Withdrawal/Redaction Sheet
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	David Axelrod to Noa Meyers re: Vinettes (4 pages)	01/11/1999	b(6)
002. fax	Constituent to Neera Tenden re: personal story (2 pages)	01/08/1999	b(6)
003. paper	re: personal story (1 page)	01/11/1999	b(6)
004. email	Carol Beach to Christine Macy [partial] (2 pages)	01/11/1999	b(6)
005. fax	Constituent to Neera Tanden re: short story about my daughter with epilepsy (1 page)	01/07/1999	b(6)
006. paper	re: epilepsy personal story (1 page)	01/11/1999	b(6)
007. letter	Constituent to Hillary Rodham Clinton (1 page)	01/11/1999	b(6)
008. fax	From Cure re: personal story (1 page)	01/11/1999	b(6)

COLLECTION:
Clinton Presidential Records
First Lady's Office
Christine Macy
OA/Box Number: 17209

FOLDER TITLE:
Epilepsy/HRC

Racheal Carter
2013-0936-S
rc1345

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
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P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
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C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

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Files of Christine Macy, Senior Speechwriter to the First Lady
Box 7: Files
Archived from OEOB 100 by Caroline Marvin on July 18, 2000

- VFT
- HRC/Native Americans Background
- HRC/Native Americans Speeches
- NYC Schools/HRC
- After School/HRC
  - YD/A/V
- Al Shanker/Background
- HRC/Health/Medicine
  - Health Reform
- CHIP
  - Children's Health
- Long Term Care
  - Health Reform
- Asthma
  - Health Reform
- HRC/Epilepsy
  - Health Reform
- First Ladies' Library
  - Millennium
- Microenterprise
  - Microenterprise
- Family Agenda 1999
- Littleton/School Violence
  - YD/A/V
- Education/Background
- Arts and Humanities
  - Arts
- Colon Cancer/Breast Cancer
  - Breast Cancer
  - Health Reform
- Education
- HRC/Labor
  - CS/DB
- School Violence/Speeches/Columns
  - YD/A/V
- Asthma
  - Health Reform
- Adoption
  - Adoption
- Speeches/Harvard/Medical
  - Health Reform

- HRC/Women
- Girls' Education
  - Education
- Madeira
  - Women and Girls Education
- HRC Speeches—Child Care
  - Child Care
- Early Childhood Development
  - Early Childhood Development

FIRST LADY HILLARY RODHAM CLINTON

RUSH EPILEPSY CENTER

RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER

CHICAGO, ILLINOIS

JANUARY 13, 1999

THANK YOU, LEE ANN, FOR TELLING US YOUR STORY. THANK YOU EVEN MORE FOR YOUR COURAGE AND DETERMINATION IN THE FACE OF SUCH HEARTBREAK. MUCH MORE ATTENTION NEEDS TO BE PAID TO WHAT YOU -- AND THOSE WHO I HAVE JUST MET WITH -- HAVE TO SAY ABOUT THE EXTRAORDINARY CHALLENGES FACING EPILEPSY PATIENTS AND THEIR FAMILIES EVERY DAY. I HOPE THAT WHAT WE DO HERE TODAY WILL HELP SHINE THE NATIONAL SPOTLIGHT ON EPILEPSY IN ALL OF ITS FORMS -- AND SPUR US ALL TO REDOUBLE OUR EFFORTS TO END THE SUFFERING AND FIND A CURE.

I'M VERY PLEASED TO BE HERE AT CHICAGO'S RUSH-PRESBYTERIAN- ST. LUKE'S MEDICAL CENTER -- AND TO HAVE HAD THE OPPORTUNITY TO TOUR THIS HIGHLY ACCLAIMED EPILEPSY CENTER.

THE PROGRESS BEING MADE HERE IS A TRIBUTE TO THE TIRELESS EFFORTS OF ALL OF YOU: DR. HENIKOFF (DIRECTOR OF THE MEDICAL CENTER); DR. SMITH (DIRECTOR OF THE EPILEPSY CENTER); DEDICATED STAFF; PATIENTS; AND FAMILY MEMBERS. THANK YOU FOR WHAT YOU DO, EVERY SINGLE DAY, TO GIVE PEOPLE WITH EPILEPSY THE CARE AND UNDERSTANDING THEY NEED AND DESERVE.

IT'S ALSO A PRIVILEGE TO JOIN JEANE CARPINTER FOR TODAY'S EVENT. HER PERSONAL COURAGE AND PUBLIC ADVOCACY IS AN INSPIRATION TO US ALL.

WE'VE COME TOGETHER TO DEDICATE THIS CENTER IN THE MEMORY OF THE REMARKABLE MAN WHO FOUNDED IT MORE THAN 25 YEARS AGO. A BRILLIANT SCIENTIST AND A COMPASSIONATE HUMAN BEING, DR. FRANK MORRELL COMBINED QUALITIES NOT OFTEN FOUND IN A SINGLE INDIVIDUAL. AND IN THE PROCESS — HE TRANSFORMED THE WAY WE TREAT AND CARE FOR THOSE WITH EPILEPSY. THANK YOU FOR INVITING ME TO JOIN YOU ON THIS SPECIAL OCCASION.

ALL OF YOU HERE KNOW FIRSTHAND HOW DRAMATICALLY EPILEPSY CAN CHANGE PEOPLE'S LIVES -- OFTEN OVERNIGHT -- AND HOW WIDELY IT AFFECTS FAMILIES AND COMMUNITIES HERE AND ACROSS THE COUNTRY. YET OUTSIDE THESE WALLS, THERE REMAINS ENORMOUS IGNORANCE ABOUT THIS CONDITION.

MOST PEOPLE DON'T UNDERSTAND THE TERRIBLE IMPACT OF EPILEPSY ON CHILDREN -- WHOSE SEIZURES PRODUCE DEVELOPMENTAL DELAYS AND BRAIN DAMAGE THAT CAN LEAD TO A LIFETIME OF DEPENDENCE, LONELINESS, AND UNFULFILLED DREAMS. MOST PEOPLE CAN'T SEE THE HEARTBREAK, OR HEAR THE WHISPERED PRAYERS OF PARENTS WHO WATCH THEIR CHILDREN SUFFER. MOST PEOPLE DON'T KNOW ABOUT THE SEEMINGLY ENDLESS ARRAY OF DRUGS; HOSPITAL TRIPS; CAT SCANS AND BLOOD TESTS; TREATMENTS AND SURGERIES THAT MANY PATIENTS MUST ENDURE. AND THEY ARE UNAWARE OF THE TERRIBLE TOLL THIS CONDITION TAKES ON ADULTS -- AND THEIR ABILITY TO GET OR KEEP A JOB; DRIVE A CAR; MAINTAIN RELATIONSHIPS; OR HAVE A POSITIVE SELF IMAGE.

I CAN ONLY IMAGINE HOW DIFFICULT IT MUST BE TO LIVE WITH THOSE ENDLESS "WHAT IF'S": WHAT IF I GET A SEIZURE WHEN I'M CROSSING THE STREET, OR COOKING FOR MY FAMILY, OR HOLDING MY CHILD IN MY ARMS? AND WHILE MOST PEOPLE WITH EPILEPSY CAN CONTROL THEIR SEIZURES -- THEY MUST LIVE WITH SOMETHING THEY CAN'T CONTROL: THE CRUEL SOCIAL STIGMA THAT COMES WITH WIDESPREAD IGNORANCE OF THIS DISORDER. IT CAN DAMAGE THE SPIRIT AS MUCH AS THE SEIZURES THEMSELVES — AND WE MUST DO ALL WE CAN TO END IT.

CLEARLY WE MUST DO A FAR BETTER JOB OF EDUCATING THE PUBLIC ABOUT THE EXTENT OF THE PROBLEM OF EPILEPSY IN AMERICA.

TODAY, I'M RELEASING A NEW STUDY -- SPONSORED BY THE EPILEPSY FOUNDATION OF AMERICA -- AIMED AT HEIGHTENING THAT PUBLIC AWARENESS. "EPILEPSY: A REPORT TO THE NATION" CONFIRMS THAT EPILEPSY AND SEIZURES AFFECT 2.3 MILLION AMERICANS — AT A STAGGERING COST TO FAMILIES AND COMMUNITIES OF $12.5 BILLION A YEAR.

IT ALSO REPORTS THAT 181,000 NEW CASES OF SEIZURES AND EPILEPSY OCCUR ANNUALLY — AND THAT 10% OF THE AMERICAN POPULATION WILL EXPERIENCE A SEIZURE DURING THEIR LIFETIMES.

WE HOPE THIS STUDY WILL GO A LONG WAY TOWARD EDUCATING PEOPLE ABOUT THE EFFECTS OF EPILEPSY ON PEOPLE OF ALL AGES, AND WILL HELP DISPEL THE MISINFORMATION AND MISUNDERSTANDING THAT ARE OFTEN AS DEVASTATING AS THE CONDITION ITSELF. THE REPORT ALSO TELLS US THAT WE NEED TO DO MORE — MUCH MORE — TO FIND A CURE.

THAT'S WHY I'M SO PROUD OF THE UNPRECEDENTED COMMITMENT THE PRESIDENT HAS MADE TO FIGHTING EPILEPSY, AND FINDING A CURE. UNDER HIS ADMINISTRATION, FUNDING FOR EPILEPSY RESEARCH HAS GROWN DRAMATICALLY -- FROM $54 MILLION IN 1995 TO A PROJECTED $76 MILLION THIS YEAR.

TODAY -- AS A RESULT OF IMPROVED RESEARCH AND TREATMENTS, HALF A MILLION AMERICANS ARE RECEIVING MEDICAL RELIEF FROM THEIR SEIZURES, AND ARE ABLE TO LEAD NORMAL, PRODUCTIVE LIVES. ADULTS ARE RETURNING TO WORK; CHILDREN ARE ONCE AGAIN JOINING THEIR FRIENDS ON THE PLAYGROUND. AND PARENTS AND SIBLINGS ARE DARING TO IMAGINE THE DAY WHEN LIFE CAN RETURN TO NORMAL.

