

Annual Report 2021

PH Austria - Pulmonary Hypertension Initiative

Frühe Diagnose • Beste Therapie • Lebensqualität • Heilung

PH  **AUSTRIA**

INITIATIVE LUNGENHOCHDRUCK

*für
Patienten*

Content

<i>Preface</i>	4
<i>About PH Austria – Pulmonary Hypertension Initiative</i>	5
Our purpose	5
Board of Directors	6
Members	6
<i>Our responsibilities</i>	7
Office of the Pulmonary Hypertension Initiative	7
Information events.....	7
Service for patients	7
Awareness	7
Information	7
<i>Information and support for members</i>	8
Events for Members 2021.....	8
COVID-19 Vaccination Patient Information	8
Internal member meeting Vienna.....	8
PH information event Innsbruck	9
Internal member meeting Linz.....	10
Information event Klagenfurt	11
Information event Linz	11
Information event Vienna - a virtual experience	12
<i>Information for members, affected and relatives</i>	13
Brochure.....	13
Service Hotline	13
<i>Awareness/Public relation and networkung</i>	14
Industry discussion on Rare Disease Day	14
Maleen Fischer - Speaker at the European meeting.....	14
May 5 th – World PH Day	15
Development of an app for the 6-minute walk test	16
<i>Book project: “Mein Leben, meine Lungentransplantationen und ich „, by Rani Gindl</i>	18

Self-help day.....	19
National Nurse Forum.....	20
7 th Viennese GhostRun.....	21
Throughout Europe O2Kids Campaign.....	22
Lungskids Campaign.....	24
O2DYSSEY Brochure.....	24
Continuation of the Milestones Campaign.....	25
Austrian National Institute of Health-OSR.....	25
PHA Europe.....	25
<i>Information.....</i>	<i>26</i>
Social Folder.....	26
Newsletter.....	26
Continuation und Improvement of our Website.....	26
Press review.....	27
Preview 2022.....	28
Further Plans for 2022.....	28
<i>Contacts.....</i>	<i>28</i>

Preface

Dear supporters, friends, and members,

A lot has happened for us in 2021. In cooperation with Univ. - Prof. Dr. Geiger and his team we designed a 6-minute walk app, that helps to make precise statements about the state of health in children with pulmonary hypertension. We supported the publication of the book "My Life, My Lung Transplantation and Me" by Rani Gindl, continued our project "Blue Lips Campaign" for World Pulmonary Hypertension Day and were able to carry out the 7th ghost run in Vienna's Prater on October 31st. Of course, in strict compliance with all safety precautions against Covid 19. We were and are still available to our members around the clock via our service hotline and there is a lively network via the WhatsApp groups in the individual federal states. The best news is that we were able to hold meetings again. There have already been patient meetings in Vienna, Linz and Innsbruck. During our visits to the federal states, we noticed how important these meetings are. Many asked for a one-to-one conversation, and those affected who are new to our group also benefited from it. We organized Information afternoons in Graz, Innsbruck, Klagenfurt and Linz. Real life had us back for a short while and we hope it can be again like that soon!

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 much as possible. Although much progress has been made in research in 2021, the aim of "healing" 'is still a long way off. So, we will continue to try to raise donations and to educate people about the disease.

We would like to thank our sponsors and all supporters; nothing would be possible without them.

