

Annual Report 2020

PH Austria - Initiative Lung- enhochdruck

Frühe Diagnose • Beste Therapie • Lebensqualität • Heilung

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

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Preface

Dear supporters, friends and members,

2020 put us to a particularly tough test. We have felt what it means to live in isolation, even those who do not have difficulties with everyday things. People who can easily carry their shopping home, meet up for sports after work or meet up with friends. Children who arrange to go swimming after school or frolic in the playground. They all felt what social isolation means. Words like cohesion, community, solidarity, understanding, personal responsibility and help have acquired a more important meaning.

We at PH Austria also worked from home. We planned the "Blue Lips Campaign", a cross-border online campaign for the WPHD, founded WhatsApp groups to promote cohesion, sent out online newsletters to give our patients important information as quickly as possible and we have always been available by phone around the clock. And now we all understand more than ever what it means to spend our whole life in lockdown.

The 6th Viennese GhostRun was carried out as a virtual run for the first time, which was positively received by the participants and contributed to clarification and awareness-raising.

Pulmonary hypertension is currently not curable, so research is particularly important. With our Lung Kids Research Association, we strive to support them financially as much as possible. This year we were able to support several projects and invested in pulmonary hypertension research. Although much progress has been made in research in 2020, 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

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 study in the USA 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

Board of Directors

President	Gerald FISCHER
Vice President	Eva OTTER
Secretary	Monika TSCHIDA
Vice Secretary	Josefine TOMSICH
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 400 members in Austria.

Our responsibilities

Office of the Pulmonary Hypertension Initiative

We run an office at Wilhelmstrasse 21, 1120 Vienna, which is occupied by our employees 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.

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 and always up-to-date homepage and a Facebook and Instagram account, through which our patients, members and the interested public are kept up to date.

Events for Members 2020

January 21st	Visit of the Linzer Kellertheater
February 7th	Information event Klagenfurt
June 26th	Chat meeting Graz
October 24th	Information event Vienna
November 7th	Information event Innsbruck
November 12th	Information event Linz
November 28th	Information event Graz

Visit of the Linzer Kellertheater - laughing is healthy

True to the motto "Laughter is healthy" by OÄ Dr. Regina Steringer-Mascherbauer was once again visiting the Linzer Kellertheater this year. We started the year on January 21st, 2020 together with our patients. The Linzer Kellertheater's greatest endeavor is to offer the audience entertainment at the highest level. With the performance of the classic comedy "Boeing - Boeing restarted", this has been proven once again. The completely sold-out performance was a welcome change for all members.



1st Information Event in Klagenfurt

For the first time there was an information event in Klagenfurt, in the federal state of Carinthia, for lung hypertension patients and their relatives.

Klagenfurt's pulmonary hypertension specialist OÄ Dr. Tamara Buchacher from the Klinikum Klagenfurt am Wörthersee spoke about the various forms of pulmonary hypertension and the therapies that are currently possible. Eva Otter presented the wide range of activities at PH Austria. The event was a total success. A boat tour is planned on the beautiful Wörthersee, of course there will be coffee and cake! During this get-together, social issues such as applying for a handicap pass or filling out the forms for care allowance or parking permit will not be neglected. Eva insisted on dropping by at the Lindwurm, Klagenfurt's landmark.



Information Event in Graz

At the meeting, which took place on the terrace of a coffee house on the clinic premises, the security measures were carefully observed. Eva greeted each of the 18 participants with the words "Please do not shake hands and do not hug"! Instead, there was a solution for hand disinfection as a greeting and a face mask for everyone.

Univ. Prof. Dr. Olschewski and Mr. Univ. Doz. Kovacs, both MUG Graz, gave a lecture on the effects of COVID-19 on patients with pulmonary hypertension and on the development of drugs.

In order to counteract the isolation and to strengthen the community, PH Austria set up WhatsApp groups in the time of crisis. This gave our members the opportunity to exchange ideas virtually. It was a great pleasure to finally get to know each other personally at the meeting, to feel a little normality, even if special protective measures were taken.

There was enough to talk about, with ice cream, coffee, cake and rolls the time passed in an instant.



Virtual Information Events 2020

Challenging times call for extraordinary measures. Since we always want to provide our members with the latest information and this was not possible as usual, we quickly organized the information days as virtual meetings. The meetings were recorded and uploaded to [YouTube](#). That way interested parties can stop by again afterwards.



