

# **ESPGHAN Network of Intestinal Failure and Intestinal Transplantation in Europe (NITE)**

## Terms of Reference (Version March 2019)

Chairperson : Jutta Köglmeier (1<sup>st</sup> Term 2016-2019, 2<sup>nd</sup> term 2019-2022)

### **Steering group :**

Jutta Köglmeier,  
Girish Gupte,  
Florence Lacaille,  
Lorenzo D'Antiga,  
Andreas Busch

### Definition of the group:

Network of Intestinal Failure and Intestinal Transplant in Europe (NITE) is an open group of ESPGHAN, the goals of which are to generate collaborative international research and to provide a leadership role concerning current management of Intestinal Failure and Intestinal Transplantation in children and adolescents living in Europe. It will include all ESPGHAN members who wish to participate in all activities generated inside the network.

### Aims:

1. To improve medical care for children with Intestinal Failure and following Intestinal Transplantation, by promoting good clinical practice through professional educational tools, lectures and publications.
2. To develop management guidelines and statements on behalf of ESPGHAN regarding paediatric intestinal failure and intestinal transplantation.
3. To perform collaborative research in the field of paediatric intestinal failure and intestinal transplantation as agreed within the group.
4. To develop educational activities in the field of paediatric intestinal failure and intestinal transplantation, in agreement with the Education Secretary and the Council.
5. To provide experts' opinion and advocacies on behalf of paediatric NITE patients when needed.

### **Benefits of Membership of the Group**

1. To improve the knowledge of management of intestinal failure and intestinal transplantation
2. To develop a platform for exchange of ideas
3. To carry out collaborative research amongst European Centres caring for children with intestinal failure and after intestinal transplantation

### **How to join membership of the group**

Email expression of interest to Jutta Köglmeier

[Jutta.Koeglmeier@gosh.nhs.uk](mailto:Jutta.Koeglmeier@gosh.nhs.uk)

or any member of the steering committee

The membership to NITE group is free

### **Rules and Regulations:**

1. All ESPGHAN members with an interest in paediatric intestinal failure and intestinal transplantation, may become a member of the NITE. They are invited to attend open meetings and to propose working groups and/or research projects to the Executive Committee. They can be invited to collaborate in ongoing or new activities and will then become temporarily members of the Core group.

New members will be welcomed during the open SIG meeting at the Annual ESPGHAN meeting. An updated member's data base (SIG-NITE) will be maintained by the NITE-SIG secretary and chair.

2. Updating the members' data base will be the responsibility of the NITE chair.

3. The Steering Committee of the NITE-SIG is an Advisory board composed of a closed group of paediatric NITE experts from ESPGHAN elected among the NITE-SIG members. The number will not exceed 6.

4. Each committee member will be elected by secret ballot for a term of 3 years among the members of the Core group applying as candidates with the possibility of a one-time renewal. One of these members will be elected specifically for the role of Chair of the group.

5. The Steering Committee has the duty to promote and empower the specific active working groups.

Additional duties of the Steering Committee are:

1. Maintenance of updated Members data base along with the chair,
2. Update membership with the SIG activities and publications,
3. Updating (at least once a year) of the SIG area on the ESPGHAN website,
4. Report to the Hepatology Committee on an annual basis both on activities and budget.
5. An annual budget will be allocated by the Hepatology committee upon presenting an annual action plan.
6. Liaison with the Committee on Nutrition and encouragement of joint education activities

### **Working organization and Meetings:**

1. At least one closed annual meeting will be held where ongoing activities are reviewed. This can eventually be scheduled during the ESPGHAN Annual meeting. Active core members will be asked to participate.
2. One Open meeting of the NITE-SIG during ESPGHAN Annual Meeting for all ESPGHAN members with an interest in NITE.
3. Additional ad hoc meetings could be scheduled according to needs and work development for specific activities such as guidelines or position papers. Attending costs will be partially covered provided the NITE-SIG budget allows it.
4. On-line meetings and Teleconferences will be held to promote and facilitate the working group's activities.
5. New WG / research projects, once approved by the Steering Committee, will be advertised on the ESPGHAN website (NITE-SIG area) and circulated by the NITE chair to all regular NITE members. Applications to participate from SIG regular members will be encouraged and accepted after evaluation by the Executive and the Steering Committee.