MELANNE! Jen, FYI - re: Chris Reeve

Sorry I missed you. This is a speech that I'm giving for Chris tomorrow at an NIH conference on Spinal cord injury. The conference is a direct result of the president's increasing spinal cord funding by $100,000. Also the call from Mrs. C was fabulous. (Christopher Reeve's assistant) Michael.

Reason why I'm here and Chris isn't.

I want to thank Harold Varmus, Michael Walker and Zach Hall for orchestrating this extraordinary event. And I want to thank all of you. It is wonderful to see your energy, your commitment, and to know that you represent the hopes of millions of people around the world.

Someday the world will look back on these three days as an historic turning point in finding the cure for paralysis. 50 years ago FDR laid down the gauntlet to a gathering of scientists much like yourselves. The result was the eradication of polio. Today a similar challenge is presented to all of you.

There are 250,000 spinal cord injured in the United States today, millions around the world. 10,000 newly injured each year in this country alone. Two thirds of those injured are under 30 years old. Spinal cord injury is among the cruelest of all traumas. I recently received a letter from a 13 year old boy whose best friend had a spinal cord injury. His family, after exhausting all financial resources and unable to continue caring for him at home, was forced to institutionalize him. That 13 year old boys best friend is now living in a mental institution. He wants to know if I can help? The answer is we can help.

Neuroregeneration must move to the forefront of NIH research efforts. Of course the humanitarian reasons for curing paralysis are obvious. I spent a year in rehab at the Kessler Institute, and though I received excellent care I looked out at a brick wall. I am lucky I was able to go home. The majority of spinal cord injured spend their lives looking at that brick wall. But there are also vital economic reasons. We simply cannot afford not to cure paralysis. For the estimated 250,000 severely disabled survivors of spinal cord trauma the costs to the federal government exceed $8 billion dollars a year.

That just doesn't make good fiscal sense.

In the early part of this century a scientist received the Nobel prize for proving that neurons cannot regenerate. I think we have to find that medal and get it back. The prevailing thinking until even 5 years ago was that once spinal cord injured you were in a wheelchair for the rest of your life. There is now a revolution in the neurosciences. That thinking was wrong and people in this audience have proved that.

When I met with the President in May I was heartened for two reasons. First, that the president was willing to be educated. He wasn't fully aware of the great strides and breakthroughs recently made in neuroregeneration. Second, and one of the reasons we are here today is that he along with Harold Varmus increased funding for spinal cord research by $10 million dollars.

In his acceptance speech before the Democratic National Convention, President Clinton reaffirmed his commitment to biomedical research. We also have the strong support of both the House and the Senate, Republican and Democrat.

The government cannot do it alone, and we are mobilizing the private sector. People like Joan Irvine Smith who gave $1 million dollars to establish the Reeve-Irvine center for spinal cord research at U.C. Irvine are leading the way. We are giving a wake-up call across this country to corporate America.

Drug companies, biotech corporations, the insurance industry, petrochemical companies and computer giants are all signing on.

Most importantly, we have grass roots support across the counrty. According to a 1993 Harris poll 91% of the American public feel we should spend more on medical research. Not only do they support more spending; they are willing to pay for it.

We have the federal government, the private sector and the backing of the American people. But their support is meaningless without your leadership. You are the key.

Some of you in this room have spent your whole careers working on curing paralsysis. You have worked alone in isolated labs across the world. Your perseverance was not discouraged by the darkness around you. To all of you thank you for your vision and your sense of purpose.

To the scientists in this room who come from other disciplines; from the fields of genetics, basic science, study of the eye, microbiology and many others: please make the transition to spinal cord injury research.

And there should be one more goal: that there be a free, open and unfettered international exchange of scientific and medical discoveries.

Duplication of effort must be minimal, and efficiency in research must be strengthened. This is essential.

As Zach Hall has said, "We don't have the blueprint for curing paralysis yet, but after this meeting I'm hoping we will at least have a floor-plan." With all of you in one room today we have hundreds of years of scientific knowledge focused on this one problem. I believe today marks the beginning of the end of this national health tragedy. The President speaks of the bridge to 21st century; with your help I and hundreds of thousands like me will walk across that bridge into the new century.

Thank you.

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

August 23, 1996

MEMORANDUM FOR THE CHIEF OF STAFF
HAROLD ICKES

FROM: Jacob J. Lew
Acting Director

SUBJECT: Update on NIH's Plans for Achieving the President's Commitment to Increase FY 1996 Funding for Spinal Cord Research

On May 15, 1996, Christopher Reeve met with the President to express concern that NIH funding for spinal cord research was insufficient. We understand that at the meeting the President committed to increase NIH funding for spinal cord research by *up to* $10 million in FY 1996. Christopher Reeve announced to the press that the President had promised to work with NIH "to find $10 million that will go to spinal cord research." NIH's initial FY 1996 plan included $49 million for spinal cord research.

Given the sensitivity of this issue, we asked HHS to provide a NIH spinal cord research plan for achieving the President's request. The NIH plan appears to be consistent with the President's commitment. The three elements of the plan are:

- NIH indicates that between now and September it will fund 12 grants and four awards to young investigators that would not have been supported otherwise. Thus, this means NIH will be spending an additional $5 million over the $49 million it originally intended to spend on spinal cord research in FY 1996. This increase appears to achieve the President's commitment to spend *up to* an additional $10 million on spinal cord research this fiscal year.

- In addition, NIH intends to increase its planned FY 1997 funding for spinal cord research by $10 million, which will raise FY 1997 NIH spinal cord research funding by 20%, from $50 million to $60 million.

- To foster high-quality spinal cord research grant applications and encourage researchers to enter the field of spinal cord injury research, NIH plans to hold a conference on spinal cord research at the end of September.

If you have any additional questions or concerns about NIH spinal cord research, or if we should supply this information to anyone else, please let me know.

EDITOR'S NOTEBOOK

The government has spent more on military research and development in the past four years than it has on all medical research since the turn of the century. It's no wonder we have smart bombs, but don't have a cure for cancer or for spinal cord injury. Our priorities are out of whack.

That bomb was dropped by Senator Tom Harkin (D-IA) speaking in support of Christopher Reeve's campaign to increase funds for spinal cord injury (SCI) research at a press conference in Washington, DC, to spotlight this effort.

Meet the press: Senators Specter, Arlen, and Harkin flank Christopher Reeve in Washington, *above*. *Right*, members of Congress fill the front row as Reeve asks for an increase in SCI research funding.

The setup: National media await Reeve's first press conference since his accident.

The May 15 press conference, sponsored by *Good Housekeeping*, was Reeve's first since the horseback-riding accident that left him paralyzed more than a year ago. Before a crush of camera crews and print photographers, he called for an increase of $40 million in SCI research so that he and hundreds of thousands of people like him may someday walk again. Reeve explained that medical advances have created optimism about a treatment or cure for these injuries long thought to be hopeless. However, any breakthrough depends on increased funding to support scientists in their research.

With our June cover story by Liz Smith on Reeve and his wife, Dana, we launched a GH Lobby directed to Senator Arlen Specter (R-PA) asking for an increase in SCI research funding. Since then, the response has been overwhelming as readers across the country have joined forces to support the Lobby. In Staten Island, NY, Francesca Saccheri enlisted family and friends to mail 15,000 Lobby coupons to Senator Specter's office. Fran Saccheri is the mother of 17-year-old Sal, who was paralyzed in a car accident in January. "I feel Christopher Reeve is speaking for us," she says. "And I will do everything I can to support this fight so that my son and others can walk again." The American Paralysis Association has also led a groundswell that has spurred the mailing of thousands of coupons.

In our nation's capital, Senator Specter's mailroom is reeling from the deluge of letters, with more arriving daily. We want to applaud Senator Specter, who is chairman of the appropriations subcommittee that allocates money for the National Institutes of Health, for his promise to advance the SCI research cause. He wants everyone to know that although he cannot answer your letters personally, he acknowledges each and every one of them.

To all of you who participated in this Lobby, I want to extend a personal thank-you on behalf of Christopher Reeve and the other 250,000 Americans who are paralyzed as a result of SCI. You have proven once again that GH readers really do care, and together we have the power to help and heal.

Ellen Levine

TOP PHOTOGRAPHS BY DOUG GOODMAN

THE PRESIDENT HAS SEEN
5.20.96

CHRISTOPHER REEVE

cc J. Klein

cc VP/Comm
NSC

JIM DORSKIND:
Please coordinate
the reply.

The President and Mrs. Clinton
The White House
1600 Pennsylvania Avenue
Wahsington, D.C. 20502

May 16, 1996

Dear President and Mrs. Clinton

Thank you so much for taking the time to meet with me yesterday. Of course it was more fun to shoot the breeze about jazz with Billy Crystal the last time we visited but I was tremendously uplifted by your obvious concern for me and all the others in a similar condition. When I announced the $10 million to be spent on spinal cord regeneration research there was an audible gasp in the room, followed shortly by an announcement by Senator Spector that he would offer an amendment of $40 million in this years budget. Thanks to you the gauntlet has been thrown down. I deeply appreciate your agreement that research is the real answer to our health care crisis and one of the most positive steps we can take to deal with the deficit. The scientists are ready and willing to discuss the incredible progress that has been made in just the last few years; in fact at yesterdays luncheon Dr. Ira Black gave a description of new advances in blocking growth inhibitors that was truly inspirational.

It seems clear we have entered a new era of progress and possibility in afflictions of the brain and central nervous system. With so many members of Congress willing to work together on this issue and with your leadership there is now real reason to hope. Thank you again.

Sincerely,

Christopher Reeve

11 GREAT HILL FARMS ROAD BEDFORD NEW YORK 10506

SPINAL CORD INJURIES

REEVE'S POSITION

Christopher Reeve supports increasing funding for research on spinal chord injuries by $40 million each year. He believes that, with an additional $40 million each year, paralyzing injuries could be curable in five to ten years. He also believes that ending these injuries could mean billions of dollars in savings in Medicare and Medicaid.

BACKGROUND

The Impact of Spinal Cord Injuries

About 200,000 Americans are now permanently confined to wheelchairs because of spinal cord injury. Each year, about 10,000 more people are injured, suffering paralysis and loss of sensation. About two-thirds of these people are under the age of 30. Specialized care for people with spinal cord injury costs as much as $10 billion each year.

Federal Investment in Spinal Cord Injuries

National Institutes of Health. The National Institutes of Health spent a total of $47 million on spinal chord injury research in 1995. This amount is expected to increase to about $49 million in 1996 and about $50 million in 1997. Since 1993, spending for spinal cord injury research has increased by 3.1%.

This increase is actually quite small in comparison to other areas. The total budget of the National Institutes of Health has increased by 20.1% since 1993. This includes a 79% increase in breast cancer research, a 33.3% increase in AIDS research, and a 9.4% increase in Alzheimer's Disease research.

However, there is promising new research being undertaken. For example, NIH is sponsoring research on the development of neural prostheses to restore sensation or movement. Already this program has enabled paralyzed people to pick up objects or to grasp a cup and drink without assistance and has allowed doctors to implant tiny electrodes inside the body to stimulate muscle or nerve cells. In addition, NIH is working on several projects to repair damaged DNA or to implant so-called progenitor cells in order to replace or regenerate tissue in an injured central nervous system.

Centers for Disease Control.

The National Center for Injury Prevention and Control (NCIPC) at the Centers for Disease Control and Prevention (CDC) works on spinal cord injury prevention. Christopher Reeve recently spoke with Dr. Mark Rosenberg, the Director of NCIPC. NCIPC has two main goals in addressing spinal cord injuries: (1) to prevent injuries from occurring; and (2) to reduce the impact of injury once it occurs. NCIPC is currently sponsoring research on spinal cord injuries, including research on spinal cord regeneration. Dr. Rosenberg would be happy to provide Christopher Reeve with a more detailed briefing about NCIPC's activities at his home.

Spinal Cord Injury Research

- HHS advises that NIH funding levels for spinal cord injury research are as follows:

(BA in $ millions)

FY95	FY96	FY97
47	49	50

- The quickest way to add resources to this area in FY96 would be to utilize the 1% transfer authority granted to HHS in the FY96 appropriations act (Section 211 of P.L. 104-134). Up to 1% of any HHS appropriation may be transferred to another HHS account this year. Once HHS identifies appropriate offsets, funds could be transferred immediately.

- Other options for FY96 include transmitting a supplemental request to Congress. It is not clear how likely Congress would be to act on such a request; offsets would probably be necessary as well.

- For FY97, options include having HHS pledge to use the 1% transfer authority requested in the President's FY97 Budget (which is similar to the enacted language), as well as transmitting a Budget Amendment.

- It is not clear how much additional funding for this sort of research could be utilized efficiently; $5-$10 million may be appropriate. For NIH to make research grants, it has to have high-quality proposals to fund. We will check with HHS/NIH to better understand how many high-quality research opportunities there are in this field that could benefit from an immediate infusion of additional resources.

- The Department of Veterans Affairs is the nation's pre-eminent spinal cord injury health care and rehabilitation provider. VA medical centers utilize state-of-the-art diagnostic and rehabilitation equipment and cutting edge research to help about 10,000 veterans with spinal cord injuries each year. We are checking on exact funding levels for spinal cord injury health services and research (the research figure is something less than $25 million).