We were happy to see so many participants, including those affected, relatives and friends. Our sponsors also insisted on being there. The meeting in Vienna premiered on October 24th with Univ.-Prof. Dr. Irene Lang, Priv.-Doz. Nika Skoro-Sajer, both AKH Vienna Cardiology, and Dr. Lukasz Antoniewicz, AKH Vienna Pulmology.

Univ.-Prof. Dr. Lang explained who and with which diseases - such as pulmonary hypertension - belong to the risk group.

Priv.-Doz. Skoro-Sajer explained in a very understandable way how one can recognize the presence of pulmonary hypertension in the ECG. She also described the current procedure in the PH outpatient department to protect patients, due to the corona crisis. Dr. Antoniewicz gave a lecture on the process and the significance of the Pulmonary function tests. At the end there was yoga with Rani Gindl.



Priv. Doz. Dr. Nika Skoro-Sajer



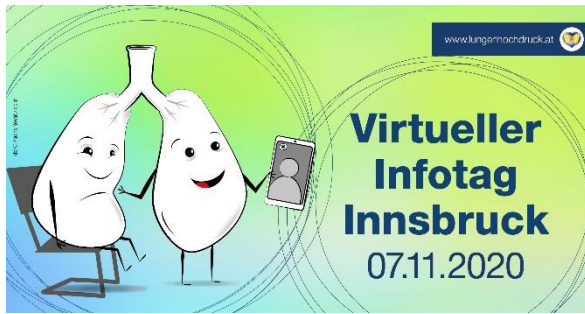
Univ.-Prof. Irene Lang



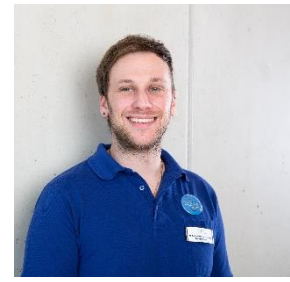
Dr. Lukasz Antoniewicz



Rani Gindl



Univ.-Prof Judith
Löffler-Ragg



Andreas Mühlbacher, MSc

On November 7th, the virtual information event in Innsbruck continued with Univ.-Prof. Dr. Judith Löffler-Ragg, Pneumology Uniklinik Innsbruck, and Andreas Mühlbacher, MSc, head physiotherapist at the Reha-Klinik Münster, Tyrol.

Prof. Löffler-Ragg heads the PH outpatient department at the Uniklinik Innsbruck, she also works as an OÄ in the emergency room and as a representative of the COVID infection service. She gave an informative talk about the extent of the pandemic.

"Looking back at the beginning of the COVID-19 pandemic, we already know more about the behavior of the virus," said Löffler-Ragg. She also explained the most common symptoms: "80% have a mild course of the infection: cough, fever, difficulty at breathing, loss of smell, loss of taste, headache, sore throat, diarrhea. The risk factors include age - older people with comorbidities are more at risk - cardiovascular diseases, diabetes, obesity. The course of COVID disease begins as an infection of the upper respiratory tract, continues into the alveoli, where the cells that are infected by the virus are located. Here the T-cells should be able to fight off the virus. If the immune response is good, the infection is over. One has an asymptomatic or mild course here. If the T-cell response fails, the virus attacks the lungs, heart, or other organs. Fever, cough, breathing difficulties are the result. The pulmonary problem always occurs in the 2nd week from the onset of the disease, which is why one speaks of a mysterious lung disease. The X-ray shows white spots as a result of the pulmonary affliction. If the patient is stable again, the disease can no longer be proven after 6 months." The New York Times published an article about the experiences made by the team at Uniklinik Innsbruck.



