

## 7<sup>th</sup> International Conference on Fetal Alcohol Spectrum Disorder 2017

**Fetal Alcohol Spectrum Disorder Research: Results and Relevance**  
*Integrating Research, Policy and Promising Practice Around the World*

# Reunion Island- A comprehensive and collaborative model of prevention and research on FASD

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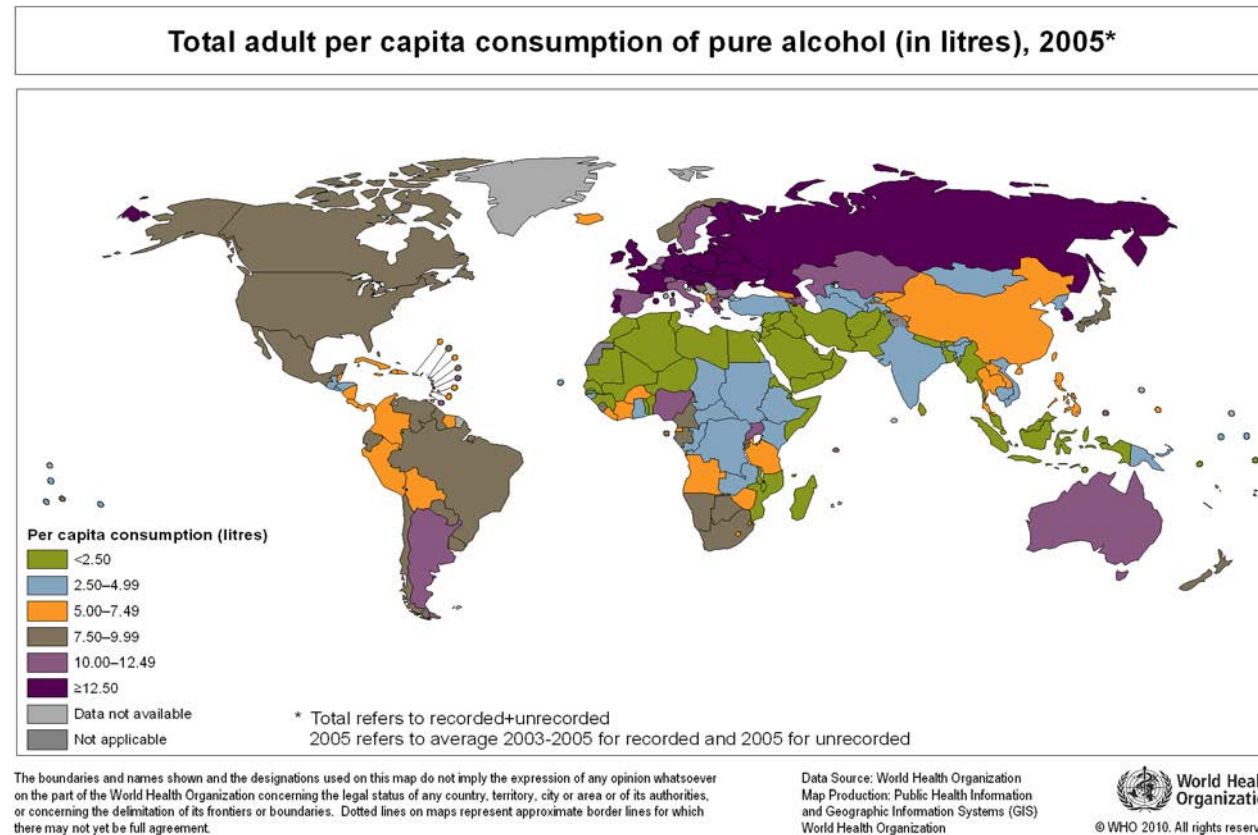
*Joëlle BALANCHE, Psychomotrician, Père Favron Foundation; Administrator, SAFFRANCE, Reunion Island, France*

# 1. Invisible to the world and yet such an everyday problem

**Increasingly adverse worldwide consumption**

## Alcohol consumption in the world

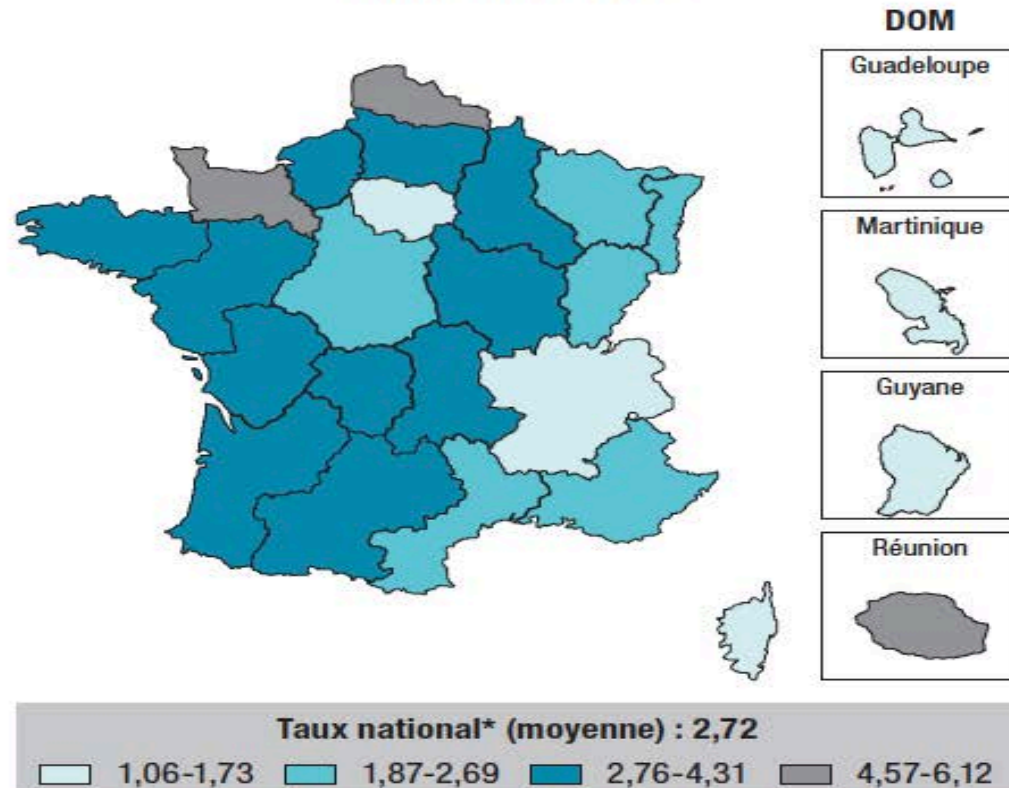
For the WHO, Alcohol consumption is a global issue. It's very high in Europe, Australia and America where the new trend of drinking has evolved to the detriment of women and adolescents.