UNFORTUNATELY, FAR TOO MANY WHO SUFFER FROM EPILEPSY ARE STILL FORCED TO CHOOSE BETWEEN DISABLING SEIZURES, AND DEBILITATING SIDE EFFECTS.

AND WHILE SCIENCE HAS BEEN ABLE TO SOLVE MANY OF THE WORLD'S MOST COMMON DISEASES IN THIS CENTURY -- THE 350,000 AMERICANS WITH INTRACTABLE EPILEPSY SUFFER AS MUCH AS THOSE WHO HAD THIS CONDITION HUNDREDS, EVEN THOUSANDS OF YEARS AGO.

I'VE HEARD SO MANY STORIES RECENTLY OF THE PAIN, AND ANGUISH, AND YET THE ENDURING HOPE OF THOSE DEALING WITH EPILEPSY. I HEARD ABOUT MEGAN, A 4-YEAR-OLD WHO IS UNABLE TO SPEAK BECAUSE OF THE RAVAGES OF HER CONDITION. AT ONE POINT SHE HAD OVER 100 SEIZURES A DAY, AND HER MOTHER SAYS SHE'S TERRIFIED THAT WHEN HER DAUGHTER HAS ONE OF HER BIG SEIZURES, "THAT WE WON'T BE ABLE TO BRING HER BACK." HER PARENTS DREAM OF THE DAY "WHEN CHILDREN LIKE MEGAN CAN LIVE A NORMAL LIFE."

CLEARLY, WE MUST DO MORE TO MAKE THAT DREAM A REALITY FOR THE MILLIONS OF AMERICANS LIKE MEGAN AND HER PARENTS WHO SUFFER FROM EPILEPSY IN ALL OF ITS FORMS.

FIRST, WE MUST REDOUBLE OUR EFFORTS TO FIND A CURE. I'VE ALREADY MENTIONED THE DRAMATIC RISE IN FEDERAL FUNDING FOR EPILEPSY RESEARCH OVER THE PAST FEW YEARS. AND TODAY, I'M PLEASED TO ANNOUNCE THAT NEXT YEAR, THE NATIONAL INSTITUTE OF HEALTH WILL CONVENE THE FIRST EVER ADMINISTRATION CONFERENCE ON EPILEPSY. MORE THAN 150 EXPERTS FROM AROUND THE COUNTRY WILL PARTICIPATE, FOCUSING ON HOW TO BEST ALLOCATE THE UNPRECEDENTED INVESTMENT THIS ADMINISTRATION HAS MADE IN EPILEPSY RESEARCH.

SECOND, WE MUST DO MORE TO EDUCATE DOCTORS ABOUT EPILEPSY. WHEN PEOPLE WITH EPILEPSY ARE MIS-DIAGNOSED, THEIR CONDITION CONTINUES TO DEGENERATE, CAUSING INCREASINGLY SEVERE EFFECTS ON BRAIN DEVELOPMENT. TO ADDRESS THIS PROBLEM, THE CENTERS FOR DISEASE CONTROL AND THE AGENCY FOR HEALTH CARE POLICY RESEARCH ARE LAUNCHING A NEW INITIATIVE THAT WILL REACH OUT TO THOUSANDS OF DOCTORS, AND INFORM THEM ABOUT HOW TO MAKE APPROPRIATE EARLY DIAGNOSES.

THIRD, WE MUST MAKE INFORMATION ABOUT EPILEPSY MORE ACCESSIBLE, IN OUR SCHOOLS, AND DOCTOR'S OFFICES, AND IN OUR COMMUNITIES.

TODAY, I'M ALSO PLEASED TO ANNOUNCE A NEW EDUCATIONAL SOURCE. THE EPILEPSY FOUNDATION OF AMERICA AND iVILLAGE, AN INTERNET COMPANY, WILL LAUNCH AN INTERNET CHAT ROOM THAT WILL OFFER CONSUMERS, PATIENTS AND FAMILY MEMBERS A SAFE AND VALUABLE OPPORTUNITY TO ENGAGE IN LIVE DISCUSSIONS WITH EPILEPSY SPECIALISTS.

IF WE ARE GOING TO END THE ANGUISH AND SUFFERING OF THOSE WITH EPILEPSY, AND FIND A CURE, THEN ALL OF US MUST GET INVOLVED. WE'VE HEARD TODAY ABOUT SOME OF THE NEW STEPS BEING TAKEN BY THE GOVERNMENT, BUSINESS, AND THE NON PROFIT SECTOR.

TONIGHT, I WILL BE ATTENDING A FUND RAISER FOR CURE -- AN ADVOCACY GROUP THAT HAS JUST BEEN FOUNDED HERE IN CHICAGO TO RAISE MONEY FOR EPILEPSY RESEARCH.

SO WHETHER WE'RE INVOLVED IN RAISING PRIVATE FUNDS, LOBBYING FOR MORE PUBLIC SUPPORT; OR HELPING TO EDUCATE OUR FRIENDS AND NEIGHBORS -- WE CAN ALL HELP BRING THE DAY CLOSER WHEN THERE IS NO MORE IGNORANCE, AND NO MORE SUFFERING. THE DAY WHEN WE FINALLY FIND A CURE FOR EPILEPSY. WHAT BETTER WAY TO CARRY ON DR. MORRELL'S LEGACY THAN TO COMMIT OURSELVES TO FULFILLING THAT VISION OF HOPE.

THANK YOU.

Noa A. Meyer 01/13/99 08:28:17 AM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:
Subject: HRC column 1/13/99

TALKING IT OVER

BY HILLARY RODHAM CLINTON

RELEASE: WEDNESDAY, JANUARY 13, 1999, AND THEREAFTER

Not long ago, I had the opportunity to catch up with an old friend from Chicago. In the course of the conversation, he told me about his daughter, Lauren. Although Lauren was a happy, healthy baby at birth, she began to have seizures at the age of 7 months. Seventeen years later, the seizures continue, the cause has never been identified, and Lauren's development has been irrevocably delayed. She will never live independently and will require lifelong supervision and support. As her father spoke, I could see and hear the devastating impact Lauren's epilepsy has had, not only on her own life but also on her entire family.

When I heard Lauren's story, I was determined to learn more about this condition and bolster this administration's efforts to improve treatment and find a cure.

Nearly 200,000 Americans are diagnosed with epilepsy each year. Current treatments control symptoms in most of their cases. Yet the word epilepsy still provokes profound fear and misunderstanding.

Epilepsy is a chronic brain disorder characterized by spontaneous, recurrent seizures that range from brief lapses in attention to prolonged losses of consciousness with convulsions. It affects more than 2 million Americans -- one out of every 100. Of these, 300,000 are children.

Head injuries, brain tumors, stroke, lead poisoning, genetic conditions and infectious illnesses can cause epilepsy. But in more than half of all cases -- like Lauren's -- no explanation is ever found.

According to a new report, "Epilepsy: A Report to the Nation," sponsored by the Epilepsy Foundation of America, anti-seizure drugs and other forms of treatment can control or eliminate seizures in 75 percent of those affected. These people live nearly normal lives -- lives that can be both personally and professionally fulfilling. But even they never escape the uncertainty or the potential social stigma that comes out of ignorance -- a stigma that can crush the spirit as surely as the disorder debilitates the body and the brain.

Tragically, though, for the nearly 600,000 like Lauren, the disorder is intractable. Drugs, diet, surgery and other treatments just don't bring their seizures under control.

One of the most heartbreaking aspects of epilepsy is the toll it takes on children. Seizures in early childhood often produce developmental delays and

brain damage that can lead to a lifetime of dependence and extraordinary costs. Children with epilepsy are at special risk for learning problems. They fall behind in reading, language development and general knowledge. Children who have frequent seizures can't even go to school. Perhaps worst of all, they live in constant fear of their next seizure.

If these children are ever to live the normal, healthy and happy lives they deserve, we must dedicate ourselves to finding a cure now.

I'm pleased that the President's budget for this year includes a 14 percent expansion for the National Institutes of Health, the largest funding increase ever. Of this, an unprecedented $76 million is for epilepsy research alone. But we must still do more.

This week, I'll be in Chicago for the dedication of a new epilepsy center at Rush Presbyterian-St. Luke's Hospital and a major nationwide fund-raiser for epilepsy research. There, I'll release the Epilepsy Foundation's report and talk about the administration's next steps in the effort to eliminate the disorder.

Next year, NIH researchers will convene the first-ever administration conference on epilepsy, bringing together more than 150 experts and members of the public focused on finding a cure. In addition, the Centers for Disease Control and the Agency for Health Care Policy Research together will launch a campaign to educate medical practitioners about the critical need for early and accurate diagnosis.

I have heard from many families around the country who have been touched by epilepsy. Some share the pain of lives destroyed and promising futures extinguished. Others marvel at the seemingly miraculous -- when drugs, surgery or diet actually bring an end to the nightmare.

But the message is the same: More research dollars are critical if we are to devise innovative, safe and effective treatments or find a cure. No one has said it better than the parents of 12-year-old Philip Gattone, whose seizures ceased following a combination of successful surgery and drug therapy. They wrote:

"Today, Philip plays sports, participates in school activities and clubs, and loves learning. He has friends that care about him. He is our hero.

"There are so many children that need help. The fight for a cure is a daily battle, and it is real. It is a fight that must be won. Only research and new treatments will help these special families achieve their dreams of recovery from epilepsy."

* * *

For more information on epilepsy, visit the Epilepsy Foundation of America at www.efa.org.

To find out more about Hillary Rodham Clinton and read her past columns, visit the Creators Syndicate web page at www.creators.com.

