



# LA LETTRE DE WILLIAMS

**January 2007**

**Special Edition**

**RHONE-ALPES**

**3rd NATIONAL CONFERENCE  
18 and 19 MAY 2007 – SAINT ETIENNE**

**S**tep by step, our « 3rd national conference » is being organised and the aims and objectives have been set already. They follow in the footsteps of our previous editions (**POITIERS** and **LILLE**), and of the objectives of our association: we want these events to be both studious and festive, family-oriented but also turned towards the outside world.

**F**or this important event, we have received the support of the *Ordre International des Anysetiers* which this year is starting an action in favour of orphan diseases. Our association and the Association for Epidermolysis bullosa (whose patrons are Jean ALESI and Ari VATANEN) were chosen as a starting point to their action and we can only thank them for their choice.

**H**ere is the programme as it looks at present for the two day event - and to which we would like to invite you :



**F**riday 18 May, a day which has been called for and organised by the *ANYSETIERS* will essentially be a day of rejoicing and reunions. It will be held in the Geoffroy Guichard football stadium (the mythical "Chaudron Vert" or "Green Cauldron") which the children will be able to explore. A Buffet Lunch will be served in the Platini suite. Every Williams child will receive a football. But let's not say more... there will be other surprises awaiting you there!

It will be a studious day as it will be devoted to a symposium which will mainly deal with the life and integration of adults suffering from the syndrome. Several scientists and well-know figures of the social world will speak on the subject. The details of this programme are still to be finalised. On page 2, you will find a pre-programme together with a list of speakers.

**T**he two evenings will be festive: they will provide an opportunity for all of us to get together and to get to know each other, but also to have fun with our children, young and old.



**S**aturday 19 May will be chaired by **Jean François CHOSSY**, MP for the LOIRE region and recorder of the bill on Disability, and will be held in the University Hospital Centre (CHU) of Saint Etienne.



## LIST OF SPEAKERS FOR THE 2007 SYMPOSIUM

### **HONORARY Chairman: Mr Jean François CHOSSY**

MP for the LOIRE region

**Guest of honor: Docteur Fabienne PRIEUR,**  
Geneticist at Saint Etienne University Hospital Centre

**\*Docteur Christine DERUELLE,** member of our scientific council. « Hyper-sociability in the Williams Beuren syndrome: Myth or reality?

**\* Docteur Sybille GONZALES** (Neurologist)

To speak about the development of praxis and attention disorders in the adult, and to present the most recent research

**\*Sheila WAREMBOURG**

Handicap International support service for emotional life, to talk about "The emotional and sexual life of disabled people"

**\* Gilles FAURY** (Grenoble)

To speak about the ageing of the vascular system

**\*Yves BRUCHON,** Special Needs Inspector for the National Education System, on how to mobilise and improve schooling

**\*Philippe MORTEL & Richard BOURQUE** of the OVE (Observatory on student life)

**\*Roger CHATELARD,** General Secretary of the APAJH, «Homes for the disabled and the point of view of their users"

**\* Docteur COTTON** from VALENCE, to talk about the growth hormone

**\*Madame DUHAMEL,** Director of the OASIS centers (71): the housing, leisure activities, work and finances of the people taken in these centers.

**& Bernard JOURDES,** Chairman of the OASIS, parents association (UNAPEI), administrator of several centers (ESAT), homes and leisure workshops and father to Pierre, 30, suffering from the Williams Beuren syndrome.



***During its last general assembly on 9 April 2006, the association decided to create its own Scientific Council.***

***Under the responsibility of Yves DEMAZEAU researcher at the CNRS –INPG in Grenoble - but above all a Member of our association, and FATHER to a child suffering from the WILLIAMS Syndrome – this scientific council was born on 30 April last year.***

***To this day, it is composed of 3 researchers:***

***\*Docteur Christine DERUELLE : Researcher at the INCM CNRS in Marseille – Specialist in cognitive science***

***\*Professeur Pierre Simon JOUK Geneticist and researcher at the University Joseph FOURIER in GRENOBLE***

***\*Docteur Bernard LETE : Researcher at the CNRS in the University of - LYON 2 -***

### ***The council's objectives :***

***To participate in the elaboration of our scientific programmes (and especially the programme of our national conference in MAY 2007 in Saint Etienne)***

***To scientifically evaluate the research projects which arise from information gathered from members of the association and to validate their findings before they are communicated to all our members.***

***To validate all our documentation (brochures, web-site content, video, audio and multi-media files, sponsorship and grant applications)***

***The team is therefore actively involved in the organization of our national symposium of 18 and 19 May 2007.***

### **Our Honorary Chairman's profile**



***Mr Jean François CHOSSY, MP for the LOIRE region, recorder of the bill on the Equality of opportunity, Participation and Citizenship of disabled people.***

***Chairman of the Task Force on the integration of Weakened people and appointed Member of the council of the National Solidarity Fund for Autonomy, who we hope will speak about the February 2005 law and its effects 2 years on...***

# 3rd national meeting for Williams & Beuren Syndrome



WILLIAMS-FRANCE  
Région Rhône-Alpes



## THE SYMPOSIUM :

Talks, debates and information sessions over a whole day, but above all encounters, entertainment, discoveries and exchanges for families, will be at the heart of these :

**2 Days to Find Out More about the  
WILLIAMS and BEUREN SYNDROME**

For further information and reservations, please contact:  
**WILLIAMS RHONE-ALPES**  
31 rue du Brulet – 69110 SAINTE Foy les LYON, FRANCE  
00 33 (0) 6 23 17 90 06 ( Thierry BORDE )

# SAINT ETIENNE - 18 19 ET 20 MAI 2007



# Programme 2007

## Friday 18 May 2007

**(Geoffroy GUICHARD Stadium)**

° From 10.30: Welcoming of Families

\* SNCF Train Station « Saint Etienne CHATEAUCREUX »

Shuttle-buses will be available for families arriving by train

Or meet us at the Geoffroy Guichard Stadium

° 11.45: GUIDED TOUR of the stadium & Welcome drink followed by Lunch in the stadium

In the company of the ANYSETIERS of the LOIRE region,

and of the EBAE Association (Epidermolysis bullosa)

Buffet-lunch with entertainment from clowns, magicians...

