PUBLIC HEALTH SERVICE

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

October 22, 2013, 1-2:30 PM

National Institutes of Health
Bethesda, Maryland

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

Also Attending
Joseph Abrams, CDC (by phone)
Dr. Greg Germino, NIDDK
Mary Harris, NIDDK
Ryan Maddox, CDC (by phone)
Jody Nurik, NIDDK
Amy Reiter, NIDDK
Dr. B. Tibor Roberts, NIDDK
Dr. Robert Tilghman, NIDDK
Dr. May Wong, NINDS (by phone)

Dr. Leschek reported that the Westat contract has been renewed for five more years.

In 2013, one new case of CJD was neuropathologically confirmed, bringing the total number of official cohort cases to 29 (14 neuropathologically confirmed and 15 clinically confirmed). The new case is notable for having the longest incubation period of a cohort case to date: 44.2 years from the start of hGH therapy to the onset of CJD symptoms; 41.5 years from the midpoint of therapy to the onset of symptoms; and 38.8 years between the end of hGH therapy and the onset of symptoms. This case therefore extends the maximum known incubation periods for these intervals by 10.9, 11.6, and 11.0 years, respectively. A thirtieth case has been neuropathologically identified and will be officially confirmed when the death certificate is received. All 29 currently confirmed cases—as well as the anticipated thirtieth case—occurred in patients who began treatment before Dr. Albert Parlow's lab began preparing hGH in 1977.

Three cases under investigation for possible CJD were dismissed. Two were reviewed by the Neurology Review Group (NRG) and were determined to contain insufficient evidence of CJD; a third case was dismissed by the Committee due to insufficient evidence of CJD. The third case was not referred to the NRG for review because medical records and autopsy slides were unavailable, and none of the information available was strongly suggestive of CJD.

Two new international CJD cases were reported, both from the United Kingdom. This brings the total for international cases to 202.

Ms. Nurik confirmed implementation of the website changes discussed at last year's meeting.

Ms. Harris reported that there were 13 calls regarding hGH and CJD over the past year, and of these, 11 were from cohort members. None of the calls were suggestive of potential new cases of CJD.

Dr. Schonberger brought the following 4 publications to the attention of the committee:

1. Iatrogenic Creutzfeldt-Jakob disease from commercial cadaveric human growth hormone. *Emerg Infect Dis*. 19(4): 682-684, 2013.

2. Evaluation of potential infectivity of Alzheimer and Parkinson disease proteins in recipients of cadaver-derived human growth hormone. *JAMA Neurol*. 70(4): 462-468, 2013.

3. Prevalent abnormal prion protein in human appendixes after bovine spongiform encephalopathy epizootic: large scale survey. *BMJ*. 347: f5675, 2013.

4. Variably protease-sensitive prionopathy in the UK: a retrospective review 1991–2008. *Brain*. 136(4): 1102-1115, 2013.

Griffin P. Rodgers, M.D.
Director, NIDDK