### within EPTRI - European Paediatric Translational Research Infrastructure

### **BETWEEN**

### **ALBANIA**

**Agjencia Kombetare e Kerkimit Shkencor dhe Inovacionit,** with its headquarter in Rr "Papa Gjon Pali II", Nr 3, 1001, Tirana, Albania (hereinafter referred to as "NASRI"),

**Qendra Spitalore Universitare Nene Tereza**, with its headquarter in Rr e Dibres 370, 1000 Tirana, Albania, (hereinafter referred to as "UHCT")

### **AUSTRIA**

OKIDS Organisation Kinderarzneiforschung – Madecines for Children Research in Austria with its headquarter in Zimmermannplatz 10, 1090 Wien, Austria (hereinafter referred to as "OKIDS"),

**St. Anna Children's Cancer Research Institute** with its headquarter in Zimmermannplatz 10, 1090 Wien, Austria (hereinafter referred to as "CCRI")

**Medical University of Graz** with its headquarter in Auenbruggerpl. 2, 8036 Graz, Austria (hereinafter referred to as "MUG")

**University of Vienna** with its headquarter in Universitätsring 1, 1010 Wien, Austria (hereinafter referred to as "UNIVIE")

### **BELGIUM**

**Antwerp University Hospital** with its headquarters in Wijlrijkstraat 10, 2650 Edegem, Belgium (hereinafter referred to as "UZA")

Cliniques Universitaires Saint-Luc with its headquarter in Avenue Hippocrate, 10 – 1200 Bruxelles, Belgium (hereinafter referred to as "CUSL")

**Université de Liège**, public institution with legal personality, having its administrative offices in Belgium, 4000 Liège, Place du 20 Août, 7, company registration number 0325.777.171, represented by Prof. Wolper Pierre, Rector, (hereinafter referred to as "ULiège")

Centre Hospitalier Universitaire (CHU) de Liège, with main office in 4000 Liège, Domaine Universitaire du Sart Tilman B35 (VAT number: BE0232.988.060) legally represented by Monsieur Julien Compère, Administrateur délégué, in presence of Professor Marie-Christine Seghaye, Head of pediatrics (hereinafter referred to as "CHU Liège")

**Hôpital Universitaire des Enfants Reine Fabiola** with its headquarter in Avenue Crocq 15 - 1020 Brussels, Belgium (hereinafter referred to as "HUDERF")

**Institut de Pathologie et de Génétique** with its headquarter in Avenue Georges LeMaître 25, 6041 Gosselies, Belgium (hereinafter referred to as "IPG")

**KU Leuven** with its headquarter Oude Markt 13, 3000 Leuven, Schapenstraat 34, 3000 Leuven, Belgium (hereinafter referred to as "KUL"),

**Universiteit Antwerpen** with its headquarter in Prinsstraat 13 000, 2000, Antwerpen, Belgium (hereinafter referred to as "UA")

**Université catholique de Louvain** with its headquarter in Place de l'Université 1, 1348 Ottignies-Louvain-la-Neuve, Belgium (hereinafter referred to as "UCLouvain")

**Universiteit Gent - Ghent University**, public institution with legal personality, having its administrative offices in Belgium, 9000 Gent, Sint-Pietersnieuwstraat 25, company registration number 0248.015.142, for whom prof. dr. Rik Van de Walle, rector, acts by delegation pursuant to the Board of Governors' decision, acting on its own behalf and on behalf of its unincorporated division University Hospital Ghent, with main office in 9000 Ghent Corneel Heymanslaan 10 (VAT number: BE0232.987.862) (hereinafter referred to as "entity UGent" and/or "entity UZGent")

#### **CANADA**

**Institut National de la Recherche Scientifique** with its headquarter in 490, rue de la Couronne Québec (Québec) G1K 9A9, Canada (hereinafter referred to as "INRS"),

### **CYPRUS**

**Cyprus Federation of Patients' Associations** with its headquarter in Agiasmaton 10, 2230, Latsia, Cyprus (hereinafter referred to as "CyFPA"),

**European University Cyprus** with its headquarter in 6, Diogenis, Engomi, 1516 Nicosia, Cyprus (hereinafter referred to as "EUC"),

**Frederick University Cyprus** with its headquarter in 7, Y. Frederickou Str. Pallouriotisa, Nicosia 1036, Cyprus (hereinafter referred to as "FUC"),

The Cyprus Institute of Neurology and Genetics, with its headquarter in International Airport Avenue 6, Ayios Dometios, 1683, Cyprus (hereinafter referred to as "CING"),

**University of Cyprus** with its headquarter in 1 Panepistimiou Avenue, 2109 Aglantzia, Nicosia Cyprus, (hereinafter referred to as "UC"),

**University of Nicosia** with its headquarter in 46 Makedonitissas Avenue, CY-2417 Nicosia, Cyprus, (hereinafter referred to as "UNIC"),

### **CZECH REPUBLIC**

**2nd Faculty of Medicine, Charles University in Prague** with its headquarter in V Uvalu 84, Praha 5, 150 06, Czech Republic (hereinafter referred to as "LF2"),

**Faculty of Pharmacy in Hradec Kralove, Charles University** with its headquarter in Akademika Heyrovského 1203, 500 05 Hradec Králové, Czech Republic (hereinafter referred to as "FAP"),

**Fyziologicky Ustav Ceska akademie ved Verejna Vyzkumna Instituce**, with its headquarter in Videhska 1083, 142 20, Praha 4, Czech Republic (hereinafter referred to as "IPHYS")

### **FRANCE**

**Assistance Publique – Hopitaux de Paris**, with its headquarter in 3 Avenue Victoria, Paris 75004, France (hereinafter referred to as "AP-HP")

### **GERMANY**

**Charité – Universitätsmedizin Berlin** with its headquarter in Charitéplatz 1, 10117 Berlin, Germany (hereinafter referred to as "Charité"),

**Goethe University of Frankfurt** with its headquarter in Max-von-Laue-Str. 9 60438 Frankfurt, Germany (hereinafter referred to as "GUF"),

**Universitatsklinikum Erlangen** with its headquarter in Maximiliansplatz 2, 91054 Erlangen, Germany (hereinafter referred to as "UKER"),

**Universitaet zu Luebeck** with its headquarter in Ratzeburger Allee 160, 23562 Luebeck, Germany (hereinafter referred to as "UzL"),

**Universitätsklinikum Jena** with its headquarter in Bachstrasse 18, 07743 Jena, Germany (hereinafter referred to as "UKJ")

### **GREECE**

**Aristotle University of Thessaloniki** with its headquarter in University Campus 54124 Thessaloniki, Greece (hereinafter referred to as "AUTH"),

Athena Research and Innovation Center in information Communication & Knowledge Technologies with its headquarter in Artemidos 6 Kai Epidavrou, Maroussi, 151 25, Greece (hereinafter referred to as "ATHENA RC"),

Idryma Iatroviologikon Ereunon Akademias Athinon - Biomedical Research Foundation, Academy of Athens with its headquarters in 4 Soranou Ephessiou St., 115 27 Athens, Greece (hereinafter referred to as "BRFAA"),

**Centre for Research and Technology Hellas** with its headquarter in 6th km Charilaou-Thermi Rd, GR 57001 Thermi, Thessaloniki, Greece (hereinafter referred to as "CERTH"),

**National Center for Scientific Research "Demokritos"** with its headquarter in Patr. Gregoriou E & 27 Neapoleos Str, 15341 Agia Paraskevi, Greece (hereinafter referred to as "NCSR-D"),

**National and Kapodistrian University of Athens** with its headquarter in Athens 157 72, Greece (hereinafter referred to as "NKUA"),

University of Patras with its headquarter in 26504 Rio Achaia, Greece (hereinafter referred to as "UPatras"),

### **HUNGARY**

National Institute of Pharmacy and Nutrition (Országos Gyógyszerészeti és Élelmezésegészségügyi Intézet - OGYÉI), with its headquarters in Zrinyi Utca 3, 1051, Budapest (hereinafter referred to as "OGYEI")

**Semmelweis Egyetem (Semmelweis University)** with its headquarters in H - 1085 Budapest, Üllői út 26, Hungary (hereinafter referred to as "SE")

### **IRELAND**

**National Children's Research Centre** with its headquarter in Gate 5, Our Lady's Children's Hospital, Crumlin, Dublin 12 (hereinafter referred to as "NCRC"),

**Royal College of Surgeons in Ireland** with its headquarter in 123 St Stephen's Green, Dublin 2, Ireland (hereinafter referred to as "RCSI"),

**University College Cork** with its headquarter in Coláiste na hOllscoile Corcaigh College Road, Cork T12 K8AF, Ireland (hereinafter referred to as "UCC")

### **ISRAEL**

Bar-Ilan University with its headquarter in Ramat Gan, 5290002, Israel (hereinafter referred to as "BIU"),

**Hadassah Medical Center** with its headquarter in Ein Kerem, West Jerusalem, Israel (hereinafter referred to as "HMC"),

**Hebrew University of Jerusalem** with its headquarter in Q6VR+RH Jerusalem, Israel (hereinafter referred to as "HUJ"),

**Jerusalem Ministry of Health** with its headquarter in 39 Yirmiyahu St., Jerusalem 9101002 (hereinafter referred to as "JMoH"),

The Sheba Fund for Health Services and Research with its headquarter in Derech Sheba 2, Ramat Gan, Israel (hereinafter referred to as "FHSR"),

**Technion – Israel Institute of Technology** with its headquarter in Senate Building Technion City, 32000, Haifa, Israel (hereinafter referred to as "TECHNION"),

Tel Aviv University with its headquarter in Tel Aviv-Yafo, Israel (hereinafter referred to as "TAUni"),

### **ITALY**

Alma Mater Studiorum - Università di Bologna with its headquarter in Via Zamboni, 33 - 40126 Bologna, Italy (hereinafter referred to as "UNIBO"),

**Azienda Ospedaliera Universitaria Consorziale Policlinico di Bari** with its headquarter in Piazza Giulio Cesare, 11, Bari, Italy (hereinafter referred to as "AOPB"),

**Azienda Ospedaliero Universitaria Meyer** with its headquarter in Viale Pieraccini 24 50139 Firenze, Italy (hereinafter referred to as "AOU Meyer"),

**Consiglio Nazionale delle Ricerche** with its headquarter in Piazzale Aldo Moro, 7 - 00185 Roma, Italy (hereinafter referred to as "CNR"),

Consorzio per Valutazioni Biologiche e Farmacologiche, with its headquarter in via Putignani 178, 70122 Bari, Italy (hereinafter referred to as "CVBF"),

Fondazione PENTA – for the treatment and care of children with HIV and related diseases – Onlus with its headquarter in Torre di Ricerca Pediatrica Corso Stati Uniti 4 35127 Padova Italy (hereinafter referred to as "PENTA"),

Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus with its headquarter in via Abate Eustasio, 30 – 70010 Valenzano (BA) Italy (hereinafter referred to as "FGB"),

**Fondazione Telethon** with its headquarter Via Varese, 16/B, 00185 Roma, Italy (hereinafter referred to as "Telethon"),

**Italian Network for Paediatric Clinical Trials** with its headquarter in Piazza Sant'Onofrio 4, 00164 Rome, Italy (hereinafter referred to as "INCiPiT"),

**Ospedale Pediatrico Bambino Gesù**, with its headquarter in Piazza Sant'Onofrio 4, 00165, Roma (hereinafter referred to as "OPBG"),

Ospedale Pediatrico Istituto Giannina Gaslini di Genova, with its headquarter in Via Gerolamo Gaslini, 5, 16147 Genova, Italy (hereinafter referred to as "IGG"),

**IRCCS Burlo Garofolo** with its headquarter in Via dell'Istria, 65, 34137 Trieste Italy (hereinafter referred to as "IRCCS B. Garofolo"),

**Istituto Ortopedico Rizzoli** with its headquarter in via G.C.Pupilli, 1 - 40136 Bologna, Italy (hereinafter referred to as "I.O. Rizzoli"),

IRCCS "Eugenio Medea", Scientific Institute of Associazione "La Nostra Famiglia" with its headquarter in Via Don Luigi Monza, 1 - 22037 Ponte Lambro (Co) and head office located in Via Don Luigi Monza, 20 - 23842 Bosisio Parini (LC), Italy (hereinafter referred to as "IRCCS E.Medea"),

**Società Italiana di Farmacologia** with its headquarter in Via Giovanni Pascoli, 3, 20129 Milano, Italy (hereinafter referred to as "SIF"),

**TEDDY European Network of Excellence for Paediatric Research,** with its headquarter in Via Luigi Porta 14 – 27100 Pavia, Italy (hereinafter referred to as "TEDDY"),

Università di Bari Aldo Moro, with its headquarter in Piazza Umberto I, 1, 70121 Bari Italy (hereinafter referred to as "UniBa"),

Università degli Studi di Cagliari with its headquarter in Via Università 40, 09124 Cagliari, Italy (hereinafter referred to as "UniCa"),

**Università degli Studi di Milano,** with its headquarter in Via Festa del Perdono, 7, 20122 Milano, Italy (hereinafter referred to as "UniMi"),

Dipartimento di Salute della Donna e del Bambino – SDB - Università degli Studi di Padova with its headquarter in Via Giustiniani, 3 - 35128 Padova, Italy (hereinafter referred to as "UniPd"),

**Università di Milano Bicocca,** with its headquarter in Piazza dell'Ateneo Nuovo, 1, 20126 Milano, Italy (hereinafter referred to as "Bicocca"),

**Università degli Studi di Parma** with its headquarter Str. dell'Università, 12, 43121 Parma, Italy (hereinafter referred to as "UniPr"),

**Università di Pavia,** with its headquarter in Corso Carlo Alberto, 5 – 27100 Pavia, Italy (hereinafter referred to as "UniPavia"),

**Università di Roma Tor Vergata,** with its headquarter in Via Cracovia, 50, 00133 Roma (hereinafter referred to as "Tor Vergata")

### **LUXEMBOURG**

**Centre Hospitalier de Luxembourg** with its headquarter in 4 Rue Nicolas Ernest Barblé, 1210 Luxembourg (hereinafter referred to as "CHL"),

**Luxembourg Center for Systems Biomedicine** with its headquarter in 6, rue Richard Coudenhove-Kalergi L-1359 Luxembourg (hereinafter referred to as "LCSB"),

**Luxembourg Institute of Health** with its headquarter in 84, Val Fleuri, L-1526 Luxembourg (hereinafter referred to as "LIH")

### **NORWAY**

**Oslo University Hospital** (Oslo universitetssykehus HF) with its headquarter, Postboks 4950 Nydalen, 0424 Oslo, Norway (hereinafter referred to as "OUH"),

**Haukeland University Hospital** with its headquarter in Jonas Lies vei 65, 5021 Bergen, Norway (hereinafter referred to as "**HUH**")