OÄ Dr. Regina
Steringer-Mascherbauer

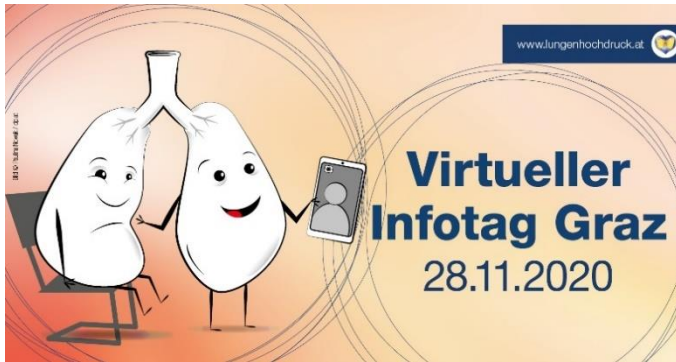


Claudia Englisch

At the beginning, OÄ Dr. Steringer-Mascherbauer went into the currently applicable rules in the PH – Ambulanz des Ordensklinikum Linz Elisabethinen. “Due to the challenging situation, the care of PH patients is different than usual. Those affected who are stable get their prescription sent home and at the same time receive a later check-up appointment.” However, she emphasized that these measures only serve to protect the patients and that the outpatient department is manned as usual. If problems arise, you will get an appointment immediately. “The aim of this handling is to minimize the contacts,” says Steringer-Mascherbauer. OÄ Dr. Steringer-Mascherbauer made an appeal to all PH patients: “stay at home, keep your distance, wear the mask if necessary, wash and disinfect your hands and reduce your contacts! Let us look forward to the time afterwards when everything will be possible again! I encourage everyone to find something to do at home, such as reading or cooking. Please ensure that you exercise enough outdoors in small groups; walking is allowed and is good for body and soul.”

The dietician Mrs. Englisch spoke about nutritional measures that can make everyday life easier for patients with pulmonary hypertension, because the most common problems are nausea, diarrhea, weight loss or loss of appetite.

OÄ Dr. Steringer-Mascherbauer had the idea of putting together a nutrition brochure. The nutrition brochure will be made available to our members free of charge upon request.



Univ. Prof. Dr. Horst
Olschewski



PD Dr. Gabor Kovacs

The fourth virtual meeting took place in Graz on November 28th. Prof. Dr. Horst Olschewski and Priv.-Doz. Dr. Gabor Kovacs, both MUG Graz, and physiotherapist Petra Odelga were among the speakers. Prof. Dr. Olschewski, head of the clinical department for lung diseases and deputy director LBI/LVR Graz, gave a case study of a patient who had a very severe course of COVID infection in his lecture. He discussed the measures that were taken as the disease progressed. He also pointed out that we are exposed to a flood of data. "It is important to know that not all information or data received can be implemented," says Olschewski. The COVID infection can take an asymptomatic course, there are mild, moderate courses and around five percent of all infections are severe. The incubation period is five to six days, after which the first symptoms appear. Before physiotherapist Petra Odelga waited for us in her workshop with good tips on breathing exercises for home, the participants' questions were answered.



Petra Odelga

Service for Patients

PH Austria in challenging times

In 2020, the corona virus presented the PH Austria team with new challenges. In addition to the routine work, we wanted to provide our members the most up-to-date information as quickly as possible and be at their side with support and advice during these difficult times.



Of course, we were and are, as usual, available around the clock via our service hotlines. In order to prevent fear, uncertainty and sadness from arising at all, we have offered additional services. WhatsApp groups were founded in all federal states in order to promote the communication among patients. We wrote a letter of recommendation to employers, counselling sessions were offered and newsletters were sent out via Mailchimp. These mailings were always provided with our new label, the “Lungis”, which indicate that the article is particularly important.

These measures ensured that all of our members knew exactly about the opening hours of the pulmonary hypertension special outpatient clinics and the availability of their pulmonary hypertension specialists in this difficult time, that the sense of community was promoted and strengthened and isolation was counteracted and the fear and uncertainty could be taken away.

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.

Education / Awareness

February 29th	Rare Disease Day
May 5th	World PH Day
June 17th	Zoolauf
October 2nd	National Nurse Forum
October 31st	Virtual GhostRun

February 29th – Rare Disease Day

On Rare Disease Day, PH Austria - Pulmonary Hypertension Initiative organized a press breakfast together with the initiators of the Perchtoldsdorfer Vespatreffen to draw attention to the planned event for PH Austria and the Lung Kids Research Association in June. Several hundred Vespa drivers should send an important signal to children who are affected

by the incurable disease of pulmonary hypertension. The proceeds of the 7th Vespa meeting should go entirely to the children. The event was planned for June 13th, 2020 but could not take place due to corona. The 7th Vespa meeting has been postponed to a date that has not yet been determined.



