

JOURNÉE NATIONALE PWF – 12 OCTOBRE 2019 - PARIS

LA RECHERCHE TRANSDISCIPLINAIRE

Maithé Tauber et Denise Thuilleaux
Centre de référence du syndrome de Prader-Willi

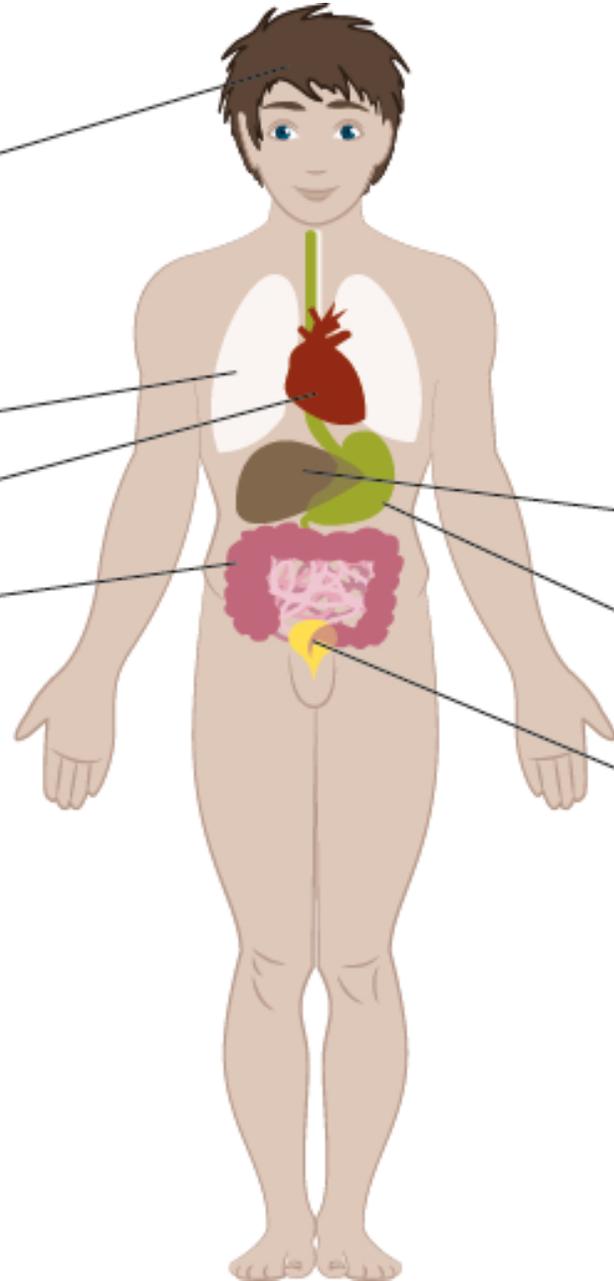
Intrication des problèmes somatiques et psychiques

Neurosciences
Imagerie
Fn neurosensorielles
Cellules IPS

Dysautonomie
Aspects
neuroendocriniens

Motricité
intestinale
Microbiote
Ghreline

Aspects physiopathologiques



Psychiatrie ,
Psychologie
Endocrinologie

Aspects
Respiratoires
Cardiaques
Vasculaires
Scoliose

Aspects
Hépatiques et
Métaboliques

Aspects Gastro-
entéro,uro
Système
nerveux
autonome

Prises en charge

2008

Comité d'organisation
Pr M. TAUBER, Dr G. DIENE
Dr E. LORENZINI
Dr B. THUILLEAUX



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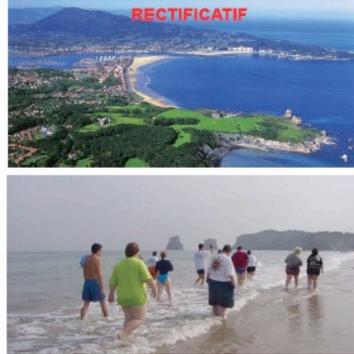


