

Annual Report 2021

Lung Kids Research Association





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Self-Presentation

The Lung Kids Research Association is an association under the Austrian Association Act. It was launched in 1999 by Gerald Fischer.

After three years of "wandering around", little Maleen Fischer was diagnosed with "pulmonary hypertension" and she was sent home as incurable with a life expectancy of two to three years.

Gerald Fischer found help in New York City, where at the Columbia University, Presbyterian Hospital, a research and treatment centre under the direction of Dr. Robyn Barst was led. When asked why there was no cure, Dr. Barst answered that there are too few patients to get pharmaceutical companies to do research. "Give me 10 million dollars and I will find a cure in three years!" was her statement at the time.

So it depended on money whether patients survive or not! Obviously, the \$ 10 million amount is not that easy to come by, but a start should be made.

Doctors from Austria were trained in America and an international symposium was organized in Vienna. The first research project initiated at the Vienna AKH was very promising and received EU funding in 2003. The Lung Kids Research Association was awarded in 2001 by Dr. Pittermann with the "Gesundheitspreis der Stadt Wien".

A medical advisory board evaluates new research projects and decides on financial support. Fundraising and intensive media work are intended to increase awareness about the disease in the population as well as among general practitioners. The fact that only ten percent of those affected know about their disease and that 80 percent of patients only recognize it in the final stadium needs to be improved.



The Lung Kids Research Association focuses primarily on research into a non-invasive (bloodless) method for measuring cardiac output. According to the latest findings, the course of the unfortunately still incurable and fatal disease “pulmonary arterial hypertension” cannot only be measured by the pressure conditions in the small circulation, but above all by the change in cardiac output. Unfortunately, this can currently only be measured using a right heart catheter, which requires strong sedation (type of anaesthesia) in children. For this purpose, the seriously ill children, unlike adults, have to stay in hospital for longer and need months to recover. The Lung Kids Research Association has set itself the task of promoting projects such as the INNOCOR project ([Cardiac Output Messungen \(meduniwien.ac.at\)](https://www.meduniwien.ac.at/en/research/innocor)) at the Vienna Children's Clinic in order to find new, simple, non-invasive methods of measuring cardiac output and to create awareness for this, especially in the medical profession.

We are very grateful for the financial support of numerous companies that can deduct their donations from tax, as the association belongs to the group of beneficiaries.

The non-profit patients' association PH Austria - initiative for pulmonary hypertension, which aims to provide (self-)help and information for those affected as well as raising public awareness, is also managed from the same office.



Board of Directors

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

Head of Department

Persons responsible for the use of donations, fundraising and data protection:

Fundraising: Gerald Fischer, Chairman and Deputy Treasurer.

Privacy: Eva Otter, 2. Auditor

Use of donations: Gerald Fischer, Chairman and Deputy Treasurer.

The medical advisory board decides to what extent a research project is eligible for funding. The selection of a research project and the award of research funds require the consent of at least two advisory board members.



Medical Advisory Board

Univ. Prof. Dr. Walter KLEPETKO	Universitätsklinikum AKH Wien
Prim. Prof. Dr. Meinhard KNEUSSL	Lungenfacharzt
Univ. Prof. Dr. Irene LANG	Universitätsklinikum AKH Wien
Mag. Sigismund MITTELBACH	Pharmosan HandelsgesmbH
OÄ Dr. Regina STERINGER-MASCHERBAUER	Ordensklinikum Linz Elisabethinen
Dr. Erika BERMAN-ROSENZWEIG, MD	New York-Presbyterian Hospital-Columbia and Cornell
Prim. Dr. Norbert VETTER	Lungenfacharzt
Univ. Prof. Dr. Ina MICHEL-BEHNKE	Universitätsklinikum AKH Wien
Ao Univ. Prof. Dr. Judith LÖFFLER-RAGG	Universitätskliniken Innsbruck
Univ. Prof. Dr. Ralf GEIGER	Universitätskliniken Innsbruck
Univ. Prof. Dr. Andrea OLSCHESKI	LKH-Universitätsklinikum Graz
Univ. Prof. Dr. Horst OLSCHESKI	LKH-Universitätsklinikum Graz
Prof. Dr. Christian M. KÄHLER	Lungenfacharzt
Dr. Franck F. Rahaghi, MD, MHS, FCCP	Cleveland Clinic Florida Weston, USA