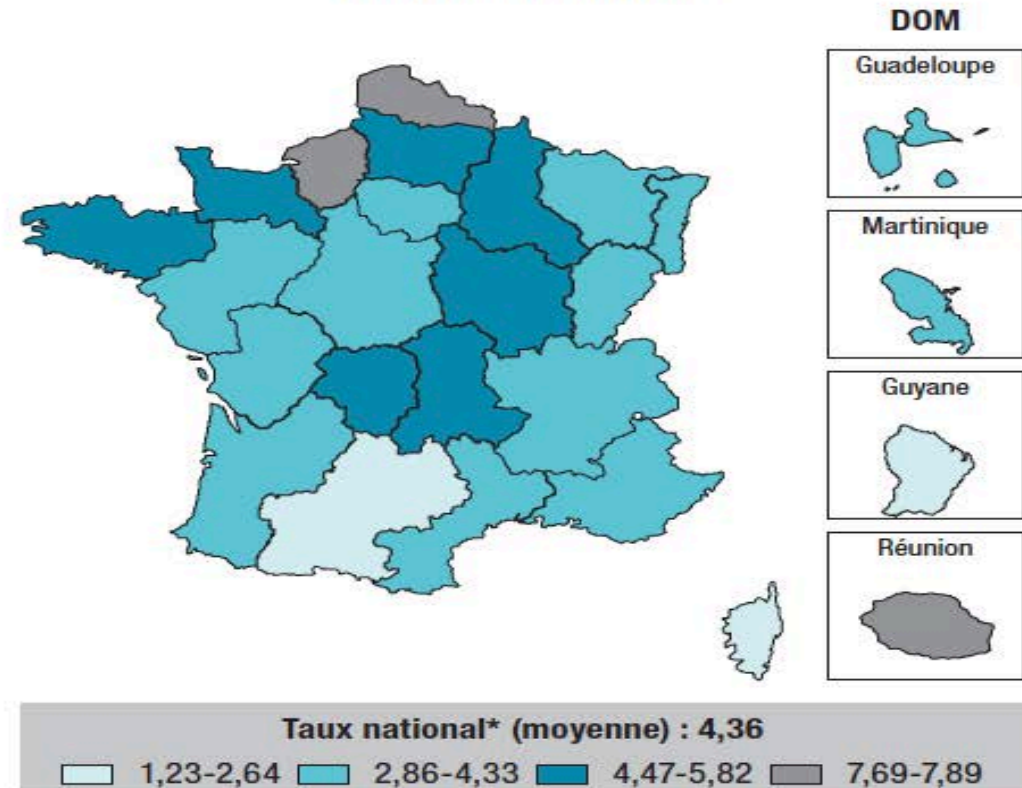
## Two french regions stand out for their high consumption of alcoholic strength

de dépendance, France, 2011

**Intoxications aiguës**



**Syndrome de dépendance**





## 2. Fetal Alcohol Spectrum Disorder, Epidemiology

**FASD is considered to be the leading cause of developmental disabilities and mental retardation worldwide**

(Journal of FAS International 2004; Roberts and Nanson 2000).



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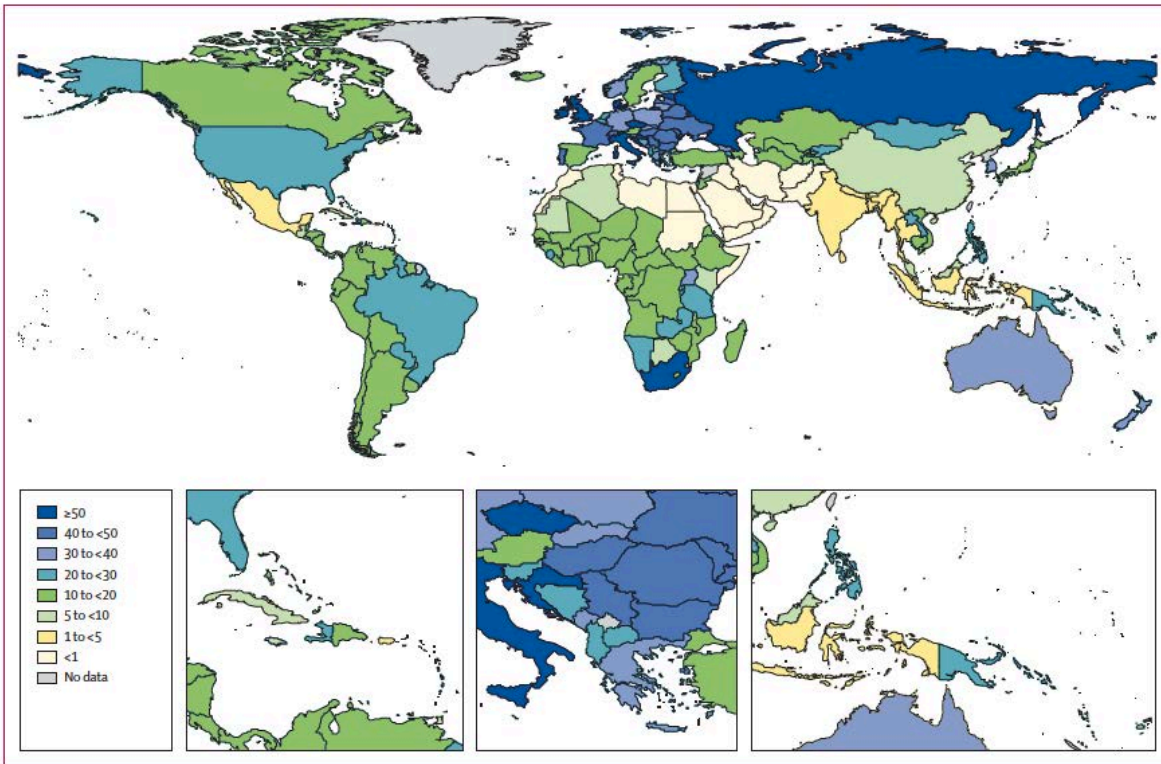


Figure 2: Global prevalence (%) of alcohol use (any amount) during pregnancy among the general population in 2012

- The global prevalence of alcohol use during pregnancy was estimated to be 9.8%
- the estimated prevalence of FAS in the general population was 14.6 per 10 000 people
- We also estimated that one in every 67 women who consumed alcohol during pregnancy would deliver a child with FAS, which translates to about **119 000 children born with FAS in the world every year.**

**In the world a child is born with FAS every 4 minutes and with FASD every 30 seconds**

Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis

Svetlana Popova, Shannon Lange, Charlotte Probst, Gerrit Gmel, Jürgen Rehm

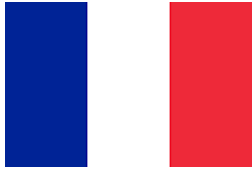
*Lancet Glob Health* 2017

Published Online

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***According to the French National Academy of Medicine (2004): Alcohol consumption during pregnancy represents the major cause of non-genetically induced mental disabilities as well as the child's social inadaptability***

In France, a collaborative expertise conducted by Inserm (National Institute of Medical Research) in 2001, estimated that between **700 and 3000** infants were concerned by a serious foetal alcohol syndrome among the 750 000 liveborns each year.

**That means that in France the prevalence of FAS is estimated between 1 and 4 per 1000**

Estimates confirmed by a survey done in 2006-2007 by J. Bloch with the National Institute for Public Health Surveillance and published in BEH, 2009

Birth defects: brain, eyes, heart, ...)

Stillbirth, premature

Growth defect and microcephaly

visual and hearing impairment

disturbance of interactions and eating

Developmental and language delay

health

difficulty of self-control, impulsivity

intellectual disability

difficulty understanding social rules

Social

autism spectrum disorders

Memory, attention deficit disorder,

difficulty in planning, organizing

School

academic learning difficulties: dyscalculia, dyslexia, dysphasia

School rupture

low self-esteem, suicide attempt, and psychiatric pathology

unaware of the consequences of their actions

easily influenced, lack of empathy

Justice

drug addiction, Alcoholism, cancer

offender, jail

Homeless, unemployed

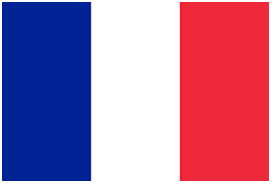


*alcohol during pregnancy*  
*Lifelong risk*



-9m Birth 3 years 5 years 12 years ado adult





# REPORT

- **The majority of :**
  - women in age to procreate and women in their early pregnancy still ignore the real risk that alcohol can bring to their unborn baby; they don't have the benefit of preventive informations
  - Women in age to procreate and pregnant women having an excessive consumption of alcohol are not identified
  - children with FASD are not identified
  - adults with FASD are not diagnosed as so.
- Ignored or denied by professionals, Those situations bring often to even more vulnerable children in those families
- Key for FASD prevention: our capacity to unite and put together all competencies needed for those families.



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### **3. FASD is preventable.**

## **What proposals to avoid them?**



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# We can avoid secondary disabilities

An early diagnosis is essential to allow access to appropriate intervention, counselling and treatment for the mother and may **prevent the birth of affected children in the future.**

Children with FASD who receive special educational services are more likely to achieve their developmental and educational potential.

.

