

UKPID Registry Committee Telephone Conference,
Monday 3rd July 2017 3pm

Present: Matthew Buckland, , David Guzman, Ben Shillitoe, Sarita Workman, Cathy Bangs

1. **Apologies:** Andy Gennery and Austen Worth

2. **Minutes of the last meeting:** (30th Jan 2017 telephone conference): accepted

3. **Centre recruitment/Validation Progress**

Cathy circulated a list of current centre recruitment and the breakdown per centre:

Total entries: 4474

Alive and Level 1 complete : 3563

Matthew asked about the transfer of data to Freiburg and David said the last transfer was on the 9th June. There isn't currently a set schedule for sending it, just as requested by Freiburg. David said they are working on a solution for automatic transfer so that there can be regular automatic data transfer.

4. **Study progress:**

- a. **unPAD** The level 2 (unPAD) data, which is for antibody deficiency patients (excluding XLA and 2nd HGG) is very time consuming to complete for the baseline entry – it can take up to an hour to find and enter all the data. Once the baseline is completed the updates are much quicker. Cathy said she has completed most of the Manchester and Salford baseline forms and a small percentage on visits to other centres. *118 entries to date have Level 2 data complete (figure provided by David after the meeting).*
- b. **Agamma Newcastle:** Ben said they have separate ethics for the study and have their own consent form. He is liaising with centres to visit to collect data. He is presenting the Newcastle data at the Edinburgh ESID meeting in September.
- c. **APDS** 22 patients are registered from the UK which is substantially more than other countries. The 3 from the Royal Free have not had data entered yet. Cathy is visiting soon and will complete what she can and let Matthew know the lab results at diagnosis and early data needed from GOSH.

- d. **Agamma study** Peter Arkwright has submitted a paper to Clinical and Experimental Immunology, "Bronchiectasis and deteriorating lung function in agammaglobulinemia despite immunoglobulin replacement therapy "
 - e. There will be a poster of the Octopharma registry data on secondary immunodeficiencies at the ESID meeting .
- 5. Registry Publication** Ben has kindly completed a first draft and sent to Matthew, who will circulate it to committee members for review. It will then be sent to the PIs for review before submission. Authorship was discussed. As data from the registry is the basis for the paper then the PI from each centre should be included. Ben will be first author, then the PIs and others in alphabetical order and Matthew last.
- 6. ESID Poster** Sinisa Savic has kindly agreed to be first author on the registry poster on genetic analysis. Cathy had submitted it but is now no longer able to attend the Edinburgh meeting and Matthew is uncertain if he can attend due to staffing problems.
- 7. Staffing/Funding**
Cathy said she will be leaving when her contract ends in November . She is currently funded 3 days a week by UKPIN and one day a week by money from Peter Arkwright's rare diseases studies. David is working on the registry on a zero hours contract on the UCL casual worker scheme, paid 3 times a year. Sary asked if it is necessary to employ a nurse for Cathy's role and Cathy said she thought it easier for it not to be a nurse as it's difficult to maintain nurse registration since it doesn't involve nursing procedures. Matthew said the university banding scheme is lower than the NHS system. Cathy suggested it would be better to have 2 people, one based in London and one further north to reduce travelling time and expense. In the next couple of weeks Matthew will have a staffing proposal to submit to the UKPIN steering group.
- 8. Next meeting** Cathy to arrange in October (avoiding the half term break)