Rules of Procedure for the Board of Directors

1. Association organs

The organs of the association are the general assembly, the board, and the auditors. The board consists of six members, namely the president, the secretaries, and the cashiers as well as their deputies. With regard to the rights and obligations of the bodies, reference is made to the statutes, as these are regulated in detail there.

2. Economy

When using the donations and funds, the principles of economy are to be applied. In particular, offers must be obtained before the selection of suppliers and the offer with the best price-performance ratio must be used.

3. Selection of Research Projects

Research institutes that support their research projects with the association "Kinder-P.P.H. Forschungszentrum" have to undergo a selection process. You have to submit your research project to the association and present the goals and content in detail. The selection of research projects eligible for funding is made by the medical advisory board and requires the consent of at least two members. Interim and final reports must be submitted for control.

4. Prohibition of unfair Advertising

The organization is committed to "integrity in advertising". In particular, the authorized representatives of the organization undertake to advertise correctly and ethically. Ultimate responsibility for fundraising and advertising on behalf of the organization is not transferred to third parties.

In the case of fundraising and advertising, the organization has, in addition to the respective state legal regulations, in particular the provisions of consumer protection (in particular §§ 3, 4, 6, 10 and 14), telecommunications (in particular §§ 101), the data protection act (in particular §§ 7- 9, 24 and 26) and the law against unfair competition (in particular §§ 1 and 2).

Funds are mainly raised through donations from private individuals and companies as well as through various charity events organized by various institutions for the benefit of pulmonary hypertension research.



The organization grants a right of withdrawal of 14 days when signing up sponsoring memberships, issuing collection orders or direct debit. If you withdraw within this period, any contributions that have already been paid will be refunded. Sponsoring memberships can be terminated at any time and with immediate effect after 12 months from the date of membership. If the sponsoring membership fee has been paid for one year in advance, there is a right to a refund of the portion paid in advance at the time of termination. The sponsoring member receives a copy of the sponsoring membership rights and is expressly advised of the right of withdrawal and the right to reimbursement of the prepaid share.

Doorstep advertising is expressly prohibited for the association. Likewise, no unsolicited telephone, fax or e-mail advertising may be undertaken without specific prior contact.

The statements made in the course of advertising must be true, clear and factually correct. No exaggerations or misleading photos or texts may be used. The limits of custom and decency must be observed. No designations, names or logos are to be used that give the impression of a relationship with other organizations.

5. Internal Control System

It is important to observe the four-eyes principle and the principle of separation of functions. For transfers of up to EUR 3,000.00 the president and the cashier are each authorized to sign, for transfers over EUR 3,000.00 the president and the cashier are authorized to sign together. The cash desk and the bookkeeping are not to be kept by the same hand. Service relationships with board members and their relatives are expressly prohibited.



Activity Report

Supported Projects 2021

"The Lung Kids Research Association supports the development of an app for the 6-minute walking 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 Pediatrics and Adolescent Medicine, and Gerry Fischer, 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 Lungenkinder research association, is a low-threshold solution that meets precisely this requirement."

It was important to Gerry Fischer to design the app in such a way that it can be used by every pediatric, 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 pediatric 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.



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Support throughout Europe O2Kids campaign

We, the Lung Children 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.

