

MEMORANDUM TO SENATOR DOLE

DA: February 16, 1995

FR: Alec Vachon

RE: FOLLOW UP TO MEETING WITH ARTHUR ULLIAN

- * You sent me Arthur's follow up letter to his meeting/photo with you on February 3d (attached). He will be at your Boston fundraiser on February 17th.
- * Ullian is a smart, fascinating guy--his personal passion is to walk again--having injured his spine in a 1991 bicycle accident. Although this would seem a commonsense attitude for anyone with a disability, rarely the focus of lobbying or advocacy.
- * Ullian believes biomedical science is on the verge of breakthroughs in preventing or treating many common neurological disorders, e.g., strokes, spinal cord injuries, cerebral palsy. Potential for huge savings--both in medical costs and related costs (disability payments, etc.).
BACKGROUND MATERIALS ATTACHED.
- * Lastly, he believes the long-term solution to controlling health and disability costs is medical research. Certainly, in the long term this view is correct--disability and disease are ultimately problems of fixing damaged tissue. However, in the short term, many new procedures save lives--but at the price of disability and continuing expensive care. Now looking into numbers.
- * As you may recall, you suggested to Ullian this might be a suitable topic for a Finance Committee hearing when the Committee resumes health care reform hearings in the Spring.
- * Ullian has also invited you to speak at the annual dinner of the National Campaign to End Neurological Disorders in Boston on May 22nd.

Original → Briefing Book

cc: Dan -
Sheila -
Vicki -

Vicki Mec



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February 8, 1995

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Handwritten signature and mark

Dear Senator Dole:

Thank you for meeting with me last Friday, February 3. I appreciate the time that you spent with me.

I have been reading Goodwin's book on Roosevelt. In it, Eleanor Roosevelt is quoted as saying with regard to her husband's affliction, that FDR gained a tremendous amount of compassion and patience. I can see the same qualities in you and I know that you understand, more fully than others, the kind of suffering persons with paralyzing disorders experience. There is such promise in the science today that could relieve this condition for so many people, that it would only make good sense to encourage this research by increasing it's funding.

Unfortunately, because funding for neurological research has been relatively constant over the past few years, none of the new promising scientific discoveries have been able to be tested. According to a recent article in the New England Journal of Medicine, a two year study done at William and Mary College found that rats, which had spinal cord injuries and were treated with an experimental drug, regained motor function and walked. Without focusing our attention on these new discoveries in the area of neurological research, including Alzheimer's, Parkinson's and spinal cord injury, only the rats will be walking.

As I mentioned during our meeting, it is clear from the experience foreign countries have had, in their attempt to control the rising costs of medical care without success, that the only way to truly get to the underlying costs is to get at the illness. Therefore, it is imperative that this research be funded, for the economic health of the country, as well as the health of many Americans afflicted with neurological diseases.

I look forward to seeing you in Boston with Herb on the 17th of February. Thank you again for your attention in this matter.

Most sincerely,
Arthur Ullian
Arthur Ullian
Chairman

NUMBERS AND COSTS

An estimated **50 million Americans** suffer from neurological disorders, which are diseases and injuries of the brain and spinal cord.

- **Alzheimer's** -- 4 million Americans -- \$100 billion/year
- **Stroke** -- 2 million Americans -- \$30 billion/year
- **Head injury** -- 100,000 people/year -- \$25 billion/year
- **Cerebral palsy, learning disabilities and mental retardation** -- \$30 billion/year
- **Epilepsy** -- 2.5 million Americans -- \$9 billion/year
- **Parkinson's** -- 500,000 Americans -- \$5.6 billion/year
- **Multiple sclerosis** -- 300,000 Americans -- \$2.5 billion/year
- **Spinal cord injury** -- 200,000 Americans -- \$6 billion/year
- **The effects of drug and alcohol abuse on the brain** -- \$160 billion/year

