U-BIOPRED – A personalised approach to severe asthma

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EFA President
EFA Board Lead of U-BIOPRED Project

The European Federation of Allergies and Airways Diseases Patients' Associations (EFA)

About

- The European Federation of Allergy and Airways Diseases Patients Associations (EFA) founded in 1991
- European network of 33 allergy, asthma and COPD patient organizations in 22 European countries
- EFA unites national patient associations at European level and improves the health and quality of life for patients and their families by facilitating collaboration and sharing knowledge as well as experiences
- EFA has Central Office in Brussels, Belgium

  www.efanet.org

Unbiased Biomarker for the Prediction of Respiratory Disease Outcomes (U-BIOPRED)

Aim: to better understand the different types of severe asthma.

Starting Date: 01 October 2009 with duration of 60 months. This will enable us to:

- Better consider individual characteristics of patients (personalised medicine) in their diagnosis and management
- Make it easier to develop new and more effective medicines by overcoming the present bottlenecks to advancing new therapies.
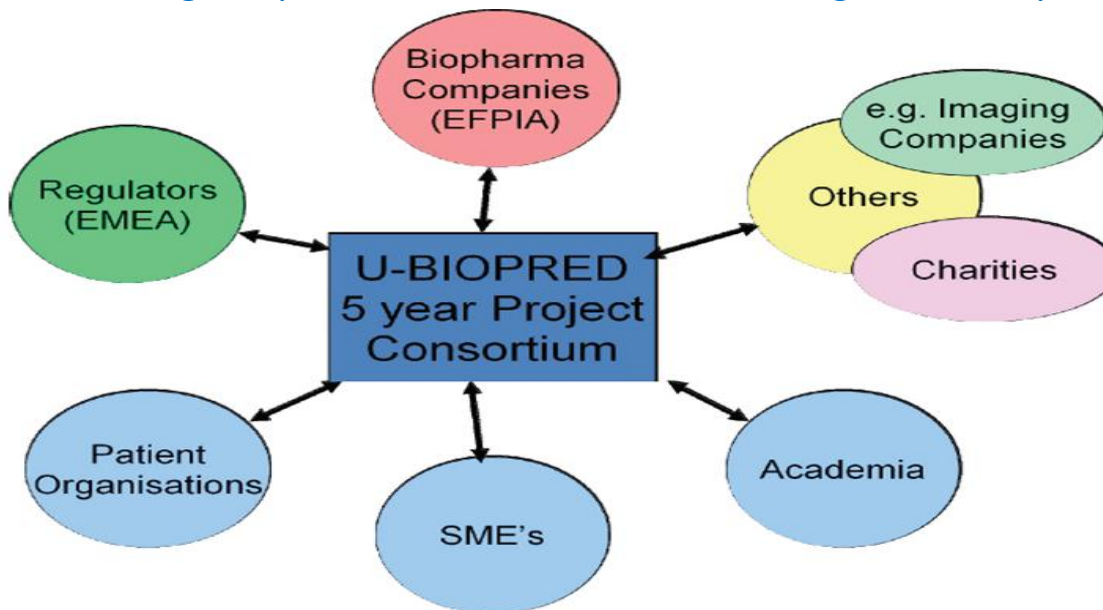
Patient input (EFA, Netherlands Astma Fonds and Asthma UK):
- ✓ Patient-oriented outcomes
- ✓ Defining research questions
- ✓ Disease knowledge
- ✓ Access to patient networks
- ✓ Ethics
- ✓ Safety
- ✓ Strategic Advise
- ✓ Help in planning and running study
- ✓ Teaching
- ✓ Informed consent
- ✓ Dissemination, training, exchange
- ✓ Patient-public-private partnerships
- ✓ Consensus generation

U-BIOPRED: Aims to help us better understand severe asthma to improve patient care

- **The problem:**
  - Our poor understanding of the different phenotypes within the severe asthma population
  - Lack of biomarkers that enable us to effectively track disease progression or the impact of a novel therapy on disease in clinical studies
- **Which means:**
  - Many people with severe asthma do not have precise enough diagnosis and their 'real life asthma is not understood
  - There are no effective or not effective enough treatments for them and no possibility for truly individual management plan
  - They suffer, use lots of healthcare resources and are limited in their daily life leisure , work, school

- ***U-BIOPRED prepares the ground for solutions***

U-BIOPRED

efpia

U-BIOPRED Strategy

1. Reaching international consensus on diagnostic criteria
2. Creating adult/pediatric cohorts and biobanks
3. Creating new phenotype "handprints" by combining biologic, clinical and patient reported data
4. Validating such "handprints" in relation to exacerbations and disease progression
5. Refining the "handprints " by using preclinical and human exacerbation models
6. Predicting efficacy of gold standard and new interventions
7. Refining the diagnostic criteria and phenotypes
8. Establishing a platform for exchange, education and dissemination

