

**EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH
INFRASTRUCTURE
abbreviated EPTRI or EPTRI IVZW
INTERNATIONAL NON-PROFIT ASSOCIATION
Herestraat 49
3000 Leuven
ESTABLISHMENT**

THE YEAR TWO THOUSAND TWENTY-THREE

On October 5

Before Us, Maître Charles HUYLEBROUCK, Notary, member of the limited liability company "Charles Huylebrouck, Notary" with registered office at 1000 Brussels, Regentlaan 24, registered in the Register of Legal persons of Brussels under number 0688.925.375

In Brussels, at the registered office

HAVE APPEARED:

- 1) The **Catholic University of Leuven**, ...
- 2) The public law association **Hospital Association of Brussels - Queen Fabiola University Children's Hospital**,
- 3) The foundation **The Cyprus Institute of Neurology and Genetics**,
- 4) The public research institute **Fyziologicky ustav AV CR v.v.i.**,
- 5) The University **Alma Mater Studiorum - Università di Bologna**,
- 6) The Consortium **Consorzio per Valutazioni Biologiche e Farmacologiche**, ...
- 7) The Foundation **Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus**,
- 8) The University **Università degli Studi di Bari 'Aldo Moro'**,
- 9) The University **Università degli Studi di Milano-Bicocca**, ...
- 10) The Civil Recognized Ecclesiastical Body **Associazione "La Nostra Famiglia" scientific section IRCCS "Eugenio Medea"**,
- 11) The Research Institution **Children's Memorial Health Institute**,
- 12) The Foundation **Fondazione Penta ONLUS**,
- 13) The public utility Institution **Sheffield Children's NHS Foundation Trust**,



Charles
HUYLEBROUCK
Notary

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Bd du
Régent, 24/8
1000
Brussels

14) The public legal entity subject to private law **Athena Research and Innovation Center in Information, Communication and Knowledge Technologies,**

Here all represented, according to private powers of attorney which will remain attached here, by Mrs. LEONARDO Cindy, assistant of the undersigned Notary, choosing residence at the office of the saying Notary

Hereinafter referred to as "THE FOUNDER(S)" or "THE APPEARING PARTY(IES) ".

All the founders declare that they are authorized and competent to draw up the legal acts laid down in this deed and that they are not subject to any measure which might create an incapacity to do so, such as bankruptcy, collective debt settlement, appointment of administrator, etc.

EXPLANATORY NOTES TO THE ACT - READ IN WHOLE OR IN PART

The full deed will be explained by the instrumenting notary and founders are always free to ask the notary for additional explanations about any provision of this deed before signing it.

Founders acknowledge having received a full reading of all the foregoing, and declare that, in particular, their above-mentioned identity data are complete and correct.

The notary informs then the founders that the deed will be read in full if at least one of them wishes to do so, and if at least one of them considers that the draft of this deed has not been communicated to him or her in timely prior to its execution.

Thereupon all the founders declare that they have received the draft timely before the deed is executed, that they have taken note of it, and therefore do not need a full reading of the deed. Any changes that have been or will be made to the draft of the deed will always be read out in full.

INCORPORATION

Which founders request the undersigned notary to state that they have from now on established among themselves an international non-profit association and to draw up the articles of associations of an international non-profit association, called **EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE**, abbreviated "EPTRI" or "EPTRI ivzw", established at 3000 Leuven, Herestraat 49, Belgium.

ARTICLES OF ASSOCIATION

The founders declare that the articles of association of the international non-profit association are as follows.

TITLE I: LEGAL FORM - NAME - REGISTERED OFFICE - DURATION - PURPOSE - OBJECT

Article 1 - Legal form and name

The association takes the form of an international non-profit association, as stipulated in Book 10 of the Companies and Associations Code.

The name of the association is "**EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE**", abbreviated "**EPTRI**" or "**EPTRI ivzw**".

All documents, invoices, notices, disclosures and other documents, whether or not in electronic form, issued by the association, must indicate its name, immediately preceded or followed by the words "international non-profit association", and the address of its registered office.

Article 2 - Registered Office

The registered office of the association is located in Belgium, in the Flemish Region.

It may be moved to any place in Belgium, subject to compliance with the legislation and regulations on languages, by simple decision of the Board of Directors, published in the annex to the Belgian Official Gazette.

Article 3 – Duration

EPTRI ivzw is established for a duration of six (6) years. The duration can be extended, based on the decision of the Board of Directors.

Article 4 – Purpose – Organisation – Activities and Services

The core of EPTRI's activities is selfless by nature.

The purpose of EPTRI is to set up an innovative system which, also in collaboration with other relevant paediatric initiatives, encompasses the entire paediatric medicinal product development workflow, and to make available at each step of this procedure the competences, technologies and methods adapted to the specific paediatric needs.

The EPTRI vision is to broaden the knowledge of human development and ontogeny, supporting new therapies dedicated to children.