### **POLAND**

**Instytut Pomnik Centrum Zdrowia Dziecka**, with its headquarter in Aleja Dzieci Polskich 20, 04730 Warszawa, Poland (hereinafter referred to as "IPCZD"),

**Medical University of Gdansk** with its headquarter in Marii Skłodowskiej-Curie 3a, 80-210 Gdańsk, Poland (hereinafter referred to as "MUG")

### **PORTUGAL**

**Instituto Universitário Egas Moniz** with its headquarter in Monte de Caparica 2829 - 511 Caparica, Portugal (hereinafter referred to as "IUEM"),

**Universidade de Lisboa** with its headquarter in Cidade Universitária, Alameda da Universidade, 1649-004 Lisboa, Portugal (hereinafter referred to as "ULisboa")

### **ROMANIA**

**Fundatia Romanian Angel Appeal** with its headquarter in Strada Rodiei, București, Romania (hereinafter referred to as "RAA"),

**University of Medicine and Pharmacy, Cluj-Napoca** with its headquarter in Victor Babeş 8, 400012, Cluj-Napoca, Romania (hereinafter referred to as "UMFCJ")

### **RUSSIAN FEDERATION**

Center for Strategic Research «North-West» Foundation, with it headquarter in Building 2, Litt. A, 15, 26th Line, Vasilyevsky Island, 199106, St. Petersburg, Russian Federation (hereinafter referred to as "CSR "North-West"),

**National Research Lobachevsky State University of Nizhny Novgorod**, with it headquarter in Gagarin Ave 23, 603950, Nizhny Novgorod, Russian Federation (hereinafter referred to as "UNN"),

**Samara State Medical University** with its headquarter in 89 Chapayevskaya St., 443099, Samara, Russian Federation (hereinafter referred to as "SamSMU")

### **SLOVENIA**

**University Medical Centre Ljubljana** with its headquarter in Zaloška cesta 7, 1000 Ljubljana, Slovenia (hereinafter referred to as "UMCL"),

**University of Ljubljana, Medical Faculty** with it headquarter in Kongresni trg 12, 1000 Ljubljana, Slovenia (hereinafter referred to as "UL")

### **SPAIN**

**Fundació Sant Joan de Déu** with its headquarter in are in Calle Santa Rosa, 39-57, 08950 Esplugues de Llobregat, Barcelona, Spain (hereinafter referred to as "FSJD"),

Fundación para la Investigación del Hospital Universitario La Paz with its headquarter in Paseo de La Castellana, 261. 28046 - Madrid (hereinafter referred to as "FIBHULP"),

**Servizo Galego de Saúde** with its headquarter in Edificio Administrativo de San Lazaro, 15781 Santiago de Compostela, Spain (hereinafter referred to as "SERGAS"),

**Universidad de La Laguna** with its headquarter in Calle Pedro Zerolo, s/n, 38200 San Cristóbal de La Laguna, Santa Cruz de Tenerife, Spain (hereinafter referred to as "ULL")

### **SWITZERLAND**

**Universität Bern** with its headquarter in Hochschulstrasse 6 3012 Bern Schweiz, Switzerland (hereinafter referred to as "UniBern")

### THE NETHERLANDS

**Erasmus MC Kanker Instituut** with its headquarter in Dr. Molewaterplein 40, 3015 GD Rotterdam, The Netherlands (hereinafter referred to as "EMC"),

**Stitching Duchenne Data Foundation** with its headquarter in Warmoesdreef 10, 4514 HC, Bergen op Zoom, the Netherlands (hereinafter referred to as "DDF"),

**Stichting Katholieke Universiteit**, doing business as the Radboud university medical center with its headquarter in Geert Grooteplein Noord 9, 6525 EZ, Nijmegen, The Netherlands (hereinafter referred to as "RUMC"),

**Universiteit Leiden** with its headquarter in Rapenburg 70, 2311 EZ Leiden, the Netherlands (hereinafter referred to as "UL"),

## UK

Alder Hey Children's NHS Foundation Trust with its headquarter in Eaton Road Liverpool, L12 2AP, United Kingdom (hereinafter referred to as "AlderHey"),

**Cardiff University** with its headquarter in Cardiff CF10 3AT, United Kingdom (hereinafter referred to as "Cardiff"),

The University of Newcastle upon Tyne with its headquarter at King's Gate, Newcastle upon Tyne, Tyne and Wear NE1 7RU, United Kingdom (hereinafter referred to as "NewcastleUni"),

**Sheffield Children's NHS Foundation Trust** with its headquarter in larkson St, Broomhall, Sheffield S10 2TH, United Kingdom (hereinafter referred to as "Sheffield Children"),

**University College London**, with its headquarter in Gower Street, WC1E 6BT, London, United Kingdom (hereinafter referred to as "UCL"),

**University of Liverpool,** with its headquarter in Brownlow hill 76 Foundation Building, L69 7 7ZX, Liverpool, United Kingdom (hereinafter referred to as "ULIV"),

**University of Nottingham** with its headquarter in Nottingham NG7 2RD, United Kingdom (hereinafter referred to as "Nottingam"),

### **UKRAINE**

RE Kavetsky Institute of Experimental Pathology, Oncology and Radiobiology, National Academy of Sciences of Ukraine with its headquarter in Kyiv-03022, 45, Vasylkivska str, Ukraine (hereinafter referred to as "RE Kavetsky"),

**State Institute of Genetic and Regenerative Medicine of NAMS of Ukraine** with its headquarter in Vyshhorodska St, 67, Kyiv, Ukraine (hereinafter referred to as "IGRM"),

State Institute of Pharmacology and Toxicology of National Academy Medical Sciences of Ukraine with its headquarter in 03057, m.Kyyiv, SHevchenkivskyy rayon, VULYTSIA ANTONA TSEDIKA, budynok 14, Ukraine (hereinafter referred to as "IPT"),

State Institute of Paediatrics, Obstetrics and Gynaecology named after academician O. Lukyanova of National Academy of Medical Sciences of Ukraine with its headquarter in 8, Platona Mayborody str., 04050 Kyiv, Ukraine (hereinafter referred to as "UKR"),

**Ukraine Association of Biobank** with its headquarter in Lermontovska str. 26, Kharkiv 61000, Ukraine (hereinafter referred to as "UAB")

## Hereinafter referred to as "Party" or collectively referred to as "Parties"

### **GIVEN THAT**

Minors represent 20% of the European population and their care is one of the most important priorities and challenge for Europe. Even if paediatricians routinely give adult drugs to children in a 'off-label' prescription (50% up to 90% according to disease areas and age), researchers have demonstrated that children often do not respond to medications in the same way as adults or have different and more serious drug adverse reactions. This is the effect of the large variability of many biological and physiological functions changing during human growth, requiring the paediatric population to be subdivided in at least 5 smaller age groups, defined by the maturation process and having a huge impact on the individual pharmaco-toxicological characteristics. Also, the implementation of leads technologies in the drug development processes (such as -genetic/genomic derived innovation and data science innovation) requires paediatric adjustments and specific paediatric competences and tools.

So far, some progress in the field of paediatric translational research have been realised due to a very large paediatric research community (more than 300 research units mapped within the ID-EPTRI project, H2020 GA n. 777554, <a href="https://eptri.eu/">https://eptri.eu/</a>) but a structured paediatric research infrastructures is still lacking and the existing resources are still dispersed and underfunded.

It is therefore necessary to organise the international scientific community for paediatric research, not only through networks and initiatives, but also by constituting an Infrastructure dedicated to paediatric research, involving the various subjects interested in basic research and innovation in the development of drugs, devices and therapies for the paediatric population.

EPTRI (European Paediatric Translational Research Infrastructure) is a new proposed infrastructure dedicated to paediatric research that will work to accelerate and expand the paediatric drug development processes by enhancing innovative technologies and methods. The EPTRI Infrastructure will collaborate and integrate organisations with international initiatives dedicated to paediatric clinical research that will help to reduce the time developing new drugs and therapies and increase their availability for patients. To this aim also regulatory consulting and support to approach Paediatric Investigation Plans (PIP) applications, Orphan Drug Designations (ODD) and Advanced Therapy (AT) qualifications procedures will be provided.

The European Paediatric Translational Research Infrastructure – EPTRI (<a href="https://eptri.eu/">https://eptri.eu/</a>) has the following objectives:

- to extend the knowledge of the normal and pathological human development process in order to move from the current approach based on adult drugs that are adapted to children and still often administered off label to a new approach characterised by medicines studied and marketed for children, and consequently to reduce the existing gap on medicines availability for children;
- to involve multiple experts and competences to create multidisciplinary scientific and technology groups working to integrate basic science with key technologies (from biological, technological and data science advancements) to drive innovative medicines and health products discovery and development;
- to create a unique paediatric research framework able to accelerate the paediatric drug development processes from medicines discovery, biomarkers identification and preclinical research to

developmental pharmacology, age tailored formulations and medical devices, with the final goal to facilitate the translation of the acquired new knowledge and scientific innovation into paediatric clinical studies phases and medical use.

- to promote pediatric research through ethical, legal, social and regulatory issues (from the preclinical phase to the clinical phase and the use of medicines, to access and training policies) involving children and young patients in research-related decisions and health care as well as raising awareness among the main stakeholders, including the authority and the public, on the needs and peculiarities that are still unsatisfied with pediatric research.
- to enable companies to accelerate the development of tailored solutions for the paediatric population.

EPTRI will provide a platform to connect paediatric research at different levels thus to overcome the bottlenecks which delay both the transfer of basic research results into clinical applications and the feedback of clinical observations to the basic investigation in paediatrics.

The design phase of EPTRI has been funded by the European Commission under the INFRADEV-01-2017 call and has been coordinated by Consorzio per Valutazioni Biologiche e Farmacologiche in the framework of the Project ID-EPTRI (Grant Agreement n. 777554) with the duration of 28 months, (01.01.2018 – 30.04.2020) and involving 29 partners from 21 EU and non-EU countries.

### CONSIDERING ALSO THAT:

- a) The signing Parties of the present Memorandum of Understanding (hereinafter referred to as "MoU") have an Institutional role and/or have carried out important interdisciplinary research activities at national and international level within EPTRI's research fields and recognise its high scientific, social and economic value.
- b) The Parties have complementary competences consistent with the aims of EPTRI and express their interest in strengthening the scientific research in this area thanks to the establishment of a distributed Infrastructure at a pan-European level.

### THE FOLLOWING IS HEREBY AGREED

### 1. Purpose

The purpose of this Memorandum of Understanding (MoU) is to state the intent of all the Parties to take steps towards the Preparatory and Implementation phases of the EPTRI Distributed Research Infrastructure (DRI).

### 2. EPTRI Partnership and Governance

### 2.1 GOVERNANCE

EPTRI governance model is designed to facilitate the interdependence between the decision-making, operational and management functions in order to integrate and align the interests of all EPTRI

stakeholders. The structure of EPTRI is based on a Central Hub (C-Hub) that incorporates two decisional boards, the Assembly with Member States Representatives (Governing Board) and the Board of Directors (ExeB). Operational bodies will include a Scientific Advisory Board (SAB), an Ethics Advisory Board (EAB), an Access Management Committee (AMC) and a Central Management Office (CMO). Advisory Board will not have formal authority to govern the EPTRI organisation, rather it serves to make recommendations and/or provide key information and materials to the decisional Boards in accordance with the Rules of Procedure (RoP) that will be stated as part of EPTRI governing rules.

At operational level EPTRI will be organised in Thematic Research Platforms (TRP) in which the involved research units will be grouped according to their specific expertise, equipment and facilities. The following four Thematic Research Platforms have been already identified: Paediatric Medicines Discovery, Paediatric Biomarkers and Biosamples, Developmental Pharmacology, Paediatric Medicines Formulations. Other Thematic Research Platforms could be established following a process of identification, i.e. Medical Devices, etc.

### 2.1.1 Assembly with Member States' Representatives (Governing Board)

The GovB of EPTRI will have full decision-making power. The Governing Board will consist of one delegate and her/his deputy appointed by each Member State and Associated Country officially participating to EPTRI, with representatives' number and voting rights to be detailed in the RoP that will be agreed among its members. Representative of the States or other legal entities with the status of Observers, will not have voting rights. Below is a preliminary description of the contents regarding decisional power, meeting frequency and voting rights.

The GovB will make strategic decisions such as:

- Adopt a strategic plan (technological, scientific and administrative), based upon advice from the Advisory Boards;
- Adopt the annual budget and plan prepared by the ExeB;
- Approve audited financial statements;
- Approve the annual report prepared by the CMO and proposed by the ExeB;
- Admit new member states;
- Revoke the membership;
- Terminate the Infrastructure if necessary;
- Appoint the EPTRI ExeB members;
- Establish the two Advisory Board upon proposal from the ExeB.

The GovB will elect amongst its members a Chairperson and a deputy for a two-year term. The GovB will meet at least once a year and will be responsible for the overall direction and supervision of EPTRI.

## 2.1.2 Board of Directors (Executive Board)

The executive level of EPTRI will be represented by the ExeB, which is the executive authority and legal representative of the Infrastructure. The ExeB will provide strategic leadership and direct activities. It will be responsible for building the EPTRI community and for directing and coordinating operational bodies and activities. The ExeB will be accountable solely to the GovB and will operate

according to the RoP approved by the GovB. The members of the ExeB will make executive decisions regarding the implementation of EPTRI's operations and for implementing the GovB strategy and policies. It will be able to initiate activities and sign agreement according to the content of the EPTRI Annual Plan and in agreement with the strategies and policies defined by the GovB. It will be in charge to hire or terminate the personnel of the CMO. It will operate according to the Statutes and to RoP approved by the GovB. The General Director may delegate some function to the CMO director(s) to facilitate the daily operation but will sign all the legally binding documents. The CMO will perform the secretarial functions for the ExeB meetings. The ExeB will meet at least once a month and will be responsible for the overall direction and supervision of EPTRI operations

## 2.1.3 Scientific Advisory Board (SAB)

The Scientific Advisory Board is a body which members are key scientists and experts in the EPTRI domains having the primary function to advise the EPTRI Governing Bodies and CMO on EPTRI activities and plans to ensure that they are scientifically sound, in scope with the aims of EPTRI and aligned with the applicable ethical and regulatory requirements.

The Board composition will ensure the representation of different and complementary expertise covering the main areas of EPTRI activities and including ethic experts and patients' representatives. The SAB will also have a central role in supporting access to services and service provision. The SAB composition will be proposed by the ExeB and established by the GovB. The SAB will elect amongst its members a Chairperson and one deputy for a two-year term. Unless decided otherwise, the Chairperson will chair all meetings of the SAB and will be assisted by the deputy.

