

A-Reg Task Force meeting, EAACI Congress Geneva

19th June 2012

Present: Nikos Papadopoulos (Chair), Carsten Flohr (Secretary), Christian Apfelbacher, Peter Burney, Aziz Sheikh, Margitta Worm, George Konstantinou

Apologies: Pascal Demoly, Moises Calderon

NP summarised the overall aims of the Allergy Registry Task Force (called A-Reg), in particular to evaluate the feasibility for EAACI to set up/coordinate patient registries related to allergic diseases. The plan is to prepare a paper describing the current allergic disease registry situation in Europe but to also produce a feasibility report for the EAACI Executive.

CF then reported on a number of ongoing activities linked to the A-Reg TF, in particular Dr Moises Calderon's European Adverse Systemic Reactions Survey in allergen-specific immunotherapy (EASSI-pilot), which is well under way, the European treatment of severe atopic eczema in childhood taskforce survey (TREAT) that CF has already conducted among 750 dermatologists in 8 European countries, and the PARENT Initiative, an EU funded project that aims to coordinate efforts to set up chronic disease registries across European borders. A-Reg has been an official Collaborating Partner of PARENT since inception in June 2012.

There was then an open discussion about how best to conduct the survey of existing allergy registries within and outside of EAACI. It was decided that Survey Monkey software was going to be used, purchased from the A-Reg budget and coordinated by Dr Christian Apfelbacher with support from the rest of the TF members. A systematic literature search, also lead by CA, will be conducted for the position paper.

Due to time pressures, there was little time to talk about the new EU research grant programme 'Horizon 2020'. CF reported that he had contacted Dr Alain Van-Vossel at DG Sanco earlier in the year (facilitated by Peter Burney) and there appeared to be interest within DG Sanco to fund patient registry research. Consequently, A-Reg was been invited to send DG Sanco a short proposal to form the basis for further discussions to influence the Horizon 2020 call. However, no decision was made as to whether this should be pursued by TF members.

The next meeting will take place in Athens in October, hosted by NP, following completion of the registry survey. A date will be decided in due course.