

KIDS LUNG REGISTER FOUNDATION
Kinderlungenregister e. V.

CONSTITUTION

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Kids Lung Register Foundation e.V. Constitution

Preamble

The Kids Lung Register Foundation (Kinderlungenregister e.V.)(KLR e.V.) promotes the development of pathophysiology, diagnostics, therapy, prophylaxis and epidemiology of all rare diseases involving the lungs. The KLR e.V. also promotes the continuation and support of all related research projects during and after the end of the respective funding programs. To this end, all necessary structures and standards should be created, maintained and further developed. In particular, the KLR e.V. acts as the responsible and responsible authority of the children's registry and the biobank.

§ 1 Name, registered office, financial year

1. The name of the foundation is "Kinderlungenregister e.V."
2. The registered office of the foundation is located in Munich. The foundation is registered in the association register at the District Court Munich.
3. The foundations office is the place of employment of the president of the foundation.
4. The financial year of the foundation is the calendar year.
5. The foundation is non-political, as well as confessional and ideological neutral.

§ 2 Common public interest

1. The foundation exclusively serves the non-profit purpose in the field of childhood lung diseases in terms of the paragraph tax-privileged purpose of German tax law. The foundation is working selfless, it serves no commercial purpose.
2. The funds of the foundation are only allowed to be used for purpose according to the constitution. The members may not receive grants from the funds of the foundation.
3. A person may not benefit from expenses, which are opposed to the purpose of the foundation or by a disproportional high reimbursement. The president and voluntary personnel (e.g. physicians) may receive a reimbursement of a maximum of 500 Euro per year. The payment of this reimbursement is only permitted if there are enough funds available.
4. In the event that dissolution of the foundation becomes necessary, or in case of loss of tax-privileged purpose, the assets of the foundation will be passed on to the "Gesellschaft für Pädiatrische Pneumologie e.V.", which has to spend it for charitable or beneficial purposes.

§ 3 Purpose of the foundation

The purpose of the foundation is to improve and continuously develop the care of patients with rare lung disease. Therefore the following objectives are to be realized:

1. Creation of conditions for an efficient and high-quality research of the diagnostic and therapeutic care of children with lung disease by a structured and central data capture in the children's registry and provision of these data for scientific questions.

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2. The foundation supports the improvement of clinical diagnostics, treatments, epidemiology and prophylaxis of childhood lung diseases. The foundation is dedicated to the promotion, research and dissemination of knowledge in the frame of the Kids Lung Register Foundation for rare lung diseases.

This is realized by

- organizing diagnostic conferences
- annual meetings of the working groups during the congress of the “Gesellschaft für pädiatrische Pneumologie” (German Society for Pediatric Pneumology) and meetings at the annual congress of the European Respiratory Society,
- initiation and realization of clinical trials,
- the realization of translational research projects to understand the mechanism of rare lung diseases and
- the realization of epidemiological and genetic studies.

In addition the foundation is responsible for the handling and application of the gained knowledge.

3. The foundation ensures compliance with the data protection concept.
4. The foundation aims for a strong collaboration with the “Gesellschaft für pädiatrische Pneumologie” (German society for pediatric pneumology) as well as with the German-speaking Societies for Pediatrics.
5. Internationally, the foundation collaborates with the national childhood lung registers and analogous organisations in other countries. It aims for a strong collaboration with all national and international societies that work on further development of diagnosing and treating rare childhood lung diseases.
6. The foundation supports the public relations for the children’s registry. It campaigns donations and is responsible for their use in the objective of the foundation.
7. The foundation supports research projects and their research networks in their conceptual development and especially in the establishment and further development of the Children’s lung registry and biobank.
8. The foundation intends to ensure the objectives 1.-7. in long-term, even after termination of the financial funding of a particular research project.

§ 4 Membership

1. The foundation consists of ordinary and supporting members.
2. The following natural and legal persons as well as institutions may become ordinary members of the foundation:
 - a. All natural persons, who are professionally involved in the health care of patients with lung disease and who are interested in supporting the foundation
 - b. Scientists
 - c. legal persons and institutions, that who are involved in the health care of patients with lung disease and who are interested in supporting the foundation
 - d. Lay people who support the goals of the foundation

Each ordinary member has the same rights and duties.

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3. Supporting members are those natural and legal persons and institutions, who provide an annual membership fee about a minimum of 1000.- € and who actively contribute towards the purpose of the foundation. They may participate at the member's general meeting of the foundation without vote.
4. The written application for membership has to be addressed to the Board, who will decide about the application with single majority. The membership will enter into force with the delivery of a written declaration of acceptance. The refusal by the Board is not debatable. A claim for acceptance does not exist.

§ 5 Termination of membership

1. The membership of the foundation will be terminated
 - a. By voluntary resignation
 - b. By exclusion
 - c. By death.
2. The voluntary resignation is possible in compliance with the cancellation period of three months to the end of the calendar year, if the annual membership fee for the current year has been paid. The resignation has to be announced to the Board in written form. To comply with the cancellation period it is necessary that the declaration of resignation reaches one member of the Board in due time.
3. Each member can be excluded from the foundation by the Board with immediate effect, if he/she negligent and grossly breaches the interests of the foundation. Breaches of the interests of the foundation are especially
 - a. Gross breaches of the constitution or the decisions of the body of the foundation
 - b. Relevant violation of the purpose of the foundation
 - c. If a member is in arrear with the annual membership fee for more than one year despite two payment reminders, he/she can be excluded from the foundation.

§ 6 Membership subscription fee

The foundation can order an annual membership fee for members. The member's general meeting will decide about the amount and due-time of the membership fee.

