

### **Terms of Reference**

# **Graft Injury Group Observing Long-term Outcome in Paediatric Liver Transplantation**

# **ESPGHAN Special Interest Group Under umbrella of Hepatology Committee**

## **Membership Constitution**

#### Aims and objectives of The Graft Injury Group:

- I. Describe the nature of graft injury and measure its effects on allograft function from childhood through transition into late adult life (lifespan of patient and graft, morbidity)
- II. Develop standardised recommendations for performing protocol biopsies, methods of histological assessment and nomenclature relating to graft injury
- III. Identify biomarkers to identify at-risk sub-groups using existing serological markers and alloantibodies (including donor specific antibodies)
- IV. Provide a platform for the future identification of the disease mechanisms (genetic, immunological) of graft injury, non-invasive markers for the presence of disease and treatment response,
- V. Identify targets for new therapy to prevent graft fibrosis

#### **Benefits of GRAFT INJURY GROUP Membership:**

- Sharing knowledge and experience
- Future collaborative research opportunities
- Access to Tissue and Data for approved research projects.
- Protocol development
- Free attendance at scientific and annual GRAFT INJURY GROUP
- meetings

#### How to Join as a member

 E-mail expression of interest to GRAFT INJURY GROUP project manager – Mrs Carla Lloyd, carla.lloyd1@nhs.net



#### **Steering Group Committee Members**

The steering group will consist of a minimum of 6 people: A Chair and representatives from centres with an interest in Transplant Surgery; clinical care of Patients; Research; Histopathology and Project Manager. Expression of interest to join the Steering Group will be invited at intervals of 3 years.

#### **Roles of Steering Group Committee Members**

Chair: Term of Office – 3 years, renewable for one term (maximum 6 years)

Appointed by: Steering Group members

Co-ordinate and manage Aims and Objectives of the Graft Injury Group
Participate in teleconferences with members of Steering Group
Chair at least two face to face steering group and working group meetings each year
– one at ESPGHAN annual meeting
Supervise Project Manager

Steering Group Members; Term of Office – 3 years, renewable for one term (maximum 6 years)

Expression of interest to join Steering Group will be invited at intervals of 3 years

Manage specific Aims and Objectives of the Graft Injury Group related to their particular interest

Participate in teleconferences with members of Steering Group Identify funding sources and apply for grants

#### **Project Manager:**

Arrange teleconferences for steering Group

Arrange and attend face to face meetings with steering and working group members Minute teleconferences and meetings and circulate as appropriate Submit annual reports to ESPGHAN and other funding bodies Assist with grant applications and manage budget



#### **Confirmation of Group membership**

All applications will be acknowledged and there will be no formal review process. All centres applying for membership will be accepted as members of the group.

#### **Centre Membership**

Centres who perform paediatric liver transplants (<18 years of age); and perform protocol liver biopsies (1yr where possible); 5yr, 10yr and 15 years post transplant will be given the opportunity to register as a Centre Member and submit data to Certain-Li registry.

Certain-Li registry is the repository for all data that can be accessed for future audit and research projects. Details on how to register your centre for Certain-Li will be sent on confirmation of centre membership together with details on how to apply for use of Data

#### Membership fee

There is no membership fee to join GRAFT INJURY GROUP

#### **Meetings**

**Group:** The GRAFT INJURY GROUP will meet at least once a year. These meetings will be held in conjunction with international meetings i.e. ESPGHAN, AASLD, EASL in expectation that members may attend these international meetings and also attend the GRAFT INJURY GROUP meetings

**Scientific meetings:** These will be organised at international meetings every 18-24 months.

**Attendance:** All Members are invited to meetings.

#### **Funding:**

**CERTAIN-Li registry data entry:** There is no funding to support members of GRAFT INJURY GROUP centres for data entry

**Tissue storage:** Centres are asked to store surplus tissue at their own centres as GRAFT INJURY GROUP does not have a centralised biobank facility.



