

Developing Partnerships within Europe for Collaborative Research into Prader-Willi Syndrome (PWS)

**16 –17 December 2008 Meeting
Current PWS Research Group**

**17 – 18 December 2008 Meeting
Future European PWS Research Group**



**Fitzwilliam College
University of Cambridge**

Host:
Learning Disability Research Group
Section of Developmental Psychiatry
University of Cambridge
www.LDRG.org.uk



SIXTH FRAMEWORK PROGRAMME PRIORITY 1
Life Science, Genomics and Biotechnology for Health
Contract Number: LSHM-CT-2005-512136
www.pwseu.eu

Developing Partnerships within Europe for Collaborative Research into PWS

Dear Colleague,

Welcome to Cambridge. This meeting marks the near completion of a European Union funded collaborative research project that started in December 2005 and officially ends on 31st May 2009. This project has brought together clinicians and basic scientists from different European countries and from Israel. The main foci for this project have been a number of studies involving different mouse models of PWS, genetic investigations, studies on human hypothalamic tissue, and the establishment of an internet-based clinical research database to enable future collaborative clinical studies of PWS between different countries. Central to the project has been the exchange of ideas within and between the many disciplines involved in the different studies. Part 1 of this meeting provides a further opportunity for current members of this European funded project to meet and to report on and discuss their findings.

In Europe there are major contributors to research in PWS from several strong national research groups. In addition, in Europe we have committed and energetic national PWS Associations that are strong advocates for people with PWS and important partners in clinical research projects. The clinical part of the EU project emerged from a recognition of the need for different countries to collaborate to support those studies that require large numbers of participants with PWS across different age groups and genetic sub-types, both genders, and on or off growth hormone. It came from the vision of those who were then, and many who still are, leaders in their respective national PWS Associations. Whilst some studies can effectively be undertaken in any one country and the findings from such studies in turn benefit all, regardless of country of origin, there are other studies that struggle because of the need to obtain sufficiently large numbers of participants to obtain meaningful results. The internet-based database that has been established as part of this project is a 'research tool' to support and enable such cross-national studies to take place. It establishes an agreed set of assessment instruments and data fields in order to structure data collection, thus making the combining and sharing of data in an anonymous and agreed manner possible. What comes next?

Part 2 of this meeting is about the future. The undertaking of further basic science studies depends on forming and maintaining the necessary collaborations and obtaining funding. Specific clinical studies require collaboration within and between national clinical research groups and strong and agreed collaborative arrangements. Shared databases are only possible if the data entered is reliable, confidentiality is ensured, and agreed arrangements are in place for how data is

shared and published. Whilst very good clinical and basic science research in PWS is possible in any one country, it is clear that the complexity of the science, the range of skills needed, and the particular problems relating to PWS being such a rare disorder also require and benefit from a collaborative approach, such as those that have been undertaken over the last three years as part of this current EU project. There is a further and most important benefit to co-operation across Europe - that is the wide dissemination of research knowledge and also the establishment of agreed standards of care and support for people with PWS and their families, such as those initiated at the recent meeting in Herne, Germany. As new interventions and treatment programmes are developed for the eating disorder and/or for the psychiatric and physical aspects of PWS there will be the need for formal trials and the subsequent implementation of findings if such treatments are found to be successful. Such future research will be more possible by having in place established collaborations and agreed protocols.

In Part 1 of this meeting those partners in the current project will have the opportunity to consolidate their findings and reflect on the nearly completed project and in Part 2 to briefly present their findings to the larger group. Part 2 aims to further this process of co-operation and collaboration by providing the opportunity for an enlarged group of basic scientists, clinicians, and parent representatives from across Europe to meet and share ideas. The meeting is very much focussed on research and it is hoped that ideas will emerge that clearly require and benefit from further investigation and that collaborative partnerships will be formed. Fitzwilliam College, being one of the newer Colleges of the University of Cambridge, is comfortable and warm and ideal for such meetings!

I look forward to hearing your contributions at this research gathering. As the holidays are fast approaching here in Cambridge, we also hope you are able to experience some of the Christmas spirit of the city by taking the time to venture beyond Fitzwilliam to explore some of the other Colleges.

Tony Holland, Co-ordinator
EU Prader-Willi Syndrome Research Project

December 2008

Objectives

Part 1:

Final combined meeting of the basic science and clinical groups of the current PWS EU Research Project funded under Framework 6 of the EC.