Message Sent To: _____

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rc1345

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OA/Box Number: 17209

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"Carol M. Beach" <cmbeach @ email.msn.com>
01/11/99 06:09:48 PM

Record Type: Record

To: Christine N. Macy/WHO/EOP

cc:
Subject: A little uninspired prose:

Draft #1
FIRST LADY HILLARY RODHAM CLINTON
TALKING IT OVER /CREATORS SYNDICATE
COLUMN FOR PUBLICATION JANUARY 12, 1999

Let me share a letter I received recently:

[004]

(b)(6) I am 15 years old and I have epilepsy. I began having seizures in 1992 when I was 8 years old. In November of 1992 I had brain surgery to try to control the seizures.

I still have seizures almost every day. I don t go to school because my seizures make me fall down and I can get hurt. I have a tutor. Sometimes I miss being with the other kids. The hardest part of having seizures is that I don t know when they will happen. Sometimes I get really sad because having epilepsy is difficult.

Everyday I hope that the doctors and scientists will come up with a cure for epilepsy. There are many kids who have seizures and who really need help. A lot of people don t understand how serious epilepsy is. I hope that someday more people will understand.

I am so grateful to (b)(6) for sending me this letter, because he s so right a lot of people don t understand how serious epilepsy is.

Epilepsy is a chronic brain disorder characterized by spontaneous, recurrent seizures that range from brief lapses in attention to prolonged losses of consciousness with convulsions.

Epilepsy affects more than two million Americans of all ages. Of these, 300,000 are children. Approximately 181,000 new cases occur each year.

Head injuries, brain tumors, stroke, lead poisoning, genetic conditions and infectious illnesses can all cause epilepsy. But in more than half of all cases, no cause can be found.

For many people, antiseizure drugs and other forms of treatment can control, or even eliminate seizures and, according to the Epilepsy Foundation, these people live nearly normal, personally and professionally fulfilling lives. But for 25 percent of those affected nearly 600,000 Americans drugs, diet, surgery and other treatments have failed to bring their seizures under control.

One of the most heartbreaking aspects of epilepsy is the toll it takes on children. Seizures in early childhood often produce developmental delay and brain damage that can lead to a lifetime of dependence and extraordinary costs. Children with epilepsy are at special risk for learning problems. They fall behind in reading, language development and general knowledge. And, children like (b)(6) who have frequent seizures, can t go to school at all.

As our population ages, the incidence of epilepsy and the resulting costs to society will increase. This is because several conditions associated with aging, including stroke, cardiovascular disease, brain tumors and Alzheimer s disease, are all causes of epilepsy.

Women with epilepsy face unique problems. New research shows that the risk of seizures varies with hormonal changes and that epilepsy may result in reduced fertility. Pregnancy presents special challenges as both seizures and the drugs taken to control them may affect the developing child.

There is some evidence that the sooner a seizure disorder is diagnosed and treated, the better the chance of a positive long-term outcome. These finding underscore the urgent need for additional research into the most effective treatments and strategies.

Although surgery holds promise for some patients, the stakes are high and a number of questions remain unanswered. More research is needed to determine how best to select candidates for surgery, whether surgery is more effective earlier in the course of the disorder, and whether cognitive function and school performance will be affected.

Some children find relief from their seizures when they adhere to a strict high-fat, low-calorie, low-carbohydrate diet. But such a regimen has its own side effects and additional research is critical if we are to understand which children can be helped and why.

The President s budget for this year included an almost $2 billion, or 14 percent expansion the National Institutes of Health, the largest funding increase ever. An unprecedented ???? of this is for epilepsy research alone. Next year, researchers there will convene the first administration conference on epilepsy, bringing together more than 150 experts and members of the public to focus on how best to allocate these valuable research dollars.

I have received so many letters from children like (b)(6) and their parents. Some share the pain of lives destroyed and promising futures extinguished. Others marvel at the seemingly miraculous, when drugs, surgery or diet actually bring an end to the nightmare.

But the message is the same, and no one has said it better than the parents of 12 year-old, Philip Gattone, whose seizures ceased following a combination of successful surgery and drug therapy. They wrote:

Today, Philip plays sports, participates in school activities and clubs, and loves learning. He has friends that care about him. He is our hero.

There are so many children that need help. The fight for a cure is a daily battle, and it is real. It is a fight that must be won. Only research and new treatments will help these special families achieve their dreams of recovery from epilepsy.

(814 words)

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Fax Cover Sheet

To:	Neera Tanden	**From:**	Ann Scherer
Fax:	202-456-2878	**Pages:**	21 (including cover sheet)
Phone:	202-456-6275	**Date:**	01/06/99
Re:	Epilepsy Foundation Special Report	**CC:**	[Click **here** and type name]

☐ **Urgent** ☐ **For Review** ☐ **Please Comment** ☐ **Please Reply** ☐ **Please Recycle**

• **Comments:**

Good evening, Neera. Attached is the final draft of our Report to the Nation. We are currently putting in the footnotes and references. We will then have it printed up for distribution. Can you let us know when you will need the finished copies and how many of them are needed for the Chicago event. We look forward to getting back with you tomorrow for the conference call. If you have any questions about this report, please let me know.

You can reach me at 301-459-3700 Ext 634 (I can be paged if away from my desk) or my web address is ascherer@efa.org

Final draft – Jan 5.99

Epilepsy: A Report to the Nation

It starts when a tiny cluster of brain cells begins to emit rapid, highly rhythmic, synchronized, and repetitive electrical discharges. The malfunction may remain localized to a small area or, within seconds, like a ripple in a pond, involve the entire brain. The result is a seizure, the form of which may range from a brief staring episode or sudden drop attack to a massive, prolonged, life-threatening convulsion. In Rochester, Minnesota, a community whose health has been meticulously characterized by researchers in recent decades, 3% of the population will develop epilepsy by age 75 and 10% will experience at least 1 seizure during their lifetimes.

The phenomenon of recurrent seizures is termed epilepsy, from the Greek word *epilambanein,* meaning to seize or to attack. Epilepsy has been recognized as a unique disorder for thousands of years, and references to its symptoms occur through the ages, from Babylonian tablets to the Bible.

Today, seizures and epilepsy develop in approximately 181,000 Americans of all ages each year. Overall, more than 2 million of us have been diagnosed with epilepsy. Thanks to new antiseizure drugs and other forms of treatment which have been developed in recent decades, the control, or even elimination, of seizures has become an attainable goal in many people with epilepsy, often with minimal drug side effects. These people with epilepsy are able to live near-normal, personally and professionally fulfilling lives.

When seizures persist, however, epilepsy is once again as devastating a disorder today as it was 100 years ago – or 1,000.

For hundreds of thousands of Americans, epilepsy is an unsolved problem that affects all aspects of life and wreaks havoc on family life and employment prospects. Drug dosages may be increased in an attempt to control convulsions, but often the trade-off is unpleasant adverse effects caused by the medications themselves. Too often, the person with epilepsy may be forced to choose between living with disabling seizures—or disabling side effects.

Although intractable seizures cut across all demographic lines, the medical literature and newer findings by leading experts clearly demonstrate one cruel fact: The young bear an inordinate burden. Repeated seizures damage developing brains, and lives may be irrevocably changed. Many of the most devastating forms of epilepsy are thought to have a genetic basis; some genes have already been identified; there is an urgent need for more research in this area.

Recurring seizures (by definition, epilepsy) are an additional burden for those who live with other neurological disorders, including cerebral palsy, mental retardation, autism, Alzheimer's disease, stroke, multiple sclerosis, tuberous sclerosis and a whole variety of genetic syndromes. Typically, seizures accompanying other neurological deficits are also more difficult to treat.

While children are deeply affected by severe and recurring seizures, adults face unique risks themselves. Just a single episode in an otherwise healthy adult can have extraordinarily serious ramifications on employment, driving privileges, social interactions, self-image, and an uncertain future. Anxiety grips even people whose seizures are currently well-controlled with antiepileptic medication. For them, ancient fears and stigmas, which should have no place in our world, cast long shadows nonetheless.

The gains made against seizure disorders in recent years have been important ones, but we are very far from complacency. We've reached a point at which our nation must go on the offensive against this devastating, pervasive disorder by:

- Making the cure of intractable seizures and all forms of epilepsy a research priority.
- Ensuring access to specialized care for all people with epilepsy who need it.
- Educating the public so that seizure-related stigma and discrimination are eliminated.
- Providing employment, special education, and other targeted programs so that people with epilepsy are fully integrated into society.
- Developing new strategies to prevent epilepsy.

The scope of epilepsy and seizures in the United States

According to most recent estimates, epilepsy and seizures will develop in 181,000 otherwise healthy Americans of all ages this year. In 1995, the last year for which complete data are available, 2.3 million Americans had been diagnosed with epilepsy, had been taking anticonvulsant medication for at least 5 years, or had experienced an unprovoked seizure (a seizures not associated with an acute nervous system insult such as high fever, infection, or head trauma). Of these 2.3 million, 1.4 million were adults aged 15 to 64 years and 550,000 were citizens aged 65 and over. Most poignant, 300,000 were children aged 14 years and younger—children in the prime of life and at a crucial stage in their educational and social development.

The severity of epilepsy varies from person to person. In an ongoing study sponsored by the Epilepsy Foundation on the impact of epilepsy and the cost of the illness, several distinct patient

groups were identified. In about 60%, no additional seizures occurred after 1 year. In an additional 15%, several seizures occurred over time, but eventually ceased.

And in an unfortunate subset, amounting to 25% of the total epilepsy population, seizures persist despite treatment and are considered intractable.

Ineffective treatment, delayed or lack of access to high-quality, specialized care, and the severity of the underlying neurological disorder are all possible contributors to the development of hard to control seizures. Whatever the cause, the result is the same: a lifetime of dependence, enormous cost to society, and a formidable barrier to individual productivity and happiness.

Although seizure disorders strike all demographic groups, the prevalence is higher among minority populations living in poverty than among the general population. It is not known whether this discrepancy is due to racial variations or socioeconomic factors. Death rates are also elevated in people with epilepsy, especially when seizures are not controlled.

