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To: Elise Heuvelin
Subject: SHARP CRC Newsletter Issue 2 - January 2019

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COMMUNICATION



SHARP

Severe Heterogenous Asthma
Research collaboration
Patient-centered

Newsletter issue 2 - January 2019

Progress on integrating severe asthma registries - SHARP

Dear SHARP Collaborators,

Thank you very much for your continued and enthusiastic participation in the SHARP (Severe Heterogenous Asthma Research collaboration, Patient-centred) Clinical Research Collaboration (CRC) during 2018!

To begin, please accept our very best wishes for 2019!

Our CRC has made much progress over the past year, implementing the agreements from

our Zurich meeting. We are therefore very pleased to circulate this second issue of the SHARP Newsletter to share our achievements and remind ourselves of the plans for 2019.

Fast Mover project

The Fast Mover project is a central element for the concept validation of SHARP. The project has gathered together the data of more than 3,000 patients obtained from 10 European registries (Belgium, Germany, Hungary, Italy, Netherlands, Poland, Slovenia, Spain, Sweden and United Kingdom). This will give us a much better understanding of the data from the current registries by addressing the following research questions:

1. What are the baseline clinical characteristics recorded in registries of individuals with severe asthma?
2. What are the treatment regimens prior to the start of add-on therapies for severe asthma therapies (biologics, thermoplasty, high altitude therapy) or six months after stopping?

The preliminary findings were presented during the ERS Congress in Paris and a full publication is currently being prepared.

Editorial

As part of the CRC Editorial series, SHARP published an **editorial** in the November 2018 issue of European Respiratory Journal (ERJ) which outlines the SHARP vision and the complementary aspirations of the four SHARP stakeholder groups for a new dawn in asthma research.

Research agenda and setting up of projects

In 2018, the main achievement was the kick off, during the April Stakeholder board meeting in Zurich, of a strong and worthy partnership between the different stakeholders and the setup of the first set of research priorities which set the project direction of SHARP.

From there, six working groups were constituted to define the key aims for each working group, and integrate those different elements into three SHARP projects:

1. Registry integration and new national registry setup.
2. Analysis of the registries.
3. Prospective study with new types of data: digital, patient-centred outcomes questionnaire and the linkage of patient centered outcomes to mechanisms.

We reviewed progress and consolidated further our plans when we met in Paris at the ERS meeting.

2019: a rise in SHARP activity

The key objective for 2019 is to ensure that we all work together to deliver on the aims of SHARP.

In order to stimulate interest even more, and link interest to concrete outputs, we propose a strategy around a set of indicative publications that we can give priority to and which can engage our members and to identify leads for the individual projects all of which will result in publications. This will help us to focus and fuel ambitions, especially amongst the younger members of SHARP. You will get more information about this initiative in the coming weeks and will be able to express your interest to contribute to SHARP manuscripts.

To this aim, regular educational '*Mastermind*' sessions will be held starting in January, where the processes we are deploying in SHARP to design and deliver consortium-based projects/manuscripts will be presented and where you will see how everyone can engage to make SHARP a success.

- Please join the first session '**Learning the process of developing and delivering projects in SHARP**' on 23 January, 13:00 CET.

Developing our Registry

One of the new initiatives started in November 2018 was the production of a preliminary 'Guide for Setting up a new National Registry' for countries that do not yet have a national registry but would like to get started. This guide is based on the model used by the Danish and Dutch registries. It provides the initial platform needed for the process for developing, as the next stage, a more elaborate SHARP data model with new capabilities, including follow-up assessments. This is again based on the Dutch registry model that enables patients to enter their own data into the registry.

Stakeholder board meeting

The 2019 Stakeholder board meeting will be scheduled during the spring (date and venue to be confirmed) with the different Stakeholders groups: National leads, Scientifics, Industry partners and Patients. The objective will be to deliver an update on the progress, generate discussion around the analysis of subprojects and seek ideas from you all for new ideas and initiatives. You will receive additional information shortly about the venue and dates.

We very much look forward to an exciting and successful collaboration with you all.

With best wishes,



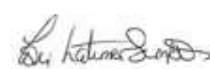
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