Objective:

To provide a forum for the presentation and discussion of clinical and basic science research outcomes from the present EU study.

Part 2:

Enlarged meeting with representatives from elsewhere in the EU

Objective:

To bring together representatives of EU National PWS Associations, and clinical and research scientists from Europe and associated countries to consider the following:

- a. Collaborative research in PWS between different EU countries;*
- b. Research and dissemination strategies to inform clinical and social care policy for people with PWS across the EU.*

Programme: Part 1

Attendees: basic science and clinical participants
of the current EU project

Tuesday 16th December

1.00	Arrival and buffet lunch	Dining Hall Hall Building
2.00 – 3.30	<u>Basic Science</u> Presentations on the research findings from each of the basic science groups to both the clinical and basic science groups - discussion of cross-cutting themes. Chair: Françoise Muscatelli	Reddaway Room Hall Building
3.30 - 4.00	Tea break	Screens, Ground floor Hall Building
4.00 – 5.00	Resumption of Basic Science discussion	Reddaway Room Hall Building
7.00	Informal dinner	Dining Hall Hall Building

Wednesday 17th December

9.00 - 10.30	<u>Clinical</u> Presentation of the clinical research PWS database Joyce Whittington, Tony Holland and representative from HC-Forum	Reddaway Room Hall Building
10.30 – 11.00	Coffee	Screens, Ground floor Hall Building
11.00 – 12.30	Review of outcomes from the present grant focussing on achieving the deliverables and the publication of scientific and position papers. Chairs: Françoise Muscatelli and Tony Holland	Reddaway Room Hall Building
12.30 – 1.00	<u>Future Research</u> General discussion	Reddaway Room Hall Building
1.00	Buffet lunch	Dining Hall Hall Building

Programme: Part 2

Attendees: Participants in the current EU project and clinicians, researchers and representatives of national PWS Associations from the EU

Wednesday 17th December

1.00 – 2.00	Buffet lunch	Dining Hall Hall Building
2.00 – 2.15	Welcome	Reddaway Room Hall Building
2.15 – 3.15	Summary presentations from two members of the EU PWS research group to the larger EU group, summarising outcomes. Tony Holland and Françoise Muscatelli	Reddaway Room Hall Building
3.15 – 3.45	Tea break	Screens, Ground floor Hall Building
3.45 – 5.00	What are the issues requiring cross national research from the perspectives of PWS Associations? Christel Nourissier, Narinder Sharma and other representatives from European National PWS Associations	Reddaway Room Hall Building
6.40	Bus leaves from Fitzwilliam College for dinner at St Catharine's College	Main entrance, Storey's Way
7.00	Drinks reception	Old Combination Room St Catharine's College Trumpington Street
7.30	Conference dinner	Senior Combination Room, St Catharine's College
10.30	Bus leaves from St Catharine's College to return to Fitzwilliam College	

Thursday 18th December 2008

9.00 – 9.45	Best practice guidance in the care of people with PWS Maithe Tauber	Reddaway Room Hall Building
9.45 – 10.30	Establishing an EU PWS clinical and research network: the future use of the PWS clinical research database. Clinical research group and HC-Forum	Reddaway Room Hall Building
10.30 – 11.00	Coffee break	Screens, Ground floor Hall Building
11.00 – 12.30	Ideas for future collaborative research in PWS across the EU.	Reddaway Room Hall Building
12.30 – 1.30	Buffet lunch	Dining Hall Hall Building
1.30 – 3.00	Continuation of informal discussion in one large or several small groups.	Reddaway Room Hall Building
3.00	Departure	

Conference Information

Rooms

Meetings will take place in the Reddaway Room in Hall Building.

Tea and coffee will be served in Screens, the coffee bar area on the ground floor of the Hall Building. A water cooler will be available in the Reddaway Room.

Meals will be served in the Dining Hall in Hall Building, with the exception of dinner on Wednesday night, which will be at St Catharine's College, Trumpington Street. (See map for further directions.)

Internet access

Ethernet connections and wireless access are available in the Reddaway Room.

Email and web access is available in the Cyber Café, next to the Reddaway Room.