EPTRI is a distributed Research Infrastructure (OI), aimed at facilitating basic, preclinical and translational research into the discovery and development of paediatric medicines, providing access to key technologies, standardized models and analytical working tools, and expertise specifically implemented for or adapted to the pediatric setting.

EPTRI is working to play a decisive role in connecting academic research units with biotech, medical devices and pharmaceutical companies, in order to promote new health technologies adapted to the paediatric setting, accelerate the development of tailor-made solutions for the paediatric population, and implement innovative collaborative models to lower the barrier to entry for new working tools and practices.

EPTRI will be an open science space, allowing researchers to collaborate without geographical, institutional or financial boundaries, and a system with many interconnected research areas, which will contribute to bringing new paediatric medicines, therapies and medical devices to the market for the benefit of children. EPTRI will also promote stakeholders' engagement and knowledge translation processes by integrating the perspectives of young patients and



families, policymakers and payers, regulators and researchers, agencies and charities, academies and industries.

EPTRI ivzw will develop a Gender Equality Plan (GGP) as part of the EU strategy to reduce persistent significant gender inequality across Europe.

EPTRI ivzw will promote the paediatric scientific development also through open access publications and research material via open platform and using open-source software and open standards in line with all the EU mandatory requirements.

EPTRI was developed as a distributed Research Infrastructure, according to a Hub and Spoke model, with a Central Management Office, a Single Access Point (SAP), interconnected with the distributed research units, grouped within both Thematic Research Platforms (TRPs) (according to their area of expertise), and National Nodes (according to their location).

The EPTRI Thematic Research Platforms (TRPs) are defined by aggregating research units into specific research domains and under the coordination of leading scientists.

Some TRPs were already designed:

1. PAEDIATRIC MEDICINES DISCOVERY, which covers the early-stage discovery and development of drug molecular targets, specific to pediatric diseases, as well as the discovery of new drugs using models that reproduce specific pediatric populations.
2. PAEDIATRIC BIOMARKERS AND BIOSAMPLES, conducting studies to identify, characterize and validate novel biomarkers for diagnosis, prognosis and personalized therapies in paediatric diseases, and providing access to/deposit of annotated paediatric biological samples.
3. DEVELOPMENTAL PHARMACOLOGY, related to studies of pharmaceutical characteristics of drugs and related body reaction, based on the knowledge of the growth and development / maturation of the organs and their functions.
4. PAEDIATRIC MEDICINES FORMULATIONS, which develops adapted age-appropriate formulations, and adapted drug delivery systems for preterm newborns, preschoolers, toddlers and adolescents.
5. PAEDIATRIC MEDICAL DEVICES to bridge the gap in medical devices tailored for children, addressing change in growth and psychosocial maturation, physiology, and pathophysiology, and inappropriate repurposing of adult technologies.

Additional specific paediatric research domains may be considered to become new EPTRI Thematic Research Platforms.

The research units participating in the EPTRI TRPs can also be aggregated into National Nodes, in any country where a National EPTRI organisation has been set up by signing a Joint Research Unit (JRU) agreement or any other form of cooperation.

In order to achieve its social purpose, EPTRI ivzw will carry out the following activities:

- monitor/analyse progress on biomedical sciences supporting and improving paediatric research, and lobby for the inclusion of paediatric research in the EU and National Roadmaps expanding the interaction and pooling of skills of paediatric centres of public and private institutions;
- support initiatives aimed at promoting technology and knowledge transfer, with the aim of improving international competitiveness;
- support academic and paediatric research organisations to strengthen their basic knowledge and technological know-how;
- involve the national communities of paediatric researchers in the sharing of technology and knowledge, and coordinate themselves to solve operational

problems, meeting common needs through the creation of National Nodes N-EPTRI (National EPTRI Infrastructures) in each Member State partnering with EPTRI, where they will be called EPTRI-XX (e.g. EPTRI-IT in Italy, EPTRI-PL in Poland, etc.);

- promote collaborative activities that could add value to improve paediatric research with all stakeholders;

- develop and apply project proposals to national, international and EU calls. EPTRI will take initiatives to establish a stakeholder forum, including the representation of children and young patient groups in different disease groups. The EPTRI ELSI service includes a focus on children and patients. EPTRI has a strong link with the Young Patients Advisory Groups (YPAGs) and their networks. EPTRI may carry out limited economic activities on the condition that they are close to EPTRI's main tasks and do not jeopardize their achievement.

The provision of the EPTRI Services will be ancillary to the main institutional activities. They will be provided by the EPTRI Institutions in accordance with the institution's expertise / technology capacity. In exchange for the service, the Institution will be compensated with a fair market value of the services provided. The EPTRI ivzw will provide three types of services:

- Centralised services, provided and managed directly by the Central Management Office (CMO) as well as in cooperation with the relevant Thematic Research Platforms and the National Nodes.
- Integrated services, provided by one or more EPTRI research units of the Thematic Research Platforms and managed by the CMO in cooperation with the Service Coordinators.
- Joint services, in cooperation with other biomedical national and/or international organisations with an interest and competence in paediatric research.

