	Hoffingergasse 35/1/2 1120 Wien
2. Rechnungsprüfer	<b>Manfred NEFFE</b> geb. 2.10.1942/Wien	Kaiserebersdorferstr. 88/7/39 1110 Wien

### *Members*

The PH Austria pulmonary 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 staffed weekdays from 8:00 a.m. to 4:30 p.m. by our employees. Our team consists of 2 employees and a volunteer (chairman). Tel.: 01/402 37 25, Fax: 01/8157300 10 E-Mail: [info@phaustria.org](mailto:info@phaustria.org)

#### *Information days*

We hold large information days with scientific lectures four times a year to keep our patients up to date. There are also chatting meetings 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 (Vienna general hospital). We also look after 24-hour hotlines 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 zoorun for the sixth time this year, in addition there were big events, such as the fourth Vienna GhostRun in the Vienna Prater, a giant wuzzler tournament on the occasion of the World PH-Day and a styling day in the Wiener Riesenrad and much more.

#### *Information*

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

## *Member events*

<b>17. February</b>	Information day Vienna
<b>10. April</b>	Information day Innsbruck
<b>5. May</b>	World PH Day
<b>09. Mai</b>	Chatmeeting Linz with Sklerodermie
<b>9. June</b>	Family day Vienna
<b>20. June</b>	Wiener Zoolauf
<b>29. June</b>	Information day Linz
<b>25. September</b>	Chatmeeting Vienna + Visit of the Old Vienna Schnapsmuseum
<b>5.+ 6. Oktober</b>	Nurse Forum for professional health care
<b>12. October</b>	Information day Graz
<b>24. October</b>	Chatmeeting Innsbruck
<b>30. October</b>	GhostRun at the Prater
<b>25. November</b>	Self-help day Vienna City Hall

## *Information day in Vienna*

- I was amazed, how many new things were presented
- an interesting, informative day
- there was enough time to speak to other affected people
- top-class lecturers
- I was finally able to speak to my doctor in peace outside the hospital
- the day was planned perfectly, I felt really comfortable

We are talking about our info day in Vienna, which took place on February 17th.

Previous difficulties were forgotten. Unfortunately, some lecturers had to cancel due to illness and replacements were urgently needed. Miss Dr. Resch contracted a cruciate ligament tear and was therefore unable to hold her lecture. We wish everyone a speedy recovery!



Fortunately, Prof. Dr. Long took over another lecture. We would like to thank her very much for this! On the one hand, Prof. Dr. Long in great detail about the latest medical developments in pulmonary hypertension, on the other hand, in her second lecture, she explained to us, based on a case study, that it is important to not only evaluate a blood parameter, but more the totality of the blood findings are meaningful and lead to a diagnosis. Miss Dr. Christina Binder gave us a very clear description of what is important for an ultrasound examination. Many pictures contributed to a better understanding. Interested came from Vienna, Lower Austria, Upper Austria, Carinthia, Styria, even from Vorarlberg and Bavaria. Representatives from industry such as Actelion, AOP Orphan and MSD also came to take part in our meeting. At this point, a big thank you to our sponsors, without whom all these great meetings could not take place. Good, plentiful food and lively discussions rounded off this successful event.

For the first time since these patient events started, the lectures were broadcast live! You could follow them on YouTube and Facebook. If you did not have the opportunity to visit our information day, you can still watch the lectures at [www.youtube.com/phaustria](http://www.youtube.com/phaustria).

