



# EMBARC

## The European Bronchiectasis Registry



Autumn 2018



### The interaction between airways disease and bronchiectasis - An initiative of the EMBARC and SHARP CRC's -

The EMBARC and SHARP (Severe Heterogenous Asthma Research collaboration, Patient-centered) clinical research collaborations have come together in organising a two day seminar which will discuss and debate respiratory overlap syndromes. This two day event will be held in Barcelona 7-8th February 2019. This research seminar will bring together key groups in asthma, bronchiectasis, and additional respiratory conditions to examine the knowledge and gaps regarding disease "overlap syndromes" with the goal of generating new collaborations and shared learning.

There are a limited number of spaces available for attending this seminar. If you are interested in attending, registration must be completed by 30th November 2018.

For more information on the seminar, registration or poster submission please follow this [link](#)

### EMBARC Presents at ERS 2018

The annual European Respiratory Conference is being held in Paris this month.

EMBARC will be there to update everyone on your recruitment success.

Find some of our posters and discussions in the various locations below;



**ERS**  
**INTERNATIONAL CONGRESS 2018**  
PARIS France, 15-19 September

#### Sunday 16th

Session 56 08:30—10:30

**Poster discussion: The global impact of bronchiectasis and nontuberculous mycobacteria (NTM)**

**PA348:** Characteristics of patients with pulmonary non-tuberculous Mycobacterial infection in bronchiectasis: Data from the EMBARC registry

**PA350:** Rhinosinusitis is associated with increased symptoms and more frequent exacerbations among patients with bronchiectasis- data from the EMBARC registry

**PA356:** Validity of COPD diagnosis in Bronchiectasis patients: data from the EMBARC registry

**PA359:** Primary ciliary dyskinesia in adults with bronchiectasis: Data from the EMBARC registry

#### Monday 17th

Session 256 10:45—12:45

**Poster discussion: Respiratory epidemiology: from COPD to factors that associate with lung function and infections**

**PA2282:** Sex differences in bronchiectasis patient characteristics: an analysis of the EMBARC cohort

Session 281 12:50—14:40

**Thematic poster: Improving the quality of life of patients with bronchiectasis**

**PA2676:** The heterogeneity of bronchiectasis patient characteristics, management and outcomes across Europe: Data from the EMBARC registry

**PA2678:** Impact of Inflammatory bowel disease in bronchiectasis (IBD-BR) data from the EMBARC registry

Session 285 12:50—14:40

**Thematic poster: Pulmonary tuberculosis: long term complications, rehabilitation and challenges**

**PA2748:** Post-Tuberculosis Bronchiectasis in India: Outcomes of the Indian EMBARC Registry

#### Tuesday 18th

Session 449 14:45—16:45

**Oral presentation: Bronchiectasis: phenotypes, endotypes and new therapies**

**OA4951:** Determinants of quality of life in bronchiectasis using the quality of life bronchiectasis (QOL-B) questionnaire: data from the EMBARC registry

**OA4952:** Phenotypes in Bronchiectasis from the EMBARC India Registry

#### Wednesday 19th

Session 532 08:30—10:30

**Oral presentation: Latest advances in pulmonary rehabilitation assessment and content**

**OA5201:** Variability in access and referral to pulmonary rehabilitation in European bronchiectasis patients enrolled in the EMBARC registry



The 3rd World Bronchiectasis Conference was another huge success with over 300 attendees, more than 50 abstracts and poster presentations and speakers from around the world attending.

A link will be available soon where you will be able to view a wide variety of the conference presentations and see photo highlights from the event.

### EMBARC Projects - Update



The European NTM Registry

The first patients have been recruited to the NTM registry and invites for participation are being sent to more sites. A great number of sites across 10 countries have contacted us expressing their interest in taking part in this sub-study of EMBARC. We will be in touch with more information as further approvals are issued.

**BRIDGE—Bronchiectasis Research Involving Databases, Genomics and Endotyping to match the right treatment to the right patient.**

We are getting close to completion of set-up for the key study in work package 3 of the EMBARC2 project which is called the BRIDGE study. This will recruit a large number of patients across Europe with sampling for "omics" and extensive phenotyping and endotyping. The pilot study for this is far advanced and we hope to present results of the pilot study to you at the ERS congress.