An Information System will ensure coordination and management, networking and communication between the different components of the research infrastructure, access to services based on transparent procedures, data fairification, data security and data protection.

TITLE II: MEMBERS



Members of the EPTRI ivzw are Research Organisations, originating from the Academic Sector, involved in basic, preclinical and translational paediatric research.

EPTRI Members are all those Institutions (with their own research units) that provide research services, aggregated by EPTRI Thematic Research Platforms based on expertise and by National Nodes based on organization at national level.

EPTRI Members must have a substantial and significant interest in meeting the needs for tailor-made medicines and devices developed for children, and must be willing to contribute to the impact that EPTRI can have on the progress of pediatric research.

All Members must constitute a legal entity established in accordance with the laws and customs of the country of origin.

All signatories of the EPTRI Memorandum of Understanding (as listed on the EPTRI website) are considered potential members of the EPTRI ivzw, and they may be allowed as observers until they formalise their participation.

Article 5 – Membership

MEMBERSHIP FEE

Together with the fixing of the budget, the General Assembly determines the annual membership fee to be paid by the Members for the following financial year, on the proposal of the Board of Directors.

RIGHTS AND DUTIES OF THE MEMBERS

Members have the following rights:

- attending the meetings of the General Assembly
- voting at the General Assembly meetings
- defend itself personally before the General Assembly, before its membership is withdrawn
- resign from the EPTRI ivzw
- participate in the activities of EPTRI ivzw
- propose candidates for the Board of Directors
- chair operational and advisory bodies of EPTRI ivzw.

Members have the following duties:

- pay the annual membership fee
- comply with the Articles of Association of EPTRI ivzw, with the decisions of the Board of Directors and of the General Assembly.

AFFILIATED MEMBERS

The following entities, not from the 'Academic sector', can become "Affiliated Members" of EPTRI ivzw:

- Patients – parents organisations
- Non-governmental organisations
- Associations, foundations and other non-profit organizations
- Public institutions and agencies
- Companies and their organisations.

The Affiliated Members of EPTRI ivzw will also be called Members in the following articles but they will not have the right to vote.

The Affiliated Members can participate in the EPTRI ivzw activities in various ways, e.g. through a public-private partnership (PPP) model, and can also receive services from EPTRI ivzw on favorable terms.

The General Assembly can take decisions on membership fees for the Affiliated Members, which can be differentiated per category.

ADMISSION

Application for admission as a Member will be submitted in writing by sending an application for admission. Membership is authorized by the general assembly upon receipt and approval of the applications.

DISMISSAL

Members can resign, or their membership can be terminated. Likewise, a membership automatically comes to an end and with immediate effect, when a Member has been dissolved or liquidated, or no longer meets the eligibility requirements.

Resignation from membership must be notified to the Board of Directors. Members can submit their resignation by registered letter or by certified e-mail at any time.

The General Assembly may terminate the membership of any member after hearing the defense of the organisation concerned:

- in the event of a serious infringement against the Articles of Association of EPTRI ivzw, or against a decision of the General Assembly or of the Board of Directors, and if the Member has not succeeded in rectifying

- this infringement within three (3) months after formal notification of the infringement has been given;
- in the case of conduct in a way that can seriously damage the reputation of EPTRI ivzw;
 - in case of non-payment of the financial contribution, after an official reminder has remained unresolved for more than ninety (90) calendar days after the date of issue;
 - for any other serious reason it deems justified, if the Member has failed to rectify this infringement within three (3) months of formal notification being given to put an end to the conduct.

The General Assembly will justify its decision to end membership.

The Member whose membership has been terminated by dismissal, dissolution, liquidation, because it no longer meets the conditions of admission or otherwise, has no right to the assets of the EPTRI ivzw or to the membership fee already paid.

Any unpaid membership fee that has not yet been paid must be paid in full for the year in which the termination takes place. Moreover, if the dismissal of a member should occur less than six (6) months before the end of a financial year, the full membership fee for the following financial year will be also due despite the dismissal.

LIABILITY

Members are not liable for the commitments entered into by EPTRI ivzw.

Members shall not be obliged to fulfil the obligations contracted by the Association, nor shall they be obliged to cover any losses, or bear any disbursement other than the payment of the annual membership fee approved by the Statutory Bodies.

TITLE III: STATUTORY BODIES

Article 6 – General Assembly

COMPOSITION AND COMPETENCIES

The general assembly (GA) is the highest statutory body of EPTRI ivzw and consists of one (1) delegate per voting member.

