

Friday, December 4, 1998

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PHOTOCOPY
PRESERVATION

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THE WHITE HOUSE

WASHINGTON

December 3, 1998

MEETING WITH REPRESENTATIVE CHARLES RANGEL

DATE: Friday, December 4, 1998
LOCATION: Oval Office
TIME: 1:30 pm - 1:45 pm
FROM: Larry Stein *LS*
Chuck Brain *CB*

CA
JK
R

Copy to
Smith
Podles

I. PURPOSE

To meet at the request of Congressman Charles Rangel (D-NY) to discuss legislative strategies for the upcoming Congressional session.

II. BACKGROUND

In the recent House Democratic organization meeting, Congressman Rangel was selected as one of the Vice Chairmen for the Democratic Congressional Campaign Committee (DCCC). In addition, Congresswomen Ellen Tauscher (D-CA) and Frank Pallone (NJ) were also selected as Vice Chairs, with Congressman Patrick Kennedy (D-MA) selected as Chairman. In his new role, Congressman Rangel is pursuing political and legislative strategies that will enable Congressional Democrats to regain control of the House of Representatives.

As a Vice Chair of the DCCC, Congressman Rangel will be responsible for mobilizing voter participation and coordinating the national get out the vote drive. Congressman Rangel will coordinate efforts with Congresswoman Tauscher who will be responsible for Member participation while Congressman Pallone will be responsible for finances. Congressman Rangel was selected in large part for his success in mobilizing the African American voter base in a number of targeted Congressional races in the 1998 elections.

Congressman Rangel would like to discuss the merit of having a coordinated legislative agenda between the White House and House Democrats. He believes a well crafted domestic agenda will provide a vehicle for Democrats to promote issues that have wide voter appeal. He believes that such an agenda would not only serve as both a political asset for Congressional Democrats in the 2000 election, but also as an amplified method for promoting the Administration's priorities.

As an example of such an issue, Congressman Rangel may urge new initiatives aimed at improving education in rural and inner city schools. He will likely highlight school modernization as a policy that improves K-12 education in these communities. This issue enjoys wide electoral appeal and is consistent with both Administration and Congressional Democratic priorities.

It is possible that Congressman Rangel may also mention the Africa Trade bill. You will recall that this bill passed the House and the Senate Finance Committee but was not brought to the Senate floor. Congressman Rangel strongly supports this legislation and has, at times, questioned our commitment to its passage. If it is raised, you can assure him that you continue to support this initiative and that it continues to be an Administration priority

With the exception of the Africa Trade bill and education, he is not likely to go into much depth with any particular issue, but rather discuss the feasibility of coordinating a combined legislative agenda. You should reiterate your commitment towards working with the Democratic Congressional Leadership. In addition, you may wish to discuss the legislative agenda items from your meeting with the Senate Democratic leadership on Wednesday, December 2. Enclosed is a copy of those items highlighted from the meeting.

Please note, Congressman Rangel will be participating in the Social Security Conference next week.

III. PARTICIPANTS

Pre-Brief

None

Meeting

President

Representative Rangel

John Podesta

Larry Stein

Craig Smith

IV. PRESS PLAN

Closed Press.

V. SCENARIO

As usual.

VI. REMARKS

None.

VI. ATTACHMENTS

See enclosed legislative agenda items.

CS

286650 SS

FG001-07

THE WHITE HOUSE
WASHINGTON

December 5, 1998

MR. PRESIDENT:

We thought you would want to see
this letter from Rep. Rangel.
We have sent copies to Gene,
Bruce Reed, and Jack Lew.
We will prepare a reply for your
signature.

Sean Maloney 

THE PRESIDENT HAS SEEN

12-7-98

copied
Reed
Sperting
Podesta

12-7-98

98 DEC 4 PM 5:42

~~cc: all this to
Brend / G. Sullivan~~
~~BR~~

Also attached is the *New York Times* story to which the Congressman alluded. In addition, Greg Craig and I are pursuing the other suggestions the Congressman made.



HOUSE OF REPRESENTATIVES
WASHINGTON, D. C. 20515

CHARLES B. RANGEL
15TH DISTRICT, NEW YORK

December 4, 1998

President William Clinton
The White House
Washington, DC 20500

Dear President Clinton:

With nearly 90 percent of our children enrolled in public schools, and our business sector increasingly hard-pressed to find the talent it needs to compete in the global economy, there is no question that education is our nation's most vital challenge. Despite the shrinking disparity in graduation rates among the races, no one is satisfied with the condition of our schools.

You could leave no greater legacy to our nation than a sound public school system. Indeed, you have been consistent since your first campaign for the Presidency, in underlining education as your number one priority. Foremost among Presidents, you have outlined for the American people the need to address aggressively the real problems in education.

I commend your recent success in working with your supporters in Congress to reduce class sizes by helping local communities hire 100,000 more teachers. However, much more remains to be done in fulfilling the mandate given us by the voters in the November 3rd election.

Today, 1.7 million Americans are locked behind bars. Seventy percent of them are illiterate, drug-addicted and unemployable. The annual cost to society in criminal justice and related costs alone are at least \$450 billion. If current trends continue, the United States will spend \$100 million per day to incarcerate individuals with serious drug and alcohol problems.

Hundreds of billions more are wasted in lost productivity due to the combined effects of bad education and poverty. Drug addiction, welfare, premature pregnancy, AIDS and related health problems are decimating our communities, destroying our families and weakening the nation.

President William Clinton
December 4, 1998
Page 2

Far too many Black youngsters who survive the pitfalls of drugs and crime through high school, armed with worthless diplomas, are still faced with the tragedy of long-term unemployment. Yet at least 40 percent of the achievement gap between racial and ethnic groups would disappear if poor and minority youngsters had access to teachers of the same quality as other students.

Reflecting policies that have favored incarceration over education, our national priorities remain grossly misplaced. In 1998, the national investment in education per pupil was \$6100, while the average cost of incarceration was \$24,000 per inmate. Overall, in the area of higher education, the states spent 30 percent more on prison budgets and 18 percent less on colleges in the years between 1987 and 1995.

In the 106th Congress, I am prepared to work with you, once again, to provide funding mechanisms to renovate and modernize our public schools, one-third of which are in serious disrepair. We must do more to extend the information superhighway through every neighborhood and every school. Additionally, we must work harder on those priorities that will make our schools work better, including expanded affordable child care.

Mr. President, I look forward to working with you in creating a legacy for our nation that can never be taken away and that will never be forgotten.

Sincerely,

CHARLES B. RANGEL
Member of Congress

CBR/em

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December 3, 1998, Thursday, Late Edition - Final

SECTION: Section B; Page 1; Column 2; Metropolitan Desk

LENGTH: 1676 words

HEADLINE: Wanted: A Permanent Home;
Plight of 2 Schools Shows Why Construction Is Slow

BYLINE: By JACQUES STEINBERG and JOHN SULLIVAN

BODY:

For more than a generation, West Side High School has been a nomad within the New York City school system, trying to teach 600 students while migrating from one temporary location in Manhattan to another.

At various turns, West Side was flush with promise that the city's school construction process would finally deliver a permanent home. But the outcome always seemed to embody the chronic problems of planning and building schools in New York City over the last two decades, a process characterized by dashed hopes, unanticipated problems and a lack of money.

In 1981, West Side moved from a converted synagogue to a turn-of-the-century elementary school scheduled to undergo a top-to-bottom renovation. But that school was condemned, and West Side had to evacuate.

In 1994, hope blossomed again when school officials budgeted \$44.3 million for a new West Side building. But the planned site was recently taken away from West Side and given to two other schools deemed to have more pressing needs, school officials said. So West Side's students continue to make do in the makeshift space they have occupied for five years: floors 7, 10 and 11 in a garment district office building, where long lines of teen-agers wait each morning to take a converted freight elevator to class.

"It makes us feel sometimes as if we were just a bunch of nobodies," said Maggie Hernandez, 18, a senior from the Bronx.

When the Board of Education released its latest five-year construction plan two weeks ago -- a plan that, pending city and state approval, would spend \$11 billion over the next five years -- the hopes were raised for hundreds of schools throughout the city.

But moving plans from paper to reality has often been difficult, as illustrated by the experiences

of West Side and those of another school, the High School of Telecommunications Arts and Technology in Brooklyn, a Gothic fortress built in 1912 that has been entrenched in a decadelong renovation.

In the five years since the board's last construction budget was approved, and long before, the story of building and repairing schools in New York has been constantly revised. Schools move onto the priority list, are bumped off and go back on as the system's needs shift -- one year it was emergency asbestos removal, another year the installation of hundreds of classrooms on trailers -- and its finances seem tethered to a yo-yo.

With seven months left in the current \$4.6 billion construction plan, school officials have completed only about a third of the major repair projects that they identified as priorities when the plan was initiated in July 1994.

And those that they will not be able to get to as they scramble to a finish -- representing at least \$1 billion in work -- are to be laid over into the next five years.

Part of the reason is money: over the last five years, the school construction budget was whittled from the \$7.3 billion that Schools Chancellor Ramon C. Cortines initially requested in 1993 to as low as \$2.9 billion by Mayor Rudolph W. Giuliani in 1995, only to be pumped back up by the Mayor and City Council since then.

But the delays also say much about the finger-in-the-dike nature of trying to maintain a system in which half the 1,100 schools were built before World War II, while also creating new space for as many as 20,000 new students each year.

Steven Sanders, the chairman of the State Assembly's Education Committee, said that while more money was needed, the stories of "one bungled job or another" raised serious questions about the city's School Construction Authority, which carries out most of the board's building program. He has scheduled hearings on the subject for this month.

"The central question is, has the School Construction Authority been equal to the task they have been charged with?" Mr. Sanders said. "We have to make a decision whether this agency is the best vehicle for funneling billions of dollars over the next five years."

But at West Side, as at Telecom in Brooklyn, the principals and students have sought to work around the system rather than wait for it to solve their problems.

When the halls and bathrooms in West Side's leased space at 35th Street and Eighth Avenue needed painting, the students, a number of them written off by previous schools, raised the money to buy the paint themselves. When there was no custodian to do the work, the students arrived on Sunday afternoons, brushes in hand. And when the board was slow to replace burned-out fluorescent light bulbs, the principal reached into his own pockets.

"Here we don't say petty cash," said the school's principal, Edward Reynolds. "We say 'Eddie

cash.' "

But industriousness can go only so far. Many of West Side's students, impatient with the school's sluggish elevator, take as many as 11 flights of stairs down to lunch each day. For some, it is their only exercise, because there is no gym, only a small room with two hotel-style universal weight machines.

And West Side's students are not the only ones who have been left wanting.

Renovations at Telecom began in 1990, intended to convert the old Bay Ridge High, an all-girls school, into a modern coeducational high school. Plans called for the upgrade of science laboratories that were installed before penicillin was discovered, the expansion of a library with shelves so immovable that oversize books have to be laid on their sides, and the replacement of wooden auditorium seats that still have holes for inkwells and are too cramped for boys six feet tall.

