

Huntington's Disease Sleep Medical Advisory Meeting 9-10 March 2009 Princeton, NJ

Advisors:	CHDI Attendees:
Derk-Jan Dijk, PhD	Beth Borowsky, PhD
University of Surrey	Director, Translational Medicine
Ken Evans, PhD	Susanna J Dodgson BSc(Hons), PhD
Ontario Cancer Biomarker Network	Medical Writer
Anna Goodman, PhD	Joseph Giuliano
Cambridge Centre for Brain Repair	Director, Clinical Operations
Thomas Kilduff, PhD	Ignacio Munoz-Sanjuan, PhD
Stanford Research Institute	Vice President, Biology
Andrew D. Krystal, MD	Allan Tobin, PhD
Duke University Medical Center	Senior Scientific Advisor
Wallace Mendelson, MD	Dan van Kammen, MD, PhD
The University of Chicago	Chief Medical Officer
Kathleen M. Shannon, MD	John Warner, PhD
Rush University School of Medicine	Director, Biostatistics
Francis Walker, MD	
Wake Forest University School of Medicine	
Phyllis Zee, MD, PhD	
Northwestern University School of Medicine	

Meeting Objective:

The goal of this meeting is to secure the advice of sleep experts, HD researchers and clinicians on the best design for a sleep research program that will answer some of the key questions about the sleep disturbances in HD and ultimately a trial with therapeutic intervention(s) that will explore the impact restorative sleep may have on disease progression in HD. Outcomes and discussions during this meeting will be summarized in a meeting report and specific recommendations on study designs will be incorporated into protocol outline(s).



9 March 2009

	Topic	Responsibility	Time
1.	Continental breakfast		8:30 to 9:00
2.	Welcome and Introductions	Joe Giuliano	9:00 to 9:15
3.	Overview of CHDI Goals and Objectives for Sleep in HD	Dan van Kammen	9:15 to 9:45
4.	Overview of Basic Research in Sleep and HD Discussion	Tom Kilduff	9:45 to 10:30
	Break		10:30 to 10:45
5.	Overview of Clinical Research in Sleep and HD Discussion	Francis Walker	10:45 to 11:30
6.	Overview of Effects of Sleep Deficits on Cognition	Phyllis Zee	11:30 to 12:15
	Lunch		12:15 to 13:00
7.	Discussion (based on what was presented in the morning session):		
	• What are the sleep disturbances in pre-manifest and early HD?	All	13:00 to 14:30
	• Is there a sleep phenotype? If so, what is it?		
	• What are the causes and consequences of sleep problems in HD subjects?		
	Break		14:30 to 14:45
8.	Presentation of Study Concepts for Discussion and Recommendations	Joe Giuliano	14:45-15:00
9.	Based on our current understanding of Sleep and HD:		
	• What direction should CHDI take to achieve the goals of better characterizing the sleep problems in?	All	15:00 to 16:30
	• What recommendations does the group have for designing an intervention study that will show if improving sleep in this population will also have an effect on cognition (a measure of disease progression)?	All	15.00 to 16.30
10	. Develop Group Recommendations	All	16:30 to 17:00
	Dinner –		19:00
	The Ferry House in Princeton		-2.20



March 10, 2009

Topic	Responsibility	Time
1. Continental breakfast		08:30 to 09:00
2. Review of previous day	Joe Giuliano	09:00 to 09:15
3. Discussion of Protocol Outline in light of discussions from previous days – will this study design meet the objectives?	All	09:30 to 11:00
Break 4. Discussion		11:00 to 11:15
a. General study designb. Study objectives and endpointsc. Inclusion/Exclusion Criteriad. What drugs should be used for treatment intervention?e. Other important considerations?	All	11:15 to 12:30
Lunch		12:30 to 13:30
5. Finish morning discussions, next steps & adjourn	All	13:30 to 14:30