Despite their many problems, however, people with epilepsy struggle to live normally, and may indeed minimize the difficulties with which they are faced. Some research evidence suggests that people with epilepsy have low expectations for their medication regimens: In a survey conducted among people with epilepsy, 50% of the respondents stated that their disorder was in "good" control, even though 25% of them had experienced a seizure within the previous year. In fact, only 13% of this group had experienced a seizure-free interval of more than 1 year. In 37%, the longest time without a seizure was 3 months; 22% had a reprieve of 1 month;10% had gone 1

week without seizure activity; and 4% reported that their longest seizure-free interval was 1 day. Their experience – and their stoic acceptance of it -- contrasts sharply with the stated goal of epilepsy therapy: the elimination of all seizures.

The economic impact of epilepsy in the United States

According to the results of a cost-of-illness study issued in 1978 by the Commission for the Control of Epilepsy and its Consequences, Department of Health, Education, and Welfare, the national economic burden of epilepsy in 1975, including direct medical costs, and the costs of residential care, unemployment, and special education, totaled $3.6 billion. Adjusted only for inflation, that number could be in the neighborhood of $16 billion today.

Even this estimate may be missing some current costs, and in fact we do not yet know the medical costs alone for this condition. Since 1975, new antiseizure drugs have become available, and these are more expensive than older medications. In addition, surgery to prevent seizures has become a more widely used option for some people with epilepsy, a striking—and expensive—advance.

Preliminary findings of the recent study conducted to provide 1995 figures of the lifetime and annual costs of epilepsy (using data from actual cases as a basis for the estimates) shed further light on the issue. In this study, direct cost estimates are based on clinical data on the course of epilepsy and associated medical utilizations from the time of diagnosis up to 9 years later in 608 people selected from 2 population-based cohorts in Houston, TX, and Rochester, MN.

Where do the costs of medical care come from? First, the onset of seizures often requires an extensive diagnostic workup to determine the type of seizure, whether the seizure was caused by a condition that can be corrected, and what the optimal treatment might be. Hospitalization typically lasts for 3 to 6 days, and necessary but expensive tests, including MRI (magnetic resonance imaging), CT (computerized tomography), and EEG (electroencephalographic) monitoring are usually performed. Regular visits to the doctor, often a neurologist, are a lifelong feature of epilepsy--and another source of ongoing expenditures. Finding the right medication for a particular person may require considerable trial-and-error, along with close observation of blood levels and side effects. As already noted, for some patients (usually those in whom drugs provide unsatisfactory effects or do not control seizures), surgery may be an option. Compared to people whose epilepsy responds well to antiseizure drugs, people whose seizures remain uncontrolled despite optimal medical intervention incur medical costs that are quite large.

Long term treatment with antiepileptic drugs, essential for most people with seizures, accounts for nearly 30% of direct costs attributable to epilepsy. According to these data, other large components of direct medical care costs include inpatient hospital care and physician visits, at 21.8% and 12.2%, respectively.

Effects on employability, self-support, and income

Epilepsy's costs to society go beyond the immediate medical expenses. The indirect costs of lost earnings and housework production losses among this population are expected to be in the billions, especially among people with uncontrolled seizures. We also know from the literature and from many patient surveys that epilepsy often has devastating effects on employability.

Consider that respondents to a community-based survey of people with epilepsy were reasonably well-educated: 56% had a high school diploma, 38% had earned some college credits, and 15% had completed college degrees. Despite this background, 25% of working age respondents were unemployed. Of those who were unemployed, 64% said that they were unemployed as a direct result of their epilepsy. At the time the survey was conducted, in the mid-1990s, the average unemployment rate in the United States was slightly over 5%.

As in other aspects of life, the severity of epilepsy influences the degree to which employment is affected. Among people whose seizures continue despite treatment, the probability of work is reduced by 47% in men and 41% in women, compared to people with no disability. Even when seizures are better controlled, the probability of continued employment is still substantially affected -- reduced by 26% in men and 21% in women compared to the general population. It is significant, and costly to society, that one fifth to one quarter of people with controlled seizures are significantly less likely to work than people in the general population. Greater attention must be paid to this waste of human potential. Programs and incentives to bring people with epilepsy into the workforce and to improve their chances of getting and holding a job are desperately needed.

Impact on the intellectual development of children

The potentially devastating effect of epilepsy in early childhood on brain development has already been cited. It is one of the most difficult, challenging, and heartbreaking aspects of the unsolved problem that is epilepsy. The severe epilepsy syndromes of this period of life produce

developmental delay and brain damage that can lead to a lifetime of dependence on others and continually accruing costs to the healthcare system and society at large.

Yet very young children are not the only ones whose lives are affected and whose futures are put in doubt. Perhaps the most persuasive evidence in favor of aggressive, focused research into new epilepsy treatments comes from consideration of how epilepsy impacts the social and intellectual development of children in general, including those who attend regular schools.

In a recent nationwide survey of people with epilepsy, 54% of the respondents who were still in school reported that epilepsy had a negative impact on their academic performance, and 40% to 50% said that cognitive problems (difficulties with memory, thinking, and concentration) were major concerns of theirs.

Other studies confirm that educational attainment is affected As already noted, only 56% of people with epilepsy attended 4 years of high school, and 15% finished college, versus national norms of 81.7% and 23%. These discrepancies in educational attainment may be attributable to cognitive impairment caused by seizures, drug side effects that interfere with intellectual development, or -- the bane of the person with epilepsy—the fears and stigma still associated with the disorder.

It's also clear from the literature that children with epilepsy are at special risk for learning problems. On average, they tend to be 1 year behind the expected reading level. Several studies conducted in the United States and Europe have documented deficits in language, visual-spatial

function, problem-solving, and adaptive behaviors among children with seizure disorders. In one British study, general knowledge scores were 50% lower among children with epilepsy than among their peers. Compared to other kids, those with seizures tend to repeat grades more often, and adolescents drop out of school at higher rates.

Children are susceptible to chronic diseases other than epilepsy. Diabetes and asthma are among the more common ones. Both have elements in common with epilepsy – they are, for the most part, hidden disabilities; they may involve unexpected, temporarily incapacitating episodes that can be upsetting to others; all three conditions require children to take medication to prevent illness. Are the school problems in children with epilepsy specific to this disorder, or merely a general reflection of the burdens imposed by chronic illness?

Despite the parallels with these other disorders, epilepsy, it seems, strikes the young in a unique fashion. In a recently completed comparison of academic achievement in children with epilepsy and those with asthma, researchers found that kids with epilepsy had significantly lower achievement scores than those with asthma, and boys were at especially high risk. Girls entering adolescence who had continuing seizures had the most problems with self-concept, depression and behavior. Among all children with seizure disorders, those with the most severe disorder, with negative attitudes, and with the poorest adjustment in the classroom had the most severe academic impairments. It's worth noting that academic achievement is often impaired even when a child with epilepsy is of normal intelligence.

Another study compared self-esteem and behavioral adjustment in children with epilepsy and in those with diabetes. Again, children with seizure disorders had consistently more behavior

problems and more damaged self-esteem. Compared with kids who had diabetes, twice as many children with epilepsy were enrolled in special education classes.

It is thus fair to say that seizures in childhood have a measurable negative effect on educational achievement and future employability of children, and that the more severe the medical problem, the greater the effects. Another recent study confirms this. It details some of the long-term consequences of epilepsy in children. Among its other findings, this investigation shows that even among children whose seizures are in complete remission and who do not need medication, educational and professional attainment and the likelihood of marriage and future childbearing are dramatically reduced. The investigators showed that these impairments were not due to societal discrimination or lower socioeconomic status. They concluded that "even the mildest forms of childhood epilepsy can have a lifelong effect on employment status."

Clearly, research focused on the prevention and improved treatment of epilepsy at this vulnerable time of life should be a national priority.

The growing burden of epilepsy in the older population

The U.S. population is aging – and unless better solutions are found, the number of elderly people with incapacitating seizures, and their costs to society, is going to grow. Stroke, cardiovascular disease, brain tumors and Alzheimer's disease are all causes of epilepsy in the over 65's.

The results of the community-based study of people with epilepsy in Houston, TX and Rochester, MN, demonstrated that direct medical costs are greater for the elderly than other

groups. This was due in part to the longer than average hospitalizations required for older people than younger ones. The addition of seizures to the existing health problems of older Americans is often the final blow to an independent life and an invitation to residential care. Ten percent of people in nursing homes are being treated with antiseizure medications.

For those elders who can continue to live at home, there are additional medication costs. While not all children with seizures start antiepileptic medications after the first seizure, nearly all adults do, thereby increasing the cost differential between this population and other segments of the spectrum that is epilepsy. As already noted, people of all ages with intractable seizures have higher medical costs, especially during the first year, than people whose seizures are well-controlled by medication, and this holds true for the elderly as well. As the baby boomers age, there will be increasing numbers of age-related seizure disorders. At this time, it's estimated that 61,000 new cases of epilepsy occur each year among elderly Americans.

Barriers to self-fulfillment and independence

The burden of epilepsy is not limited to high medical costs and frustration in employment. It exacts a profoundly personal toll, as well.

According to Census Bureau norms, the marriage rate among Americans is 63% for men and 59% for women. However, most studies of people with epilepsy find lower marriage rates for both sexes, with men more affected than women. Divorce rates in people with and without epilepsy are comparable, though. Overall, up to one third of the community study group reported

that epilepsy caused strains and difficulties with family and friends, and 21% reported difficulties of a sexual nature.

In this same study, people with epilepsy reported that limits on lifestyle, school, driving, and employment were major barriers in their lives. Being unable to drive is often cited by people with epilepsy as a major impediment to independent living, and this group of survey respondents was no exception, with 36% of those who were employed citing driving difficulties as the single major challenge posed by the condition. A total of 17% of this population said that problems on the job were the chief challenge posed by the seizure disorder.