The work was to have been completed by 1993, for \$11 million. Now, the renovation has been extended until 2003, at a final cost that school officials estimate to be \$45 million. The reasons for the delays include shortfalls in financing, the removal of a contractor and architect who were ultimately deemed incapable and continual revisions in design -- problems that have plagued other projects citywide, but rarely on such a large scale.

With the problems at the school mounting -- a leaky roof was sprouting more holes, and wooden windows installed only in 1985 were rotting -- the principal, Charles Amundsen, and his assistant principal for operations, John Tuminaro, took their case to the political arena. Feeling that the project had been abandoned by 1995, they began lobbying Howard Golden, the Brooklyn Borough President; William C. Thompson Jr., the Brooklyn representative on the Board of Education who became its president in 1996, and Schools Chancellor Rudy Crew.

Each was led on a tour. What they saw was an architectural treasure, a tan-brick castle whose stained-glass windows, 15-foot ceilings and statue of Joan of Arc made it look as if it had been plucked from a European university campus and placed on the corner of 67th Street and Fourth Avenue.

But they also saw mind-boggling examples of ineptitude and neglect: a new air-conditioning unit for the auditorium that was left unplugged for five years because the supporting electrical work had yet to be done; a new television studio, a critical component of the school's mission, which had been partly built but had no equipment, and "the elevator to nowhere," which was brand new but had carried no passengers for three years because it had somehow been built to stop 18 inches above each floor.

"The contractor said, 'That's the way it is in the plans,' " said the principal, Mr. Amundsen.

Dr. Crew, who first visited the school soon after he became Chancellor in October 1995, acted swiftly,

the principal said, forming a task force to foster better communication among the school, the architects and the School Construction Authority.

By early last year, the school had its new roof. Soon after, the elevator was finally operational, its landings raised to bridge the gaps between floors. And in just two months last summer, every window in the sprawling building was replaced, a feat that Mr. Amundsen had predicted could never be done so quickly.

Interior renovations are to begin late next spring, and Mr. Amundsen says he now has real reason for hope.

"This school is a classic example of good and bad with the S.C.A.," Mr. Amundsen said. "I think, in a lot of ways, the S.C.A. has matured. I'm optimistic."

In one sense, there is cause to be: in 1996, 88 percent of the authority's projects were running behind schedule; last year, authority officials have said, the number of projects completed behind schedule was reduced to 33 percent.

But whether the project at Telecom will be finished completely and under its new timetable, by 2003, will hinge somewhat on whether it can avoid running out of money, as it did during the early 1990's.

The school system's last construction budget, passed in 1994, was for \$3.4 billion over five years -- a number that Mayor Rudolph W. Giuliani pared by \$500 million. Even though the money was eventually restored, dozens of projects like Telecom were derailed.

But for the five-year calendar beginning next summer, school officials have estimated that they will need \$11 billion to address most of their needs, and some of that money is far from assured.

While \$8.5 billion is reasonably secure, backed by direct financing from the city and state, the rest depends on less certain sources. They include long-sought reimbursements from the state that the board says it is owed and the largess of a Congress that has looked unfavorably on school construction.

If any of that money fails to come through, school officials said, projects will have to be shelved.

At West Side last week, Mr. Reynolds, the principal, was worried by reports from administrators that the new building promised to his school four years ago had been given to two smaller high schools now sharing space in other schools.

Though Mr. Reynolds was hopeful that yet another building would be built for his students, he still could not bring himself to look in the school board's construction plan for the next five years.

His fears were not ill founded. There is no money for West Side.

GRAPHIC: Photos: Students at West Side High School in a building once occupied by workers in the garment district have to take a slow, converted freight elevator to the 7th, 10th and 11th floors. Sgt. Henrick Martinez recently guarded the entrance. (Nicole Bengiveno/The New York Times); Construction delays at the Gothic-style High School of Telecommunication Arts and Technology in Bay Ridge, Brooklyn, have pushed the completion date of renovations to 2003 from 1993. Outdated classroom seats fill the auditorium, above. (Photographs by Linda Rosier for The New York Times)(pg B1); Edward Reynolds, the principal of West Side High School, and his students work around the system. When the hallways needed painting, the students raised the money to buy the paint. And then they did the painting. (Nicole Bengiveno/The New York Times)(pg. B8)

LANGUAGE: ENGLISH

LOAD-DATE: December 3, 1998



HOUSE OF REPRESENTATIVES
WASHINGTON, D. C. 20515

CHARLES B. RANGEL
15TH DISTRICT, NEW YORK

December 4, 1998

President William Clinton
The White House
Washington, DC 20500

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President William Clinton
December 4, 1998
Page 2

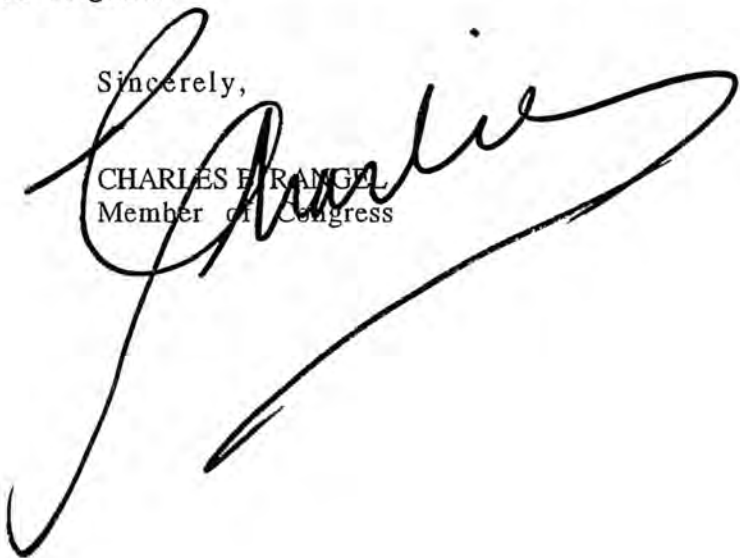
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Sincerely,


CHARLES E. RANGEL
Member of Congress

CBR/em

supported
Bergin
Bell Cohen
M. Albright

THE PRESIDENT HAS SEEN
12-4-98

NEIGHBORHOOD WATCH: EHUD YA'ARI



Better This Way

THERE'S NO REASON TO MOURN THE FACT THAT the war didn't start, as planned, on Saturday, November 14 at five in the afternoon (Israel Time). It was just a repeat performance in the long-running series, another "inevitable" U.S. strike against Iraq, averted at the last minute

because Saddam Hussein is not convinced that his personal immunity will survive one more test. For us in Israel, it's better that way.

From our point of view, the preferred scenario for dealing with Iraq has been, and remains, a combination of UNSCOM weapons inspectors on the ground working under a firm boss like Richard Butler; American forces on alert in the area capable of launching 150 Tomahawk missiles and carrying out dozens of bombing sorties at short notice; renewed isolation of Saddam in the international arena (even though Washington exaggerates the strength of Arab reservations about him); and a U.S. administration committed to responding to the next provocation with an attack, with or without Security Council approval, and engaged in a more direct effort to change the regime in Baghdad.

With all the weaknesses of this system of containment, it does effectively buy us time by delaying Iraqi plans to renew production of forbidden chemical and biological weapons, to assemble missiles and to continue the search for fissionable material, for sale under the table. However intrusive and exhaustive their upcoming searches, the inspectors will not get to the bottom of Saddam's deepest secrets in the next few months. He, of course, has no intention whatsoever of revealing the things he's kept hidden for the past seven years, even in return for the lifting of sanctions. But the presence of the weapons inspectors does get in the way, and deters Iraq from engaging in a full-scale pursuit of weapons of mass destruction (WMD). The cameras and sensors mounted at suspicious sites force the Iraqis to transfer their clandestine efforts to other locations less equipped for VX nerve gas and anthrax experiments. The inspectors are also able to follow up on intelligence information, and themselves produce information that cannot be obtained from aerial photography, communications interception or undercover operations.

It is abundantly clear that a war would not have destroyed Saddam's WMD production capability. On the contrary, it would probably have served as an incentive for the Iraqis to improvise some quick results in this sphere. And without eliminating Saddam — a goal that would have remained undeclared, of course — there was always the risk that, in the end, he would have been left bruised

and bleeding but on his feet, and without any bothersome supervision committee poking around his quarters. "Downgrading" Iraq's WMD potential — the administration's declared goal — was a formula meant to lower the sights, to give Clinton an out from the war at whatever point he desired, while allowing him to claim that the operation had been successfully completed.

In fact, the postponement of the confrontation — probably for several weeks or months, but not years — means that when zero hour finally comes, the American blow will be harder, freer of reservations and focused on the very foundations of Saddam's regime, rather than on the toys he collects.

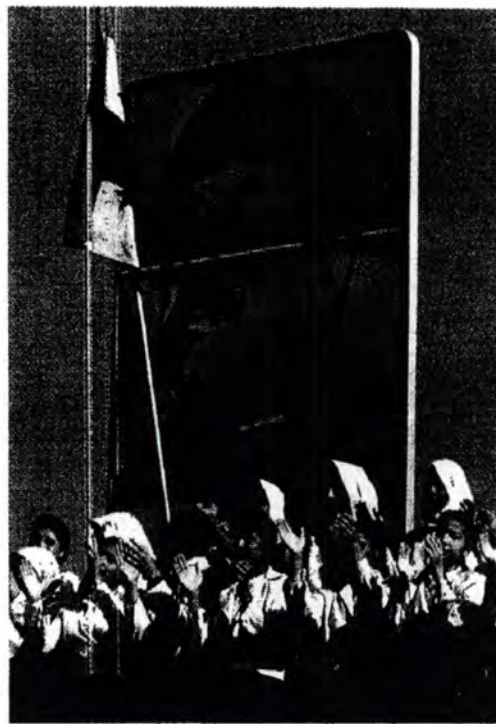
Saddam came out of the latest crisis deeper in "the box" than ever. He showed the Arab throngs who'd been pinning their hopes on him that his obstinacy is not to be relied upon. Even the Palestinians hardly came out and demonstrated for him, though there is no mistaking where their sentiments lie. (Take note: Throughout the latest crisis, Yasser Arafat kept an open channel to Saddam by means of one of his ministers, Azzam al-Ahmad, an old protégé of Baghdad. This was a kind of secondary insurance, just in case Saddam won the gamble.)

Along the way, Saddam lost some of his gains in the north, since the United States managed to broker another reconciliation agreement between the two rival Kurdish leaders, Masoud Barazani and Jallal Talabani. And Turkey, meanwhile, has changed its approach, from seeing Iraq as capable of sealing its border with Turkey against the PKK, to a policy of accusing Saddam, instead of Syria, of sponsoring the Kurdish PKK rebellion.