The general assembly elects its chair for a term of three (3) years, which may be re-elected for one (1) subsequent term. The general assembly elects the members of the Board of Directors for a term of three (3) years. The directors may be re-elected for one (1) subsequent term. The Chair shall chair the meetings of the general assembly and of the board of directors.

The general assembly has all the powers except those expressly reserved or delegated to the other bodies of EPTRI ivzw according to the law, these Articles of association of EPTRI ivzw or by a resolution of the general assembly.

In particular, the general assembly shall have the power to decide on:

1. any amendment to the Article of Associations of EPTRI ivzw;
2. appointment, resignation and discharge to the statutory auditors and fixing of their remuneration;
3. the appointment, resignation and discharge to the members of the board of directors and the statutory auditors;
4. the appointment and resignation of operational and advisory bodies;
5. the approval of the participation of EPTRI ivzw in relevant projects, partnerships, etc. (which should be specified as such in the agenda);
6. the adoption of the annual budget and accounts;



7. the dissolution of EPTRI ivzw as well as the transformation or any other restructuring;
8. admitting and excluding members;
9. fixing the membership fee.

REPRESENTATION AT MEETINGS OF THE GENERAL ASSEMBLY

The general assembly meets twice a year and more frequently if necessary. It shall be convened at the request of one fifth of the members. The convocation must be made forty (40) calendar days in advance.

Members may propose items for the agenda up to thirty (30) calendar days before the meeting. The members of the general assembly shall receive all relevant documents at least twenty (20) calendar days before the meeting.

In duly justified exceptional cases of urgency, the time limit for convening the meeting and for sending the draft agenda and all relevant documents shall be reduced to seven (7) calendar days.

Each member may appoint representatives who do not have to be members themselves. The proxy must be in accordance with the form prescribed by the board of directors. It must be submitted to the general assembly. A proxy granted remains valid for each subsequent meeting of the general assembly, provided that the agenda remains unchanged.

Members may appoint some experts to attend meetings of the general assembly without voting rights.

QUORUM

The general assembly shall deliberate validly if at least half of the members are present or represented.

If a quorum is not reached, the board of directors must convene a second meeting of the general assembly no earlier than ten (10) calendar days after the first. The second meeting of the general assembly has the right to adopt valid resolutions, regardless of the number of members present or represented.

VOTE

The general assembly shall endeavour to adopt its resolutions by consensus. If a vote proves necessary, the general assembly shall adopt its resolutions as follows:

The general assembly may deliberate only on the items on the agenda, unless all members are present or represented and unanimously decide to add additional items to the agenda.

Voting can be done by a show of hands, by means of a ballot paper or by electronic means.

The decisions of the general meeting shall be validly taken by a simple majority of the members present or represented.

However, the following resolutions shall require a two-thirds majority of the votes of the members present or represented:

1. the resignation of a member;
2. the amendment of the Articles of Association of EPTRI ivzw;
3. issues related to the high-level strategy (to be included as such in the agenda);
4. the dissolution of EPTRI ivzw;
5. the election and dismissal of the members of the Board of Directors.

Each member shall have one (1) vote.

In determining the various majorities provided for in these EPTRI ivzw Articles of Association, only votes cast for or against a position shall be taken into account.

Members who are in arrears with the payment of contributions are not eligible to vote.

In order to allow for anonymous voting, members' votes should not be disclosed to other members by the choice of the systems used.

(WRITTEN AND ELECTRONIC) MEETINGS – REMOTE VOTING

Members may, within the legal limitations, unanimously and in writing adopt resolutions falling within the competence of the general assembly, with the exception of amendments to the Articles of Association of EPTRI ivzw.

The Board of Directors may allow members to participate remotely in the general meeting, provided that EPTRI ivzw can verify the capacity and identity of the participating person concerned by the electronic means of communication used.

The convocation of the general assembly shall contain a clear and precise description of the procedures relating to remote participation.

In any case, without prejudice to any restrictions imposed by or pursuant to Belgian law, the electronic means of communication must at least enable members to participate directly, simultaneously and continuously in the deliberations of the general assembly and, as far as members are concerned, to exercise their right to vote on all matters on which the general assembly is required to deliberate. The electronic means of communication should also enable members to take part in deliberations and to ask questions.

Members may also vote remotely before the general assembly, provided that the board of directors has approved the means of communication to be used, which should allow the identification of the person who wishes to vote remotely before the general assembly. The remote voting procedure must contain at least the following information: (i) the name of the member and his registered office, (ii) the agenda of the general assembly, including the proposals for resolution, (iii) the period within which EPTRI ivzw must receive the remote vote, (iv) the member's signature, handwritten or electronic (in the manner provided for by Belgian law), (v) the voting method on each proposal for resolution.



MINUTES

The resolutions adopted by the general assembly shall be recorded in minutes, which shall be communicated to each member by e-mail and made available on the reserved space of the EPTRI ivzw website within fifteen (15) calendar days of the meeting. Members then have ten (10) calendar days to respond with proposals for amendment, followed by subsequent cycles of ten (10) calendar days for the board of directors to act on the changes and ten (10) calendar days for members' approval.

