Seasons greetings from the EMBARC team
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Wishing you all the best for 2020

EMBARC Success - 2019 in review

It has been another very successful year for EMBARC, we are extremely proud of the collaborations we have with you all and are very grateful for the continued hard work and support you all provide in the network. Without you, there would be no success.
Looking back over the past 12months, the registry continues to go from strength to strength with over 16,000 patients enrolled worldwide. This is an incredible achievement since our initial target was 10,000 participants by April 2020! With so much bronchiectasis data now available, we strongly encourage you to continue sending in applications to use this massive resource. Data application forms can be found on the main website.

In the past year, members of the network have contributed over 50 publications to the bronchiectasis field, with several key EMBARC papers published in the Lancet family of Journals, American Journal of Respiratory and Critical Care Medicine and the European Respiratory Journal among others. The EMBARC manual was published and has so far been downloaded over 12,000 times showing just how much interest people have in bronchiectasis. With so much work being carried out, we continued to be well represented at all the major conferences and even co-hosted the very first NTM and Bronchiectasis Workshop in Vienna.
In July 2020 the next World Bronchiectasis Conference will be held in Barcelona– Registration is now open! Abstract submission is also open for the European Respiratory Society congress in Vienna and EMBARC will be well represented.
The foundations for further collaborations were set early in the year when the EMBARC and SHARP research collaborations met to discuss how the 'gaps' in overlap syndromes can be filled using shared knowledge and generating new task forces.

A new EMBARC study called BRIDGE was launched earlier this year aiming to collect genomic, microbiome and biomarker information on over 1000 patients in Europe and this study is already recruiting well. This is the second new EMBARC study to be launched in the past year following the NTM registry which started towards the end of 2018.

Congratulations need to be extended to the European Lung Foundation who have worked closely with us in advancing patient education through the Patient Priorities website. The website has been specifically designed with patients, for patients and covers areas of interest including, but not limited to, self-management videos, answers to frequently asked questions and information about clinical research. Much of this information has also been made available in multiple languages with further congratulations extending to Dr Pieter Goeminne from Belgium who recently secured a grant to cover the cost of translating even more patient information.

Opportunities to Participate in Current Studies

ZAMBON
PROMIS study

EMBARC is working with Zambon to support the PROMIS trials. The Promis program is an ongoing phase III registration trial program, aiming to provide the first licensed treatment for patients with Non-CF Bronchiectasis with chronic Pseudomonas aeruginosa infection. The study is global with sites in the American, European and Asia Pacific regions. In order to support the studies and sites conducting the study a website has been developed to raise awareness of the programme among patients and non-participating site. The aim of the site is to give some general information and insights on what a clinical study entails and what impact it has on a study participant. You can access the website by clicking on the following link: www.promisclinicalstudy.com

ELF
NTM survey

The European Lung Foundation is running a survey for patients and families with experience of non-tuberculous Mycobacterial infection. The survey is closing in January so now is the last chance to encourage your patients to participate. The survey is available in multiple languages and will collect invaluable data on patients awareness and experiences of NTM.
Please visit the following link to support the project.
https://www.europeanlung.org/en/news-and-events/news/share-your-experiences-of-bronchiectasis-and/or-ntm-infection-in-a-new-survey

The European NTM Registry

The pulmonary NTM registry is underway and continues to recruit new specialist centres. If your centre specialises in pulmonary NTM and would like to take part in this sub-study, please contact info@bronchiectasis.eu

The 4th World Bronchiectasis and NTM conference will be held in Barcelona next July. Professors Blasi, Aliberti and Chalmers have put together a promotional video for the conference to explain what can be expected from WBC 2020
https://www.youtube.com/watch?v=amjEKjrBzgc

Highlights from the European NTM & Bronchiectasis Workshop 2019 can also be viewed here

Publications

Call for Data Applications

If you have a research question which can be answered using the EMBARC dataset and wish to access EMBARC data please complete a data applications form and send to the research coordinator, info@bronchiectasis.eu
Data request forms can be downloaded from the EMBARC website or accessed from this link.

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iABC Inhaled Antibiotics in Bronchiectasis and Cystic Fibrosis

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