



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 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 co-ordinator or contact info@bronchiectasis.eu for more information.



1st World Bronchiectasis Conference

July 07 – 09
Hannover, Germany

Joining forces for a breakthrough in bronchiectasis



ELF EUROPEAN LUNG FOUNDATION



Following a meeting in Barcelona earlier this year, 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.

IMPORTANT

Changes to the Case Report Form

EMBARC strive to gather high quality data and pride themselves on developing a database which has the most accurate and informative bronchiectasis data like no other.

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

Known comorbidities

Cardiovascular diseases Yes No

Myocardial infarction Yes No
 Angina Yes No
 Stroke or Transient ischaemic attack Yes No
 Coronary artery bypass graft Yes No
 Congestive cardiac failure Yes No
 Pulmonary hypertension Yes No
 Atrial fibrillation Yes No
 Others

Liver Cirrhosis Yes No

Osteoporosis Yes No

Depression Yes No

Anxiety Yes No

Chronic renal failure Yes No

Haemodialysis Yes No Unknown

Currently prescribed non respiratory medications

Statins Yes No

Angiotensin-converting-enzyme inhibitor Yes No

Angiotensin II receptor blocker Yes No

Aspirin Yes No

Non-aspirin platelet inhibitors (eg Clopidogrel) Yes No

Warfarin/Oral anticoagulants Yes No

β-Blocker Yes No

Proton pump inhibitor Yes No

Additional medications can be recorded in the respiratory treatments section.

It is crucial to include your patients when collecting their data. We expect patients to be able to answer some of the data fields at the time of consent, thus providing the most accurate up to date information. These data points are termed Patient Response Questions and include all questions asked in the Bronchiectasis Background Information page (except spirometry which is termed essential data); Medical History such as history of Tuberculosis, Whooping Cough, HIV, Gastro-oesophageal reflux disease; Use of Long term Oxygen therapy; Influenza Vaccination received in the previous 12 months; All Physiotherapy and Activity Questions.

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.

If you have not already done so - please do not forget to submit your signed Data Sharing Agreement to the EMBARC team. Without this we cannot pay you for your hard work!!

All invoices need to be in English and addressed to;

The European Bronchiectasis Registry
Clinical Research Centre
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;
m.l.crichton@dundee.ac.uk

Please do not send invoices directly to the finance department.