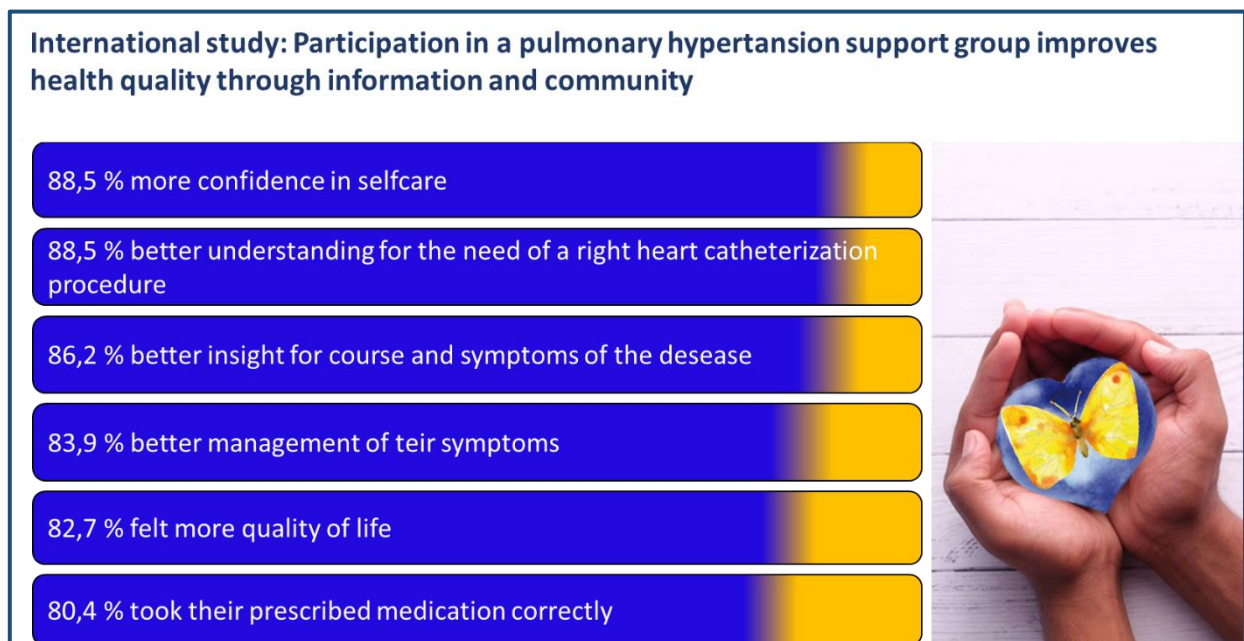
Gerald Fischer
President

About PH Austria – Pulmonary Hypertension Initiative

The PH Austria - Pulmonary Hypertension Initiative is a non-profit organization that supports everyone who suffers from pulmonary hypertension in gaining access to information, treatments, and support services. The association also represents those affected and advocates earlier diagnosis, better care, a higher quality of life and medical care. With the associated Lung Kinds Research Association, research into therapeutic options for pulmonary hypertension is promoted or made possible.

Our purpose

Our purpose is to ensure equality for 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, to support them in social matters. We support all patients with help and advice with our service and always have an open ear for them. It is important for us to give patients the feeling that they are being heard and understood. We are the contact point for all PH patients throughout Austria, no problem is too small for us! A US study of patient organizations - more on this at <https://lnnk.in/akhf>- determined the following:



Board of Directors

President	Gerald FISCHER
Vice President	Eva OTTER
Secretary	Monika TSCHIDA
Vice Secretary	Manuela BERGER
Cashier	Benita FISCHER
Vice Cashier	Maleen FISCHER
1 st Auditor	Hildrun SCHMIED
2 nd Auditor	Manfred NEFFE

Members

Currently the association PH Austria - Pulmonary Hypertension Initiative has almost 420 members in Austria.

Our responsibilities

Office of the Pulmonary Hypertension Initiative

We run an office at Wilhelmstrasse 21, 1120 Vienna, from monday to friday from 8:00 a.m. to 4:30 p.m. Our team consists of two employees and one volunteer (President). Tel.: 01/4023725, E-Mail: info@phaustria.org

Information events

Four times a year we organize information events with scientific lectures, to keep our patients up to date. In addition, chat meetings take place several times a year. There our patients have the opportunity to exchange ideas and be among themselves.

Service for patients

In addition to social care and counselling, we offer our patients counselling hours in the AKH and a 24-hour telephone service and are therefore always available for them. In 2020 we were also able to continue our projects to offer all PH patients psychological and nutritional support. For further networking, we supervise additional WhatsApp groups in the individual federal states.

Awareness

In order to make the rare disease of pulmonary hypertension better known, we regularly organize events, such as the GhostRun in the Viennese Prater, which took place virtually for the first time in 2020.

Information

We send out a newsletter four times a year for all of our patients and supporters. In addition, we operate an informative homepage that we have just created from scratch. Our patients, members and the interested public will be kept up to date via our Facebook and Instagram accounts and our YouTube channel.

Information and support for members

Events for Members 2021

January 30st	Virtual Patient Information
June 30th	Patient meeting Vienna
July 7th - 9th	Information event Innsbruck
July 12th	Patient meeting Linz
August 2nd	Information event Graz
September 9th	Information event Klagenfurt
September 16th	Information event Linz
November 20th	Virtual information event Vienna

COVID-19 Vaccination Patient Information

On January 30th, a virtual patient meeting took place with Prof. Löffler-Ragg about the COVID-19 vaccination <https://lnnk.in/dOdU>. Many questions were answered and published in our newsletter. "The group of vulnerable people is better protected through testing and vaccination. So, the extend of disease can be reduced. In this way you can make the return to normal possible. "



Internal member meeting Vienna

The first small meeting after almost a year took place in Vienna on June 30th. The requirements were and are that only vaccinated people are allowed to take part. In addition, everyone quickly did an antigen - rapid test at home, so that everything is safe. In the wonderful garden of Cafe Diglas, we enjoyed being together, the exchange of information and of course our breakfast.