To capture the concerns of people with epilepsy in their own words, the researchers asked them an open-ended question, "What is the worst thing about living with epilepsy?" Underscoring the urgent need for more effective treatments, nearly half of the people in this group reported that the single worst thing about epilepsy was living with the fear of another seizure. When will it happen? Where will it occur? How serious will it be? Many feared incurring injuries during a seizure. Others were afraid that a seizure would come while they were driving and cause an accident.

Stigma associated with epilepsy is still a huge concern for people living with epilepsy. A telling finding from this study was that only 12% of the respondents worried about social stigma or the reactions of others when they first received the diagnosis of epilepsy. Subsequently, however, 24% reported that they experienced anxiety about these same issues. Apparently, they had experienced the effects of stigma and social isolation since their diagnosis.

Special challenges associated with epilepsy

In addition to the personal, economic, and medical costs of epilepsy, the condition poses additional special burdens on its victims and their loved ones. These must be considered when assessing the personal and societal costs of epilepsy.

Life expectancy, for example, is reduced in persons whose seizures continue unabated. Causes include:

- Accidents
- Cerebrovascular disease
- Other circulatory diseases
- Tumors of the central nervous system
- Suicide
- Sudden, unexplained death in an otherwise healthy young adult.

Compared to people without epilepsy, those with seizure disorders are more likely to experience injuries and accidents as a direct result of the seizures themselves and the setting in which they occur. Fractures and burns are a major hazard. In the elderly, stroke is a major cause of the seizures and cerebrovascular and circulatory problems may be associated with death. Suicide rates have been cited as two to five times the rate in the general population.

Compared to their healthy peers, young people aged 20 to 40 years with poorly controlled epilepsy are also more susceptible to sudden, unexplained death – with devastating and long lasting effects on families. It occurs more often in men than in women, although both sexes are

at risk. While statistics are hard to come by, sudden, unexplained death may occur in up to 10% of patients with epilepsy who die. Experts estimate that compared to the general healthy population, the death rate overall in people with epilepsy is doubled. In ages 5 to 44 years it is five times higher than in the general population.

Seizures themselves may sometimes be fatal, especially if prolonged. It is estimated that up to 195,000 cases of potentially deadly seizures which continue longer than 30 minutes occur each year in the United States. Doctors call these episodes *status epilepticus*. In 42% of cases they occur in people with an established diagnosis of epilepsy, but in the remaining cases there may be no previous seizure history, but rather an underlying acute condition affecting the brain. Up to 42,000 fatal episodes of status epilepticus occur annually. The mechanisms behind such seizures are not well understood; their cost to society and their potential for brain damage in those who survive such episodes is also substantial. They, too, are part of the unsolved problem that is epilepsy.

Women with epilepsy: a population at risk

Women with epilepsy face related epilepsy-problems throughout their reproductive lives. New research shows that in many women the risk of seizure occurrence varies according to hormonal status; and that the mechanisms involved in epilepsy may reduce fertility and affect endocrine and other key bodily functions.

Pregnancy has special challenges for women with epilepsy. Seizures during pregnancy may affect the developing child – and so may the drugs taken to prevent seizures. As a result, some

women are told by their doctors that pregnancy carries unreasonable risks and that they should forego childbirth altogether. In fact, well managed pregnancies can have excellent outcomes, but too few women – or their doctors – are aware of that fact. Research to improve the health of women with epilepsy and their babies is an area too long neglected.

The need for more effective treatments is urgent

Consider these facts, which reflect the burden of epilepsy on the American people in the mid-1990s:

- Approximately 2.3 million Americans of all ages have seizures and epilepsy.
- Approximately 500,000 Americans are receiving medical care which successfully controls their seizures.
- Approximately 1 million will get inadequate relief from their seizures.
- Twenty five percent (almost 600,000) will have intractable seizures.
- Of all American children aged 14 and under, 89,000 have an active seizure disorder
- At least 550,000 elderly Americans are living with a seizure disorder, with 61,000 new cases per year
- Among people who are now receiving medical treatment for seizures, twice as many have had seizures recently than have complete, reliable seizure control.
- A community–based study, in which 29% of the subjects were on Medicaid or Medicare, showed that 89% of the people with epilepsy had had a seizure within the last year.

The implications are clear: We need research answers now that will provide people who suffer from epilepsy with more effective treatment. In particular, we cannot continue to allow children to be assaulted by seizures.

Early recognition and treatment—reducing the personal burden

Some evidence suggests that the sooner seizure disorders are diagnosed and effective treatment started, the better the chances of a positive long-term outcome. Remission or longer seizure-free periods may be possible with prompt diagnosis and treatment and, when necessary, referral to an epilepsy center for specialized care. Given the documented disruptions in education, employment, self-esteem, and personal life that are caused by seizures, the quest for early recognition and treatment should be urgent.

Early recognition of epilepsy may also lead to lower healthcare expenditures. For the approximately 100,000 people in this country every year who have a single seizure or go into remission quickly within the year, direct long term medical costs are minimal. Medical expenses are limited primarily to the initial ones for a diagnostic workup. In contrast, the medical care expenditures for people with uncontrolled seizures are high and continuing.

Recently, neurologists who followed a group of children with epilepsy into adulthood report those who responded early to drug therapy have the best long-term outcome, and that those who responded within the first year of treatment do best. In contrast, those who do not respond within 2 years may be candidates for brain surgery. These findings underscore the urgency of finding new antiepileptic medications that can produce more rapid remissions, especially in children.

Increasingly, patients with intractable epilepsy who meet certain diagnostic standards are having brain surgery. Various techniques are used, from removal of small segments in non-vital areas of the brain to operations severing connections between the two hemispheres, to massive surgery to remove half the brain in very severe cases. Although surgery holds promise for many people, a large number of questions remain. The stakes are high. Each year, more children and adults are evaluated for epilepsy surgery, and preliminary data suggest that the operations may eradicate seizures in some of them and improve quality of life. Nonetheless, definitive, long-term data are lacking. We need additional research to determine how people—especially children—should be screened and selected for surgery. Is surgery more effective early in the course of the disorder in children—or later? Will cognitive function and school performance be affected? These questions need answers soon.

For some children, the answer to uncontrolled seizures is the ketogenic diet – a strict high fat, low calorie, low carbohydrate regimen that helps two thirds of the children who try it but has its own side effects and stresses on family life. Better understanding of which children can be helped and whether the benefits of the diet can be more easily accessed can only come through research.

In addition to early recognition and improved treatment of seizure disorders, several groups of researchers are looking at ways to predict – and possibly to prevent -- seizures in people with known epilepsy. This might be possible if tell-tale warning signals could be identified in EEG recordings in advance. The implanted vagus nerve stimulation device, designed to prevent

seizures through intermittent, pre-programmed electronic stimulation of the brain, may be a step in this direction, but a lot more research in these and other areas is needed.

Finally, we must address the issue of stigma, individually and as a nation. Medical solutions to epilepsy's problems will not have the impact on people's lives that they deserve so long as ignorance and fear control the way the rest of us react to this condition. Public education efforts will go a long way toward alleviating the burden of prejudice still carried by a group of fellow citizens who are already struggling to live as normally and productively as possible.

Summary

Seizures and epilepsy affect very large numbers of Americans. Thanks to medical advances, some do well with current treatment. But not enough. Too many of our fellow citizens live precarious lives, never sure when the next seizure will strike, or where. For those with uncontrolled seizures, the simplest activity is clouded by "what if." What if a seizure happens while I'm cooking? Lighting the gas stove? Crossing the street? Standing on a subway platform? Holding a grandchild? What if it happens in a subway train and people think I'm on drugs and the police arrest me before I'm fully aware of where I am or what's happening to me?

For young children, epilepsy can mean a future devastated by the disorder and its effects. All are part of the total burden that epilepsy and seizures impose on this country, in both medical and social costs.

For all these reasons, epilepsy remains a major health problem that is not yet solved. Its extent and its human cost must command greater national attention – for research, for prevention, for services, and in improved access to medical care.

The Decade of the Brain has produced a wealth of new tools and new knowledge. Now we must put them to work to solve and cure the unique problems of this most ancient of human ills.

National Institute of Neurological Disorders and Stroke

Gerald D. Fischbach, M.D., ***Director***
Building 31, Room 8A52
31 Center Drive
Bethesda, Maryland 20892-2540

January 6, 1999

NOTE TO: Neera Tanden, Office of the First Lady

Dear Neera,

Here is a short summary of background material on epilepsy, current areas of promising research, funding, and some future plans.

I hope this information is helpful to the First Lady. Please keep me informed.

Best regards,

GD Fischbach

Gerald D. Fischbach, M.D.

EPILEPSY

What is epilepsy?
Epilepsy is a chronic brain disorder characterized by spontaneous, recurrent seizures. Seizures are caused by "electrical storms" in the brain, during which groups of nerve cells in the brain fire electrical impulses in synchrony at a rate of up to four times higher than normal. The severity and specific manifestations of epileptic seizures vary depending on which parts of the brain are affected. Seizures range from brief lapses of attention (absence seizures) to limited motor, sensory, or psychological changes (partial seizures) to prolonged losses of consciousness with convulsions (tonic-clonic seizures). The frequency of seizures also varies greatly in different cases, but in severe epilepsy seizures are so common that they can severely incapacitate a person's ability to work, study, or maintain social and family relationships.

What causes epilepsy?
There are many types of epilepsy, each with its own natural history and response to treatment. Head injuries, brain tumors, cerebrovascular incidents (e.g., stroke), lead poisoning, neurodevelopmental problems, certain genetic conditions, and infectious illnesses can all cause epilepsy, but in more than half of all cases no cause can be found.

Who is affected by epilepsy?
As a conservative estimate, 50 million people worldwide have epilepsy. Epilepsy is estimated to affect one percent of the U.S. population, approximately 2.5 million Americans, at a cost of more than $3 billion per year. Epilepsy can affect people of all ages. The incidence rates are high in childhood, plateau in the late teens to 65 years, and rise again among the elderly.