Date limite d'inscription 25 juillet 2008

JOURNÉES DE FORMATION MÉDICALE : PRISE EN CHARGE DU SYNDROME DE PRADER-WILLI



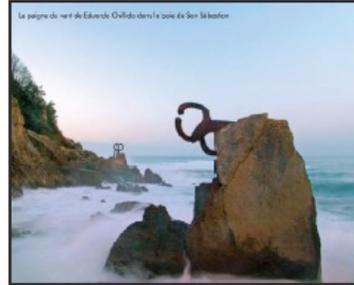
5 - 6 DÉCEMBRE 2008



2011

TROUBLES DU COMPORTEMENT ALIMENTAIRE ANOREXIES, BOULIMIES, OBÉSITÉS, SYNDROME DE PRADER-WILLI
DU 27 JUIN AU 1ER JUILLET 2011

UNIVERSITÉ D'ÉTÉ



2013

PLAN OBÉSITÉ, CENTRE DE RÉFÉRENCE SYNDROME DE PRADER-WILLI
Le 29 JANVIER 2013 de 11h15 à 15h30
Salle de réunion 3, 1er étage bâtiment restauration

PLAN OBÉSITÉ : PR ARNAUD BASDEVANT
PU-PH - SERVICE DE NUTRITION HÔPITAL PITIÉ-SALPÊTRIÈRE - PARIS
11h15-11h45

- ✓ Présentation
- ✓ Impact sur le syndrome Prader-willl et obésités syndromiques
- ✓ Rôle de l'Hôpital Marin

CENTRE DE RÉFÉRENCE PRADER-WILLI : PR MAÏTÉ TAUBER
PU-PH - SERVICE D'ENDOCRINOLOGIE PÉDIATRIQUE HÔPITAL DES ENFANTS MALADES - TOULOUSE
11H45-12h15

- ✓ Centre multi sites (Toulouse-Pitié-Necker-Hendaye)
- ✓ Bilan de 9 ans de fonctionnement
- ✓ Perspectives d'avenir
- ✓ Relations avec le Plan Obésité

12h15-12h45 **VISITE DE BRETONNEAU**
12h45-13h45 **DÉJEUNER**

RÉFÉRENTIEL SUR LE MÉDICO SOCIAL : M. FRANÇOIS BESNIER
PRÉSIDENT DE L'ASSOCIATION FRANCE PRADER-WILLI
14h00 -14h30

- ✓ Présentation du projet de référentiel (travail avec la Caisse Nationale de Solidarité pour l'Autonomie)

UN SERVICE SPÉCIALISÉ À L'HÔPITAL MARIN D'HENDAYE : DR DENISE THUILLEAUX
Médecin Chef de Pôle
14h30-15h00

- ✓ Bilan de 13 ans de fonctionnement
- ✓ Perspectives à court-moyen long terme

15h00-15h30

- ✓ Echanges avec les participants

VISITE DES DIFFÉRENTS SITES DE PRISE EN CHARGE
15h30-16h00

- ✓ Rotonde
- ✓ Salle de sport
- ✓ Equithérapie

16h00 **CLÔTURE DE LA JOURNÉE**



ASSISTANCE PUBLIQUE HÔPITAUX DE PARIS

PROGRAMME

Réunion Centre de référence 22-23 Janvier 2016



2019



2006



L'HÔTEL-DIEU SAINT-JACQUES

Comprehensive care of patients with PWS – consensus, questions and future directions

Venue
The meeting will be held in Toulouse, France at L'Hôtel-Dieu Saint-Jacques.
L'Hôtel-Dieu Saint-Jacques
2, rue Viguerie
TSA 80035 – 31059 Toulouse Cedex 9
France

Scientific Committee
Anthony Goldstone, London, United Kingdom
Berthold Hauffa, Essen, Germany
Anita Hokken-Koelga, Rotterdam, The Netherlands
Anthony Holland, Cambridge, United Kingdom
Maihé Tauber, Toulouse, France

Local Organizing Committee
Gwenaëlle Diene, Toulouse
Mélanie Glattard, Toulouse
Catherine Molinas Cazals, Toulouse
Maihé Tauber, Toulouse
Denise Thuilleaux, Hendaye

CME Credits
CME accreditation has been requested.

