

WESTAT

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MEMORANDUM

TO: Judith Fradkin, M.D.
FROM: Janet Bykoski
SUBJECT: HGH Followup Study Progress Report

October 11, 2001

Attached is the quarterly progress report showing the status of the death followup activities. The next report will be in January 2002.

Please let me know if you have any questions.

cc:

Co-Project Officers:

Dr. Mills, NICHD
Dr. Schonberger, CDC
Dr. Wysowski, FDA

Westat:

Mr. Durako
Ms. Camarca, M.P.H.

**HGH FOLLOWUP STUDY
PROGRESS REPORT
10/11/01**

| | |
|---|----------|
| Original Cohort of NHPP HGH Recipients..... | 6284 |
| Duplicates | 10 |
| Removed from Cohort (did not receive NHPP hormone)..... | <u>2</u> |
| Current Cohort..... | 6272 |
| Non-CJD Deaths Published (2/91) | 254 |

New Deaths Since Publication:

| | |
|---|------------|
| Reported by family, DC received..... | 49 |
| Reported by physician, DC received..... | 1 |
| Reported from cohort mailing, DC received..... | 26 |
| Reported from NDI, DC received | <u>185</u> |
| Total Confirmed New Deaths Since Publication | 261 |

Total Confirmed Deaths **515

Status of Medical Records for deaths since publication (N=261)

| | |
|--|------------|
| Medical records only obtained | 113 |
| Treatment and medical records only obtained..... | 32 |
| Treatment only records obtained | 22 |
| Medical records requests in progress | 4 |
| Medical records not obtained..... | 90 |
| Records could/would not be released from hospital..... | 3 |
| No authorization for release received..... | 87 |
| Medical records obtained in year prior to death | 94 |

** This total does not include confirmed CJD deaths.

Authorizations for release of Medical Records

| | |
|---|-----|
| Total Authorizations Obtained | 144 |
| Total Authorizations not Obtained | 117 |
| Parent/Relative refused to sign..... | 45 |
| Parent/Relative unlocatable | 28 |
| Parent/Relative not found except on death certificate | 4 |
| Parent/Relative specified no contact at time of interview | 4 |
| Parent/Relative did not comply despite JF contacts | 19 |
| Family being traced | 1 |
| Request in progress, but not yet received | 15 |
| No living relatives..... | 1 |
| | |
| Status of New Deaths Since Publication: | 261 |
| Reviewed and closed out by Dr. Fradkin..... | 238 |
| Waiting for medical records | 4 |
| Waiting to receive authorizations from parents | 15 |
| Ready for Dr. Fradkin's first review..... | 1 |
| Ready for Dr. Fradkin's re-review | 3 |
| | |
| Dr. Fradkin Recommended NRG Review: | 79 |
| NRG reviews completed | 79 |
| | |
| Total Autopsies: | 101 |
| Autopsies with known brain slides | 43 |
| Retrievable slides received..... | 38 |
| Retrievable slide reviews completed..... | 38 |

| | |
|--------------------------------------|-----------|
| Confirmed CJD Cases | 22 |
| CJD Cases In Cohort | 17 |
| CJD Cases Not In Cohort | 5 |