GOALS ACHIEVABLE BY THE END OF THE DECADE

Source: The National Advisory Council of the NINDS

- Prevention of 80% of strokes
- Effective therapies for brain and spinal cord injuries
- Genetic treatments for Tay-Sach's and Huntington's disease
- Amelioration of progressive dementias including Alzheimer's and cerebrovascular disease
- Treatments that prevent or reverse neurological loss in Parkinson's disease and Multiple Sclerosis
- Treatments protecting the brain threatened by alcohol and substance abuse
- Relief of chronic pain
- New approaches to life saving therapy for brain tumors in children and adults
- Development of new drugs to reduce spasticity, dystonia, and abnormal movements for persons with Cerebral Palsy and other degenerative diseases
- A new, more effective generation of anti-epileptic medicines

THE FOLLOWING EXAMPLES ILLUSTRATE HOW RESEARCH CAN DIRECTLY CUT COSTS AND HELP PEOPLE:

TRAUMA (stroke, spinal cord injury, traumatic brain injury)

EXAMPLES:

STROKE:

Numbers: 2 million Americans

Cost: \$30 billion/year (direct and indirect)

SPINAL CORD INJURY:

Numbers: 200,000 Americans

Cost: \$6 billion/year (direct and indirect)

Research: Research in neuroprotective drugs and powerful "clot busters", some now in clinical trials, will significantly decrease paralysis and ensuing disability for *stroke*, *spinal cord injury*, and other trauma survivors. 80% of stroke will be eliminated within 5-7 years with sufficiently funded research to find these neuroprotective drugs.

Savings: If you eliminate the paralysis from the disorder, you eliminate the majority of the \$36 billion just in these disorders.

Even partial treatments will produce immediate savings. For instance, many people with spinal cord injury have paralyzed bladders and must catheterize themselves several times daily. A sterile catheterization kit costs about \$8. If we assume very conservatively that half of about the 220,000 spinal-injured people in the country use two kits daily, the bill comes to \$5840 per person or \$642 million per year. One effective treatment for one problem in one disease can return the Federal government investment in all of neurological research. Incidentally, the budget of the National Institute of Neurological Disorders and Stroke at NIH is \$642 million this year.

DEGENERATIVE DISORDERS (Parkinson's, Alzheimer's, ALS, Multiple Sclerosis etc.)

EXAMPLE:

ALZHEIMER'S:

Numbers: 4 million Americans

Cost: \$100 billion/year in direct and indirect costs

Research: The discovery of the protein *beta amyloid* which in excess causes brain cell death has led scientists to develop a simple test to block excess production of the protein. With additional funding many more strategies to find the blocker drug can be tested leading to early treatments.

Savings: This drug, when found, will slow down the progression of Alzheimer's by 1/3--leading to shortened nursing home stays and a savings of over \$20 billion annually.

The New York Times

Founded in 1851

ADOLPH S. OCHS, Publisher 1896-1935
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Paying for Medical Research Cuts Health Costs

To the Editor:

The newly unveiled health care plan of Senator Edward M. Kennedy (front page, May 10), in addition to insuring small business protection and broadening individual choice of insurance, recognizes how uncured illness underlies health care costs.

Symptomatic relief and control are the most expensive stages in disease treatment, and many of today's most prevalent diseases are merely controlled, not eliminated. In other words, halfway technology has brought us to a point in history in which people with devastating illnesses and injuries live for years with no hope of cure. Mr. Kennedy's adoption of the Harkin-Hatfield plan in his proposal — to add \$7.5 billion over five years to Federal funds for biomedical research — will lead to finding cures, thus reducing health care expenditures, which would otherwise keep skyrocketing.

In neurological disorders alone, which make up the bulk of long-term care costs, increases in funds for research will save billions annually. Neurological disorders include degenerative diseases — Alzheimer's, Parkinson's, multiple sclerosis, stroke and cerebral palsy — and the traumatic conditions of spinal cord and brain injury. This country spends more than \$400 billion a year in direct and indirect costs to maintain its neurological patient population.

Neuroscience holds great promise for finding treatments and cures for many of these disorders. For instance, scientists are confident that with sufficient funds, they could eliminate 80 percent of stroke in 5 to 10 years. It costs the country \$25 billion a year to support stroke survivors; partial prevention of stroke would effectively pay back the \$7.5 billion invested in all biomedical research.

The Kennedy proposal is the first to understand that medical research is inherent to cutting health care costs. Only by cutting health care costs will we truly be able to afford universal coverage.

ARTHUR ULLIAN
Acting Chairman, Natl. Campaign
to End Neurological Disorders
Boston, May 16, 1994