January 2016

EMBARCing on a New Year!

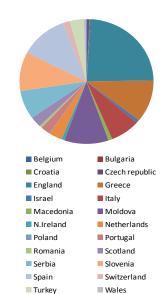
The EMBARC team have been overwhelmed by the success of the European registry in it's first 6 months of recruitment. The response to develop the EMBARC network and contribute to the registry has been outstanding. Due to the hard work of research teams all across Europe and further afield, you have enabled us to comfortably surpass multiple targets.

With the new year, brings new expectations and challenges. We anticipate 2016 to be even more exciting, fast paced and inspiring, with July promising the world's first bronchiectasis conference and the introduction of a new educational programme; Bronchi-Expert, aimed at young physicians, specialist nurses and physiotherapists. To kick start the year, EMBARC have published the protocol in the European Respiratory Journal not only to further promote the registry but to encourage researchers in other fields to set up similar registries. The published article can be found here

EMBARC will continue to encourage and support applications for fellowships such as the Long-Term Research Fellowships (LTRF) and provide advice and information surrounding various bronchiectasis research and networking.

We would also be extremely keen to see some EMBARC data being presented at the European Respiratory Society in London this year. As a reminder, the deadline for abstract submission is the 12th of February, for more information please visit

Recruitment **Distribution Summary**





Welcome to the registry!



Congratulations to both Dr Mateja Jankovic Makek in Croatia and also to Prof. Yordan Radkov Dimitrov in Bulgaria for registering their first participants another two countries added to our growing list!



Registry Data: Access & Entry

Please Remember

Patients must be 18 years of age and over.

Spirometry, microbiology and questionnaire data must not be more than 12months old. Patients must have a CT scan of chest demonstrating bronchiectasis (bronchial dilatation)

affecting 1 or more lobes and a clinical history consistent with bronchiectasis (cough, chronic sputum production and/or recurrent respiratory infections). Please contact the study team with any uncertainties.

Only one review to be done annually. Please do not complete reviews to show individual updates throughout the year - this information will be captured at the next annual review.

Consent 6 is **optional** for the patient.

This consent allows your team (not EMBARC) to contact the patient about any further

review boards. Details of your local review boards can be inserted on page 2 of the PIS.

bronchiectasis studies conducted at your centre, which have been approved by your local



EMBARC data has been made as freely available as possible for anyone with research questions surrounding bronchiectasis. As active investigators, you have unrestricted access to the

data collected from your own centre which can be downloaded from your account. In order to access a wider range of data for a particular research question, an application form must be submitted to the EMBARC study coordinator. We have now advertised this information through a direct link on the website which provides further details and a downloadable application form. The page can be accessed directly here If you have not already done so - please do not forget to submit your

cannot pay you for your hard work!!

All invoices need to be in English and addressed to;

James Arrott drive

signed Data Sharing Agreement to the EMBARC team. Without this we

The European Bronchiectasis Registry Clinical Research Centre

University of Dundee

Ninewells Hospital and Medical School Dundee DD1 9SY, UK

Please do not send invoices directly to the finance department.

Alternatively, they can be emailed directly to the study coordinator;