PH information event Innsbruck

Information was exchanged over a total of three days in July, as many members had asked for one-on-one meetings. This meant filling out many forms, such as for the disability card, or for the care allowance, precise explanations and of course listening very carefully and recommending solutions. At the common information day, there was an interesting lecture on oxygen by DGKP Helmut Täubl, MSc from the LKH Hochzirl -Natters. Mrs. Prof. Dr. Löffler-Ragg from Innsbruck University Hospital fo-



ocused in her presentation on the aim of treatments for PH and went into the latest studies



and developments in diagnostics and therapy. During meals, during the common discussions to exchange ideas, and also during getting to know new members, it was felt again, how necessary these meetings are. Because of knowing: "You are not alone with this illness, there is someone who has an open ear for me" is very important, especially in these turbulent times!

Internal member meeting Linz

A happy togetherness was waiting for our members on July 12 in Linz. A lot of interesting news were reported over a lunch in the guest garden of the restaurant "Schiefer Apfelbaum." The



same rule applied here as at the other meetings too. Members were only allowed to attend if they had been vaccinated and tested. Brochures with nutritional tips tailored to the disease pulmonary hypertension and the brand-new information booklet for the patient-doctor discussion were available for all participants.

Information Event in Graz

The first information day took place in Graz on August 27th. With a lot of information material in our luggage, we were able to welcome 38 participants there. As guest speakers we could welcome Univ.-Prof. dr Horst Olschewski and Ass. - Prof. PD dr Gabor Kovacs, both from Med Uni Graz. The latest developments in diagnostics and therapy were discussed in a question-and-answer session with the two PH specialists. Other main topics, like the flu vaccination and the 3rd partial vaccination for Covid-19 were answered by Prof. Dr. Olschewski and Prof. Dr. Kovacs answered exactly. It was an informative and also intense emotional day for the PH community. One participant summarized it up like this: "It was an honor to be there, we went home richer than before."



Information event Klagenfurt

The personal meeting on September 9th in Klagenfurt with many affected people from Kärnten was particularly important to us, as it had to be postponed several times due to Covid-19. There was already a lot to talk about during lunch. Forms such as for the disability pass or the care allowance were filled out and deputy chairman and affected Eva Otter was able to give one or the other advice through her many years of experience. Above all, listening was important, and with it the awareness that we always have an open ear for the patients and their relatives. Ms OÄ Dr. Tamara Buchacher, who was also invited to the meeting, patiently answered all participants' questions about vaccination and also reported on the latest developments in diagnostics and therapy for PH. Another information day is already planned in Klagenfurt, which hopefully can take place in April 2022.



Information event Linz

The long-awaited personal meeting took place on September 16th in Linz. As with the other information days, only vaccinated patients and relatives were allowed to attend. All of them had themselves tested again on the day of the meeting to be sure. A separate room had been rented in advance for the numerous guests who had appeared, so that they could comfortably



exchange ideas among themselves. Eva also welcomed some new members whom she was finally able to get to know. Eva welcomed some of our sponsors from AOP Orphan and MSD. At this point, a big thank you to all our supporters, without whom meetings of this kind would not be possible. Of course, there was a question - answer session with Ms. OÄ Dr. Steringer - Mascherbauer. She reported on news regarding diagnosis and therapy for pulmonary hyperten-

sion. There were also questions about vaccination. Since the flu vaccination is also recommended in autumn and the 3rd COVID-19 vaccination is already in the offing for many, the question of how was not long in coming. Ms. OÄ Steringer - Mascherbauer explained to us: There must be 4 weeks between the flu vaccination and the Covida vaccination, whichever comes first is not relevant.

Information event Vienna - a virtual experience

Actually, we all wanted to meet again on the information day, chat with each other, see each other again. But for security reasons we decided to hold the meeting virtually. And it was a complete success! All the preparatory work had been worth it. Over 50 participants eagerly awaited the many presentations. Gerry Fischer



reported on the activities and projects that PH Austria tackled and successfully carried out even in stormy times. We opened the meeting with a panel discussion. Members talked about how they are coping with life with PH. Sandra, Franziska, Ursula and Najat reported on life after the diagnosis. Sandra talked about how her everyday life with 2 children is like. Franziska reported on the positive change that the implantation of the pump brought with it, Ursula told how life in the family changes when a child has pulmonary hypertension and Najat spoke very impressively about the changes in her life her husband was diagnosed with PH <https://lnnk.in/aPfr>. After a short break, everyone was waiting eagerly for Mrs. Univ. - Prof. Dr. Irene Lang's lecture, which was about the new approaches in diagnostics and therapy and about the current study situation. First, she reminded us of the risk score from the European guidelines, which provide information about how a PH patient is classified. The diagnostic importance of the right heart ventricle and BMPR2, the gene that triggers pulmonary hypertension and the importance of genetic testing, was also the subject of the lecture. She encouraged me by reporting that several new promising studies are available. For example Sotatercept and Seralutinib. <https://lnnk.in/d7c4>

Ms. Assoc. Prof. Univ. Doz. Skoro - Sajer dedicated herself to the comorbidities that can be found in addition to pulmonary hypertension, such as diabetes or kidney diseases <https://lnnk.in/d9c1>.