Kuwait, to the south, has become a supporter of the idea of a Shi'ite uprising in southern Iraq — under an American umbrella — and is less anxious about the danger of an Iranian takeover of such an experiment.

In short, if it seemed only last summer that cracks were appearing in the siege of Saddam — principally the opening of the borders to Syria and Iran — the opposite is now the case.

Clinton and his team, as expected, have portrayed the way the crisis ended in the overly bright colors of victory. Nevertheless, one still gets the impression that this time, even if the Americans weren't enthralled with the idea, they were at least ready for military action — something that was lacking in previous rounds. The fact that the bomb-laden B-52s had already taken off from Diego Garcia island by the time that Saddam backed down will allow the Americans to drive a very hard bargain next time. ●



When zero hour finally comes, the U.S. blow will focus on the very foundations of Saddam's regime

To Sandy / ca Bill Cohen
on Alhager

THE PRESIDENT HAS SEEN

12-4-98

approved
Binger
Bill Cohen
M. Albright

12-4-98

Cohen & Alhager
memos dispatched
by Sec Sec Ofc -

C. C. C.

NEIGHBORHOOD WATCH: E

Better This Way

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When zero hour finally comes, the U.S. blow will focus on the very foundations of Saddam's regime

12-4-98

KUNHARDT PRODUCTIONS, INC.
FOUR SCORE, INC.

30 West Main Street, Mount Kisco, NY 10549 Telephone: 914/366-1111

November 19, 1998

Joe L. / Kunhardt
I definitely want to do this

BK

President Bill Clinton
The White House
Washington, DC

Dear Mr. President:

Tommy Caplan has indicated that you are willing and able to squeeze an interview into your busy schedule and be part of our ten-part PBS series *The Presidents: In Their Own Words*. The series is hosted by Hugh Sidey who has already conducted interviews with Presidents Ford, Carter and Bush. It will air during the 2000 primaries. In order for us to be able to include your interview in the companion volume, it is necessary to conduct it before mid-January. I appreciate whatever you can do to make that happen.

Attached is a breakdown of the series. As you will see, our approach is thematic, not chronological. Your interview will be part of the episode "The Balance of Power," which will examine Presidential leadership in an era of increasingly divided government.

I have attached a proposed list of questions. The interview will take one-hour and our preference is to do it in the White House.

Thank you again Mr. President for fitting this in. Please let Tommy know what our next step should be.

Sincerely,

Peter Kunhardt

Peter Kunhardt
Executive Producer

copied
Lockhart
Lewis
COS
Scheduling

Questions for President Clinton
The Presidents: In Their Own Words
PBS

1. What was different about the Presidency than what you had imagined?
2. Is there one special moment where the enormity of being President hit you?
3. You have admired many Presidents who have stretched their executive powers. Are they models for you and for many of the initiatives you have taken?
4. You preside in an era of divided government. How hard is it to exercise Presidential power in our system today?
5. Has Congressional partisanship become too intense? What effect has it had on your Presidency?
6. How do you think the media has altered Presidential power?
7. What about the office of the Special Prosecutor? What has been its impact on the power of the Presidency?
8. Given these increased restraints, do you think our system of checks and balances is working? Where do you think the Presidency is heading?
9. 1998 was a difficult year for you both personally and professionally. It has raised the issue of character. From your own experience, how important is that issue of character for a President?
10. The American people spoke out loud and clear in the 1998 elections. Let's discuss the power of the people and the role the public plays in exercising political power.
11. Have you wandered through the White House and looked at other Presidential portraits with new sympathy?
12. Has the Presidency changed your views about any of those other Presidents?
13. As the father of the Constitution and one of the inventors of the Presidency, is James Madison a hero of yours?

14. As the father of the Constitution and one of the inventors of the Presidency, is James Madison a hero of yours?
15. How important has Hillary Clinton been to your Presidency? How would you describe her role in the White House?
16. What do you want historians to say about your Presidency?
17. Let's look back at your evolution into the Presidency. Did your second grade teacher really tell your mother you would be President some day? What was it in your early years that shaped your interest in politics?
18. What was the most valuable experience that helped prepare you for the Presidency? Was it your legal training?
19. You were Governor at age thirty-two. What was it like to be so successful in politics at so young an age?
20. Then you lost your re-election bid. How did that 1980 defeat affect you?
21. You once said, "The God I believe in is a God of second chances." Can you explain that?
22. What's the best word to describe you during your Presidential campaigns?
23. When you ran in 1992 you said, "You may only be fit to be President when you are not obsessed with it." What do you mean by that?
24. How did it feel the moment you realized that you had won the election in November 1992? Was it a different feeling when you were victorious again in 1996?
25. How did you feel when you first walked into the White House as President? Can you recall walking into the Oval Office or up to the living quarters for the first time as President?
26. On balance, has it been fulfilling?
27. Has the Presidency changed you?
28. What is your mark on the office?

THE PROGRAMS

Ten 60-Minute Episodes on the Presidents

1. An Office And Its Powers

Jackson, Cleveland, T. Roosevelt, Nixon

Though the powers of the presidency have expanded with the growth of the nation, the process has been anything but consensual or smooth. The prerogatives of the presidency are uncertain and their assertion is invariably contested. These four presidencies are benchmarks in the development of executive power. We see here the emergence in practice of our modern conception of the executive office, and we take the measure of the men who fought to sustain it.

2. The Heroic Posture

Washington, W.H. Harrison, Grant, Eisenhower

From the beginning, the presidential office has beckoned to national heroes renowned for their selfless service to their country. This affinity is especially strong for men of military fame for the President is formally Commander-in-Chief as well as symbolically the steward of the national interest. The President-as-national hero has been quite effective in rallying the people to his side, but he does so by appearing to stand above or beyond politics. He exemplifies the value we all place on authenticity in governance. He evokes ancient images of the great republican tribunes, men of proven strength and courage who could be relied upon to protect the interests of the whole. We explore here four personifications of this ideal, suggesting a wide-ranging reality behind an enduring standard.

3. The World Stage

Monroe, McKinley, Wilson, Bush

We live at a time when statesmen are trying to fashion a new order in the world and Americans are debating what role they should play in it. The President has no greater responsibility than representing the nation on the world stage. Securing a stable world in which American interests can be asserted and defended has been a basic part of the President's job description from the very beginning of our constitutional history. These four men engaged in this task at critical times in our national history and their achievements on the world stage stand as their most durable legacy.

4. An Independent Cast of Mind

J. Adams, Taylor, Hayes, Carter

While the President alone is accountable for his administration, his office is surrounded by powerful interests, and he is continually being pushed and pulled on all sides. Every President struggles to chart his own course, but for the Presidents grouped together here, independence in action was raised to a point of principle, and it became a test of character. Each took on powerful interests with which he was himself politically affiliated, determined to stand on his own ground despite the potential damage to his political base.

5. Family Ties

J.Q. Adams, B. Harrison, FDR, Kennedy

While the presidency retains some of the trappings of kingship, it remains a republican office with no formal bloodline. That certain American families have achieved prominence in the office testifies to a strong ethic of public service cultivated at home. The Presidents arranged here had high ideals of republican statescraft instilled in them from childhood. Each seems to have gained something a bit different from their famous political relations, but all brought to the office a keen sense of their family ties and of the responsibilities connected to the family name.

6. The Professional Politician

Van Buren, Buchanan, Lincoln, LBJ

At our nation's founding, active participation in political affairs was considered a duty and an honor, but not a way of life. All that had changed by the mid-nineteenth century when politics emerged as a vocation, a life's work for a worthy man. Each of these Presidents dedicated their lives to cultivating the art of politics, and each brought to the office decades of experience in the uses of power. Exemplified by cunning and ambition, they also were unmatched in the essential skills of forming coalitions, bargaining with adversaries, resolving conflict and building consensus.

7. Happenstance

Tyler, Fillmore, A. Johnson, Arthur, Truman

Happenstance has always played a part in government and politics. In the presidency it has played quite a large part. Almost one-quarter of our Presidents were chosen as Vice-Presidents and rose to power on some chance occurrence. Selected for reasons that have often had little to do with their suitability for the highest office, they have nonetheless exercised its powers in full. Of the five Presidents considered here, only one was able to gain election to the presidency in his own right, but each made his presence felt in the office, at times significantly changing the course of events.

8. Compromise Choices

Pierce, Garfield, Harding, Ford

Ever since Lord Bryce asked the question in the late-nineteenth century, Americans have wondered why relatively obscure figures are so prominently featured in the American presidency. Much of the answer lies in the operation of American government during the middle years between Jackson and FDR. Political parties were the central organizing powers in those days and great men were often passed over for the presidential nomination precisely because their strong views threatened to remake those organizations rather than simply represent them. The consensus-building potential of the dark horse was discovered through scores of ballots on the convention floor. Today, true dark horse candidates no longer exist. But in the context of changing political times, compromise choices continue to be made.