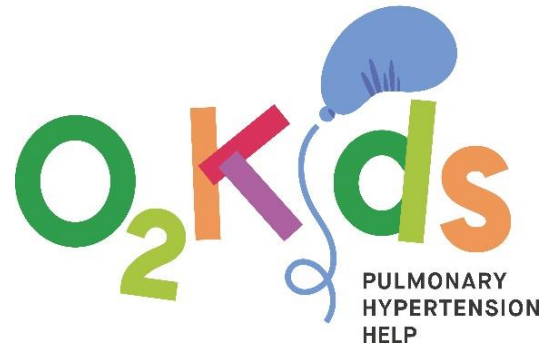
Among the wishes were a special voice computer that enables the child to communicate with its surroundings, a tricycle to give a child mobility, an electric wheelchair, an oxygen concentrator, and a laptop to enable the child to take part in lessons, electric bikes to give kids the opportunity to keep 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!



Awareness Projects

Blue Lips Campaign

Our Blue Lips campaign was hugely popular 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 in order to publicize this important topic. The international campaign aims to show that blue lips are sometimes a visible sign of pulmonary hypertension.



Blue illuminated Ferris Wheel

On World Pulmonary Hypertension Day, landmarks around the world are illuminated in blue to draw attention to the rare disease. In 2021, we asked the owners of the Ferris wheel in Vienna's Prater 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 reply. This is how the attraction showed up in the dark in a magnificently illuminated blue, and thus set a sign for pulmonary hypertension.





O2 Kids Campaign

We have been working on a new Europe-wide awareness campaign called "O2Kids" since autumn 2015. In cooperation with a young advertising agency, posters and subjects for advertising films have already been created. We were supported by our umbrella association PHA-Europe.



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Fundraising Campaigns

7th Viennese [GhostRun](#) – Halloween



More than 800 (ghost) runners started at the 7th GhostRun in aid of the lung kids. On Sunday, October 31, 2021, it was finally that time again: Our Halloween charity run took place again in the Vienna Prater. Around 800 runners, including many children and adults dressed up in creepy costumes, ran for a good cause in the most beautiful autumn weather and generated more awareness of the rare but incurable disease pulmonary hypertension. "We run away from the Grim Reaper" - this is the motto of the annual running event. Big and



small ghosts, zombies and witches run alone or in a group for one and a half or six kilometers through the Vienna Prater. After the GhostRun only took place virtually last year due to corona, it was particularly nice to be able to organize a live event again this year, in which not only the idea of competition was in the foreground, but also the happy togetherness. In times of Corona, we all have been confronted with the experience what isolation means. Especially for the children this is a sad everyday life and that's why we are very happy that so many participants were at

the start. In addition to the well-known sports event presenter Martin Patak, who led through the GhostRun 2021 with wit, charm and sovereignty, other prominent supporters, including Hademar "Hadschi" Bankhofer and his family in the Prater, were there to cheer on the young and old runners! Between the family and friends run, the main run and the award ceremony, the drummers of the Austrian percussion band Batala Boom ensured a lively atmosphere. The prizes, snow globes from the Original Wiener Schneekugel Manufaktur, were presented by the district manager of Vienna's second district, Alexander Nikolai. The man from Leopoldstadt emphasized on stage that his participation in the GhostRun was a matter close to his heart. Our chairman Gerry Fischer noted to the GhostRun 2021: "My thanks go to everyone involved: the many volunteers, the participants and the spectators! You all made the 7th GhostRun to something very special!" We at PH Austria - Initiative for Pulmonary Hypertension and the Lung Children Research Association use the income from the entry fees as well as the sale of merchandise and masks to give patients access to information, therapy, and support options to improve their quality of life and to advance research projects to defeat the disease, which is still incurable.





Further Projects

Austrian Health Council, OSR
Rare disease subcommittee

According to the EU regulation, every EU country had to draw up an action plan on rare diseases by the end of 2013. For this purpose, a sub-commission in the Austrian health council was established in Austria. This consists of representatives from the Ministry of Health, Ministry of Social Affairs, Main Association, Pharmig, ÖGAM, university clinics - research area and patient representatives. We are very happy that our president Gerald Fischer was elected to this committee as patient representative.