Scientific Secretariat
Equipe d'Endocrinologie
Hôpital des Enfants
TSA 70034 – 31059 Toulouse Cedex 9,
France

Contact person Catherine Molinas Cazals
E-mail congres-pws2006@chu-toulouse.fr
Phone/Fax +33 5 67 77 12 59

Administrative Secretariat
All matters regarding registration, hotel bookings, social events and general information are handled by Congrex Sweden AB. CONGREG

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Phone +46 8 459 66 00
Fax +46 8 661 91 25
E-mail pws2006@congrx.se
www.congrx.com/pws2006

Registration
On-line registration will open early April 2006 on www.congrx.com/pws2006

PWS Meeting Website
All further information can be found on www.congrx.com/pws2006.
The website will be updated on a regular basis until the meeting takes place.

www.congrx.com/pws2006

FIRST ANNOUNCEMENT

Comprehensive care of patients with PWS

– consensus, questions and future directions



Second Expert Meeting
26–27 October 2006, Toulouse

Supported by an unrestricted educational grant from
 Endocrine care

www.congrx.com/pws2006

2014

PROGRAMME

16–17 May 2014

Mercure Toulouse Compans Caffarelli,
Toulouse, France

Endocrinology
FIRST
A Pfizer Programme

Prader Willi Syndrome:
Translating knowledge into future care

Goals/Objectives

The aim of this expert meeting is to review the progress we have made in understanding the genetics, metabolic and behavioural aspects of PWS and translate this knowledge into management of patients.

Scientific Planning Committee

Prof Maïthé Tauber (Chair) Hôpital des Enfants and Prof Sabater Bordeaux Toulouse, France	Prof Véronique Beauloye CHU de Liège Cellule d'obésité diabète Borah, Belgium	Prof Tony Goldstone Hammersmith Hospital Imperial College London, UK	Prof Berthold Hauffa University Children's Hospital, Essen, Germany	Prof Anita Hokken-Koelga Erasmus University Medical Center Rotterdam, Netherlands	Prof Jennifer Miller University of Florida College of Medicine Florida, US	Prof Arnick Vogels University Hospitals Leuven Leuven, Belgium
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Agenda

Friday 16 May 2014

Time	Topic	Chair/Co-chair	Speaker
8:20–8:30	Welcome and Program Overview		Maihé Tauber (France)
8:30–9:00	PWS in 2014		Maihé Tauber (France)
Session 1: Eating behaviour and beyond			
9:00–10:30		Jennifer Miller/ Jean-Paul Thissen	
	Hypersphagia in PWS is not just the hypothalamus		Tony Goldstone (UK)
	Does acetylated and non-acetylated Ghrelin matter in PWS?		Renée Kuppens (Netherlands)
	Does Oxytocin offer hope for PWS?		Maihé Tauber (France)
	What do infant studies tell us about hypersphagia onset in PWS?		Véronique Beauloye (Belgium)
	Hot Topic		
10:30–11:00	Break		
Session 2: Metabolic aspects			
11:00–12:30		Véronique Beauloye/ Anita Hokken	
	Mitochondrial dysfunction in white adipose tissue and obesity		Martin Waldbitsch (Germany)
	Should we treat obesity with targeting brown/beige adipocytes?		TBC
	Adipose tissue in children and adults		Christine Peltou (France)
	Hot Topic		
12:30–13:30	Lunch		

Time	Topic	Chair/Co-chair	Speaker
Session 3: Behavioural problems and psychiatric disorders			
13:30–15:05		Arnick Vogels/ Tony Holland	
	Behavioural features in PWS		Denise Thuilleaux (France)
	Psychiatric features in PWS		Arnick Vogels (Belgium)
	Practical consequences of emotional, social and cognitive impairments in children?		Sindie Le (Netherlands)
	Practical consequences of emotional, social and cognitive impairments in adults?		Johan Chevalere (France)
	Hot Topic		
15:05–15:30	Break		
Session 4: Growth hormone in paediatrics and adolescents			
16:00–17:30		Maihé Tauber/ Alessandro Salvatori	
	How has long term GH treatment changed the PWS phenotype in children?		Anita Hokken (Netherlands)
	What is the right age to start GH in childhood?		Véronique Beauloye (Belgium) Gwenaëlle Diene (France)
	Is monitoring IGF1 levels of value in GH treatment in children? (debate)		Prof Jennifer Miller (US) Against: Berthold Hauffa (Germany)
	What do we do with GH in transition?		Alessandro Salvatori (Italy)
	Hot Topic		
17:30–18:30	Poster session		