§ 7 Administration

Bodies of the association are:

1. The managing board
2. The general meeting of members
3. The committee for data protection

§ 8 Managing board

1. The Board consists of the President, the Vice President, the Secretary, who also takes over the function of the Treasurer and two other members of the managing
- Translation based on German version 2.0 Date of decision 30th March 2017

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board, one of which conducts the committee for data protection.

The association is represented in court and out of court by the Chairman of the Board together with a further member of the Management Board.

The Board is authorized to transfer the power of attorney to a qualified representative to undertake legal transactions or official acts for the foundation.

2. The members of the Board are elected by the general meeting of members each with simple majority for the duration of 4 years. Re-election is possible. The function of a Board member is terminated with his/her resignation from the foundation. If a member of the Board resigns before the end of his/her term of office, the general meeting of members has to be summoned within three months to elect a successor.
3. The Board is in charge of the management of the foundation, of the realization of the decisions made by the general meeting of members and of the foundation's trust administration. This consists especially in the following duties:
 - a. The general meeting of the members elects the members of the Management Board by a simple majority.
 - b. The Board creates its rules of order. It takes its decisions with single majority. The Board has a quorum if after correct call-up more than half of its members, including the President, are present in person or via telecommunication devices.
 - c. In urgent cases the Board can arrange a vote by the Board members in written form or by telephone. The result has to be announced at the next Board meeting.
 - d. The Board makes decisions concerning special issues of the foundation. This contains especially questions of realization and quality assurance of the children's registry.
 - e. Board meetings need to take place at least once a year. They have to be called by the President. The written call has to be accompanied by an agenda and has to be sent to the members before the meeting. The notification period is two weeks. If needed or if at least two Board members request to, further board meetings can be called.
 - f. The Board can appoint scientific advisory boards in all necessary issues, which the President is also part of. The scientific advisory boards have a consultant function to the Board.
 - g. The Board has to submit a written annual report to the general meeting of members.

§ 9 General meeting of members

1. The general meeting of members has to be called
 - a. If it is necessary in the interest of the foundation, but at least
 - b. Once a year;
 - c. If the call is demanded in written form by at least one quarter of all members with declaration of objective and cause.
2. The general meeting of members has to be called in written form by the President at least 4 weeks in advance with a declaration of the agenda. Petitions to the general meeting of members must be proposed to the Board in written form at least 7 days in advance.
3. An extraordinary general meeting of members has to be called by the Board at least two weeks in advance if it is necessary in the interest of the foundation or if it is requested by at least 10% of all members in written form with a declaration of

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objective and cause. Decisions can only be taken concerning those issues that were the cause for the calling of the extraordinary general meeting of members (§37 BGB).

4. The general meeting of members has the following duties:
 - a. Election of the Board
 - b. Decisions on petitions proposed
 - c. Decisions on amendments to the constitution
 - d. Decisions on possible dissolution
 - e. Discharge of the Board
 - f. Approval of the annual financial statement
 - g. Determination of the amount and due-date of the annual membership fee

5. The general meeting of members has a quorum independent from the number of present members, as long as it has been called correctly. Each ordinary member has one vote; supporting members only have an advisory vote. For the exercise of voting rights, another member may be authorized in written form. The authorization has to be given for each general meeting of members separately. Decisions are taken with single majority with the following exclusions:
Deselection of a Board member, amendments to the constitution and dissolution of the foundation require a three quarters (3/4) majority of the present members, changes of the objective of the foundation require unanimity of the present and represented members.

6. Voting takes place by show of hands. Upon request of at least 10% of the present members, the voting has to be in written form and in secret. Abstentions or, in case of written vote, invalid votes are not taken into account. In the event of an equality of votes, the petition shall be deemed to be rejected.

7. The general meeting of members can appoint working groups for specific issues. The plenum of the general meeting of members defines subjects and aims of these working groups.

8. The Secretary will provide minutes of the decisions of the general meeting of members that have to be signed by himself and by the President. Each member has the right to view the protocol.

§ 10 Decisions outside the general meeting of members

1. The Board can achieve decisions of the general meeting of members also in written form. Therefore it is necessary that four fifth (4/5) of the members with voting power give their written consent to vote outside of the general meeting of members in written form. In all other circumstances § 9 (5) applies with the limitation, that amendments to the constitution cannot be decided this way. The voting about the procedure of the written vote as well as about the topic itself can be undertaken in one step.

2. If a decision is made it has to be announced immediately to all members.

§ 11 Certification of decisions

The decisions made by the Board and the general meeting of members are to be written down in a report that has to be signed by the President and the Secretary.

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§ 12 Committee for data protection

1. The foundation is supported by a committee for data protection, which consists of a maximum of five members, but at least of one director.
2. The members of the committee are to be elected by the general meeting of members.
3. The committee for data protection is in charge of the rules for all questions concerning the transfer and input of data. These particularly include:
 - a. Assessment and authorization of the requests of scientists for provision of research data. For that matter, the content of the research proposal, the procedures and the requirement of data have to be considered in particular. The proposal must contain a description of the required dataset, which is suitable for the research project, further a description of the selection filter which has to be used, as well as the approach to pseudonymized and anonymized data.
 - b. Assessment and authorization of the request for transfer of research results to the patient by the treating physicians.

§ 13 Financial report

1. The treasurer has to provide a financial report for every year, which has to be verified by two members of the foundation before the annual general meeting of members. The verifiers are elected by the general meeting of members.
2. Upon a decision of the general meeting of members the verification of the financial report can be conferred to persons, who are not members of the foundation but who are experts in the field.

§ 14 Protection of form via e-mail

All contractual declarations to the institutions and members are distributed via email. If in the constitution the written form is required, then the electronical message of this form is sufficient. All members are obligated to give their email-address to the foundation, to which notifications and declarations concerning foundation issues will be sent to.