### 2.1.4 Ethics Advisory Board

Considering the heterogeneity and complexity of applicable ethical framework to the paediatric translational research, an external Ethics Advisory Board will be set up to provide an oversight of all EPTRI activities and guarantee that they fulfil the applicable European/international ethical requirements, promote transparency and harmonised practices in accordance with ethical and legal norms, taking into account the best interest of the child within EPTRI. It should include independent and multidisciplinary experts (dealing with biomedical research and healthcare policy and governance issues also in a children-oriented perspective) as well as representative of patients, families and patients advocates. Ethics Advisory Board members will be proposed by ExeB and nominated by GovB. The EAB will elect amongst its members a Chairperson and one deputy for a two-year term. Unless decided otherwise, the Chairperson will chair all meetings of the EB and will be assisted by the deputy.

### 2.1.5 Central Management Office (CMO)

The Central Management Office will be the headquarter of EPTRI supporting both decisional bodies, secretarial work and facilitating the communication among all the EPTRI components. It will include responsibility for, either through direct performance or through outsourcing, managing access to EPTRI, the IT supporting Infrastructure, accounting, legal and regulatory activities, communication, as well as being the central co-ordinating point for EPTRI activities. The Central Management Office

will support both decisional boards with secretarial help and facilitate the communication between the two boards.

### 2.2 PARTNERSHIP

### 2.2.1 Member States, Associated Countries and Observers

The Preparatory and Implementation phases of EPTRI will be supported by the Member States (and Associated Countries) directly or through a mandate to a national representative. Their representatives sit in the GovB and approve the financial and scientific annual plans, controlling the activities of the Research Infrastructure. Observers are typically representing governmental Institution which will have no governing role and may pay a reduced contribution. The Observers status is envisaged as a transitory condition which would lead to their becoming full Members in a given time frame.

Full members will have voting rights and may participate, by means of their national Research Institutions, to EPTRI activities. Additional countries may be able to join according to Membership Rules stated in the ERIC statute.

## 2.2.2 Research Institutes as Participants

The research Institutions participating in EPTRI are able to provide Research Units with a high level of expertise and services relating to paediatric research that will be organised in groups by country (N-EPTRI) and by operational technology-based Thematic Research Platforms (TRPs). The N-EPTRI nodes link the scientific community (e.g., universities, hospitals, research Institutions and resource centres) of a country to EPTRI while the TRPs organise services based on specialization of the pertaining research units across all participating countries. In order to participate in the Infrastructure, the Institution will pay a fee covered by its national funder or directly. The form which this national support should take depends upon national policy.

In order to join EPTRI, each Institution will sign a bilateral long-term Framework Agreement (FrAg) with the ExeB, as EPTRI legal representative. The content of such agreement will describe obligation and rights of the EPTRI participants. FrAg contract template will be consulted with National EPTRI Infrastructure Coordinators.

The FrAg content should be determined in detail before the initiation of operations as it represents the basis of the services offered to third parties. It is very important that all such agreements are in all material aspects mirror agreements (i.e. there must be no differences to any clauses that could provide an advantage or disadvantage to one participating Institution over another). Non-material differences may be required to reflect specific national, institutional or structural requirements. This will constitute a general collaboration agreement which allows for multiple projects and would remain in place for as long as the Institution participate to EPTRI activities.

The Framework Agreement will at least include:

- Services capacities;
- Rights and responsibilities to access projects and services requests;
- Publishing and acknowledgement stipulations and principles;
- Confidentiality;
- Intellectual Property rights;
- Adherence to standards, guidelines and laws;
- Mutual use of name, trademarks, etc.

### 2.2.3 National EPTRI Infrastructures (N-EPTRI)

The N-EPTRI would gather participating Institutions from a single Member State, with additional rights and responsibilities including extra information sharing, enhanced communication and possible commitment of co-ordination of resources.

In each country participating to EPTRI, it is suggested to identify one Institution or to establish a legal entity (e.g. a Joint Research Unit or other associative forms with a coordinating Institution) specifically nominated as the National EPTRI Infrastructure Coordinator to globally represent each country within EPTRI. This representative would manage national operation for the internal and national users. N-EPTRI could access national funding opportunities or co-funding activities based on national resources which are not accessible by EPTRI.

It would be a national endeavour to determine which Institution is to operate as the relevant N-EPTRI representative and would be decided by the local participants or suggested by the national authorities.

### 2.2.4 Thematic Research Platforms (TRPs)

The Thematic Research Platforms (TRPs) are conceptual operational entities grouping a constellation of Research Units located in different countries able to provide research services and technologies to the paediatric research community.

In the EPTRI Hub and Spoke model all the Research Units (RUs) are grouped under the umbrella of technology-based Thematic Research Platforms (TRPs) according to their area of expertise and capacity to provide services in the same area. Each TRP is in charge to organise the RUs participation and to maintain a collaborative framework among different RUs located in different countries.

Through the EPTRI-IS (EPTRI Informative System) each TRP will act in order to facilitate information flow, activity monitoring, interactions with C-Hub and also other TRPs when services provision involve more than one TRP.

Each TRP will be coordinated by a single Research Unit or an association of them (e.g. a JRU) located in one of the Member States or Associated Countries adhering to EPTRI, who have proved to have expertise in the platform specific scientific domain and management skills to coordinate it at international level. The TRPs Coordinators will be assigned dedicated organisation and staff.

### 3. Obligations of the Parties

The Parties acknowledge that no contractual relationship is created among them by this Memorandum of Understanding, but agree to collaborate in the true spirit of partnership to ensure the creation and development (Preparatory and Implementation) of EPTRI.

Each Party involved in the creation of EPTRI, on the basis of its own competence and available resources will do its best to cooperate together to achieve EPTRI's aims and to undertake the necessary steps required to establish EPTRI as a recognised distributed research infrastructure in the ESFRI scenario.

### 3.1. Constitution of a National EPTRI Infrastructures (N-EPTRI).

An essential feature of the preparatory phase of EPTRI is the contributions made at the national level. National EPTRI infrastructures (N-EPTRI) shall be created in each member country participating in EPTRI that will be organised through the institution of a JRU or an equivalent national association. They will have a coordinating Institution to globally represent each country within EPTRI and will be specifically named EPTRI-XX (i.e., EPTRI-IT in Italy, EPTRI-PL in Poland, etc.).

### 3.2. Political and Financial support (EoS and EoC)

N-EPTRIs should liaise with their Governments in order to obtain letters of political and financial support covering the Preparatory and Implementation phases. To encourage participation and commitment from potential Member States, an Expression of political Support Letter (EoS) has been drafted in consultation with ministries / authorities and circulated for signature by the relevant signatory body for each country (at the national governmental level). The aim of the EoS is for each signatory country to:

- Recognise the work done so far to progress EPTRI;
- Declare its willingness to collaborate with the EPTRI consortium for the development of the RI in its phases by being included in the EPTRI Governing Board;
- Agree to cover costs of their own participation.

### 3.3 Inclusion in ESFRI Roadmap 2021

The Parties will support and collaborate at best in the process of inclusion of EPTRI in both the National and European roadmaps. Starting with the signature of a Memorandum of Understanding (MoU) to apply to ESFRI Roadmap 2021, EPTRI is involving all the stakeholders necessary to move the project forward.

### 4. Duration

This Memorandum of Understanding will become effective upon signature by all the Parties, and will remain in effect until signing of an agreement such as set forth in article 8 or until its modification by mutual consent of the Parties.

## 4.1 Withdrawal

Any Party can withdraw, in written, at any moment from further participation in this MoU without any (financial) obligation towards any of the other parties. For clarification, Parties agree that the confidentiality obligations, such as detailed in article 7 of this MoU, shall remain.

### 5. Disputes

The parties shall endeavor to settle their disputes amicably. Otherwise, any dispute, controversy or claim arising under, out of or relating to this MoU and any subsequent amendments of this contract, including, without limitation, its formation, validity, binding effect, interpretation, performance, breach or termination, as well as non-contractual claims, shall be submitted to mediation in accordance with the WIPO Mediation Rules. The place of mediation shall be Brussels unless otherwise agreed upon. The language to be used in the mediation shall be English unless otherwise agreed upon.

If, and to the extent that, any such dispute, controversy or claim has not been settled pursuant to the mediation within 60 calendar days of the commencement of the mediation the courts of Brussels shall have exclusive jurisdiction.

### 5.1 Special clause

Pursuant to the French public law, AP-HP cannot be subject to mediation. In any dispute involving AP-HP, the courts of Brussels shall have exclusive jurisdiction.

## 6. Amendment and Assignment

- 6.1 Any modification of this MoU requires the written and signed consent of all the Parties hereto to become effective, except changes of Party address.
- 6.2 No rights or obligations of any of the Parties arising from this MoU may be assigned or transferred in whole or in part to any third party without the other Parties' prior written approval.

## 7. Confidentiality

- 7.1 "Confidential Information" is all information in whatever form or mode of communication, (in writing, orally or by inspection of tangible objects (including without limitation documents, prototypes, samples and equipment), which is disclosed by a Party (the "Disclosing Party") to any other Party (the "Receiving Party"), either directly or indirectly (e.g., by or through any Affiliates or Representatives), in connection with this MoU in the framework of EPTRI which has been explicitly marked as "confidential" at the time of disclosure.
- 7.2 Each Party agrees that it shall protect the secrecy of and shall prevent any unauthorised disclosure and/or use of the Confidential Information.
- 7.3 Without limiting the foregoing, each Party shall take at least those measures to protect Confidential Information received or developed under this agreement that it takes to protect its own Confidential Information.
- 7.4 Except to the extent necessary for the opportunity under the present MoU, a Party shall not make any copies of the Confidential Information of another Party.
- 7.5 The obligations contained in this Article shall become effective as soon as this MoU is signed by all the Parties and shall remain effective for five years from its termination.

### 8. Validity of the MoU

- 8.1 A specific agreement will rule relationships between the parties when specific activities will start with reference to the establishment of the EPTRI ExeB and GovB.
- 8.2 This MoU will be binding for each Institution upon the signature of the agreement mentioned at point 8.1 above which will integrate administrative and financial obligations.

# **European Paediatric Translational Research Infrastructure**

# Agjencia Kombetare e Kerkimit Shkencor dhe Inovacionit (NASRI)

ep. kanber 3, 2020

Name of the person authorised to sign: Mirela Muca

**Position: General Director** 

Place and Date: Tirana,

Signature:

Stamp:

# **European Paediatric Translational Research Infrastructure**

# **Qendra Spitalore Universitare Nene Tereza**

Name of the person authorised to sign:

JANIELA NIKA

Position: DEPUTY GENERAL STRECTOR

Place and Date: TERANA, 08.09.2020

Signature: Camble Nileo Goder

Stamp:

# **European Paediatric Translational Research Infrastructure**

# OKIDS Organisation Kinderarzneiforschung - Madecinesfor Children Research in Austria

Name of the person authorised to sign: Prof.Dr. Ruth Ladenstein

Position: General Manager OKIDS

Place and Date: Vienna, 18.06.2020

Signature:

Stamp:

O. K. idf OKIDS GmbH

Zimmermannplatz 10, 1090 Wien, Austria
Firmenbuch: HG Wien, FN 385313m
Geschäftsführung: Prof.Dr. Ruth Eadenstein,
+ 43 1 40470 4750, ruthJadenstein@okids-net.at
Projektmanagement: Andrea Mikolasek,

+ 43 1 40470 4990, andreasmikhlusekellesside net at

# **European Paediatric Translational Research Infrastructure**

## St. Anna Children's Cancer Research Institute

Name of the person authorised to sign:

Position:

Place and Date:

Signature:

Stamp:

Scient fix Director

Vienn 23th Jue 202

St. Anna Kinderkrebsforschung CHILDREN'S CANCER RESEARCH INSTITUTE

Zimmermannplatz 10, 1090 Wien, Austria  $\Gamma$  +43(1)40470-0 • F +43(1)40470-7150 ZVR Zahl 395401202 • www.CCRl.at

**European Paediatric Translational Research Infrastructure** 

Medical University of Graz - Dapartinent of Orlhopedic Geryon
Name of the person authorised to sign: Prof. Dr. A. Welhberg
Position: leady research but trusulo sheletal Tromakricus Surjean, redical hundring fra 2
Place and Date: fas 21.05.2020
Signature: Stamp:
Stamp:

Universitätsklinik für Orthopädie und Traumatologie A-8036 Graz, Auenbruggerplatz 5

# **European Paediatric Translational Research Infrastructure**

# **University of Vienna**

Name of the person authorised to sign: Univ. Prof. Dr. Gerhard Ecker

Position: Dean of the Faculty of Life Sciences

Place and Date: Vienna, 06.05.2020

Signature:

Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

# **Antwerp University Hospital**

Name of the person authorised to sign: Johnny Van der Stractan

Position: CEO

Place and Date: Edepen, 29/04/62

Signature:

Stamp:

J. Van der Straeten
Managing Director
Antwerp University Hospital

## **European Paediatric Translational Research Infrastructure**

# **Cliniques Universitaires Saint-Luc**

Name of the person authorised to sign: Jean-Louis Vanoverschelde

Position: Medical Director

Place and Date: \$1 42020
Signature:

Stamp (if applicable): L. VANOVERSCHELDE

Prof J. VANOVERSCHELDE Cliniques universitaire Saint-Luc

1200 Bruxelles

# **European Paediatric Translational Research Infrastructure**

# Université de Liège

Name of the person authorised to sign: Prof .Pierre Wolper

**Position: Rector** 

Place and Date: Liège,

2 9 JUIN 2020

Signature:

Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

# CHU de Liège

Name of the person authorised to sign: Monsieur Julien Compère

Position: CEO

Place and Date:

0 6 JUIL, 2020

Signature:

Stamp (if applicable):

Name of the person authorised to sign: Professeur Marie-Christine Seghaye

Position:

Head of 2 fortain

Place and Date:

Lg 23.6.62

Signature:

SERVICE DE PEDIATRIE CHU LIEGE

Stamp (if applicable):

PROFESSEUR MC. SEGHAYE **CHEF DE SERVICE** 1/6464957690

# **European Paediatric Translational Research Infrastructure**

# Hôpital Universitaire des Enfants Reine Fabiola

Name of the person authorised to sign: Dul Yhu &.

Position: CEO

Place and Date: Sum la & Huly 606

Signature:

Stamp (if applicable):

Höpital Universitaire des Enfants Reine Fabiola Universitair Kinderziekenhuis Koningin Fabiola Dirk THIELENS Directeur Général a.i. Algemeen Directeur a.i.