9. The American Way

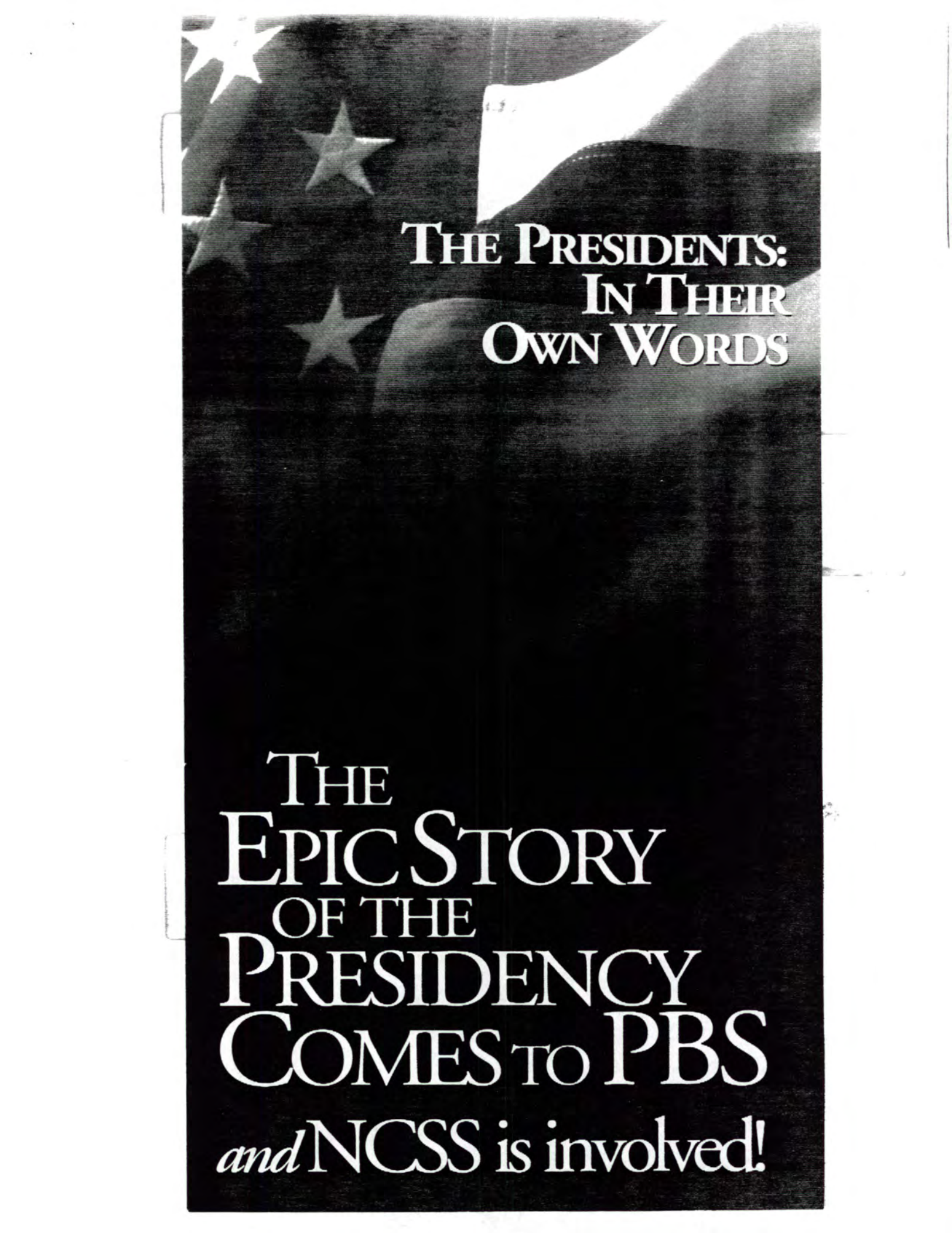
Jefferson, Coolidge, Hoover, Reagan

It is often observed that American national identity is less a condition than an idea. No one is better positioned to express that idea than the President. What we have come to refer to as "the vision thing" is an expectation that our Presidents will bring to office a particularly strong sense of national mission. They may have understood the special character of America in different ways, but in each case a belief that there was a distinctly American way of doing things guided their decisions.

10. The Balance of Power

Madison, Polk, Taft, Clinton

This final episode will bring the series up to date by examining presidential leadership in an era of an increasingly divided government. The American presidency was conceived as one part of a larger system of institutions, and its significance rests in good measure on its relationship to the whole. The constitutional design of three branches of federal power each of equal status was a break from traditional hierarchical arrangements, and while we tend to think of the President standing at the head of government, it might be more accurately understood as an integral part of a balance of powers. As our constitutional system has developed, this idea of balance has been elaborated in new and unexpected ways. The Presidents arrayed in this episode suggest four different conceptions of this constitutionally structured balancing act.

The background of the entire poster is a close-up, high-contrast image of the American flag, showing the stars and stripes in a dramatic, slightly blurred manner.

THE PRESIDENTS:
IN THEIR
OWN WORDS

THE
EPIC STORY
OF THE
PRESIDENCY
COMES TO PBS
and NCSS is involved!

THE PRESIDENTS: IN THEIR OWN WORDS. A new part series on the history and impact of the American presidency will air on the Public Broadcasting Service in Spring 2000. The new series—written and produced by Kimball Phillips—will be presented on PBS by historian W.H. F. in New York and made possible by New York City as the first to explore the history of the office through the stories of the 41 very different men who have held it.

The series is also poised to air during the height of the political primary season, when interest in the national office is keen. The series, and the materials that accompany it, will help students understand the scope and limitations of the president's powers, trace the development of the American electoral process, and develop the historical frame of reference they need to become responsible voters.

The National Council for the Social Studies has endorsed the project and will play a partnership role in the development of classroom materials designed for distribution to teachers nationwide. NCSS members are invited to work on the outreach (see below). Honoraria will be paid for all work done.

The series will be a valuable and flexible tool for teachers. The presidents are grouped thematically as explained in the series overview below, and each individual presidential profile (pt. 1-17) is 15 minutes, making them ideal for classroom use.

NCSS were approached to participate in this outreach more than six months ago, says Executive Director Matthew Caffrey. It's our hope that several hundred NCSS members will ultimately participate in the creation of the materials. They will represent a very unusual degree of involvement by NCSS and we hope will guarantee that the materials are appropriate and easy to use.

THE SERIES

Doug Sisk, the White House's chief pundit for *Time* magazine for four decades, hosts and narrates the program. Harvard scholar Richard Neustadt, who has been called by *Atlantic* "the single most brilliant commentator on the Presidency," offers his perspective on each of the presidents profiled.

Four presidents are profiled in each hour. Each program concludes with a president speaking in his own voice, either from earlier recorded sources or through on-camera interviews with narrator Sisk. (Sisk speaks only for the series.) The remaining presidential words are spoken by public figures, from the world of politics and journalism, including John Glenn, Walter Cronkite, Morley Safer, James H. Brown, Joseph, James, Carville, and many others.

Here is an overview of the series:

1 AN OFFICE AND ITS POWER

Though the powers of the presidency have expanded over time, the process has been anything but smooth. The four presidents profiled in this hour were born into a time of the definition of presidential power.

Andrew Jackson
Grover Cleveland
Theodore Roosevelt
Richard Nixon

James Carville
Governor Lowell Weicker
William F. Buckley
Himself

2 THE HEROIC POSTURE

From the beginning, the presidency has beckoned to national heroes, renowned for service to their country—and especially to military men. The president as hero can be effective in rallying the people to his support, but he does so by appearing to stand above politics. Is the hero always an effective president? This hour explores four presidential careers in search of the answer.

George Washington
William Henry Harrison
Ulysses S. Grant
Dwight D. Eisenhower

Walter Cronkite
Senator Lloyd Bentsen
General H. Norman Schwarzkopf
Himself

3 THE WORLD STAGE

The president has no greater responsibility than representing the nation on the world stage. Securing a stable world in which American interests can be asserted and defended has been a basic part of the president's job description from the very beginning. Achievements on the world stage stand as the most durable legacy of the four men in this program.

James Monroe
William McKinley
Woodrow Wilson
George Bush

Robert MacNeil
George Schulz
Senator George Mitchell
Himself

4 AN INDEPENDENT CAST OF MR.

Some presidents view themselves as above party politics, not subject to the pressures of partisan interests. For the presidents grouped in this program, independence in action was raised to a point of principle, and it became a test of character. This is a romantic stance, but is it an effective one?

John Adams
Zachary Taylor
Rutherford B. Hayes
Jimmy Carter

Morley Safer
Tom Wicker
Senator John Glenn
Himself

5 FAMILY TIES

While the presidency retains some of the baggage of kingship, it remains a republican office with no formal bloodline. That said, some American families achieved political prominence that extended to the Oval Office. Each of these presidents brought with him deep family traditions rooted in public service and a sense of family ties.

John Quincy Adams
Benjamin Harrison
Franklin Delano Roosevelt
John Fitzgerald Kennedy

George Will
To be set
James Roosevelt, Jr.
Himself

6 THE PROFESSIONAL POLITICIAN

At the heart of our nation's leadership, active participation in public affairs was considered a duty of an honor, but not a profession. In the mid-19th century, politics emerged as a vocation, a life's work. The four presidents featured in this hour were professional politicians, with professional skills, forming coalitions, negotiating with adversaries, resolving conflicts, and building consensus.

Martin Van Buren
James Buchanan
Abraham Lincoln
Lyndon B. Johnson

The Honorable Edward J. Keen
To be set
Senator Paul Simon
Himself

7 HAPPENSTANCE

Happenstance has always played a part in the history of the presidency. Almost one-quarter of our presidents were chosen as vice presidents and rose to the Oval Office on a chance occurrence. Selected for reasons that often have little to do with their suitability to hold the highest office in the land, they have nonetheless exercised its powers in full at home, significantly changing the course of events.

John Tyler
Millard Fillmore
Andrew Johnson
Chester Arthur
Harry Truman

To be set
To be set
To be set
To be set
Himself

8 COMPROMISE CHOICES

Why have so many relatively obscure figures attained the presidency? In the years between Andrew Jackson and Franklin Delano Roosevelt, political parties held absolute sway over the nominating process and often turned to consensus, building "dark horse" candidates rather than strong individuals who might impose an individual agenda. This program focuses on four of them.

Franklin Pierce
James Garfield
Warren G. Harding
Gerald Ford

To be set
To be set
To be set
Himself

9 THE AMERICAN WAY

It was briefly called "the vision thing," a belief that there was a way of doing business that was consistent with the national identity that was distinctly American. Some presidents have demonstrated a particularly strong sense of national mission. They may not always be uncontroversial, but they are remembered for the consistency of their policies and decisions.

Thomas Jefferson
Calvin Coolidge
Herbert Hoover
Ronald Reagan

To be set
To be set
To be set
Himself

10 THE BALANCE OF POWER

The final program will bring the series up to date by examining presidential leadership in an era of increasingly divided government. The American presidency was conceived as one part of a larger system of institutions, and its significance rests in good measure on its relationship to the whole. As our Constitutional system has developed, the "balance of power" has been interpreted in new and unexpected ways.

James Madison
James Knox Polk
William Howard Taft
Bill Clinton

To be set
To be set
To be set
Himself



FROM THE PRODUCERS OF "THE PRESIDENTS: IN THEIR OWN WORDS"

Peter W. Kunhardt, Philip B. Kunhardt III,
Philip B. Kunhardt, Jr.

Kunhardt Productions is a family enterprise bringing together three generations of journalism and history. Peter W. Kunhardt has been producing documentaries for the past twenty years and is a three-time Emmy winner. His brother, Philip B. Kunhardt III, co-authored and produced *Lincoln: An Illustrated Biography*, *P.T. Barnum*, and *The People's Palace*. Their father, Philip B. Kunhardt, Jr., is a former managing editor of LIFE magazine and the author of numerous books, including the *Christopher Award*-winning memoir, *My Father's House*. Kunhardt Productions' body of work includes two previous presidential documentaries — *JFK: In His Own Words*, and *Lincoln*. The Kunhardts are the co-authors of the companion book to the series, published by Riverhead Books, a division of Putnam.)

The television series *The Presidents: In Their Own Words* is a highly entertaining and informative look at what our nation's presidents have done for the country. It is the first to look at all 41 presidents — and look at the multi-faceted character of a truly American office — through the stories of the individuals who have held it.

These stories will be produced thematically, allowing presidents from different eras to be compared and contrasted. When lesser-known figures are matched alongside more familiar ones, we suddenly appear side their experiences in a new way.