Saturday 17 May 2014

Time	Topic	Chair/Co-chair	Speaker
Session 5: Genetics to patients			
8:30–10:30		Tony Goldstone/ Francoise Maccatelli	
	General overview of genetics of PWS (MORF, future)		Berthold Hauffa (Germany)
	Learning from Mice (models) and Men: 2 Case presentations SNORD 116		Jerome Cavalier (France) Francoise Maccatelli (France) Christian Patrick Schaaf (US)
	How to define, explore and manage a PWS-like patient: criteria, diagnostic steps and care. Round table discussion		Maihé Tauber (France), Jennifer Miller (US), Berthold Hauffa (Germany) and Bernhard Horsthemke (Germany)
10:30–11:00	Break		
Session 6: Adults			
11:00–12:30		Berthold Hauffa/ Graziela Gougné	
	How to manage puberty in PWS and sex steroid replacement?		Antonino Cirio (Italy)
	What are the benefits of GH in adult PWS including bone health?		Charlotte Hoybye (Sweden)
	How to assess and improve QoL in adolescents and adult PWS?		Tony Holland (UK)
	Hot Topic		
12:45–13:00	Closing Remarks		Maihé Tauber (France)
13:00	Lunch and departures		

Pfizer Ltd has initiated and sponsored the "Prader-Willi Syndrome: Translating knowledge into future care" meeting. The Scientific Planning Committee (SPC) of this event is comprised of speakers who provide scientific and planning oversight for the overall programme and content. Its members are engaged experts in the field of PWS and they receive an honorarium from Pfizer Ltd for this work. The communications of this meeting represent the scientific opinions of the individual presenters and may not necessarily represent the opinions of Pfizer Ltd, or any of its subsidiaries, partners or employees.

Financial support provided by Pfizer Ltd.

Endocrine

CME accreditation by the European Accreditation Council for Continuing Medical Education (EACCME) has been applied for.

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**RECHERCHE
FAITE
À TOULOUSE**