### *Information day in Innsbruck*

This year again we chose the Hotel Innsbruck, located on the Innrain, as the venue for our information day in Western Austria. Here, the service is perfectly tailored to our patients. At this point, thank you to the staff for their efforts. Eva, supported by Monika, was able to present the activities and projects of our initiative. In her lecture she emphasized how important it is for those affected to belong to a patient initiative in order to be



informed and thus to be able to escape isolation. Supported by top-class speakers, an interesting, informative afternoon continued. It started with Prof. Dr. Judith Löffler-Ragg. She is currently in Natters and, in addition to being a geneticist, is a specialist in pneumology. After a warm welcome, Prof. Dr. Löffler-Ragg that she will take over the outpatient clinic management again at the Uni Klinik Innsbruck from January 1st, 2019 and will look after the pulmonary hypertension patients with a lot of power and new ideas. On the information day, she talked about the functions of the heart in her lecture and also explained vividly what problems occur when the organ malfunctions.

She also described the possible symptoms that can adjust to those affected. After a short coffee break, the next program item was up. With Mr. Prim. Dr. Peter Heininger, from REHA Center Münster we learned everything about oxygen intake. Using everyday live



examples, he explained how oxygen gets into the body, how the supply of the individual organs in the body is regulated and where and how the gas exchange takes place. Also what happens when oxygen is missing, because not enough "air" can be absorbed, was explained by Mr. Primarius very precisely and very understandable. Mr. Prim. Dr. Heininger will take charge of pulmonology at the Natters Clinic from May 1, 2018. We congratulate him very much and wish a good start for the new area of responsibility. At the end there was a Feldenkrais workshop, led by the Physiotherapist and Feldenkrais trainer Marlene Graf. This was very well received. For this informative and emotional day, we would like to thank all of our supporters, without whom such a meeting would not have been possible!

### *Chatmeeting Linz with Sklerodermie*

Since the first meeting between patients suffering from pulmonary hypertension and patients suffering from systemic sclerosis was a complete success, there was an event again this year. As in the previous year, our joint meeting took place at the Hotel Ibis in Linz. Adi Brandstätter from SHG Scleroderma and Eva Otter from PH –Austria welcomed numerous members again this year. The meeting was made even more interesting by a presentation by a representative of the Chronically Ill association, who took a foray through the most important points in the social sector. Of course, the focus was on the mutual discussions that were held over rolls, cake and coffee. An afternoon that brought a good mood and calls for a repeat! We thank the company Actelion, who made this meeting possible.



### *Family day in Vienna*

On Saturday, June 9th, was a family information day for the first time, where parents of children suffering from pulmonary hypertension not only had the opportunity to exchange ideas with the specialists, but also gave specialist lectures. Interested came from Vienna, Lower Austria, even from Vorarlberg. Chairman Gerry Fischer presented our



initiative. He reported on the changes from then and now, and also mentioned the many events for patients and their relatives that had already taken place this year and are still being organized. Gerry also reported on our great concern to help those affected in the social field. We were particularly proud of Prof. Dr. To be able to win Ralf Geiger as a lecturer. Prof. Dr. Geiger is the clinical director of the Pediatric Department for Cardiology, Pneumology, Allergology and Cystic Fibrosis at the Medical University of Innsbruck. He reported on new guidelines from EMA (European Medicines Agency), FDA (US Medicines Agency) & Health Canada for endpoints in pediatric studies. An interesting, but also serious topic, by Prof. Dr. Geiger excellently explained. Afterwards, a lecture by the Ministry of Social Affairs was on the program. Ms. Sabine Knopf also examined the issue of the disabled pass for children and adolescents. There were numerous questions that Ms. Knopf had to answer. Most recently, it was Mr. Alfred Faller's turn from the Federal Ministry of Finance, who gave a lecture on annual compensation. Our TCM nutrition expert, Anja Walter, was also available to answer questions. So a lot of information for parents, grandmas and aunts. At the same time, a discussion was held in the adjoining room for the young people, in which growing up was discussed. Everything was discussed about school, everyday life, physical changes and growing personal responsibility to take the LH medication correctly and on time. The interview was conducted by Dr. Sulaima Albinni, Pediatric Cardiology Vienna General Hospital. Information that is extremely important for the young participants. Maleen Fischer also took part. A WhatsApp group was founded on the same day in order not to lose sight of each other and to be able to exchange ideas. The little ones were looked after by two kindergarten teachers. Many different games, crayons with coloring books, cars, books for reading aloud and music shortened the afternoon for them. Dieter Kulla, Chairman of the PH Association Germany and President of PHA Europe, Hall Skaara, Chairman of the PH Association in Norway and Oksana Kulish, President of the PH Association in Ukraine, also took part in this information day. All in all a successful day that definitely calls for a repetition that we are happy to organize again. We would like to thank all of our sponsors who made this beautiful and informative afternoon possible.