Research / lobbying on EU – level
FP7 – EU-Framework program research

Since funding in Austria is of course limited, we are increasingly trying to attract EU research funding for pulmonary hypertension. This requires close cooperation with the Austrian EU health representatives in the EU Parliament. We will inform you about pulmonary hypertension and ask you to attend sessions on "rare diseases", "pulmonary diseases" and especially "pulmonary hypertension" in order to raise our concerns and make the disease more prominent. The aim is to obtain pulmonary hypertension research funding from the EU's FP7.



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 service. The content is revised continuously, and we continue to work on search engine optimization (SEO).

PH Austria and the Lung Children Research Association inform and connect those affected and supporters via our [Facebook](#), [Instagram](#) and [YouTube](#) channels.



Aktion Meilensteine

We were again able to attract a lot of attention and raise donations for the benefit of the children with lung diseases through our place of [milestones](#) in the Vienna Prater. We plan to expand the project and set up another place in Reifnitz am Wörthersee.



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.**



INITIATIVE LUNGENHOCHDRUCK

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



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Vergissmeinnicht

The initiative for the good testament

The lung children research association has been a member of [Vergissmeinnicht](#) since the beginning of 2021 - the information platform on the subject of "inheritance for charitable purposes". Information is provided on how, in addition to family members, a non-profit organization such as the "Lung kids research association" can be included in a testament in Austria. We find the idea of doing something good beyond one's own life, giving those affected hope for healing through research and being remembered, really beautiful and worth supporting.



Vergiss
mein
nicht



We received prominent support for this project from Klaus Eberhartinger. With his statement he meets the harsh reality, but at the same time touches our hearts. We are pleased that we were able to win him as a testimonial.

Klaus Eberhartinger:

„Healthy children have many dreams. Sick children only one. You can help!“

Amazon Smile

Donate at no cost ...

Yes, that is actually possible! And via Amazon Smile.

That's how easy it is:

Click on the following link and log in with your own Amazon access data.

<https://smile.amazon.de/ch/29-91-64521>



Shop++

With online purchases, it is possible to donate to pulmonary hypertension research at the same time. To do this, you have to go to the website "www.shopplusplus.at" in advance and select the Lung Hypertension Research Association as the beneficiary organization. There are no additional costs for buyers



Donation hotline

You can donate around the clock under the number: +43 800/228888.


Many thanks to the organizers of the charity events and a big thank you to all donors

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Tax Rebate for Donors

<p>An Lungenkinder Forschungsverein c/o Providentia Wirtschaftstreuhand Steuerberatung GmbH Lerchengasse 2 2340 Mödling</p>	<div style="border: 1px solid black; padding: 5px; transform: rotate(-5deg); display: inline-block;"><p>PROVIDENTIA WTSB GMBH EINGELANGT - 5. Okt. 2020 Erl:</p></div> <div style="display: inline-block; text-align: right;"> BMF FINANZAMT</div>	<p>Bundesweite Fachabteilung Spendenbegünstigungen</p> <p>Finanzamt Wien 1/23 Marxerg. 4 1030 Wien</p> <p>Telefon +43 50233 510393 Fax +43 50233 5914001 e-Mail: post.fa09-ea@bmf.gv.at DVR 0009091</p>
<p>GZ. F 014/99</p>	<p>Wien, den 29.09.2020</p>	

Spendenbegünstigungsbescheid
für Forschungs- und Lehreinrichtungen
gemäß § 4a Abs. 2 Z. 1 und Abs. 3 Z. 4 bis 6 EStG

Es wird festgehalten, dass die oben genannte Einrichtung weiterhin zum begünstigten Empfängerkreis der Forschungs- und Lehreinrichtungen gemäß § 4a Abs. 2 Z. 1 und Abs. 3 Z. 4 bis 6 EStG gehört.

Dieser Bescheid ergeht unter dem Vorbehalt des jederzeitigen Widerrufs gemäß § 294 BAO.

Der Widerruf des Bescheides erfolgt, wenn die schriftliche Rechtsgrundlage und/oder die tatsächliche Geschäftsführung, deren Überprüfung sich die Fachabteilung Spendenbegünstigungen am Finanzamt Wien 1/23 vorbehält, nicht im Sinne des § 4a Abs. 2 Z. 1 und Abs. 3 Z. 4 bis 6 EStG auf die ausschließliche und unmittelbare Erfüllung des begünstigten Zweckes ausgerichtet sind, sowie bei Nichterfüllung der Sonderausgaben-Datenübermittlungsverpflichtung gemäß § 18 (8) EStG.