Laboratoire de
Psychologie

Laboratoire CLLE
UMR 5263



Sociologie de
l'alimentation

Emotion
Cognition



CERTOP
UMR 5044



FHU HoPeS

Comportement
alimentaire

Trouble du sommeil

Base de données

Biobanque

Ocytocine

Unité
Méthodologie



Expertise
Clinique

Unité
Néonatalogie



Epidemiologie
Qualité de vie

SPHERE
UMR 1027



ToNIC
UMR 1214

Imagerie
Cérébrale

Neurosciences

Intégration
des signaux



CerCo
UMR 5549

Hyperactivité
CRA



Métabolisme
I2MC
UMR 1048

Microbiote



Biochimie
Addiction
Cellules IPS
UMR 1043

CPTP
UMR 1043

**RESEAU CLINIQUE
FRANÇAIS ET EUROPEEN**

Support
logistique



Support
Recherche Clinique



**RESEAU
NATIONAL DE
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ACADEMIQUE**

Modèle
murin



Addiction IGF



Laboratoire
Neurobese



Modèle murin
Cellule neuronale

UMR 1172
Modèle murin



Obésités
génétiques
Métabolisme

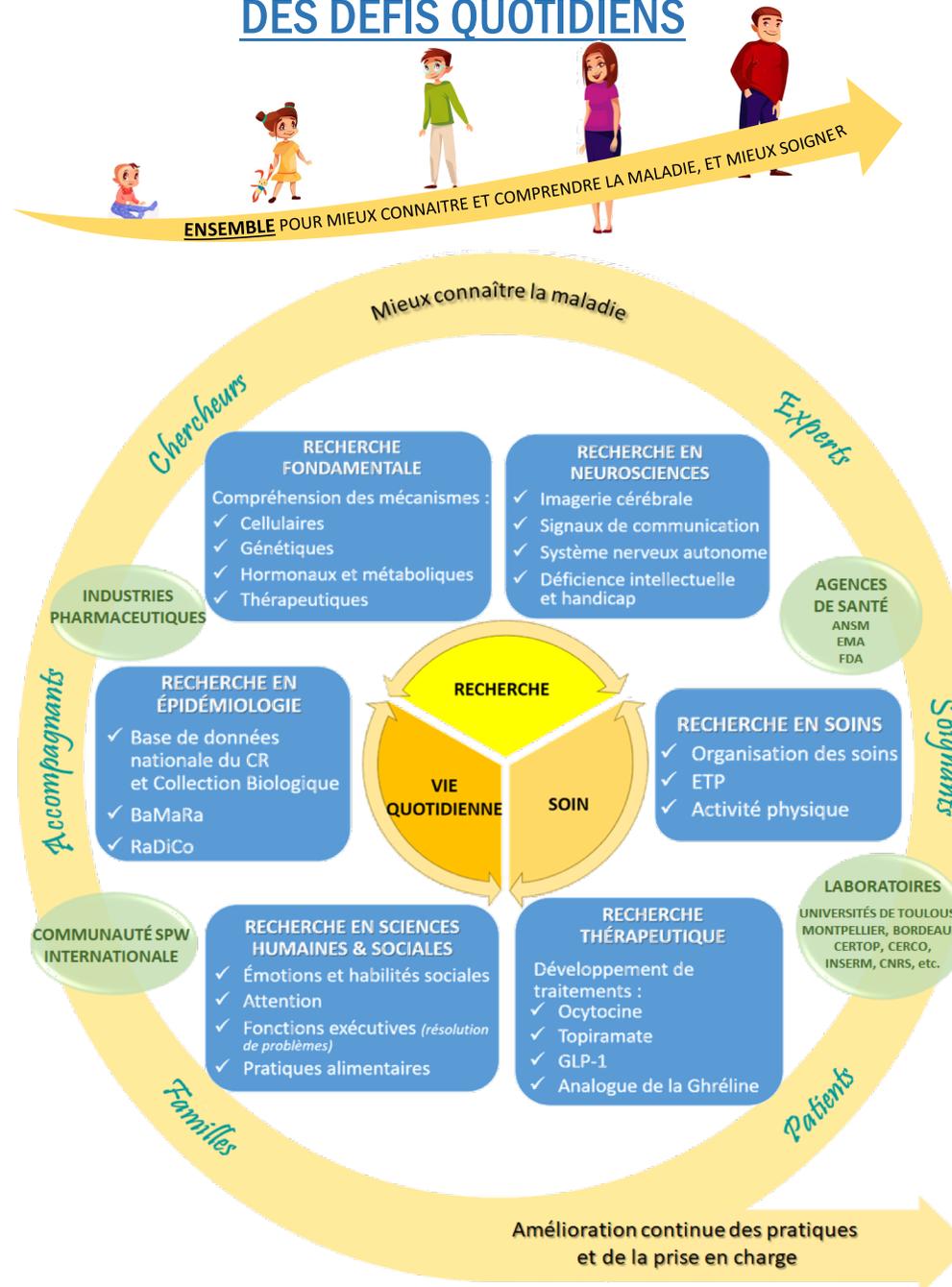


ICube
UMR7357

Evaluation
succion du
nouveau-né



LA RECHERCHE AU CENTRE DE RÉFÉRENCE DU SYNDROME DE PRADER WILLI : DES DÉFIS QUOTIDIENS



Le Centre de Référence (CR) a initié des programmes de recherche innovants, multidisciplinaires et multi-sites

Un continuum de la recherche fondamentale à la clinique, pour l'amélioration des soins et de la vie quotidienne

L'HISTOIRE DE L'OCYTOCINE DANS LE SYNDROME DE PRADER-WILLI

Maithé Tauber et Denise Thuilleaux
Centre de référence du syndrome de Prader-Willi