At Yale University's "Clayton" Library, we spent the first months of the project listing out overarching categories in which to group the presidents. When we finally agreed upon a categorization, we were all happy with it because the intellectual framework for this series allows us to make quite fascinating juxtapositions: for example, Thomas Jefferson with Ronald Reagan, John Adams with Jimmy Carter, James Monroe with George Bush, James Madison with Bill Clinton. And it allows us to look at the most familiar presidents in less familiar ways. Abraham Lincoln is an example of the profound political and moral leadership of his family line. Harry Truman for his unexpected elevation to the highest office.

Each episode concludes with a profile of a president speaking in his actual recorded voice, including several through an original interview conducted by our series' narrative presidential journalist Hugh Sidey. Another important alliance that was formed as the project unfolded was with Harvard scholar Richard Nixon. (Our decision to ask him to share his unique perspective as the on-camera commentator for each group has ended up deeply shaping the series.)

Behind the research that has gone into the creation of our first script, we have made a massive effort to collect a pictorial record of the presidents. Building on the strengths of our own private archive, the *Morse-Kunhardt Collection*, we have gathered thousands of stunning images and thousands of feet of rare newsreel footage. And at dozens of presidential home sites across the country, we have filmed extensively on location.

Our goal for the series is to help viewers see the presidency afresh, and to think about its incumbents in a new way. If some are inspired to a deeper level of citizenship, it will be a tribute to the public service of the presidents we are profiling. By looking at the variety of individuals who have held the high office and by contrasting their abilities and their major choices in the presidency, we hope to tell what is an extremely important story, as well as an enlightening history of a vital American institution.

THE PRESIDENTS: A PERSONAL PERSPECTIVE By Hugh Sidey

TIME magazine's special correspondent on the presidency for four decades, Hugh Sidey has a unique perspective on the Oval Office — and on the men who have occupied it. He will serve as the narrator of *THE PRESIDENTS: IN THEIR OWN WORDS*, and will also create exclusive columns for the series' Web site, which is being undertaken in partnership with NCSS.)

After President John F. Kennedy's death, I went to the White House. They told him it would cost \$40 billion (a huge sum then) and take ten years, and they could not guarantee that the "Hubert" Library would be the "Secret House" to the nation. Kennedy grimaced, ran his fingers through his hair, and went back to his chair in the Cabinet Room. He wanted Americans on the moon — and first, "I want some answers." He told the small group of aides: "Ask the question over there if you have to. But I want to know how and where we can get to the moon."

By night he would go to bed, and he would be the first to go to bed, and he would be the first to get up. On that April evening in 1961, that with a few weeks he had been told the nation was in a capital situation. And it must have been the same with the visionary Thomas Jefferson, who doubled the size of the U.S. with the Louisiana Purchase, and the pioneer lawyer Abraham Lincoln, who marshaled the most powerful army the world has known to abolish slavery. And Theodore Roosevelt, who sent his engineers to build the Panama Canal. With vision and a free people, and these three Presidents — and the others — profoundly transformed civilization. In our time there is no more effective and powerful public influence on the face of the earth. We do not know and learn that lives, march with these men — and someday soon, women.

Some of the 41 men who have been president have left their mark. Some more positive than others. "No president wants to fail," Lyndon Johnson once pointed out when he was asked about the Vietnam War. "You do the best you know how." In the midst of that tragic conflict, he was a father, for better education and health care. And Richard Nixon, who would be driven from office by the Watergate scandal, had a long, thoughtful journey through China, offering America a friendship for the first time after 25 years of Chinese isolation.

The presidency, like democracy, is not an easy game. "I'm going to give the job to Nixon," JFK once quipped when things were going badly. "I know better. He's got the great chest, quite as, he called it. That is why so many people now fight for the right to be president — they're doing on this, because it's not more than 80 years now. There is no more fascinating and thrilling — and often devastating — arena that we can address."

My great hope that as *THE PRESIDENTS: IN THEIR OWN WORDS* unfolds, every viewer will hear the voices, and the bugle calls, and the heartbeats, and then feel the excitement of these men calling their nation to the most magnificent efforts in war and peace that have known.

ABOUT THE OUTREACH

The educational outreach in support of these films is being funded by New York Life, the series' underwriter. The effort will be aimed at social studies teachers in middle school, high school, and at the post-secondary level. Although the outreach will offer the traditional television support materials — teachers' guides, student projects and activities, and related resources — it will also go beyond these tools.

Central to the project will be a site on the World Wide Web that will offer a wide variety of assets for teachers. Among them will be:

1. A spectrum of teaching materials for downloading, focusing on the series, on presidential history, and on the national election of 2000.
 2. An organized "portal" to the Internet, offering access to hundreds of presidential and election online resources, selected and evaluated by teachers.
 3. An "instant polling" feature that will allow students to make their voices heard in real time regarding the issues that arise in the campaign.
 4. An original column by Hugh Sidey, exclusive to the site and available nowhere else.
 5. An electoral game in which students will learn about modern elections by guiding a virtual candidate through the process that leads up to the nomination.
 6. Interviews with candidates, political professionals, pollsters, and news and media spokespersons.
 7. Collaborative projects for teachers and students, including a national student political magazine.
 8. Teachers' chat areas and student discussion boards.
- ... and much, much more.

In addition to the website, printed materials will be mailed out. Many of the elements in these print packages will also be distributed in NCSS publications.

Everything distributed to NCSS members will be created by NCSS members. The goals of this outreach are to involve as many classroom teachers as possible and to reach as many classroom teachers as possible.

GET INVOLVED!

Do you want to participate in shaping the NCSS outreach that will help your colleagues take advantage of *THE PRESIDENTS: IN THEIR OWN WORDS*? IT'S EASY!

We need classroom teachers who would like to:

1. Evaluate World Wide Web sites related to presidential history and the election.
2. Generate materials for distribution online and in print.
3. Review materials developed by other teachers.

Honoraria will be paid to all participating teachers. It will be very helpful if you have, or can get, an e-mail address.

If you'd like to get involved, write a note and e-mail it to Tim Hallinan of Hallinan Consulting at this address:

timh@primenet.com

Or use the U.S. Postal Service to reach him at

Tim Hallinan
Hallinan Consulting
15 Avenue 26
Venice, CA 90291

Be sure to mention *THE PRESIDENTS: IN THEIR OWN WORDS*.

THE PRESIDENTS: IN THEIR OWN WORDS is written and produced by Kunhardt Productions and is made possible by New York Life, the series' sole underwriter, which is also funding the educational outreach effort. The series is presented on PBS by Thirteen/WNET New York, the flagship public television station and one of the nation's foremost producers of quality television.



Thirteen · wnet



THE
EPIC STORY
OF THE
PRESIDENCY
COMES TO PBS
and NCSS is involved!

GIULIANI CHIC
By Dan Barry

DOCUMENTARIES
DEVOUR
PRIME TIME
By Tom Vanderbilt

DIGGING OUT
HONDURAS
Photographs by
Larry Towell

The New York Times Magazine

DECEMBER 6, 1998 / SECTION 6

"First Run"
Not for Color

12-4-98

copied
Jennings
Podesta

Their 19-month-old boy was deteriorating, and Richard and Jordana Sontag had come to Yale, desperate and angry.

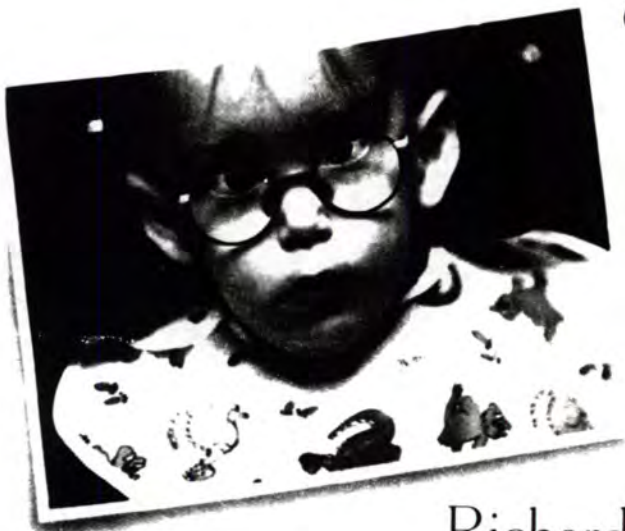
An experimental gene therapy was their only hope, but the scientists were not sure it was safe.

The couple spotted Dr. Margretta Seashore in the lobby. 'Look at him,'

Richard said, thrusting Jacob in her face. 'You tell him why this protocol is delayed while he's dying. ...You look at my son dying. Tell it to him.'

Keeping Jacob Alive

By Michael Winerip



←
Jennings
Podesta

Until recently, there was no hope for a child with Canavan disease. But when the Sontags learned that their only child was born with it, they were prepared to sacrifice anything to get him the experimental treatment he needed. They didn't know that might include their marriage.

Fighting for Jacob

By Michael Winerip

Jordana and Richard Sontag were speeding toward Yale University, angry, desperate, ready to unleash their secret weapon, which they had carefully loaded into the back of their Grand Cherokee. For a year, they had done everything in their power to save their dying baby boy, Jacob. The well-to-do young couple and relatives had donated more than \$200,000 to Yale to underwrite experimental gene-therapy research aimed at curing the rare genetic disease that plagued Jacob. They had helped pay to bring two leading researchers from the other side of the world to Yale and to transport from a lab in Germany the precious concoction of healthy genes that might save their son and a dozen other dying children with Canavan disease. They had hired lawyers and enlisted United States Senators to lobby the medical oversight committees for approval of the experimental procedure.

And then they waited. Week after week, Yale officials assured them that the medical school's review committees and the governmental agencies would soon take action. But spring had given way to summer, and summer to fall, and still nothing. Jacob's adorable blond head had grown too heavy for him to hold up, and he had little control of his limbs, which hung at his sides, making him floppy like a rag doll.

In hopes of speeding the review, Jordana had assembled two notebooks full of records documenting the complete medical history of 1½-year-old Jacob Ross Sontag, starting with the first sonogram. The names of all those committees and agencies that had to approve the experimental treatment made her head throb and at night turned her dreams dark and anxious: the Human Investigation Committee and Biological Safety Committee at Yale; the Recombinant DNA Advisory Committee at the National Institutes of Health; a staff review at the Food and Drug Administration. All had to say "yes" before the children could be treated. But as the

Richard and Jordana with Jacob, after he was hospitalized with a 103-degree fever.

Photographs by James Estrin





Dr. Seashore didn't tell the Sontags, but she, too,



Above: Richard and Jacob at mealtime. Right: Jordana in a moment of quiet anguish.

Sontags knew, H.I.C. wouldn't act until B.S.C. did; B.S.C. preferred R.A.C. to give an expedited approval first; and R.A.C. was waiting until H.I.C. ruled. And how did the Sontags explain that to friends who asked, "How's it going?"

