

INTERNATIONAL REGISTRY OF CONGENITAL PORTO-SYSTEMIC SHUNTS (IRCPSS)

WORKING GROUP - TERMS OF REFERENCE

1.) Background and Rationale

IRCPSS is an international consortium of centers treating children and adults. Its main objective is to record congenital porto-systemic shunts (CPSS) with the aim to understanding their natural history and prevalence.

At present, this rare clinical problem affecting both children and adults is managed and studied in a few specialized centers thereby lending itself well to the creation of a collaborative registry with the goals to a) characterize the natural history of CPSS b) develop a clear, consensual nomenclature c) identify subjects at risk of developing complications and d) standardize care of patients with CPSS.

2.) Terms

This Terms of Reference (ToR) is effective from 20.04.2018 and will be ongoing until terminated by agreement between the parties.

3.) Participants

Principal Investigator:

Prof. V. McLin in Geneva (Switzerland)

Steering Committee Members:

Prof. Maurice Beghetti (Cardiology)

Prof. Dominique Debray, MD, PhD (Pediatric Hepatology)

Prof. Emmanuel Gonzales (Pediatric Hepatology)

Prof. Valérie McLin (Pediatric Hepatology)

Dr Florent Guérin (Pediatric Surgery)

Prof. Barbara E. Wildhaber (Pediatric Surgery)

Dr Marco Zambelli (Pediatric Surgery)

Prof. Stéphanie Franchi-Abella, MD, PhD (Diagnostic/Interventional Radiology)

Dr PD Anne-Lise Hachulla (Diagnostic/Interventional Radiology)

Prof. Marie-Victoire Senat (Obstetrics)

Dr Laurent Savale, MD, PhD (Pulmonology)

Advisory Committee Members:

Dr Olivia Boyer (Nephrology)

Dr Michele Colledan (Surgery)

Dr Jean de Ville de Goyet (Surgery)

**UNITE DE GASTROENTEROLOGIE HEPATOLOGIE ET
NUTRITION PEDIATRIQUES**

Département de la femme, de l'enfant et de l'adolescent
Rue Willy-Donzé 6
CH – 1205 Genève

Prof. Mark Davenport (Surgery)
Dr Simone Kathemann (Endocrinology)
Dr Christian Korff (Pediatric Neurology)
Dr. Anne-Laure Rougemont (Pathology)
Prof. Catherine Guettier (Pathology)
Dr Maxime Ronot (Radiology)
Dr Frédéric Lador (pneumonology)

Partners:

Dr José Ernesto Lipsich MD - ARGENTINA
Prof. Winita Hardikar FRACP PhD -AUSTRALIA
Prof. Xavier Stephenne –BELGIUM
Dr Peter Witters- BELGIUM
Dr Simon C. Ling, MBChB – CANADA
Dr Stéphanie Franchi-Abella, MD, PhD – FRANCE
Prof. Dominique Debray, MD, PhD – FRANCE
Dr Maxime Ronot MD PhD – FRANCE
Dr Aurélie Plessier - FRANCE
Dr. med. Simone Kathemann - GERMANY
Dr. Ekkehard Sturm, MD PhD - GERMANY
Dr. med. Eberhard Lurz - GERMANY
Prof. Dr. med. Philip Bufler - GERMANY
Dr Ino Kanavaki – GREECE
Dr Sharat Varma – INDIA
Dr Yael Mozer-Glassberg, MD – ISRAEL
Dr. Eyal Shteyer – ISRAEL
Dr Jean de Ville de Goyet – ITALY
Dr Chiara Grimaldi – ITALY
Dr Michele Colledan, MD, FEBS – ITALY
Dr. Isabel Gonçalves, MD – PORTUGAL
Prof. Tudor Lucian Pop, MD PhD – ROMANIA
Dr Loreto Hierro – SPAIN
Dr Maria Magnusson, MD, PhD – SWEDEN
Prof. Valérie McLin – SWITZERLAND
Dr Patrick Buehr - SWITZERLAND
Dr Frank Bodewes, MD, PhD - THE NETHERLANDS
Dr Bart GP Koot - THE NETHERLANDS
Prof Ozlem Durmaz Ugurcan – TURKEY
Dr Girish Gupte - UNITED KINGDOM
Dr Mark Davenport - UNITED KINGDOM
Dr Rajesh Krishnamurthy, MD - UNITED STATES OF AMERICA

4.) Roles and responsibilities

The IRCPSS includes 34 centers as of October 2018 and Prof. V. McLin in Geneva (Switzerland) is the Principal Investigator for the project. All centers are considered partners of the IRCPSS. There is one representative per center. Larger volume centers may have two representatives.

The Principle Investigators of each center are responsible for communicating with the members of their respective groups. This list is currently preliminary as additional groups will join the consortium in the future.

The **Steering Committee** (SC) oversees the development, planning, implementation, maintenance and scientific productivity of the IRCPSS. The members are responsible for providing scientific oversight and approval of ancillary projects. They also ensure that this Memorandum/data sharing agreement is properly implemented. Each SC member will participate actively in fund raising for the project. They are tasked with communicating on IRCPSS activities and to encourage the publication and dissemination of IRCPSS results. Their role also includes increasing awareness about this malformation and liaising with colleagues of other medical disciplines who may see patients with this rare malformation.

The SC members are the founding members and any other member who has contributed significantly to the development of IRCPSS. The significance of the contribution is evaluated and voted on by the SC (majority). SC members serve three year terms as either Chair, Vice-chair, Secretary, or Treasurer. A term is renewable once. Any new member will be put to the vote of the SC. Any change in the roles of members will be put to a vote. When a vote ends in a tie, the Chair's vote is final.

The SC is assisted by the expertise of members of the **Advisory Committee** which includes experts in disciplines of interest in the assessment of the natural history of CPSS.

5.) Chair

The working group is chaired by one of the members of the SC for a maximum of 3 years with the possibility of a one-time renewal, which means a maximum of 6 years for each chair. The chair is elected by the SC.

6.) Meetings

SC members meet physically at least once per year for a 1-2-day meeting. In addition, a quarterly teleconference is held. Frequency of meetings may increase as the registry develops. SC members will also evaluate each submission for ancillary projects. Voting will be held during quarterly teleconferences.

7.) Amendment, Modification or Variation

This ToR may be amended, varied or modified in writing after consultation and agreement by the SC members.