# **European Paediatric Translational Research Infrastructure**

Institut de Pathologie et Génétique

Name of the persons authorised to sign:

Karin Dahan

Jérémie Gras

Jean-François Ghidetti

Position:

**Head of the Centre of Human Genetics** 

**Medical Director** 

**Chief Executive Officer** 

Place and Date:

Gosselies, 29<sup>th</sup> June, 2020

Signature:

Stamp:

INSTITUT DE PATHOLOGIE ET DE GENETIQUE A.S.B.L Avenue Georges Lemaître,25 6041 GOSSELIES

# **European Paediatric Translational Research Infrastructure**

## **KU Leuven**

Name of the person authorised to sign: prof. Luc Sels

Position: Rector KU Leuven

Place and Date: Leuven 21 april 2020

Signature:

Prof. Luc Sels

Stamp (if applicable): rector KU Leuven

CATHULIERE UNINCHAITEL LEUVER ONDERZOEKSCOÖRDINATIE Huis Bethlehem, Schapenstraat 34 B-3000 LEUVEN (BELGIUM)

# **European Paediatric Translational Research Infrastructure**

# **Universiteit Antwerpen**

Name of the person authorised to sign: Prof. Dr. Ronny Blust

**Position: Vicerector Research** 

Place and Date: 13.05.2020, Antwerp

Signature:

Stamp (if applicable):

Prof. dr. Ronny Blust Vicerector Onderzoek

# **European Paediatric Translational Research Infrastructure**

1- DURANT p.o.

Name of the person authorised to sign: Professor Vincent Blondel

Position: Rector

Place and Date: Louvain la Nuve 24 July 2020 Signature: Surart

Stamp:

# European Paediatric Translational Research Infrastructure

# **Universiteit Gent (Ghent University)**

Name of the person authorised to sign: Rik Van de Walle

Position: Rector

Place and Date: Ghent, 22 April 2020

Signature:

Stamp (if applicable):



# **European Paediatric Translational Research Infrastructure**

# Institut National de la Recherche Scientifique

Name of the person authorised to sign: Claude Guertin

Position: Director of centre Armand-Frappier Santé Biotechnologie

Place and Date: Laval, June 4th 2020

Signature:

Stamp:

# **European Paediatric Translational Research Infrastructure**

# **Cyprus Federation of Patients' Associations**

Name of the person authorised to sign: Marios Kouloumas

Position: President CyFPA

Place and Date: 10 Agiasmaton str, 2230 Latsia, Nicosia Cyprus, 20 July 2020

Signature:

Stamp:

ATGENON KYTPOY

# **European Paediatric Translational Research Infrastructure**

# **European University Cyprus**

Name of the person authorised to sign: Prof. Kostas Gouliamos, PhD

**Position: Rector** 

**European University Cyprus** 

Place and Date: Cyprus 8th July 2020

Signature

Stamp:

# **European Paediatric Translational Research Infrastructure**

# Frederick University, Cyprus

Name of the person authorised to sign: Dr Christoforos Charalambous

Position: Director of Administration & Finance

Place and Date: 03//07/2020, Nicosia

Signature:

Stamp:

## **European Paediatric Translational Research Infrastructure**

## The Cyprus Foundation for Muscular Dystrophy Research – CING

Name of the person authorised to sign: Marios Flouros

Position: Financial and Administrative Director

Place and Date: Nicosia, 14 July 2020

Signature:

Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

**University of Cyprus** 

Name of the person authorised to sign: Marios Demetriades

Position: Head of the Research Support Service Legal Representative of the University of Cyprus

Place and Date: Nicosia, 30 June 2020

Signature:

### **European Paediatric Translational Research Infrastructure**

### **University of Nicosia**

Name of the person authorised to sign: finding followiths

Position: Chief brewhire Officer

Place and Date: Nilosia, Cypno 26 June 2020

Signature:



### **European Paediatric Translational Research Infrastructure**

## 2nd Faculty of Medicine, Charles University in Prague

Name of the person authorised to sign: Vladimir Komarek

Position:Dean

Place and Date: PRAGUE, 5.5.2020

Signature:

Stamp: Charles University

Second Faculty of Medicine

\* V Úvalu 84, 150 06 Prague 5, Czech Republic

#### **European Paediatric Translational Research Infrastructure**

**Faculty of Pharmacy in Hradec Kralove, Charles University** 

Name of the person authorised to sign: Tomas Simunek

Position: Dean

Place and Date: Hradec Kralove 2020-05-05

Signature:

Stamp (if applicable):

UNIVERZITA KARLOVA FARMACEUTICKÁ FAKULTA Akademika Heyrovského 1203 S00 OS Hradec Králové ① ICH DOZINZBA DIĚ CZOBZIGZOS

### **European Paediatric Translational Research Infrastructure**

## Fyziologicky Ustav Ceska Akademie ved Verejna Vyzkumna Instituce - IPHYS

Name of the person authorised to sign: Jan Kopecky, MD, D.Sc.

Kopiels

Position: Director

Place and Date: Prague, May 7, 2020

Signature:

**INSTITUTE OF PHYSIOLOGY** ASCR

Stamp (if applicable):

Institute of Physiology ASCR, v.v.i.
Vídeňská 1083, Prague 4
142 20, Czech Republic
IČ: 67985823 – DIČ: CZ67985823

#### **European Paediatric Translational Research Infrastructure**

## Assistance publique - Hôpitaux de Paris (AP-HP)

Name of the person authorised to sign: Florence Favrel Feuillade, on behalf of Martin Hirsch

Position: Director of the clinical research and innovation department of AP-HP

Place and Date:

1 0 JUIL 2020 PARIS

Signature:

Stamp:

Fiorence FAVREL-FEUILLADE DRCI - AP-HP

Directrice

## **European Paediatric Translational Research Infrastructure**

Charité – Universitätsmedizin Berlin

Katharina unterschrieben von

Digital Katharina Flemming Flemming Datum: 2020.06.05

Name of the person authorised to sign:

Position: Head of Contract Management, Research Department

Place and Date: Berlin, 5.6.2020

Signature:

Stamp (if applicable):

### **European Paediatric Translational Research Infrastructure**

## **Goethe University of Frankfurt**

Name of the person authorised to sign:

Dr. Sabine Monz

Position:

Head of Research Service Center

Place and Date:

Frankfurt, 3<sup>rd</sup> July 2020

Signature:

Stamp:

JOHANN WOLFGANG GOETHE-UNIVERSITÄT

Die Präsidentin Theodor-W.-Adorno-Platz 1 60629 Frankfurt am Main

Fall-ID: 3008939

## **MEMORANDUM OF UNDERSTANDING**

## **European Paediatric Translational Research Infrastructure**

Universitatsklinikum Erlangen

Name of the person authorised to sign: DI, Jur. Albrelt Bender

Position: Comme cicel Director

Place and Date:

Signature:

Dr. jur. Albrecht Bender
Kaufmänrlischer Direktor
Universitätsklinikum Erlangen

Stamp (if applicable):

Prof. Dr. Wolfe Director der Kinder- und Jugend Klinik

Proj. Dr. A. Newbort

Head Parediadric Chinical Study Centre

Wen 6 &

par

## **European Paediatric Translational Research Infrastructure**

### Universitaet zu Luebeck

Lübeck, Germany, 18.06.2020

Signature:

Stamp:

Das Präsidium der Universität zu Lübeck Ratzeburger Alleo 160, 23562 Lübeck

Prof. Dr. med. Christopher Baum

Vice-President

## **European Paediatric Translational Research Infrastructure**

, ain 3.7.70

JINIVERSITATE ALIMINUM JENÄ

Dr. Tobias Neumann Forschungskoordinator Postfach 07/40 Jena

## Universitätsklinikum Jena

Name of the person authorised to sign: Dr. Brunhilde Seidel-Kwem

Position: Speaker of the Board of Directors

Place and Date:

Signature:

Stamp:

Dr. Brunhilde Seidel-Kwem Kaufmännischer Vorstand Universitätsklinikum Jena

Additional signatures:

Dr. Tobias Neumann, Research Coordinator:

Prof. Udo Markert, UKJ's principal investigator EPTRI

Prof. Dr. Udo Markert Universitätsklinikum Jena Forschungszentrum - Haus F2 Placenta-Lebor

Klinikum 1, 07747 Jena

## **European Paediatric Translational Research Infrastructure**

## Aristotle University of Thessaloniki

Name of the person authorised to sign: Prof. Efstratios Stylianidis

Position: Vice Rector

Place and Date:

Signature:

Stamp (if applicable).



#### **European Paediatric Translational Research Infrastructure**

Athena Research and Innovation Center in Information, Communication and Knowledge Technologies

Name of the person authorised to sign: Prof. Yannis Ioannidis

Position: President of the Board and General Director of ATHENA RC

Place and Date: Athens, 04.09.2020

Signature:

Stamp:

ATHENA

RESEARCH AND INNOVATION CENTRE IN INFORMATION, COMMUNICATIONS AND KNOWLEDGE TECHNOLOGIES ARTEMIDOS 6 & EPIDAVROU 5M., 151 25 MAROUSSI GREECE TEL +30 210 6875300 - FAX: +30 210 6875485

### **European Paediatric Translational Research Infrastructure**

ldryma latroviologikon Ereunon Akademias Athinon - Biomedical Research Foundation, Academy of Athens

Name of the person authorised to sign:

THE PRESIDENT OF THE BOARD

Position:

LUCAS PAPADEMOS ROFESSOR - ACADEMICIAN

Place and Date: Athens, 18 June 2020

Signature:



### **European Paediatric Translational Research Infrastructure**

## Centre for Research and Technology Hellas, Institute for Bio-Economy and Agri-Technology

Name of the person authorised to sign: Dionysios Bochtis

Position: Director of the Institute for Bio-Economy and Agri-Technology, Centre for Research and

**Technology Hellas** 

Place and Date: Volos, 13/03/2020

Signature:

Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

National Cent	er for	Scientific	Research	"Demokritos"
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Name of the person authorised to sign:

Vassilis Kilikoglou

Position:

President of the Board and Acting Director N.C.S.R "DEMOKRITOS"

Place and Date:

Signature!

Agia Paraskevi, 20/05/20

stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

## **National and Kapodistrian University of Athens**

Name of the person authorised to sign: Professor Nikolaos Voulgaris

Position: Vice Rector of Research and Lifelong Learning

Place and Date: Athens, 어니어 2020

Signature:

### **European Paediatric Translational Research Infrastructure**

## **University of Patras**

Name of the person authorised to sign: VENETSANA E. KYRIAZOPOULOU

Position: RECTOR

Place and Date: PATRAS 30/ 66 /2020

Signature:

Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

## National Institute of Pharmacy and Nutrition OGYEI

Name of the person authorised to sign:	Mátyás Szentiványi, MD, PhD
Position:	Director General
Place and Date:	Budapest, 29 June, 2020
Signature:	5-0-
Stamp (if applicable):	ATRIO . WARRY

## **European Paediatric Translational Research Infrastructure**

## **Semmelweis University**

Name of the person authorised to sign:

Béla Dr Merkely

Position:

Dr. Ferdinandy Péter tudományos és innovációs rektorhelyettes

rector

Place and Date:

2020 JÚN 10.

Signature:

Stamp:

Name of the person authorised to sign:

Irén Baumgartnerné Holló

Position:

Baumgartnerné Hollo frén kancellar ahalanos helyettese

deputy exercising the chancellor's rights

Place and Date:

2020 IGN 119

Signature:

### **European Paediatric Translational Research Infrastructure**

#### National Children's Research Centre

Name of the person authorised to sign: Dr Jacinta Kelly

Position: CEO

Place and Date: Dublin, 30.06.20

Signature: Jaunta Kelh.

Stamp: Retional Unitdren's Hesearch Centre'

Address: Our Lady's Children's Hospit

Cumin Dain 12

property of the second of the

### **European Paediatric Translational Research Infrastructure**

## **Royal College of Surgeons in Ireland**

Name of the person authorised to sign:	Fergal O'Brien
Position:	Director of Research & Innovation
Place and Date:	Dublin, 1 May 2020
Signature:	Fergal O'Brien Fergal O'Brien (May 1, 2020)
Stamp (if applicable):	

### **European Paediatric Translational Research Infrastructure**

### **University College Cork**

Name of the person authorised to sign: David O'Connell

Position: Director Research Support Services, University College Cork

Place and Date: Cork, 10/07/2020

Signature:

Stamp:

VICE PRESIDENT FOR RESEARCH UNIVERSITY COLLEGE CORK, IRELAND

TEL: +353 21 4903501 FAX: +353 21 4903506 E-MAIL: vpresearch@ucc.ie

### European Paediatric Translational Research Infrastructure

### **Bar-Ilan University**

Name of the person authorised to sign:

Position:

Yossi Kalifa, PhD Director, Research Authority Bar-Ilan University

Place and Date:

Bar Ilan Israel 7.9.2070

Signature:



## **European Paediatric Translational Research Infrastructure**

**Hadassah Medical Organization** 

Name of the person authorised to sign: Prof. Eyal Mishani

Position: Head Research and Development Division

Place and Date: Jerusalem. Sep 6th 2020

Signature:

Prof. EYAL MISHANI
Head, Research & Development Division
Head, Cyclotron / Radiochemistry Unit
Hadasseh Hebrew University Hospital
Jerusalem

## **European Paediatric Translational Research Infrastructure**

## **Hebrew University of Jerusalem**

Name of the person authorised to sign: Dr. Pablo Kizelsztein

Position: Director, The Authority for Research and Devolopment

Place and Date: Jerusalem, 7 September 2020

Signature:







## **European Paediatric Translational Research Infrastructure**

Israel Ministry of Health – Chief Scientist Office (CSO-MOH)

Name of the person authorised to sign Prof. Avi Israeli

Position: Chief Scientist

Place and Date:

Signature:

Stamp:

MZ OF ALE OF ISRAEL

02-6725833 פקס: 02-5082163

## **European Paediatric Translational Research Infrastructure**

#### The Sheba Fund for Health Services and Research

Name of the person authorised to sign: Prof. Dror Harats

Position: Chair the Division for R&D

Place and Date: Ramat Gan, Israel September 7, 2020

Signature:

Prof. Dror Herets MD Chair the Division of R&D The Shebs Fund for Health Services and Research (R.A. 580301992)

Stamp:

The Sheba Fund for Health Services and Research (R.A. 580301992)

# Executive Vice President for Research המשנה לנשיא למחקר



#### **MEMORANDUM OF UNDERSTANDING**

#### **European Paediatric Translational Research Infrastructure**

Technion - Israel Institute of Technology - TECHNION

Name of the person authorised to sign: Prof. Jacob (Koby) Rubinstein

Position: Executive Vice President for Research

Place and Date: 06/09/2020

Signature:



## **European Paediatric Translational Research Infrastructure**

### **Tel Aviv University**

Name of the person authorised to sign: Prof. Yoav Henis

Position: Vice President for Research and Development

V. Henis

Signature:

Name of the person authorised to sign: Mr. Gad Frank

Position: Director General

Signature:

Place and Date: Tel Aviv, September 7, 2020



## European Paediatric Translational Research Infrastructure

Alma Mater Studiorum - Università di Bologna

Name of the person authorised to sign: prof. MIRKO DEGLI ESPOSTI

Position VICE PICTOR

Place and Date: BOLOGNA

Signature: 03/09/2020

## **European Paediatric Translational Research Infrastructure**

Azienda Ospedaliera Universitaria Consorziale Policlinico di Bari
Name of the person authorised to sign:
Position:
Place and Date: BARI 28 AGOSTO 2020
Signature:
IL DIRETTORE GENERALE  Pr. Giovanni MicLiore