Username: Conf01

Password: Dop08

If you wish to connect your personal computer to the internet in your bedroom there is a charge for this service, payable by credit card. You will need a lead to connect to the network socket. (RJ45 network leads may be obtained from the porters' lodge). The charge is a connection fee of £5 and then £5 per day.

Accommodation

All bedrooms are in New Court, Fitzwilliam College. On your day of departure, please vacate your room by 9.30am. Suitcases and belongings can be left in the Luggage Room in the Auditorium Meeting Room.

Conference Dinner

The conference dinner will be held in St Catharine's College, Trumpington Street. There will be a coach transporting people from Fitzwilliam College to St Catharine's College, leaving from the Storey's Way entrance to Fitzwilliam College at 6.40pm.

The coach will also take people back to Fitzwilliam College, leaving from St Catharine's College at 10.30pm.

7.00pm Drinks Reception in Old Combination Room

7.30pm Dinner in Senior Combination Room

Attendees Part 1 and Part 2

Leopold Curfs	Netherlands	curfs@msm.nl
Marion Gourin	France	marion.gourin@hcforum.fr
Tony Goldstone	UK	tony.goldstone@csc.mrc.ac.uk
Tony Holland	UK	ajh1008@cam.ac.uk
Alex Huttenhofer	Austria	alexander.huettenhofer @i-med.ac.at
Anat Lavi-Itzkovitz	Israel	anat.lavi@weizmann.ac.il
Ann Christin Lindgren	Sweden	ann.christin.lindgren@ki.se
Fabienne Marly	France	
Francoise Muscatelli	France	muscatelli@inmed.univ-mrs.fr
Christel Nourisser	France	christel.nourissier@eurordis.org
Andreas Ploner	Austria	andreas.ploner@i-med.ac.at
Anne Rieusset	France	
Dick Swaab	Netherlands	d.f.swaab@nin.knaw.nl
Annick Vogels	Belgium	annick.vogels@uz.kuleuven.ac.be
Joyce Whittington	UK	jew1000@cam.ac.uk
Narinder Sharma	UK	nsharma@pwsa.co.uk
Jorgelina Stegmann	Argentina	fundacionspine@gmail.com

Attendees Part 2 only

Irune Achutegui	Italy	irune@fastwebnet.it
Susanne Blichfeldt	Denmark	s.blichfeldt@dadlnet.dk
Nicola Bridges	UK	n.bridges@imperial.ac.uk
Fernando Briones	Spain	presidente@amspw.org
Valentino Colossa	Italy	valentino.colosso@zoppas.com
Antonino Crino	Italy	crino@opbg.net
Dorica Dan	Romania	doricad@yahoo.com
Gwenaella Diene	France	
Urs Eiholzer	Switzerland	urs.eiholzer@pezz.ch
Stense Farholt	Denmark	stenfarh@rm.dk
Donatella Greco	Italy	dgreco@oasi.en.it
Graziano Grugni	Italy	g.grugni@auxologico.it
Nobert Hodebeck- Stuntebeck	Germany	norbert.hoedebeck- stuntebeck@wittekindshof.de
Charlotte Hoybye	Sweden	charlotte.hoybye@karolinska.se
Lorenzo Iughetti	Italy	lorenzo.iughetti@unimore.it
Catherine Molinas	France	molinas.c@chu-toulouse.fr
Mariona Nadal	Spain	mnadal@amspw.org
Maria Grazia Natali-Sori	Italy	natalisora.mariagrazia@hsr.it
Jean Philips-Martinsson	Sweden	jeanpws@aol.com
Maria Puiu	Romania	maria_puiu@umft.ro
Beppe Quaglia	Italy	beppe@quaglia.it
Letizia Ragusa	Italy	lragusa@oasi.en.it
Martin Ritzen	Sweden	martin.ritzen@ki.se
Christina Rusu	Romania	abcrusu@gmail.com
Alessandro Salvatoni	Italy	alessandro.salvatoni@uninsubria.it
Tiina Silvast	Finland	silvast.pws@elisamet.fi
Hubert Soyer	Germany	hubert.soyer@regens-wagner.de
Maithe Tauber	France	tauber.mt@chu-toulouse.fr
Pablo Garcia Tobin	Spain	ptobin@bloomberg.net
Kate Woodcock	UK	conferences@katewoodcock.com
Jackie Waters	UK	jwaters@pwsa.co.uk