Once approved, the minutes shall be signed by the Chair and kept in a register at the disposal of members.

Article 7 – Board of Directors

COMPOSITION AND COMPETENCIES

The board of directors is appointed by the general assembly and is composed of the Chair and the directors appointed in their personal capacity. A person can no longer be a delegate of the general assembly once he has been

appointed to the board. The appointments of the Chair and the directors shall be deposited and published in accordance with the legal provisions.

The board is chaired by the Chair. The board of directors shall include among its members representatives of EPTRI Thematic Research Platforms and EPTRI National nodes established through a formal agreement between EPTRI members in the same country. The general meeting decides on the number of directors.

The general assembly strives for a balance in terms of gender, diversity, geographical distribution, expertise and representation of stakeholders.

The board of directors may, on a proposal from the Chair, appoint the Vice-Chair and the Treasurer from among its members. The members of the board of directors shall remain in office until they are re-elected or become new members, as provided for in the articles of association.

The board of directors oversees the achievement of the purpose and the direction of the activities of EPTRI ivzw by implementing the decisions, instructions and recommendations adopted by the general assembly.

The board of directors shall have the power to:

1. convene the general assembly,
2. prepare the meetings of the general assembly and make proposals for resolutions,
3. prepare the budgets and annual accounts, including annual membership fees, and submit them to the general assembly for approval;
4. propose amendments to the Articles of Association of EPTRI ivzw,
5. make recommendations on the admission or revocation of members,
6. monitor the implementation of the resolutions of the general assembly,
7. propose the appointment and resignation of operational and advisory bodies, subject to ratification by the general assembly,
8. appoint and dismiss the Vice-Chair and the Treasurer among its members,
9. represent EPTRI ivzw at external events, promote the visibility of EPTRI ivzw, provide public relations and set up networks,
10. make proposals for the appointment and dismissal of the auditors subject to ratification by the general assembly.

The Chair shall:

1. act as legal representative of EPTRI ivzw,
2. acting as spokesman for EPTRI ivzw,
3. lead EPTRI ivzw, together with the board of directors,
4. convene meetings of the board,
5. chair the meetings of the general assembly and the board of directors,
6. promote, together with the board, relations and cooperation with strategic partners and other institutions in order to increase the impact of EPTRI ivzw,
7. decide on necessary ad hoc measures (limited to non-strategic issues) between the meetings of the statutory bodies,
8. be responsible for the ongoing activities of EPTRI ivzw and the preparation and implementation of the resolutions of the general assembly and the board,
9. propose the Vice-Chair and the Treasurer within the directors for appointment by the Board of Directors.

The Vice-Chair shall replace the Chair if the latter is prevented.

The Treasurer is responsible for:

1. the revision of the annual budget of EPTRI ivzw;

2. the revision of the financial reports and the keeping of the accounts of EPTRI ivzw;
3. the supervision of the finances of EPTRI ivzw.

The members of the board do not have the right to vote in the general assembly.

END OF MANDATE

A director may resign by notifying the chair of its decision. The chair may resign by notifying the board, which shall then inform the general assembly. A chair and/or director who is no longer an employee or representative of a member or who is part (employed or contracted) of a member who leaves EPTRI ivzw shall be deemed to have resigned with immediate effect from the date of termination of employment or representation or membership.

In the event of a vacancy or any other reason preventing the Chair from performing his or her duties, the Vice-Chair shall temporarily hold this position until the general assembly has elected a new Chair.

In the event of a vacancy or for any good reason preventing a director from performing his duties, the remaining directors shall remain in office. The Board may provisionally replace the director who is unable to perform his duties until the next general assembly, which will decide on a final appointment.

CONFLICT OF INTEREST

Each director shall inform the board of directors of any direct or indirect conflict of interest before the board of directors takes a decision and shall under no circumstances participate in the Board's deliberations on that act or vote in connection therewith.

If all members of the board of directors have a direct or indirect conflict of interest, the resolution shall be referred to the general assembly. If the general meeting approves the resolution, the board of directors may implement the resolution.

BOARD MEETING

The board of directors shall meet at least four (4) times a year. The meetings may be convened by the Chair or by at least three (3) directors. The convocation contains the place, date, time and agenda of the meeting. It must be sent to all members of the board of directors at least eight (8) calendar days before the date of the meeting of the board. The directors may propose items for the agenda up to five (5) calendar days before the meeting of the board of directors. In case of urgency, the meeting may be convened within three (3) calendar days.

The directors can attend a meeting of the board of directors in person, by telephone or by digital means.

Each member of the board of directors shall have the right to authorize another member of the board of directors to be represented at a meeting of the board. A member of the board of directors may not have more than two (2) proxies. A power of attorney granted shall remain valid for each subsequent meeting of the board of directors, provided that the agenda remains unchanged.