Next up was nutrition and psyche. Here we learned about the influence of both parameters. <https://lnnk.in/aRfo>

It continued with an introduction to the world of Ayurveda. <https://lnnk.in/aTfh>

At the end there was a workshop with the Feldenkrais trainer Mag. Theresia Paal.

We would like to thank all speakers, the numerous participants and our sponsors, who made the virtual meeting a great experience.

Information for members, affected and relatives

Brochure

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

Service Hotline

We operate three hotlines through which our patients can reach us at any time. No problem is too small for us. We always have an open ear and provide information, advice, and support on many topics.



Awareness/Public relation and networking

February 29th	Rare Disease Day
April 21st	MEP Lung Health Event
May 5th	World PH Day
June 17th	Viennese Zoo Run
September 26th	Self-help day
October 2nd	National Nurse Forum
October 31st	GhostRun
Since autumn 2021	O2kids campaign

Industry discussion on Rare Disease Day

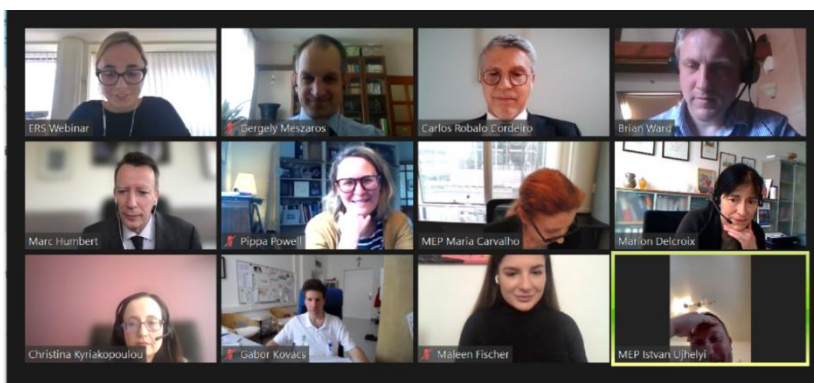
To be left alone is the worst: For people with rare diseases, the corona pandemic has exacerbated an already difficult situation. For that reason an industry discussion was held by “Die Presse” on this highly explosive topic on February 19th. Among the participants were Univ. - Prof. Irene Lang, who unfortunately could only participate virtually, patient advocate Dr. Gerald Bachinger, AOP



Orphan - founder Dr. Rudolf Widmann and PH Austria, represented by Eva Otter. The occasion for the panel discussion was the Rare Disease Day, which takes place annually on February 28th. The consensus was: rare diseases need a stronger voice!

Maleen Fischer - Speaker at the European meeting

In addition to ERS President Prof. Marc Humbert, MD PhD, Prof. Dr. Irene Lang, to name just a few, board member Maleen Fischer was also invited as a speaker at the MEP Lung Health Event, i.e., the European Meeting for Lung Health. <https://lnnk.in/hycs>
Her talk was about the benefits, patients experience from research.



May 5th – World PH Day

With three projects, we set a strong signal on WPHD - World Pulmonary Hypertension Day, to increase awareness of the disease:

with the illumination of the Ferris wheel, the implementation of our blue lips campaign and the development of an app for the 6-minute walk test, which we will present in more detail on the next page.

Due to its great success in recent years, we asked the owners of the Ferris wheel in the Vienna Prater again whether the Ferris wheel, which is one of Vienna's main attractions, could shine in blue again in time for May 5th. "Of course!" was the answer. So the attraction showed up in the dark in a magnificently illuminated blue.

Our blue lips campaign was met with great success last year. For this reason, we have decided to continue this project this year. Many of our sponsors and



members took part again by painting their lips blue or holding blue painted lips in front of their own to publicize this important issue. The international campaign aims to show that blue lips are sometimes a visible sign of pulmonary hypertension.



