

RAPSODI Newsletter 3



Dear members of the RAPSODI team,

Please find below some updated information about our severe asthma registry.

Inclusion of patients

The number of patient's inclusions in our asthma registry keeps increasing. We already have data from **734** patients and despite the COVID-19 crisis many centers took the opportunity to update the RAPSODI database, *thank you all again for the great team work!*

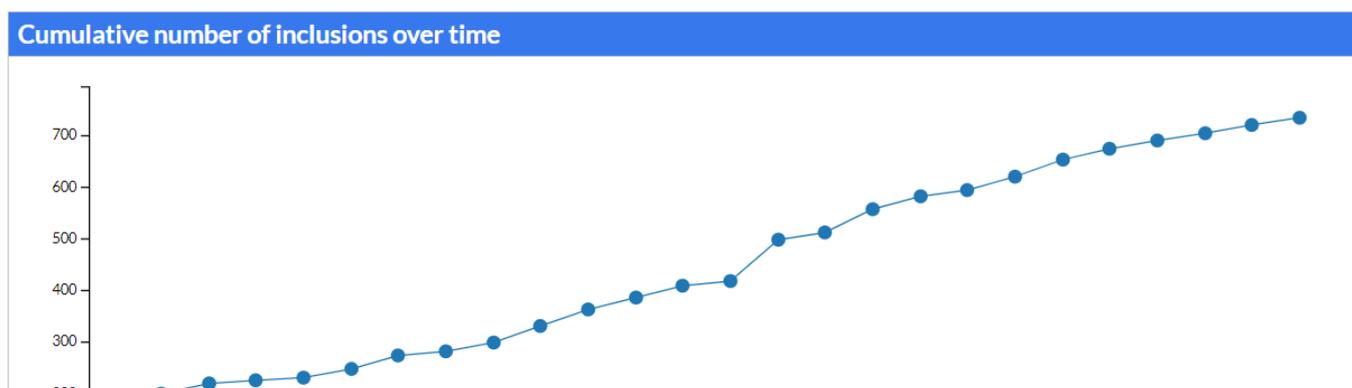


Fig. 1. Cumulative number of patients included in RAPSODI since the start of the registry (updated 17-6-2020)

Inclusion per site

Academisch Medisch Centrum: 269	Isala: 32
Medisch Centrum Leeuwarden: 117	Jeroen Bosch Ziekenhuis: 26
St. Franciscus: 80	Ziekenhuis Gelderse Vallei: 16
Deventer Ziekenhuis: 37	Nederlands Astmacentrum Davos: 10
Rijnstate: 37	Amphia Ziekenhuis: 5
Catharina Ziekenhuis: 36	Meander: 3 Canisius
Medisch Spectrum Twente: 33	Willhelmina Ziekenhuis: 1
Haga Ziekenhuis: 32	Martini: 0

Table 1. Inclusion of patients per site (total number of patients= 734)

Annual Follow-up

We realised that in some centers the annual follow-up visits are behind schedule. **Please keep these visits in mind** and in case of any specific problem contact the RAPSODI coordinator (S.hashimoto@amsterdamumc.nl). It would be amazing to have updated data from our patients to perform new analyses.



RAPSODI website

We are very happy to announce that the RAPSODI registry website has been launched. There you can find the most relevant information regarding our registry, including publications, documents and milestones. You can access the website using the link: <https://www.rapsodiregister.nl/>



Fig. 2. Screenshot from the RAPSODI Register website (d.d. 17/6/2020)

RAPSODI and COVID-19

The way that the COVID-19 outbreak has been affecting our lives and our patients has no precedents. We are planning to gather data on COVID-19 infections of our RAPSODI patients but this requires some preparation work. For the time being we would like to ask that you **add "COVID-19" to the field "Comorbidities" in the CASTOR database** such that we can retrieve this information in an easier way.



Please contact the RAPSODI coordinator if you have any questions regarding this topic.

Outstanding research questions

In addition to a RAPSODI-COVID-19 study, there are still many other questions that can be answered with RAPSODI data. In recent years, several publications have appeared in the literature about severe asthma patients in real-life that have already answered many questions that we had in mind for RAPSODI. One of the questions that may still be of interest is a comparative study between "super responders" and "non-responders" on anti-IgE, anti-IL-5/IL-5Ra and anti-IL-4Ra. That doesn't seem too difficult to analyse.

Are there any volunteers who want to coordinate such research project? Please let us know!



Thank you again for your great work !!

Simone Hashimoto and Elisabeth Bel,

On behalf of the RAPSODI steering committee