INTRODUCTION

Dear Colleagues

Welcome to the September 2019 LKD network newsletter.

Apolipoprotein-L1 (APOL1) genotyping in donor evaluation

Assessment of future risk of end stage renal disease (ESRD) is an important component of living donor work up. Known risk factors for ESRD include first-degree relatives, young age, male sex, obesity and African ancestry (AA) [1].

APOL1 risk variants have emerged as a predictor of renal disease in individuals with AA [2]. In living kidney donors, the effect of the APOL1 genotype on the risk of developing ESRD is unknown, but it is reasonable to predict that donors carrying the high risk genotypes for APOL1 will be at higher lifetime risk of ESRD than donors with low risk genotypes. A genomic DNA analysis of stored samples on 203 donors from a single renal unit in the UK identified the presence of two APOL1 at risk alleles in 47.3% (26) of donors with AA, 3.1% of Asian donors and was not found in Caucasian donors. The mean length of follow up was 4 years and at this point reassuringly there was no significant difference in creatinine clearance between the groups [3].

Current UK guidelines for living kidney donor transplantation do not mandate APOL1 testing in donors and do not preclude someone from donating on their APOL1 genotype. However as APOL1 genotyping is now available on the NHS it is reasonable to include APOL1 testing as part of donor work up for those with AA. This information can be added to the age, sex and BMI of the donor to individualise his or her lifetime risk of ESRD to aid their decision regarding donation.

Long term follow up for Living Kidney Donors

For us to truly inform potential donors in the UK about their lifetime risks of both CKD and ESRD it is essential that we prioritise the collection of annual follow up data as a network. The NHSBT annual report on Living Donor Kidney Transplantation 2018/19 shows huge variation in serum creatinine data return and significant fall off in data returns over time (table 1). In reality this means that we don’t know the kidney function in over 2000 UK donors who donated >10 years ago.

Table 1-Donor follow up –Serum Creatinine NHSBT annual report 2018/19

<table>
<thead>
<tr>
<th>Donor follow up</th>
<th>Number of eligible donors (2004-2018)</th>
<th>% data returned</th>
<th>Variation in % return rate across UK centres</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year</td>
<td>4085</td>
<td>80%</td>
<td>61-93%</td>
</tr>
<tr>
<td>5 years</td>
<td>5222</td>
<td>55%</td>
<td>13-87%</td>
</tr>
<tr>
<td>10 years</td>
<td>3487</td>
<td>41%</td>
<td>13-80%</td>
</tr>
</tbody>
</table>

By improving the annual return data we can significantly improve the long term donor outcome data we have in the UK.

For newsletters, information about the network and resources about living kidney donation please visit https://www.odt.nhs.uk/living-donation/uk-living-kidney-donation-network/

Yours sincerely

Dr Caroline Wroe
Chair of the UK Living Kidney Donation Network
Consultant Nephrologist
South Tees NHS Foundation Trust

Dr Katie Vinen
RA Lead for Living Kidney Donation
Consultant Nephrologist,
Kings College Hospital


‘Upcoming events’
- Recipient and Living Donor Coordinator Induction
  25th/26th September 2019, ODT, Stoke Gifford, Bristol
  Registration closed
- UK LKD Network Meeting
  Thursday 13th February 2020
  Jury's Inn, Birmingham
  Registration opening October 2019 - details to follow
- BTS events - registration for both events open via www.bts.org.uk

UPCOMING EVENTS
Living Donor Forum & Winter Ethics Symposium 2019
“Expanding the Living Donor Pool: Incentives & Beyond”
28th November 2019
Park Inn by Radisson, York

For more information visit: https://bts.org.uk/events-meetings/