- We have attached an HHS information sheet on spinal cord injury research.

SPINAL CORD INJURY RESEARCH

About 200,000 Americans are now permanently confined to wheelchairs because of spinal cord injury. Each year, about 10,000 more people are injured, suffering paralysis and loss of sensation. About two-thirds of these people are under the age of 30. Specialized care for people with spinal cord injury costs our Nation as much as $10 billion each year. Within the National Institutes of Health, research on spinal cord injury is primarily supported by the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Child Health and Human Development (NICHD).

The NINDS supports several large, multiproject centers devoted to clinical and basic research on spinal cord injury. The projects range from fundamental studies of cellular responses to injury to clinical studies of movement in chronic spinal cord injury. A recent addition to the spinal cord injury portfolio is the Multicentered Animal Spinal Cord Injury Study. This consortium of laboratories tests promising pharmacological agents in a standardized model of spinal cord injury. It is hoped that such collaborations may make more drugs available for clinical testing.

One strategy being pursued by NINDS grantees to restore nervous system function is the development of neural prostheses to restore sensation or movement. Already this program has yielded: a hand-grip prosthesis that enables paralyzed people to pick up objects or to grasp a cup and drink without assistance; tiny electrodes, measuring about one-third the width of a human hair, that can be implanted inside the body and used to stimulate muscle or nerve cells; new understanding of the nervous system and its pathways that will help scientists place future prostheses in the most effective location; and artificial sensors that may help paralyzed patients to better control movement.

DNA damage is present in central nervous system (CNS) injury and defects in repair mechanisms are associated with neurodegenerative disease. NINDS supported a workshop, "DNA Damage and Repair," in September 1995, to bring together scientists and clinicians with expertise in DNA injury and repair, with investigators in CNS trauma, to foster research in this new area of science. The participants explored the connections between these fields and identified gaps in knowledge in order to expand investigations on the mechanisms of cell damage.

In March 1996, NINDS issued a Request for Proposals to investigate the use of implanted progenitor cells to treat central nervous system trauma. Recent discovery of the presence of progenitor cells within the adult nervous system has suggested another potential source of replacement tissue for the injured CNS. The feasibility of using these cells is now unknown. The

contract project seeks to identify precursor cells from the adult central nervous system, expand these populations in tissue culture, develop the protocol of growth factor stimulation necessary to produce stable neurons, and evaluate the survival of these neurons after transplantation into the chronically-injured adult nervous system.

The National Center for Medical Rehabilitation Research (NCMRR, a component of the National Institute of Child Health and Human Development, NIH) is emphasizing the support of research to promote the independence, productivity, and health of people with spinal cord injury. Included in that research are studies seeking: (1) better ways of preventing urinary tract infections and skin problems to which people with spinal cord injury are prone, (2) improvements in uses of computer-controlled electrical stimulation to make walking possible, and (3) more effective means of dealing with the chronic pain which many of these people experience.

DHHS-National Institutes of Health

Spinal Cord Injury
(In $000)

Funding:	'95	'96 (est.)	'97 P.B.
NIH, Total	47,048	49,395	50,368

Keep! Jen

Date: 05/15/96 Time: 18:13
CClinton Promises Actor $10 Million for Spinal-Cord Research

WASHINGTON (AP) Christopher Reeve says his family's support and the hope of a medical breakthrough have kept him going since a near-fatal accident left him a quadriplegic almost a year ago.

Speaking at a luncheon on Capitol Hill, Reeve flashed a victorious smile as he announced from his respirator-equipped wheelchair that President Clinton has earmarked $10 million for spinal-cord research.

``For President Clinton to find $10 million in this year of such strife ... is a very significant step forward, a very significant first step,'' Reeve said after the luncheon.

``I hope it will also provide an incentive for Congress to appropriate the funds that are really needed to find a cure,'' he said.

Reeve, 43, was paralyzed from the neck down in a May 27 fall from a horse. The ``Superman'' star has teamed up with Good Housekeeping magazine to lobby Congress to increase money for spinal-cord injury research. He met with Clinton at the White House before his appearance on Capitol Hill.

White House aides said Clinton directed that $10 million in the National Institutes of Health budget be dedicated to spinal-cord research. The current budget already appropriated $49 million for such research.

At a news conference before the luncheon, Sen. Tom Harkin, D-Iowa, and Sen. Arlen Specter, R-Pa., said they support Reeve's cause.

``We will work with you ..., and we will try to help you with the necessary funding,'' Specter said. ``When we saw you come in ... and the progress you're making, we really understand that you are truly Superman.''

Reeve said that as chairman of the American Paralysis Association he will spearhead a campaign to seek funds not only from the government but from private business.

At the luncheon, an aide fed Reeve his lunch grilled chicken, sauteed vegetables and rice and helped him drink water through a straw.

With new technology and funding for research he hopes to walk again in seven years, he said, and not in 10 years as he has said in previous interviews.

How has the accident changed him?

``I think it's made me value, even more than previously, the love and support of people that I'm close to,'' Reeve said.

Asked his feelings as the one-year anniversary of his fall nears, the actor smiled and said:

``I'm really not thinking of those terms. I don't think in terms of one year, two years.''
APNP-05-15-96 1816EST

Previous Story: **Jemima Goldsmith, Imran Khan Expect Baby**
Next Story: **The Top 20 Prime Time TV Programs: May 6 - 12**

Wednesday May 15 3:36 PM EDT

Christopher Reeve Seeks Funding For Spine Research

By Joanne Kenen

WASHINGTON (Reuter) - Paralyzed actor Christopher Reeve came to Congress Wednesday to lobby for more funds for spinal cord research so that he and hundreds of thousands of people like him could someday walk again.

Advances in neuroscience have spurred unprecedented optimism about a treatment or cure for spinal cord injuries, long thought to be hopeless. But Reeve, a screen idol best known for his "Superman" films, said the breakthrough could take another four decades if funding is not increased.

If scientists are adequately funded, he said, he might be walking seven years from now, in time for his 50th birthday.

``I would like to stand up and toast everyone at the party,'' he told a news conference on Capitol Hill.

Injured a year ago this month in a horseback riding accident, Reeve is restricted to a wheelchair and severely disabled. But he speaks clearly, grins warmly and had a Capitol conference room packed, with standing room only even for members of Congress.

About 250,000 Americans, and many more people throughout the world, are paralyzed because of spinal cord injuries.

``Many people do not know -- and they should know -- that a cure for spinal cord injuries is now obtainable,'' Reeve said. "I will walk again,'' he said.

Reeve met President Clinton earlier Wednesday and said the president assured him of at least $10 million more this year earmarked specifically for spinal cord research.

Republican Sen. Arlen Specter of Pennsylvania, chairman of a Senate subcommittee with jurisdiction over health research funds, accompanied Reeve and said he planned to put in motion Wednesday a $40 million funding increase.

The congressional appearance was sponsored by Good Housekeeping magazine, which features Reeve and his wife Dana on their June cover. In that article, Reeve said he hoped to continue his career in entertainment as a director of plays and movies.

He is also supposed to be the voice of King Arthur in a new Warner Brothers animation, ``The Quest for Camelot'' and is in demand as a speaker. ``I'm booked for speaking engagements for more money than I was ever offered when I was upright,'' he told the magazine.

TALKING POINTS FOR MEETING WITH CHRISTOPHER REEVE
THE OVAL OFFICE
MAY 15, 1996

- I'd like to thank you for your strength and courage. You have really been a model for all of us.

- I'd also like to thank you for the commitment you have shown to others. As with all of the other causes you have taken on during your life, you bring to this effort unparalleled passion and dedication. It would have been enough of a challenge to focus on your own path to recovery over the past year. Instead, your work on behalf of others with spinal cord injuries and more generally for people with disabilities has already begun to make a difference in people's lives.

- I know you are commited to increasing funding for research on spinal cord injuries. I would like to work with you, the National Institutes of Health, and Members of Congress to make this a priority.

THE WHITE HOUSE

WASHINGTON

May 14, 1996

PHOTO OPPORTUNITY AND VISIT WITH CHRISTOPHER REEVE

DATE: May 15, 1996
LOCATION: Oval Office
TIME: 10:00 to 10:20 AM
FROM: Alexis Herman
Bill White

I. PURPOSE

To give Christopher Reeve the opportunity to discuss his efforts to obtain increased federal funding for spinal cord injury research.

II. BACKGROUND

Christopher Reeve, paralyzed in a horseback riding accident in May, 1995, is visiting Washington to raise public awareness of spinal cord injury and funds to affect a cure. Despite his disability, Christopher claims to be busier now than before the accident, and is currently writing a book, directing a movie, and even performing in one. During a recent interview, he said, "The choice is whether to wallow in self-pity and musing about the past, or take a proactive stance about the future."

Throughout his career, he was always the activist, taking on the GOP's attempt to cut funding for the arts in 1994. During his rehabilitation, Christopher continues to speak out, turning his attention now to health and disability issues. When Christopher learned that his insurance capped his benefits at $1.2 million, he actively worked for the passage of the Jeffords amendment, which attempted to raise lifetime health insurance caps to $10 million.

Christopher's current focus, and the purpose of his trip to Washington, is to lobby for increased National Institute for Health (NIH) funding for spinal cord injury research. Christopher believes that if the government commits an additional $40 million a year to spinal cord research, paralyzing injuries could be curable in five to ten tears. Furthermore, Christopher believes additional funding could lead to billion in savings in Medicare and Medicaid.

Christopher will ask for your and the First Lady's support for his initiative. In 1995, the NIH spent $47 million for spinal cord injury research. That increases to $49 million in 1996, and the Administration currently plans to request $50 million for 1997. You should indicate your continued support for increasing research funding for spinal cord research during a time of decreasing budgets.

Following the meeting, Christopher will travel to the Hill to hold a press conference calling for increased federal funding for spinal cord injury research. Speaking at the press conference, and a luncheon that follows, will be Senator Arlen Specter (R-PA) and Senator Tom Harkin (D-IA). Both Senators Specter and Harkin will speak in support of increased spinal cord funding, but will not endorse a specific amount.

The ABC News program 20/20 will film the opening greeting at the top of the meeting. The footage will be used for an update of the Barbara Walters portrait on Christopher's rehabilitation and his efforts with regard to health and disability issues.

Last month, on Larry King Live, Christopher spoke very favorably of your phone calls to him after his accident. Christopher is able to speak and breathe with the assistance of a portable ventilator that fits behind his wheelchair. In case of an emergency, his medical assistants will be holding in the Cabinet Room.

III. PARTICIPANTS

The First Lady
Christopher Reeve

IV. PRESS PLAN

Closed press. (ABC's 20/20 will only film the opening of the meeting.)

V. SEQUENCE OF EVENTS

- o You and the First Lady will greet Christopher Reeve upon his entrance into the Oval Office. (20/20 will only film the opening of the meeting.)
- o You and the First lady will take seats on the couch. Christopher will be situated in his wheelchair near the couches.
- o After 10 minutes, the First Lady and Christopher will depart the Oval Office, and continue their visit in the Map Room.

VI. REMARKS

Not required.

Attachments

Tab A - Federal Research on Spinal Cord Injury
Tab B - Lifetime Limits on Health Insurance Benefits

LIFETIME LIMITS ON HEALTH INSURANCE BENEFITS

REEVE'S POSITION

Christopher Reeve strongly opposes lifetime limits on benefits in health insurance plans. Reeve has a $1.2 million cap on benefits in his primary insurance policy, a fact which he did not discover until after his injury. Because his yearly expenses are about $400,000, he expects to exceed the cap in his primary policy in about two more years.

THE JEFFORDS AMENDMENT AND KASSEBAUM-KENNEDY

Last month, Senator Jeffords introduced an amendment to the Health Insurance Reform Act of 1996 (Kassebaum-Kennedy) which would have required health plans to have a lifetime limit on total benefit payments of not less than $10 million. The amendment was withdrawn before a vote in committee. Reeve strongly supported the Jeffords amendment.

The Administration took no position on the Jeffords amendment. We did this because of our overall strategy on Kassebaum-Kennedy to avoid supporting controversial amendments that might reduce the chances for passage of the bill. As you may remember, however, the Health Security Act would have eliminated all lifetime benefit caps.

BACKGROUND ON LIFETIME LIMITS

The inclusion of lifetime benefit caps in insurance policies became common in the 1970s. The most common limit was $1 million. Currently, about sixty percent of health plans have lifetime limits on benefits.

Lifetime limits have not kept pace with inflation. The caps in most policies have not been adjusted for inflation. As a result, the value of limits are much lower today: a $1 million limit imposed in 1975, if adjusted for inflation, would be approximately $10 million today.

A growing number of people reach the cap each year. Price Waterhouse has estimated that 1,500 people exceeded their lifetime limits in 1995, and this number increases significantly each year as inflation erodes the value of the typical $1 million limit.

The cost of removing lifetime limits is small. A number of private sector actuaries (including Price Waterhouse and Towers Perrin) have estimated that the cost of eliminating lifetime limits ranges from 1 to 3 percent of existing premiums.

