2nd International-DSD Registry Steering Committee Meeting

Thursday 20th September 2012, 2pm – 4pm

ESPE 2012, Room 12 Level 2 Conference Facility, Leipzig Conference Centre, Leipzig, Germany

Minutes

Attending: Prof. Faisal Ahmed (deputy chair), Dr Jillian Bryce, Prof. Feyza Darendeliler, Prof. Olaf Hiort, Prof. Ieuan Hughes, Prof. David Sandberg, Prof. Richard Sinnott
Apologies: Dr. John Achermann, Prof Ian Ford, Mr. Jipu Jiang, Ms. Ellie Magritte, Dr. Berenice Mendonca, Dr. Martina Rodie, Dr John Watt, Prof. Claudia Wiesemann

ACTION

1. Welcome
The committee was welcomed by the deputy chair, Prof Faisal Ahmed.

2. Approval of Minutes of 1st SC Meeting
Approved

3. Action List Update
The Action List from the 1st SC Meeting was discussed.
1. Is a separate Scientific Subcommittee required or just use the existing Steering Committee? It was decided that research projects will come to the PMG in the 1st instance and external experts will be employed as necessary.
2. SC composition will change over time and will include surgeons and more scientists
3. Invited speakers to I-DSD symposium will appear on the website in October   JB
4. I-DSD Registry is now on the UK NIHR portfolio.
5. User accounts were reviewed and inactive ones deleted. Users were advised of updates to the Registry
6. Research partners were sent a questionnaire to return with current or planned studies (discussed later)
7. SC charter now completed and signed by all members
8. User profiles now captured automatically at first registration, facilitating the creation of a network of users.
9. SOP feedback – undergone many versions. The final version will be circulated to the SC before submission to Ethics. OH pointed out that the Registry is medico-science based but patient leaflets should be amended to the specifications of patient groups (e.g. EM). EM has   JJ asked for access to an empty registry to look at the terminology. Self registration by patients   J is a consideration for the future.
10. I-DSD budget for the meeting has been allocated.
11. Capture of Research Activity on the website. Metrics on this are required. A citation is given in the SOP to use on any publications using Registry data. Recognition of I-DSD should be encouraged in talks as well. It was agreed that a statement would be placed on the EuroDSD   OH website directly traffic to I-DSD. RS suggested a list of research studies on the website with a   JB/JJ button to 'Add Patient' to that study.
12. Password changes are now being enforced at 6 monthly intervals
13. The meeting flyer and 1st newsletter are completed and are available in printed form at ESPE. Both are available on the website and the flyer has been circulated around various networks by e-mail. More networks will be identified and publicity sought in the coming months   JB including P Moriquand for the journal.
14. Appraisal of cases for data quality is a huge task. We need to build in some form of feedback   JB/JJ system to assess whether cases are useful. RS pointed out that there are a lot of cases with

no biosamples, but secondary research can still be carried out on the data.

15. Research Studies – planned, such as the CAH study. Much more data is required so there is a need to recruit each patient that comes on to the registry. IH suggested that the resource be advertised via a Newsletter on the website for example. FA is looking at the range of congenital malformations in the Registry; data such as these will attract more investigators to the Registry. Regarding data quality it is advisable for the researcher to contact the centre to check for accuracy. FD thought that young researchers interested in DSD could be working on the database.   A developmental day for DSD could be integrated into the I-DSD symposium programme. OH suggested seeking additional funds for that activity. DS said that for the Training Session, the team come to a centre of excellence. Role playing scenarios could be played out. E.g. if a surgeon sees the patient 1st what is the outcome?   FD/JB

16. Metrics to collect? – needs further discussion

17. Sub-group for communications with patients.   This could be a satellite to the I-DSD symposium involving EM and other Support Groups   EM/JB

4. Current Tasks
Covered already in review of Action List

5. Ethical Scrutiny
SOP currently in revision and will be submitted to Ethics as a substantial revision soon.   JB/FA
DS raised the need for clarity for a prospective investigator as to how the data in the Registry can be used for future research. A flow chart on the website would be helpful.   JB

6. Patient & Parents Input
No specific discussion in absence of EM but a number of points were covered in the action points above.

7. Australian activity
RS reported on projects he is involved in in Australia including the DSD network Australia which is based on the original EuroDSD model. 700 cases on a spreadsheet are about to be migrated in. In addition, Endocrine Genomics VL has $1MAUS funding covering Diabetes, Thyroid, Bone and DSD
Ensat Cancer – is an example of what I-DSD could become. Specific records can be searched in a modular form. I-DSD could also be augmented with bio-banking and labelling to quickly identify a sample. Samples are stored in their own centres. There is a need to get results of sample testing back into the registry.   ALL

8. EU & IRDiRC activity
No specific discussion

9. Latin America
No specific discussion

10. North America
DS provided a summary of the translational research network that is dealing with DSD in the USA.

11. AOB
MRC interested in studies rather than patient numbers

Date for next meeting
The next I-DSD Steering Committee meeting will take place during the 4th I-DSD symposium in Glasgow on 7th June 2013 at 18:30 (Humanities Lecture Theatre, University of Glasgow)   ALL

WHO	ACTIONS	DUE
JB/FA	Submit revised SOP to Ethics as a substantial revision.	25/10/12
JB	Invited speakers to I-DSD symposium will appear on the website in October	31/10/12
JB/FA	Identify more networks and publicity resources (including P Moriquand's journal) for publicising I-DSD Symposium.	31/10/12
FD/JB	Integrate a developmental day for DSD into the I-DSD symposium programme.	31/10/12
JJ	Create an empty registry and allow EM access.	15/11/12
OH	Place a statement on the EuroDSD website directly traffic to I-DSD.	15/11/12
EM/JB	Plan a satellite or parallel session on communications with patients for the I-DSD symposium	1/12/12
JB	Add a flowchart to the website to give guidance for researchy studies	Dec 12
JB/JJ	Add a list of research studies on the IDSD Registry website with a button to 'Add Patient' to that study	Feb 13
JB/JJ/FA	Consider how to build in some form of feedback system to assess whether cases are useful	Feb 13
ALL	Consider inviting more Clinical Geneticists, Scientists and Urologists onto the SC	future