

PUBLIC HEALTH SERVICE
Interagency Coordinating Committee on
Human Growth Hormone and Creutzfeldt-Jakob Disease (CJD)

September 23, 2026, 4 pm

- Virtual Meeting -

Hosted by the National Institutes of Health Bethesda, Maryland

Committee Members in Attendance

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 the Westat contract was officially terminated as of June 30, 2026, the final day of contract option year 3. Westat completed all assigned tasks within budget by this date, including digitization of (1) key historical documents, (2) CJD case records, and (3) records for possible cases of Alzheimer's disease. Digitized records were transferred to Dr. Avindra Nath, and spreadsheets containing key cohort data were sent to Dr. Ellen Leschek.

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 (those either neuropathologically or clinically confirmed) is still 36.

Potential Link Between Alzheimer's Disease and Pituitary hGH

In response to a 2024 [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 AD experts expressed skepticism that the published data establish clear evidence for AD and [published a commentary](#) to this effect. The UK group subsequently [published a report](#) of 4 additional cases in 2026.

Of the ~1,485 NHPP cohort deaths identified when surveillance was discontinued in late 2025, 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. 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. Based on supplementary information obtained, 3 are not consistent with AD, and AD cannot be ruled out (or confirmed) in the other 3.

Based on this information, Drs. Maddox and Abrams will analyze data for preparation of a manuscript describing the NHPP's experience with AD.

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. Questions during the past 6 months (since the Committee's last meeting) came from individuals believing they may have received growth hormone through the National Hormone Pituitary Program (NHPP). They contacted the NIH to determine whether they were members of the cohort. Dr. Leschek spoke to each of these individuals. All but one were not members of the cohort. After communicating with each, it was determined that some had not received growth hormone but rather another hormone supplement. Because the NHPP was the primary source of growth hormone between 1960 and 1985 (growth hormone rarely came from industry or another country), it was unlikely that individuals whose names did not appear in our cohort had received growth hormone. The one person confirmed to be a member of the cohort was not having any issues consistent with CJD or Alzheimer's disease. Rather, they were seeking information on how to stay updated on advances. They were given information on how to find the online fact sheet.

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 CJD cases associated with pituitary hGH treatment. The total number of foreign cases remains at 217. Drs. Maddox and Abrams will be attending the international prion conference in November and will inform the Committee if they learn of any new foreign/commercial cases.

Dr. Maddox reported that the prion center at Case Western Reserve University has been funded for next year. He also indicated that Chronic Wasting Disease (CWD) has now been observed in 37 states (Delaware has now been added).

Dr. Maddox shared that Dr. Brian Appleby, Director of the National Prion Disease Surveillance Center at Case Western Reserve University, reported 2 RT Quick-positive patients who reported that they were in the NHPP cohort. These individuals were not members of the cohort according to our records. It is possible that they were non-cohort recipients, but we have no way of confirming or refuting this.

Recent Progress in CJD Research

The following publications will be added to the *Articles from Medical Journals* resource list linked to the fact sheet:

Banerjee G, Edgren G, Zhao J et al. [Risk of transmission of amyloid \$\beta\$ pathology via transfused blood products](#). *NIH external link. Lancet*. 2026 Aug;408(10556):753-760. DOI: 10.1016/S0140-6736(26)00767-1. PMID 42624157

Hannaoui S, Pritzkow S, Jürgens-Wemheuer WM et al. [Limited transmission of cervid prions to nonhuman primates provides insights into the zoonotic potential of chronic wasting disease](#). *NIH external link. Sci Adv*. 2026 May 29;12(22)eaeb7613. DOI: 10.1126/sciadv.aeb7613. PMID 42202024 PMCID PMC13215175 Free PMC article

Banerjee G, Mok TH, Hyare H et al. [High-level Alzheimer disease neuropathological change following iatrogenic exposure](#). *NIH external link. JAMA Neurol*. 2026 May 1;83(5):435-441. DOI: 10.1001/jamaneurol.2026.0437. PMID 41910964 PMCID PMD13036638 Free PMC article

The following information will be added to the *General Information* resource list linked to the fact sheet:

[Study – PrProfile: A Study to Assess the Safety, Tolerability of Pharmacokinetics and Pharmacodynamics of ION717 – a first-in-human study involving intrathecal delivery of ION 717 \(Ionis Pharmaceuticals, Inc.\) in individuals with prion disease.](#)

Interagency Coordinating Committee Plans

A subset of Committee members (Drs. Leschek, Mills, Maddox, Abrams, and Schonberger [a past, longstanding Committee member]), along with Dr. Brian Appleby from the National Prion Disease Pathology Surveillance Center at Case Western Reserve University), are drafting a manuscript describing the CJD outbreak associated with NHPP growth hormone and projecting the potential number of future cases.

Drs. Maddox and Abrams will analyze data for preparation of a manuscript describing the NHPP's experience with AD. It does not appear that there is 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 2027. 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 surveillance portion of the project has ended.

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