SPINAL CORD INJURIES

REEVE'S POSITION

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BACKGROUND

The Impact of Spinal Cord Injuries

About 200,000 Americans are now permanently confined to wheelchairs because of spinal cord injury. Each year, about 10,000 more people are injured, suffering paralysis and loss of sensation. About two-thirds of these people are under the age of 30. Specialized care for people with spinal cord injury costs as much as $10 billion each year.

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This increase is actually quite small in comparison to other areas. The total budget of the National Institutes of Health has increased by 20.1% since 1993. This includes a 79% increase in breast cancer research, a 33.3% increase in AIDS research, and a 9.4% increase in Alzheimer's Disease research.

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DHHS-National Institutes of Health

Spinal Cord Injury
(In $000)

Funding:	'95	'96 (est.)	'97 P.B.
NIH, Total	47,048	49,385	50,368

NIH Funding for Spinal Cord Injury Research and Other Selected Areas of Research
(dollars in thousands)

Selected Research Area	FY 1993 Actual	FY 1997 Estimate	Percent Change
Alzheimer's Disease	287,239	314,159	9.4%
AIDS Research	1,073,957	1,431,808	33.3%
Cancer Research	2,225,214	2,612,819	17.4%
Diabetes	285,649	313,334	9.7%
Infant Mortality (LBW)	301,473	347,136	15.1%
Parkinson's Disease	71,934	77,703	8.0%
Sleep Disorders	58,089	77,294	33.1%
Spinal Cord Injury & Regeneration	48,842	50,368	3.1%
Stroke	106,771	121,943	14.2%
Sudden Infant Death Syndrome	45,353	46,821	3.2%
Breast Cancer	228,937	409,545	79%
NIH Total Budget	10,328,117	12,406,300	20.1%

05/14/96

Question:

Mr. Reeve is seeking to increase funding for spinal cord research by $40 million. What would be the effect of such an increase?

Answer:

There are a number of promising areas in spinal cord injury and regeneration that could be pursued, or developed faster, with such a sizable increase in funding across the next three to five years. In the area of basic research, projects could be developed to explore DNA injury and repair specific to spinal cord injury; the role of hormones in the exacerbation of injury; the role of astrocytes and other glia in SCI; animal models of cervical spinal cord injury; and the basic mechanisms of cell death and excitotoxity in the spinal cord.

The development of neural prostheses holds great promise to restore nervous system function to spinal cord injury patients. The NINDS is in the process of soliciting proposals to develop a prosthesis that would allow a paraplegic in a wheelchair to stand independently and remain standing. However, the current funding will allow only one project to be funded across the next three years; additional funds could allow several projects to be pursued simultaneously, or permit expansion of this research to provide the ability to walk. A prosthesis is now capable of restoring some hand function to quadriplegics; additional efforts could restore full arm movement, including wrist movement, and ultimately allow sensation as well as movement.

In the clinical area, several avenues are ripe for exploration. Additional compounds could be screened and selected for testing through the National Acute Spinal Cord Injury Study (NASCIS) group to treat patients with acutely injured spinal cords by pharmacologic therapy. The data analysis is currently underway for the recently completed NASCIS III trial (methylprednisolone and tirilazad), and this clinical trials structure could be used to test other compounds that have shown promise preclinically in animal models of spinal cord injury. Early Phase I trials could be developed to evaluate cellular therapy, i.e. cell implantation, which is an area of interest to both investigators and biotechnology firms. The arena of growth factor therapy for acute and chronic spinal cord injury (already being pursued in Alzheimer's disease) could be explored in early phase I trials with an infusion of funding into clinical development. The NINDS research portfolio could expand into treatment paradigms for chronic injury including electrophysiology, behavior, and infection. Finally, there are broad issues, such as methodologies for selecting compounds for testing, surrogate endpoints, and protocol design, that require resolution and definition before major new Phase III clinical trials in SCI could be explored. These major issues could be addressed by leading researchers and clinicians with additional funding.

NINDS Research Planning and Priorities

NINDS has always been oriented strongly in the direction of investigator-initiated research. This reflects not only a management philosophy, but it is the logical process for the neurological sciences. Our understanding of the brain has expanded dramatically in recent years, largely due to the innovative proposals of individual scientists, healthy competition to answer questions of major importance, and the accompanying development of technologies to support those efforts. This work is now beginning to bear fruit in the form of clinical applications, which until recently were very limited for brain disease.

However, the NINDS is not just a passive observer of the scientific scene. For many years the Institute's policy has been to award the first 80 percent of uncommitted grant funds according to scientific priority score. The remaining 20 percent is allocated to projects of special relevance or promise as identified by staff and the National Advisory Neurological Disorders and Stroke Council. During the past year NINDS has made some major improvements in how those allocations are made, resulting in a more interactive process within the Institute and with Council. As a result, the process has become more consistent.

The Institute also takes a longer view of priorities. Each year the intramural and extramural components of NINDS identify areas to be emphasized through program announcements and contract solicitations, as well as conferences and workshops to be supported or organized by staff in order to stimulate or assess given areas of research. Future goals include engaging the external scientific community more in this process.

Planning and priority-setting also occur through interaction with several components of the Office of the NIH Director that are engaged in planning and policy for an NIH perspective. The Institute interacts in a variety of ways: through its budget office and science policy office, which have counterparts in the OD, and with a variety of central offices and trans-NIH committees on which its scientific or science policy staff serve. NINDS has found that the current structure provides a good balance between the need for a unified approach and the need to incorporate the scientific and policy concerns of the Institutes and Centers. A good example is the process through which the NIH Institutes have been invited to propose areas of emphasis in future budget proposals or advise on the allocation of funds controlled by the Director for the current year.

Dr. VARMUS. Clearly, Mr. Porter, the magnitude of the impact of illness is a factor to be considered as we put the budget together. But as many of my colleagues, especially Doctor Lenfant, have pointed out to me, budget building by body count is not the right way to go, nor is simple economic impact the right way to go. We have to consider the opportunities for scientific advancement that spreads more widely through our portfolio. We need to consider the quality of applications that we get in certain categories. We need to recognize that if we simply considered impact on the economy or on mortality figures as a major criterion, we would be spending very little on rare diseases. We know, first of all, that rare diseases are important to those who are afflicted by them; and secondly, that many of the most important discoveries we have made have come from the pursuit of rare diseases. I mentioned just a few moments ago the recent discovery of a gene that is involved in premature aging in a rare disease (Werner's Syndrome). My personal belief is that studying those genes and their protein products is going to be extremely revealing about many components of the aging process, including cancer and other diseases, ~~that occur during aging~~. Unless we adapt our budgeting of the research monies in accord with the scientific priorities as well as the public health impact, we're going to be failing to take advantage of many opportunities that currently exist.

(CDC)

NCIPC Funding of Spinal Cord Injury Related Projects
(1987-1996)

Project Title: Long Term Renal Function Following Spinal Cord Injury
Total Funding to Date: $602,098

Project Title: Spinal Canal Geometry Changes in Vertebral Fracture
Total Funding to Date: $395,994

Project Title: Biomechanics of Cervical Spinal Cord Injury
Total Funding to Date: $1,039,471

Project Title: Rehabilitation Following Lower Extremity Fracture
Total Funding to Date: $1,360,701

Project Title: Rehabilitation Efficacy for Brain and Spinal Injury
Total Funding to Date: $284,065

Project Title: Acute Treatment of Contusion to the Spinal Cord
Total Funding to Date: $694,975

Grand Total: $4,377,304

National Center for Injury Prevention and Control, CDC

NCIPC Budget Figures

Funding for program activities was appropriated as follows:

Fiscal Year	NCIPC Appropriation
1991	$24.0 million
1992	$27.4 million
1993	$31.8 million
1994	$39.3 million
1995	$43.6million
1996	$46.3million

All
Spent on Rehabilitation:

FY1996	FY1995	FY 1994
$4.1 million	$4.1 million	$3.2 million

DEPARTMENT OF HEALTH AND HUMAN SERVICES
ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF HEALTH POLICY

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Number of Pages (Including Cover): _____

Comments:

Lifetime Limits on Health Insurance Benefits

Background

Last month, Senator Jeffords introduced an amendment to the Health Insurance Reform Act of 1996 (S. 1028, introduced by Senators Kassebaum and Kennedy) which would have required health plans to have a lifetime limit on total benefit payments of not less than $10 million. The amendment was defeated. (The President's health insurance proposal would have eliminated all lifetime benefit caps. The House did not consider such an amendment when it considered insurance reform legislation in March).

The inclusion of lifetime benefits in policies became common in the 1970's. The most common limit was $1 million. Removal of the limit would extend protection for people who most need it, and prevent some costs from being shifted to the government.

The primary arguments for lifting lifetime caps on benefits are:

1. **Lifetime limits have not kept pace with inflation:** Most policies do not adjustment their limits for inflation. As a result, the value of limits is much lower today: a $1 million limit imposed in 1975, if adjusted for inflation, would be approximately $10 million today.

2. **The cost of removing lifetime limits is small:** A number of private sector actuaries have estimated the cost of eliminating lifetime limits on premiums. The cost varies depending on the existing limits and the nature of the benefits covered by a plan, but the range of costs is generally from less than 1 percent to 3 percent of existing premiums for most plans.

3. **A growing number of people reach the cap each year:** Price Waterhouse has estimated that 1500 people would exceed their lifetime limits in 1995, and this number is increasing significantly each year as inflation erodes the value of the typical $1 million limit.

4. **Savings will occur to the government if lifetime caps are removed:** Price Waterhouse has estimated that the government would have saved $440 million in the Medicaid program in 1995 if there had been no lifetime caps.

Why do we not support it?

Estimate (Nexis) of when he will exceed limit

SPINAL CORD INJURY RESEARCH

About 200,000 Americans are now permanently confined to wheelchairs because of spinal cord injury. Each year, about 10,000 more people are injured, suffering paralysis and loss of sensation. About two-thirds of these people are under the age of 30. Specialized care for people with spinal cord injury costs our Nation as much as $10 billion each year. Within the National Institutes of Health, research on spinal cord injury is primarily supported by the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Child Health and Human Development (NICHD).

AP wire story HRC column Good Housekeeping article $400,000/yr cap is 3 yrs = Fed $ 1.2 Million

The NINDS supports several large, multiproject centers devoted to clinical and basic research on spinal cord injury. The projects range from fundamental studies of cellular responses to injury to clinical studies of movement in chronic spinal cord injury. A recent addition to the spinal cord injury portfolio is the Multicentered Animal Spinal Cord Injury Study. This consortium of laboratories tests promising pharmacological agents in a standardized model of spinal cord injury. It is hoped that such collaborations may make more drugs available for clinical testing.

One strategy being pursued by NINDS grantees to restore nervous system function is the development of neural prostheses to restore sensation or movement. Already this program has yielded: a hand-grip prosthesis that enables paralyzed people to pick up objects or to grasp a cup and drink without assistance; tiny electrodes, measuring about one-third the width of a human hair, that can be implanted inside the body and used to stimulate muscle or nerve cells; new understanding of the nervous system and its pathways that will help scientists place future prostheses in the most effective location; and artificial sensors that may help paralyzed patients to better control movement.

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necessary to produce stable neurons, and evaluate the survival of these neurons after transplantation into the chronically-injured adult nervous system.

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DHHS-National Institutes of Health

Spinal Cord Injury

Funding: (In $000)	**'95**	**'96 (est.)**	**'97 P.B.**
NIH, Total	47,048	49,395	50,368

Millions?

Mark Rosenberg, CDC
→ Cure for paralysis
→ Resume prof. life
→ Strong family life

Medicare/Medicaid $s being spent on people w/ these injuries

DHHS-National Institutes of Health

Spinal Cord Injury

(Dollars in thousands)

Participating ICDS	1993 Actual	1994 Actual	1995 Actual	1996 Estimate	1997 Estimate	Percent Change
NINDS	$41,712	$39,169	$39,251	$41,242	$42,147	2.19
NICHD	2,700	3,233	2,723	2,800	2,800	0.00
NEI	3,860	4,289	3,480	3,651	3,709	1.59
NIA	0	0	0	0	0	
NIMH	0	0	1,140	1,197	1,197	0.00
NCRR	394	258	275	305	305	0.00
NINR	176	200	179	200	210	5.00
NIH	48,842	47,150	47,048	49,395	50,368	1.97

R:\KARIS\1997\SPINAL\CO.WK4

May 10, 1996

↑
Over entire period?

He wants doubled each year?

How compare to funding for other diseases?

How many people affected?

Under what goes on in NIH as a whole?

DEPARTMENT OF HEALTH AND HUMAN SERVICES
ASSISTANT SECRETARY FOR PLANNING AND EVALUATION
OFFICE OF HEALTH POLICY

POTUS –

- Thank you for own your strength, courage, and dedication / you have shown to others.
- Work w/ NIH, and Coord with Sens Specter, Harkin and others on the will to make this a priority.

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Number of Pages (Including Cover): 13

(1) Costs = $400,000 a year - 3 years To cap of $1.2M
(Source HRC + Reevequote Ladies Home Journal)

Comments:

(2) Advances include: Price Waterhouse + Towers-Perrin

(3) The 4th bullet is fed. gov't but don't use per HCFA OACT - They think the estimate assumptions are very questionable.