## **European Paediatric Translational Research Infrastructure**

## Azienda Ospedaliero Universitaria Meyer

Name of the person authorised to sign: Alberto Zanobini

Position: Chief Executive Officer

Place and Date: Florence, Italy – August 7, 2020

Signature:

Azienda Ospedaliero Universitaria Meyer
Il Direttore Generale
Pr. Alberto Zanobini

## **European Paediatric Translational Research Infrastructure**

Consiglio Nazionale delle Ricerche	
Name of the person authorised to sign:	
Position:	
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Place and Date:	
Signature:	INGUSCIO MASSIMO 05.08.2020 09:02:44 CEST
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## **European Paediatric Translational Research Infrastructure**

## Consorzio per Valutazioni Biologiche e Farmacologiche

Name of the person authorised to sign: Donato Bonifazi

**Position: CEO** 

Place and Date: Bari, 28/07/2020

Signature:

Stamp:

CONSORZIO PER VALUTAZIONI BIOLOGICHE E FARMACOLOGICHE

VIA NICOLÒ PUTIGNANI 178 • 70122 BARI • ITALY TEL. +39 080 97 51 974 • VAT 01897720189 WWW.CVBF.NET • INFO@CVBF.NET

## **European Paediatric Translational Research Infrastructure**

Fondazione Penta for the treatment and care of children with HIV-Onlys - PENTA

Name of the person authorised to sign: CALO GI AQUIND

Position: PRESIDENT

Place and Date: PADOVA (7/07/2020)

Signature: Clo A

## **European Paediatric Translational Research Infrastructure**

## Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus

Name of the person authorised to sign: Fedele Bonifazi

Position: President

Place and Date: Valenzano (BA), 23.07.2020

Signature: Field Parispos

### **European Paediatric Translational Research Infrastructure**

#### **Fondazione Telethon**

Name of the person authorised to sign: Manuela Battaglia

Position: Head of Research

Place and Date: Milan, 23/06/2020

Signature:

Stamp:

FONDAZIONE TELETHON

Via Varese, 16 b 00185 Roma

C.F. e P.IVA 04879781005

## **European Paediatric Translational Research Infrastructure**

## **Italian Network for Paediatric Clinical Trials**

Name of the person authorised to sign: Prof. Paolo Rossi

Position: President

Place and Date: Rome, 26-07-2020

Signature:

Stamp: n/a

## **European Paediatric Translational Research Infrastructure**

#### Ospedale Pediatrico Bambino Gesù

Name of the person authorised to sign: NARIEUA ENOC

Position: LEGAL REPRESENTATIVE

Place and Date: Rorl , 0105 2020

Signature:



### **European Paediatric Translational Research Infrastructure**

## Ospedale Pediatrico Istituto Giannina Gaslini di Genova

Name of the person authorised to sign: Dr. Paolo Petralia

Position: Director General

Place and Date: GENOA, 15 Apr 2020

Signature: L DRETTORE GENERALE (Dr. Proto Petralia)
Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

IRCCS Burlo Gar	ofolo			
Name of the per	rson authorised to sign: prof. I	Fabio Barbone		
Position: Scienti	fic Director			
Place and Date:	Trieste, 09/07/2020			
Signature:	Memo	2		
Stamp:	IRCCS BURLO GAROFOLO • Il Direttore Scientifico prof. Fabio Barbone	TRIESTE		
				*
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		-		

### **European Paediatric Translational Research Infrastructure**

### Istituto Ortopedico Rizzoli

Name of the person authorised to sign: DR. ANSELMO CAMPAGNA

Position: DIRETTORE GENERALE

Place and Date: Bolsowa 07/09/2525
Signature:

Stamp:

FERTH ( T. NEGOZIBRO B GUAL A GALVETTORE EGISALIPRO DE URA TRE INSPESSOR

## **European Paediatric Translational Research Infrastructure**

IRCCS "Eugenio Medea", Scientific Institute of Associazione "La Nostra Famiglia"

Name of the person authorised to sign: Luisa Minoli

Position: President and Legal Representative

Place and Date: Ponte Lambro, Italy - 23 June 2020

Signature: Cerisolefense:

LA PRESIDENTE

Stamp: dell'Associazione "LA NOSTRA FAMIGLIA"

dr.ssa Luisa Minoli

#### **European Paediatric Translational Research Infrastructure**

## Società Italiana di Farmacologia

Name of the person authorised to sign: Giorgio Racagni

Position: President

Place and Date: MILAN, 31/8/20,20

Signature:

# **European Paediatric Translational Research Infrastructure**

# **TEDDY European Network of Excellence for Paediatric Research**

Name of the person authorised to sign: Annagrazia Altavilla

Position: Chair/Legal Representative

Place and Date: Pavia, 23.07.2020

Signature:

Stamp: N/A

#### **European Paediatric Translational Research Infrastructure**

#### Università di Bari Aldo Moro

Name of the person authorised to sign: Prof. Stefano Bronzini

**Position: Rector** 

Place and Date: Bari, 31/64/2020

Signature:

IL RETTORE
Stefano BRONZINI

Of Scaling

### **European Paediatric Translational Research Infrastructure**

Università degli Studi di Cagliari

Name of the person authorised to sign: Maria Del Zompo

Position: Rector, Legal Representative University of Cagliari

Place and Date: Cagliari Italy, August 27th 2020

Signature:

Università degli Studi di Cagliari IL RETTORE Prof.ssa Maria Del Zompo



# **European Paediatric Translational Research Infrastructure**

# Università degli Studi di Milano

Name of the person authorised to sign: Elio Franzini

**Position: Rector** 

Place and Date:

MILANO(IT)

[0]2 |SET 2020

Signature:

Stamp:

IL RETTORE

### **European Paediatric Translational Research Infrastructure**

## Dipartimento di Salute della Donna e del Bambino – SDB - Università degli Studi di Padova

Name of the person authorised to sign: Prof. Giorgio Perilongo

Position: Director / Legal Representative

Place and Date: Padova, 04/09/2020

Signature:

Stamp:



Reed O

## **European Paediatric Translational Research Infrastructure**

## Università di Milano Bicocca

Name of the person authorised to sign: Prof. Marco Emilio Orlandi
Position: Deputy Rector
Place and Date: Milan, 8/9/2020
Signature: Digitally Signed in accordance with D.Lgs. 82/2005, Art. 24 – Italian Law
Stamp:

# **European Paediatric Translational Research Infrastructure**

Università degli Studi di Parma

Name of the person authorised to sign:

IL PRORETTORE VICARIO
Paolo Martelli

Position:

Place and Date: PARMA

Signature:

IL PRORETTORE ALCARIC

Stamp:

1

## **European Paediatric Translational Research Infrastructure**

### Università di Pavia

Name of the person authorised to sign: PROF. FRANCESCO SVELTO

**Position: RECTOR** 

Place and Date: PAVIA 26 AUGUST 2020

Signature:

## **European Paediatric Translational Research Infrastructure**

## Università di Roma Tor Vergata

Name of the person authorised to sign: Prof. Orazio Schillaci

**Position: Rector** 

Place and Date: Rome

Signature:

SCHILLACI ORAZIO

02.10.2020 09:02:36 UTC

## **European Paediatric Translational Research Infrastructure**

## Centre Hospitalier de Luxembourg

Name of the person authorised to sign: Dr Romain NATI

Position: Directeur général

Place and Date: Luxembourg, 14/05/2020

Signature:

# **European Paediatric Translational Research Infrastructure**

University of Luxembourg, on behalf of its Luxembourg Center for System Biomedicine

Name of the person authorised to sign: Prof. Dr. Jens Kreisel

Position: Vice-Rector for Research

Place and Date: Luxembourg, 27/05/2020

Signature:



# **European Paediatric Translational Research Infrastructure**

## **Luxembourg Institute of Health**

Name of the person authorised to sign: Dr. Ulf NEHRBASS

Position: CEO

Place and Date: Luxembourg, 03 March 2020

Signature:

Stamp (if applicable):

Luxembourg Institute of Health 1A-B, rue Thomas Edison L-1445 Luxembourg Phone: +352 26970-777 Fax: +352 26970-717

## European Paediatric Translational Research Infrastructure

Oslo University Hospital

Name of the person	on authorised to sign:	ERLE	ROOT	WELT
Position: HE	FO ST	PIVISIO	W.	
Place and Date:	Ole	Saul	41.0	700
Signature:	ige	Roslev	0	
Stamn <sup>,</sup>	7			

Stamp:

Terje Footwelt

Head of Division of paedictric and adolescent medicine

Professor, MD, PhD

Oslo University Hospital and University of Calo

Pb. 4956 Nydalen 0424 Oslo, Norway Mobil: +47 95 83 16 31

e-mail: terje.rootwelt@ous-lif.no

# **European Paediatric Translational Research Infrastructure**

**Haukeland University Hospital** 

Name of the person authorised to sign:

RENATE GRÜNER

Position:

Director of Resea

Place and Date:

\$ignature:

### **European Paediatric Translational Research Infrastructure**

### Instytut "Pomnik-Centrum Zdrowia Dziecka"

Name of the person authorised to sign: dr. n. med. Marek Migdał

Position: CEO of the Instytut "Pomnik-Centrum Zdrowia Dziecka"

Place and Date: Wayaw

8th June, 2020

Signature:

dr n. med. Marek Migdał

Stamp:

INSTYTUT

Pomnik "Centrum Zdrowia Dziecka" 04-730 Warszawa, Al. Dzieci Polskich 20 Regon 000557961; NIP 952-11-43-675

# **European Paediatric Translational Research Infrastructure**

# **Medical University of Gdansk**

Name of the person authorised to sign: Marcin Gruchała

REKTOR

Place and Date: Golonia 14.05.2020

Signature:

GDAŃSKI UNIWERSYTET MEDYCZNY

80-210 Gdańsk

Stamp (if applicablesk todowskiej-Curie 3A NIP: 584-09-55-985

# **European Paediatric Translational Research Infrastructure**

# Instituto Universitário Egas Moniz

Name of the person authorised to sign: JOSÉ JOAO BALTAZAR MENDES

Position: PRESIDENT

Place and Date: Monte de Capacica, 27-05-2020

Signature:

Stamp (if applicable): 35 this in o supra

### **European Paediatric Translational Research Infrastructure**

#### Universidade de Lisboa

Name of the person authorised to sign: Prof. Doutor António Manuel da Cruz Serra

**Position: Rector** 

Signature:

Place and Date: 08/05/2020

Assinado com Assinatura

Digital Qualificada por:

ANTÓNIO MANUEL DA CRUZ

**SERRA** 

Universidade de Lisboa

Data: 08-05-2020 12:04:11

## **European Paediatric Translational Research Infrastructure**

## **Fundatia Romanian Angel Appeal**

Name of the person authorised to sign: Silvia ASANDI

Position: General Manager

Place and Date: Bucharest, 10 June 2020

Signature:

## **European Paediatric Translational Research Infrastructure**

## University of Medicine and Pharmacy "Iuliu Hatieganu", Cluj-Napoca

Name of the person authorised to sign: Prof. Dr. A	nca Dana Bazolana
Position: Rector	ANNW TO THE

Place and Date:
CLUZ - NAPOCH, 15.06, 2020

Signature:

# **European Paediatric Translational Research Infrastructure**

# Center for Strategic Research «North-West» Foundation

Name of the person authorised to sign: Marina Lipetskaya

**Position: Director** 

Place and Date: Saint Petersburg, Russia, 12th March 2020

Signature:

## **European Paediatric Translational Research Infrastructure**

# National Research Lobachevsky State University of Nizhny Novgorod

Name of the person authorised to sign: Prof. Viktor Kazantsev

Position: Head of the Department of Neurotechnology (Institute of Biology and Biomedicine)

Place and Date: Nizhny Novgorod, 11.05.2020 Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

# Samara State Medical University

Name of the person authorised to sign: Prof. Alexander Kolsanov

Position: Rector

Place and Date: Samara, 12.03.2020

Signature:

### **European Paediatric Translational Research Infrastructure**

## **University Medical Centre Ljubljana**

Name of the person authorised to sign: JANEZ POKLUKAR

Position: Director General

Place and Date: Ljubljana, January 30th, 2020

Signature:

# **European Paediatric Translational Research Infrastructure**

Ljubljana

## **University of Ljubljana**

Name of the person authorised to sign: Igor Papič

Position: Rector

Place and Date: Ljubljana, February 4, 2020

Signature:

Stamp (if applicable)

PO POOBLASTILU: BY AUTHORITY OF:

prof. dr. Matjaž Krajne prorektor/vice-rector



### **European Paediatric Translational Research Infrastructure**

Fundació	Sant Joan	de	Déu
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Name of the person authorised to sign: Emili Bargalló Angerri

**Position: Director** 

Place and Date: Carrer Santa Rosa, 39-57, 3<sup>rd</sup> floor, 08950 Esplugues de Llobregat, Barcelona,

Spain

Signature:

## **European Paediatric Translational Research Infrastructure**

# Fundación para la Investigación Biomédica del Hospital Universitario La Paz

Name of the person authorised to sign: Ana Coloma Zapatero

**Position: Director** 

Place and Date: Madrid, 18th May 2020

Signature:

Stamp (if applicable):

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INVESTIGACION BIOMEDICA DEL HOSPITAL
UNIVERSITARIO LA PAZ, CeES
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## **European Paediatric Translational Research Infrastructure**

## Servizo Galego de Saúde

Name of the person authorised to sign: Antonio Fernández-Campa García-Bernardo

Position: Manager of SERGAS

Place and Date: Santiago de Compostela, 30 June 2020

Signature:



# **European Paediatric Translational Research Infrastructure**

# Universidad de La Laguna

Name of the person authorized to sign: Prof. Dr. Ernesto Pereda De Pablo,

Position: Vice-rector of Research and Transfer of Knowle

Place and Date: Tenerife (SPAIN), June 7th, 2020

Signature:

43809972D Digitally signed by 43809972D ERNESTO ERNESTO PEREDA (R: Q3818001D) Date: 2020.06.08 14:28:12 +01'00'

Stamp:

C/ Padre Herrera s/n 38207 La Laguna Santa Cruz de Tenerife. España

## **European Paediatric Translational Research Infrastructure**

## **Universität Bern**

Name of the person authorised to sign: Prof. Christiane Albrecht

Position: PI

Place and Date: Bern, 11th of August, 2020

Signature:

Stamp:

Prof. Dr. Christiane Albrecht Institut für Biochemie und Molekulare Medizin Universität Bern Bühlstrasse 28 CH-3012 Bern, Schweiz

