

# **Cilia Awareness Day & Launch of Ciliopathy Alliance UK**

**Institute of Child Health, UCL  
29/11/2010**



# Ciliopathy Alliance UK

- A new alliance of family support groups, research scientists and doctors representing the patients suffering from ciliopathy diseases
- We can gain mutual benefit from collaboration between groups involved in ciliopathy diseases: family support, disease research, clinical management, health and benefits policy
- Initial founders' meeting 10<sup>th</sup> March 2010

# Ciliopathy Alliance Aims

- Present a strong and united front for all people with ciliopathy diseases
- Share knowledge and understanding of, and promote awareness of, ciliopathy diseases and their patient organisations
- Organise events and meetings
- Share information relevant to all patients and health professionals
- Share expertise in fund-raising and changing health and benefits policy
- Encourage and carry out collaborative research that will help people with ciliopathy diseases
- To encourage patient involvement in research and clinical management

# Membership



- Membership is open to all organizations and individuals with an interest in ciliopathy diseases

# Objectives 2010

- Organize 'Cilia Awareness Day' to launch the Alliance and promote awareness
- Ensure all ciliopathy patient groups are invited to join the Alliance
- Establish a Scientific Advisory Committee
- Develop a mailing list of members and a website with links to Alliance members and information sources
- Support applications for collaborative research
  - Grand Challenge PhD, Health Economics MSc

# Launch Event generously supported by:

deafness research uk



<http://www.deafnessresearch.org.uk/>



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<http://www.ucl.ac.uk/public-engagement/>



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