"If you want an example of whether or not it could happen to you, here's Superman. ... He has a cap of $ 1.2 million. His costs are $ 400,000 a year. In three years, he exceeds the cap. ... What about people who do not have the resources of a Christopher Reeve?"

LANGUAGE: ENGLISH

LOAD-DATE: April 19, 1996

PAGE 3

FOCUS - 2 OF 19 STORIES

The Hill

March 13, 1996

SECTION: OPEN SECRETS; Pg. 12

LENGTH: 134 words

HEADLINE: Christopher Reeve may hit the Hill

BYLINE: Compiled by Eamon Javers;Marcia Gelbart, Craig Karmin, and Jamie Stiehm contributed to this page.

BODY:

Sen. James Jeffords (R-Vt.) has a neat idea: He wants to amend the Kassebaum-Kennedy health insurance bill to raise the lifetime limit to $10 million on health care for catastrophic injuries. And he is bringing in some help from Hollywood , actor Christopher Reeve, who was recently paralyzed in a horseback-riding accident. Reeve, who played Superman in the movie series, may come to Washington to make the case for the amendment, according to Jeffords' office.

But there's one small hitch: Sen. Edward Kennedy (D-Mass.), who supports the concept in principle, does not want the catastrophic

HEADLINE: REEVE'S COURAGE SENDS STRONG MESSAGE TO THOSE IN POWER

BYLINE: HILLARY RODHAM CLINTON

BODY:

I always admired Christopher Reeve as an actor. I never saw him on Broadway, but like most people, I loved his movie portrayal of Superman and his role in the fantasy romance Somewhere in Time.

My admiration has only grown since his riding accident last May. Reeve is no longer playing a part that's heroic. He's living one.

Hooked up to a ventilator and paralyzed from the neck down, he has inspired millions with his courageous response to a tragic and freak fall from a horse. Who wasn't moved by his candor and grace in the memorable interview he gave to Barbara Walters just a few months after his spinal cord was crushed?

Now, along with his painstaking recovery, he faces medical bills totaling $ 400,000 a year. With an insurance policy that limits the lifetime benefits he can receive, his coverage is due to run out after three years.

Still, he never dwells on his own situation. As a celebrity, he knows he can make a living giving speeches and directing films. He is far more worried about the tens of millions of Americans who can't get or keep medical coverage because of the misplaced priorities of our health care system.

Reeve wants to know why our country is willing to spend billions of dollars on Medicare and Medicaid payments to cover nursing-home fees for quadriplegics and those suffering from neurological diseases like Lou Gehrig's, Parkinson's and Alzheimer's but not spend the lesser amounts it would take to find cures.

I know the health care reform effort I worked on was not successful. But the issues it raised and the problems it sought to resolve are still with us today.

The United States is the only industrial society in the world where insurance companies are allowed to deny coverage to people who are sick or have lost a job. And insurance companies continue to get away with limiting people's lifetime benefits.

As Reeve said recently, ''These issues are crucial to our

welfare.''

There are ways to make progress without a massive overhaul of the health care system.

Right now, a bipartisan bill that deals with some of these issues is stuck in Congress. Sponsored by Republican Sen. Nancy Kassebaum of Kansas and

Democratic Sen. Edward Kennedy of Massachusetts, the bill would make long-overdue changes in the ways insurance companies treat Americans.

It would prevent insurers from denying coverage to a person who already has a medical condition. It would forbid insurance companies from dropping longtime customers when they become chronically ill.

And it would require insurance companies to sell policies to workers who have been covered for at least 18 months by their employers so that they remain insured even if they lose or leave a job.

There is also an amendment to the bill, sponsored by Republican Sen. James Jeffords of Vermont, that would help the 230,000 Americans in situations similar to Reeve's. It would raise the lifetime limit on benefits to a minimum of $ 10 million.

The Kennedy-Kassebaum bill has support from dozens of Republicans and Democrats. It is now ready for a vote by the full Senate. Very few legislators have publicly opposed the bill.

So why hasn't it passed?

Because a handful of senators have used parliamentary

From CDC

BACKGROUND INFORMATION FOR CHRISTOPHER REEVE VISIT
WITH PRESIDENT AND MRS. CLINTON

He called Mark Rosenberg;

- Christopher is interested in 3 things: (1) finding a cure for paralysis; (2) resuming his professional career (as a director); and (3) maintaining a strong family life.

- The President should inform Christopher that there is a Center that was established to be the lead agency for injury prevention; namely, the National Center for Injury Prevention and Control at CDC.

- NCIPC is sponsoring research on the issue of spinal cord injuries, including research on spinal cord regeneration.

- The President could tell Christopher that he knows Christopher spoke with Dr. Mark Rosenberg, Director of CDC's National Center for Injury Prevention and Control. The President might urge Reeve to visit the Center, or [the President could indicate that he would ask] Dr. Rosenberg and some of his colleagues at the Center to provide him with a briefing at his home, so that Reeve can learn more about what the Government is doing, or what needs to be done, in order to (1) determine the extent of the problem; (2) improve trauma care; (3) improve rehabilitation; (4) determine how and to whom injury-related disabilities occur; and (5) reduce disabilities and secondary conditions.

Spinal Cord Injury Prevention Activities
Centers for Disease Control and Prevention
National Center for Injury Prevention and Control

CDC is the nation's prevention agency--addressing the prevention of disease, injuries, and disabilities. CDC's National Center for Injury Prevention and Control is responsible for conducting and coordinating injury control efforts in the United States.

Injuries remain an enormous health problem in the United States. More than 145,000 Americans die each year from injuries and over 70,000 will live with a disability resulting from injury. Injuries are costly--the impact on the economy is tremendous. Injuries may cost the United States more than $224 billion a year.

CDC fills a unique niche in the field of injury prevention and control. CDC links injuries to health outcomes, uses public health methods to address the problem, and works with public health and health care communities throughout the country.

A central part of the CDC's injury prevention and control activities involve disability and rehabilitation--focusing on traumatic spinal cord and traumatic brain injury.

CDC does use a unique approach. We look at the entire group of persons who sustain spinal cord injuries--not just those who receive care at the tertiary acute care and rehabilitation facilities. It is important to know about spinal cord injuries broadly.

CDC has two main objectives in addressing spinal cord injuries:

- to prevent injuries from occurring
- to reduce the impact of the injury once it occurs

Spinal cord injury (SCI) prevention

Using the public health approach to prevent spinal cord injuries, we ask four questions:

- **What's the problem?** From our monitoring activities, we know :

  - about 10,000 persons sustain spinal cord injuries each year
  - over 75% of the injuries occur among males
  - young males between ages 15 and 34 are at highest risk
  - SCI cost the US economy $7.4 billion

- **What is the cause?**

  - major causes of injury are motor vehicle crashes, falls and firearms
  - among African-Americans, the leading cause of injury is firearms

- **What works to prevent these injuries?**

  - CDC supports programs addressing the major causes of spinal cord injuries
  - We are evaluating prevention programs addressing motor vehicle drivers and passengers, falls, and interpersonal violence.

- **How do you do it?**

  - Lessons learned from our evaluation are disseminated widely

Reducing the impact of spinal cord injury once it occurs

Recently, CDC began addressing **disability associated with spinal cord injury**. To address health and other problems, such as pressure sores, we need to take the same approach:

- **What's the problem?**

  - Persons with spinal cord injury are at high risk of pressure sores.
  - Over 15% of persons with SCI have pressure sores at any given time
  - Medical care for pressure sores may cost over $90,000 for each one
  - other problems are depression, substance abuse and urinary tract infections

- **What is the cause?**

  - in one CDC study (conducted by the Arkansas Spinal Cord Commission), lack of knowledge about skin care was associated with more pressure sores

- **What works to prevent pressures sore?**

  - the CDC study (conducted in Arkansas) showed that an in-home education program for persons with SCI, their families, and care givers about pressure sore prevention resulted in fewer pressure sores occurring

- **How do you do it?**

  - Lessons learned have been disseminated and additional studies have been funded

CDC funds ten Injury Control Research Centers (ICRCs), which work in the three phases of injury control: prevention of injury, acute care for the injured, and rehabilitation. ICRCs also serve as training centers for public health professionals, as well as information centers for the public. One of these centers, located at the University of Alabama, is a comprehensive injury

control research center with research and training projects that address all three phases of injury control, with a specific focus on rehabilitation. Its rehabilitation core includes studies on outcomes following severe spinal cord, head, burn, and fracture injuries; science projects that will provide information on the body's rehabilitation process; research on physical complications related to spinal cord injury; development; and research on barriers to vocational rehabilitation.

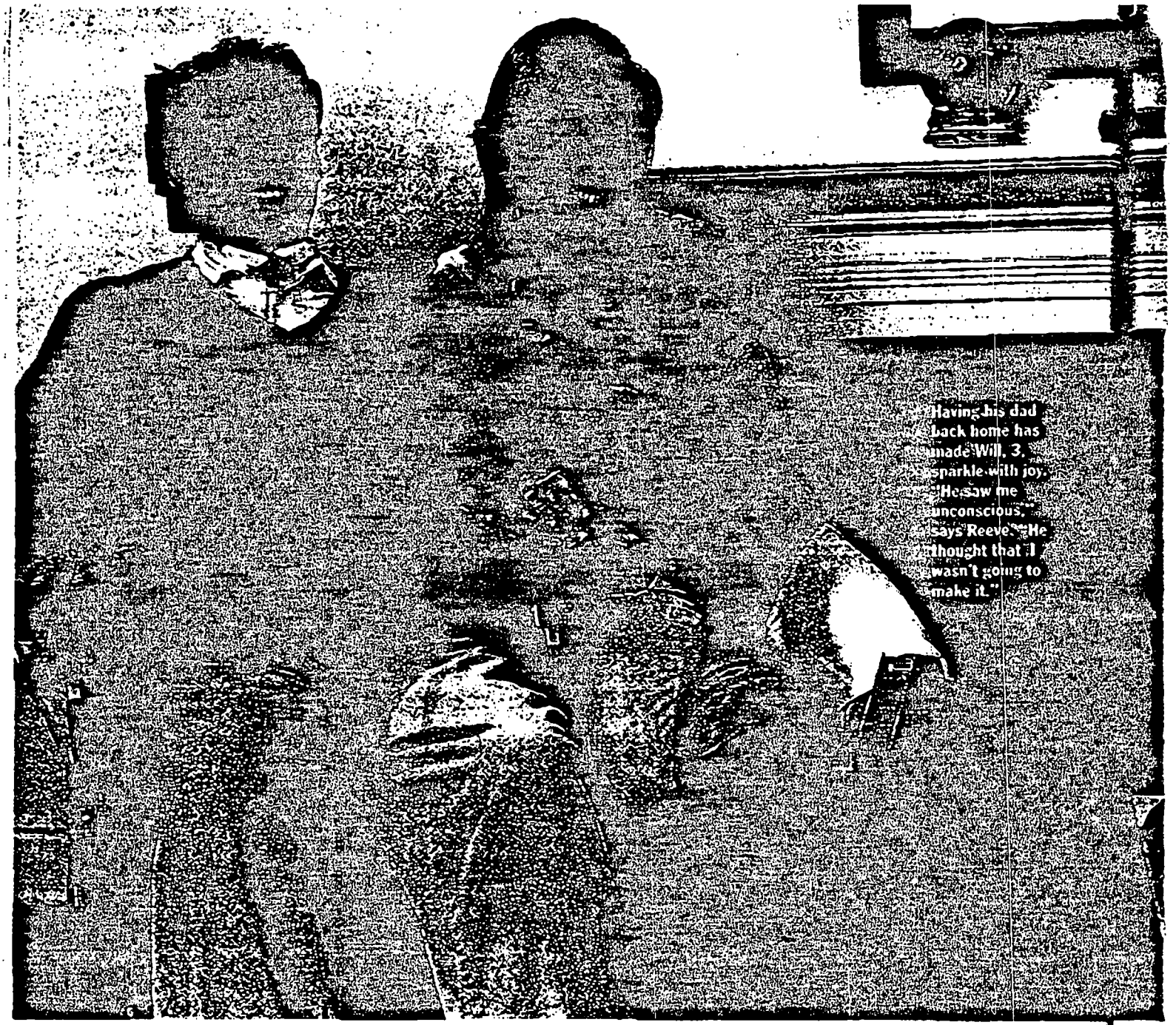
CDC will continue with these important activities:

- monitoring the impact of SCI -
  We need to know what problems persons with SCI are having so the problems can be prevented

- developing prevention strategies
  We need to develop new and better ways to reduce the impact of these injuries once they occur

- monitoring access to health care of persons with SCI
  With current changes in the delivery of health care, persons with SCI may be left out. This needs to be documented for policy makers, so that we can make sure this does not happen.

- funding ICRCs such as the rehabilitation-focused center at the University of Alabama.



Having his dad back home has made Will, 3, sparkle with joy. "He saw me unconscious," says Reeve. "He thought that I wasn't going to make it."