The Chair may invite non-voting third parties to attend a meeting or part of a meeting of the board.

DECISIONS

The board of directors shall deliberate validly if at least half of the members of the board are present or represented. If this quorum is not reached, a new meeting of the board shall be convened no earlier than five (5) calendar days



after the first meeting. The second meeting of the board shall have the right to make valid decisions, regardless of the number of members of the board of directors present or represented.

The board of directors may deliberate only on the items on the agenda unless all members of the board are present or represented and unanimously decide to add additional items to the agenda.

The board of directors shall endeavour to adopt its decisions by consensus. If a vote proves necessary, each member of the board shall have one (1) vote.

The board of directors shall deliberate by a simple majority of the votes cast by the members of the board of directors present or represented. Abstentions, blank votes and invalid votes shall not be counted towards the total number of votes cast by the members of the board present or represented. In the event of a tie, the chairman's vote shall be decisive.

Voting can be done by a show of hands, by means of a ballot paper or by electronic means. The vote shall be transparent unless at least two (2) members of the board of directors request a secret ballot.

MINUTES

The decisions taken by the board of directors shall be recorded in minutes, which shall be sent by email to each member of the board within ten (10) calendar days of the board meeting. Thereafter, board members have five (5) calendar days to respond with proposed amendments, followed by subsequent cycles of five (5) calendar days for the chair to decide on the changes and five (5) calendar days for approval by board members.

After approval, the minutes are signed by the chair and kept in a register available to the members of the board. Members of EPTRI ivzw may request access to the minutes, which may be provided in edited form (e.g. in the case of personal data).

REPRESENTATION

EPTRI ivzw is legally represented in court and vis-à-vis third parties, including public officials, by

1. the Chair;
2. an ad hoc delegate appointed by the general assembly.

Limited liability

The members of the board of directors are not personally liable for the obligations of EPTRI ivzw. They are only liable for the (non-)performance of their duties, including misconduct in their responsibilities and duties.

Liability insurance for the chair and the directors will be paid by the ivzw.

TITLE IV: OPERATIONAL AND ADVISORY BODIES

Article 8 – Central Management Office (CMO)

The CMO supports and acts as secretary of the general assembly and the board of directors. The staff of the CMO is compensated for its work.

The CMO is responsible for:

1. day-to-day management, including all administrative operations and other necessary arrangements;
2. supporting the financial and legal activities of EPTRI ivzw;
3. the management of the Single Access Point (SAP) of EPTRI's services;
4. the coordination and delivery of certain EPTRI services;

5. the communication and dissemination activities of EPTRI ivzw;
6. drawing up the operational plans of EPTRI ivzw;
7. the implementation of the resolutions of the general assembly under the direction of the board of directors.

The day-to-day management comprises both those acts and decisions which do not exceed the needs of EPTRI ivzw's daily life and those which, either because of the low importance they represent or because of their urgency, do not require the intervention of the board of directors.

Article 9 – Advisory bodies

EPTRI ivzw can set up advisory bodies to provide advice on the fulfilment of the mission of EPTRI ivzw.

Each advisory body may consist of one or more working groups.

The proposal for its establishment and dissolution is made by the board of directors and must be ratified by an approval of the general assembly. The objectives, tasks and expected duration of operation of these bodies are described in a frame of reference.

The chairperson(s) of the advisory bodies must come from members of EPTRI ivzw. Members of advisory bodies may be internal or external to EPTRI ivzw. Members of the board of directors may not be part of an advisory body. However, they may act as a liaison between the chairperson(s) of the advisory body or sub-group and the board of directors as a whole. The appointment, duration of term of office and revocation of the position of the Chairpersons are the responsibility of the board of directors.

TITLE V: FINANCING - FINANCIAL YEAR - BUDGET - AUDITOR - PRESERVATION OF DOCUMENTS

Article 10 – Financing

The reporting currency of EPTRI ivzw is the euro for the annual accounts and all other official accounting, tax and legal documents.

EPTRI ivzw is funded by:

- 1.the membership fees of its members,
- 2.EU/national/international funding,
- 3.payments for EPTRI services by users,
- 4.grants or allowances from members, other organisations or legal entities, subject to acceptance by the board of directors,
- 5.unencumbered donations or sponsorships, subject to assessment and acceptance by the board of directors and in accordance with the Law,
- 6.other incomes (i.e. contributions in kind).



Article 11 – Financial year

The financial year coincides with the calendar year.

Article 12 – Auditor(s)

An auditor (or a college of auditors) is appointed by the general assembly for a term of office of three years to regularly audit the accounts of EPTRI ivzw.

The auditor shall submit an audit report for the previous financial year to the board of directors no later than six weeks before the general assembly convened for the approval of the annual budget. The report contains proposals

regarding the exemption from liability on the part of the board of directors of EPTRI ivzw.