## **European Paediatric Translational Research Infrastructure**

## **Stitching Duchenne Data Foundation**

Name of the person authorised to sign: George Paliouras

Position: Chairman of DDF

Place and Date:

Athens (Greece), June 1st 2020

Signature:

Stamp (if applicable):

DUCHENNE DATA FOUNDATION

Duchenne Data Foundation Warmoesdreef 10 4614 HC Bergen op Zoom The Netherlands Chamber of Commerce: 64601188

## **European Paediatric Translational Research Infrastructure**

# **Stichting Katholieke Universiteit**

Name of the person authorised to sign: dr. Eric Caldenhoven

**Position: Head Grant Support Office** 

Place and Date: Nijmegen

Signature:

Dr. Eric Caldenhoven 2020.05.06 11:00:38

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Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

## **Universiteit Leiden**

Name of the person authorised to sign: Prof do. Hubertus Irth

Position: Scientific Director

Place and Date: Leiden, 30-6-2025

Signature:

## **European Paediatric Translational Research Infrastructure**

## **Alder Hey Children's NHS Foundation Trust**

Name of the person authorised to sign: Professor Matthew Peak

Position: Director of Research

Place and Date: Alder Hey Children's NHS Foundation Trust, Eaton Toad, Liverpool, L12 2AP, UK

12<sup>th</sup> May 2020

Signature:

Alder Hey Children's NHS Foundation Trust

## **European Paediatric Translational Research Infrastructure**

# **Cardiff University**

Name of the person authorised to sign: Dr Elid Morris

Position: Head of Research Grants

Place and Date: Cardiff, Wales, United Kingdom, 11th June 2020

Signature:

Dr Elid Morris Head of Research Grants Office

Stamp: Research and innovation Services

## **European Paediatric Translational Research Infrastructure**

# Name of the person authorised to sign: Professor Brian Walker Position: Pro-Vice-Chancellor, Research Strategy and Resources Place and Date: Newcastle upon Tyne, 04/05/2020 Signature:

Stamp (if applicable):

#### **European Paediatric Translational Research Infrastructure**

## Sheffield Children's NHS Foundation Trust

Name of the person authorised to sign: Prof. Paul Dimitri

Position: Professor of Child Health; Director of Research and Innovation

Place and Date: Sheffield, UK; 27th March 2020

Signature

Stamp:

Professor Paul Dimitri

Director of Research & Innovation

Sheffield Children's NHS Foundation Trust

## **European Paediatric Translational Research Infrastructure**

# **University College London**

Name of the person authorised to sign: Giles Machell

Position: Head of EC Contract Management

Place and Date: 9.9.20 London

Signature:

Stamp:

University College London Gower Street London WC1E 6BT

## **European Paediatric Translational Research Infrastructure**

## **University of Liverpool**

Name of the person authorised to sign:

Position:

David McVey

Solicitor - Head of Research Contracts

Legal & Compliance

University of Liverpool

Place and Date: Liverped / 8/6/20

Signature:

Stamp:

ţ.

# **European Paediatric Translational Research Infrastructure**

## **University of Nottingham**

Name of the person authorised to sign: Rachel Brereton

Position: Director of Research & Innovation Operations

Place and Date: Nottingham, 12/05/2020

Signature:

Stamp (if applicable):

Rachel Brereton

Director of
Research & Innovation Operations

University of
Nottingham

University of Nottinghem

## **European Paediatric Translational Research Infrastructure**

State Institution "Institute of Genetic and Regenerative Medicine of National Academy Medical Sciences of Ukraine"

Name of the person authorised to sign: Gennady M. Butenko

Position: Director, academician of the National Academy of Medical Sciences of Ukraine, professor

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature:

Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

State Institution "Institute of Pharmacology and Toxicology of National Academy of Medical Sciences of Ukraine"

Name of the person authorised to sign: Tetiana A. Bukhtiarova

Position: Director, corresponding member of the National Academy of Medical Sciences of Ukraine

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature:

Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

State Institute "Institute of paediatrics, obstetrics and gynecology named after O. Lukyanova of National Academy of Medical Sciences of Ukraine"

Name of the person authorised to sign: Yurii G. Antypkin

Position: Director, academician of the National Academy of Medical Sciences of Ukr professor

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature: Stamp (if applicable)

# **European Paediatric Translational Research Infrastructure**

## **Ukraine Association of Biobank**

Name of the person authorised to sign: Dr. Svitlana M. Gramatiuk

TAN ANS 3585747A THE MICTO XNOT

Place and Date: 06/03/2020 OSTEM CE

Signature:

Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

Azienda Ospedaliera Universitaria Consorziale Policlinico di Bari
Name of the person authorised to sign:
Position:
Place and Date: BARI 28 AGOSTO 2020
Signature:
IL DIRETTORE GENERALE  Dr. Giovanni MicLiore

# **European Paediatric Translational Research Infrastructure**

# Azienda Ospedaliero Universitaria Meyer

Name of the person authorised to sign: Alberto Zanobini

Position: Chief Executive Officer

Place and Date: Florence, Italy – August 7, 2020

Signature:

Azienda Ospedaliero Universitaria Meyer
Il Direttore Generale
Pr. Alberto Zanobini

# **European Paediatric Translational Research Infrastructure**

Consiglio Nazionale delle Ricerche	
Name of the person authorised to sign:	
Position:	
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Place and Date:	
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# **European Paediatric Translational Research Infrastructure**

# Consorzio per Valutazioni Biologiche e Farmacologiche

Name of the person authorised to sign: Donato Bonifazi

**Position: CEO** 

Place and Date: Bari, 28/07/2020

Signature:

Stamp:

CONSORZIO PER VALUTAZIONI BIOLOGICHE E FARMACOLOGICHE

VIA NICOLÒ PUTIGNANI 178 • 70122 BARI • ITALY TEL. +39 080 97 51 974 • VAT 01897720189 WWW.CVBF.NET • INFO@CVBF.NET

## **European Paediatric Translational Research Infrastructure**

Fondazione Penta for the treatment and care of children with HIV-Onlys - PENTA

Name of the person authorised to sign: CALO GI AQUIND

Position: PRESIDENT

Place and Date: PADOVA (7/07/2020)

Signature: Clo A

## **European Paediatric Translational Research Infrastructure**

# Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus

Name of the person authorised to sign: Fedele Bonifazi

Position: President

Place and Date: Valenzano (BA), 23.07.2020

Signature: Field Parispos

## **European Paediatric Translational Research Infrastructure**

## **Fondazione Telethon**

Name of the person authorised to sign: Manuela Battaglia

Position: Head of Research

Place and Date: Milan, 23/06/2020

Signature:

Stamp:

FONDAZIONE TELETHON

Via Varese, 16 b 00185 Roma

C.F. e P.IVA 04879781005

# **European Paediatric Translational Research Infrastructure**

# **Italian Network for Paediatric Clinical Trials**

Name of the person authorised to sign: Prof. Paolo Rossi

Position: President

Place and Date: Rome, 26-07-2020

Signature:

Stamp: n/a

## **European Paediatric Translational Research Infrastructure**

## Ospedale Pediatrico Bambino Gesù

Name of the person authorised to sign: NARIEUA ENOC

Position: LEGAL REPRESENTATIVE

Place and Date: Rorl , 0105 2020

Signature:

Stamp (if applicable):



## **European Paediatric Translational Research Infrastructure**

## Ospedale Pediatrico Istituto Giannina Gaslini di Genova

Name of the person authorised to sign: Dr. Paolo Petralia

**Position: Director General** 

Place and Date: GENOA, 15 Apr 2020

Signature: L DRETTORE GENERALE (Dr. Proto Petralia)
Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

IRCCS Bur	lo Garoi	folo
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Name of the person authorised to sign: prof. Fabio Barbone	=	
Position: Scientific Director		
Place and Date: Trieste, 09/07/2020		

Stamp:

IRCCS BURLO GAROFOLO - TRIESTE Il Direttore Scientifico prof. Fabio Barbone

## **European Paediatric Translational Research Infrastructure**

## Istituto Ortopedico Rizzoli

Name of the person authorised to sign: DR. ANSELMO CAMPAGNA

Position: DIRETTORE GENERALE

Place and Date: Bolsowa 07/09/2525
Signature:

Stamp:

TETM ( T. NEGOZIBIO BIOUR. A DA VETTORE EGISATISIO DE URA TRE PERSEGO.

## **European Paediatric Translational Research Infrastructure**

IRCCS "Eugenio Medea", Scientific Institute of Associazione "La Nostra Famiglia"

Name of the person authorised to sign: Luisa Minoli

Position: President and Legal Representative

Place and Date: Ponte Lambro, Italy - 23 June 2020

Signature: Cerisolefense:

LA PRESIDENTE

Stamp: dell'Associazione "LA NOSTRA FAMIGLIA"

dr.ssa Luisa Minoli

## European Paediatric Translational Research Infrastructure

# Società Italiana di Farmacologia

Name of the person authorised to sign: Giorgio Racagni

Position: President

Place and Date: MILAN, 31/8/20,20

Signature:

Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

# **TEDDY European Network of Excellence for Paediatric Research**

Name of the person authorised to sign: Annagrazia Altavilla

Position: Chair/Legal Representative

Place and Date: Pavia, 23.07.2020

Signature:

Stamp: N/A

## **European Paediatric Translational Research Infrastructure**

## Università di Bari Aldo Moro

Name of the person authorised to sign: Prof. Stefano Bronzini

**Position: Rector** 

Place and Date: Bari, 31/64/2020

Signature:

IL RETTORE
Stefano BRONZINI

Of Scaling

## **European Paediatric Translational Research Infrastructure**

Università degli Studi di Cagliari

Name of the person authorised to sign: Maria Del Zompo

Position: Rector, Legal Representative University of Cagliari

Place and Date: Cagliari Italy, August 27th 2020

Signature:

Università degli Studi di Cagliari IL RETTORE Prof.ssa Maria Del Zompo



# **European Paediatric Translational Research Infrastructure**

# Università degli Studi di Milano

Name of the person authorised to sign: Elio Franzini

**Position: Rector** 

Place and Date:

MILANO(IT)

[0]2 |SET 2020

Signature:

Stamp:

IL RETTORE

## **European Paediatric Translational Research Infrastructure**

## Dipartimento di Salute della Donna e del Bambino – SDB - Università degli Studi di Padova

Name of the person authorised to sign: Prof. Giorgio Perilongo

Position: Director / Legal Representative

Place and Date: Padova, 04/09/2020

Signature:

Stamp:



Reed O

## **European Paediatric Translational Research Infrastructure**

## Università di Milano Bicocca

Name of the person authorised to sign: Prof. Marco Emilio Orlandi
Position: Deputy Rector
Place and Date: Milan, 8/9/2020
Signature: Digitally Signed in accordance with D.Lgs. 82/2005, Art. 24 – Italian Law
Stamp:

# **European Paediatric Translational Research Infrastructure**

Università degli Studi di Parma

Name of the person authorised to sign:

IL PRORETTORE VICARIO
Paolo Martelli

Position:

Place and Date: PARMA

Signature:

IL PRORETTORE ALCARIC

Stamp:

1

## **European Paediatric Translational Research Infrastructure**

## Università di Pavia

Name of the person authorised to sign: PROF. FRANCESCO SVELTO

**Position: RECTOR** 

Place and Date: PAVIA 26 AUGUST 2020

Signature:

Stamp:

## **European Paediatric Translational Research Infrastructure**

## Centre Hospitalier de Luxembourg

Name of the person authorised to sign: Dr Romain NATI

Position: Directeur général

Place and Date: Luxembourg, 14/05/2020

Signature:

# **European Paediatric Translational Research Infrastructure**

University of Luxembourg, on behalf of its Luxembourg Center for System Biomedicine

Name of the person authorised to sign: Prof. Dr. Jens Kreisel

Position: Vice-Rector for Research

Place and Date: Luxembourg, 27/05/2020

Signature:



## **European Paediatric Translational Research Infrastructure**

## **Luxembourg Institute of Health**

Name of the person authorised to sign: Dr. Ulf NEHRBASS

Position: CEO

Place and Date: Luxembourg, 03 March 2020

Signature:

Stamp (if applicable):

Luxembourg Institute of Health 1A-B, rue Thomas Edison L-1445 Luxembourg Phone: +352 26970-777 Fax: +352 26970-717

## European Paediatric Translational Research Infrastructure

Oslo University Hospital

Name of the person	on authorised to sign:	ERLE	ROOT	WELT
Position: HE	FO ST	PIVISIO	W.	
Place and Date:	Ole	Saul	41.0	700
Signature:	ige	Roslev	0	
Stamn <sup>,</sup>	7			

Stamp:

Terje Footwelt

Head of Division of paedictric and adolescent medicine

Professor, MD, PhD

Oslo University Hospital and University of Calo

Pb. 4956 Nydalen 0424 Oslo, Norway Mobil: +47 95 83 16 31

e-mail: terje.rootwelt@ous-lif.no

# **European Paediatric Translational Research Infrastructure**

**Haukeland University Hospital** 

Name of the person authorised to sign:

RENATE GRÜNER

Position:

Director of Resea

Place and Date:

\$ignature:

Stamp:

## **European Paediatric Translational Research Infrastructure**

## Instytut "Pomnik-Centrum Zdrowia Dziecka"

Name of the person authorised to sign: dr. n. med. Marek Migdał

Position: CEO of the Instytut "Pomnik-Centrum Zdrowia Dziecka"

Place and Date: Wayaw

8th June, 2020

Signature:

dr n. med. Marek Migdał

Stamp:

INSTYTUT

Pomnik "Centrum Zdrowia Dziecka" 04-730 Warszawa, Al. Dzieci Polskich 20 Regon 000557961; NIP 952-11-43-675

# **European Paediatric Translational Research Infrastructure**

# **Medical University of Gdansk**

Name of the person authorised to sign: Marcin Gruchała

REKTOR

Place and Date: Golonia 14.05.2020

Signature:

GDAŃSKI UNIWERSYTET MEDYCZNY

80-210 Gdańsk

Stamp (if applicablesk todowskiej-Curie 3A NIP: 584-09-55-985

# **European Paediatric Translational Research Infrastructure**

# Instituto Universitário Egas Moniz

Name of the person authorised to sign: JOSÉ JOAO BALTAZAR MENDES

Position: PRESIDENT

Place and Date: Monte de Capacica, 27-05-2020

Signature:

Stamp (if applicable): 35 this in o supra

## **European Paediatric Translational Research Infrastructure**

#### Universidade de Lisboa

Name of the person authorised to sign: Prof. Doutor António Manuel da Cruz Serra

**Position: Rector** 

Signature:

Place and Date: 08/05/2020

Assinado com Assinatura

Digital Qualificada por:

ANTÓNIO MANUEL DA CRUZ

**SERRA** 

Universidade de Lisboa

Data: 08-05-2020 12:04:11

## **European Paediatric Translational Research Infrastructure**

## **Fundatia Romanian Angel Appeal**

Name of the person authorised to sign: Silvia ASANDI

Position: General Manager

Place and Date: Bucharest, 10 June 2020

Signature:

Stamp:

## **European Paediatric Translational Research Infrastructure**

## University of Medicine and Pharmacy "Iuliu Hatieganu", Cluj-Napoca

Name of the person authorised to sign: Prof. Dr. A	nca Dana Bazolana
Position: Rector	ANNW TO THE

Place and Date:
CLUZ - NAPOCH, 15.06, 2020

Signature:

Stamp:

## **European Paediatric Translational Research Infrastructure**

## Center for Strategic Research «North-West» Foundation

Name of the person authorised to sign: Marina Lipetskaya

**Position: Director** 

Place and Date: Saint Petersburg, Russia, 12th March 2020

Signature:

## **European Paediatric Translational Research Infrastructure**

# National Research Lobachevsky State University of Nizhny Novgorod

Name of the person authorised to sign: Prof. Viktor Kazantsev

Position: Head of the Department of Neurotechnology (Institute of Biology and Biomedicine)

Place and Date: Nizhny Novgorod, 11.05.2020 Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

# Samara State Medical University

Name of the person authorised to sign: Prof. Alexander Kolsanov

Position: Rector

Place and Date: Samara, 12.03.2020

Signature:

## **European Paediatric Translational Research Infrastructure**

## **University Medical Centre Ljubljana**

Name of the person authorised to sign: JANEZ POKLUKAR

Position: Director General

Place and Date: Ljubljana, January 30th, 2020

Signature:

# **European Paediatric Translational Research Infrastructure**

Ljubljana

## **University of Ljubljana**

Name of the person authorised to sign: Igor Papič

Position: Rector

Place and Date: Ljubljana, February 4, 2020

Signature:

Stamp (if applicable)

PO POOBLASTILU: BY AUTHORITY OF:

prof. dr. Matjaž Krajne prorektor/vice-rector



## **European Paediatric Translational Research Infrastructure**

Fundació	Sant Joan	de	Déu
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Name of the person authorised to sign: Emili Bargalló Angerri

**Position: Director** 

Place and Date: Carrer Santa Rosa, 39-57, 3<sup>rd</sup> floor, 08950 Esplugues de Llobregat, Barcelona,

Spain

Signature:

## **European Paediatric Translational Research Infrastructure**

## Fundación para la Investigación Biomédica del Hospital Universitario La Paz

Name of the person authorised to sign: Ana Coloma Zapatero

**Position: Director** 

Place and Date: Madrid, 18th May 2020

Signature:

Stamp (if applicable):

29151547J ANA

Firmado digitalmente por 29151547J ANA ALICIA
COLOMA (R: G83727057)

Nombre de reconocimiento (DN): 25.4.13=Ref.AEAT/
AEATTR3117/PUSTO 1/39706/26122018132702,

serialNumber=IDCE5-29151547J, givenName=ANA
ALICIA COLOMA (R: G83727057, 25.497=VATEATO)

ALICIA COLOMA (R: G83727057, 25.497=VATEATO)

(R: G83727057, 0=FUNDACION PARA LA
INVESTIGACION BIOMEDICA DEL HOSPITAL
UNIVERSITARIO LA PAZ, CeES
Fecha: 2020.05.18 21:01:04 +02:00\*

## **European Paediatric Translational Research Infrastructure**

## Servizo Galego de Saúde

Name of the person authorised to sign: Antonio Fernández-Campa García-Bernardo

Position: Manager of SERGAS

Place and Date: Santiago de Compostela, 30 June 2020

Signature:

Stamp:



## **European Paediatric Translational Research Infrastructure**

## Universidad de La Laguna

Name of the person authorized to sign: Prof. Dr. Ernesto Pereda De Pablo,

Position: Vice-rector of Research and Transfer of Knowle

Place and Date: Tenerife (SPAIN), June 7th, 2020

Signature:

43809972D Digitally signed by 43809972D ERNESTO ERNESTO PEREDA (R: Q3818001D) Date: 2020.06.08 14:28:12 +01'00'

Stamp:

C/ Padre Herrera s/n 38207 La Laguna Santa Cruz de Tenerife. España

## **European Paediatric Translational Research Infrastructure**

#### **Universität Bern**

Name of the person authorised to sign: Prof. Christiane Albrecht

Position: PI

Place and Date: Bern, 11th of August, 2020

Signature:

Stamp:

Prof. Dr. Christiane Albrecht Institut für Biochemie und Molekulare Medizin Universität Bern Bühlstrasse 28 CH-3012 Bern, Schweiz

## **European Paediatric Translational Research Infrastructure**

## **Stitching Duchenne Data Foundation**

Name of the person authorised to sign: George Paliouras

Position: Chairman of DDF

Place and Date:

Athens (Greece), June 1st 2020

Signature:

Stamp (if applicable):

DUCHENNE DATA FOUNDATION

Duchenne Data Foundation Warmoesdreef 10 4614 HC Bergen op Zoom The Netherlands Chamber of Commerce: 64601188

## **European Paediatric Translational Research Infrastructure**

## **Stichting Katholieke Universiteit**

Name of the person authorised to sign: dr. Eric Caldenhoven

**Position: Head Grant Support Office** 

Place and Date: Nijmegen

Signature:

Dr. Eric Caldenhoven 2020.05.06 11:00:38

+02'00'

#### **European Paediatric Translational Research Infrastructure**

#### **Universiteit Leiden**

Name of the person authorised to sign: Prof do. Hubertus Irth

Position: Scientific Director

Place and Date: Leiden, 30-6-2025

Signature:

Stamp:

## **European Paediatric Translational Research Infrastructure**

## **Alder Hey Children's NHS Foundation Trust**

Name of the person authorised to sign: Professor Matthew Peak

Position: Director of Research

Place and Date: Alder Hey Children's NHS Foundation Trust, Eaton Toad, Liverpool, L12 2AP, UK

12<sup>th</sup> May 2020

Signature:

Alder Hey Children's NHS Foundation Trust

Stamp:

## **European Paediatric Translational Research Infrastructure**

## **Cardiff University**

Name of the person authorised to sign: Dr Elid Morris

Position: Head of Research Grants

Place and Date: Cardiff, Wales, United Kingdom, 11th June 2020

Signature:

Dr Elid Morris Head of Research Grants Office

Stamp: Research and innovation Services

## **European Paediatric Translational Research Infrastructure**

# Name of the person authorised to sign: Professor Brian Walker Position: Pro-Vice-Chancellor, Research Strategy and Resources Place and Date: Newcastle upon Tyne, 04/05/2020 Signature:

#### **European Paediatric Translational Research Infrastructure**

#### Sheffield Children's NHS Foundation Trust

Name of the person authorised to sign: Prof. Paul Dimitri

Position: Professor of Child Health; Director of Research and Innovation

Place and Date: Sheffield, UK; 27th March 2020

Signature

Stamp:

Professor Paul Dimitri

Director of Research & Innovation

Sheffield Children's NHS Foundation Trust

## **European Paediatric Translational Research Infrastructure**

## **University of Liverpool**

Name of the person authorised to sign:

Position:

David McVey

Solicitor - Head of Research Contracts

Legal & Compliance

University of Liverpool

Place and Date: Liverped / 8/6/20

Signature:

Stamp:

ţ.

## **European Paediatric Translational Research Infrastructure**

## **University of Nottingham**

Name of the person authorised to sign: Rachel Brereton

Position: Director of Research & Innovation Operations

Place and Date: Nottingham, 12/05/2020

Signature:

Stamp (if applicable):

Rachel Brereton

Director of
Research & Innovation Operations

University of
Nottingham

University of Nottinghem

## **European Paediatric Translational Research Infrastructure**

State Institution "Institute of Genetic and Regenerative Medicine of National Academy Medical Sciences of Ukraine"

Name of the person authorised to sign: Gennady M. Butenko

Position: Director, academician of the National Academy of Medical Sciences of Ukraine, professor

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature:

#### **European Paediatric Translational Research Infrastructure**

State Institution "Institute of Pharmacology and Toxicology of National Academy of Medical Sciences of Ukraine"

Name of the person authorised to sign: Tetiana A. Bukhtiarova

Position: Director, corresponding member of the National Academy of Medical Sciences of Ukraine

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature:

### **European Paediatric Translational Research Infrastructure**

State Institute "Institute of paediatrics, obstetrics and gynecology named after O. Lukyanova of National Academy of Medical Sciences of Ukraine"

Name of the person authorised to sign: Yurii G. Antypkin

Position: Director, academician of the National Academy of Medical Sciences of Ukr professor

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature: Stamp (if applicable)

### **European Paediatric Translational Research Infrastructure**

#### **Ukraine Association of Biobank**

Name of the person authorised to sign: Dr. Svitlana M. Gramatiuk

TAN ANS SESTATA AND THE MICTO XNOT

Place and Date: 06/03/2020 OSTEM CE

Signature:

Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

Azienda Ospedaliera Universitaria Consorziale Policlinico di Bari
Name of the person authorised to sign:
Position:
Place and Date: BARI 28 AGOSTO 2020
Signature:
IL DIRETTORE GENERALE  Pr. Giovanni MicLiore

## **European Paediatric Translational Research Infrastructure**

## Azienda Ospedaliero Universitaria Meyer

Name of the person authorised to sign: Alberto Zanobini

Position: Chief Executive Officer

Place and Date: Florence, Italy – August 7, 2020

Signature:

Azienda Ospedaliero Universitaria Meyer
Il Direttore Generale
Pr. Alberto Zanobini

## **European Paediatric Translational Research Infrastructure**

Consiglio Nazionale delle Ricerche	
Name of the person authorised to sign:	
Position:	
Diameter (	
Place and Date:	
Signature:	INGUSCIO MASSIMO 05.08.2020 09:02:44 CEST
oignature.	Monim luguri:
Stamp:	
Stamp:	,

## **European Paediatric Translational Research Infrastructure**

## Consorzio per Valutazioni Biologiche e Farmacologiche

Name of the person authorised to sign: Donato Bonifazi

**Position: CEO** 

Place and Date: Bari, 28/07/2020

Signature:

Stamp:

CONSORZIO PER VALUTAZIONI BIOLOGICHE E FARMACOLOGICHE

VIA NICOLÒ PUTIGNANI 178 • 70122 BARI • ITALY TEL. +39 080 97 51 974 • VAT 01897720189 WWW.CVBF.NET • INFO@CVBF.NET

#### **European Paediatric Translational Research Infrastructure**

Fondazione Penta for the treatment and care of children with HIV-Onlys - PENTA

Name of the person authorised to sign: CALO GI AQUIND

Position: PRESIDENT

Place and Date: PADOVA (7/07/2020)

Signature: Clo A

#### **European Paediatric Translational Research Infrastructure**

## Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus

Name of the person authorised to sign: Fedele Bonifazi

Position: President

Place and Date: Valenzano (BA), 23.07.2020

Signature: Field Parispos

#### **European Paediatric Translational Research Infrastructure**

#### **Fondazione Telethon**

Name of the person authorised to sign: Manuela Battaglia

Position: Head of Research

Place and Date: Milan, 23/06/2020

Signature:

Stamp:

FONDAZIONE TELETHON

Via Varese, 16 b 00185 Roma

C.F. e P.IVA 04879781005

### **European Paediatric Translational Research Infrastructure**

### **Italian Network for Paediatric Clinical Trials**

Name of the person authorised to sign: Prof. Paolo Rossi

Position: President

Place and Date: Rome, 26-07-2020

Signature:

Stamp: n/a

#### **European Paediatric Translational Research Infrastructure**

#### Ospedale Pediatrico Bambino Gesù

Name of the person authorised to sign: NARIEUA ENOC

Position: LEGAL REPRESENTATIVE

Place and Date: Rorl , 0105 2020

Signature:

Stamp (if applicable):



#### **European Paediatric Translational Research Infrastructure**

#### Ospedale Pediatrico Istituto Giannina Gaslini di Genova

Name of the person authorised to sign: Dr. Paolo Petralia

Position: Director General

Place and Date: GENOA, 15 Apr 2020

Signature: L DRETTORE GENERALE (Dr. Proto Petralia)
Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

IRCCS Bur	lo Garoi	folo
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Name of the person authorised to sign: prof. Fabio Barbone	=	
Position: Scientific Director		
Place and Date: Trieste, 09/07/2020		

Stamp:

IRCCS BURLO GAROFOLO - TRIESTE Il Direttore Scientifico prof. Fabio Barbone

#### **European Paediatric Translational Research Infrastructure**

#### Istituto Ortopedico Rizzoli

Name of the person authorised to sign: DR. ANSELMO CAMPAGNA

Position: DIRETTORE GENERALE

Place and Date: Bolsowa 07/09/2525
Signature:

Stamp:

TETM ( T. NEGOZIBIO BIOUR. A DA VETTORE EGISATISIO DE URA TRE PERSEGO.

