



The EMBARC registry celebrated its first birthday this month by looking back at the successes achieved over the past 12 months.

Some of the highlights for us have been smashing the annual recruitment target within the first 6 months, closely followed by the annual target of contributing countries. Following the data release from the first 1000 EMBARC patients at ERS 2015 and not forgetting the publication of The EMBARC protocol by ERJ earlier this year, we are extremely delighted to be fast approaching 3000 participants.

Looking to the year ahead we are already seeing the first follow up data starting to enter the registry while we are in excited anticipation of much more to follow.

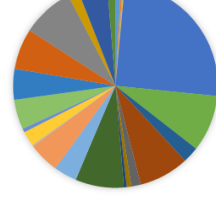
As always, we would like to thank each and every one of you who have worked hard and contributed to the registry, without your help, none of this would be possible!



Follow us on Twitter @EMBARCnetwork



### RECRUITMENT DISTRIBUTION SUMMARY



- Belgium
- Croatia
- England
- Israel
- Kyrgyzstan
- Malta
- N.Ireland
- Poland
- Romania
- Serbia
- Spain
- Turkey
- Bulgaria
- Czech Rpb
- Greece
- Italy
- Macedonia
- Moldova
- Netherlands
- Portugal
- Scotland
- Slovenia
- Switzerland
- Wales

## Welcome and Congratulations!

EMBARC would like to welcome to the registry; Professor Neville Berkman from Israel, Dr Ceyhan Berrin from Turkey, Professor Wei Shen Lim, Dr Graham Miller and Dr Liz Fuller all from England and Professor Pawel Sliwinski from Poland. We would also like to congratulate Dr Berrin and team on being the highest recruiters in the registry throughout April, closely followed by Dr Oriol Sibila Vidal from Spain.



## Personalised Medicines Initiative

Thank you to all who submitted details of their local data sets in order to assist the EU initiative investigating use of microbiomes to produce "personalised medicine" for airway diseases.

Another great response from the EMBARC network!

## 7<sup>th</sup> Portuguese Bronchiectasis Study Group Meeting

EMBARC is delighted to be participating in the 7<sup>th</sup> Portuguese Bronchiectasis Study Group Meeting in Porto on the 7<sup>th</sup> May. Researchers from the Portuguese bronchiectasis study group, the SEPAR bronchiectasis group and physicians from across Portugal and Spain will meet to discuss important issues in bronchiectasis and stimulate research in collaboration with EMBARC.

For more information on the agenda of the weekend please click [here](#)

## American Thoracic Society 2016

EMBARC will also be meeting with the American Bronchiectasis Registry during the ATS Conference to discuss the exciting collaboration of upcoming projects.

Members of the EMBARC team will also be presenting microbiome data from 9am on 16th May in Room 3016/3018 Level 3 of the West Building. We look forward to seeing you there!



## 1<sup>st</sup> World Bronchiectasis Conference

July 07 – 09  
Hannover, Germany

Joining forces for a breakthrough in bronchiectasis



## ERS will be accepting late-breaking abstracts between 1–31 May for the ERS International Congress September 2016.



Present your work at the ERS International Congress, and gain worldwide recognition for your work whilst boosting your profile among leading respiratory experts.

Late-breaking abstracts will only be accepted on the basis that they contain novel data, which only became available after the standard submission deadline in February. Further to that, late-breaking abstracts should have a major impact on clinical practice or scientific reasoning to be considered.

## New Publications from EMBARC Network Members

- Telomere Dysfunction and Senescence-associated Pathways in Bronchiectasis.* Birch J, Victorelli S, Rahmatika D, Anderson RK, Jiwa K, Moisey E, Ward C, Fisher AJ, Soyza AD, Passos JF. <http://www.ncbi.nlm.nih.gov/pubmed/27082536>
- Quality standards for the management of bronchiectasis in Italy: a national audit.* Aliberti S, Hill AT, Mantero M, Battaglia S, Centanni S, Cicero SL, Lacedonia D, Saetta M, Chalmers JD, Blasi F; SIP Bronchiectasis Audit Working Group. <http://www.ncbi.nlm.nih.gov/pubmed/27076581>
- Annual direct medical costs of bronchiectasis treatment: Impact of severity, exacerbations, chronic bronchial colonization and chronic obstructive pulmonary disease coexistence.* de la Rosa D, Martínez-García MA, Oliveira C, Girón R, Máiz L, Prados C. <http://www.ncbi.nlm.nih.gov/pubmed/27072020>

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.

## Registry Documents and eCRF Accounts

- We have been contacted by patients asking how to sign up to the registry after receiving EMBARC information sheets during clinics. Please ensure all Patient Information Sheets and Informed Consent Forms have been localised to your centre so patients know how to contact you in order to proceed with participation.
- We have noted a significant volume of cases pending submission - please contact the study coordinator if you require assistance on submitting cases or if cases need to be deleted from your account.
- All UK centres: Please do not use patient identifiers/hospital identifiers as the Case Number.

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](mailto:m.l.crichton@dundee.ac.uk)

Please do not send invoices directly to the finance department.