### *Information day Linz*

On June 29th it was time again. Our annual info day in Linz, held at the Hotel Park Inn by Radisson in Linz, could start at 14:00. Monika and Eva were there 2 hours before the start of the event to prepare everything and to discuss the technical details. Eva was allowed to start and present our initiative and talk about the many activities that take place all year round. She mentioned the in-



formation days and chatting meetings in the federal states, the many events and social support. Ms. OÄ Dr. Steringer – Mascherbauer, from the KH Elisabethinen Linz, spoke about the supporting measures in the medical field in her lecture, but it was also of great concern to her that everyone can do something for their well-being. Mag. Wille – Wagner, also from the Ordensklinikum Linz, looked at the patient and his illness from a psychological point of view. She particularly mentioned that there are many ups and downs in every disease, including pulmonary hypertension. Of course there were also suggestions for solutions and tips on where to get help. After a short coffee break, Mr. Mirschitzka asked for our breathing muscles. With practical exercises, the respiratory physiotherapist showed us how we can keep our muscles going at home.

Afterwards there was a good buffet, partly to recover from the efforts in the workshop, but also to encourage many good conversations among the participants. Of course there was also a lot of laughter. Laughter is known to be the best medicine! At this point a big thank you to the representatives of the industry, such as Actelion, AOP, MSD and Vivisol, without whose support these important meetings would not be possible.

### *Chatmeeting Vienna*

Chat meetings are therefore that patients and their relatives can chat in a relaxed atmosphere. There is no program and no lectures. Of course, we always ensure a good snack. These types of events have evolved over time to talk to Eva about personal matters and to get help filling out forms on site and to learn which official channels need to be taken. Both chat meetings cry out for repetition, they are funny, but also very necessary! That's how it was in Vienna: On September 25th we met in Gerry's Altwiener Schnapsmuseum in Vienna's 12th district. Gerry led us through his schnapps museum, which he is running in the 5th generation. We were informed about the product range and were told the difference between brandy and schnapps, and heard about the production of liqueurs. After the interesting tour there was something good to eat in the nearby inn. A nice way to end a tour of a special kind.



## *Information day Graz*

On October 12, 2018, a joining information day for patients suffering from pulmonary hypertension and patients suffering from pulmonary fibrosis took place for the first time. Their relatives were also cordially invited. An interesting program was offered with contributions from representatives of PH Austria's Lung Hypertension Initiative, Lung Fibrosis Forum Austria, the Medical University of Graz, University Clinic for Internal Medicine, Clinical Department for Lung Diseases and the Ludwig Boltzmann Institute for Lung Vascular Research. The venue was the lecture hall center of the Medical University of Graz. Around 90 participants took the opportunity to learn about these diseases.



PH – Austria was represented by Eva and Monika. Eva was able to present the projects and services offered by our initiative in a short lecture. The topics ranged from, difficulty diagnosing a Pulmonary hypertension in the presence of another lung disease "through" Possibilities of drug therapy for PH in the case of pulmonary fibrosis "to the most important contribution" When do I need how much oxygen damage or benefit "by Prof. Dr. Olschewski was presented Priv. Lecturer Dr. Kovacs gave a lecture on the connections between the pulmonary vessels, airways and lung tissue. With an excellent buffet, the participants had time to exchange ideas. This is an essential part of the information day, because here not only patients but also relatives have the opportunity to exchange experiences, but above all to talk about how to keep the normality of everyday life as long as possible and what everyone can contribute. Of course, the good mood was an essential part of the event. So all in all a successful event! Our special thanks go to our sponsors who support us again and again and we can continue to organize such great, informative meetings.