May 5th – World PH Day

“Set a loud signal” was the motto again this year on May 5th, World Pulmonary Hypertension Day (WPHD).

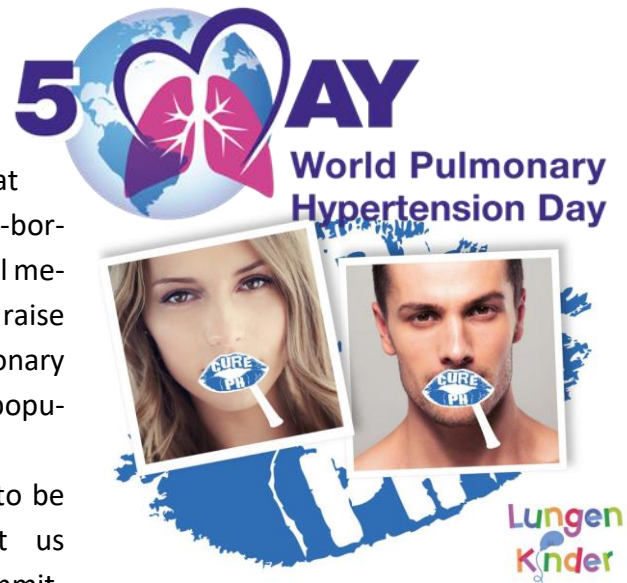
Since no major events were allowed to take place, we at PH Austria took this as an opportunity to initiate a cross-border online campaign, the "blue lips campaign", via social media such as Facebook, Instagram or Twitter in order to raise



awareness of pulmonary hypertension in the population.

Those who wanted to be there and support us through their commitment found the instructions for participation on our Facebook page. You also had the opportunity to have “blue glitter lips” conjured up on Snapchat.

Many members sent in photos, there was also support from bloggers, influencers, celebrities and our sponsors. On the evening of May 5th, Vienna's landmark, the Viennese Riesenrad, was illuminated in blue. PHA Europe started a photo contest at the WPHD in which many member states took part.



9th Viennese Zoolauf

After the government announced that all events had to be cancelled until the end of August 2020, the 9th Viennese Zoolauf was also affected.

For a long time, we puzzled over an

alternative. Due to the light conditions in autumn, it is unfortunately not possible for us to simply postpone the Zoolauf for a few months. That's why we had to cancel it, even though the popular charity run is so important for us and the zoo.

Thanks to donations from the participants and our partners and sponsors, we were able to achieve a total donation of € 20,000 this year, despite the cancellation, which was divided equally between PH Austria and the Schönbrunner Zoo.



National Nurse Forum

The annual national nurse forum could not be held in the usual way either. In order to give the participants, including doctors, nursing staff, physiotherapists and representatives of PH Austria, the opportunity to continue their education and training, the meeting was held virtually on October 2nd. Under the scientific direction of OÄ Dr. Regina Steringer-Mascherbauer from the Ordensklinikum Linz Elisabethinen was all about the care and support options for PH patients. The speakers included Priv. Doz. Badr Eslam, AKH Vienna, Cardiology, OÄ Dr. Albinni, AKH Vienna, Pediatric Cardiology, Univ. Prof. Dr. Löffler-Ragg, Uniklinik Innsbruck, and rehabilitation specialist Prim. Puchner from the Reha-Klinik Münster. DGKP Karin Hahn and Verena Tremel MSc, both KH Linz Elisabethinen, dealt in their workshops with the management of PH-specific care and diagnostics for right heart catheters from the care perspective. Overall, this was an interesting and innovative virtual event that was planned and supported by the MSD company.



OÄ Dr. Steringer-Mascherbauer

6th Viennese GhostRun

Every year, many sports enthusiasts take part in the GhostRun under the motto "We run away from the Grim Reaper". Due to Covid-19, the charity run took place virtually for the