Development of an app for the 6-minute walk test

A new app was created as part of a joint project by Univ. Prof. Dr. Ralf Geiger, University of Innsbruck, Clinic Director Department for Paediatrics and Adolescent Medicine, and Gerry Fischer, chairman of PH Austrian and founder and chairman of the Lung Children Research Association. For the first time, this app enables medical professionals to use a mobile application to measure the z-scores of the 6-minute walking distance in a standardized way during growth in children and adolescents. We know that it is important to receive a diagnosis quickly, because the earlier therapy can be initiated. Thanks to the 6 min.test app including Z-Score calculator, measurements can now be assigned to reference values in a time-efficient manner. This app also allows for accurate assessment of mobility and better monitoring of the impact of an intervention or treatment



Why do you need a z-score? A z-score indicates the distance of a measured value from the mean value in standard deviations. In this case, the measured value refers to the walking distance covered. Z scores cannot replace clinical assessment and cannot serve as the sole criterion for assessing deterioration or improvement in cardiopulmonary disease. Prof. Geiger reports: "My team and I have developed a modified test in our department so that we can create reference values for all age groups. Our aim was to achieve a better comparability of test results in young, chronically ill children as they grow. The new app, which could only be implemented with the great support of the Lungkids research association, is a low-threshold solution that precisely meets this requirement."

It was important to Gerry Fischer to design the app in such a way that it can be used by every paediatric, cardiology and pulmonology center worldwide: "We have made it our mission to promote the development and use of non-invasive measurement methods. We are very proud of our joint project and hope that the 6 min.test app will be used by many doctors."

Gerry wrote an informative letter that was sent to all paediatric cardiologists and pulmonologists. We have also designed a folder that explains how easy it is to download the app for free. Getting kids to do a 6-minute walk test isn't easy. For this reason, we had wheels made specifically for this purpose. They are light and easy to handle for children. As a special "treat" there is a red rubber dragon on the wheel. For interested, we will provide such a wheel free of charge. The project was published as part of WPHD (World Pulmonary Hypertension Day). The 6 min.test app is available free of charge from the [Apple Store](#) and [Google Playstore](#).



6 min.test app

App for determining the submaximal exercise capacity in children and adolescents

What is the 6 min.test app?

The app was created as part of the joint project between the University of Innsbruck and the Lungenkinder Forschungsverein (Lung Children Research Association) of the PH Austria – Initiative Lungenhochdruck. For the first time ever, this mobile application provides medical staff with a standardized means to determine 6-minute walk test Z-scores* for children and adolescents (4-19 years). This is extremely helpful when monitoring chronic illness as children grow. The app is based on published, validated publications. <https://6-min-test.org/studien/>

The creation of the app

The 6-minute walk test has been used in cardiology and pulmonology for decades to determine the performance, or rather the functional training capacity, of adults. Univ.-Prof. Dr. Ralf Geiger, Clinic Director Department for Pediatrics and Adolescent Medicine, and his team developed a modified test specifically for children and adolescents. The aim was to make it easier to compare test

results even for young and chronically ill children as they grow.

Free of charge in the app store

The 6 min.test app can be downloaded free of charge from the Apple Store and the Google Playstore. If you don't want to use an app, you can use the online test at: <https://6-min-test.org/>

Distance measuring wheel designed for children

But how do you motivate children and adolescents to take a 6-minute walking test? We at PH Austria were inspired by Dr. Prof. Geiger and purchased distance measuring wheels that are specially adapted to the needs of children and adolescents. Their suitable design motivates children and adolescents to participate in the test. Are you interested in a distance measuring wheel? We are happy to provide them for free. Simply contact us at: info@phaustria.org

How to use the app

In 3 easy steps to the result

Step 1

Do the 6-minute walk test with your patient.



Step 2

Enter all the patient's data (gender, age, height, etc.).



Step 3

Enter the results of the 6-minute walk test.

The Z-score is provided immediately and can be emailed directly to you.



Book project: "Mein Leben, meine Lungentransplantationen und ich „ by Rani Gindl

Rani Gindl's debut work shows how, despite an incurable illness, one can affirm life and not lose courage. The diagnosis of pulmonary hypertension forces Rani Gindl to deal with mortality and the meaning of life. A burnout prompted her to complete training in yoga, Ayurveda and burnout prevention. To the diagnosis of pulmonary hypertension two lung transplants following by at intervals. Everything changes in her life, and she also has to cope with a lot in her private life. Despite all the difficulties, she starts to study Indiology and begins to write her first book.

In her book "Mein Leben, meine Lungentrasplantation und ich" she processes all the moments she has experienced in 135 pages and shows how, despite all the adversities, one can adjust to a new everyday life and experience it consciously. Her main concern is to pass on the knowledge about a healthy and active life, despite and with illness.

The book was published by Vindobona Verlag, Frankfurt am Main.

The release date was June 30, 2021.

