



**A.A.L.**

*Syndrome d'Aicardi*

Déclarée à la Préfecture de M.&- le 09/04/02 sous le n° 014743

Parue dans le Journal Officiel du 27/04/02 sous le n° 20020017

SIRET : 450 085 030 00010 - Code NAF : 913 E

Siège : 1, rue Marguerite des Prés F- 54270 Essey-lès-Nancy

Rép./Fax : ++ 33 (0) 825.955.285



Nancy-Université  
Université  
Henri Poincaré



ville de  
**Nancy**



A.A.L. 04/07



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*Syndrome d'Aicardi*

1, rue Marguerite des Prés  
54270 ESSEY-LES-NANCY  
FRANCE

Owing to the new TGV EST line opening on 10<sup>th</sup> June 2007, our 3rd European « Aicardi Families » congress will take place closer to you...

This meeting is for all people concerned with AICARDI SYNDROME but it is open to all families and those who are professionally interested in :

**MULTIPLE DISABILITIES,  
SEIZURES,  
RARE OR/AND GENETIC DISEASES**

**Friday 16/06/07**

- **15.00:** optional Visit to the cytogenetic molecular laboratory for the wishful Aicardi families - **EA3441-CHU Nancy-Brabois** (54500 Vandoeuvre) -visits will be in English and French.

- **20.30:** Organ and Gospel concert for the profit of AAL Syndrome of Aicardi Association, in the Church Saint Pie X and Saint Luc, rue du General Leclerc à Essey-lès-Nancy (54270), free of charge

*First part :* Mr Dominique Breda, titular organist at the church St Léon of Nancy and also teacher at the music academy of Metz and at the institutes of musicology at the university of Metz and Nancy (it the program : J.S. Bach, F. Mendelssohn, P. Camonin, P.Cholley ...)

*Second part :* The « Nancy Gospel Singers », directed by Mrs Sara Klopfenstein, chorus conductor and she is accompanied by Mr Régis Magnard, the Pianist, will perform; *He's Got the Whole World, Swingin' with the Saints, Oh Happy Day...*

**Sunday 17/06/07**

- **10.00:** optional guided tour of Nancy in both languages English and French for "Aicardi Families"

**Saturday 16/06/07**

Communauté Urbaine du Grand Nancy  
22-24 Viaduc Kennedy  
54000 NANCY  
reception from 8.30 a.m.

*Moderator*

Doctor Jean-Luc SCHAFF,  
Epileptolog at CHU de Nancy  
and at COCEE (OHS de Flavigny - 54630)  
(Centre d'Observation et de Cure pour Enfants Epileptiques)

*Morning*

- **9.00 :** reception at room of council by M. François Werner, vice president delegated to the University Businesses of the Urban Community, Assistant of the Mayor of Nancy delegated to Finances and the Budget; and word of welcome by Mr. Olivier Vauchelet, president of AAL-Syndrome d'Aicardi.

- **9.30 :** Doctor Monique André, Neuropediatrist at Maternity of Nancy: " *Telling the Diagnosis* "

- **10.15:** Doctor Jean-Luc Schaff, Epileptolog: " *Last treatments of Epilepsy & Vagus Nerve Stimulation* "

- **11.00:** Doctor Marie-Dominique Devignes, from laboratory LORIA, Professor Philippe Jonveaux and Ms Saliha Yilmaz from laboratory of molecular cytogenetics - EA3441 -: " *Aicardi Syndrome: Research, initiated in Nancy City, update* "

- **12.00:** questions/answers

*Afternoon*

- **14.00:** Doctor François Roussel, pediatrist in specialized establishment: " *Dealt with multidisciplinary of multiple disabilities* "

- **14.45:** Mr Jean-Marie Lacau will speak about two investigations under development within the association Réseau-Lucioles (01330 Villars les Dombes):

" *Deglutition & Digestion disorders...* ": this investigation is a research task to improve our knowledge and the consultations to give to the parents and professionals. This was done due to the collaboration with Catherine Senez and Irene Bénigni, specialists, respectively speech therapist and dietician.

" *How to accompany as well and as soon as possible?* " inquire on the initiative of the Réseau-Lucioles, in partnership with the ANECAMSP (Association Nationale des Equipes Contribuant à l'Action Médico-Sociale Précoce / National Association of the Teams Contributing to the Early Medico-social Action) and AIR (Association Information Recherche).

- **15.45 :** Doctors Bénédicte and Dominique Rémy «Aicardi Parents»/Doctors: " *Siblings* "

- **16.30 :** Questions/Answers



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est une association loi 1901

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*Créer des liens entre les familles touchées par le syndrome d'Aicardi,*

*Faire connaître ce syndrome,*

*Soutenir la recherche le concernant.*

• **Take part in our 3rd congress !**

*And return now this reply coupon  
before May 15, 2007 (limited places)*

*by notching the boxes  for yes - Thank you -*

Name :   
First name :   
Address :   
Post Code :   
Town :   
Country :   
Phone :   
E-mail :   
Will take part in the congress June 16 (all or part time)

*Interested in:*

Aicardi Syndrome   
Another rare and/or genetic disease   
Seizures   
Multiple disabilities   
Personally   
Professionally