Can epilepsy be treated?
Drugs can control seizures in more than half of people with epilepsy. After many years of no new antiepileptic drugs, five new medications have been approved for use in the past five years. NINDS' Epilepsy Therapeutics Research Program (formerly the Antiepileptic Drug Development Program) supports preclinical studies and clinical evaluations of antiepileptic drugs, cooperating with academia and industry. Since 1975, well over 18,000 compounds have been evaluated through the Anticonvulsant Screening Project, and several promising drugs and drug delivery methods are being designed or tested.

For people whose seizures can not be adequately controlled by drugs, surgery is increasingly being used. Extensive presurgical testing attempts to localize the seizure focus, that is, to determine which part of the brain triggers electrical storms. Surgeons then must remove the epileptic foci without damaging vital brain areas.

Is current treatment adequate?
More than 350, 000 Americans suffer from epilepsy that cannot be controlled with currently available drug treatments, including twenty to thirty percent of all children with epilepsy. Even for those persons whose seizures can be controlled with drugs, better medications, with less severe side effects are badly needed.

What research is being done to provide better treatments for epilepsy?
NINDS supports a broad spectrum of epilepsy research studies by investigators at universities and medical centers throughout the country. Epilepsy research draws upon all areas of modern neuroscience and medicine to find the causes of epilepsy and to use that understanding to develop better treatments. A few highlights:

Genes and epilepsy: Modern genetics promises to revolutionize our understanding of epilepsy. More than 100 forms of epilepsy are caused by defects in single genes. Genetic susceptibility, most often from multiple inherited genes, probably contributes to one third of all epilepsy syndromes. In just the last few years new brain imaging techniques than reveal even subtle changes in the brain, together with genetic studies in animals, are showing that developmental malformations of the brain contribute to epilepsy in many more children than previously suspected.

Genetic studies of inherited forms of epilepsy offer promise even for epilepsy that is not inherited. The same brain molecules and control systems that are damaged in inherited forms of epilepsy may also be affected the environment. Mutations in neurotransmitter receptors through which nerve cells communicate with one another, ion channels that control electrical behavior of nerve cells, and transporters that carry crucial substances into and out of cells are among the genes implicated in inherited seizure disorders so far, and each of these genetic findings reveals rational targets for the development of new drugs to control seizures. Genetic studies in mice are also providing better animal models of seizure disorders that are crucial for developing and testing new drugs and other therapies.

Recent innovations in drug therapy: A unique *gel* form of the drug diazepam introduced last year safely reduces the severity of acute repetitive seizure episodes in both children and adults. Acute repetitive seizures are episodes of multiple seizures that may progress to a potentially fatal condition of sustained seizures called status epilepticus. Informed caregivers can be trained to recognize the onset of acute repetitive seizures and to administer treatment with the gel in the home privately, quickly, safely, and much less expensively than emergency room treatment. This advance is an example of effective collaboration between a private company, clinical investigators, and NINDS to meet a critical medical need.

Diet therapy: Prelimary data suggests that a high-fat low-carbohydrate diet, called a ketogenic diet, may help control seizures in certain types of epilepsy in children that may be unresponsive to other forms of therapy, especially in seizures of Lennoz-Gastaut Syndrome. However, there is considerable controversy about the safety and efficacy of this treatment. The ketogenic diet produces ketosis, a drastic alteration the metabolic balance of the body, and is potentially dangerous. NINDS is currently supporting clinical trials of the ketogenic diet for children with severe epilepsy that cannot be adequately treated with drugs and studies in animals to try to understand how dietary changes affect predisposition to seizures.

Hormones and epilepsy: Women with epilepsy face special problems. For example, a significant proportion of women with epilepsy experience increased seizure frequency during phases of the menstrual cycle in which estrogen is elevated. Scientists are now attempting to understand hormonal effects on epilepsy in both human clinical and animal studies.

Surgery and diagnostics: Of an estimated 350,000 epilepsy patients in the United States who suffer from partial seizures that are intractable to medical therapy, more than 100,000 are considered candidates for surgical resection of the area of the brain from which the seizures originate (seizure focus). In each patient surgeons must determine which parts of the brain start seizures and which parts must be carefully preserved because they serve crucial functions such as language. These problems are often the limiting factor in applying surgery for epilepsy. NINDS is supporting research to find the best brain imaging methods to guide surgeons treating adults and children with epilepsy, including studies of SPECT (single photon emission computed tomography), MRI (magnetic resonance imaging), fMRI (functional magnetic resonance imaging, which can monitor brain activity as well as structure), PET (positron emission tomography), EEG (electroencephalography), and MEG (magnetoencephalography).

NINDS Intitatives and Plans:
NINDS has increased its support of epilepsy research in recent years and is continuing its broad-based research program towards the goal of ultimately learning to prevent or cure epilepsy, with the major focus on behalf of those with uncontrolled seizures. Ongoing clinical efforts include studies of drug, diet, and surgical therapy, including application of advanced brain imaging. Research also continues to seek better understanding of what controls brain excitability and what goes awry in epilepsy. NINDS is planning two major scientific meetings to engage scientific experts from many areas of neuroscience in epilepsy research .

1) Genetics of epilepsy. The Institute has designated epilepsy genetics as an area of exceptional opportunity for special emphasis in the coming year. As part of that effort a major workshop this spring will bring together about 50 leading scientific investigators from both within and outside the field of epilepsy research to examine new research approaches to the genetics of the epilepsies, ranging from the collection and clinical evaluation of families with inherited forms of epilepsy, through gene discovery, to strategies for therapy.

2) Epilepsy: Pathogenesis and Cure. Next year NINDS will convene a large, national conference on epilepsy on the NIH campus with the participation of more than 150 experts and the public. The broad meeting will consolidate current understanding of epilepsy and determine which areas of modern basic and clinical neuroscience hold the most promise for preventing and curing epilepsy.

NINDS Funding for epilepsy research:
1995: $54,295,000 1996: $51,287,000 1997: $68,002,000

RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER
RUSH UNIVERSITY

1700 WEST VAN BUREN, SUITE 250
CHICAGO, ILLINOIS 60612-3833

RUSH

Date: January 5, 1999

No. Of Pages (including Cover Sheet):4

TO:	***Neera Tanden***
	Asssoc. Dir, Domestic Policy
Phone:	
Fax Phone:	*202-456-2878*

FROM:	**John Pontarelli**
	Director
	Media Relations
Phone	*312/942-5949*
Fax Phone	*312/942-5581*

Attached are draft Fact Sheets on Rush-Presbyterian-St. Luke's Medical Center and the Rush Epilepsy Center. Final drafts will be available later this week.

Draft

The Rush Epilepsy Center

Rush-Presbyterian-St. Luke's Medical Center

The Epilepsy Center at Rush-Presbyterian-St. Luke's Medical Center, Chicago, is internationally known for its efforts to restore epilepsy patients' control over their disease and, ultimately, their lives. The center has been in existence since 1972 and its focus has been to provide specialized care to patients unresponsive to standard medical management. The center is one of the most comprehensive facilities for diagnosis, monitoring and treatment of epilepsy in the country.

Each patient at the center is evaluated by a team of experts that devclops an individualized program to combat the patients' symptoms. The multidisciplinary staff includes epileptologists, neuropsychologists, physiologists, pediatric neurologists, a neurosurgeon, clinical nurse specialists and social workers. Together, they focus on all aspects of epilepsy as it affects the patient -- medically, socially and psychologically -- including the practical problems of daily life.

The Rush Epilepsy Center evaluates and treats both adults and children with all types of epilepsy, as well as persons experiencing symptoms that may be epilepsy. The diagnostic and treatment options available to patients and referring physicians include diagnostic monitoring, surgical workup, implanted electrodes and surgery.

Dr. Michael Smith is director of the Rush Epilepsy Center.

The Monitoring Unit at the Rush Epilepsy Center

Patients are monitored using the most advanced technology, including a split screen video system, 24 hour EEG monitoring digital electroencephalography, as well as a variety of sophisticated pharmacological diagnostic tests.

Over the past 27 years, the center has grown from one monitoring room bed to four specially designed monitoring room beds.

The monitoring center will be named in memory of Dr. Frank Morrell (1926--1996) who was one of the nation's leading experts on the diagnosis and treatment of epilepsy and related seizure disorders.

Draft

RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER
Facts

Rush-Presbyterian-St. Luke's Medical Center is the center of a comprehensive, health care system designed to serve some 3 million people through its own resources and in affiliation with other health care institutions.

It includes Rush University, which comprises Rush Medical College, the College of Nursing, the College of Health Sciences, the Graduate College, and a cooperative educational network of 14 liberal arts colleges and universities in six states from Tennessee to Colorado.

Rush is the center for basic and clinical research, with physicians and scientists involved in more than 2,000 investigations, many of them involving two or more disciplines.

The seven Rush Institutes draw together patient care and research to address major health problems, offering primary healthcare services as well as the latest treatments for arthritis and orthopedic problems, cancer, heart disease, mental illness, diseases associated with aging and neurological problems.

Rush System for Health

The medical center is the tertiary hub of the Rush System for Health, a comprehensive health care system capable of serving about two million people through its outpatient facilities and member hospitals. Rush has affiliated with other institutions to meet the demands of an ever-changing health-care environment. Hospitals in the Rush system include: Rush-Presbyterian-St. Luke's Medical Center, Holy Family Hospital, Lake Forest Hospital, Rush North Shore Medical Center, Illinois Masonic Medical Center, Oak Park Hospital, Riverside HealthCare, and Rush-Copley Medical Center.

Research at Rush

Medical research has been central to the mission of the medical Center since Rush Medical College was founded in 1837. External funding for research as Rush has been steadily growing each year for the past 20 years. Research awards for 1997-98 $50,447,035 to support more than 2,300 research projects.