Furthermore, the auditor will:

- advise on and exercise control over the establishment and enforcement of internal financial procedures, including the retention of financial documents; and
- audit the annual accounts of EPTRI ivzw in accordance with the Law.

Article 13 – Document

All financial documents relating to incomes and expenditure, as well as audit reports, both in printed and electronic form, are kept by EPTRI ivzw for a period of 10 (ten) years.

TITLE VI: AMENDMENT OF THE ARTICLES OF ASSOCIATION - DISSOLUTION

Article 14 – Amendment of the Articles of Association

The board of directors proposes to the general assembly to amend the articles of association of EPTRI ivzw.

Proposals for amendment must be notified to members at least 30 days before the date of the general assembly which is to adopt a resolution on them. Article 6 describes the voting procedures for amending the Articles of Association.

Article 15 – Dissolution and liquidation

The general assembly may, on a proposal from the board of directors or from the auditor when one fifth of the members request it, decide to dissolve and liquidate EPTRI ivzw and appoint and determine the powers and fees of one or more liquidators. The liquidators are responsible for the recovery of all claims and the payment of debts incurred by the Association.

The remaining net assets are invested in an association or foundation with similar or closely related objectives as those of EPTRI ivzw.

Article 6 describes the voting procedures for the dissolution of EPTRI ivzw.

TITLE VII: GENERAL PROVISIONS

Article 16 – Notifications and choice of place of residence

All notifications concerning EPTRI ivzw to the members of the general assembly and of the board of directors and to the liquidators shall be made at the last e-mail address communicated to EPTRI ivzw or, in the absence of acknowledgement of receipt, at the last postal address communicated to EPTRI ivzw.

The members of the general assembly and of the board and the liquidators may choose domicile at the place where they pursue their professional activity. In that case, only this address will be communicated in the documents filed with the enterprise-court. Any change will be communicated to the Chair by e-mail/letter with acknowledgement of receipt or by certified e-mail/letter.

If such an address is not known, all notices, communications, reminders, summonses and servings relating to the affairs of EPTRI ivzw shall be validly affected at the registered office of EPTRI ivzw.

Article 17 – Internal Rules

The general assembly, on the proposal of the Board may adopt Internal Rules which implement and specify the provisions of these Articles of Association and regulate the daily activities of EPTRI ivzw.

Article 18 – Applicable law

The Articles of association of EPTRI ivzw, the resolutions of the general assembly and the board of directors are governed by the Belgian law. For everything not provided for in these Articles of Association, only the provisions of the Law apply.

Article 19 – Jurisdiction

The courts of the jurisdiction in which the registered office is located shall have exclusive jurisdiction in disputes between EPTRI ivzw, its members, chair, directors, auditors and liquidators relating to the affairs of EPTRI ivzw and to the implementation of these Articles of Association of EPTRI ivzw, unless EPTRI ivzw expressly waives this provision.

Article 20 – Language

The working language of EPTRI ivzw is English, without prejudice to applicable legal obligations.

The Articles of Association are drawn up in Dutch and English. In case of difference between the versions, the Dutch version prevails.

TITEL VIII: FINAL AND/OR TRANSITIONAL PROVISIONS



The founders take the following decisions, which shall have effect only from the filing at the registry of an extract of the deed of incorporation, in accordance with the law.

START OF ACTIVITIES – FIRST FINANCIAL YEAR

EPTRI ivzw begins its activities from the signing of this document.

The first financial year shall begin on this day and shall end on 31 December 2023.

APPOINTMENTS

The following has been agreed:

(a) appointment of the members of the GA:

- 1) The **Catholic University of Leuven**,
- 2) The public law association **Hospital Association of Brussels - Queen Fabiola University Children's Hospital**,
- 3) The foundation **The Cyprus Institute of Neurology and Genetics**
- 4) The public research institute **Fyziologicky ustav AV CR v.v.i.**,
- 5) The university **Alma Mater Studiorum - University of Bologna**,

- 6) The consortium **Consorzio per Valutazioni Biologiche e Farmacologiche**,
- 7) The foundation **Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus**,
- 8) The university **Università di Bari 'Aldo Moro'**,
- 9) The university **Università degli Studi di Milano-Bicocca**,
- 10) the civil recognized ecclesiastical body **Associazione "La Nostra Famiglia" scientific section IRCCS "Eugenio Medea"**,
- 11) The research institution **Children's Memorial Health Institute**,
- 12) The foundation **Fondazione Penta ONLUS**,
- 13) The institution of public utility **Sheffield Children's NHS Foundation Trust**,
- 14) The public legal entity subject to private law **Athena Research and Innovation Center in Information, Communication and Knowledge Technologies**,

All for report.

(b) appointment:

The chair of the Board of Directors is: Mr Karel Marcel Allegaert.

