EMBARC

The European Bronchiectasis Registry

February 2017

What Does EMBARC Mean for You?

As EMBARC grows at an extraordinary rate we want to remind you that the registry is not about gathering data for someone else's study, but is in fact your own resource. EMBARC has become the backbone for starting National registries, it has homogenized the management of bronchiectasis patients in clinics around Europe by allowing clinicians to share experiences from data collection and has prompted discussion on local, national and international questions and strategies. Recruiting to the registry allows great potential for academic publication and opens your department up to great opportunities as we are often approached for assisting in site selection for upcoming trials. In the next year we will be starting our first couple of trials using this network. As a reminder to UK centers who continue recruiting, portfolio credits will continue despite the UK recruitment budget ending.

Follow us on Twitter @EMBARCnetwork



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"I want to let you know that the registry helps me to treat patients with bronchiectasis by making us be more rigorous"

"we see the study as a great way of potentially providing a local dataset for future local analysis and for identifying potential patients for future trials"

EMBARC and Global Collaborators

As mentioned in last months newsletter, EMBARC is extremely keen on collaborating with research teams from across the globe. Studies as large as EMBARC would not be as successful without the help of various infrastructures such as CAPNETZ who support PROGNOSIS in Germany, SIP and GREPI who are Italian and French societies supporting EMBARC and of course we also have partners in India who have now recruited over 1000 patients in association with RRNI and not forgetting friends in Australia who are now set up and recruiting from over 14 center's with the help of Lung Foundation Australia.

In order to show our gratitude for the ongoing support we receive from the various collaborations we are building a new page on the website which will provide details and weblinks for further information.

Currently CAPNETZ information can be found here or www.capnetz.de for more detailed information.





Win a Free Registration!

EMBARC and IRIDE would like to offer two free places to the 2nd World Bronchiectasis Conference. Researchers are invited to apply for their registration by emailing info@bronchiectasis.eu outlining your previous experience in bronchiectasis and the reasons why you wish to attend the conference.

The team are particularly keen to support young investigators with a proven interest in bronchiectasis research and those who intend on submitting/ presenting an abstract at WBC2. The outcome of the applications will be announced in May.

Find further details of WBC2, abstract submission and registration fees here









***** IMPORTANT *****

There are still a number of invoices being sent to the wrong address and/or with incorrect details. We cannot stress how important it is to follow the below instructions.

- Payment can only be made for cases which have been quality checked and Approved for the registry. You can see which cases have been Approved under the 'status' column on the eCRF.
- Invoices must also clearly state a breakdown of how many Baseline cases are being invoiced for and how many Review cases are being invoiced for as these are costed differently.
- The billing address must contain University of Dundee
- Invoices can only be paid to institution accounts and not personal accounts. It is at the discretion of the centre to how this recruitment payment is spent eg staff payments, however the money must first pass through your hospital/University/Department.
- Please ensure those who raise invoices for your centre are aware of the above information.
- Delays in payment should be expected when instructions are not followed.

It is the responsibility of each Centre to raise invoices for their recruitment. The central team will not send reminders. All invoices must 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

New Publications from the EMBARC Network

O Bronchiectasis Severity is an independent risk factor for vascular disease in a bronchiectasis cohort Evans IE, Bedi P, Quinn TM, Hill AT. Chest. 2017 Feb;151(2):383-388. doi: 10.1016/j.chest.2016.09.022. https://www.ncbi.nlm.nih.gov/pubmed/27720881 Bronchiectasis and the risk of cardiovascular disease: a population-based study. Navaratnam V, Millett ER, Hurst JR, Thomas SL, Smeeth L, Hubbard RB, Brown J, Quint JK. Thorax. 2017 Feb;72(2):161-166. doi: 10.1136/thoraxjnl-2015-208188. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5284336/ New therapies for the prevention and treatment of exacerbations of Bronchiectasis Abo-Leyah H, Chalmers JD. Curr Opin Pulm Med. 2017 Feb 16. doi: 10.1097/MCP.000000000000368 https://www.ncbi.nlm.nih.gov/pubmed/28212153 ◊ Longitudinal assessment of sputum microbiome by sequencing of the 16s rRNA gene in non-cystic fibrosis bronchiectasis:patients Cox MJ, Turek EM, Hennessy C, Mirza GK, James PL, Coleman M, Jones A, Wilson R, Bilton D, Cookson WO, Moffatt MF, Loebinger MR. PLoS One. 2017 Feb 7;12(2):e0170622. doi: 10.1371/journal.pone.0170622 http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0170622



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Questions or comments? E-mail us at info@bronchiectasis.eu