From latest Ladies' Home Journal

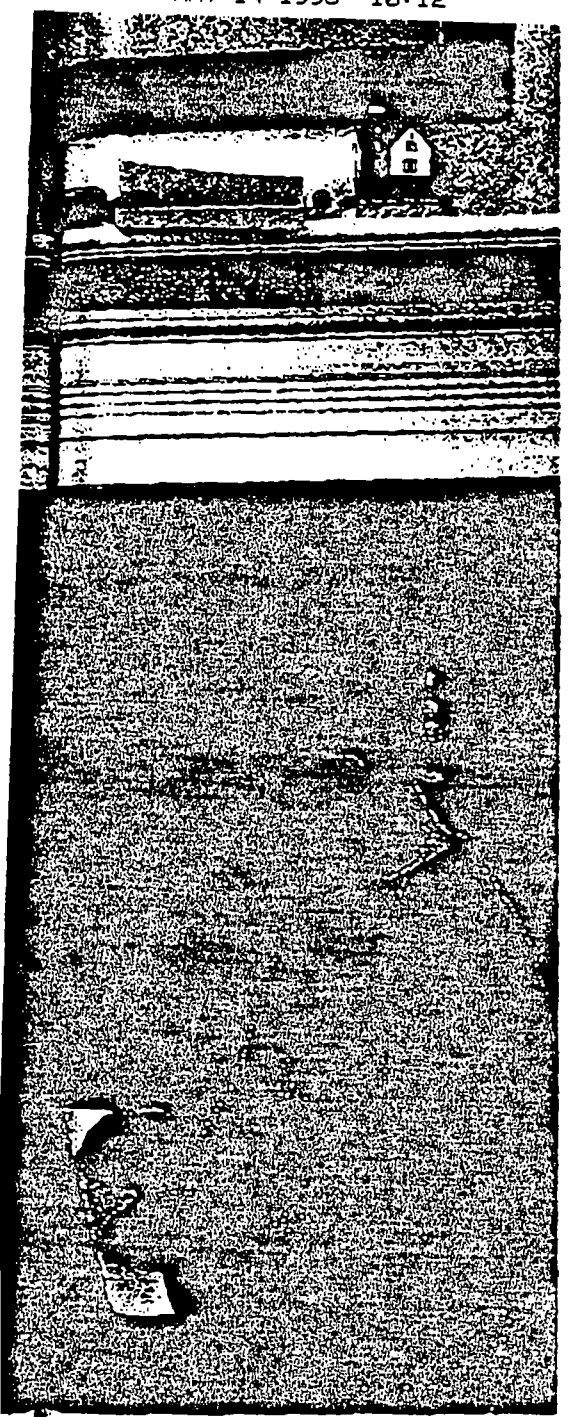
It's a modern suburban farmhouse, with a few outbuildings, fences, and a big van in the driveway. The buzz of a saw and the ring of a hammer indicate some renovation is going on. Upstairs a little boy is taking a nap. His mother is busy on the telephone. The man of the house is in the kitchen eating a salad.

In fact, everything seems run-of-the-mill at this bucolic spread in Westchester County, NY. Only a new aluminum ramp leading into the living room hints at the sudden catastrophe that has befallen this family.

Finished with her calls, Dana Reeve greets me wearing chinos, a flannel shirt, and a faintly distracted air. Then her husband propels himself into the room, blowing into a gadget that moves his wheelchair. Christopher Reeve stops near the fireplace and tilts his headrest back a bit. Still as good-looking as he was in his signature role of Superman, he has a healthy color, and his piercing blue eyes sparkle with alertness. But Chris, 43, and Dana, 34, have clearly struggled through overwhelming adversity since last May, when a grisly horseback-riding accident left him a quadriplegic.

My heart was in my mouth, so worried was I that I might do or say the wrong thing. But the Reeves know how to set empathetic first-time visitors at ease. They apologized that the house was "a mess." And soon I was kidding them that I didn't get a gift from my friend Barbara Walters last Christmas

PHOTOGRAPH BY KEN REGAN; Hair by Ron Ardnam; Makeup by Barbara



"We Draw Strength from Each Other"

One year after his tragic accident, Christopher Reeve is bravely defying the odds—and determined to walk again. Now he and his wife, Dana, talk intimately about their ordeal and the love that keeps them together.

BY LIZ SMITH

because she'd decided to give her money to his foundation instead. They laughed, and instantly nothing felt strange at all.

LS: What was it like coming home after six months at the rehab center?
CR: The first time I pulled up the driveway, I had a moment when the tears let loose. There was a Rip Van Winkle effect. I had been away for so long, and there I was, home again, but under very different circumstances. I couldn't walk up the steps. But day by day, you get used to it. You say, "Wait a minute. So I've got a ramp. It's not the end of the world." The essential things in life have come to the fore, and the minor things, like not being able to flip a tuna steak on the grill, have faded. I did those things; I enjoyed them. They aren't the essentials.

When I came home, the doctors said it would be a difficult adjustment that might lead to serious depression. But instead it was a tremendous boost. My doctor visited after a few days. He found my breathing was better. My blood pressure, oxygen levels, blood count, and protein count—everything had gone up.

LS: How did Will, your 3-year-old, react?
CR: He had visited me at the rehab center; it wasn't his favorite thing to do. To have both his parents at home all the time has sent his spirits soaring.

LS: I heard that Will said he liked it better before you were injured, but he was thrilled to have you back.
CR: He's very straightforward! He has a lot of memories of things we did before: sailing on our boat, the *Sea Angel*, and throwing rocks in the water down at the dock. Playing, roughhousing in bed, and tramping out in the woods. Will and I had started owling—looking for owls. But the main thing is, his greatest fear was not realized.

LS: What was his greatest fear?
CR: He thought that I wasn't going to make it...when they put me in the helicopter after the accident, and Dana was told to say good-bye to me. People were talking about making plans for a funeral, and telling her she should be ready to decide what to do with me. Pretty hard stuff to take. Dana coped incredibly well with it. But Will saw a lot of it, and he saw me unconscious....

LS: He was there at the time of the accident?
CR: The three of us had gone down to Virginia for a weekend with no nanny, no grandmother, nobody to pass him off to. It was our weekend. Will and his mother were back at our hotel at the time of the accident, but he was there when Dana got the call. Over the next few hours, he realized something was wrong. Then I pulled through the operation, and he could see that I was alive. Gradually I could talk. And as I improved, he began to develop a stronger sense of security.

I used to take him to swim class. He was always reluctant to jump off the side of the pool. I had to coax him:

"Come on, jump into my arms." After the accident and my survival, he got braver. There was a pool at the hotel, and he started leaping into the water and taking off his water wings, swimming under water. He became fearless. It was as though he had looked his worst fear in the face, and had nothing else to worry about. His confidence multiplied a hundredfold.

Now he uses me as a jungle gym. He climbs on me all the time, and when he wakes up from his nap, he'll come right in and jump on me. I'm so pleased. It would have been distressing if he had been afraid of me because I'm in a wheelchair.

LS: What do you remember about the accident?

CR: Nothing whatsoever. My memory's blank from when I warmed up the horse until four days after the accident when I came to.

LS: Do you feel any resentment toward the horse?

CR: Oh, no. Not at all. This was a freak accident. He's a wonderful horse. His name is Eastern Express and he's now with a trainer near Boston. He's in great shape and I hope someone will want to buy him. We were a good team. Actually, the accident happened on one of the easiest jumps. It was like tripping over your shoelaces. I got into trouble because he stopped very suddenly, and I caught my hand in the bridle. The bridle came off, and my hands were tied up in it, and I couldn't break my fall. Otherwise, it would have been just a sprained wrist.

LS: Do you dream about yourself pre-accident?

CR: Yes, sleeping is great fun. Down in Virginia, it wasn't so much fun at first, because I would wake up at two in the morning and stare out the window and feel fairly sorry for myself. Now at night, I go on wonderful adventures—Dana and Will and I go sailing, and I'm still in one piece. It's always a shock when I wake up and realize that I'm a little stuck.

LS: During those times in the night when you woke up and faced reality, did you go through a major depression? Did you ever want to die or pull the plug?

CR: No. Four days after the injury, I came to, and first realized my situation. Dana and I were alone in the hospital room. This was before the operation, and the doctors said I might not pull through. I remember saying to Dana that maybe it wasn't worth the trouble, maybe we should just let me go. If Dana had looked at the floor or taken a pause, it would have been difficult because I would have thought, *She's just being noble*. But without missing a beat, she looked me right in the eye and said, "But you're still you and I love you." And that saved my life right there. That put an end to any thought of giving up. Then my three kids came in—besides Will, I've got Alexandra, who's 12, and Matthew, 16. And I asked myself, "How can I possibly leave them?" Of course I've had moments of feeling sorry for myself. I look at pictures of our boat and at people who can walk up stairs, and I think I've been dealt a lousy hand. But through it all, I never had any thoughts of suicide.

LS: Are there people who are afraid to come to see you, afraid they will depress you, or you them?

CR: A very odd thing happens. People visit and I sense them throwing glances around, being uncomfortable and uncertain. But within moments, I can see them relax. I have found no one who looks at me with pity. Any anxiety, fear, or awkwardness fades away almost immediately.

LS: How much therapy do you do?

CR: Breathing exercises two or three times a day for endurance. I'm up to 90 minutes without the respirator, although I always need the respirator when I speak. The StimMaster bicycle, which has electrical stimuli, enables me to exercise my legs. And I get strapped on a Tilt table and placed in a vertical position, which allows me

JOIN THE GOOD HOUSEKEEPING LOBBY!

If you believe the government should help fund a search for a cure for the more than 200,000 Americans paralyzed as a result of spinal cord injuries, fill in this coupon and mail it to Senator Arlen Specter (R-PA), who chairs the Senate subcommittee that decides how funding for medical research within the National Institutes of Health will be spent.

Senator Arlen Specter, Chairman
Subcommittee on Labor, Health and Human Services, and Education Appropriations
Hart Senate Office Building, Room 530
Washington, DC 20510

Dear Senator Specter:

Please add my name to the list of supporters of increased funding for spinal cord injury (SCI) research during fiscal year 1997. Scientists have proven that it is possible for spinal cord nerves in animals to regrow and reconnect. Now they need additional funding to continue their research.

I urge your subcommittee to appropriate the highest possible level of funds for SCI research. Because SCI primarily afflicts young people with long life spans, experts predict the investment could return thousands of people to more self-sufficient lives. By investing an additional $40 million a year in SCI, the U.S. government could eventually save billions a year in Medicare and Medicaid.

Sincerely,

Name _____

Address _____

_____

A Year of Miracles

May 27, 1995: Christopher Reeve shatters two top vertebrae when thrown from his horse during an equestrian event in Culpeper County, VA. Is not expected to live.

Four days later: Regains consciousness, recalling nothing of the accident. Doctors give him a fifty-fifty chance of survival. Suffers from pneumonia; doctors must wait to operate.

June 5: Undergoes six-hour operation at University of Virginia Medical Center in Charlottesville, VA; doctors implant titanium wires, fusing together the two fractured vertebrae and stabilizing his head and neck.

Three weeks later: Sits upright; some upper-body feeling is restored, but learns he will be a quadriplegic.

June 28: Travels by airplane from U.Va. Medical Center to Kessler Institute for Rehabilitation in West Orange, NJ.

May–November: Receives 3,000 calories a night through feeding tube. Doctors question if he will ever breathe without a respirator.

October 16: Makes first public appearance at an awards dinner in New York City, at which old friend Robin Williams is an honoree.

Early November: Begins breathing feebly without respirator for ten breaths at a time. Three days later, breathes for seven minutes on his own. Doctors are impressed.

December 13: Leaves Kessler and moves home to Westchester County, NY; breathes off respirator for 15 minutes; discontinues use of feeding tube.

January 10, 1996: The Reeve-Irvine Research Center, dedicated to spinal cord research, is founded. (For information or donations write: The Reeve-Irvine Research Center, UCI, Irvine, CA 92717-5605.)

January 16: Rushed to Northern Westchester Hospital Center, where he helps doctors diagnose his condition—autonomic dysreflexia—resulting from a urinary tract infection. Blood pressure hits 210 over 150.

January 22: Released from hospital.

Early February: Breathes off respirator for 90 minutes; 75 percent sensation in left leg restored; increased shoulder movement.

March 10: Jets to Toledo for first public speaking engagement.

March 25: Receives tearful standing ovation at the 68th Annual Academy Awards during a surprise appearance.

May 13–15: Scheduled to lobby for spinal cord research in Washington, DC.

to experience my body weight again. I also have E-stim—electrical stimulation—which I do five days a week. Electrodes are placed on my legs and the muscles contract. I love it. Because I'm doing something that's forward progress.

LS: Do you feel any physical pain?

CR: No, except when I get autonomic dysreflexia, which I was hospitalized for in January. It's a common condition with spinal cord injuries—there's a sudden spike of blood pressure to a dangerous level that can cause stroke or heart attack. One of the signs you get is a pain in your head that feels like an ice cream headache multiplied by about four thousand!

LS: Do you have any awareness of your body?

CR: I have sensation in my upper spine, and I have almost normal sensation in my left leg. When they stretch my legs, I can feel all the muscles moving. Sometimes my legs feel cramped, like I've been sitting in the backseat of a car too long. I have muscle spasms that come with fatigue.