If you are curious and would like to read the book, here is the ISB number:

ISBN: 978-3-949263-02-6, available for €13.90.

We at the PH – Austria Initiative, a research association for children with lungs, find this project particularly worth mentioning and have therefore financially supported the publication of Rani's first book.



Self-help day

On the self-help day the Vienna City Hall had the motto “We have air to breathe”, a predestined topic for PH Austria. The event of the Vienna Health Promotion (WiG) took place for the seventh time on Sunday, September 26th. Due to the pandemic, the event was held outdoors for the first time



in the newly designed covered arcade courtyard in the Vienna City Hall. Many interested visitors were enthusiastic about the offer of 50 exhibiting self-help groups and organizations. Peter Hacker, the Vienna Health Council, emphasized the importance of non-profit institutions. The lectures were streamed onto large screens, so that all visitors could attend lectures about lungs by well-known doctors such as Univ. - Prof. Dr. Marco Idzko. There was also the opportunity to take part in workshops on breathing techniques, yoga, or Nordic walking, which met with great interest. Of course, there was also an oxygen barrel for refuelling, provided by Vivisol. In addition to all of this, organizations such as the Lungenunion and PH Austria were able to introduce themselves with a presentation. Eva was able to report on the variety of activities of PH Austria. She also encouraged people who experience shortness of



breath, chest pressure, or are struggling with extreme exhaustion to see a cardiologist to remember that it might be pulmonary hypertension. She pointed out that the earlier the diagnosis is made, the longer and higher the survival rate. With the participation of numerous non-profit organizations, Self-Help Day promotes public awareness of what these groups have to offer.

National Nurse Forum

At this year's National PH Nurse Forum, PH Austria was represented by Eva with a lecture on the subject of "Advising and caring for patients with PH - what has changed due to Corona". She was invited together with Daniela Kleinschek, MUG Graz, Pulmonology. This year the National PH Nurse Forum, planned and organized by the MSD company, took place in Saalfelden - Leogang. For the fourth time, the participants had the opportunity, including PH specialists, nursing staff, study nurses and physiotherapists, to continue



their education and training. The first day was under the scientific direction of OÄ Dr. Steringer - Mascherbauer, Elisabethinen Linz. In her lecture, she dealt with the challenges that the treatment and care of pulmonary hypertension patients brought with them in times of COVID-19. Dr. Anna Böhm, Innsbruck University Hospital, explained Corona vaccinations for PH patients. OÄ Dr. Albinni, AKH Vienna, Pediatric Cardiology, gave an interesting lecture on the effects of infections in children with PH. The following workshops dealt with RHK - diagnostics, management of PH - specific therapy in times of corona and respiratory physiology. In the evening Univ.-Prof. Dr. Irene Lang led in her lecture from the PH - Past to the Future and also presided over the next day. There were lectures by Assoc. Prof. Dr. Gabor Kovacs,



MUG Graz, on the importance of blood gas analysis and Mag. Birgit Wille - Wagner, Elisabethinen Linz, about the the psychological aspects during the pandemic. In her presentation, Eva emphasized how important it is to strengthen the sense of community, which PH Austria has achieved very well by founding the WhatsApp groups, the virtual meetings and the numerous phone calls.

7th Viennese GhostRun

On Sunday, October 31, 2021, the time had finally come again: Our charity run, the "GhostRun" on Halloween took place again in Vienna's Prater. Around 800 runners, including many children and adults in scary disguises, ran for a good cause in beautiful autumn weather and generated more attention for the rare but incurable disease of pulmonary hypertension.



"We run away from the Grim Reaper" - this is the motto of the annual running event, in which large and small ghosts, zombies and witches, alone or in a group, run 1.5 or 6 kilometers through the Vienna Prater. After the GhostRun took place only virtual last year because of Corona, it was particularly great to host a live event again this year, in which not only the idea of competition, but also happy

togetherness was in the foreground again. In times of Corona, we all learned what isolation means. This is a sad everyday life, especially for the children, and that is why we are so happy that so many participants took part. In addition to the well-known sports event moderator Martin Patak, who led through the GhostRun 2021 with humor, charm and sovereignty, other prominent supporters such as Hademar "Hadschi" Bankhofer and his family were there in the Prater to cheer on the little and big runners!

Between the family and friends run, the main run and the award ceremony, the drummers from the Austrian percussion band Batala Boom created a lively atmosphere. The prizes, snow globes from the Original Wiener Schneekugelmanufaktur, were presented by District Chairman Alexander Nikolai.



