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**The PRES European Network of Registries for Autoinflammatory Diseases in childhood.**

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## Coordinator, Leader contact and partners

- Assistance publique Hôpitaux de Paris-Centre Hospitalo-Universitaire de Necker-Enfants Malades - APHP-CHU Necker
- Vivantes Netzwerk für Gesundheit GmbH - VIVANTES (from 08/10/2010)
- Ziekenhuisschool Universitaire Ziekenhuizen K U Leuven VZW - UZLeuven
- Assistance publique Hôpitaux de Paris-Centre Hospitalo-Universitaire de Bicêtre - APHP-CHU de Bicêtre
- Bambino Gesù Pediatric Hospital, Scientific Institute - OPBG
- University Medical Center Utrecht - UMCU
- University of Würzburg - UW (until 31/05/2009)
- University College London - UCL
- Hacettepe University Faculty of Medicine - HUFM

## Outputs

- D 2 Informative webpages on Autoinflammatory diseases
- D1 Permanent network of registries on Autoinflammatory diseases in children
- D3 State of the art on the treatment of Autoinflammatory diseases
- Final report - Final report
- Interim report 1 - Interim report 1
- Website
The PRES European Network of Registries for Autoinflammatory Diseases in childhood.

JA2015 - GPSD [705038]

| START DATE: | 01/07/2008 |
| END DATE:   | 01/07/2011 |
| DURATION:   | 36 month(s) |
| CURRENT STATUS: | Finalised |
| PROGRAMME TITLE: | First Programme of Community action in the field of public health (2003-2008) |
| PROGRAMME PRIORITY: | - |
| CALL: | Health Information (Hi 2007) |
| TOPIC: | Developing strategies for information exchange and responding to non-communicable health threats |
| EC CONTRIBUTION: | 341733.46 EUR |
| KEYWORDS: | Children, Diagnostic, Health system, Rare diseases and disorders, Treatment |
| PORTFOLIO: | Healthcare, Rare diseases |
General objectives

The general aim of this project is to build a network on autoinflammatory diseases in childhood. In particular the project would like to complete and integrate already existing initiatives in this field with the following actions:
- sensitize paediatricians and paediatric rheumatologists to the prompt recognition of these diseases,
- give a proper information among families affected by these conditions,
- increase the knowledge on the clinical presentation, response to treatment and complications of these rare disorders.

Strategic relevance and contribution to the public health programme

The project will be devoted to development of strategies and mechanisms for exchange information among people affected by rare diseases and promotion of better epidemiological studies, codification, classification and definition. Moreover this project is aimed to support European networks of references for rare diseases in order to establish guidelines for best practice on treatment and to share knowledge on these diseases.

Methods and means

The following instruments will be used:
- a web-based survey on the prevalence of diagnosed or suspected autoinflammatory diseases among all European Paediatric Rheumatology Centers,
- international registries for all those diseases lacking of a web-based method for data collection,
- survey on the efficacy of treatment in these disorders and elaboration of outcome measures for possible future therapeutic trials,
- informative webpages on each disorders for patients and physicians

Expected outcomes period

The project will contribute to better exchange of information on autoinflammatory diseases among the paediatric rheumatology centres dealing with these disorders and other already existing initiative on rare diseases. It will improve the early diagnosis and the global management of the autoinflammatory syndromes and to disseminate proper information to paediatricians and affected families.
COORDINATOR

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D 2 Informative webpages on Autoinflammatory diseases
Istituto Giannina Gaslini IRCCS - IGG
The PRES European Network of Registries for Autoinflammatory Diseases in childhood. (EuroFever)
Published on: 01/07/2008

D1 Permanent network of registries on Autoinflammatory diseases in children
Istituto Giannina Gaslini IRCCS - IGG
The PRES European Network of Registries for Autoinflammatory Diseases in childhood. (EuroFever)
Published on: 01/07/2008
2007332_familial_mediterranean_fever.mht

D3 State of the art on the treatment of Autoinflammatory diseases
Istituto Giannina Gaslini IRCCS - IGG
The PRES European Network of Registries for Autoinflammatory Diseases in childhood. (EuroFever)
Published on: 01/07/2008
http://azorina.cc.cec.eu.int:8082/publications/2007332/2007332_d3_eurofever_received_2010_03_31.doc

Final report - Final report
Istituto Giannina Gaslini IRCCS - IGG
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Published on: 01/07/2008