We're turning our garage into a gym so I can continue to take a proactive role in my recovery. I totally believe that within a decade, I'm going to be up and walking again. So I want to be in shape. The point of rehab is not to just sit there with your motor in neutral, but to move up.

LS: You have enormous willpower. Does it stem from having been so athletic? You certainly lived your life to the fullest.

CR: I think so. There's a succession of pictures of me sailing, riding, flying, on the mantelpiece. And I've always been an avid skier and tennis player. Sports were an important part of my life, and I actually regard this as a different kind of sport.

LS: How did you get to be such a good fighter?

CR: As a kid, I was always competitive and I've always responded well to a challenge. If someone says, "You've got to try twenty repetitions of this exercise," that gives me an incentive to do 30 or 35. You have to push. My doctors at Kessler had basically given up on my breathing without a respirator. But in November I said, "I want to try this again." They came to my room and I tried taking ten breaths. I averaged 80 cc [cubic centimeters] of air per breath, which wouldn't keep a parakeet alive. The next day, my motivation was very strong, and I was able to average 450 cc per breath. The doctors were stunned. The next day, I took 560, and then the day after that, I said, "Take me off the vent; let me see how long I can breathe." I breathed for seven minutes. After that, it built up rapidly. I just did it.... I'm not going to be chained to this respirator the rest of my life.

LS: You are able to work on a special voice-activated computer.

CR: It's a software program based on Dragon Dictate, and it was given to me by AM Technologies in Newton, MA. These guys are wonderful. I taught the computer to recognize my voice. Now when I tell it to wake up and do things, it does.

LS: It's like a person, almost.

CR: Yes! I can also work on the Internet and send E-mail. I can talk to my two older kids in England, where they go to school. I ask them how their day was, and play chess with Matthew. It's good fun.

LS: Your marriage has undergone a catastrophic event. Would you have thought it would be so resilient?

CR: Yes, because Dana's so terrific. When you have an accident like this, it magnifies your situation. If you had a bad marriage before, it's going to get worse. If you have a wonderful marriage, it's going to get even better. Our relationship has been fantastic since we first got together. But I would say this is our highest level.

LS: Have you both had to learn patience?

DR: Yes, we improved on that. We spend more time together now by necessity. And we're more focused on what really matters—the family and how far love can take you. How far commitment *(continued on page 172)*

Eric Draper/AP Wide World Photos

REEVE

(continued from page 89)

can take you, to help you through something like this. We draw strength from each other.

LS: And Dana, you can't imagine walking away from this?

DR: No, I can't at all. I could easily see how this could break up a rocky marriage. You'd say, "Forget it. I can't take it." Because it's a burden. There's a lot about this that's a burden.

CR: I often joke with her about the line in our marriage ceremony "in sickness and in health." I say, "This is a little more than you bargained for...." And she has never flinched from the commitment for a second. We're very lucky that we were together for five years before we got married. And we really knew by the time that we got to say those vows that they would have the full intent and meaning.

DR: Yes. We took it very seriously. Our wedding was tiny and simple.

CR: ...just a few people there.

LS: And now your life has become complicated...

DR: But at the same time, oddly simplified. Pared down.

LS: Chris, how have your parents reacted to this?

CR: They divorced when I was 4. I was sort of out of touch with my father, and we've gotten much closer since the accident. My mother is a journalist and very organized. She's taken it upon herself to deal with my mail. It's unbelievable. There are boxes of letters coming in and I wish I could answer everyone's. I don't know if I'll ever be able to do it. But I do want to say thank you to people.

LS: You were always politically active, and now you're taking your fight for spinal cord research funding to Washington. What do you want to accomplish?

CR: I hope that with a groundswell of public support we can convince Washington to spend money on research to cure people with spinal cord injuries, rather than just take care of them. Each year the federal government spends billions of dollars on Medicaid and Medicare payments to Americans who suffer neurological afflictions, including spinal cord injuries. This does nothing to improve them; it just keeps them ticking. An increased investment in research to prevent and cure these conditions would radically reduce the costs to both the public and private sectors, now estimated at $8.7 billion a year. Scientists project that if they spent another $40 million a year on research over the next decade, there would be significant improvements. That is a relatively small sum of money. If we can convince Congress that they should fix people like me, they could save billions on Medicaid and Medicare. *(See GH Lobby coupon, page 88).*

LS: What kind of research is being done that would improve your condition?

CR: Scientists are working on a cure. They've proven it is possible for spinal cord nerves in animals to regrow and reconnect. So, I'm very optimistic. I have a break in the nerves of my spinal cord. It's like the bridge is out. Somebody's got to come in and rebuild the bridge and connect those nerves again.

LS: What are you going to do to make a living in the meantime?

CR: I have a part as the voice of King Arthur in the new Warner Bros. animated movie *The Quest for Camelot.* Also, I was supposed to direct a film last fall. The producers made it very clear that when I was ready to do it, it was still there for me to direct. The Merchant/Ivory movie company said they'd be interested in my directing something for them. The Williamstown Theatre Festival in Massachusetts has asked me to direct a play this summer. I'm booked for speaking engagements for more money than I was ever offered when I was upright. I'm also writing a book.

LS: Your insurance has a spending cap. What are you going to do?

DR: It's terrifying. At this rate, our insurance will run out in three years. And since Chris has a preexisting condition he won't be able to get more insurance.

LS: Do you ever get mad that this happened to you?

CR: Of course.

DR: Oh, yes.

CR: Even though I am clearly in the position to help a lot of people in my situation, I have moments when I say, "Well, I'd rather not bother. I'd rather just worry about mowing the lawn." But I am very lucky, compared to other people with this kind of injury who are literally lying in a corner somewhere. I'm able to do more.

LS: You have said you would like to have another child. Is that a reality?

DR: Yes, it is a reality.

LS: How would you do it? In vitro?

DR: Probably. We have a meeting with our doctors coming up to find out the nitty-gritty details.

LS: Are you able to relate to each other in an intimate physical way?

CR: Yes, we are lovers, and I hope we always will be. You'd be surprised. We are very, very close. I will always be in love with Dana.

DR: And I will always be in love with Chris. ★

2 OLD 2 DRIVE

(continued from page 93)

in daylight, for example—or lose their license altogether. Senior citizens have legitimate concerns about the harm that loss of driving privileges would cause. A driver's license is a powerful emotional and psychological symbol of freedom. Take a license away when a person reaches advanced age, and it's an in-your-face reminder of mortality. "One driver we tested said, 'The ability to drive is like a test to see if you're alive,'" says Kalina. That explains why withdrawal and depression are common reactions to a senior's loss of a license.

Equally important is the practical matter of mobility. How will grounded elders get around—especially in suburban and rural areas without mass transit?

Senior citizen vans and other mass-transit-style schemes are providing spotty service around the country, but the real solution may lie in an ingenious pilot program now operating in Portland, ME, through the nonprofit Independent Transportation Network (ITN). Its seven volunteers and four paid drivers pick up some 151 ITN customers at their doors and take them, by car, wherever they want to go. The specially trained drivers are more attuned to seniors' needs than standard cab drivers are. They'll escort seniors to the car, for example, and help with their packages. ITN customers pay more than they would on a bus but less than they would for a cab.

ITN is also perfectly tailored to the new era of government spending cuts: the customers—not the taxpayers—pay for the rides. With ITN, customers set up an account into which they can deposit the money they would have spent each year on auto insurance, gas, maintenance, and registration. A local auto dealer can turn the older drivers' cars into cash for deposit into the ITN account. And loved ones can buy their elderly relatives gift certificates.

The result has been inspirational, says Katherine Freund, executive director of ITN. Once-housebound seniors who had been uncomfortable driving their own cars now use the service for church, shopping, doctor visits, and even trips to the symphony. "It's like they've been sprung from prison," she says.

Clearly, impaired older drivers are a safety hazard that must be addressed. The solutions—credible age-based screening tests and senior-friendly transportation alternatives—are obvious. The missing element is legislators with the backbone to do what's necessary in the face of opposition from special-interest groups. ★

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

13-May-1996 06:18pm

TO: (See Below)

FROM: Patrick M. Steel
Scheduling and Advance

SUBJECT: RE: Christopher Reeve 5/15

Bill,

A couple of things:

The meeting will be in the Oval Office. It is scheduled from 10:00am - 10:10am (10 minutes). A 20/20 crew (per McCurry) will briefly film the meeting at the top, otherwise it will be closed press.

I have Caputo, Yager listed on the schedule as the staff contact. You should do a briefing memo for the meeting. The Press Office will do an addendum on the 20/20 piece.

The contact for Christopher Reeves is Ellen Levine the Exec. Editor of Good Housekeeping Magazine (Ph: 212-649-2477). The magazine, it is my understanding, is paying the expenses of the trip. Levine is serving as host, escort, etc. Reeves also has meetings set up later in the day on Capitol Hill.

Another number for you to have is Kristine from Accessibility Associates (Ph: 908-988-4500. I think she will have information as to who exactly is travelling with Christopher Reeves (in addition to his wife Dana, and Ellen Levine). Arrangements will need to made to clear all the vehicles in the travelling party into West Executive Drive. There is handicapped accesss to the Oval via that route.

I hope this is helpful.

Patrick

Distribution:

TO: William White

CC: Lisa M. Caputo

November 20, 1995

Mr. Christopher Reeve
Kessler Institute
for Rehabilitation, Inc.
1199 Pleasant Valley Way
West Orange, New Jersey 07052

Dear Christopher:

Thanks for your warm letter and the draft of your op-ed piece. I appreciate your kind thoughts, and I'm glad to know that you are doing better.

This is a crucial time in the budget debate, and your voice on this vital subject is so important. I know that Jennifer Klein has been in contact with your staff, and I hope you will stay actively involved in the effort to save Medicare and Medicaid.

I also want to tell you that the courage you display daily in the face of pain and adversity is an inspiration to people everywhere. At a time when most people in similar circumstances would understandably be preoccupied with themselves, you have found time to care about others, and I salute you for that.

Hillary and I are thinking of you, and we extend our best wishes to you and Dana.

Sincerely,

BILL CLINTON

BC/SEM/JRS/emu-efr-emu-emu-jfc-emu-ws-emu-ech-jfc
(Corres. #2523530)
(10.reeve.c)

cc: Jennifer Klein
Response suggested by Jennifer Klein. She is calling them. Do not send out letter until she confirms that she has spoken to the Reeves.

Xeroxed copy of personally signed original to NH through Todd Stern

CLEAR THRU TODD STERN
PRESIDENT TO SIGN

THE WHITE HOUSE

WASHINGTON

October 11, 1995

Jen –
Is there a way we can make good use of this w/o any complications?
Erskine

MEMORANDUM TO ERSKINE BOWLES

FROM: Jennifer Klein J.K.

SUBJECT: Christopher Reeve

The Staff Secretary and I thought you might be interested in seeing this. I'm happy to follow up on it if that's okay with you.

Lisa Kasteler
310-208-68~~04~~ 40

Send to
Katie Roberts
212-556-1234
Michael 201-243-6849

KESSLER
INSTITUTE FOR REHABILITATION, INC.

October 6, 1995

Mr. Bill Clinton
President of the United States
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20500

Dear Mr. Clinton:

Thank you so much for your kind note of September 28. It amazes me that with all you must have on your mind, you could find time to send yet another message of encouragement to me. And, yes, I did have a very nice birthday.

I hope you won't mind my taking the liberty of enclosing a draft of an OpEd piece I have written for The New York Times. It would mean a lot to me if you could circulate it among your staff or send it to whomever you think appropriate.

With deepest gratitude for your interest,

Sincerely,

Christopher Reeve

Christopher Reeve (By Dana Reeve)

CR:jjp

Enclosure

Mailing Addresses: West & East Facilities: Pleasant Valley Way, West Orange, NJ 07052 (201) 731-3600
North Facility: 300 Market Street, Saddle Brook, NJ 07662 (201) 587-8500

First Draft - Christopher Reeve OpEd - New York Times

Like most Americans, I have watched the debate rage on Capitol Hill over the best way to fix Medicaid and Medicare. As someone who has now consumed more health care services in the past four months than many people will in a lifetime, it seems to me that Congress is approaching this problem backwards. In the long run, the way to save money in the health care system is to invest now in the research that will eliminate the disease and disability that drives costs up. If we do that, we won't have to spend tax dollars maintaining people who could have been cured in the first place.

Spinal cord injuries cost our nation $5 billion every year. That figure includes initial hospitalizations, ongoing related health problems, rehabilitation services, personal care attendants, adaptive equipment, lost productivity. It's an expensive condition. And yet, scientists working in the field of nerve regeneration estimate than an additional $40 million investment each year would greatly hasten the day when these expenses will be unnecessary.

Some people argue that the benefits of research are elusive, far in the future, not concrete enough to justify the investment. The medical history of this century tells a different story. Relatively small investments in research have given us antibiotics and vaccines against illnesses that once killed millions every year (polio, measles, smallpox, diphtheria, influenza, tuberculosis). Thirty years ago, a diagnosis of cancer was a virtual death sentence. In the 1970's, the research community received additional funds to wage war on this disease. Ask the half-million people who now survive cancer every year, and their families, if the investment was worth it.

