

PUBLIC HEALTH SERVICE

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

November 30, 2021, 2:30 PM

- Virtual Meeting -
Hosted by the National Institutes of Health
Bethesda, Maryland

Committee Members Attending

Dr. William Cefalu, NIDDK
Dr. Ellen Leschek, NIDDK
Dr. James Mills, NICHD
Dr. Avindra Nath, NINDS
Dr. Griffin Rodgers, NIDDK, Chair
Dr. Lawrence Schonberger, CDC
Dr. Youjin Wang, FDA

Also Attending

Dr. Joseph Abrams, CDC
Ms. Alicia Clement, NIDDK
Dr. Gregory Germino, NIDDK
Dr. Ryan Maddox, CDC
Ms. Amy Reiter, NIDDK
Dr. B. Tibor Roberts, NIDDK
Dr. Robert Tilghman, NIDDK
Ms. Alyssa Voss, NIDDK

Westat Contract

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

National Hormone and Pituitary Program (NHPP) Cohort Update

Dr. Leschek reported that there had been no additional confirmed cases of CJD within the cohort since last year's meeting, and there are no new clinically suspicious cases. The total number of official cases (i.e., clinically or neuropathologically confirmed) remains at 35. The CDC has been attempting to obtain medical records for the most recent clinically confirmed case, but these efforts have been hampered by the COVID-19 pandemic.

There are two cases currently under investigation. One is a case that was described in the 2020 meeting summary (a person in the cohort who died in 2016 with a diagnosis of dementia); no new information has been found for this case. The consensus of the Committee is to classify this case as "clinically suspicious, insufficient information to confirm." The other case under investigation is a person in the cohort who died in their mid-sixties from dementia. No autopsy was performed, and Dr. Leschek is going to work with the CDC to obtain more information.

Suicide Rates in Cohort

Dr. Leschek discussed the results of preliminary analyses of the rates of suicide in the cohort. She presented analyses that compared suicide deaths with total deaths in the cohort, considering variables such as short stature, hormone deficiency, and other conditions that could potentially

be identifiers for a subpopulation in the cohort that may be at higher risk for suicide. The Committee discussed a draft of a manuscript for publication.

Updates on Fact Sheet and Public Inquiries

Ms. Clement stated that the comprehensive and summary fact sheets were merged into a single resource to streamline the information and better meet the public's needs. The fact sheet was updated to reflect the two new confirmed cases of CJD in the cohort and the one new foreign case that were reported in the 2020 meeting. Scientific papers discussed at the 2020 meeting were added to the resource list. For reference, the [comprehensive fact sheet is here](#), and the [resource list is here](#).

Ms. Voss reported that there were 16 inquiries regarding hGH and CJD over the past year, compared to seven the year before. Nine were from confirmed cohort members. None of the calls were suggestive of potential new cases of CJD.

Recent Progress in CJD Research

Dr. Schonberger and Dr. Nath noted six recent publications of interest:

1. Bizzi A, Pascuzzo R, Blevins J, *et al.* [Subtype Diagnosis of Sporadic Creutzfeldt-Jakob Disease with Diffusion Magnetic Resonance Imaging](#). *Ann Neurol.* 2021; 89: 560-572. (Also see commentary: Fyfe I. [Machine learning enables subtyping of sporadic CJD](#). *Nat Rev Neurol.* 2021; 17:64.)
2. Luk CC, Mathiason CK, Orrù CD, *et al.* [Creutzfeldt-Jakob disease in pregnancy: the use of modified RT-QuIC to determine infectivity in placental tissues](#). *Prion.* 2021; 15: 107-111.
3. Carta M, Aguzzi A. [Molecular foundations of prion strain diversity](#). *Curr Opin Neurobiol.* 2021; 72: 22-31.
4. Young MJ, O'Hare M, Matiello M, Schmähmann JD. [Creutzfeldt-Jakob disease in a man with COVID-19: SARS-CoV-2-accelerated neurodegeneration?](#) *Brain Behav. Immun.* 2020; 89: 601–603.
5. Ciolac D, Racila R, Duarte C, *et al.* [Clinical and Radiological Deterioration in a Case of Creutzfeldt–Jakob Disease following SARS-CoV-2 Infection: Hints to Accelerated Age-Dependent Neurodegeneration](#). *Biomedicines* 2021; 9: 1730.

Report on CJD in Foreign and Commercial GH Recipients

Dr. Schonberger reported one new 2021 case from France (bringing the French total to 123 for hGH-related cases). The reported incubation period for this case was 36 years. This brings the total to 216 foreign cases.

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