## *Chatmeeting Innsbruck*

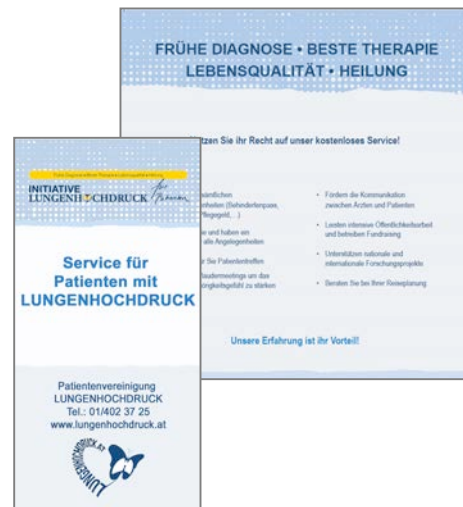
This is how it was in Innsbruck: The date for the Innsbruck chat meeting was on October 24th. Eva met 25 patients in the Hotel Innsbruck. An excellent cold buffet and a good mood awaited us there. Eva was particularly pleased to see many old friends again and to welcome new members. An afternoon, packed with intensive discussions and many questions about social issues, flew by in a flash



## 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.



### Ambulance 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.

### Oxygen 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.

### 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

### *World PH Day*



### *7. Vienna Zoorun*

2000 runners braved the enormous heat and started for the good cause at the 7th Vienna Zoo Run in Schönbrunn Zoo. Some runners even put on funny animal costumes to walk the six-kilometer route through the zoo. Half of the net proceeds from the charity run will go to the "Healing for pulmonary hypertension" initiative and the Schönbrunn Zoo. The zoo is using its share to build a new



aquarium house. This charity run was made possible on the one hand by the runners and on the other hand by all of our sponsors such as BILLA, BIPA, Coca-Cola, Eskimo, Gesund in Schönbrunn, HypoNOE, yes! Of course, Carinthian milk, Kattus, Manner, MSD, Ringana and Wien Energie, to whom we thank you very much for your support. We would also like to thank our event planners Doris Heidler (agency for event marketing) and Marion Trska (sports supporter) who, together with Claudia Schmidberger-Slond and Patrik Quatember from Schönbrunn Zoo, Gerry Fischer, Eva and Monika from PH Austria, Initiative Lungenhochdruck, have planned this run in many meetings. The day before the run, preparation work began in the orangery of the zoo. First 2000 starter bags were filled, followed by the start number, which continued the next morning. The construction work was done a few hours before the start. Our inflatable arch and the large inflatable lungs were set up at the main gate in Hietzing, where the start was, some lung high pressure banners were hung up on the route and beach flags were put up at the finish. Monika and Eva, employees of the Schönbrunn Zoo, as well as many volunteers, worked tirelessly on both days. Thank you to everyone who was there.

#### 4. Vienna Ghostrun – Halloween

4. Wiener Ghostrun - Halloween On October 30th it was time again. For the fourth time, many creepy characters took on the challenge of running away from the Grim Reaper. This year the route ran along the main avenue in the Vienna Prater. As every year there were 3 competitions. First, the students started on the 1.5 km route. This was



followed by the family run, where there were also 1.5 km to run. The family run had prominent support from Hadschi Bankhofer and his family. In the evening hundreds of ghosts set out to master the 5 km route. But before all ghosts could start, a lot of preparation work was necessary. First, posters had to be printed, and the Bösmüller printing house supported us a lot. The correct running route with the appropriate length had to be measured and marked, as well as marshals, employees for the start number issue and helpers who distributed water to the runners at the finish line had to be found. Many permits also had to be obtained. This year the start numbers were given out in a large tent that was set up in the morning before the competitions started. Then the only thing left to do was wait until the creepy running experience could take place. Monika, Eva and Patrick helped hard. At the same time, the 3 supervised a presentation stand to present the projects of the pulmonary hypertension initiative. A big thank you goes to all sponsors who made this charity run possible. Our sponsors included Actelion, Druckerei Bösmüller, Gewista, Heindl, Manner, MSD, Prater, Radio Wien, Stadt Wien Marketing, Ströck, ViennaComicCon and Vertical. We also thank you for the great support from all volunteers and our event planners Doris Heidler and Marion Trska.