Today, researchers are on the brink of discovery for many other devastating and costly disorders, including Alzheimer's, Parkinson's, and Multiple Sclerosis. The humanitarian and economic argument for giving scientists a chance to progress toward

these discoveries is irrefutable. It is a tragedy for all of us when important scientific work languishes on the laboratory shelves for lack of funding.

When President Kennedy told NASA scientists early in the 1960's of his vision to land a man on the moon by the end of the decade, they said it was impossible. They were nowhere near the technology necessary to do it in that time frame. But Kennedy stood fast and told them they'd better figure it out. His conviction, his confidence and his leadership challenged them to go back to the drawing board leading, of course, to the stunning success in July 1969.

Medical scientists today need the same challenge. They need to be able to work together, to share information, and most of all, they need the money and tools to do the job. The public must voice our belief that they can stop the terrible diseases that rob this country of so much talent and consume so much of the federal budget. We must voice our demand that our nation invest in this greatest of human achievements--the conquest of disease. The economic realities of today are pushing us towards this challenge. **The time to respond is now**.

Copy for Todd

KESSLER
INSTITUTE FOR REHABILITATION, INC.

Dedicated to the care of the physically disabled. Kessler is an accredited nonprofit hospital affiliated with the University of Medicine and Dentistry of New Jersey.

October 6, 1995

Mr. Bill Clinton
President of the United States
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20500

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Sincerely,

Christopher Reeve

Christopher Reeve (By Dana Reeve)

CR:jjp

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Today, researchers are on the brink of discovery for many other devastating and costly disorders, including Alzheimer's, Parkinson's, and Multiple Sclerosis. The humanitarian and economic argument for giving scientists a chance to progress toward

these discoveries is irrefutable. It is a tragedy for all of us when important scientific work languishes on the laboratory shelves for lack of funding.

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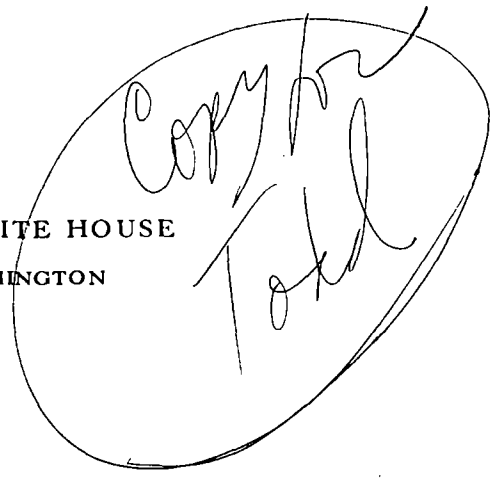
Medical scientists today need the same challenge. They need to be able to work together, to share information, and most of all, they need the money and tools to do the job. The public must voice our belief that they can stop the terrible diseases that rob this country of so much talent and consume so much of the federal budget. We must voice our demand that our nation invest in this greatest of human achievements--the conquest of disease. The economic realities of today are pushing us towards this challenge. **The time to respond is now**.



THE WHITE HOUSE

WASHINGTON

November 13, 1995

Mr. Christopher Reeve
Kessler Institute
for Rehabilitation, Inc.
1199 Pleasant Valley Way
West Orange, New Jersey 07052

Dear Christopher:

Thanks for your warm letter and the draft of your op-ed piece. I appreciate your kind thoughts, and I'm glad to know that you are doing ~~well~~ better.

This is a crucial time in the budget debate, and your voice on this vital subject is so important. I know that Jennifer Klein has been in contact with your staff, and I hope you will stay actively involved in the effort to save Medicare and Medicaid.

Hillary and I are thinking of you, and we extend our best wishes to you and Dana.

Sincerely,

November 9, 1995

Mr. Christopher Reeve
Kessler Institute
for Rehabilitation, Inc.
1199 Pleasant Valley Way
West Orange, New Jersey 07052

Dear Christopher:

Thank ~~you~~ for your warm letter and the draft of your op-ed piece. I appreciate your kind thoughts, and I'm glad to know that you are doing well.

This is a crucial time in the budget debate, and your voice on this vital subject is so important. I know that Jennifer Klein has been in ~~contact~~ activity with you, and I hope you will stay involved in the ~~our~~ effort to ~~achieve sensible reform~~ save ~~protect~~ Medicare and Medicaid, preserve and strengthen them. (staff)

Hillary and I are thinking of you, and we extend our best wishes to you and Dana.

Sincerely,

BC/SEM/JRS/emu-afr-emu-emu-jfc-emu-ws
(Corres. #2523530)
(10.reeve.c)

cc: Jennifer Klein

Response suggested by Jennifer Klein. She is calling them. Do not send out letter until she confirms that she has spoken to the Reeves.

Xeroxed copy of personally signed original to NH through Todd Stern

CLEAR THRU TODD STERN

PRESIDENT TO SIGN

NOV 13 1995

TO: Seth Maguet

FROM: Jennifer Klein

Seth -
Can I look at this one more time?
Thanks -
Jen

THE WHITE HOUSE
WASHINGTON

October 30, 1995

Mr. Christopher Reeve
Kessler Institute
for Rehabilitation, Inc.
1199 Pleasant Valley Way
West Orange, New Jersey 07052

Dear Christopher:

Thank you for your warm letter and the draft of your oped piece ~~about medical research~~. I appreciate your kind thoughts, and I'm glad to learn that you are doing well ~~and that you are making yourself heard on this vital subject.~~

I understand that my staff has been in contact with you, ~~I welcome your input, and~~ and I hope you will stay involved in the weeks and months to come.

Hillary and I are thinking of you, and we extend our best wishes to you and Dana.

Sincerely,

As Republicans in Congress plunge ahead with their plans to take $440 billion from Medicare and Medicaid, this is a crucial time in the debate.

~~An~~ Your oped ~~noted~~ in your oped, ~~this~~ is a crucial time in the debate ~~longer had about Medicare and Medicaid.~~

~~Your oped and your appearance on 20/20 were~~ I ~~even~~ appreciate your ~~making yourself heard on this vital subject.~~

Your voice on this vital subject is so important.

OCT 31 1995

KESSLER
INSTITUTE FOR REHABILITATION, INC.

October 6, 1995

Mr. Bill Clinton
President of the United States
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20500

Dear Mr. Clinton:

Thank you so much for your kind note of September 28. It amazes me that with all you must have on your mind, you could find time to send yet another message of encouragement to me. And, yes, I did have a very nice birthday.

I hope you won't mind my taking the liberty of enclosing a draft of an OpEd piece I have written for The New York Times. It would mean a lot to me if you could circulate it among your staff or send it to whomever you think appropriate.

With deepest gratitude for your interest,

Sincerely,

Christopher Reeve

Christopher Reeve (By Dana Reeve)

CR:jjp

Enclosure

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First Draft - Christopher Reeve OpEd - New York Times

Like most Americans, I have watched the debate rage on Capitol Hill over the best way to fix Medicaid and Medicare. As someone who has now consumed more health care services in the past four months than many people will in a lifetime, it seems to me that Congress is approaching this problem backwards. In the long run, the way to save money in the health care system is to invest now in the research that will eliminate the disease and disability that drives costs up. If we do that, we won't have to spend tax dollars maintaining people who could have been cured in the first place.

Spinal cord injuries cost our nation $5 billion every year. That figure includes initial hospitalizations, ongoing related health problems, rehabilitation services, personal care attendants, adaptive equipment, lost productivity. It's an expensive condition. And yet, scientists working in the field of nerve regeneration estimate than an additional $40 million investment each year would greatly hasten the day when these expenses will be unnecessary.

Some people argue that the benefits of research are elusive, far in the future, not concrete enough to justify the investment. The medical history of this century tells a different story. Relatively small investments in research have given us antibiotics and vaccines against illnesses that once killed millions every year (polio, measles, smallpox, diphtheria, influenza, tuberculosis). Thirty years ago, a diagnosis of cancer was a virtual death sentence. In the 1970's, the research community received additional funds to wage war on this disease. Ask the half-million people who now survive cancer every year, and their families, if the investment was worth it.

Today, researchers are on the brink of discovery for many other devastating and costly disorders, including Alzheimer's, Parkinson's, and Multiple Sclerosis. The humanitarian and economic argument for giving scientists a chance to progress toward

these discoveries is irrefutable. It is a tragedy for all of us when important scientific work languishes on the laboratory shelves for lack of funding.

When President Kennedy told NASA scientists early in the 1960's of his vision to land a man on the moon by the end of the decade, they said it was impossible. They were nowhere near the technology necessary to do it in that time frame. But Kennedy stood fast and told them they'd better figure it out. His conviction, his confidence and his leadership challenged them to go back to the drawing board leading, of course, to the stunning success in July 1969.

Medical scientists today need the same challenge. They need to be able to work together, to share information, and most of all, they need the money and tools to do the job. The public must voice our belief that they can stop the terrible diseases that rob this country of so much talent and consume so much of the federal budget. We must voice our demand that our nation invest in this greatest of human achievements--the conquest of disease. The economic realities of today are pushing us towards this challenge. **The time to respond is now**.

And that is what I want every American to start considering. Think about this budget debate -- not as a Republican or an Independent or a Democrat -- think about it as a parent, as a grandparent, as an aunt, as an uncle.

Don't get so wrapped up in the statistics and the policy papers that we forget our basic obligations. We know as parents what we owe our children. We know what we try to do in order to meet those needs.

I looked into the faces just a few minutes ago of mothers and fathers who have given up everything to take care of sick children -- and who among us would not do the same?

But when it comes to legislating and making policy, parents turn into partisans and good parental instincts seem to retreat. Would we ever say as parents that only one of four of our children could go to a doctor or get a vaccination or have a hearing test? Of course not. We would demand and work for the right to make sure they were all taken care of.

Would we ever say as parents with a child that had spinal bifida or congenital heart disease or cystic fibrosis that they no longer deserved treatment and care? Of course not. We would do everything within our power to make sure our child was taken care of.

But in this time we live in today, with the kind of reckless, ideological effort to meet fixed budget targets to prove a point, we are undermining what parents try to do every single day.

Let me give you just a few examples. The Republican budget would eliminate Headstart for 100,000 American preschoolers. It would deny tens of thousands of children right here in New York the opportunity to have the kind of personal attention in school to acquire the skills that they need.

It would eliminate Goals 2000 which sets standards for teaching and learning in America.

It would eliminate summer jobs for 600,000 young people and do away with the President's national service program known as Americorps in which young men and women earn their way to college by performing community service.

The Republican budget cuts would eliminate health care coverage through Medicaid for nearly one-half million children in New York alone, and four and half million nationwide by the year 2002.

More than half of the children on Medicaid live in families with working parents -- parents who are doing the best they can to earn their own livings, but cannot meet the medical needs of their children.

That means those children would no longer be able to get immunizations or check-ups or other preventive services now covered by Medicaid. It means that they would use the emergency room as so many uninsured families who make just a little too much money in order to qualify for Medicaid do for their health

care coverage now.

Medicaid is the primary source of health coverage for millions of children who are disabled or who suffer from chronic illness.

It is the primary health care coverage for nine out of 10 children with HIV and AIDS.

Medicaid is the primary source of prenatal and maternal health care for low-income, pregnant women.

Medicaid is also an important source of coverage for the health care of older Americans living in extreme poverty or with serious disabilities and is the largest insurer for over two-thirds of nursing home residents.

Medicaid is literally a lifeline for many, many millions of Americans.

Ripping apart this safety net is not the American way.

It is not the American way to deny infants the shots they need to stay healthy.

It is not the American way to deny treatment to children who are disabled or desperately ill.

It is not the American way to punish hardworking parents whose family health care coverage vanishes with a job loss or a job change.

It is not the American way to make the oldest among us give up their possessions, sell their house, sell their car, and live a life of poverty if their spouse has to go into a nursing home.

Cutting $182 billion from Medicaid will force families to make grim choices that you or I would not wish to make and no American family should be forced to make. Choices between health care for children or nursing home care for parents. Choices between education and vaccinations; between food and prescription drugs.

We know that any mother or father or aunt or uncle or grandparent or concerned adult would not take comfort in knowing that for all the rhetoric we hear, often coming out of the United States Congress about helping children, the Republican budget will in fact deny millions of children the basics they need to live productive lives.

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They will be denied health care they now have, schooling they can count on, proper food, a safe place to live, a secure neighborhood, air and water that we can count on as being clean enough to breathe and drink.

We are not talking about only poor children. I wish that -- if that's all we were talking about -- there would be an uproar and an outcry from every person in our country, that we should not do to the most vulnerable children among us what we would not let anyone do to our own children.

But these budget cuts go much further. These budget cuts -- in the way they undermine health and food safety; the way they strip away environmental protections; the way they put at risk many of the services that all Americans and their children count on -- is an assault on every child's future -- my child, as well as any child in this room, or living within a few blocks of this hospital.

We as a society are doing things we would never do as parents. How can we legislate what we would not approve of as parents? How can we vote for people who would do that? How can we permit it to happen?

Any family does its best to take care of its old and its young. There is an inner-generational compact that is more important than any kind of contract for legislation.