# We can avoid secondary disabilities

## DUO

**Working in early care as a psychomotrician with children presenting FASD**

*Joëlle BALANCHE, Psychomotrician, Père Favron Foundation; Administrator, SAFFRANCE, Reunion Island, France*



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FONDATION PERE FAVRON





# Importance of

- Early support
- Duo aftercare

This presentation is based on the experience acquired through years working as a psychomotrician in early care and more precisely with children presenting Fasd.

My intention is to share my workpractice and approaches, constataions, reflections, results.



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# PSYCHOMOTRICIAN

- Specialist of the psychomotor development
- Psychomotricity integrates cognitive, emotional, physical /sensorimotor interactions in the child's capacity to be and to act, in a psychosocial context.
- Work in an interdisciplinary context



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# Observation/premise

## Troubles linked to fetal alcohol consumption:

- Psychomotor development delay
- Maladjusted interactions with others (ToM)



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# PSYCHOMOTOR ASSESSMENT

*Every child is unique and getting a true understanding of the individual child's strengths and challenges is a complex process*

Assessment :

**=>Therapeutical project and proposal of an adapted personalised aftercare**

**=>The earliest possible, to reduce the impact of fetal alcohol consumption**



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## PSYCHOMOTRICITY



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# FOLLOW UP

Intervention based on the use of :

- Spontaneous activity
- Playing and games/Transitional space (Winnicott)
- Movement, expressive activities ,sensorimotor experiments (playing music, singing, dancing, swimming...)
- Body awareness practices
- Psychomotor relaxation
- Graphomotor activities/painting

# GROUP

- **Socialisation**

- Facilitating communication modalities, interactions
- Learn how to share and respect peers, activities, frame, limits, rules...
- Allow to extract benefit and pleasure from that

- **Particular skills development** :gross and fine motor activities, communication/expression, time and space structuration...



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# Idea and conception of « Duo » originated from

- Group is not a satisfying enough approach:
  - Too many stimulations, multisensorial informations, children to deal with=> Confusion
  - Increase of excitability/ instability
  - Difficulty to focus on a task ...
  - Difficulty to recognise the other one's emotions and develop adapted relations due to the number of children /adult **make little sense and**
- **Little benefits from those experiences**
- **Less efficiency of the aftercare...**
- « by chance »

Association of 2 kids presenting 2 different syndromes:

  - Asperger Autism
  - Fetal Alcohol Syndrome



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# DUO = Association of

- 2 children of approximate age:  
from 12/18 months to 6 years old
- 2 children with complementary disabilities:  
language / motor skills (Alex/ Andr)  
Inhibition/hyperactivity (Sor/ An-Lor)  
...



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# The role of the psychomotrician

- Ensures the rules, the safety of the seance and its time and space frame
- Brings clues to help the children direct themselves towards good strategies/solutions/choices
- Encourages and facilitates: cooperation, initiative,creativity,respect...
- Enhances their field of experience and knowledge



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# DUO

Through **games, play**, sensori motor experiences:

**1/ Facilitate the practice of adapted relationship with a peer**

**2/ Enhancement of skills and competences by  
complementarity or reenforcement**

**one major support :Imitation**

**3/ Support for further socialisation in bigger group**



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# 1/ Facilitate the practice of adapted relationship with a peer

- The other one is an other « **Me** »
- sharing the same space and time and facing only one other child

=> **facilitation of**

- \*The gestion of « **my** » emotions (frustration/ acceptance/ take turn...)
- \*The deciphering of the feelings /emotions of the other one
- \*The comprehension of the concepts of causes/effects and of the consequences of my acts while interacting with the other child

## 2/Enhance skills and competences by complementarity and reinforcement

### THROUGH

- Observation/ inspiration
- Imitation
- Guidance/ « tutor »
- Commutativity and integration
- Cooperation
- Self control



...  
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=>Learning

=>Communication

=>development of social competencies  
as Empathy

Capacity to identify verbal or non verbal subjective signals  
in the other one

=>Increased ability to develop adjusted behaviours  
(speech or actions) in answer to those signals

Empathy necessitates mental flexibility and so Duo  
approach generates a co-construction of empathy and  
flexibility



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# IMPACT OF THE EARLY EMULATION THROUGH DUO APPROACH

## Improvements:

### \*Relational

#### Personal construction :

Better : self esteem / self image / self awareness/ affective sharing/ self control/ gestion of emotions ...

#### Social abilities :

- Higher quality of relations with the others
- Decode/decrypt better the signals sent by the others
- => anticipate and help => development of empathy
- Respect rules, limits, the place of the other one..



# ...Improvements...

## \*Neuropsychological :

Attention

Empathy

Mental flexibility

Representation

Reasoning (cause / effect)

Language / communication (comprehension/ expression)...

Learning

## Facilitator s for the acquisition of other abilities



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...improvements..

**\*Sensorimotor /physical skills**

- Better control of their body and motricity(B.I./B.S)
- Less impulsivity /hyperactivity
- Better fine motor efficiency
- Enrichment through sensori motor experiments (space/time...)

**=>More harmonious psychomotor development**



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# ...Most important improvements..

## Personal and Social competencies

- Personal construction
- Higher quality of relations with the others
- Decode/decrypt better the signals sent by the others  
=> anticipate and help
- Respect rules, limits, the place of the other one..



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### 3/support for further socialisation in bigger group

In Duo children are less overwhelmed by the multiple sources of informations, sensorial nuisances found in larger group

=> First facilitating experience of socialisation

Children benefiting from a Duo approach integrate more easily in larger group/school



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# On 20 Duos

**\*6 => 7 years old** (= CP/CE1)

- 2 encounter no problem about learning and have autonomous adapted relations with peers and adult
- 2 have good results at school but require further framing for their instability, though they develop good relations with others and have no problem facing rules and limit
- -3 are slower than the others but are still in the average and well integrated in their school

**\*3=>6 years old** : 5 children are well integrated socially and have adapted behaviour at home and school/ 1 still presents lability of attention but no social maladjustment

**\*18 months => 3 years old**: 5 children

All have better adjusted relations / control of their motricity

- 2 have reached a normal psychomotor development
- 2 still present psychomotor and language delays



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- Through those years of practice, Duo appears a good alternative to enhance the children 's own competencies and overall their ability to enter in relation with others , live socially in a better adjusted way.
- The results of the early Duo practice are positive until now regarding the global psychomotor development of the children and overall their social integration and behaviour.



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## 4. FAS and FASD in France

- 1968 : Dr Lemoine in Nantes, Ouest Médical; 25:476-482
- 1968-2015, 47 years without strategic program addressing alcohol consumption during pregnancy



## 5.Reunion Island : a model for France and other countries ?



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# Reunion Island: a diverse population



































**In Reunion Island, FAS is the first cause of non genetic mental disabilities. In specialised institutions 15 % of children are diagnosed FASD.**

R.Serreau, T. Maillard, R.Verdier, L.Bouchara, C.Catteau, C.Hervé, A.Fourmaintraux, D.Lamblin, J.F.Lesure, E. Jacqz-Aigrain : Etude clinique et prévalence du syndrome d'alcoolisation fœtale pris en charge dans les établissements médicosociaux de l'île de la Réunion. Arch Pédiatr 2002 ; 9 : 14-20



**Amongst pregnant women 5% are consuming alcohol  
= 700 at risk pregnancies**

**75 to 240 FASD children / year**



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*First: the majority of women  
who occasionally drink alcohol,*

can stop if they learn that it is dangerous to drink during pregnancy.

“If you do not want to hurt for your baby, the message is :  
**no alcohol during pregnancy**”



Aware of this issue, French government has decided to tackle this problem and **FASD prevention has become a public health priority**



July 2004: **acknowledgement of FASD as a health issue priority** with the 3 amendements to the Public Health government bill by A.M. Payet (Senator, Réunion Island)

- information campaigns** regarding FAS prevention aiming to encourage pregnant women to abstain from drinking
- implementation** of annual information sessions for high-school students
- Training** of medical and social professionnels.



