



## Welcome and Congratulations!

EMBARC would like to congratulate Dr Marlene Murriss for entering the first French bronchiectasis data to the registry this month. Also, Dr Lorna Murray who is entering data from Scotland and contributing to the English cohort; Dr Michael Loebinger, Dr Tom Bewick, Dr Kat Ebbrell, Professor Alyn Morrice and Dr Alan Hart-Thomas. Welcome to the EMBARC network and thank you for your contributions.



Congratulations also to Dr Matonhodze who is the lead investigator at Walsall Manor Hospital, England, for being this month's highest recruiter!

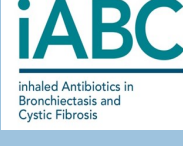
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Please remember to visit the EMBARC homepage for links to all the latest publications and news in regards to our Network members. If you have a recent paper we have not displayed and would like it to be highlighted on the homepage please let us know. If there is anything in particular you wish to see in the newsletter or online, please do let us know, [info@bronchiectasis.eu](mailto:info@bronchiectasis.eu)



## IMI General Assembly 2016



The iABC consortium general assembly is on 7th June in Basel, linked to the European CF conference. As part of the iABC initiative funded by the IMI, EMBARC representatives will travel to Switzerland to update the assembly on the progress of the network.

This includes not only the registry, but also the progress of both the clinical and patient-led educational platforms and the online courses being developed for healthcare professionals.

## American Thoracic Society 2016

We were extremely excited to see such a great turn out of bronchiectasis posters, abstract and symposia being presented at ATS this year.

From microbiome and biomarker data to validation of prognostic tools in disease severity, quality of life, morbidity and mortality. Baseline data and protocol details for large randomized trials of inhaled ciprofloxacin and inhaled tobramycin (BATTLE study) were also presented.

If you were not able to attend ATS this year, abstracts for those mentioned above and many more can be found [here](#)

We look forward to seeing even more bronchiectasis data being presented at the Worlds First Bronchiectasis Conference in Hannover. For more information on how to register to this conference please follow this [link](#)



## 7th Portuguese Bronchiectasis Group/ 1st Iberian Bronchiectasis Meeting

Representatives of the EMBARC steering committee, the Portuguese Bronchiectasis study group and SEPAR, the Spanish society, met in Porto this month to discuss all aspects of bronchiectasis care and research.

Spain and Portugal are already leading contributors to the registry, and through local meetings like this we hope to spread best practice and enthusiasm for bronchiectasis research. Look out for future meetings at [www.bronchiectasis.eu](http://www.bronchiectasis.eu)



## 1st World Bronchiectasis Conference

July 07 – 09  
Hannover, Germany

Joining forces for a breakthrough in bronchiectasis



## \*\*\*\*\* IMPORTANT \*\*\*\*\*

We have a number of Data Sharing Agreements still to be returned. Please can you make sure this document has been signed and returned to the central team as this is a legal requirement for study participation and also secures payment for your data contributions. Without a signed copy of this agreement, we cannot authorise payments.

Please can all non-UK centres ensure confirmation of their ethics approval has been emailed to the study coordinator, Megan Crichton [m.l.crichton@dundee.ac.uk](mailto:m.l.crichton@dundee.ac.uk) This is also a legal requirement of the study and without this your centre will be inactivated until such time confirmation has been received by the central team. If your country does not require ethical approval to participate in a registry please email the coordinator with confirmation of this.

## New Publications from EMBARC Network Members

- ◆ *Non CF-bronchiectasis: Aetiological approach, clinical, radiological, microbiological and functional profile in 277 patients.*  
Katerina Dimakou, Christina Triantafillidou, Michail Toumbis, Kyriaki Tsikritsaki, Katerina Malagari and Petros Bakakos  
<http://dx.doi.org/10.1016/j.med.2016.05.001>
- ◆ *Gastroesophageal Reflux in Cystic Fibrosis and Non-CF Bronchiectasis*  
Ans Pauwels, Daniel Stifrim and Lieven Dupont  
[DOI: 10.1007/978-1-4614-5502-8\\_9](https://doi.org/10.1007/978-1-4614-5502-8_9)
- ◆ *Lung transplantation for non-cystic fibrosis bronchiectasis.*  
Rademacher J, Ringhousen FC, Suhling H, Fuge J, Marsch G, Warnecke G, Haverich A, Welte T, Gottlieb J  
[doi: 10.1016/j.rmed.2016.04.007](https://doi.org/10.1016/j.rmed.2016.04.007). Epub 2016 Apr 20.
- ◆ *Recommendations for aetiological diagnosis of bronchiectasis.*  
Pulmonology Portuguese Society Bronchiectasis Study Group. Amorim A, Gamboa F, Sucena M, Cunha K, Anciães M, Lopes S, Pereira S, Ferreira RD, Azevedo P, Costeira J, Monteiro R, da Costa JC, Pires S, Nunes C.  
<http://www.ncbi.nlm.nih.gov/pubmed/27134122>

## Registry Documents and eCRF Accounts

\* Thank you to everyone who has started entering their Annual Review data! We cannot stress enough how important this data is to the study. We are working on the notification system to remind users of which cases are due review, however in the meantime please note the coloured exclamation marks next to the submission date. Amber icons will present at 9 months following consent as a reminder and will turn red at 12months to show the case is due.

\* Currently the CRF accounts are linked to one email address per centre. We realise this is not practical for answering data queries and receiving notifications in a timely manner. We are currently working on multiple email association which will allow all study team members to receive the notifications in regards to their centre.

\* We are aware some "unknown" options are still available on the eCRF (in particular, the aetiology page) but are not available on the paper CRF – please follow the paper CRF and we hope to have the eCRF updated soon. We are gathering feedback from centres in order to make all required changes in one stage.

\* The new CRF documents can now be downloaded from the website <https://www.bronchiectasis.eu/study-documents> along with the Patient Information Sheet and the Informed Consent Form.

\* We have noted nearly 1000 cases are pending submission - please contact the study coordinator if you require assistance on submitting cases or if cases need to be deleted from your account. By submitting these cases alone, we would surpass our 2 year target well ahead of schedule!

Date	Status	Actions
18/08/2015	Awaiting approval	Approve, Revoke, Create Review, Create Subcentre
19/08/2014	Awaiting approval	Approve, Revoke, Create Review, Create Subcentre
30/07/2015	Awaiting approval	Approve, Revoke, Create Review, Create Subcentre
31/07/2015	Approved	Approve, Revoke, Create Review, Create Subcentre
31/07/2015	Approved	Approve, Revoke, Create Review, Create Subcentre
09/07/2015	Approved	Approve, Revoke, Create Review, Create Subcentre
17/10/2015	Approved	Approve, Revoke, Create Review, Create Subcentre
07/09/2015	Awaiting approval	Approve, Revoke, Create Review, Create Subcentre
02/03/2016	Awaiting approval	Approve, Revoke, Create Review, Create Subcentre
13/08/2014	Approved	Approve, Revoke, Create Review, Create Subcentre

**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.**



Questions or comments? E-mail us at

[info@bronchiectasis.eu](mailto:info@bronchiectasis.eu)