### **Collborating Centres (August 2018):**

Country	GRAFT INJURY GROUP Lead and Members	Institute
Argentina	Dr Marcelo Dip	Hospital Garrahan Argentina
Australia	Jeremy Rajanayagam	Royal Children's Hospital, Melbourne
	Michael Stormon	Children's Hospital at Westmead
Brussels	Etienne Sokal Francoise Smets Mina Komuta Xavier Stephenne	UCL, Louvain
China	Guangxiang Gu	Renji Hospital, Shangai*
France	Emmanual Gonzales	Bicetre
	Dominique Debray Florence Lacaille Muriel Girard	Hôpital Necker-Enfants* Malades
	Olivier Boillot	Hopital Edouard Herriot Lyon
Germany	Ulrich Baumann Imeke Goldschmidt	Hannover Medical School Universitatskilinik,
	Ekkehard Sturm Steffen Hartleif	Tuebingen*
	Brukhard Toenshoff Kai Krupka	University Children's Hospital, Heidelberg
India	Dr Rajiv Locha	Aster CMI Hospital Karnataka
Israel	Yael Mozer	Glassberg Schneider Children's Medical CenterIsrael
Italy	Lorenzo d'Antiga Angelo di Giorgio Marco Sciveres	ASST Ospedale Papa Giovanni XXIII, Bergamo*
	Jean-De Ville De Goyet Rosa Liotta	ISMETT and UPMC Palermo



	Angelo Luca	
	Francesco Tandoi Pier Luigi Calvo	Citta della Salute, Turin*
	Marco Spada Daniela Liccardo Roberta Angelico	Bambino Gesu, Rome*
Japan	Hinori Haga	Kyoto University
Netherlands	Henkjan Verkade Annette Gouw	University Medical Centre, Groningen**
New Zealand	Starship Children's Health	Helen Evans
Poland	Piotr Czubkowski Piotr Kalicinsk	Centrum Zdrowia Dziecka, Warsaw*
Portugal	Isabel Goncalves Sandra Ferreira	Hospital Pediátrico de Coimbra*
Spain	Loreto Hierro	Hospital Infantil Universitario La Paz, Madrid
	Jesus Quintero Bernabeu	Barcelona*
Sweden	Bjorn Fischler	Karolinksa Institutet
Switzerland	Valerie McLin Jean Villard Vladimir Cousin	University Hospital, Geneva**
Turkey	Ozlem Durmaz	Istanbul*
UK	Deirdre Kelly Carla Lloyd Wolfram Haller Nicola Ruth	Birmingham Children's Hospital*
	Stefan Hubscher James Ferguson Rachel Brown David Adams Ye Oo	University Hospital, Birmingham
	Emer Fitzpatrick Anil Dhawan Alberto Sanchez-Fueyo Dino Hadzic	King's College Hospital, London
USA	Dominic Muogbo Sandy Feng	Leeds General Infirmary University of California, San
		Francisco



	Jake Demetris George Mazariegos Patrick McKiernan Jim Squires Drew Lesniak Neslihan Celik	Children's Hospital of Pittsburgh*
	Udeme Ekong	Yale New Haven Hospital Transplantation Centre*
	Nada Yazigi	MedStart George Town Transplant Institute in Washington, DC
	Elke Lainka	Texas Children's Liver Centre
	Estella Alonso Saeed Mohammad	Children's Memorial Hospital, Chicago
	John Buculavas	
	Ryan Fischer	Kansas
Patient and Parent Representative Groups:		
UK	Alison Taylor	Children's Liver Disease Foundation

#### **GRAFT INJURY GROUP steering committee Members:**

Chair: Professor Deirdre Kelly, CBE; UK Sandy Feng, US
Etienne Sokal, Belgium
Jake Demetris, US
Valerie McLin, Switzerland
Stefan Hubscher, UK
Ekkehard Sturm, Germany
Steffen Hartleiff, Germany
Henkjan Verkade, Germany
Burkhard Tonshoff, Germany
Kai Krupka, Germany

Project Manager: Carla Lloyd, UK