October 2007: **compulsory labelling of alcoholic beverages** as part of the Law on Equal Rights and Opportunities, Participation and Citizenship of People with Disabilities



But where is it







Logo in place since  
october 2007

Proposition of SAFFrance  
1,5 \* 1,2 cm

the proposition of SAF France to enlarge the size of the logo was validated recently by the CIH (Comité interministeriel du Handicap) on the 2<sup>nd</sup> Dec 2016 presided over by the prime minister



*The second case refers to binge drinking  
among adolescents*

It can be the cause of early pregnancy

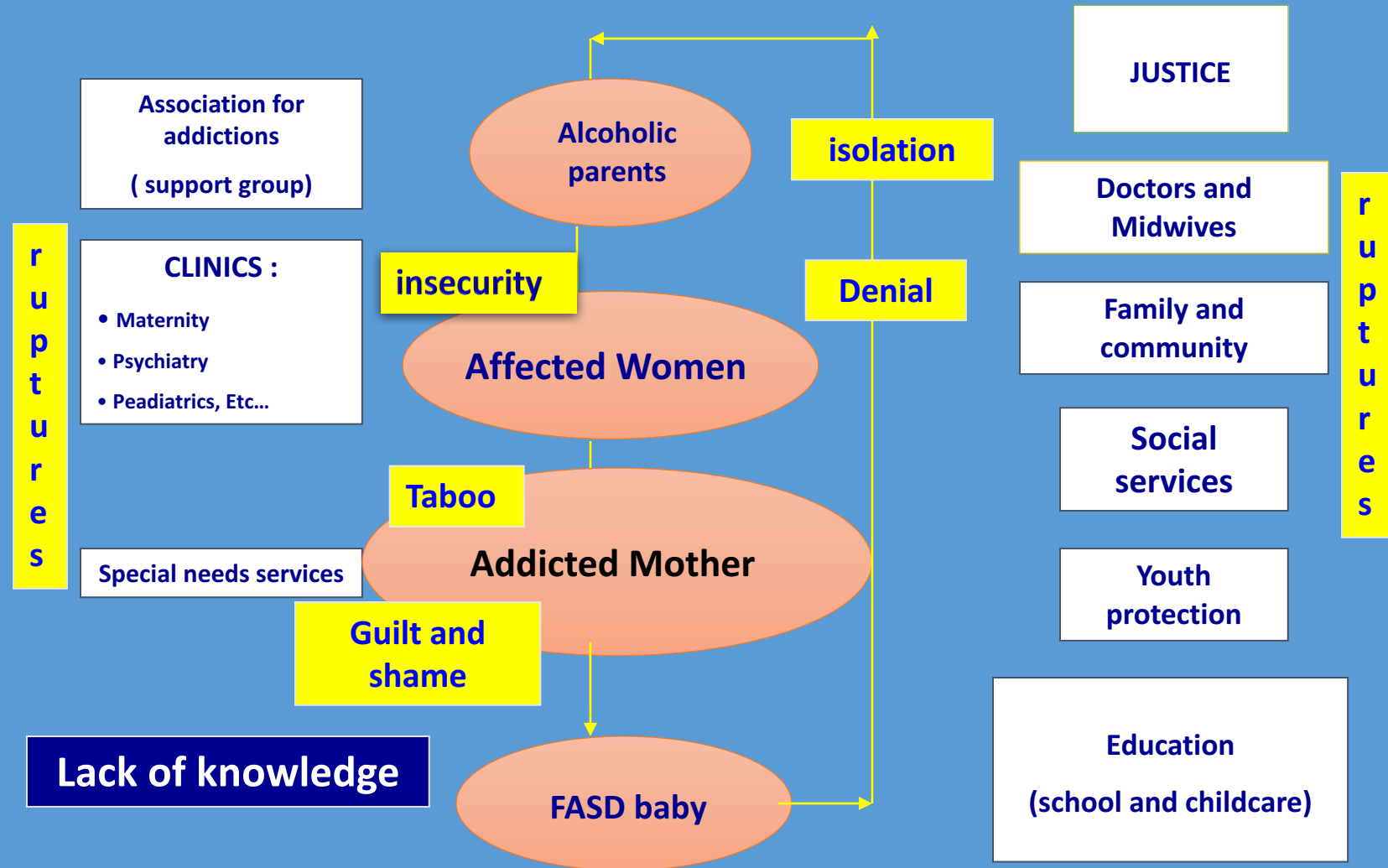
In France, public awareness to prevent adolescent  
alcohol abuse is now a priority and a law.

## *alcohol-addicted women*

- cannot speak about their problem in our society because alcohol consumption by women is taboo.
- This leads them to shame and loss of self-confidence.

They must be helped by a very large network made up of medical, social and pedagogical workers trained to tackle this problem, such as the one that has been set up on Reunion Island ( a network whose aims is to prevent damage done to other offspring in families who already have a child with FASD)

The network core Reunisaf a team that reaches out to families and professionnels, to create links and help overcome...





## « Core of Network »

### Rewards of the Core of the Network

Benefits, during 11 years:

- 387 families followed
- 1.600 sensitised professionals



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## « Core of Network »

**54% of mothers abstained from drinking alcohol**

20 % have reduced their consumption

= improvement in the health of 74% of them



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## « Core of Network »

**26** non-alcohol exposed children

are born to mothers, who previously gave birth to  
children affected

...

+ hundreds of spared pregnancies with an efficient  
birth control system.



## FASD prevention is a profitable investment

### What is the social return on investment in prevention of FASD?

- Cost of the south network: 150.000 euros / year = 1.6 millions euros/11 years
- Economies:
  - 26\*600000 euros= 16 millions euros
  - +... improved health for mothers
  - +... avoided foster care
  - +... hundreds of spared pregnancies

**Rapport cost-effectiveness  $\geq 1/10$  and overall a saved generation**



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\*Nguyen Xuan Thanh., Egon Jonsson. Liz Dennett and Philip Jacobs, Fetal Alcohol spectrum disorder-Management and Policy Perspectives of FASD. Edited by Edward P.Riley.Sterling Clarren, Joanne Weinberg, and Egon Jonsson copyright 2011  
WILEY-VCH Verlag GmbH and Co.KGaA, Weinheim pour nbre moyen TCAF  $(75+240)/2=157$

- This success and our work was brought to the common knowledge by Senator Anne-Marie PAYET from Reunion Island, to whom we owe, amongst other things, the logo of prevention affixed on every bottle of alcoholic beverage.
- Our network was also awarded by the National Academy of Medicine for the fight against alcoholism in 2005.



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**6. Since 2008, the work of REUNISAF was undermined and SAFFRANCE reacted against this harmful decision**



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# 1.SAF France try to convince the various ministries to extend the action of Reunion Island and build a real National program

- Lobbying at all Ministries concerned by FASD: Health, Social Welfare, Education, Justice



