Highlights of 2011

First of all, we would like to thank you for your great participation in the Registry in 2011, which has been a highly successful year. Besides many papers being published and submitted, many visiting researchers performed studies within the registry.

Jerome Harambat (France) visited the Registry for one year. His first project resulted in a review on epidemiology in CKD which has been published in Pediatric Nephrology and a paper on oxalosis which has been accepted by the clinical JASN. One other paper on transplant policies is under review and details of his project can be found below. Finally a final paper on final height is under way.

Elke Wühl (Germany) visited the registry for one month during the summer for a project on congenital anomalies of the kidney and the urinary tract. They both received a fellowship grant from the ERA-EDTA.

We are also very happy to inform you that Danilo Lofaro from Italy received a generous grant from the ERA-EDTA to perform a 6 months project on risk factors for graft failure starting from February 2012.

This year we started the online data collection. Currently, eight countries provided data via this tool and we hope in the future many more countries will be using it. More information on this tool can be found below.

In 2011, so far 5 papers are accepted and published (see list of publications), and another 3 have been submitted for publication.

As all these projects were not possible without the work of all the experts involved in the registry, and all those contributed with data, we would like to thank everybody for the great participation and enthusiasm. We hope to collaborate with you in the future to make 2012 such a successful year as well.

44th ESPN Annual Scientific Meeting in Dubrovnik

During the ESPN congress in Dubrovnik the Registry was well represented. Four research projects were presented orally: one on transplantation policies in Europe, one on anemia in children on dialysis, one on neonatal onset of RRT, and one on the comparison of growth charts for height. Furthermore, also four posters were presented.

Poster by Marjolein Bonthuis entitled: ‘Prevalence of underweight and overweight in European pediatric patients on RRT’
Internet-based data collection

The on-line data entry system allows for a safe data entry. Countries who want to contribute data via this system can obtain a login-name and password via the registry. They only have access to their own patients. This access allows them to enter patient data such as baseline data, events and follow-up data in a secure way. Furthermore, these entries are directly checked for accuracy.

In the future we want to extend this programme with direct feedback to the data-contributor about how the patient is doing compared with his or her peers.

Funding

The ESPN/ERA-EDTA registry is generously funded by the ESPN and the ERA-EDTA. Furthermore, the research projects by the visiting researchers have been funded by the QUEST project and short-term fellowship grants from the ERA-EDTA. If you would like to perform an internship on the registry, there are also small funds available by the ESPN.

Please contact the registry staff if you would like to obtain more information about performing an internship on the registry.

Project of Jerome Harambat

Policies and practices of paediatric kidney transplantation

Paediatric kidney allocation policies and transplantation practices may vary according to the country. These variations may lead to unequal access to kidney transplantation within Europe, and therefore to differences in morbidity and survival in children with ESRD.

In 2011, a survey was distributed among renal registry representatives in 38 European countries. There were considerable differences in practices and access to paediatric kidney transplantation across Europe, as 5.7 per million children population received a transplantation, but this ranged from 0 to 13.5 between countries. A median of 17% of transplants was performed preemptively while a median of 43% received a graft from a living donor. Access to kidney transplantation was associated with non-medical factors such as the Gross Domestic Product per capita, and medical factors including national deceased donation rate, paediatric priority category, and living donor paediatric transplant rate.