

PUBLIC HEALTH SERVICE

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

March 2, 2026, 10:30 am

- Virtual Meeting -

Hosted by the National Institutes of Health Bethesda, Maryland

Committee Members Attending

Dr. William Cefalu, NIDDK

Dr. Gregory Germino, NIDDK

Dr. Ellen Leschek, NIDDK

Dr. Ryan Maddox, CDC

Dr. James Mills, NICHD

Dr. Avindra Nath, NINDS

Dr. Griffin Rodgers, NIDDK, Chair

Also Attending

Dr. Joseph Abrams, CDC

Westat Contract

Dr. Leschek reported that in July 2025, Westat started the third option year of their current 5-year contract to support the Committee's work. This will be the final full contract year. It is possible that the first 2-3 months of year 4 will be optioned to complete close-out of the project. Following that, the contract will be terminated.

National Hormone and Pituitary Program (NHPP) Cohort Update

Dr. Leschek reported that no new CJD cases have been confirmed since the 2024 meeting. Therefore, the total number of official cases (*i.e.*, those either neuropathologically or clinically confirmed) is still 36.

Dr. Leschek mentioned 3 cases under investigation. These cohort members had neurological issues at the time of death that did not seem to be fully explained by other known diagnoses. For all three, information could not be obtained through next of kin, so Dr. Maddox is working on getting additional information from the states in which the deaths occurred. One of the 3 cases was exclusively treated with post-1977 NHPP hGH, making CJD an unlikely diagnosis. Dr. Maddox stated that based on the information we already have, none of the 3 cases is suggestive of CJD.

Potential Link Between Alzheimer's Disease and Pituitary hGH

In response to a [published claim](#) from the UK that there have been 8 cases of transmitted Alzheimer's disease (AD) in their ~1848-person cadaveric hGH cohort (which also had a much higher rate of CJD transmission than the US cohort), Dr. Nath,

Dr. Leschek, and 3 Alzheimer's experts expressed skepticism that the published data establish clear evidence for Alzheimer's and [published a commentary](#) to this effect.

Of the ~1,485 NHPP cohort deaths to date, 4 included AD as a cause of death on the death certificate. Three are suspicious for AD, while AD is highly unlikely for the fourth case. According to Dr. Abrams, 4 cases of AD (our official number of cases as coded on death certificates) among the NHPP deaths is consistent with what would be expected in the general population. There are also 2 known living cohort members with a clinical diagnosis of AD. Dr. Nath has evaluated both and believes that they have familial forms of AD.

Six additional death certificates list unspecified dementia as a cause of death. Of these, 3 are under consideration as suspicious for CJD (referenced above) and/or AD (1 was treated exclusively post-1977), 2 are possible cases of AD, and 1 is unlikely to be AD. Dr. Maddox is working on getting additional information from the states in which the deaths occurred. Once we have gathered the available information, we will adjudicate each of these cases.

Updates on Fact Sheet and Public Inquiries

The fact sheet will be updated to reflect current information and new scientific papers and resources. For reference, the [comprehensive fact sheet is here](#). The fact sheet will remain active and will be updated as needed.

Dr. Leschek is currently fielding all NHPP inquiries. The only queries over the past year relate to the 2 living cohort members with possible AD. Dr. Leschek's contact information will remain on the fact sheet as the primary point of contact.

Report on CJD in Foreign and Commercial Growth Hormone Recipients

Dr. Maddox reported that there are no new international iCJD cases associated with pituitary hGH treatment. The total number of foreign cases remains at 217.

Recent Progress in CJD Research

Drs. Maddox and Nath noted one preprint about the E200K mutation that is associated with familial CJD. This manuscript has not yet been peer reviewed/published, so we will not include it on the fact sheet at this time.

Drs. Maddox and Nath pointed out that there are currently many clinical trials targeting various stages of CJD, including many utilizing gene therapy. This information can be found at [CJD \(Creutzfeldt Jakob Disease\) | ClinicalTrials.gov](#). This information will be added to the fact sheet.

Interagency Coordinating Committee Plans

After the final cohort data set is closed, a subset of Committee members (Drs. Leschek, Mills, Maddox, Abrams, and possibly Schonberger [a past, longstanding Committee member]) will write a manuscript comprehensively describing the NHPP cohort and advances made over the 41 years of study and follow-up.

Once Dr. Maddox has obtained as much information about the pending possible CJD and AD cases, adjudication will occur and a subgroup of the Committee will prepare a manuscript describing the NHPP's experience with AD. To date, there is no evidence suggesting an increase in AD in the NHPP cohort compared to the general population or implicating transmission of AD in the NHPP cohort.

The Committee will remain intact and will meet again in Fall 2026. There is no longer a representative from the FDA on the Committee, as the most recent FDA member left the agency and will not be replaced on the Committee since the project will be ending between June and September 2026.

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