Madame S.Neuville

Minister in charge of disabled persons and fight against exclusion

## 2.SAFFrance (NGO) relied on international support to increase awareness by:

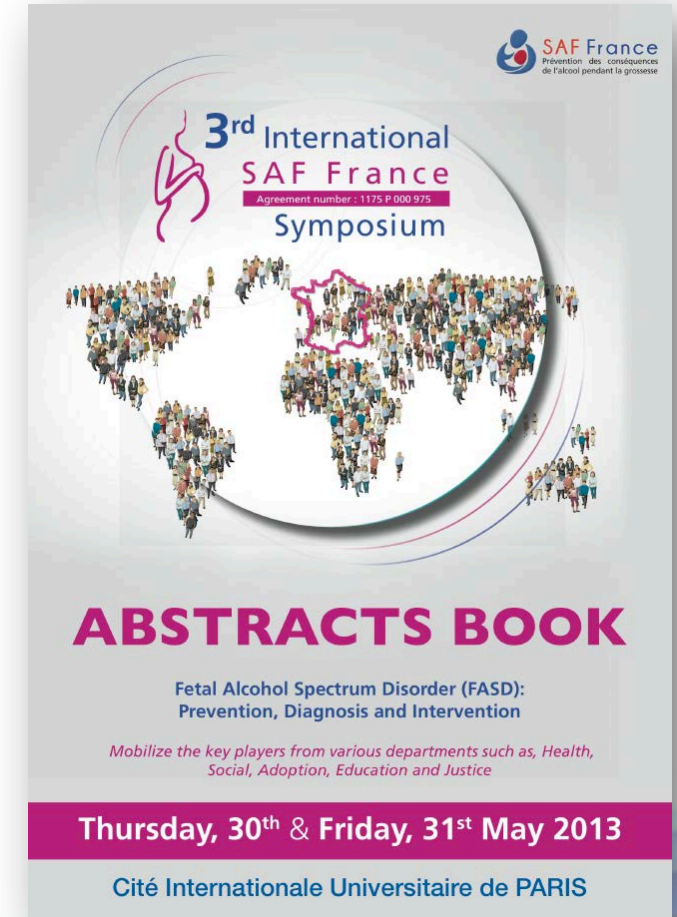
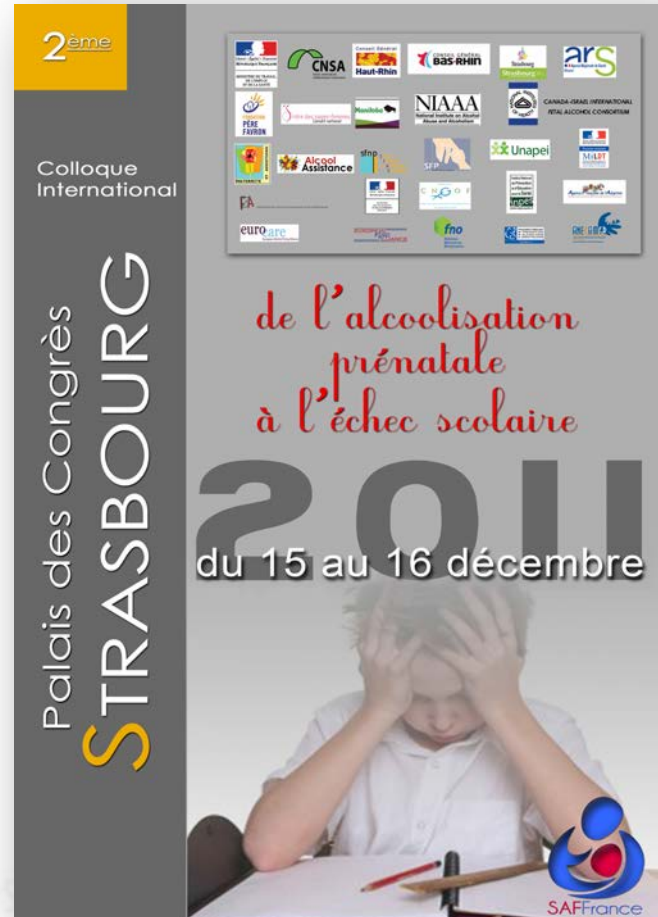
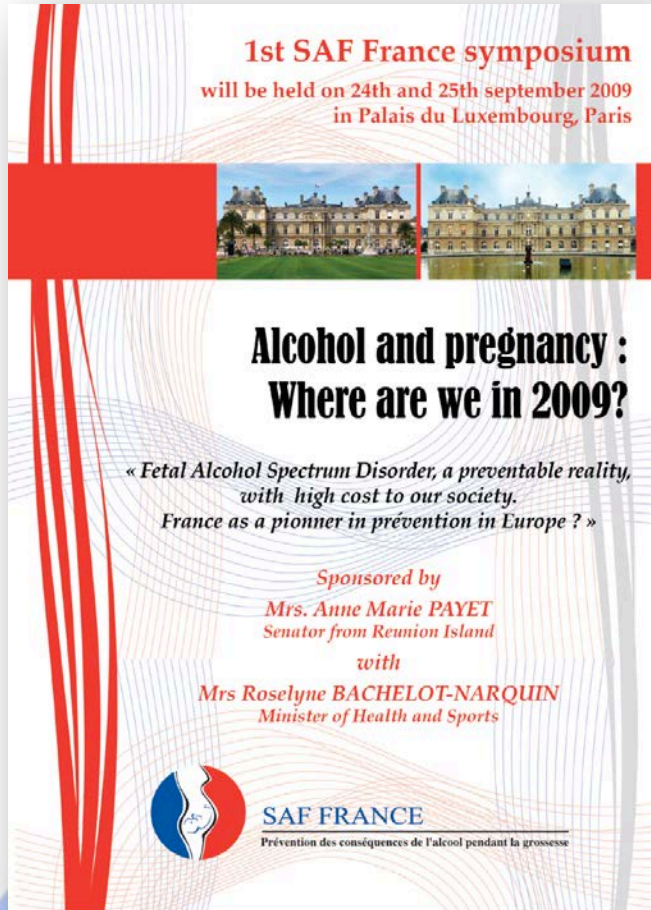
- ⑧ Organising **3 international conferences**
- ⑧ **Communicating on the experience of Reunion Island** and the difficulties encountered in France,
- ⑧ **Establishing a formal partnership with the Government of Manitoba** and its experts to show the way ahead for France.
- ⑧ **Calling for the defense of the International Rights of Children** undermined by this non-prevention
- ⑧ **Based the International Charter for the Prevention of FASD**, a real vehicle for raising awareness of the co-responsibility of the different parties.



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# 1.Organising 3 international conferences

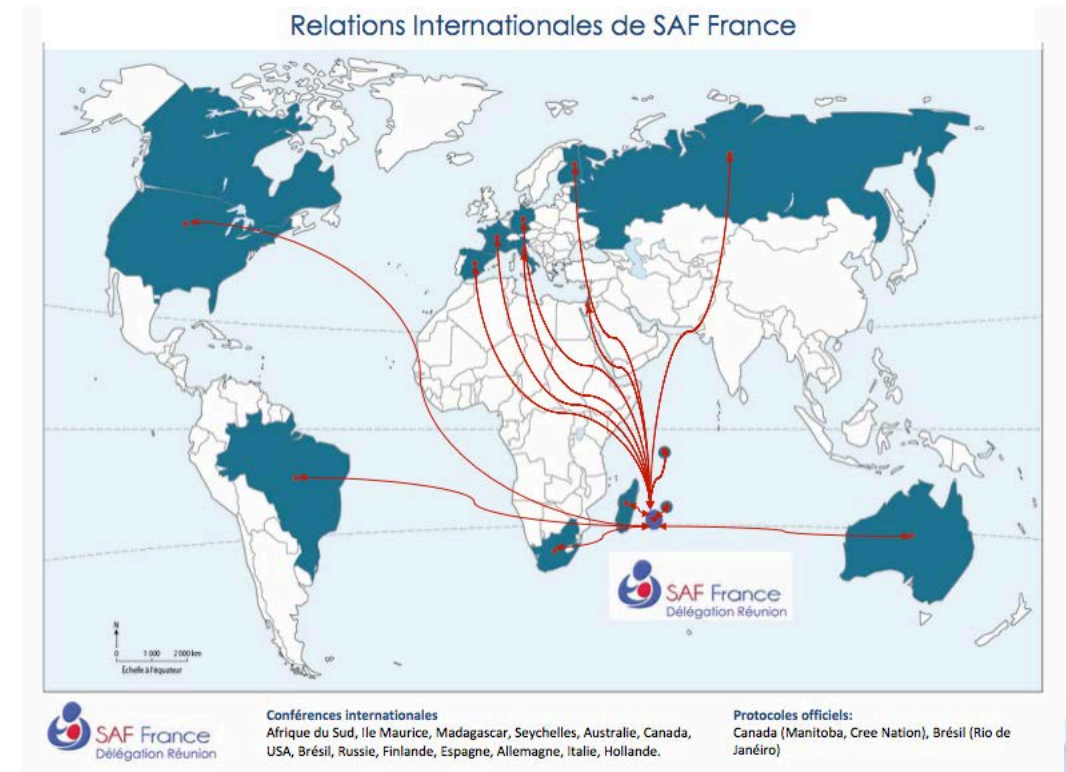
2009 ( Paris )      2011 ( Strasbourg )      2013 ( Paris )





## 2.Communicating on the experience of Reunion Island and the difficulties encountered in France

- and that during the last 4 international conferences in Victoria and Vancouver
- and also at 30 conferences abroad (Russia, Brazil, Germany, Quebec, Italy, Spain, England ...) to demonstrate that this issue is REAL and GLOBAL and that the model of Reunion Island is worthwhile and exportable.



