

11 January 2015

Dear all,

Here is the 5th update (older versions below – will be posted on electronic platforms from now on) – thanks to all for your major contributions – very impressive lines of activities as summarised below – we are off to an excellent start – several important action items below ! :

1. **Contract.** DNRF has now signed off on the contract – waiting for Rigshospitalet to do the same as part of constructive dialogue.
2. **Concept sheet of PERSIMUNE** – enclosed (please disseminate at your discretion).
3. **Official opening on 4th February** (14.30-17.00) – invitation from Jannik Hilsted, chief medical officer at Rigshospitalet, enclosed.
4. **First PERSIMUNE scientific retreat planned for 3rd (from noon-18.00) and 4th February (from 08.00-14.00) at PERSIMUNE HQ, Øster alle 56, 5th floor.**
 - a. Magnus Fontes and several of his colleagues from Paris and several of the statisticians from UCL lead by Amanda Mocroft will be in house.
 - b. Retreat will be a good opportunity to initiate the discussions on which initial projects PERSIMUNE will focus on.
 - c. Detailed agenda will be developed when there is more clarity on which persons are available when. Areas for discussions include:
 - i. Database structure and planning of analysis.
 - ii. Specific design of core initial projects (microbiome analyses of samples from sterile sites of immunodeficient patients with infectious-like syndromes; patients with overt immunodeficiency and their family members for exome sequencing/analysis, etc ?)
 - d. *You are also welcome to circulate this invitation to other people interested in participating in the development of the research agenda for PERSIMUNE.*
 - e. Please let us know whether you plan to attend and if so, which times you can join the meeting by sending a mail to persimune.rigshospitalet@regionh.dk – please do so by 16th January.
5. **Communication** – please mark the following and be active on the social media platforms so knowledge of PERSIMUNE starts to be disseminated:
 - a. Website: www.PERSIMUNE.org
 - b. Twitter: @PERSIMUNE
 - c. Facebook: <https://www.facebook.com/PERSIMUNE>
6. **Information of leadership (centre directors and department leadership) including entering formal agreement with departments at Rigshospitalet**
 - a. Plans underway once contract has been signed – planned within governance working group (next meeting on 23rd January @ 14.30 at 8632)
 - b. At the governance working group meeting on 2nd January, it was decided to form a 9-member executive committee with representatives from clinical departments, research departments and international collaborators responsible for strategic direction of the centre; a scientific advisory committee will ensure peer-review of incoming proposals and make recommendations to the executive committee; a number of scientific interest groups will be formed allowing inclusive involvement in centre scientific and operational conduct; leadership and representatives not yet decided.
7. **Inaugural meeting of the immunology working group (lead by Peter Garred)**
 - a. Monday 12th January, 16.00-17.00 at section 8632 – all welcome.
8. **Next clinical working group meeting – defining basic LABKA package – Tuesday 13th January @ 16.00 at 8632). All welcome.**
 - a. Two types of patients will be included as part of the PERSIMUNE cohort:
 - i. Populations characterised for their increased risk of infections relative to the background population (e.g. HIV-infection, use of immunosuppressive therapy (e.g. transplant recipients, those receiving chemotherapy & anti-cytokine therapy etc), and patients with known genetic defects)

- ii. Individuals known to suffer from repetitive and/or opportunistic infections not readable explained by excess exposure to infectious pathogens
 - b. Cohort will be enrolled prospectively with possibility to re-establish cohort of patients that entered care previously (to be defined when entering formal agreement with clinical departments – see comment # 6 above)
9. **Next biobank working group meeting – 21st January 08.00-09.00 at PERSIMUNE HQ, Øster alle 56, 5th floor.** The PERSIMUNE biobank (full blood and plasma) is operational by 1st March.
 10. **Next bioinformatics working group meeting** – will be part of the scientific retreat on 4th February (see comment # 4 above); respective roles of the departments of Genomic Medicine (Finn Cilius) and Immunology (Peter Garred) as well as our formal international collaborators (groups lead by Fugger and Fontes) in various activities to be defined.

Stay tuned,

Jens