That compact says loud and clearly: "We owe each other something. We have obligations to one another and besides, we never know what might happen to us."

There, but for the grace of God, go our child, our spouse, our parent -- and we ought to be a little more humble in the face in the unpredictability that life deals all of us.

Our children are our present and our future, a test of our humanity and our faith. And our children are watching. Will we pass this test or will we fail them and ourselves?

Last week, Republicans in both houses of Congress passed reconciliation bills slashing health care, education and other essential programs for our nation's children. As the debate over the Federal budget continues, I hope that all of us will take part in this discussion not as Republicans or Democrats, but as parents, grandparents, aunts and uncles.

As parents, we know what our children need, and we do whatever we can to meet those needs. For most Americans, that means working hard to put food on the table, sitting with our kids as they struggle with their math homework, and missing work on the rare occasions when a child has the flu. For others, meeting their childrens' needs poses greater challenges. On a recent visit to Babies and Childrens' Hospital in New York, I talked to mothers and fathers who have given up everything to take care of sick children. As each family told their story, I was struck by the tremendous sacrifices they had made and by the powerful feeling that I would of course make equal sacrifices for my own child. And I guarantee you that each of us would do the same.

When it comes time to legislate, however, it seems that parents turn into partisans. Would we ever say as parents that only one of four of our children could go to a doctor or get a vaccination or have a hearing test? Of course not. We would make certain that all four were treated. Would we ever say as parents of a child with spina bifida or congenital heart disease that the child no longer deserved treatment and care? Of course not. We would do everything in our power to make sure our child got whatever care he or she needed.

But in an ideological, even reckless, attempt to balance the budget in too short a time and to cut taxes for wealthy Americans, Republicans in Congress are forgeting what they would do as parents and undermining what parents across the country try to do every single day.

Let me give you just a few examples. The Republican budget would eliminate HeadStart -- the program that helps children get ready to learn -- for 180,000 American children. It would eliminate Goals 2000 which sets standards for teaching and learning in America. It would cut nutrition assistance for 14 million children and reduce funding to keep drinking water clean. It would do away with the President's national service program known as Americorps in which young men and women earn their way to college by performing community service.

The Republican budget cuts would eliminate health care coverage through Medicaid for four and a half million children nationwide by the year 2002.

Medicaid is the primary source of health coverage for nearly one-quarter of all children in the United States and one-third of all children under 3. More than half of those children live in

families with working parents.

Medicaid is the primary source of health coverage for almost one million children who are disabled or who suffer from chronic illness.

Medicaid is the primary source of health coverage for nine out of ten children with HIV and AIDS.

Medicaid is the primary source of prenatal and maternal health care for low-income, pregnant women.

And Medicaid is an important source of long-term care for older Americans. Nearly seven out of every 10 nursing home residents get some help from Medicaid. That's not surprising given that nursing homes cost an average of $38,000 a year.

Medicaid is literally a lifeline for 36 million children and families in this country.

Ripping apart this safety net is not the American way.

It is not the American way to deny infants the shots they need to stay healthy.

It is not the American way to deny treatment to children who are disabled or desperately ill.

It is not the American way to punish hardworking parents whose family health care coverage vanishes with a job loss or a job change.

It is not the American way to make the oldest among us give up their possessions, sell their house, sell their car, and live a life of poverty when their spouse has to go into a nursing home.

Cutting over $170 billion from Medicaid will force families to make grim choices that no American family should be forced to make. Choices between health care for children or nursing home care for parents. Choices between education and vaccinations; between food and prescription drugs.

We know that any mother or father or aunt or uncle or grandparent or concerned adult would not take comfort in knowing that for all the rhetoric we hear about helping children, often coming out of the United States Congress, the Republican budget will in fact deny millions of children the basics they need to live productive lives.

It will deny children the health care they now have, schooling they can count on, proper food, a safe place to live, a secure neighborhood, and air and water that are clean enough to breathe and drink.

We are not talking only about poor children. I would hope that if these cuts effected only the poor, every person in our country would cry out that we should not do to the most vulnerable children what we would not let anyone do to our own children. But these budget cuts go much further. They are an assault on every child's future.

How can we legislate what we would not stand for as parents? How can we vote for people who would do that? How can we permit it to happen?

Every family does its best to take care of its old and its young. There is an inter-generational compact that is more important than any so-called legislative contract.

That compact says loudly and clearly that we owe each other something. That we have obligations to one another, especially to our children. and besides, we never know what might happen to us. There but for the grace of God go our child, our spouse, our parent -- and we ought to be a little more humble in the face of the unpredictibility that life deals all of us.

Our children are our present and our future, a test of our humanity and our faith. And our children are watching. Will we pass this test or will we fail them and ourselves?

FIRST LADY HILLARY RODHAM CLINTON
REMARKS FOR THE CIRCLE OF CARE CONFERENCE
THE NATIONAL INSTITUTES OF HEALTH
SEPTEMBER 27, 1995

[Acknowledgements: Dr. Harold Varmus; Scott Oki, organizer of Circle of Care; David Nathan, Physician-in-Chief at Children's Hospital in Boston]

Thank you all very much for inviting me to join you for this historic discussion of children's hospitals and their vital place in our health care system. It is a privilege to be a part of such a formidable gathering of concerned citizens and health care professionals and to serve as honorary chair of the Circle of Care.

I have been very fortunate in my life to have been associated with Children's Hospitals, particularly Arkansas Children's Hospital, where I served on the board and helped raise money, and where my daughter was born.

Like many of you, I have experienced children's hospitals as a parent and I think we all agree that there is something undeniably special about these hospitals.

I know from my experience on the board of Arkansas Children's what it takes to raise private funds through private philanthropy. And it is because of committed, dedicated, and generous citizens like you that these hospitals continue to lead the way in the research and treatment of children's diseases, as well as the training of doctors and specialists to care for children.

I also know that the continued existence of children's hospitals depends on government support -- support that appreciates the important differences that go into the treatment of children and adults.

It is fitting that this first Circle of Care conference is being held here at NIH, which is synonymous with so much of the cutting edge medical research being done in our country.

NIH is a symbol of our government's historic commitment to medical research. Similarly, the cardiologists, radiologists, oncologists, surgeons, and nephrologists at children's hospitals around the country were able to develop their expertise and training because the federal government decided to help defray the costs of training these medical specialists twenty years ago.

It is precisely that commitment to medical research and to

our academic health centers that is at risk in the current debate going on in our country over health care today.

It is a debate filled with statistics, policy statements, and budget numbers. But behind the charts and graphs and position papers, it is really a debate about our core values as Americans -- about what we believe in, how we define ourselves as a people, and how we envision our future.

Throughout our history, we have thought of ourselves as an American family. A family whose greatest priority was our children. A family that was committed to helping the most vulnerable among us -- so that they, in turn, could help themselves.

As Americans, we have always prided ourselves on our compassion . . . and on the high expectations and aspirations we hold for our children and for ourselves as a people.

For decades, this has been the American way: to put people, especially children, first. And because we have adhered to the American way, the American Dream has stayed alive for generation after generation and our country has remained the strongest on earth.

But today, we are losing our sense of ourselves as an American family. We are allowing ourselves to be torn apart, divided, put in competition with each other over resources that are ever more scarce.

As the traditional underpinnings of our larger family are undermined, individual families are being jeopardized.

Most parents in America are working as hard as they can to be good parents. I have met with working women across our country over the last few months, and I know that they and their husbands are making huge sacrifices to put food on the table, pay the mortgage or rent, cover the medical bills, and instill an ethic or work and responsibility in their children.

Of course, parents bear the primary responsibility for their children, and they should. Parents must provide the care, nurturing, love and discipline that every child needs.

As the National Council of Catholic Bishops said in a pastoral letter in 1991 entitled, Putting Children First: "No government can love a child, and no policy can substitute for a family's care."

But at the same time, the Bishops go on to say: "Government can either support or undermine families as they cope with the moral, social, and economic stresses of caring for children."

Let's not fool ourselves. National policies -- whether they are about education, health care, work, welfare, taxes -- are mirrored every day in the lives and experiences of our children. And government has played an invaluable role in safeguarding the interests of children and their families.

Unfortunately, what is happening today is no less than a rejection of America's historic commitment to children.

Today, the social safety net known as Medicaid is being dismantled at breakneck pace. It is being dismantled with very little discussion and no real dialogue. Decisions are being made in great haste -- not only about who pays for health care in America -- but about who gets health care, and who doesn't.

We are all for balancing the budget. And we are all for giving states greater flexibility to administer programs.

But as the President has said many times, there is a right way and a wrong way to get our economic house in order.

The wrong way is to cut health care coverage for millions of children, disabled citizens and the poorest of older Americans -- all to finance a $245 billion tax cut for the wealthiest families in our country.

Let's not confuse flexibility with what is really going on here: raw and mean-spirited budget cuts that affect real people.

Medicaid is the primary source of health coverage for nearly a quarter of all children in America -- and one third of children under age 3. More than half of those children live in families with working parents -- parents who are not receiving welfare checks.

Medicaid is the primary source of health coverage for millions of children who are disabled or who suffer from chronic illnesses.

Medicaid is the primary source of health coverage for 9 out of 10 children with HIV and AIDS.

Medicaid is the primary source of prenatal and maternal health care for low-income pregnant women.

Medicaid is an important source of coverage for older Americans living in extreme poverty or with serious disabilities, and the largest insurer for over two-thirds of nursing home residents.

It is a lifeline -- literally -- for millions of children and families in America.

Ripping apart this safety net is not the American way.

It is not the American way to deny infants the shots they need to stay healthy.

It is not the American way to deny treatment to children who are disabled or desperately ill.

It is not the American way to punish hard-working parents whose family health coverage vanishes with a job change.

It is not the American way to make the oldest among us give up their possessions and live a life of poverty to pay for a spouse's nursing home costs.

Cutting $182 billion from the Medicaid program will force families to make grim choices -- choices between health care for their children or nursing home care for parents, choices between education and vaccinations, between food and prescription drugs.

You of all people alsoknow that it will mean grim choices for children's hospitals. Children's hospitals represent only one percent of all hospitals, but they provide vital health care services to many children -- including the poorest, sickest and most vulnerable.

They devote nearly half of their care to children of low income families and more than three-quarters of their care to children with chronic or congenital conditions.

They care for the premature baby who needs intensive care for the first months of his life and extensive rehabilitation therapy for years to come. For the small child who is severely injured when she is hit by a car and sent to a pediatric intensive care unit at a nearby children's hospital.

And they care for the eight year old boy who contracts viral encephalitis, loses his health insurance, and is covered by Medicaid because of his high medical costs and severe disabilities.

The proposed cuts in Medicaid will be particularly devastating for children's hospitals. Medicaid patients on average account for 46 percent of the inpatient days in these hospitals.

As you well know, it costs more to care for sick children than adults. And children's hospitals are not able to shift these higher costs to adult patients like other hospitals can. Already Medicaid pays children's hospitals on average less than 80 cents for every dollar spent to care for a child. The impact of a $182 billion in Medicaid is clear; children's hospitals

simply will not be able to provide all of the crucial health services that they do today.

We need to protect the safety net provided by our children's hospitals. A safety net that enables children to continue to have access to desperately needed specialized care. That continues to train pediatricians and other care-givers for children. And that pursues research on the prevention and treatment of childhood disease.

As this health care debate continues in the weeks and months ahead, I hope that policymakers, wherever they are, begin to think about these issues not as partisans, but as parents.

I hope that they will not get so wrapped up in statistics and policy papers, budget battles and partisan rhetoric that they forget the most basic concern of all: the well-being of all of America's children.

Many of you know from your own experience what it is like when your child is very sick. Nothing else in the world matters to you. Will he or will she feel better? Is this a passing flu or the beginning of something really threatening? Is the life of the most precious person in the world in any danger? As parents, we want answers and we want cures. And we want them fast.

As parents, we use our wisdom and knowledge to plan ahead for the health of our children. We make sure they get the shots they need. We try to get them to eat right. We try to avoid exposing them to other kids who might be sick. And when they do get sick, we try to get treatment from doctors and nurses trained in children's medicine.

But suddenly, when it comes time to legislate and make policy, parents turn into partisans and good parental instincts retreat.

Would we ever say as parents that only one of our four children could go to the doctor, or get a vaccination, or have a hearing test? Of course not. We would demand the right to take each of them whenever they needed care.

Would we ever say as parents that a child of our own with spina bifida or cerebral palsy no longer deserves treatment and care? Of course not. We would give up the summer vacation and the new car to make that child's life as pain-free and as fulfilling as possible.

But in a precipitous and even reckless attempt to meet fixed budget targets, we are now as a society doing things we would never do as parents. We are ratcheting back the medical care our children. We are violating our most sacred duty and value: caring

for your young.

How can we legislate what we would not approve as parents? How can the restriction of medical care for our children become the public policy of our nation?

The answer is it must not.

As the Bishops said in their pastoral letter: Our children are our present. Our children are our future. Our children are a test of our humanity and our faith.

And our children are hurting.

Thank you for doing your part to ensure that every child in America has the opportunity of health care and the chance for a healthy and productive life.

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