### 3. Calling for the defense of the International Rights of Children

undermined by this non-prevention



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Paris le 9.09.16

## 4.Establishing Partnership with the Government of Manitoba



to show the way ahead  
for France



## 5. Based on the International Charter for the Prevention of FASD, a real vehicle for raising awareness of the co-responsibility of the different parties



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## **7. this work of lobbying by SAFFrance has brought huge progress in 2013 / 2016**



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Paris le 9.09.16

# From 2013 to 2015

SAF France has allowed positive outcomes for France:

## 1. The creation of the screening guidelines (HAS)

## 2. The registration in the National Plan of two resource centers in two pilot regions (MILDECA Program 2013-2017)



### Objectif

Aider les médecins généralistes, pédiatres, pédopsychiatres, psychiatres, addictologues, médecins de PML, médecins scolaires, chirurgiens-dentistes, gynéco-obstétriciens, sages-femmes, puéricultrices à repérer et à orienter :

- les femmes enceintes susceptibles d'avoir un problème de consommation d'alcool et dont l'enfant risque d'être atteint de troubles causés par l'alcoolisation fœtale ;
- les enfants à risque susceptibles d'avoir subi les effets d'une exposition prénatale à l'alcool.

En dépit d'un risque de stigmatisation de l'enfant et de sa famille, le repérage a pour but de permettre un diagnostic précoce des troubles, de guider les recherches des malformations associées, d'élaborer un programme d'intervention adapté à l'enfant, et un accompagnement des parents. Il peut aussi permettre de prévenir la consommation d'alcool au cours d'une autre grossesse, et de porter un diagnostic des troubles chez un aîné de la fratrie.

Le repérage repose sur une connaissance des troubles et nécessité de parler avec la mère de sa consommation d'alcool au cours de la grossesse.

### Messages-clés

#### Chez la mère

→ Demander systématiquement aux femmes désirant une grossesse, aux femmes enceintes et aux femmes venant d'accoucher leurs habitudes de consommation d'alcool<sup>1</sup> ; en faire préciser les modalités d'usage et les périodes de consommation au cours de la grossesse ;

→ S'aider de questionnaires ou de questionnaires auto-administrés comme par exemple la FACE, l'AUDIT ou le T-ACE<sup>2</sup>.

#### Chez l'enfant

→ Orienter les parents d'un nouveau-né ou d'un enfant vers un médecin (ou une équipe pluridisciplinaire) formé au diagnostic des troubles du développement pour son évaluation diagnostique dans les situations suivantes :

- une consommation prénatale d'alcool significative (consommation régulière importante ou épisodes de consommation excessive) est confirmée par la mère ou notaire,
- l'enfant a trois éléments de la dysmorphie faciale : des fontes palpébrales raccourcies, un sillou naso-labial lisse, allongé, effacé et une lèvre supérieure mince,
- l'enfant a au moins un élément de la dysmorphie faciale associé à un retard de croissance<sup>2</sup>, et une exposition prénatale significative à l'alcool est confirmée ou probable,
- l'enfant a au moins un élément de la dysmorphie faciale associé à au moins un trouble du système nerveux central, et une exposition prénatale significative à l'alcool est confirmée ou probable,
- l'enfant a au moins un élément de la dysmorphie faciale, associé à un retard de croissance et à au moins un trouble du système nerveux central, et une exposition prénatale significative à l'alcool est confirmée ou probable ;

→ Penser à des troubles liés à une alcoolisation fœtale devant un retard de croissance, une microcéphalie, une malformation, un retard psychomoteur, un trouble des apprentissages, un trouble de l'attention, un trouble du comportement et/ou de l'adaptation sociale inexpliqués, même en l'absence de notion d'alcoolisation durant la grossesse.

1. Cf. « Alcool et grossesse, parlez-en », Guide à l'usage des professionnels : [http://www.has-sante.fr/Media/48400/et\\_grossesse\\_santonsen2.pdf](http://www.has-sante.fr/Media/48400/et_grossesse_santonsen2.pdf).

2. Taille, poids ou périmètre crânien prénatal ou postnatal égal ou inférieur au 10<sup>e</sup> percentile (score-type de 1,5 ou-dessous de la moyenne).



**2015 / 2016**



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7.this work of lobbying by SAFFrance has brought huge progress in 2015 / 2016

# **1. 2016.Creation of the first french FASD ressource centre with two diagnosis centres**



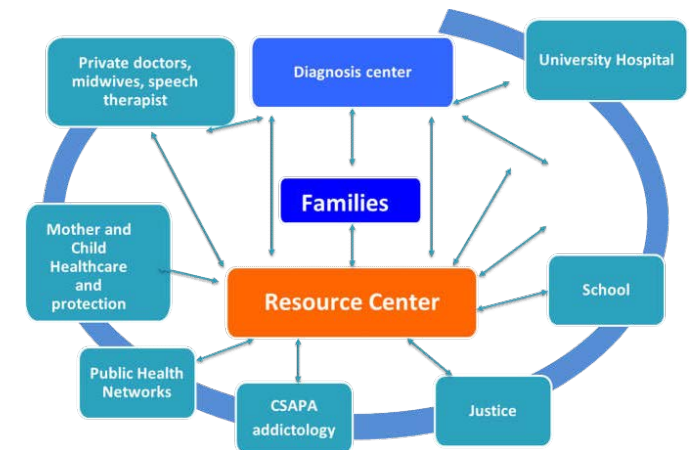
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# 1. Creation of the first french FASD ressource centre

In Reunion Island, the First RESSOURCE CENTRE was opened in APRIL 2016

TO LINK, TO CONNECT

- The different actors involved in the program: to work together
- To develop synergy between the common law systems for families at risk
- To increase the national cooperation
- To promote international collaborations
- To strengthen the links with the associations (SAFFrance SAFOI, VALSAF)





## 1. Creation of the first french FASD ressource centre

### A national awareness and the regional answer

- Government Plan 2013-2017 : experimentation in one or two French regions of a prevention and support program for FASD.
- Regional Health Agency of Indian Ocean (ARS): candidate for this experiment in 2015 like ARS Nouvelle-Aquitaine



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## 1. Creation of the first french FASD ressource centre



### REUNION ISLAND REGIONAL ACTION PLAN

- Focus 1: To influence behavior through information and prevention`
- Focus 2: To promote the identification of situations of risk for women
- Focus 3: To promote access to diagnosis and assessment of children and adults with disorders related to prenatal alcohol consumption ( **Two diagnosis centre** )
- Focus 4: to organise support of women, children and adults with FASD
- **Focus 5: To create a resource Centre**
- Focus 6: To involve institutional partners in the regional steering of the action plan 9



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1. Creation of the first french FASD ressource centre

## The RESSOURCE CENTRE Missions

1. To promote Initial and continuing formation
2. To establish a catalogue of professionals and resources on Reunion island
3. To coordinate and to follow the care pathway for each patient
4. To participate in the epidemiological surveillance,
5. To stimulate and coordinate
  1. research
  2. National and International collaborations



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## TWO DIAGNOSIS CENTRES to confirm or not the FASD diagnosis, and to propose support for children and their families in collaboration with the Ressource Centre

- Two sites: women and children's hospitals (Saint-Denis and Saint-Pierre)
- Operational by mid 2017
- Possibly also teen and adult prisons



## ORGANISATION and ESTIMATED ACTIVITY DIAGNOSTIC CENTRES

- Initial consultation, followed by 2/3 days outpatient RDV with **multidisciplinary Team**
  - Neurologist Pediatrician, pediatric, geneticist
  - Neuropsychologist, psychomotor or occupational therapist, speech pathologist
  - Social worker
  - Specialist physicians (endocrinologist pediatrician, ...)
- Complementary investigations: Brain MRI, polysomnography, genetic exams...