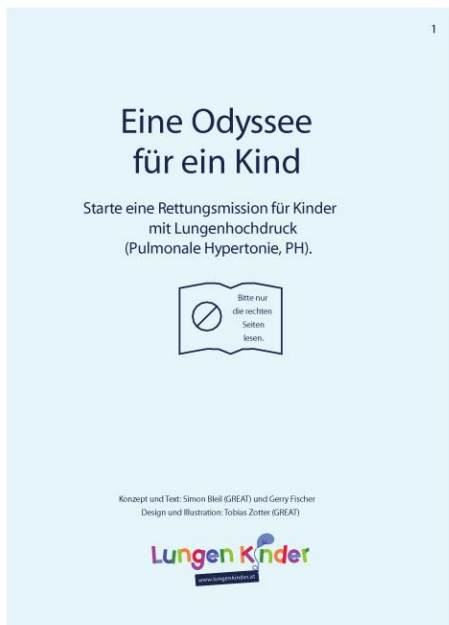
first time this year - with complete success! We were happy to see more than 250 participants who took part in the family run over a distance of 1.5 km or in the 6 km long main run from October 30th to November 1st, 2020. All the GhostRunners ran away from the Grim Reaper on their favored route, some even in eerily beautiful disguise. The personal running results were entered online by the participants. So, they could take part in the virtual victory ceremony. The fastest three received their prize in the mail. The switch to a virtual run posed a major challenge for the organizers. But the reward was inevitable, many ghosts sent us photos, whereupon proud and happy faces could be seen. Of course, Alexander Bichl was right at the front again. Even the family man and supporter of our charity runs said: "Of course it is important for me to win, but the GhostRun is primarily about creating awareness for the disease. Thus, all runners who participate are winners! "

Lung Kids Campaign

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



O2DYSSEY Brochure



Continuation of the Milestones Campaign

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

Supporters of the Lung Kids 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.

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!

PH AUSTRIA
INITIATIVE LUNGENHOCHDRUCK

Austrian National Institute of Health-OSR

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 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 2020 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

We are constantly in the process of making our [homepage](#) even clearer and disseminating even more information in this way. We are working with a specialist on an even better SEO.

In addition, our [Facebook page](#) will be structured more clearly and interactively in order to address even more people.

Observer

In 2020 we were happy to receive 186 press articles in which they reported on pulmonary hypertension, the initiative, and our activities.



Meine Fakten im Blick

1843 PH Austria Analysezeitraum: 2020



Meine Daten

Clippings	easyAPQ
201	€ 1.208.942,47
Druckauflage	Clipgröße
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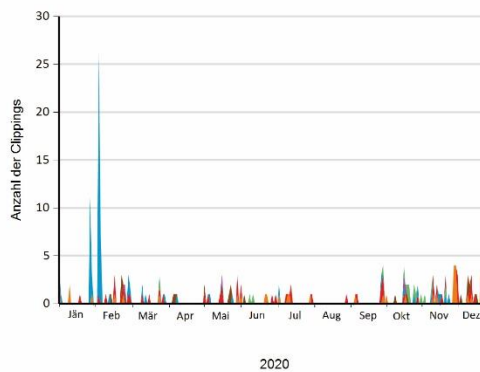
Meine Medien



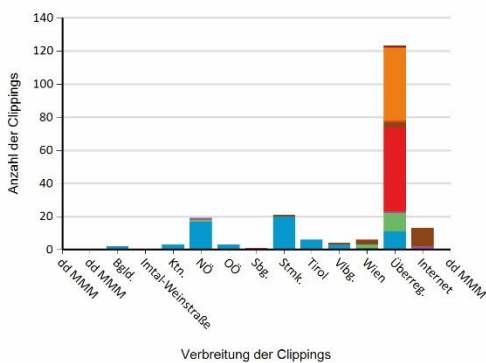
Meine Suchbegriffe*



Suchbegriffe-Chronologie*



Regionale Verbreitung*



Meine Medientypen



Bei den mit * gekennzeichneten Charts herrscht Farbkongruenz.

Einfach den Überblick behalten.



Schedule 2021

Preliminary schedule 2021

- **Online meeting on Covid 19 vaccination for pulmonary hypertension**
- **General Assembly PH Austria online**
- **Rare Disease Day**
- **Information events for patients in Vienna, Linz, Graz, Innsbruck und Klagenfurt**
- **Information events for families in Vienna**
- **Chat meetings in Vienna, Linz, Graz, Innsbruck und Klagenfurt**
- **Perchtoldsdorfer Vespatreffen**
- **World PH Day**
- **Viennese Zoolauf**
- **GhostRun**
- **Awareness month November**

Plans for 2021

- We will continue our counsellings 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 2021!

Contacts

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