The Vice-Chair of the Board of Directors is: Mrs Adriana Ceci.

The Treasurer is: Mr Marek Migdal.

The directors of the Board of Directors are:

1. Karel Marcel Allegaert
2. Carsten Werner Lederer
3. Hana Kubova
4. Pier Luigi Martelli
5. Donato Bonifazi
6. Giovanni Migliaccio
7. Adriana Ceci
8. Fedele Bonifazi
9. Carlo Giaquinto
10. Emilia Biffi
11. Nunzio Denora
12. Giovanna Iannantuoni
13. Paul John Dimitri
14. Georges Jacques Casimir
15. Marek Migdal
16. Emmanouil Mikros
17. Elke Louisa Smits
18. Oscar Della Pasqua
19. Catherine Lucette Charline Tuleu
20. Stefania La Grutta
21. Aleš Benjamín Stuchlík

ADDRESS OF THE REGISTERED OFFICE

The address of the registered office is located at **3000 Leuven, Herestraat 49**.

AUDITORS

Since the company is not obliged to do so under the legal criteria, the founders decide not to appoint a statutory auditor at this time.

ASSUMPTION OF COMMITMENTS ON BEHALF OF THE ASSOCIATION IN FORMATION

All obligations and all obligations arising therefrom, and all activities undertaken since **one January two thousand and twenty-three** by the founders in the name and on behalf of the association in formation shall be taken over by the association incorporated by this deed by decision of the Board of Director which shall have effect from the acquisition of the legal personality by the association.

PROXIES

Each third party has been appointed as the ad hoc delegate of the association, in order to dispose of the funds, sign all documents and complete all necessary formalities in the administration of VAT and with a view to registering with the Crossroads Bank for Enterprises.

To this end, the ad hoc delegate has the power to enter into all commitments on behalf of the association, to make all useful declarations and to sign all documents and, in general, to do everything useful and necessary for the performance of the mandate with which he is entrusted.

AUTHORIZATION TO OPEN AND AMEND THE ELECTRONIC SECURITIES REGISTER

The founders authorise the instrumenting notary to open an electronic securities register in the name of the association and to execute and sign the registrations resulting therefrom this deed, as well as to take all actions required for this purpose as an authorised representative of the association.

The instrumenting notary is also authorised to transfer to the UBO register on behalf of the association any data that must be included in this register according to the legal provisions.

These authorisations shall continue to apply to subsequent entries and amendments to the electronic securities register which would, where appropriate, be requested from the notary by the association.

COSTS AND REPRESENTATIONS OF THE PARTIES

The founders declare that the amount of all costs, fees and charges borne by the association by virtue of its incorporation is one **thousand one hundred and sixty-one euros fifty-five cents (1,161.55 €)**.

They acknowledge that the undersigned notary has drawn their attention to the fact that the association, in execution of its purpose, may be obliged to obtain the necessary prior authorisations or permits or to fulfil certain conditions, having regard to the regulations in force concerning access to the profession.



RIGHT TO WRITINGS

The right to writings is one hundred euros (€ 100.00).

OF WHICH NOTE

Done and past date as aforementioned.

The founders declare that they had received the draft of this deed before it was signed and that this period was sufficient to enable them to become acquainted with it.

After commented reading, in full with regard to the parts of the deed designated for this purpose by the law, and partly with regard to the other mentions, in English and Dutch, the founders signed with us, Notary.

DEFINITIONS

In these Articles of Association of EPTRI ivzw the following words/terms have the following meanings

"Articles of Association of EPTRI ivzw" means these articles of association of EPTRI ivzw.

"Auditor's Office" means the auditor(s) of EPTRI ivzw as stated in article 12.

"Board" means the board of directors of EPTRI ivzw as stated in article 7.

"Law" means the law on the basis of which the Articles of Association of EPTRI ivzw have been drawn up in accordance with the Law of 23 March 2019 introducing the Companies and Associations Code and containing various provisions.

"CMO" means the Central Management Office of EPTRI ivzw as referred to in Article 8

"Directors" means the members of the board of directors of EPTRI ivzw as stated in article 7

"EPTRI ivzw" means the European Paediatric Translational Research Infrastructure ivzw.

"General assembly" means the general assembly of EPTRI ivzw as stated in article 6.

"Members": the members of EPTRI ivzw as referred to in section II.

"National Node" means the group of research units participating in EPTRI and cooperating within a country.

"Chair" means the chair of EPTRI ivzw as referred to in article 7.

"Research infrastructure" means the term used to denote facilities, resources and services used by the research communities to conduct research and promote innovation in their field.

"A single access point" means the access point for all requests for services.

"Thematic Research Platform" means an operational set of research units aimed at providing integrated services in one of EPTRI research areas.

"Treasurer" means the treasurer of EPTRI ivzw as stated in article 7.

"Vice-Chair" means the Vice-Chair of EPTRI ivzw as referred to in Article 7.