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BeTheCure Newsletter - for collaborators and interested external parties - 1/2013

## Prestigious acknowledgements to BTCure members



**Lars Klareskog**

The Crafoord Prize in Polyarthritis 2013 was awarded to Peter K. Gregersen, **Lars Klareskog** and Robert J Winchester. "for their discoveries concerning the role of different genetic factors and their interactions with environmental factors in the pathogenesis, diagnosis and clinical management of rheumatoid arthritis.



**George Kollias**

In recognition of eminent scientific discoveries and contributions to science, Fleming researcher **Professor George Kollias** was elected March 14th 2013, full member of the Academy of Athens, the most prestigious academic institution in Greece.

Photo, courtesy of <http://www.academyofathens.gr/echome.asp?lang=2>

## News in short

- The BTCure ENSO (Exploring New Scientific Opportunities) application has been approved by IMI. This include, not only additional funding to identified new projects, but also that GSK will be a new official EFPIA-partner in BTCure. With this newsletter we want to welcome the GSK team to the BTCure consortium.
- Migration work is currently ongoing between the old internal collaboration platform and the new one. All files and documents will be in place shortly and all BTCure members will receive information on login and account during the first weeks of April.
- There will be an interim evaluation of the BTCure work on May 7 in Brussels. All WP-leaders who have announced their availability will be present to report on their respective WP before an external review board. Feed-back from the reviewers will be given on the same day.
- Upcoming workshop on Animal Models, June 5-7, Divani Palace Acropolis, Athens, Greece Agenda and invitation have been distributed via e-mail. If you did not receive this, please contact [chandras@fleming.gr](mailto:chandras@fleming.gr).
- Our BTCure initiative and consortium will be presented in the next issue of the EULAR/PARE newsletter.
- The workshop on "Developing guidelines for Rheumatology Biobanking" that was planned to be held in Leeds in April, will be held in conjunction to the annual meeting in Prague, September 15-17.

## New quarterly BTCure highlights:

## WP2 and 9 success stories

### Inventory of data and biomaterial collections

BTCure successfully completed a major objective to create inventories of existing data and biomaterial collections. The current cohort inventory summarizes study details and data sharing information for 32 different RA cohorts, including available information on clinical variables, immunology, genetics, environmental factors, et cetera. All cohorts are linked directly to available tissue collections and genetic material. Here, a substantial amount of data on biomaterial and DNA collections, processing and storage methods for nearly 15 partners was collated. The current inventory can be understood as a road map and first source of information with regard to available details on BTCure cohort and registries throughout Europe. We are happy to announce that the inventory already serves BTCure partners as a basis for the design of collaborative, scientific follow-up projects.

### Data sharing and analysis of similar but non-identical datasets

**Saedis Saevarsdóttir (KI) leading demo project investigating ACPA fine**

#### specificities in response to therapies

Two large, collaborative demonstration projects were initiated after a workshop in Stockholm last January (WP2 demo workshop). These projects are based around state of the art scientific questions to which BTCure partners are expected to deliver world-leading data and know-how. The objectives are two-fold: (i) to address the scientific questions in focus (better understand treatment response in RA), and (ii) simultaneously demonstrate hurdles and means to improve collaborative sharing of data and joint but centralized de novo analyses of existing samples/data.

The currently initiated demonstration projects received a huge commitment to participate from at least 6 interested academic partners and the interest of at least two EFPIA partners. The Coordinators are Saedis Saevarsdóttir (KI) and Anne Barton (Manchester).



### Harmonization of future data and sample collections



**Helga Radner, (MUW), Coordinator of**

#### clinical data harmonization

During the work with the cohort inventory the urgent need to harmonize studies and data collections for forward-looking research projects became clear. Now, a project has been initiated (coordinated by Vienna, to define desirable clinical core domains, and variable definitions in each domain. To ensure a legacy beyond BTCure, this work will liaise with the EULAR Study Group on Registers. The plan is to publish new recommendations and guidelines within 2013.