200 cases / year : 10% FAS, 50% FASD, 40% others



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## 2.The "Défenseur des Droits des Enfants » (independant advocacy) Miss Genevieve AVENARD , resuming the recommendations of SAFFrance



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# The prevention of FASD participates to the International Rights of Children

In vancouver 2015, I talked about how the prevention of FASD participates to the international rights of children.

The "Défenseur de Droits des enfants » (independant advocacy) Miss Genevieve AVENARD , resuming the recommendations of SAFFrance, declared in **December 2015**:

« FAS illustrates:

- *All the importance of early prevention of disability, especially in the case of vulnerable families . Data : 17% of the population of children receiving Social Welfare are carriers of this handicap / This is 7 times more than in the general population*
- *The problems created by misdiagnosis or worse by the lack of diagnosis.*
- *Alcohol consumption is rarely mentioned during early prenatal care /consultations and FASD are misdiagnosed.*
- *Disorders caused by fetal alcohol could be avoided with appropriate prevention and the settlement of a network of on the ground professionals .*
- *Misdiagnosis of FASD could lead to unnecessary interventions by welfare services : professionals badly diagnosing these disorders could decrypt them as an educational problem and so a danger to the children.*

## The international rights of children (2)

- The Advocacy regretted that the multiplicity of professionals, coming from different fields (social, justice, health, education) , with their **compartmentalised interventions**, logic and projects , would make them difficult to comprehend by families, especially if they are vulnerable.
- She recommends that **priority should be given to inter-institutional training and activities** for professionals within the fields of health and child welfare



this work of lobbying by SAFFrance has brought huge progress in 2015 / 2016

### **3.The members of the National Academy of Medicine recommend FASD to be a GREAT NATIONAL CAUSE**



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## The members of the National Academy of Medicine recommend FASD to be a GREAT NATIONAL CAUSE

The National Academy of Medicine, who auditioned SAFFRANCE , concluded , in **March 2016**

Considering:

- The extreme seriousness of the disorders caused by alcohol consumption during pregnancy in children to be born
- The disturbing frequency of alcohol consumption during pregnancy
- The significant advances in research attesting to the neurotoxic effects of alcohol on the sensitive structures of the brain
- The possibility of detection of maternal and fetal alcoholization by self validated questionnaires and specific and reliable biomarkers assays
- That fetal alcohol syndrome, as a chronic disease, requires preventive and curative care, just as gestational diabetes and pregnancy-induced hypertension.

# The French National Academy of Medicine recommendations :

## 1. To enlarge and ensure a better development of the logo. To reposition the health message.

## 2. To settle a wide information and training plan:

- For women of childbearing age during contraception and birth preparation / consultations.
- For all health professionals connected to birth and children: gynecologists, obstetricians, midwives, pediatricians, general practitioners, pharmacists, during the initial and/or specialised studies.
- Towards the public, by repeated information campaigns in the media, television without stigmatising or blaming messages.
- For the government to face the importance of human and social consequences compared to the economic benefits of the alcohol business.
- Registration of "effects of alcohol during pregnancy" in school curricula.

## 3. Institute a policy of prevention for pregnancy:

- Promote pre-conceptional consultation:when stopping contraception for desired pregnancies.
- for young adult (or teenagers ) for the 25% of unwanted pregnancies.
- To give the midwife a privileged place, at the antenatal 4th month consultation,to advise stopping alcohol for the rest of the pregnancy.
- To involve the addiction specialist and make sure that the parturient receives an appropriate follow up.
- Generalise self-questionnaire and use the biomarker assays : capillary sampling in the mother and meconium in the newborn.

#### 4. Develop a health network of support for children with FASD

- The various existing structures for early medical and social support (CAMSP, CMPP, CMP);
- The creation, under the supervision of the ARS or of the Regions, **of Regional Resource Centres** for the prevention of FASD. First, experimental, then generalised: to ensure family education ,social and psychological support ; to promote social and educational integration of the children.

#### 5. Undertake a National Action Research dedicated to the "Fetal Alcoholisation"

#### 6. Declare FASD "GREAT NATIONAL CAUSE " in the purpose to protect the young and their future with one watchword:

**"Zero tolerance of alcohol during pregnancy."**





this work of lobbying by SAFFrance has brought huge progress in 2015 / 2016

## 4.The « Cour des comptes » (Court of Auditors) asks the government to react



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# The « Cour des comptes » (Court of Auditors) asks the government to react

Cour des comptes



**June 2016**, the "Cour des Comptes » in charge of the control of public expenditures, in a report on political struggles against harmful alcohol consumption, quotes that France doesn't build its capacity to fight efficiently against toxic alcohol consumptions which cost 120 billions €/year

It recommends to develop preventive actions and to communicate about fetal alcohol consumption towards the most vulnerable : young people, pregnant women .

In this context, it is important to pay particular attention to the prevention of violence against women.

this work of lobbying by SAFFrance has brought huge progress in 2015 / 2016

## **5. With the signature of the « International Charter » by different Regions, SAF France instils a collective dynamic in France**



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## REUNION ISLAND

14000 births/year



## SIGNATURE OF THE REGIONAL CHARTER WITH THE JUSTICE DEPARTMENT





## FRENCH GUIANA



7000 births/year



## SIGNATURE OF THE REGIONAL CHARTER IN FRENCH GUIANA

a



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## NEW - AQUITAINE

50000 Births/year



## **These recommendations are a source of hope, but we are also fully aware of the existing obstacles to be able to apply them in France:**

1. The level of knowledge of professionals and the public at large about the consequences of alcohol consumption during pregnancy is very low.
2. In France there is no multidisciplinary team structured and trained to diagnose and support the FASD individuals. The first diagnosis center, provided for in the regional plan launched in September 2015 has not yet been put in place in Reunion Island.
3. The over-sanitised vision of the issue and the fragmentation of the political system do not make it possible to generalise the experience of REUNISAF. The old French demons return, decisions are taken from above disconnected from the departments of social services, justice, national education and overall with the concerns of families.
4. Our culture strongly attached to the consumption of wine reinforces the denial of the consequences. This, in addition to the constant lobbying of producers and distributors of alcohol.
5. Unlike Anglo-Saxon countries, public health policy in France prioritises care rather than prevention.



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Like many Anglo-Saxon countries, SAFFrance has moved this issue from the exclusive health field to register it in a more global vision for our societies.

Our vectors for change, such as the respect of Children's rights, the International Charter and the recommendations of the National Academy of Medicine must drive our leaders to consider the challenges facing this prevention as an investment in its youth for a more egalitarian, supportive and creative society.

The know-how of SAFFrance is becoming known by french regions (Guyana, Aquitaine ...) and countries (Russia, Moldova, Brazil ...) are beginning to solicit it to develop this prevention.



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- 4 years ago, the unique experience of Reunion Island was at risk of being lost .The national and international lobbying of Safrance, and your engagement by our side, led to general support and as first results, the creation of 2 pilot regions in France .
- The situation is still fragile but an essential first step to improve prevention in France.
- Reunion Island, France, Europe need your support to convert the try and generalise it to all countries worldwide.



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# FASD

## Testimony and Proposals of a Father

### Reunion Island - France



*Patrick CHAUVIN*



1. TESTIMONY
2. PROPOSALS
3. MEANS

## 1999. BIRTH OF MY CHILD



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# SUMMARY

1. TESTIMONY
2. PROPOSALS
3. MEANS



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## 1. TESTIMONY

### 2. PROPOSALS

### 3. MEANS

- Creating my company
- The mother secretly consuming alcohol during pregnancy
- Family break up when my daughter is 8 months old
- Obtention of parental authority



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1. TESTIMONY
2. PROPOSALS
3. MEANS

## Early warning signs

**0 – 3**

An hypotonic baby  
Limited expressions

Delays in :

- walking ( ≈ 2 years old)
- potty training ( ≈ 3 years old)
- talking / first words ( ≈ 3 years old)

No language... so biting and complaints from parents in infant school

First encounters with a psychologist...