Rush University Faculty and Staff Statistics

Rush Medical College	2,655
College of Nursing	330
College of Health Sciences	228
The Graduate College	122
Medical Staff	1,241

Employees

Rush-Presbyterian-St. Luke's Medical Center employees, as of 6/98: 8,373

Rush University Students

Rush Medical College	487
College of Nursing	586
College of Health Sciences	208
The Graduate College	67
Rush University unclassified Students	52
Residents and Fellows	615

Community Service

Through three major programs, Rush reaches out to the Chicago community by providing the following services:

- Rush Community Services Initiatives Program - With more than 75 percent of Rush's medical student volunteers, Rush University provides a network of community programs to address social and health care needs of the community.
- Rush is in partnership with the YMCA of Metropolitan Chicago and the Homan Square Community Center in providing neighborhood services.
- The Science and Math Excellence Network, a public-private partnership to improve the science and math skills of inner-city children.

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
006. paper	re: epilepsy personal story (1 page)	01/11/1999	b(6)

COLLECTION:
Clinton Presidential Records
First Lady's Office
Christine Macy
OA/Box Number: 17209

FOLDER TITLE:
Epilepsy/HRC

2013-0936-S
rc1345

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.
PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
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b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

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007. letter	Constituent to Hillary Rodham Clinton (1 page)	01/11/1999	b(6)

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First Lady's Office
Christine Macy
OA/Box Number: 17209

FOLDER TITLE:
Epilepsy/HRC

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Carol-
I'm not sure
how helpful this is!

THE ABRAHAMS BOY, INC.
501 10TH STREET
SANTA MONICA, CALIFORNIA 90402
TELEPHONE (310) 395-6751
TELECOPIER (310) 917-3310

Neera Tanden
The First Lady's Office
202/456-2878

CHARLIE'S STORY

On March 11, 1993, on his first birthday, I was pushing our son, Charlie, in a swing when his head twitched and he threw his right arm into the air. That was the beginning of an agony I am without words to describe. Nine months later, after literally thousands of a variety of epileptic seizures, an incredible array of drugs, eight hospitalizations, a mountain of EEG's, MRI's, CAT scans and PET scans, weekly blood draws, one fruitless brain surgery, five pediatric neurologists in three cities, two homeopathists, one faith healer, and countless prayers, Charlie's seizures were unchecked, his development "delayed," and he had a prognosis of continued seizures and "progressive retardation."

Then in December, 1993 my wife and I learned that since 1928 the people at Johns Hopkins Department of Pediatric Neurology have been stopping seizures in half the kids they put on the ketogenic diet and significantly improving another 25%. We took Charlie there, he started the diet and since the end of 1993 Charlie has been drug and seizure free, his development has dramatically picked up, and even his EEG which had been "grossly abnormal" before the diet has become normal.

After the euphoria of Charlie's miracle began to sink in, we suddenly realized that most of what he had been put through was unnecessary. 99% of his seizures were unnecessary. 99% of the drugging was unnecessary. The tests and blood draws were unnecessary. The surgery was unnecessary. The developmental delay from which he still suffers today is unnecessary. Had somebody merely taken the time to explain the diet to us and told us the fact that after the first drug failed there was a 10-15% chance a second drug would work and that there was only a 20% chance drugs will ever stop his seizures, then obviously we would have tried the ketogenic diet months earlier. According to the National Epilepsy Foundation, there are 380,000 children in America alone today with uncontrolled seizures. Clearly we were not alone in this horror.

So, in March, 1994 we started the Charlie Foundation To Help Cure Pediatric Epilepsy in an effort to spread the word. Today there are dozens of ketocenters around the United States and thousands of kids on the diet. New research is revealing the mechanisms of the diet and it has been refined and simplified enormously. Our hope is that in the next several years the diet will be reduced to pill form and available to those afflicted with epilepsy everywhere.

Today, Charlie remains on the ketogenic diet—drug and seizure free.

First Lady Announces New Initiatives to Address Epilepsy

January 13, 1999

Today, the First Lady traveled to Chicago's Rush Presbyterian- St. Luke's Hospital to announce new efforts to address epilepsy as she dedicates the hospital's new epilepsy center. She will release a new report by that details the cost of epilepsy to the economy, announce the first-ever Administration conference on epilepsy, and new efforts to educate physicians about the need to diagnose epilepsy early.

New Report Demonstrates that Epilepsy Affects Millions of Americans, at Great Cost to the Nation. The First Lady will release "Epilepsy: A Report to the Nation," sponsored by the Epilepsy Foundation of America, which found that epilepsy and seizures affect 2.3 million Americans of all ages. This disease has an annual cost of $12.5 billion in direct and indirect costs, according to preliminary research. Approximately 181,000 new cases of seizures and epilepsy occur each year; 10%of the American population will experience a seizure in their lifetime; 3% will develop epilepsy by age 75. In 1995, 300,000 children aged 14 and under had epilepsy; 1.4 million adults under age 64, and 550,000 aged 65 and over had epilepsy. Advances in medical treatment enable many people to live normal lives free of seizures and to achieve personal and professional success. Approximately 60% achieve remission after the first year; 15% achieve control at a later date, but in 25% seizures resist control and become intractable. For this group, comprising roughly 350,000 to half a million Americans, many of them children, epilepsy remains a formidable barrier to normal life, affecting educational attainment, employment, and personal fulfillment.

a

Suggest

LANDMARK

New Conference to Search for a Cure: Next year, the National Institute for Neurological Disorders and Stroke will convene the first ever Administration conference on epilepsy on the NIH campus with the participation of more than 150 experts and the public. The broad meeting will consolidate current understanding of epilepsy and determine which areas of modern basic and work towards finding a cure for epilepsy. The Conference will focus on how to best allocate the unprecedented investment the Clinton Administration has made in epilepsy research -- $X dollars.

b

New Efforts to Educate Doctors About Epilepsy: A number of people with epilepsy are inaccurately diagnosed with the disease, while their disease degenerates, affecting brain development. In order to address this problem, the CDC is starting a new initiative to inform practitioners on early diagnosis. The CDC will: →

New Efforts to Educate Patients with Epilepsy: The First Lady will announce that the Epilepsy Foundation will offer a service to educate people about epilepsy. Take from colon cancer one pager: web site

Chat Room

AOL: Internet

Talk w/ Epilepsy Specialist - real conversation about your symptoms -

Record Type: Record

To: Christine N. Macy/WHO/EOP

cc:
Subject:

New Efforts to Educate Doctors About Epilepsy: A number of people with epilepsy are inaccurately diagnosed with the disease, while their disease degenerates, affecting brain development. In order to address this problem, the CDC is starting a new initiative to inform practitioners on the importance of early and accurate diagnosis. The CDC will bring together representatives of the major primary care physicians organizations to wo order to disseminate information on epilepsy. They will also disseminate information to thousands of doctors in order to assist them in making the appropriate early diagnosis of this disease.

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
008. fax	From Cure re: personal story (1 page)	01/11/1999	b(6)

COLLECTION:
Clinton Presidential Records
First Lady's Office
Christine Macy
OA/Box Number: 17209

FOLDER TITLE:
Epilepsy/HRC

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Dr. Frank Morrell appointed to Armour Presidential Chair

Frank Morrell, MD (left), is congratulated by Rush President Leon M. Haimoff, MD, (middle), and Dean Emil R. Unanue, MD, as he accepts the appointment to the Armour Presidential Chair on September 11.

Some physicians are known as wonderful clinicians, held in high regard by patients for their compassion and skill. Still others gain respect as investigators who revolutionize medicine with their landmark research. But relatively few physicians are able to excel both in the lab and at the bedside.

That's why neurologist Frank Morrell, MD, is so remarkable, say his colleagues. In a career that has spanned more than four decades, he has gained international acclaim for his brilliant scientific insights. His laboratory research has contributed to our understanding of how epilepsy affects the brain. His clinical studies have helped set the standards for how epilepsy is treated today.

At the same time, Dr. Morrell is beloved by his patients for his skill and caring, down-to-earth approach. "He's never too busy to listen to my problems and give me thoughtful answers to my questions. I really believe that he cares about me as a person, not just a patient. He's what you always wish a physician would be," says Georgianne AuBuchon, a patient of Dr. Morrell's since 1989.

In tribute to his remarkable achievements in research and patient care, Dr. Morrell was recently named the inaugural A. Watson Armour III and Sarah Armour Presidential Professor.

"Frank Morrell is one of those rare people who has the research skills to make important discoveries in the laboratory, and the clinical skills to apply these discoveries to patient care — and to make them work. His research has led to treatments that dramatically improve quality of life for people with severe epilepsy," says Jacob H. Fox, MD, the Jean Schweppe Armour Professor and Chair of Neurology, and executive director of the Rush Neuroscience Institute.

"I can think of no one more deserving of this honor," says Dr. Fox. "Frank is really the paradigm of what academic medicine is supposed to be."

A member of the medical staff since 1972, Dr. Morrell came to Rush from New York Medical College, where he had been a professor of neurology for three years. From 1961 to 1969, Dr. Morrell was professor and chairman of neurology at California's Stanford University School of Medicine. He established the Rush Epilepsy Center in 1972, and has directed the program ever since.

Among the treatment advances pioneered by Dr. Morrell is a surgery called multiple subpial transection, which offers hope to certain epilepsy patients who cannot be helped by traditional medical or surgical means. Patients who have benefited from this surgery include many children with a form of epilepsy called Landau-Kleffner syndrome, which affects the area of the brain responsible for speech and language comprehension.

Children with Landau-Kleffner gradually lose the ability to communicate and are often misdiagnosed as autistic. "We were desperate. We went to specialist after specialist, and no one could tell us what was going on with our son," recalls Gina Malone, whose son, Justin, was ultimately diagnosed as having Landau-Kleffner by Dr. Morrell.

Justin underwent the surgery at Rush in 1990, at age 5. Six years later, he is a healthy, normal 11-year-old. "Dr. Morrell's expertise and caring have made a tremendous difference for our family — and especially for Justin," says Mrs. Malone.