"We plan to see anyone who will see us," said Richard on the drive to Yale. "We'll look into offices, the cafeteria — we'll find them!" That fall day in 1997, as they hurried through the lobby of Yale-New Haven Hospital wheeling the secret weapon, they couldn't believe their luck. There was Dr. Margretta Seashore! The enemy! To the Sontags, Dr. Seashore epitomized all the bureaucratic delays that were killing them. She is an internationally known genetics professor, appointed by Yale to shepherd the experimental procedure through the review process. At 59, Seashore is careful, thorough, academic — precisely the type of person who was driving the Sontags crazy. Seashore was a generation older

than the bold team of junior Yale researchers who had actually developed the new gene therapy, tested it on 300 rats, 4 monkeys and 2 children in New Zealand and pronounced it ready to go for its first trial in the United States.

As far as the Sontags were concerned, Seashore represented the establishment, when they needed a firebrand to shake up Yale.

Seashore was waiting in the lobby to meet a group of medical students for a tutorial and was surprised to see the Sontags. She tried to make small talk, but they would not be distracted. "I'm sorry I can't sympathize," said Jordana. "We're living with a dying child the past 18 months."

Richard unfastened the secret weapon and began yelling. "You look at him!" he screamed, lifting Jacob out of the stroller and pushing him at Seashore. "You tell him why this protocol is delayed while he's dying!" The father was speaking so loud, people in the lobby were staring. Seashore noticed that her four medical students had arrived and appeared to be in shock.

"How could you prevent our child from treatment?" Richard yelled. By then, Richard was crying, Jordana was crying, Jacob was howling and Seashore looked ready to burst into tears.

"I do understand your desperation," Seashore said. "You have to understand, the biosafety committee is trying to be safe." She suggested that they consult the medical-school dean about the delays. "I'm under tremendous pressure the past months, overseeing this protocol."

"That's a luxury compared to being parents of a terminally ill child," said Jordana.

Seashore's hands were trembling. She warned she'd take herself off the protocol if this pressure continued: "If I do, this trial is dead."

"You look at my son dying," Richard screamed. "Tell it to him!"

Seashore would later call that Sept. 24, 1997, showdown a watershed. "I was shocked at their behavior in public," she said. "What that said was: We have desperate people here; they're going to blow the place up; we have to make a deci-

Michael Winerip is a staff writer for the magazine.

thought Yale's biosafety committee was stalling. 'If you just tell people we're putting foreign DNA into the brains of small children, jaws drop,' she said.



sion." After the Sontags' visit, the assistant to the medical-school dean spoke to members of the Yale biosafety committee and told them that it was time to decide — yes or no — but soon. The next week, the committee approved the therapy, and in the following months the other committees did, too. The Sontags' desperate plan had worked. On Jan. 2, 1998, Jacob Sontag was scheduled for surgery at Yale, the first time doctors in this country planned to treat a genetic disease by shooting a syringe full of healthy genes directly into the brain.

The four medical students who witnessed that confrontation have told Seashore it's the best clinical lesson they've had at Yale, and indeed, many of the forces shaping medical practice and research converged that day in the lobby to detonate the nasty explosion. For the Sontags, the experimental therapy was the sole hope they had to reverse the degeneration of their only child, precious Jacob, suffering from a rare disease that eventually leads to paralysis, blindness, severe retardation and death, typically between ages 5 and 10. To the Sontags, gene therapy — intro-

ducing healthy genetic material into malfunctioning cells so that they can produce a missing enzyme Jacob's body needs — was brilliant, and they knew from news articles that the approach was being used in hundreds of trials on cancer, cystic fibrosis and heart disease.

In the Sontags' corner were two junior Yale researchers, Dr. Matthew During, 41, and Paola Leone, 34, a neurobiologist. Since 1995, when parents of another dying child had begged During and Leone to apply their skills to Canavan, the two had moved at a breakneck pace. The Sontags understood these researchers had their own reasons — there will be great rewards for the scientist who figures out how to deliver large amounts of healthy genetic material to the right cells. For During and Leone, Canavan could be the template for other genetic therapies, revolutionizing medicine; the dying children promised to be the perfect human subjects. As for the parents, they just thanked God that anyone would take on such a rare "orphan" disease.

On the other side were Seashore and three dozen colleagues on Yale's oversight commit-

tees, many of them fearful that in this era of deregulation safety standards are being lowered, allowing treatments like the fen-phen diet drugs to reach the public without adequate testing. "The heart of the question," Seashore said, "is when is it time for something in a scientific lab to be made available to people?" Seashore had seen the career of one of her colleagues, the geneticist Dr. Reuben Matalon, upended by moving too quickly from the test tube to humans. In the early 1990's, Matalon thought he had developed a pregnancy screening test for Canavan. And then, to his horror, four pregnant women who had tested negative gave birth to babies with the disease. "I wasn't going to let anything like that happen to me," Seashore said.

I first met Jordana and Richard Sontag in May 1997. Richard's sister, Deborah Sontag, is a friend and colleague (the Jerusalem bureau chief of *The Times*) and had told me of her younger brother's quest. She was skeptical, but also in awe of how determined her brother and sister-in-law were to find a cure and how open they were about Jacob. A few months before, in Feb-



Richard comforting Jacob as Dr. Charles Duncan, center, and his assistant, Dr. Sung Lee, inject the new genes.

ruary 1997, to celebrate Jacob's first birthday, Richard and Jordana had rented a restaurant banquet room, hired a Musical Munchkin and invited 50 friends and relatives to the party.

Until recently, there was no hope for a child with Canavan, which is most prevalent among Ashkenazi Jews like the Sontags — affecting 1 in 6,000 Jewish infants. Both parents must be carriers for the disease to manifest in the offspring. Children have a defective gene that can't produce a key enzyme needed to break down an acid in the brain known as NAA. Scientists hypothesize that a surplus of NAA develops, which in turn interferes with the formation of myelin, the white coating that covers nerve cells. Without myelin, the brain's nerve cells can't relay messages to the body, eroding motor control to the point of paralysis. Autopsies reveal spongy brains full of tiny holes.

At birth, the baby appears normal. But by 3 months, parents notice a lack of responsiveness. Misdiagnosis is common. Jacob was first thought to have developmental and vision problems. At 4 months, he was fitted for glasses. At 5 months, a specialist said it was Leigh's disease. By the time Canavan was identified, Jacob was 7 months old.

Most families had only bleak things to tell the Sontags. They met parents who medicated

their children around the clock, who felt any physical therapy was a waste. A mother from Philadelphia said: "Don't get him glasses. It won't matter to him, and you don't want people staring." There were parents who confided that they quietly let the children die instead of rushing them to a hospital during a seizure. "The best thing you can do," they said, "is have another child who is healthy." To Jordana and Richard, this was Canavan's defeated old guard speaking.

The couple was not used to failure. In 1992, when Richard was 30, he bought out a two-man firm that produced battery-heated socks and in five years built it into Nordic Gear, a multi-million-dollar outdoor accessory company with three factories and 350 employees. At an age when many are still deciding what to be, Richard was flying to the Orient first class on business and arranging meetings with his bankers. For her part, Jordana was a creative public-relations executive, savvy enough to get one of Richard's items featured on an Oprah Winfrey pre-Christmas show highlighting great gift ideas.

In the spring of 1997, in the midst of their quest for treatment, they bought a seven-bedroom, seven-bathroom home with a pool on 1.75 acres in a wealthy Westchester County suburb. That

enormous house made Jordana uneasy, but Richard saw it as a testament to his business success.

They were determined to treat their son as normally as possible. When I first met Jacob, at 15 months, if his head fell onto his chest, Richard would say: "Pull up your head Jacob. Come on Boo." And slowly, Jacob did. "Say hi," Richard coached, and light came into Jacob's eyes, a smile appeared, his mouth opened and a tiny "Hi" came out. Then Richard would kiss him all over, turn him upside down and make gassy noises against his neck while Jacob beamed.

"Other Canavan families are amazed by Jacob," said Jordana. "They've never seen a Canavan child so advanced." The Sontags made sure Jacob had extensive weekly therapy — physical, speech, occupational — all publicly financed as part of a Federal early-intervention program for disabled preschoolers. They constantly read to him. On a trip to Philadelphia, Jordana sat in the back seat and read and sang the entire two hours while Jacob was mum, staring through his blue-rimmed glasses: "Is Clifford in his doghouse? Is that where Clifford is? Little Man, how come you're so smart?"

They were delighted he was already 25 pounds, while a 7-year-old Canavan girl they'd met, Morgan Gelblum, weighed *Continued on page 61*

The genes they had been waiting so long for, the genes that could change their son's life, had arrived, in an ice bucket that looked borrowed from a Motel 6.

just 30. Instead of giving him a mushy diet — he had limited chewing control — they fed him Cheerios, waffles, chicken soup with matzoh balls. Canavan children tend to have trouble sleeping — imagine not being able to shift your body for 10 or 12 hours — and most parents sedate them. “They put them to sleep with one pill and wake them with uppers,” said Richard. If Jacob cried, they checked on him, but let him cry himself to sleep.

Strangers saw Jacob's stylish glasses and his polo shirts and commented on how much he looked like the boy, Ray, in the film “Jerry Maguire.” “People don't realize he's handicapped,” said Jordana. But the Sontags were no fools. Jordana was constantly downloading articles, and one described how much of the brain's development is completed by age 2. “Every month he doesn't have the surgery, he's losing,” she said. “At 6 months, he wasn't far behind other children. Now at 15 months, he should be walking, and the distance from where he should be and where he is gets larger. He'll have to do so much more to catch up after the surgery.” While the Canavan literature lists retardation as a symptom, it is not clear at what age mental deterioration becomes irreversible. Jordana and Richard were convinced there was a bright little boy trapped in that body, and they based that on the light in his eyes and his beautiful smile. They were in a race against time to reach that trapped person before he disappeared forever.

THEY WERE NOT THE FIRST. THE KARLINS of New Fairfield, Conn., were. In 1994, Canavan was diagnosed in Lindsay Karlin. Her father, Roger, an internist, and mother, Helene, a psychologist, began a frantic hunt for scientists doing gene therapy and found During and Leone nearby at Yale. At the time, the researchers were using Parkinson's disease to investigate ways to deliver genes into brain cells of rats. They were testing a nonharmful virus that could be loaded with replacement genes and would then transport those genes through the membranes of brain cells.

The Karlins brought Lindsay to meet During and Leone. After several visits, the researchers agreed to focus on Canavan. The disease offered an objective measure of gene therapy's effectiveness. If, after gene injection, a brain scan showed the children's NAA decreased and their myelin increased, it would be evidence that the implanted genes had done the job. There were human reasons, too, in the Karlins' favor. Like the Sontags, they were educated people who understood the ethics of offering up their daughter and promised to be able fund-raisers.

At that time, During, a native New Zealander, was being wooed to return to Auckland. While

scores of labs in the United States were doing gene therapy, in New Zealand he would be first. He saw a chance to do more, faster, with greater resources. Indeed, shortly after returning to New Zealand, the pioneer geneticist was fielding phone calls from reporters. On March 6, 1996, he oversaw his first human gene trial — on Lindsay Karlin and on a second American child, Alyssa Mushin.