... without concrete results

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1. TESTIMONY
2. PROPOSALS
3. MEANS

## Early emergence of differences...

### 4 – 5

An encouraging evolution at infant school

But...

---

### 6 – 10

Appearance of learning difficulties

- Concentration / attention
- Mémorisation
- Comprehension



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1. TESTIMONY
2. PROPOSALS
3. MEANS

## Confirmation of the differences

### 11 – 15 ans

Increasing learning difficulties and troubles at school

At 15 years old, average results : 3.95 / 20.

Social : difficulty to keep friends

---

### 16 – Nowadays

Orientation towards a professional training

Encouraging marks

Pre diagnosis of FASD made by Dr LAMBLIN / **Reunion Island**

Once the diagnosis is known and explanations given

- A significant well-being



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## 1. TESTIMONY

## 2. PROPOSALS

## 3. MEANS

# Closed doors

Consultations

Child psychiatrist

Speech therapist

## **FAS is self diagnosed**

- Total denial from the specialists encountered
- Maternal abandonment : sole conclusion
- Years of speech therapist... without results



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1. TESTIMONY
2. PROPOSALS
3. MEANS

## Conclusion

Unrecognised troubles

Ignorance of FASD from the professionals

Fragmentation of the system making of it an obstacle course



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2. PROPOSALS
3. MEANS

## Consequences

Non adapted care

Child more disturbed by the inadequate response towards her uneasiness

Feeling of isolation



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1. TESTIMONY
- 2. PROPOSALS**
3. MEANS

## Proposals

### For the official recognition of the troubles

Training for the professionals (Health / Social services / Justice / Education)  
and support for the families

Creation of Diagnosis and Resource Centers

Adapting the follow up in view of social autonomy



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1. TESTIMONY
2. PROPOSALS
3. MEANS

## My involvement

### Actions of training

- Increase knowledge of professional , families and carers
- Increase public awareness
- Help to create network of support systems (REUNISAF)



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1. TESTIMONY
2. PROPOSALS
3. MEANS



1. TESTIMONY
2. PROPOSALS
3. MEANS

september **8<sup>th</sup>** and **9<sup>th</sup>** 2017

nine months for Life.  
**OR,**  
**Why to**  
**say no ?**

 **SAFTTHON**   
let's act to protect our children 



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Thanks for your  
attention

Patrick CHAUVIN  
coordo.saffrance@gmail.com



- Reunion Island, France, Europe need your support to convert the try and generalise it to all countries worldwide.



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# How ?



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**A little logo...**



**... big effects**



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not for pregnant women sign (see image in margin). There is evidence that this French labelling is having a positive impact in terms of awareness regarding drinking during pregnancy, and some alcohol manufacturers have actually embraced it. Pernod-Ricard, for example, labels all its products for sale across the EU with the French pictogram. "Providing accurate information about drinking, including during pregnancy, is the responsible thing to do, and has been taken up as a voluntary commitment by some leading alcohol producers", says Marjana Martinic, Head of Science and Policy at the International Alliance for Responsible Drinking in Washington DC, USA (a not-for-profit funded by producers of beverage alcohol). But a warning given does

## The French formal complaint was the first change of the deal

- Legal proceeding based on the fact that Government must enforce the law.
- Immediately following, there was an awareness of both the real issues and legal responsibilities.
- A **special law** was adopted in February 2005 :
  - **Information given at schools** for children and teenagers
  - **Special teaching for health professionals**
  - **Regular campaigns in media**
- Since October 2006, labels are compulsory.  
**THIS SITUATION MAY BE EXACTLY THE SAME IN ALL EUROPE.**



[www.thelancet.com/neurology](http://www.thelancet.com/neurology) Vol 14 April 2015 – ADRIAN BURTON



- *Still in France the fight goes on and we appreciate all feedback which enable us to impact on public awareness and develop our programs.*
- *And this through your participation to the first SAFTHON September 8th and 9 Th 2017.*
- *Show your solidarity and support us. We need it .*

**nine months for Life.**  
**or,**  
**Why to say no ?**

september **8<sup>th</sup>** and **9<sup>th</sup>** 2017

30 hours of national and international solidarity to raise awareness.  
 • Informations / debates / events / actions  
 • Fund raising

**Why participate ?**  
 • To contribute to an innovative action  
 • To support countries fighting for the recognition of this global issue

For any SAFTHON registration and information, please contact :  
 Denis Lamblin, Saffrance President  
[presidentsaffrance@me.com](mailto:presidentsaffrance@me.com)

Joëlle Balanche, Saffrance Secretary and in charge of the international missions  
[international.saffrance@gmail.com](mailto:international.saffrance@gmail.com)

**SAFTHON**  
let's act to protect our children.

Recycle symbol: Please do not litter. If it is of no interest to you, pass it on to someone else. Thanks.

**neuf mois pour la Vie.**  
**ou,**  
**Pourquoi dire non ?**

les **8<sup>e</sup>** et **9<sup>e</sup>** septembre 2017

30 heures de solidarité nationale et internationale pour faire prendre conscience.  
 • Information / débats / événements / actions  
 • collecte de fonds

**Participer pour :**  
 • Contribuer à une action innovante  
 • Soutenir les pays qui luttent pour la reconnaissance de cette problématique mondiale

Pour toute inscription au SAFTHON et informations merci de contacter :  
 Denis Lamblin, président Saffrance  
[presidentsaffrance@me.com](mailto:presidentsaffrance@me.com)

Joëlle Balanche, secrétaire et chargée des missions internationales SAFFRANCE  
[international.saffrance@gmail.com](mailto:international.saffrance@gmail.com)

**SAFTHON**  
agissons pour protéger nos enfants.

Recycle symbol: Ne pas jeter nos documents sur la voie publique. Si jamais il ne vous intéresse pas, merci de le donner à quelqu'un.



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The

SAFTHON



*9 months for Life*



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**AFFECT 8000 CHILDREN**

For a great  
cause

Based on the same concept as the Telethon, we have decided to launch the **SAFTHON** whose purpose is to highlight the major avoidable cause of social marginalisation.



➤ **To raise awareness about FASD**

- To develop public knowledge and care.
- To encourage individuals and institutions to join us in our fight for an important health issue .

➤ ***To collect funds***

to develop actions on the ground .

➤ ***To show***

the dynamism of the Reunion Island network, on a collective and supportive society project.



## For a great cause

In France, the funds raised will be donated to SAFFRANCE association .

The goals:

- To increase public knowledge on FASD
- To finance projects through yearly call for projects



# What we HOPE from you ?

- Firstly : to show that we are all linked and fighting that global issue
  - Register and engage yourself by our side and develop a **SAFTHON** in your country :
    - be part of both a supportive global action and communication on this issue .
    - support, by doing so, countries still struggling to create FASD awareness in their homeland.
    - raise funds for your own **SAFTHON** projects.

# What we HOPE from you ?

- secondly : we need you and a feedback of what is happening for 9/9 in your countries .
  - For that, we would ask you to put the logo of the safthon on your actions and videos, pictures and send them back to us.

Promote the **SAFTHON** by putting its logo on the actions developed in your country on 9/9.



contact : [presidentsafrance@me.com](mailto:presidentsafrance@me.com)



september **8<sup>th</sup>** and **9<sup>th</sup>** 2017

nine months for Life.  
**OR,**  
**Why to**  
**say no** ?



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# Thanks for your attention



Centre Ressources ETCAF



SAFFrance



FONDATION PERE FAVRON



EACH YEAR  
FETAL ALCOHOL  
SPECTRUM DISORDER  
AFFECTS

## 7<sup>th</sup> International Conference on Fetal Alcohol Spectrum Disorder 2017

**Fetal Alcohol Spectrum Disorder Research: Results and Relevance**

*Integrating Research, Policy and Promising Practice Around the World*