Through laboratory research, Dr. Morrell has also made important discoveries about the basic nature of epilepsy. He found, for example, that certain forms of epilepsy can spread through the brain by a process called "neurological learning," in which abnormal brain cells "teach" healthy cells to trigger seizures. "Frank's basic science back in the 1960s influenced how most epilepsy is treated today, with a combination of medications that both stop seizures and prevent the spread of the disease," says Rush neurologist Michael Smith, MD, who trained under Dr. Morrell, and now works at the Rush Epilepsy Center.

Frank Morrell has always been a physician-scientist ahead of his time, says Dr. Smith.

"Frank was always considered a pioneer — a researcher who wasn't afraid to challenge the status quo. At first, many of his theories were not broadly accepted, but they've gained wide acceptance as the research has borne them out," says Dr. Smith. "My generation of epileptologists consider him one of the important names in the field of epilepsy treatment and research." ■

As Vision and Values went to press Dr. Frank Morrell died October 22, after a brief illness.

Dr. Morrell with young patient Justin Malone in 1995.

FRANK MORRELL, M.D.

(1926 – 1996)

Frank Morrell, M.D. was a professor of neurological sciences and a senior attending physician at Rush-Presbyterian-St. Luke's Medical Center. In 1972 he founded the Rush Epilepsy Center.

Dr. Morrell was one of the nation's leading experts on the diagnosis and treatment of epilepsy and related seizure disorders. He developed a number of new and improved diagnostic and treatment techniques for epilepsy, including a particular surgical method (a collaboration with Rush neurosurgery chairman Walter Whisler, M.D., Ph.D.) to treat epilepsies that arise in critical cortical regions where standard resection techniques can not be used. This operation has made an important impact on Landau-Kleffner Syndrome, a serious speech deficit related to epilepsy in the cortical territory on which language depends.

A graduate of Columbia University, Dr. Morrell received his M.D. degree in 1948 from Columbia University College of Physicians and Surgeons. Following a year in London as a Rosenthal-Ross Fellow at National Hospital, Queen Square, Dr. Morrell was named chief resident in neurology at Montefiore Hospital in New York City. He subsequently spent a year at the Montreal Neurological Institute as a fellow in neurophysiology, during which time he earned a master of science in neurophysiology from McGill University.

Dr. Morrell served with distinction on the faculty of the University of Minnesota Medical School, Stanford University School of Medicine and New York Medical College prior to joining Rush in 1972. He was a Diplomat of the American Board of Electroencephalography and of the American Board of Psychiatry and Neurology. Over the years Dr. Morrell was honored with many awards, including being named a Fellow Great Britain's Royal Society of Health. Just prior to his death in October, 1996, Dr. Morrell was named the A. Watson Armour III and Sarah Armour Presidential Professor of Rush University.

revised 1/10/98

-410-662-4869

To: Christy
From: Neera

Marc Garufi
11/05/98 06:19:48 PM

Record Type: Record

To: Neera Tanden/WHO/EOP

cc: Richard J. Turman/OMB/EOP
Subject: Re: Epilepsy

NIH spends the following on epilepsy ($ in millions):

FY 1997	$68 million
FY 1998 Estimated	$72 million
FY 1999 Estimated	$78 million

→ Christy - put this in as a placeholder, but I think it may be more

FY 2000 numbers are not available at this time. You could say that, following the President's lead on proposing the largest dollar increase for NIH, Congress provided $2 billion (14%) increase for NIH in FY 1999....including __ for epilepsy...

Hope this is helpful. Let me know if you have other questions.

We hope to be able to announce FY 2000 #s. I'll let you know first thing.

Draft

The Rush Epilepsy Center

Rush-Presbyterian-St. Luke's Medical Center

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Each patient at the center is evaluated by a team of experts that develops an individualized program to combat the patients' symptoms. The multidisciplinary staff includes epileptologists, neuropsychologists, physiologists, pediatric neurologists, a neurosurgeon, clinical nurse specialists and social workers. Together, they focus on all aspects of epilepsy as it affects the patient -- medically, socially and psychologically -- including the practical problems of daily life.

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Dr. Michael Smith is director of the Rush Epilepsy Center.

The Monitoring Unit at the Rush Epilepsy Center

Patients are monitored using the most advanced technology, including a split screen video system, 24 hour EEG monitoring digital electroencephalography, as well as a variety of sophisticated pharmacological diagnostic tests.

Over the past 27 years, the center has grown from one monitoring room bed to four specially designed monitoring room beds.

The monitoring center will be named in memory of Dr. Frank Morrell (1926--1996) who was one of the nation's leading experts on the diagnosis and treatment of epilepsy and related seizure disorders.

THE WHITE HOUSE
WASHINGTON

OFFICE OF THE FIRST LADY

TO Christy Haas / Carol Beach

FROM Neera

FAX # Christy: 410-664-1406

PHONE # Carol 301-951-0340 (also sent via email)

OF PAGES (including cover)

COMMENTS This is an extremely rough draft - but I thought it might help you get through your first draft.

Carol - I'll be sending you a whole batch of stories later today.

Thanks,
Neera

I CAN ONLY IMAGINE HOW DIFFICULT IT WOULD BE TO LIVE WITH THOSE ENDLESS "WHAT IF'S": WHAT IF I GET A SEIZURE WHEN I'M CROSSING THE STREET, OR COOKING FOR MY FAMILY, OR HOLDING MY CHILD, OR MY GRANDCHILD? in my arms? of loss, and ~~loss~~ ~~control~~, and hope.

THERE ARE SO MANY STORIES I'VE HEARD ABOUT MEGAN, A 4-YEAR-OLD, ONE OF FOUR DAUGHTERS. AT ONE POINT, SHE HAD OVER 100 SEIZURES A DAY, AND IS UNABLE TO SPEAK. HER PARENTS HAVE TAKEN HER ALL OVER THE COUNTRY — TO SEE DIFFERENT DOCTORS, AND TRY OUT DIFFERENT ANTI-CONVULSANTS. HER PARENTS CALL MEGAN "OUR SUNSHINE." THEY SAY SHE HAS A LONG LIFE AHEAD OF HEAR — AND "~~WE~~ DREAM OF THE DAY WHEN SEIZURES NO LONGER EXIST, AND CHILDREN LIKE MEGAN CAN LIVE A NORMAL LIFE."

UNF~~ORTUNATELY, THERE ARE OVER 300,000 CHILDREN LIKE MEGAN WHO~~ SUFFER FROM EP~~ILEPSY~~. ~~BUT~~ THANKS TO DEDICATED SCIENTISTS LIKE DR. MORRELL AND SO MANY OTHER PIONEERS, AND THANKS TO STATE-OF-THE ART EPILEPSY CENTERS LIKE THIS ONE; AND THANKS TO INCREASED RESEARCH FUNDING, WE ARE MAKING IMPORTANT PROGRESS FOR TH~~OSE~~ WHO SUFFER EPILEPSY -- AND THEIR FAMILIES. the millions of Americans We are hungry ~~that~~ day that Megan + her parents dream of -- closer + closer.

Draft

RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER
Facts

Rush-Presbyterian-St. Luke's Medical Center is the center of a comprehensive, health care system designed to serve some 3 million people through its own resources and in affiliation with other health care institutions.

It includes Rush University, which comprises Rush Medical College, the College of Nursing, the College of Health Sciences, the Graduate College, and a cooperative educational network of 14 liberal arts colleges and universities in six states from Tennessee to Colorado.

Rush is the center for basic and clinical research, with physicians and scientists involved in more than 2,000 investigations, many of them involving two or more disciplines.

The seven Rush Institutes draw together patient care and research to address major health problems, offering primary healthcare services as well as the latest treatments for arthritis and orthopedic problems, cancer, heart disease, mental illness, diseases associated with aging and neurological problems.

Rush System for Health

The medical center is the tertiary hub of the Rush System for Health, a comprehensive health care system capable of serving about two million people through its outpatient facilities and member hospitals. Rush has affiliated with other institutions to meet the demands of an ever-changing health-care environment. Hospitals in the Rush system include: Rush-Presbyterian-St. Luke's Medical Center, Holy Family Hospital, Lake Forest Hospital, Rush North Shore Medical Center, Illinois Masonic Medical Center, Oak Park Hospital, Riverside HealthCare, and Rush-Copley Medical Center.

Research at Rush

Medical research has been central to the mission of the medical Center since Rush Medical College was founded in 1837. External funding for research as Rush has been steadily growing each year for the past 20 years. Research awards for 1997-98 $50,447,035 to support more than 2,300 research projects.

Rush University Faculty and Staff Statistics

Rush Medical College	2,655
College of Nursing	330
College of Health Sciences	228
The Graduate College	122
Medical Staff	1,241

Employees

Rush-Presbyterian-St. Luke's Medical Center employees, as of 6/98: 8,573

Rush University Students

Rush Medical College	487
College of Nursing	586
College of Health Sciences	208
The Graduate College	67
Rush University unclassified Students	52
Residents and Fellows	615

Community Service

Through three major programs, Rush reaches out to the Chicago community by providing the following services:

- Rush Community Services Initiatives Program - With more than 75 percent of Rush's medical student volunteers, Rush University provides a network of community programs to address social and health care needs of the community.
- Rush is in partnership with the YMCA of Metropolitan Chicago and the Homan Square Community Center in providing neighborhood services.
- The Science and Math Excellence Network, a public-private partnership to improve the science and math skills of inner-city children.

THE WHITE HOUSE
WASHINGTON

OFFICE OF THE FIRST LADY

TO Chrissy

FROM Nessa

FAX # 410-664-1406

PHONE #

OF PAGES (including cover)

COMMENTS Sorry about my previous attempt. I'm sending [illegible] background. FYI: HRC is going to see the epilepsy center on a tour and then as part of her remarks she should say something like - "I'm so happy to be part of the dedication of the new ~~Kootz~~ Harrell ~~presser~~ epilepsy center" - The center isn't new - they're just renaming it after this eminent epilepsy Dr. who died last yr. (Bio info attached)