

PUBLIC HEALTH SERVICE

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

November 22, 2022, 2:00 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. Erica Bizzell, NIDDK
Ms. Leslie Curtis, NIDDK
Dr. Gregory Germino, NIDDK
Dr. Ryan Maddox, CDC
Dr. B. Tibor Roberts, NIDDK
Dr. Robert Tilghman, NIDDK
Ms. Alyssa Voss, NIDDK

Westat Contract

Dr. Leschek reported that Westat is in the final year of the current 5-year contract. The contract is up for competitive renewal.

National Hormone and Pituitary Program (NHPP) Cohort Update

Dr. Leschek reported that there have been no additional confirmed cases of CJD within the cohort since the 2021 meeting, and there are no new clinically suspicious cases. The total number of official cases (*i.e.*, clinically or neuropathologically confirmed) remains at 35.

There is still one case under investigation, that of a person who died in their mid-60s from dementia in 2018 (first described in the [2021 meeting summary](#)). No autopsy was performed, and Dr. Leschek is working with the CDC to obtain more information.

Suicide Rates in Cohort

Dr. Leschek discussed the results of analyses of the rates of suicide in the cohort. While the overall rate of suicide in the cohort is higher than that of the general population, the difference is not statistically significant. Dr. Leschek and Dr. Joseph Abrams (CDC) are continuing to analyze the data to determine if there is a subpopulation of the cohort (*e.g.*, people within a certain age group) that could have a significantly higher rate of suicide than a comparable subgroup in the general population.

Update on Amyotrophic Lateral Sclerosis (ALS) Cases in Cohort

Dr. Leschek stated that she and Dr. Nath reviewed all deaths in the cohort that could potentially have been ALS-related, even if they were not recorded as such. No cases were found that would add to the four cases reported in the literature and discussed at the [2018 meeting](#).

Updates on Fact Sheet and Public Inquiries

Ms. Curtis stated that the fact sheet was updated to reflect the new foreign case of CJD in a recipient of pituitary hGH that was reported in the 2021 meeting. Scientific papers discussed at the 2021 meeting were added to the resource list. For reference, the [comprehensive fact sheet is here](#), and the [resource list is here](#).

Ms. Curtis also reported that there were 12 inquiries regarding hGH and CJD over the past year, compared to 16 the year before. Ten were from confirmed cohort members. None of the inquiries were suggestive of potential new cases of CJD.

Recent Progress in CJD Research

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

1. Banerjee G, Samra K, Adams ME, *et al.* [Iatrogenic cerebral amyloid angiopathy: an emerging clinical phenomenon](#). *J Neurol Neurosurg Psychiatry*. 2022; 93:693-700.
2. Mead S, Khalili-Shirazi A, Potter C, *et al.* [Prion protein monoclonal antibody \(PRN100\) therapy for Creutzfeldt–Jakob disease: evaluation of a first-in-human treatment programme](#). *The Lancet Neurol*. 2022; 21:342-354.
3. Kim Y, Jeong B. [Creutzfeldt-Jakob disease incidence, South Korea, 2001–2019](#). *Emerg. Infect Dis*. 2022; 28:1863-1866.
4. Zerr I. [Laboratory diagnosis of Creutzfeldt–Jakob disease](#). *N Engl J Med*. 2022; 386:1345-1350.

Report on CJD in Foreign and Commercial Growth Hormone Recipients

Dr. Schonberger reported that there are no new foreign cases of CJD in recipients of growth hormone. The total number of foreign cases remains at 216.

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