Though results were mixed, the Karlins were excited. Within weeks, they say, their daughter seemed to see more and do a better job holding up her head. Brain scans seemed to indicate a decrease in her NAA and increase in her myelin (although not for the other child). The Karlins were now anxious to have their daughter treated again and agreed with During that they should inject twice as much genetic material.

That fall of 1996, the Sontags were just beginning to confront Jacob's illness when they heard of the New Zealand experiment. In their usual take-charge style, Jordana and Richard were soon coordinating the next round of injections in New Zealand, on eight more children, including Jacob. To insure that every family could make the trip, the Sontags offered to underwrite any expenses the others could not afford. When New Zealand officials sent questionnaires asking parents if they understood the risks, Richard faxed sample answers to each family, urging them to slightly change the wording to the responses. The experiment was described as testing only the safety of gene injection: “The best we can hope for is that the procedure is safe; anything over and above that will be a bonus.” In Richard's advisory to parents he warned, “Do not say that you expect the gene therapy to save your child's life,” although that was what most hoped. Three times the Sontags had plane tickets for New Zealand, and three times they canceled as committees there raised objections. A backlash was setting in. Articles had appeared in *Science* and *Lancet*, and letters were sent to Washington regulators questioning whether During was using a distant country to circumvent United States oversight.

Night after night, Richard and Jordana phoned and E-mailed New Zealand. But the treatment was slipping away. By June, that country's officials were accusing During of pushing through the first trial without sufficient public debate, while he questioned their ethics. Sitting on this side of the world, Richard took the long view: “They don't give a damn about our kids. These aren't New Zealand kids dying.”



Dr. Margretta Seashore, the noted genetics professor at Yale.

The day they got the word, Richard and Jordana took Jacob to the playground. They wanted to be alone. Richard held Jacob in his lap as they went down slides. A woman watching asked, “Is he getting physical therapy?” She wasn't being intrusive; she simply wanted to be sure they knew it could help. “Some people try to ignore it,” said the woman.

Later, Richard said, “She was nice.”

“Yeah,” said Jordana.

“That's the first time a stranger realized,” said Richard. Jordana nodded.

THEY STARTED OVER AGAIN IN THIS COUNTRY. Richard flew to Washington with Roger Karlin to meet with lawyers about how to best pressure officials at Yale and the National Institutes of Health. The Institutes' next quarterly review was in mid-September; the Yale committees would have to act by late August for the protocol to be considered at that mid-September Federal review. “We don't know if we should get politicians involved or give Yale lots of money or go to the press,” said Karlin.

“That could backfire,” said Barbara Mishkin, an attorney at the firm Hogan & Hartson who specializes in human experimentation. “You could just get the committee upset.”

Bob Brady, another attorney, said: “We have to lower the decibel level, focus on the science. Inadvertently, the protocol has become notorious, both here and in New Zealand.”

Richard favored being aggressive: “What we tried to do is call Yale's president and thank him for letting us deposit \$250,000 in the Canavan research account and say to him, ‘Who do we contact about giving more?’”

Mishkin replied: “The research budget at Yale is multimillions. To influence them, you'll need much more than a couple hundred thousand.”

“You want us to tone it down,” said Richard. “We want to bring it up.” After two hours, he and

Karlin rose to leave. Karlin pulled out a photo to show the lawyers. "My daughter, Lindsay," he said. Richard pulled Jacob from his wallet. "The consequences if this is postponed?" Brady asked.

"They may go blind, become vegetables, die," Karlin said.

JORDANA HAD STOPPED WORKING AND WAS watching Jacob like a hawk for signs of changes. Was she the only one who could feel time slipping away? "He'll get to the point of no return," she said. "The gene therapy might prolong his life, but won't help him."

Sunday morning, July 20, Richard got him out of bed. Jacob looked pale and unhappy. "A cranky baby here," Richard announced and brought him downstairs. Jordana rubbed his arms, but couldn't get a smile. His lips were chalky white. He began making jerky motions; she tried to bend his legs, couldn't, then noticed his eyes rolling. "He's seizing!" she screamed.

Doctors hospitalized Jacob for several days, but couldn't find a cause for his 103-degree fever. Not even Jordana could coax a smile from him. A dizzying parade of specialists visited. At one point, when Jordana asked a doctor a question, Richard started to answer, but she cut him off.

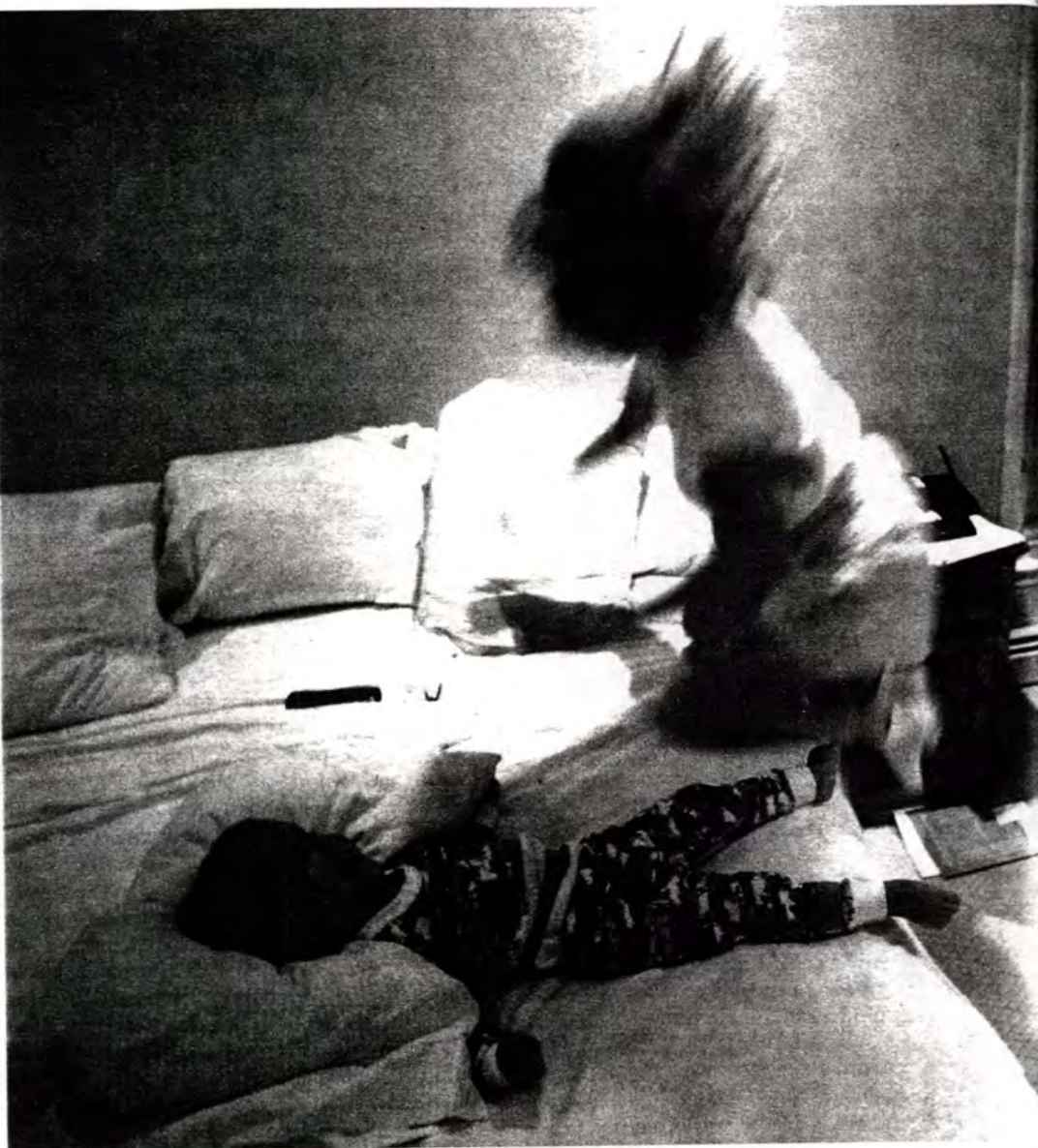
"You always do that," she said to Richard. "You jump in and answer my questions. I have important questions I don't get to ask."

"Write them down," Richard said.

"I don't have to write them down!" said Jordana. "I just don't want my son being dead because some doctor doesn't know how to treat a child with Canavan." Doctors said there should be no damage from the seizure, but the Sontags worried. Who was Jacob? A little boy with light in his eyes and a delicious smile, who liked best to be rocked in his mother's arms. There was no sign of that Jacob. Was he still in there?

For weeks they weren't sure. He was crankier, often seemed in pain. For the first time, he was having trouble sleeping, and they argued over how to handle it. When his crying persisted one night, Jordana picked him up. "Why'd you bring him out here?" said Richard. "Of course he's sweating when he's crying; he's crying himself to sleep. What's wrong? He's fine. Put him back."

He was having trouble lifting his head, too. On Aug. 15, Jordana said: "Something's definitely not the same. I can't pinpoint it yet. Richard thinks one of his eyes is starting to turn; the muscle has weakened. None of the therapists noticed anything, but it seems he used to see me sooner when I came into a room. If he was on the couch and I walked from the kitchen to



Romping with Jacob — aka Boo, Bubbles, Mr. Head or Little Man — at home.

the front door, he'd see me, want me and cry."

Jordana knew the optical nerve can degenerate without myelin and on Aug. 20 took Jacob for a checkup. The ophthalmologist found significant deterioration and strengthened Jacob's glasses. This scared her. "I can't imagine what it would be like if he couldn't see my face or Richard's," she said. "If something started to go wrong with his eyes — it's unacceptable to me."

