**WORKING GROUP FOR INTESTINAL FAILURE AND INTESTINAL TRANSPLANTATION**

Date: 9th June 2014

ESPGHAN conference venue- ICC Jerusalem, Israel

Time: 0830 to 0940

Seminar Room 311

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<td>1. Welcome and introduction</td>
<td>Dr Girish Gupte</td>
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<td>2. Position paper on IFALD: Progress report</td>
<td>Florence Lacaille</td>
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<td>3. Web based conferencing tool</td>
<td>Ekehard Sturm</td>
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<td>Discussion</td>
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<td>4. Protocol for highly sensitized recipients</td>
<td>Florence Lacaille</td>
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<td>Discussion</td>
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<td>5. Oral insulin trial</td>
<td>Nutrina Rep</td>
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<td>Questions</td>
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<td>6. Future projects and collaboration</td>
<td>Girish Gupte</td>
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**Indications for intestinal transplantation**

**Future meeting date**
Minutes of the Network Meeting held on 9th June at ICC Jerusalem

In attendance:

Dr Girish Gupte
Dr Florence Lacaille
Dr Raanan Shamir
Dr Corina Hartmann
Dr Ekkehard Sturm
Dr Edmund Rings
Dr Winita Hardikar
Dr Usha Krishnan
Dr Theo Wong
Dr Jonathan Hinds
Dr Jutta Koggemeier
Dr Keith Lindley
Dr Loretto Hierro
Dr Jessie Hulst
Dr Eletheria Roya
Dr Elena Rachman
Dr Esther Ramos
Dr Gerardo Prieto
Dr Francis Hernandez
Dr Aglaia Zellos
Dr Krish Venkatesh
Zoe McCallum
Dr Myriam Van Minckel

1. Progress report on Intestinal Failure associated Liver Disease
   A comprehensive report on IFALD has been prepared by members representing the hepatology committee and Nutrition committee.

Key Highlights

a. One of the few papers within ESPGHAN where both the committees have worked together to produce this report.

b. Lack of evidence in the literature regarding many issues relating to intestinal failure

End point
   Paper submitted to ESPGHAN in the week beginning 19th June

2. Web based conferencing tool

   Presented by Dr Ekkehard Sturm from Tubingen
   developed this tool along with Trustner
Attached leaflet gives instructions on how to join

Key points

- This tool is free to use at present
- A intestinal failure and intestinal transplantation virtual room has been created. This is a secure room and patient data can be shared as well investigations exchanged to improve management of patients. Invites will be sent within the next week. Once invite accepted then you will be able to participate in the discussion.

3. Protocol for highly sensitized recipients

Presented by Florence Lacaille (protocol attached)

Background

- Antibody mediated rejection being recognized in intestinal transplant recipients like kidney transplant recipients.
- Donor specific antibodies being recognized as a contributor to poor outcome
- Discussions previously held had an agreement between all intestinal transplant centres to contribute towards a common protocol.

Discussion points regarding the protocol

- Cut off point regarding the MFI on luminex based assay
- Use of Rituximab in antibody mediated rejection not included in the protocol
- ATG being used in protocol (most centres have basiliximab as induction protocol)
- Agreed that paediatric centers should agree on a common protocol before

Action points

- Participating centres (Paris, Bergamo, Madrid, Birmingham, Kings) to discuss the protocol with respective teams.
- Dr Gupte to invite other centers not represented at the meeting (Leuven, Groningen, Rome, Stockholm).

4. Oral insulin trial

Presented by Raanan Shamir (representatives from Nutrina)

Slides attached
Discussion regarding the protocol

There was enthusiasm from various centres to participate in the trial
All the queries regarding the trial need to be directed to Professor Rannan Shamir.

5. Common practices in home PN patients

A possibility of European wide survey (monkey survey) within various home PN centers was discussed.

Consideration was given for discussion of the common practical problems encountered by nutritional care teams. It was proposed that good practices could be shared and thus improve the outcome of children on long term home PN patients

Action points

Dr Van Minckel and Dr Hartmann were proposed to circulate proposal for two ‘hot’ topics for conducting European wide survey which would be of patient benefit.

6. Intestinal Failure and Intestinal Transplantation group

A brief discussion about this working group was held. The following points were raised for discussion

a. Frequency of meetings- consensus was that should be held on annual basis at ESPGHAN.
b. Sufficient notice of this working group meeting at ESPGHAN should be given for all the members to attend
c. Representatives of intestinal failure should be co-chairs of the group
d. Once every 2 years a network meeting should be held in different European centers to give the opportunity to individuals who cannot attend ESPGHAN.
e. Although it is a network of European centres, centers from outside Europe i.e south America and Australia would be welcome to participate in the various activities
f. Expressions of interest for holding the next biannual meeting in February 2016. (minutes of the meeting held in Tubingen enclosed)