U-BIOPRED

A sophisticated and novel integrated 'Systems Medicine' approach to understanding severe asthma

The resulting handprint will enable us to precisely characterise patients with different types of severe asthma = understanding different types of asthma better

Lina Buzermaniene, Lithuania, patient representative in the Ethics Board
Per-Ake Wecksell, Sweden, patient representative in the Safety Board

metabolomics
proteomics
clinical data
transcriptomics / genomics
PRO*

systems biology

* Patient-reported outcomes
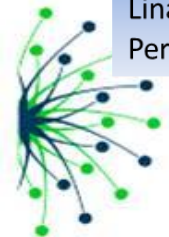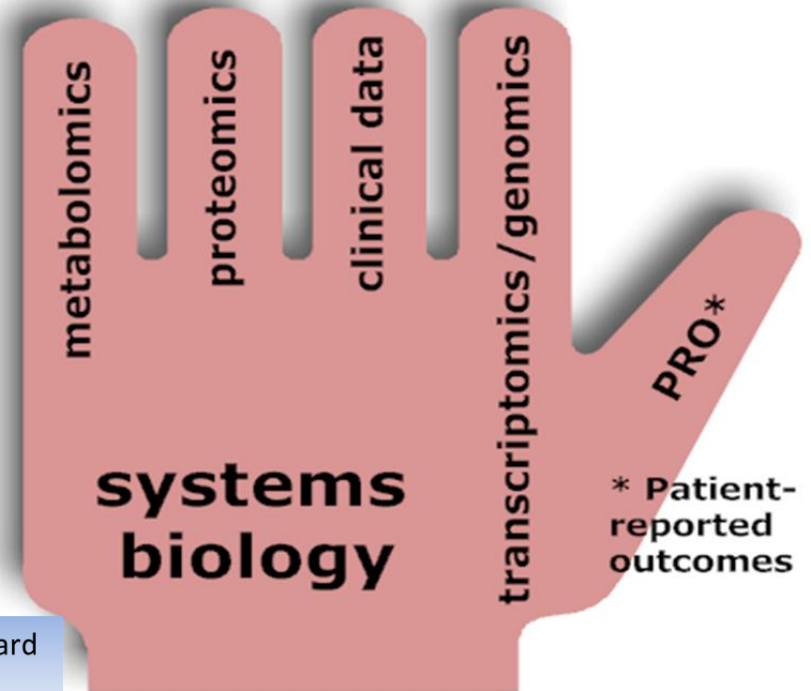
Results and Achievements Thus Far (I)

- Significant progress across all work packages

- Recruitment (as of 08/03/2013)
  - **677** adult patients
  - **289** pediatric patients

- Publications from consortium members

- Creation of an exit questionnaire for patients to collect feedback along with invitations for stories from their participation

- Bronchoscopy leaflet for dissemination to clinical trial centres

Results and Achievements Thus Far (II)

- Art Contest Concluded with winner: **Marije Kootstra** (NED)

Results and Achievements Thus Far (III)

- Website updated to www.ubiopred.eu
  - From January 1st 2012 – January 1st 2013:
    - 24,945 page views
    - 5,952 visits from 4,125 unique visitors
- Launch of LinkedIn and Twitter pages
- Updated biannual Newsletter
- Opening of U-BIOPRED Forum for interactions between Patient Input Platform (PIP) and members of the project consortium

At the Annual Meeting for the U-BIOPRED Consortium

Is maith liom bheith ag obair le othair asma, agus go mór mór le Bríd.

Val Hudson, Member of the Patient Input Platform
Pim de Boer, Astmafonds, Netherlands
Leanne Metcalf, Asthma UK

Coordinator Peter Sterk, Academic Medical Centre, Amsterdam p.j.sterk@amc.nl
EFA Board U-BIOPRED Project lead Breda Flood

IMI and personalised medicine - 20 March 2013 – Dublin, Ireland

Patient expectations: EFA/U-BIOPRED News 2014

- The mysteries of severe asthma have been unravelled
- We have identified the different phenotypes of severe asthma and they are…
- The partnership has been a success
- Patient representatives have been involved throughout the project
- The results now enable:
  - Better understanding of severe asthma by patients, HPCs, industry, policymakers
  - Development of treatment for people with different types of asthma that help them to live a normal life

In the words of Sir William Osler…

"The good physician treats the disease; the great physician treats the patient with the disease."

"He who studies medicine without books sails an uncharted sea, but he who studies medicine without patients does not go to sea at all!"

Thank You for Your Kind Attention!

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