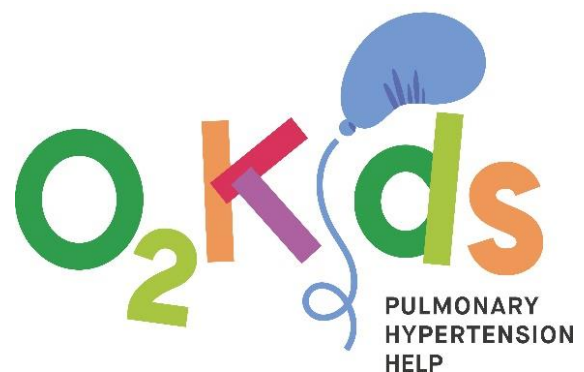
He emphasized on stage that his participation in the GhostRun was a matter close to his heart.

Chairman Gerry Fischer on the GhostRun 2021: “My thanks go to all those involved: the many volunteers, the participants, and the spectators! They all made a huge contribution to make the 7th GhostRun for something real and special. PH Austria use the income from the entry fees as well as merchandise and mask sales, this year the record sum of 15,000 euros, to give patients access to information, therapy, and support options, to improve their quality of life and research projects to push ahead to defeat the disease, which is still incurable today.

Throughout Europe O2Kids Campaign

The Lungkids Research Association, PH Austria and the umbrella organization PHA Europe, work together to support children and their families and thereby make their lives easier in the respective situation.

Together we have launched the O2Kids campaign, with which we want to pass on direct help to families and also draw attention to the situation of affected children and their families.



Through the umbrella organization PHA Europe, we have offered our member countries that families who urgently need something for their sick child but cannot afford it can submit an application to us. In the following we will try to fulfill these wishes.

So far, 15 applications have been received, with a volume of more than 17,000 euros, which are urgently needed.

Among the wishes were a special voice computer that enables the child to communicate with its surroundings, a tricycle to give a child mobility, an electric wheelchair, an oxygen concentrator, and a laptop to enable the child to take part in lessons, electric bikes to give kids the opportunity to keep up with others, a special watch to measure heart rhythm and oxygen levels all day long and much more.

Together we collect funds to be able to fulfill all these wishes!

Here in Austria, a moving, heartbreaking and yet hopeful life story has reached us. It is about Tobias from Leobersdorf. Tobias is five years old and suffers from pulmonary hypertension. The incurable disease was diagnosed when he was six months old. Tobias is a sunshine who loves life but is very often frustrated because he can hardly communicate. He had to be placed in an induced coma for several months.

During that time, medication, a feeding tube, oxygen, a colon tube and the surveillance monitor kept him alive. Therefore, both his mental and physical development is at the level of a year and a half and, above all, the speech center is massively affected.

Thanks to the self-sacrificing care and love of his parents, Tobias survives despite many setbacks. He is alive, although the doctors have often given him up.



With the help of a special voice computer, it would be possible for Tobias to communicate with his parents, his little brother and those around him - which would simplify many things in the life of the young family. Among other things, we collected donations with the O2Kids campaign for this computer and for the mobile communication aid, which was adapted for Tobias by a company in Linz!



Lungskids Campaign

We have been working on a Europe-wide awareness campaign called "Lungskids" since autumn 2015. In cooperation with a young advertising agency, posters and successfully published advertising films have already been created.



O2DYSSIEY Brochure

Our book "An Odyssey for a Child" gives insights into the isolated life of a child suffering from pulmonary hypertension. The book contributes to understand the rare disease pulmonary hypertension in a way that is suitable for children.



Continuation of the Milestones Campaign

"Giving with love & giving hope!" - that is the motto of our milestone campaign.

Supporters of the Lungkids Research Association have the opportunity to immortalize themselves with their name and a personal dedication on a "milestone" in the Vienna Prater via www.meilensteine.at.

The proceeds will be used to give patients access to information, therapy, and support options, to increase their quality of life and to advance research projects. Step by step, stone by stone, the disease pulmonary hypertension (PH), which is still incurable today, is to be conquered.

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.

PHA 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 Planetarium auf dem Thurn-und-Taxis-Platz gesetzt. Sie haben sich aber nicht nur mit einem Meilenstein verewigen, sondern auch die Erkrankung eines Lungenerkrankten durch Ihre Unterstützung leichter zu ertragen.

Für Ihre Unterstützung bedanken wir uns sehr herzlich!

Gerny Fischer
Stress
Lungenerkrankte Hochbegabte

Austrian National Institute of Health-OSR

According to the EU regulation, every EU country had to draw up an action plan on rare diseases by the end of 2013. To this end, a sub-commission was set up in the highest medical council in Austria. This consists of representatives from the Ministry of Health, the Ministry of Social Affairs, the main association, Pharmig, ÖGAM, university clinics - research area and patient representatives. We are very happy that our chairman Gerald Fischer was elected to this commission as patient representative.