## *Nurse Forum*

This conference, which took place in Salzburg in October, was all about optimal care and support for PH patients. Under the motto "Learning from each other - only together we are strong" representatives from the fields of medicine, nursing, physiotherapy, nutrition and psychology and the team from PH Austria met for the first time for a national workshop. The aim of this event is to ensure optimal care and care



for patients suffering from pulmonary hypertension. However, this is only possible if all professional groups involved actively work together. Those affected are well looked after by doctors and nursing staff during their hospital stay. However, since it is difficult to find your way again after a diagnosis or to reorient yourself, other professional groups are also required. B. that of psychologists, nutrition experts, specialists in rehabilitation and also the support of the Pulmonary Hypertension Initiative. We help those affected to find this path, are there for them when it comes to social matters, promote communication with other people affected and ensure that everyone affected learns to better understand and accept their illness. That is why we organize information days, where scientific lectures promote understanding of the disease and chat meetings where only patients can meet to exchange experiences or seek a personal conversation with us. The conference was chaired by OÄ Dr. Steringer – Mascherbauer, Elisabethinen Linz and Prim. Dr. Heining, LKH Natters. Chairman Gerry Fischer and Eva Otter were allowed in their lecture present the current and planned projects and the social efforts of the initiative. At dinner, the participants got to know each other, made contacts and also planned activities for the coming year for the benefit of the patients. We would like to thank the MSD company for supporting and planning this project.



## O2 Kids Campain

Since autumn 2015 we have been working on a new Europe-wide awareness campaign under the name "O2Kids" in cooperation with a young advertising agency. We have already created posters and successfully published advertising films.



## O2DYSSEY Brochure



### *Self help day Vienna City Hall*

This year we were again represented at the day of the self-help group in Vienna City Hall and were able to educate and inform many visitors about the rare disease of pulmonary hypertension.



### *Milestones campaign continue*

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

### *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 very intensive cooperation and are proud to be a role model within this umbrella organization as a national patient group.

## 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 they have to submit the applications and what conditions are necessary for this. The folder will be presented at our patient meetings and published on our website in 2016 and updated continuously.

### *Newsletter*

In 2018 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 at [www.phaustria.org](http://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.





## Preview 2019

### *Schedule 2019*

- **17.01.**        **Linz Kellertheater**
- **02.03.**        **Information day Vienna**
- **12.04.**        **Information day Linz**
- **30.04.**        **Information day Innsbruck**
- **02.05.**        **Kongress Baden - Lunge-Leben heißt atmen**
- **05.05.**        **World PH Day**
- **13.06.**        **Wiener Zoolauf**
- **30.10.**        **Ghost Run at the Prater**
- **follows**        **Family information day Vienna**
- **follows**        **Chatmeeting Wien**
- **follows**        **Information day Graz**
- **follows**        **Chatmeeting Linz with Sklerodermie patients**
- **follows**        **Chatmeeting Innsbruck**
- **Nov.**         **2019 Presentation self-help-day at the Vienna city hall**

### *Planned for 2019*

- We will continue our hours of care at 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 pulmonary hypertension patients (barrier-free, ...).
- 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 collaboration in 2018.

*CONTACT:*

*Self-help group pulmonary hypertension*

*Chairman: Gerald Fischer*

*Wilhelmstraße 19*

*1120 Wien*

*Tel.: 01/402 37 25*