



# A.F.H.A. Family meeting 2013

19th october 2013– Hôpital Broussais-96 rue Didot Paris

13h00 – 13h30

13h30 – 14h00

14h00 – 18h00

18H30 – 19H00

19h00 - 21h00

Welcome to families ( registration -accommodation information – badges )

Introduction -(Dominique Poncelin – AFHA président)

### Scientific session on AHC research :

Sophie Nicole PhD (geneticist - Paris)

Gaëtan Lesca PhD (geneticist - Lyon)

- Current Genetic research project (« looking for gene N°2 »)
- Further directions for genetic research after Rome symposium
- Overview of Individual diagnostic for ATP1A3 mutations for French AHC families (updated report)

Eleni Panagiotakaki MD (neurologist-Lyon) : Genotype/phenotype : first results

Diane Doummar MD, Agathe Roubertie MD (neurologists Paris - Montpellier)

- New starting research project on abnormal movements for AHC people
- Methodology - vidéo session

**AFHA Award of Excellence 2013 : to Eleni Panagiotakaki (MD neurologist)**

**Dinner** (complimentary Pizza Buffet)

20th october 2013 – Hôpital Broussais (Paris)

9h30 – 9h45

10h00 – 11h30

12h00 – 14h00

14h00 – 15h30

Welcome to families

### AFHA General Assembly :

- Activities – Financial Reports - approval
- Newsletter « Le Lien » - website
- International update (Foundations + research)
- New projects for year 2014
- Debate and questions of the members
- election of the board of directors

**Lunch** (complimentary cocktail Buffet)

**Pain for AHC children** : (moderated by AC . Sabas - relaxation therapist)

- how to recognize , to evaluate, to deal with , how to help kids (guidelines, recommandations)

Conclusion : Dominique Poncelin (AFHA President)