## The European Bronchiectasis Registry

March 2016

## Welcome and Congratulations!

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EMBARC would like to welcome both Dr Eva Van Braeckel and Dr Levein Dupont from Belgium, and congratulate them for consenting their first patients into the registry this month.



Please remember to visit the EMBARC homepage for links to all the latest publications and news in regards to our Network members. If you have a recent paper we have not displayed and would like it to be highlighted on the homepage please let us know.

Congratulations to Dr Stefano Aliberti on being this months highest recruiter. As one of the EMBARC chairs, Dr Aliberti is setting a great example for the dedication to the registry and EMBARC network.

Following on closely behind Dr Aliberti is Dr Gernot Rohde from Maastricht University Medical Centre in the Netherlands - congratulations to you both.



We are also excited to announce the success of our German partner PROGNOSIS who have now started recruiting and are fast approaching 200 patients enrolled in the German bronchiectasis register. This is great work, and with over 30 centres already contributing to this register we fully PROGNOSIS believe this to be an exciting collaboration.

## **Personalised Medicines Initiative**

As part of a EU project investigating the use of microbiomes and clinical data to produce "personalised medicine" for airway diseases, EMBARC has been asked to identify centres across Europe with existing collections of the required data. The project is being co-ordinated by the European Respiratory Society.

A short spreadsheet has been emailed to all EMBARC members asking for details of who holds a local record of biological samples linked to clinical data from their bronchiectasis patients. If you have this data and are interested in taking part in this EU initiative please remember to return the spreadsheet to the EMBARC coordinator or contact info@bronchiectasis.eu for more information.





members of EMBARC met again this week with representatives of the European Lung Foundation and a group of patients to further discuss the development of two online educational platforms providing information for both patients and physicians. The patient-led online platform will be modeled on

ELF's patient priorities programme which has a large emphasis on creating patient-led online information. Both platforms are expected to be launched in October 2016.



**Conference** 

**July 07 - 09** Hannover, Germany

breakthrough in bronchiectasis

**EMBARC** 

Joining forces for a





The European Bronchiectasis Registry



## **Changes to the Case Report Form** EMBARC strive to gather high quality data and pride themselves on developing a data-

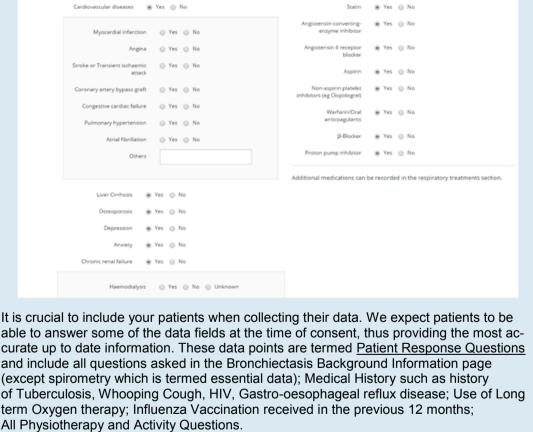
**IMPORTANT** 

base which has the most accurate and informative bronchiectasis data like no other.

removal of the "unknown" options. Sections of the CRF will be reworded to reduce the

In order to tighten data collection, increase data quality and reduce the number of data queries, there is soon to be an update to the CRF. The biggest change will be seen in the

uncertainty of the data request. For example, where the CRF was sectioned into "Comorbidities" this will now be clarified as "Known comorbidities" this removes any need for "unknown" as an option - if the patient is not aware of a comorbidity and there is no evidence of the comorbidity in their medical notes then "No" should be entered. Co-morbidities - Demographics and Background case 67356fff Currently prescribed non respiratory medications Known comorbidities



In order to fulfil the primary registry outcomes, Essential Data must be completed for all follow up cases. Essential Data includes Spirometry (inclusive of height and weight), Microbiology, MRC score and Exacerbation history. Once launched, the new eCRF will not submit without this data. If this data is missing with good reason you will need to contact the study coordinator to complete submission.

signed Data Sharing Agreement to the EMBARC team. Without this we cannot pay you for your hard work!!

If you have not already done so - please do not forget to submit your

Clinical Research Centre

All invoices need to be in English and addressed to;

The European Bronchiectasis Registry

James Arrott drive University of Dundee Ninewells Hospital and Medical School Dundee DD1 9SY, UK Alternatively, they can be emailed directly to the study coordinator;





ry breath counts

Please do not send invoices directly to the finance department.