

## Database Coordination Meeting Minutes Wednesday, July 17, 2019

**Present:** Lior Carmi, Naomi Fineberg, Michael Van Ameringen, Yossi Zohar, and Julius Burkauskas

**Regrets:** Bernardo Dell'Osso, Jose Menchon, Benedetta Grancini, Eduardo Cinosi, and Nic van der Wee

### 1) Adding to the Database:

- Lior brought up that he would like to start adding patients to the database, but that a protocol needs to be developed. This is a needed requirement before patients can be added to the database. Lior is planning on using the same questionnaires that Naomi is currently using.
  
- It was also brought up that at the previous meeting, there was discussion about using project numbers when adding to the database, to help differentiate between data from different sites. Naomi mentioned that the website developers could come up with a way of adding identifying numbers to the database, but there would most likely be an extra charge for this. She mentioned speaking to Jose to see if the ECNP would reimburse the cost of this programming. It was noted that we now need to get reimbursement approval from the ECNP before initiating projects that would require any expenditure.
  
- Naomi announced that there are now 8 patients in the database, but she is finding it hard to get more patients because of the criteria that patients cannot be highly treatment resistant. So far, Naomi is the only person who has added patients to the database. However, she mentioned that Lynne Drummond has found patients to add to the database and Naomi will follow up with this.
  
- The question was raised by Yossi as to why patients cannot be highly treatment resistant to be added to the database. Naomi mentioned that she has to follow her study's ethics approval and report to her ethics committee. She doesn't want her study compromised which is why she is limited to add treatment resistant cases. It was brought up that another study could be created, so that others would not be as restricted when adding to the database, and an algorithm created that compares treatment as usual patients with treatment resistant patients. **Action:** Members will think about creating a separate study, put together a proposal, and it can be looked at by the committee.

## 2) Datasharing:

- According to Nic van der Wee, the current data sharing agreement is out of date. He was going to explore this and possibly get some legal advice from lawyers. admin will email Nic and ask for an update, as Nic was not able to attend the teleconference.

## 3) Other Business:

- Yossi asked about the meeting in Copenhagen, as no venue has been booked for this yet. One of Michael's research assistants is looking into possible meeting venues.
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Next Meeting: End of October. admin will send out a doodle poll soon.