### Coordinated evaluation of pre-RA disease states and RA risk groups

One of the major BTCure achievements is represented by the successful initiation of countrywide research logistics allowing identification and analysis of samples stored in Swedish biobanks. With respect to the de novo collection of biomaterial, the Swedish effort to establish a pre-RA cohort has even expanded into the establishment of a national biobank linked to the nationwide clinical RA register, offering unique opportunities for assessments of etiologically and prognostically relevant biomarkers. If successful the Swedish national initiative will facilitate similar initiatives in other European countries.

BTCure members as part of the EULAR Study Group for Risk Factors for RA, have further published recommendations for the harmonized terminology and research in individuals at risk of developing RA, a publication already acknowledged by experts in the area. First studies on profiling in pre-RA patients have been published and more are under way. In addition, the 3rd pre-RA workshop was held in Stockholm (Jan 27-29), where the partner AMC presented a first summary overview of pre-RA and RA risk patient cohorts within BTCure and Europe.

First cohorts of people at risk for RA, mostly first-degree relatives of RA patients, are being established (Karolinska, Vienna, Amsterdam, Leiden, Manchester, Leeds) and the first analysis of biomarkers has been performed. AMC successfully recruited 90 people at risk for developing RA into an intervention trial trying to prevent RA. This success can be adopted by other groups interested in setting up such a trial to extend the knowledge in this very exciting field. Since RA is a prototype immune-mediated inflammatory disease with important consequences for the individual patient as well as for society, this knowledge can then be extended to other immune-inflammatory diseases, such as SLE, spondyloarthritis and Crohn's disease.

## Personalized medicine

A draft report on the review of personalised medicine features has been produced different partners of BTCure as a first step to establish personal medicine features relevant to RA in order to develop a treatment algorithm based on molecular and other profiling technologies.

Various reviews have been published and are being prepared to report on personalized medicine. Inventory of data available on personalized medicine will be explored in the literature and reported by publications with the help of various partners within BTCure. Furthermore, demonstration projects mentioned before using specific research questions in this regard, will shed light on data available at the partners of this consortium.

## Designing successful patient recruitment strategies for clinical trials

Finding suitable patients for conducting clinical trials has become more difficult due to the current practice of RA (treat to target principles towards achieving remission) and the availability of more therapies. Also, the more highly specific selection criteria required for trial participants are in contrast to the wider characteristics of patients seen in the "real world" of daily routine practice, leading to disparity between clinical trial conditions and routine clinical practice is also associated with reduced applicability of trial outcomes to real world practice. A review of the every day patient population conducted by partners of BTCure will provide information relevant to the kind of patients that would best reflect real-world practice that should be included in efficacy but particularly pragmatic trials. A list of real-life patient characteristics was determined and extracted from the local registries/databases different BTCure partners. A statistical plan to analyse these data is currently designed. Other observational datasets will be included in a later phase to add greater credibility based on a feasibility questionnaire that was circulated amongst all BTCure partners to assess which partners will be able to test the revised clinical trial eligibility criteria.

## Workshop reports

**Pre-RA workshop and WP2 demo workshop** - January 27-29, in Stockholm, please see success stories above.

**Functional Genomics workshop** - 6-8th February 2013 at St Thomas' Hospital, London. For full report, please visit <http://btcure.eu/2013/03/functional-genomics-workshop/>

**Cellular partners of autoreactive T and B lymphocytes in synovial and lymphoid tissue** - An inspiring BTCure workshop to highlight novel findings on adaptive immunity behind chronic inflammatory diseases, with a focus on rheumatoid arthritis was organized March 18-19 for and by partners of our consortium. The workshop was visited

by over 80 participants from 15 different BTCure partners, of which 11 academic institutes, and 6 industrial partners.

For the full report of the workshop, please visit <http://btcure.eu/2013/03/cellular-partners-of-autoreactive-t-and-b-lymphocytes-in-synovial-and-lymphoid-tissue/>.

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