HINWEIS: Es ist gesetzlich vorgeschrieben (siehe § 4a Abs. 8 EStG), dass das Vorliegen der Voraussetzungen im Sinne des § 4a Abs. 2 Z. 1 und Abs. 3 Z. 4 bis 6 EStG sowie die Einhaltung der anzuwendenden Rechnungslegungsvorschriften von einem Wirtschaftsprüfer jährlich im Rahmen einer den Anforderungen der §§ 268 ff des Unternehmensgesetzbuches

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entsprechenden Prüfung zu bestätigen ist. **Diese Bestätigung des Wirtschaftsprüfers ist dem Finanzamt Wien 1/23 jährlich innerhalb von neun Monaten nach dem Abschlussstichtag vorzulegen. Wird diese Bestätigung nicht bzw. nicht fristgerecht vorgelegt, ist der Spendenbegünstigungsbescheid jedenfalls zu widerrufen.** Im Falle der Änderung der Rechtsgrundlage ist auch die geänderte Rechtsgrundlage (Vereinsstatut, Satzung, Gesellschaftsvertrag, u. ä.) vorzulegen. Die Vorlage eines Jahresabschlusses ist nicht notwendig.

Ändert sich Name oder Adresse der Einrichtung, muss sie dies dem Finanzamt Wien 1/23 (Abteilung Spendenbegünstigungen) unverzüglich bekannt geben.

Stellt die spendenbegünstigte Einrichtung ihre spendenbegünstigte Tätigkeit ein oder wird sie aufgelöst bzw. liquidiert, hat sie dies dem Finanzamt Wien 1/23 (Abteilung Spendenbegünstigungen) ebenfalls unverzüglich mitzuteilen.

Begründung:
entfällt

Rechtsmittelbelehrung:

Es steht Ihnen das Recht zu, gegen diesen Bescheid innerhalb eines Monats nach dessen Zustellung bei der oben bezeichneten Behörde eine Bescheidbeschwerde einzubringen. Die Bescheidbeschwerde ist gem. § 250 BAO (Bundesabgabenordnung) zu begründen. Durch die Einbringung einer Bescheidbeschwerde wird gemäß § 254 BAO die Wirksamkeit des angefochtenen Bescheides nicht gehemmt.

Der Vorstand



Hofrat Mag. Werner Löffler

Seite 2



Spendengütesiegel



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Datum: 19. Oktober 2020

Österreichisches Spendengütesiegel

Sehr geehrte Damen und Herren,

wir freuen uns Ihnen mitteilen zu dürfen, dass Ihr Spendengütesiegel um ein weiteres Jahr verlängert werden konnte!

Wir dürfen Sie in diesem Zusammenhang auch darauf hinweisen, dass gemäß Kooperationsvertrag 2005 jede NPO jährlich, bezogen auf das vorangehende Rechnungsjahr geprüft werden muss. Wird diese Frist versäumt, verliert die NPO die Berechtigung zur Führung des Spendengütesiegels – und damit auch die Registriernummer.

Ihr nächster Verlängerungs-Stichtag ist der 30.09.2021. Bis spätestens zu diesem Termin müssen alle Unterlagen (Antrag, Bekanntgabe des Prüfungsauftrages, Bestätigung, Jahresbericht etc.) bei der KSW eintreffen und der Jahresbericht veröffentlicht werden.

Den Kooperationsvertrag sowie alle relevanten Unterlagen finden Sie unter www.osgs.at, Rubrik „Downloads“.

Für allfällige Rückfragen stehen wir Ihnen selbstverständlich gerne zur Verfügung!

Mit freundlichen Grüßen

Dr. Irmgard Krumpöck
Bereichsleitung Spendengütesiegel

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