

Dear members from the RAPSODI team,

The year of 2019 was very productive for RAPSODI and in this newsletter you will find updated information about our severe asthma registry.

Inclusion of patients

All participant sites were working hard to include new patients. There were 324 new inclusions in 2019 bringing to total of 613 patients with severe asthma in the RAPSODI. Thank you all for this amazing team work!

Attached to this letter you will find the *RAPSODI annual report from 2019* with a summary of the most important characteristics from the included patients at inclusion and first year follow-up. The report describes data for the total population of patients. In case any of the sites would like to have the data restricted to the own site please contact the registry coordinator (Simone Hashimoto, S.hashimoto@amsterdamumc.nl).

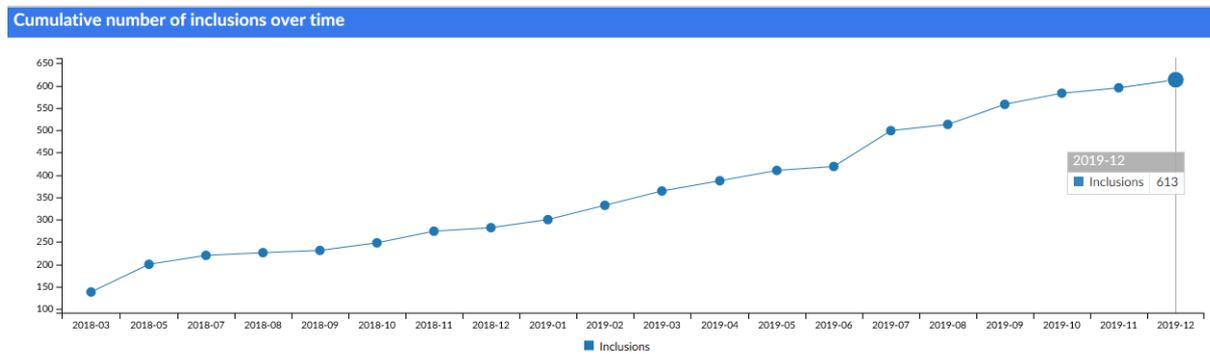


Fig. 1. Cumulative number of patients included in RAPSODI since the start of the register (updated 23-12-2019)

Inclusion per site

Academisch Medisch Centrum (AMC): 254	Haga Ziekenhuis: 21
Medisch Centrum Leeuwarden: 105	Rijnstate: 20
St. Franciscus: 74	Medisch Spectrum Twente: 20
Deventer Ziekenhuis: 34	Ziekenhuis Gelderse Vallei: 11
Catharina Ziekenhuis: 32	Nederlands Astmacentrum Davos: 10
Isala: 32	



Table 1. Inclusion of patients per site (total number of patients= 613)

Inclusion of new sites

We have 4 new sites that already signed the collaboration agreement with RAPSODI and will be recruiting patients in 2010. Welcome Amphia, Canisius Wilhelmina (CWZ), Jeroen Bosch and Martini Ziekenhuis.

New Governance document

In 2020 the RAPSODI will not be a ZonMw study anymore so it was important to update the governance and make plans for the future. Attached to this letter you can find the new governance (*Reglement voor RAPSODI, version 4.0*) that was approved by the steering committee on 20-12-2019.

Rules for analysis, publications and authorship

Our scientific committee, composed by Anke-Hilse Maitland-van der Zee, Ilonka van Veen, Frank Smeenk and Maarten van Bezouw, and the steering committee had reviewed and approved a few documents related to the analysis of data and publication rules.

The attached documents are:

- *RAPSODI template voor onderzoeksaanvragen*
- *RAPSODI publication process*
- *RAPSODI authorship agreement*

Please contact Simone Hashimoto (S.hashimoto@amsterdamumc.nl) in case you are interested in submitting a proposal for analysis or would like additional information.

Finances and sponsorship

In 2019 we had financial support from five pharmaceutical industries: GlaxoSmithKline, Novartis, Astra Zeneca, TEVA and SANOFI. All partners confirmed that they will keep the sponsorship in the year of 2020. Thank you again for this very important contribution for the RAPSODI.

Attached to this letter you can find the financial overview from 2018 and the Budget proposal for the year 2020. The financial overview from 2019 will be ready and available for consultation in the beginning of 2020.

SHARP

The collaboration with the ERS initiative for an European registry for severe asthma patients (SHARP) was consolidated. With the support from Jaap Sont and Bas Hofstee from LUMC we developed the SHARP CENTRAL database, which is fully compatible with the RAPSODI database. This will allow the integration of data from RAPSODI and other European countries in a smooth way. To date there are 2 countries (Serbia and Croatia) already registering data in the SHARP Central and other countries are busy with the paper work to start the registry.

PatientCoach app and RAPSODI website

In the beginning of 2020 we will launch the PatientCoach app and the RAPSODI website. This will be an important step to try to increase the rates of questionnaires completed by patients. Further information about the use of the app and instructions for the patients will follow soon.

Thank you again for making such a great year for RAPSODI!!

Our wishes for a wonderful holidays season and a fruitful 2020.

Best regards,

Simone Hashimoto and Elisabeth Bel,

On behalf of the RAPSODI steering committee