If you are interested in participating in either of these new EMBARC studies please contact us; [info@bronchiectasis.eu](mailto:info@bronchiectasis.eu)

### EMBARC Patient Collaboration



In collaboration with the European Respiratory Society, European Lung Foundation and the European Bronchiectasis Patient Advisory Group, EMBARC have assisted in the development of a Bronchiectasis Patient Priorities page hosted by ELF. Here, patients can find a whole host of useful support and information

much of which has been translated into multiple languages with more being added each month.

The website can be found through the patient resource tab from the EMBARC home page or directly at [www.europeanlunginfo.org/bronchiectasis](http://www.europeanlunginfo.org/bronchiectasis)

Please promote this resource in your clinics.



It is the responsibility of eligible centres to raise invoices for their recruitment within 1 year of consent. 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.j.crichton@dundee.ac.uk](mailto:m.j.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)



## Publications

When and how ruling out cystic fibrosis in adult patients with bronchiectasis. Gramegna A, Aliberti S, Seia M, Porcaro L, Bianchi V, Castellani C, Melotti P, Sorio C, Consalvo E, Franceschi E, Amati F, Contarini M, Gaffuri M, Roncoroni L, Vigone B, Bellofiore A, Del Monaco C, Oriano M, Terranova L, Patria MF, Marchisio P, Assael BM, Blasi F. Multidiscip Respir Med. 2018 Aug 9;13(Suppl 1):29. doi: 10.1186/s40248-018-0142-7. eCollection 2018. Review. <https://www.ncbi.nlm.nih.gov/pubmed/30151190>

Get together to increase awareness in bronchiectasis: a report of the 2<sup>nd</sup> World Bronchiectasis Conference Stefano Aliberti, James D. Chalmers Multidisciplinary Respiratory Medicine 2018(3) (Suppl 1) :28 <https://doi.org/10.1186/s40248-018-0138-3>

Why, when and how to investigate primary ciliary dyskinesia in adult patients with bronchiectasis. Multidiscip Respir Med. 2018 Aug 9;13(Suppl 1):24. doi: 10.1186/s40248-018-0139-2. eCollection 2018. <https://mrmjournal.biomedcentral.com/articles/10.1186/s40248-018-0139-2>

Bronchiectasis in PCD looks different to CF on CT scan. Robinson P, Morgan L Curr Pulmonol Rep. 2018 Aug 9;13(Suppl 1):24. doi: 10.1186/s40248-018-0139-2. eCollection 2018 <https://mrmjournal.biomedcentral.com/articles/10.1186/s40248-018-0139-2>

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Management of bronchiectasis in adults Visser SK, Bye P, Morgan L Med J Aust. 2018 Aug 20;209(4):177-183. <https://www.mja.com.au/journal/2018/209/4/management-bronchiectasis-adults>

Mycobacterium Avium Complex and Bronchiectasis: There's Something Happening Here .... Griffith DE, Aksami TR Am J Respir Crit Care Med. 2018 Aug 9. doi: 10.1164/rccm.201807-1243ED. [Epub ahead of print] [https://www.atsjournals.org/doi/abs/10.1164/rccm.201807-1243ED?url\\_ver=Z39.88-2003&rft\\_id=ori%3Arid%3ACrossref.org&rft\\_dat=cr\\_pub%3Dpubmed](https://www.atsjournals.org/doi/abs/10.1164/rccm.201807-1243ED?url_ver=Z39.88-2003&rft_id=ori%3Arid%3ACrossref.org&rft_dat=cr_pub%3Dpubmed)

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Bronchiectasis Economics: Spend Money to Save Money Goeminne PC, Vanfleteren LEGW. Respiration. 2018 Jul 24;1-4. doi: 10.1159/000490550. [Epub ahead of print] <https://www.karger.com/Article/FullText/489935>

The efficacy of inhaled antibiotics in non-cystic fibrosis bronchiectasis. Amaro R, Panagiotaraka M, Alcaraz V, Torres A Expert Rev Respir Med. 2018 Aug;12(8):683-691. doi: 10.1080/17476348.2018.1500179. Epub 2018 Jul 25. <https://www.tandfonline.com/doi/abs/10.1080/17476348.2018.1500179?journalCode=iexr20>

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