#### **European Paediatric Translational Research Infrastructure**

IRCCS "Eugenio Medea", Scientific Institute of Associazione "La Nostra Famiglia"

Name of the person authorised to sign: Luisa Minoli

Position: President and Legal Representative

Place and Date: Ponte Lambro, Italy - 23 June 2020

Signature: Cerisolefense:

LA PRESIDENTE

Stamp: dell'Associazione "LA NOSTRA FAMIGLIA"

dr.ssa Luisa Minoli

#### European Paediatric Translational Research Infrastructure

### Società Italiana di Farmacologia

Name of the person authorised to sign: Giorgio Racagni

Position: President

Place and Date: MILAN, 31/8/20,20

Signature:

Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

# **TEDDY European Network of Excellence for Paediatric Research**

Name of the person authorised to sign: Annagrazia Altavilla

Position: Chair/Legal Representative

Place and Date: Pavia, 23.07.2020

Signature:

Stamp: N/A

#### **European Paediatric Translational Research Infrastructure**

#### Università di Bari Aldo Moro

Name of the person authorised to sign: Prof. Stefano Bronzini

**Position: Rector** 

Place and Date: Bari, 31/64/2020

Signature:

IL RETTORE
Stefano BRONZINI

Of Scaling

#### **European Paediatric Translational Research Infrastructure**

Università degli Studi di Cagliari

Name of the person authorised to sign: Maria Del Zompo

Position: Rector, Legal Representative University of Cagliari

Place and Date: Cagliari Italy, August 27th 2020

Signature:

Università degli Studi di Cagliari IL RETTORE Prof.ssa Maria Del Zompo



## **European Paediatric Translational Research Infrastructure**

## Università degli Studi di Milano

Name of the person authorised to sign: Elio Franzini

**Position: Rector** 

Place and Date:

MILANO(IT)

[0]2 |SET 2020

Signature:

Stamp:

IL RETTORE

#### **European Paediatric Translational Research Infrastructure**

## Dipartimento di Salute della Donna e del Bambino – SDB - Università degli Studi di Padova

Name of the person authorised to sign: Prof. Giorgio Perilongo

Position: Director / Legal Representative

Place and Date: Padova, 04/09/2020

Signature:

Stamp:



Reed O

## **European Paediatric Translational Research Infrastructure**

#### Università di Milano Bicocca

Name of the person authorised to sign: Prof. Marco Emilio Orlandi
Position: Deputy Rector
Place and Date: Milan, 8/9/2020
Signature: Digitally Signed in accordance with D.Lgs. 82/2005, Art. 24 – Italian Law
Stamp:

# **European Paediatric Translational Research Infrastructure**

Università degli Studi di Parma

Name of the person authorised to sign:

IL PRORETTORE VICARIO
Paolo Martelli

Position:

Place and Date: PARMA

Signature:

IL PRORETTORE ALCARIC

Stamp:

1

#### **European Paediatric Translational Research Infrastructure**

#### Università di Pavia

Name of the person authorised to sign: PROF. FRANCESCO SVELTO

**Position: RECTOR** 

Place and Date: PAVIA 26 AUGUST 2020

Signature:

#### **European Paediatric Translational Research Infrastructure**

### Centre Hospitalier de Luxembourg

Name of the person authorised to sign: Dr Romain NATI

Position: Directeur général

Place and Date: Luxembourg, 14/05/2020

Signature:

Stamp (if applicable):

## **European Paediatric Translational Research Infrastructure**

University of Luxembourg, on behalf of its Luxembourg Center for System Biomedicine

Name of the person authorised to sign: Prof. Dr. Jens Kreisel

Position: Vice-Rector for Research

Place and Date: Luxembourg, 27/05/2020

Signature:

Stamp (if applicable):



## **European Paediatric Translational Research Infrastructure**

## **Luxembourg Institute of Health**

Name of the person authorised to sign: Dr. Ulf NEHRBASS

Position: CEO

Place and Date: Luxembourg, 03 March 2020

Signature:

Stamp (if applicable):

Luxembourg Institute of Health 1A-B, rue Thomas Edison L-1445 Luxembourg Phone: +352 26970-777 Fax: +352 26970-717

## European Paediatric Translational Research Infrastructure

Oslo University Hospital

Name of the person	on authorised to sign:	ERLE	ROOT	WELT
Position: HE	FO ST	PIVISIO	W.	
Place and Date:	Ole	Saul	41.0	700
Signature:	ige	Roslev	0	
Stamn <sup>,</sup>	7			

Stamp:

Terje Footwelt

Head of Division of paedictric and adolescent medicine

Professor, MD, PhD

Oslo University Hospital and University of Calo

Pb. 4956 Nydalen 0424 Oslo, Norway Mobil: +47 95 83 16 31

e-mail: terje.rootwelt@ous-lif.no

## **European Paediatric Translational Research Infrastructure**

**Haukeland University Hospital** 

Name of the person authorised to sign:

RENATE GRÜNER

Position:

Director of Resea

Place and Date:

\$ignature:

#### **European Paediatric Translational Research Infrastructure**

#### Instytut "Pomnik-Centrum Zdrowia Dziecka"

Name of the person authorised to sign: dr. n. med. Marek Migdał

Position: CEO of the Instytut "Pomnik-Centrum Zdrowia Dziecka"

Place and Date: Wayaw

8th June, 2020

Signature:

dr n. med. Marek Migdał

Stamp:

INSTYTUT

Pomnik "Centrum Zdrowia Dziecka" 04-730 Warszawa, Al. Dzieci Polskich 20 Regon 000557961; NIP 952-11-43-675

# **European Paediatric Translational Research Infrastructure**

## **Medical University of Gdansk**

Name of the person authorised to sign: Marcin Gruchała

REKTOR

Place and Date: Golonia 14.05.2020

Signature:

GDAŃSKI UNIWERSYTET MEDYCZNY

80-210 Gdańsk

Stamp (if applicablesk todowskiej-Curie 3A NIP: 584-09-55-985

# **European Paediatric Translational Research Infrastructure**

# Instituto Universitário Egas Moniz

Name of the person authorised to sign: JOSÉ JOAO BALTAZAR MENDES

Position: PRESIDENT

Place and Date: Monte de Capacica, 27-05-2020

Signature:

Stamp (if applicable): 35 this in o supra

#### **European Paediatric Translational Research Infrastructure**

#### Universidade de Lisboa

Name of the person authorised to sign: Prof. Doutor António Manuel da Cruz Serra

**Position: Rector** 

Signature:

Place and Date: 08/05/2020

Assinado com Assinatura

Digital Qualificada por:

ANTÓNIO MANUEL DA CRUZ

**SERRA** 

Universidade de Lisboa

Data: 08-05-2020 12:04:11

Stamp (if applicable):

#### **European Paediatric Translational Research Infrastructure**

## **Fundatia Romanian Angel Appeal**

Name of the person authorised to sign: Silvia ASANDI

Position: General Manager

Place and Date: Bucharest, 10 June 2020

Signature:

#### **European Paediatric Translational Research Infrastructure**

#### University of Medicine and Pharmacy "Iuliu Hatieganu", Cluj-Napoca

Name of the person authorised to sign: Prof. Dr. A	nca Dana Bazolana
Position: Rector	ANNW TO THE

Place and Date:
CLUZ - NAPOCH, 15.06, 2020

Signature:

## **European Paediatric Translational Research Infrastructure**

## Center for Strategic Research «North-West» Foundation

Name of the person authorised to sign: Marina Lipetskaya

**Position: Director** 

Place and Date: Saint Petersburg, Russia, 12th March 2020

Signature:

Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

# National Research Lobachevsky State University of Nizhny Novgorod

Name of the person authorised to sign: Prof. Viktor Kazantsev

Position: Head of the Department of Neurotechnology (Institute of Biology and Biomedicine)

Place and Date: Nizhny Novgorod, 11.05.2020 Stamp (if applicable):

# **European Paediatric Translational Research Infrastructure**

# Samara State Medical University

Name of the person authorised to sign: Prof. Alexander Kolsanov

Position: Rector

Place and Date: Samara, 12.03.2020

Signature:

#### **European Paediatric Translational Research Infrastructure**

# **University Medical Centre Ljubljana**

Name of the person authorised to sign: JANEZ POKLUKAR

Position: Director General

Place and Date: Ljubljana, January 30th, 2020

Signature:

# **European Paediatric Translational Research Infrastructure**

Ljubljana

# **University of Ljubljana**

Name of the person authorised to sign: Igor Papič

Position: Rector

Place and Date: Ljubljana, February 4, 2020

Signature:

Stamp (if applicable)

PO POOBLASTILU: BY AUTHORITY OF:

prof. dr. Matjaž Krajne prorektor/vice-rector



#### **European Paediatric Translational Research Infrastructure**

Fundació S	Sant Joan	de	Déu
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Name of the person authorised to sign: Emili Bargalló Angerri

**Position: Director** 

Place and Date: Carrer Santa Rosa, 39-57, 3<sup>rd</sup> floor, 08950 Esplugues de Llobregat, Barcelona,

Spain

Signature:

#### **European Paediatric Translational Research Infrastructure**

# Fundación para la Investigación Biomédica del Hospital Universitario La Paz

Name of the person authorised to sign: Ana Coloma Zapatero

**Position: Director** 

Place and Date: Madrid, 18th May 2020

Signature:

Stamp (if applicable):

29151547J ANA

Firmado digitalmente por 29151547J ANA ALICIA
COLOMA (R: G83727057)

Nombre de reconocimiento (DN): 25.4.13=Ref.AEAT/
AEATTR3117/PUSTO 1/39706/26122018132702,

serialNumber=IDCE5-29151547J, givenName=ANA
ALICIA COLOMA (R: G83727057, 25.497=VATEATO)

ALICIA COLOMA (R: G83727057, 25.497=VATEATO)

(R: G83727057, 0=FUNDACION PARA LA
INVESTIGACION BIOMEDICA DEL HOSPITAL
UNIVERSITARIO LA PAZ, CeES
Fecha: 2020.05.18 21:01:04 +02:00

#### **European Paediatric Translational Research Infrastructure**

## Servizo Galego de Saúde

Name of the person authorised to sign: Antonio Fernández-Campa García-Bernardo

Position: Manager of SERGAS

Place and Date: Santiago de Compostela, 30 June 2020

Signature:

Stamp:



# **European Paediatric Translational Research Infrastructure**

# Universidad de La Laguna

Name of the person authorized to sign: Prof. Dr. Ernesto Pereda De Pablo,

Position: Vice-rector of Research and Transfer of Knowle

Place and Date: Tenerife (SPAIN), June 7th, 2020

Signature:

43809972D Digitally signed by 43809972D ERNESTO ERNESTO PEREDA (R: Q3818001D) Date: 2020.06.08 14:28:12 +01'00'

Stamp:

C/ Padre Herrera s/n 38207 La Laguna Santa Cruz de Tenerife. España

#### **European Paediatric Translational Research Infrastructure**

#### **Universität Bern**

Name of the person authorised to sign: Prof. Christiane Albrecht

Position: PI

Place and Date: Bern, 11th of August, 2020

Signature:

Stamp:

Prof. Dr. Christiane Albrecht Institut für Biochemie und Molekulare Medizin Universität Bern Bühlstrasse 28 CH-3012 Bern, Schweiz

#### **European Paediatric Translational Research Infrastructure**

#### **Erasmus MC Kanker Instituut**

Name of the person authorised to sign:

Position:

Place and Date:

Executive Board
Rothnolon, September 4 2020

Signature:

Stamp:

Dr. J.G. Boonstra Lid Raad van Bestuur Erasmus MC

#### **European Paediatric Translational Research Infrastructure**

#### **Stitching Duchenne Data Foundation**

Name of the person authorised to sign: George Paliouras

Position: Chairman of DDF

Place and Date:

Athens (Greece), June 1st 2020

Signature:

Stamp (if applicable):

DUCHENNE DATA FOUNDATION

Duchenne Data Foundation Warmoesdreef 10 4614 HC Bergen op Zoom The Netherlands Chamber of Commerce: 64601188

#### **European Paediatric Translational Research Infrastructure**

# **Stichting Katholieke Universiteit**

Name of the person authorised to sign: dr. Eric Caldenhoven

**Position: Head Grant Support Office** 

Place and Date: Nijmegen

Signature:

Dr. Eric Caldenhoven 2020.05.06 11:00:38

+02'00'

#### **European Paediatric Translational Research Infrastructure**

#### **Universiteit Leiden**

Name of the person authorised to sign: Prof do. Hubertus Irth

Position: Scientific Director

Place and Date: Leiden, 30-6-2025

Signature:

Stamp:

## **European Paediatric Translational Research Infrastructure**

#### **Alder Hey Children's NHS Foundation Trust**

Name of the person authorised to sign: Professor Matthew Peak

Position: Director of Research

Place and Date: Alder Hey Children's NHS Foundation Trust, Eaton Toad, Liverpool, L12 2AP, UK

12<sup>th</sup> May 2020

Signature:

Alder Hey Children's NHS Foundation Trust

Stamp:

#### **European Paediatric Translational Research Infrastructure**

# **Cardiff University**

Name of the person authorised to sign: Dr Elid Morris

Position: Head of Research Grants

Place and Date: Cardiff, Wales, United Kingdom, 11th June 2020

Signature:

Dr Elid Morris Head of Research Grants Office

Stamp: Research and innovation Services

#### **European Paediatric Translational Research Infrastructure**

# Name of the person authorised to sign: Professor Brian Walker Position: Pro-Vice-Chancellor, Research Strategy and Resources Place and Date: Newcastle upon Tyne, 04/05/2020 Signature:

#### **European Paediatric Translational Research Infrastructure**

#### Sheffield Children's NHS Foundation Trust

Name of the person authorised to sign: Prof. Paul Dimitri

Position: Professor of Child Health; Director of Research and Innovation

Place and Date: Sheffield, UK; 27th March 2020

Signature

Stamp:

Professor Paul Dimitri

Director of Research & Innovation

Sheffield Children's NHS Foundation Trust

#### **European Paediatric Translational Research Infrastructure**

# **University College London**

Name of the person authorised to sign: Giles Machell

Position: Head of EC Contract Management

Place and Date: 9.9.20 London

Signature:

Stamp:

University College London Gower Street London WC1E 6BT

## **European Paediatric Translational Research Infrastructure**

#### **University of Liverpool**

Name of the person authorised to sign:

Position:

David McVey

Solicitor - Head of Research Contracts

Legal & Compliance

University of Liverpool

Place and Date: Liverped / 8/6/20

Signature:

Stamp:

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# **European Paediatric Translational Research Infrastructure**

#### **University of Nottingham**

Name of the person authorised to sign: Rachel Brereton

Position: Director of Research & Innovation Operations

Place and Date: Nottingham, 12/05/2020

Signature:

Stamp (if applicable):

Rachel Brereton

Director of
Research & Innovation Operations

University of
Nottingham

University of Nottinghem

# **European Paediatric Translational Research Infrastructure**

RE Kavetsky Institute of Experimental Pathology, Oncology and Radiobiology, NAS of Ukraine

Name of the person authorised to sign: Vasylii F. Chekhun

Position: Director, academician of National Academy of Sciences of Ukraine, professor

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature Remain

Stamp (if applicable)

ЕКСТИЕНИМЕНТАЛЬНОЇ ПАТОЛОГІЇ, ОНКОЛОГІЇ І РАДІОВІОЛОГІЇ ім. Р.Є. Кавецького в Івентифікациний

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#### **European Paediatric Translational Research Infrastructure**

State Institution "Institute of Genetic and Regenerative Medicine of National Academy Medical Sciences of Ukraine"

Name of the person authorised to sign: Gennady M. Butenko

Position: Director, academician of the National Academy of Medical Sciences of Ukraine, professor

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature:

#### **European Paediatric Translational Research Infrastructure**

State Institution "Institute of Pharmacology and Toxicology of National Academy of Medical Sciences of Ukraine"

Name of the person authorised to sign: Tetiana A. Bukhtiarova

Position: Director, corresponding member of the National Academy of Medical Sciences of Ukraine

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature:

# **European Paediatric Translational Research Infrastructure**

State Institute "Institute of paediatrics, obstetrics and gynecology named after O. Lukyanova of National Academy of Medical Sciences of Ukraine"

Name of the person authorised to sign: Yurii G. Antypkin

Position: Director, academician of the National Academy of Medical Sciences of Ukr professor

Place and Date: Kyiv, Ukraine, 1 March 2020

Signature: Stamp (if applicable)

# **European Paediatric Translational Research Infrastructure**

#### **Ukraine Association of Biobank**

Name of the person authorised to sign: Dr. Svitlana M. Gramatiuk

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Place and Date: 06/03/2020 OSTEM CE

Signature: