

PUBLIC HEALTH SERVICE

Meeting of the Interagency Coordinating Committee on Human Growth Hormone and Creutzfeldt-Jakob Disease

October 30, 2014, 1-2:30 PM

Democracy II, NIDDK Conference Room 694
Bethesda, Maryland

Committee Members Attending

Dr. Judith Fradkin, NIDDK
Dr. Ellen Leschek, NIDDK
Dr. James Mills, NICHD (by phone)
Dr. Avindra Nath, NINDS
Dr. Griffin Rodgers, NIDDK, Chairman
Dr. Lawrence Schonberger, CDC (by phone)
Dr. Diane Wysowski, FDA

Also Attending

Dr. Greg Germino, NIDDK
Mary Harris, NIDDK
Jody Nurik, NIDDK
Amy Reiter, NIDDK
Dr. B. Tibor Roberts, NIDDK
Dr. Robert Tilghman, NIDDK
Dr. May Wong, NINDS (by phone)

Westat Contract

Dr. Leschek reported that the Westat contract is in the second year of the current 5-year contract.

NHPP Cohort Update

The anticipated case discussed in the 2013 meeting report was clinically confirmed, bringing the total number of confirmed cohort cases to 30 (14 neuropathologically confirmed and 16 clinically confirmed). The incubation period for this case was 43.5 years from the start of hGH therapy to the onset of CJD symptoms; 37.8 years from the midpoint of therapy to the onset of symptoms; and 32.1 years between the end of hGH therapy and the onset of symptoms. Because the Neurology Review Group (NRG) had not yet received the autopsy report as of the date of the Committee meeting, the case currently is listed as clinically (but not neuropathologically) confirmed. Notably, however, other expert pathologists with access to the autopsy results have found them to be consistent with CJD. Therefore, the committee anticipates the NRG will reach similar conclusions, when they receive the autopsy report, and the case will then be re-listed as neuropathologically confirmed.. As with all other confirmed cases, this new case occurred in a patient who began treatment before Dr. Albert Parlow's lab began preparing hGH in 1977.

One case under investigation was deemed highly unlikely to be CJD: it was concluded that the patient had died from an unrelated respiratory illness.

Report on CJD in Foreign and Commercial GH Recipients

Five new international CJD cases were reported, all from the United Kingdom. In addition, there are two known CJD cases linked to use of commercially produced hGH, one in Austria, and one

in the United States. Thus, there are 208 cases known internationally, not including the NHPP cohort cases discussed above.

Updates on Fact Sheet and Public Inquiries

Ms. Reiter confirmed implementation of the website changes discussed at last year's meeting and stated that the website will be updated to reflect the cases confirmed in the past year and to include information on new experimental CJD diagnostic tests (see below).

Ms. Harris reported that there were 10 inquiries regarding hGH and CJD over the past year. None of the calls were suggestive of potential new cases of CJD.

Recent Progress in CJD Research: Experimental Diagnostic Tests

Dr. Schonberger and Dr. Nath discussed recent papers describing premortem tests for CJD:

1. Orru CD, Bongianni M, Tonoli G, et al. [A Test for Creutzfeldt–Jakob Disease Using Nasal Brushings](#). *N Engl J Med*. 2014; 371(6): 519-529.
2. Moda F, Gambetti P, Notari S, et al. [Prions in the Urine of Patients with Variant Creutzfeldt–Jakob Disease](#). *N Engl J Med*. 2014; 371(6): 530-539.
3. Jackson GS, Burk-Rafel J, Edgeworth JA, et al. [A highly specific blood test for variant CJD](#). *Blood*. 2014; 123(3): 452-453.
4. Douet JY, Zafar S, Perret-Liaudet A, et al. [Detection of infectivity in blood of persons with variant and sporadic Creutzfeldt-Jakob disease](#). *Emerg Infect Dis*. 2014; 20(1): 114-117.

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