PHA Europe

The Austrian Pulmonary Hypertension Initiative is one of the most active members of the European umbrella organization PHA Europe. We always endeavour to work closely together and are proud to be a role model as a national patient group within this umbrella organization.

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 our members. All social support options for pulmonary hypertension patients in Austria are summarized in the folder. In addition, those affected will find information on how and where to submit the applications and what requirements are necessary for this.

The folder was presented at our patient meetings, published on our website and has been continuously updated since it was first published in 2016.

Newsletter

We published four newsletters in 2021 under the title “Atemberaubend”. Two of these have been combined in a special edition. The fixed content includes social tips, “Von uns für uns” (a patient tells his or her personal story), a 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 available in the outpatient departments. Interested parties can also find newsletters to download on our [website](#).



Continuation und Improvement of our Website

Our new [homepage](#) is online - with a simpler user interface so that members and those who want to become members can get a quick and uncomplicated insight into our association and our services. The content is revised continuously and we continue to work on search engine optimization (SEO).

PH Austria informs and connects those affected and supporters via our [Facebook](#) and [Instagram](#) channels. We publish exciting lectures and discussions from our events on our [YouTube channel](#).



Press review

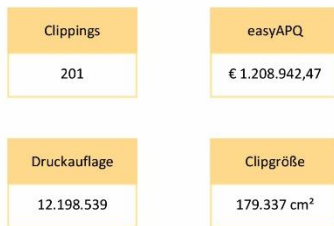
In 2021 we were pleased to receive a total of 126 media reports and articles reporting on pulmonary hypertension, the initiative and our activities. The reports in many specialist media, but also in daily newspapers such as Die Presse and Kronen Zeitung, correspond to a combined print run of around 8,500,000 pieces! The most frequent reports were in autumn, around the GhostRun and the awareness month of November.

Meine Fakten im Blick

1843 PH Austria Analysezeitraum: 2020



Meine Daten



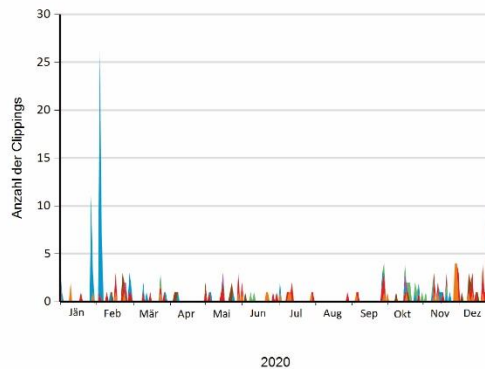
Meine Medien



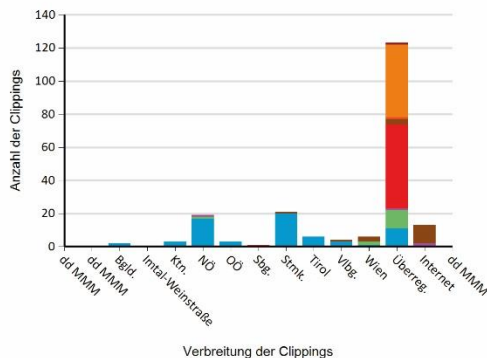
Meine Suchbegriffe*



Suchbegriffe-Chronologie*



Regionale Verbreitung*



Meine Medientypen



Bei den mit * gekennzeichneten Charts herrscht Farbkongruenz.

Einfach den Überblick behalten. >>>

Preview 2022

- 25th February 2022 General Assembly PH Austria online
- 28th May 2022 Rare Disease Day
- 05th May 2022 World PH Day
- May 2022 Kellertheater – One infidelity too much
- 18th of June 2022 Perchtoldsdorfer Vespatreffen
- 22th of June 2022 Viennese Zoo Run
- 31st of October GhostRun
- November 2022 Awareness month November
- 2022 Info-events in Vienna, Linz, Graz, Innsbruck and Klagenfurt
- 2022 Information events for families in Vienna
- 2022 Memberworkshops in Vienna, Linz, Graz, Innsbruck, Klagenfurt

Further Plans for 2022

- We will continue our counselling hours at the AKH and will be there on the first Tuesday of the month to provide our patients with active support.
- Our office is open on weekdays from 8:00 a.m. to 4:30 p.m..

We would like to thank our supporters again on behalf of all our members and look forward to a successful collaboration in 2022!

Contacts

*PH Austria -
Initiative Lungenhochdruck
Obmann: Gerald Fischer
Wilhelmstraße 21
1120 Wien
Tel.: 01/402 37 25
www.phaustria.org
info@phaustria.org*