Inborn Errors Working Party

Chair: Andy Gennery – Newcastle, UK
Secretary: Arjan Lankester – Leiden, Netherlands

Studies

New Studies:

- IEWP/PIDTC joint study – Long-term (>20 yr) follow up of SCID HSCT.
  Contact: a.r.gennery@ncl.ac.uk
  Patients with Severe Combined Immune Deficiency have been treated by transplantation since the 1960’s. There is a growing cohort of long-term survivors who continue to be followed, but there is no published evidence on the long-term outcome of transplantation for this patient group. This study will correlate genetic data, transplant donor, conditioning regimen, immune reconstitution and long-term health outcomes in patients with greater than 20 years follow up transplanted in Europe and North America.

- The PCID Study: outcomes and predictors.
  Contact: stephan.ehl@uniklinik-freiburg.de

- Cord Blood Transplantation in Leukodystrophies. (IEWP/Eurocord joint study)
  Contact: J.J.Boelens@umcutrecht.nl

Numbers in the registry

Recent Publications


- Bontant T, et al. Survey of CMV management in pediatric allogeneic HSCT programs, on behalf of the in born errors, infectious diseases and pediatric diseases working parties of EBMT. Bone Marrow Transplant. 2014;49:276-9


Future Meetings

How to transplant a patient with PID workshop
Leuven, Belgium April 24th 2015

IEWP Autumn meeting
Seville 16-18th October 2015

Further details from: Roz.Gale@ncl.ac.uk

Significant Collaborations

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