(former ASSE football players will be present – current players might not present as they have a very important match the next day against Olympique de MARSEILLE)

° 13.30: Chairmen's speeches

° 14.00 : Chairmen of Associations receive donations

° 14.30 : After the meal, a surprise awaits the children – again, presence of some former ASSE players

° 15.30 : Departure from the stadium for the different accommodation locations

Shuttle-buses will be available to take families to the different hotels and accommodation locations

° From 17.30 : Entertainment for the children and reunion of all families in the community hall « l'EMBARCADERE » of Saint JUST Saint RAMBERT

° 18.30 : Apéritif

° 20.00 : Family evening - Diner

° 20.30 : Concert by LAURILY – Patron of the Association for the Rhône Alpes region

**\*\*Shuttle-buses will be made available over the two days to take all families to the different locations where events have been scheduled.**

Saturday 19		Symposium - CHU Bellevue in Saint Etienne	
8.30 – 8.45	Welcoming of families		
8.45-9.00	<b>OPENING OF THE SYMPOSIUM</b> *Docteur Fabienne PRIEUR : CHU of St ETIENNE * Talk by Thierry BORDE or/and Patrick VIGERIE (Chairmen of the regional and national associations)		
9.30 – 10.30	SCIENTIFIC SESSION - 1		
	* Gilles FAURY: Geneticist, CEA Grenoble " Ageing of the vascular system" * Christine DERUELLE : Neurophysiologist, "Hyper-sociability in the Williams Beuren Syndrome: Myth or reality?"		
10.30 – 11.00	Coffe break		
11.00 – 12.30	SOCIETAL SESSION - 1		
	* Roger CHATELARD : General Secretary of the APAJH for the Loire region, «Homes for the disabled and the point of vue of their users» * Jean François CHOSSY : MP for the LOIRE region "The February 2005 law and its effects 2 years on » and Philippe GAUTHIER : Director of the MDPH for the LOIRE region " Homes for the Disabled and their organization: the institutional point of vue"		
	*Talk by Mr Yves BRUCHON : Special Needs Inspector for the LOIRE region (formerly AIS) - " To mobilise and improve schooling"		
12.30 – 14.00	LUNCH		
14.00-15.30	SCIENTIFIQUE SESSION - 2		
	*Sybille GONZALES : Neurologist - LYON -Richard BOURQUE :Director of the OVE (Œuvre des Villages d'enfants) and Fabrice BAK : Cognitive Psychologist		
	* SHEILA WAREMBOURG : Handicap International, support service for emotional life, to talk about "The emotional and sexual life of disabled people"		
15.30 – 16.00	Coffee break		
16.00 – 17.30	SOCIETAL SESSION - 2		
	* Madame DUHAMEL and Bernard JOURDES: Director and manager of the ESAT of CHAUFFAILLES (69) : " the housing, leisure activities, work and finances" *Talk by Docteur COTTON of Valence, to talk about growth hormones		
17.30 – 17.45	<b>CLOSING OF THE SYMPOSIUM</b> *Christine DERUELLE : For a national call and news of things to come * Talk by Thierry BORDE or/and Patrick VIGERIE (Chairmen of the regional and national associations) - To talk about future events and actions		
18.00	End of the symposium		

## Pre-registration form – To send back, together with your deposit

« 3rd national conference » 18 and 19 MAY 2007 in SAINT ETIENNE

Please send back to ASWB RHONE ALPES – 31 rue du Brulet – 69110 Sainte Foy les LYON, FRANCE

I would like to take part in the two-day event: « 3<sup>rd</sup> national conference 2007 » (18 and 19 May 07) \*

Adults	: 35 € x .....	person(s)	= .....	€
Children (under 12)	: 20 € x .....	child(ren)	= .....	€
<b>TOTAL</b>		:	= .....	

I would like to take part in the one-day Symposium on Saturday 19 May 2007 (includes lunch)

Adults	: 20 € x .....	person(s)	= .....	€
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\* Surname:..... First Name:.....

member of the association : YES/NO Country : .....

Address : ..... Postcode : ..... Town : .....

☎ : ..... E-mail : .....

Your registration will only become valid after reception of your deposit of 50 €. Cheques should be made payable to : ASWB - Rhône alpes. **The tariffs we apply are maximum registration tariff for our manifestations. Our association works hard to try and reduce your costs to a minimum.**

\* registration to the two-day event gives access to the proceedings in the « Geoffroy GUICHARD » Stadium on Friday 18 May and to the Symposium on Saturday 19. These tariffs also include 4 meals (including two family evenings), transport by shuttle-bus, entertainment and supervision of the youngsters and all your transports over the two days (according to our availability). Please note that it does not include accommodation.

In order to help us with the organisation, please answer this little questionnaire:

→ You plan to come to the conference by: Train  Car  Plane  Other (coach)

→ You would like to receive information about the different accommodation options\*:  YES  NO

\* accommodation on 18 and 19 May is at your own cost

→ In order to help us with the supervision of the youngsters: Children (how many?) : .....Age(s) : .....

Teenagers (how many) : .... Age(s) : ..... First Name of the SWB person: ..... Age : .....