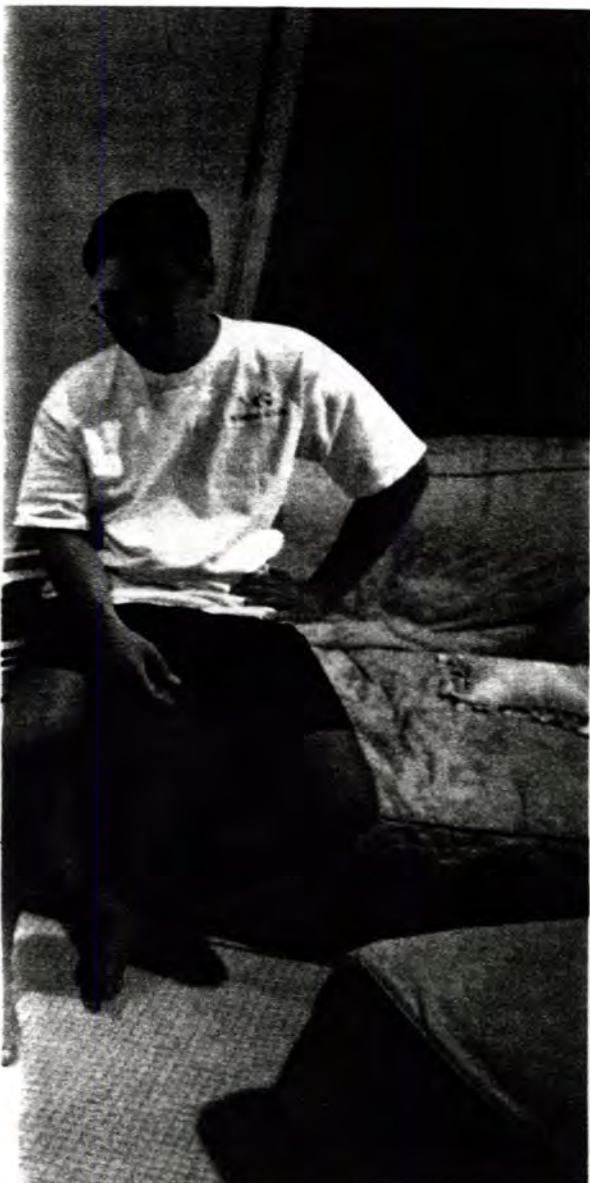
Jordana got United States Senators involved. One Canavan child was from South Dakota, and an aide to that state's senior Senator, Tom Daschle, was particularly aggressive about pressing Yale. Still, many at Yale did not feel the same urgency. At a Sept. 2 biosafety meeting, members said there were still too many questions and postponed a decision. The earliest Federal action would now be the December quarterly meeting. Jacob would be nearly 2.

"Jordana's going to explode," said Richard. "She's holding everything in. She's talking about

chaining herself to the White House fence."

Little things were destroying her: a 2-year-old niece asking when Jacob would stop being a baby. Even his pockets depressed her. "A little boy his age starts enjoying his pockets," she said, "putting different things in there, and he doesn't even know they are there." Richard would come home from work and there was nothing in the refrigerator. She had stopped grocery shopping. "It made me crazy," said Richard. "I'd say, 'Jordana what's going on — no food in the house?' She'd say to Jacob, 'Your Daddy thinks I'm crazy.'"

She had tried to explain how difficult it was taking Jacob shopping, but Richard always had an answer: "Put him in the baby seat. What's the problem?" She didn't tell Richard, but she couldn't do that to Jacob, a 1½-year-old sitting flopped in an infant seat. "It's not that I care what people think," she said. "It's making Jacob a spectacle when I'm shopping."



'I don't know why you're feeling that way,' Richard said, but Jordana cut him off. 'We're not even away from this marriage seminar for 24 hours,' she said, 'and you're trying to fix everything.'

his head," she said. "Maybe he'll say the words he knows now, loud and clear.

"What I envision is this little boy coming out of his shell — 'I'm here! Hi! Here I am!' I want him to be set free in a way. I hope he'll walk. He has the desire to walk. I put him down, he tightens his leg. You know, I'll be grateful if he can just sit up, play on his own, grab things.

"If he could just roll over. I put him to bed at night on his belly. In the morning, I come in, he's in the same position. I think about how nice it would be for him, if he could roll over and stretch — so there are my hopes."

Knowing those hopes, it was easier to understand why each new delay seemed the cruelest. On Sept. 18, Yale's biosafety committee again met without deciding. On Sept. 19, the Sontags were invited to attend a memorial service at the Jewish Guild for the Blind in Manhattan for 7-year-old, 30-pound Morgan Gelblum, who died over the summer. On Sept. 24, Jordana told Richard that whether or not he came, she and Jacob were going to Yale to confront Seashore and anyone else she could find. Richard would later say, "I was on the fence about going," but he went, as much to save his marriage as his son.

Jacob would wake at 4 A.M., they'd struggle to get him to sleep and then were up until morning, arguing. They began seeing a marriage counselor. Jordana complained Richard bullied her; Richard complained Jordana was running from life.

In mid-September, she asked for a divorce. Richard wanted to know if there was someone else. Jordana said there was not a soul — that was the problem. She was finding she couldn't talk to anyone about Jacob. "Every day there's some stupid new development, we're so immersed," she said. "It's so lonely. Even when Richard and I talk, we have totally different views." They disagreed about things as basic as the gene therapy. Richard was hardheaded: he expected the small improvements Lindsay Karlin's parents had reported, but felt a cure was years away. "I'm not in la-la land on this," he said.

Jordana thought Jacob would thrive, because he'd been an advanced Canavan child and would get twice the dose of genes that the first two girls received in New Zealand. "At some point, not right after, I see him lifting

SEASHORE DIDN'T TELL THE SONTAGS, but she, too, thought Yale's biosafety committee was stalling, afraid to make the leap. However, she also saw a need for caution. "If you just tell people we're putting foreign DNA into the brains of small children, jaws drop," she said.

There were other reasons members did not feel an urgency: many doubted it would work. While gene therapy had captured the imagination of the public and media (most hometown newspapers had done a hopeful feature on their local Canavan child), the scientific community was skeptical. An article in *Nature* that fall of '97 reviewed all gene protocols to date, including treatments for cancers, heart disease and immunodeficiencies and put it bluntly: "Although more than 200 clinical trials are currently under way worldwide with hundreds of patients enrolled, there is still no single outcome that we can point to as a success."

It wasn't a question of whether they could deliver genes to the cells. They could. It was how many and how long they'd work. Matthew During estimated that the new genes would reach 10 million of the 100 billion brain cells, or 1 in

10,000. Delivery was primitive: They shot the genetic fluid into a liquid cavity of the brain known as the ventricle and hoped it would be absorbed by adjoining brain cells. This was like pouring it into a river and seeing how much was absorbed by the surrounding land; you'd find a lot in the riverbed, some along the banks, but not much inland. The low "hit" rate was the major misgiving voiced by committee members. Even if inserting the genes proved benign, the surgery had a risk. Implanting the plastic reservoir in the brain to pump genes into the ventricle carried a 5 percent risk of serious infection, possibly death. Put another way: for the 16 children waiting, there was a 1-in-20 chance of a life-threatening crisis.

Complicating matters was During's status. He was a hero to parents, but because the protocol had bounced from Yale to New Zealand and back and was publicly criticized, some at Yale regarded him as a cowboy. Committee members questioned how successful the procedure really was in New Zealand. While both girls had a temporary decrease in NAA, the more important indicator, myelin growth, was less clear-cut. To ensure uniformity, the committees decided that all M.R.I.'s would be done in one place, Children's Hospital of Philadelphia.

With During still in New Zealand, Yale had taken the unusual step of asking Seashore to shepherd the protocol, though she was not involved in the research. "Acrimonious things were said about Matt During that weren't fair," she said. "But I would not let that happen to me. If I had to be the bad guy to parents, I'd be the bad guy."

Seashore remembered too well what had happened to her longtime friend and colleague, Dr. Reuben Matalon. At Miami Children's Hospital in the 1980's, Matalon made the key breakthroughs in Canavan research, including identifying the mutation responsible for the disease. Canavan parents considered him a godsend. In 1990, he thought he had another score, a Canavan screening for pregnant women. What happened next has never been reported in the media, but it stunned geneticists who pieced the facts together. In a 1992 issue of the *Journal of Inherited Metabolic Diseases*, Matalon published a paper detailing how his test on pregnant women had correctly predicted whether a baby would be born with Canavan 13 of 13 times. His conclusion: "It is possible to determine Canavan disease prenatally." But then, in a last-minute postscript, came the shocker: "Note Added in Proof: Subsequent to the submission of this manuscript, we determined that one

Continued on page 78

of the pregnancies predicted to be normal resulted in an affected baby."

That affected baby was Molly Green, born June 18, 1991, in Arlington, Va. Molly's parents, David, a lawyer, and Wendy, a psychologist, had already buried one Canavan child, Eli, in 1990. After hearing of Matalon's new test, Wendy got pregnant again. "He told us it was experimental," said David, "but there was nothing like an informed consent procedure or peer review. We were desperate to have a child. Our attitude was, sounds good enough to me." The pregnant Wendy sent a fluid sample to Matalon. "We were informed the results were sparkling," said David. "We were having a healthy baby."

Molly seemed perfect at birth and was even chosen as the poster baby for the Na-

tional Tay-Sachs and Allied Diseases Association, which was undertaking its annual fund-raiser. Three months later, after Molly had gone floppy and her parents knew the truth, one of the first calls the father made was to the foundation. "Rip up all those postcards of Molly," he said. "She has it." She died March 1, 1992. Three more women with sparkling screenings gave birth to Canavan babies, and two of those sued and later settled. "Reuben made a mistake," Seashore said, "but he was pressed very hard by the families to bring something into clinical service before it was ready."

In the end, the Canavan protocol was approved at Yale for very human reasons. The children were as disabled as any on the planet, and they probably would not be harmed and might benefit, or at least provide insight for researchers. I asked Dr.

Charles Duncan, one of the nation's pre-eminent pediatric neurosurgeons and the man slated to operate on Jacob, "Would you do it if it were your child?" "Oh yes," he said. "I wouldn't be doing the surgery if I didn't think so."

There was more good news. The National Institutes of Health had recently made a policy change: under streamlined guidelines, Yale's approval meant the Federal committee did not have to give its go-ahead.

Seashore, however, insisted that the protocol go for that Federal review anyway. "I don't want to be the first protocol that doesn't," she said. Leone, who had worked so closely with the parents, fought her. "They saw me as an obstacle," Seashore conceded. "I saw them as loud. It was only a couple more weeks."

THAT NOVEMBER, THE Sontags hired divorce law-

yers and put the house up for sale. The previous spring it had felt to Richard like a symbol of his power, but now, as winter neared, he seemed to have lost control of things that mattered, and the big house embarrassed him. Many rooms were still unfurnished.

Just before Thanksgiving, Jacob had a brain scan scheduled in Philadelphia to establish a baseline for myelin before gene therapy. Richard and Jordana took separate cars — agreeing to meet there. On the George Washington Bridge, Richard spotted Jordana and Jacob and waved. He knew she'd be nervous about driving alone, and sure enough, she pulled behind him. As they caravanned south on the New Jersey Turnpike, he picked up his car phone and dialed her in the Cherokee. They talked for 20 minutes, their first conversation in weeks.

Trying to get the IV in for

the anesthetic was always the worst moment of an M.R.I. Jacob's arms were flaccid and nurses had trouble pricking a vein. He cried as Richard and Jordana held him. Soon they were sobbing, too, their tears falling together on their son. The nurse tried to comfort them, saying that the IV really didn't hurt Jacob much, but that was not why the Sontags were crying.

That night, they left Jacob with their sitter and took a hotel room.

BY DEC. 18, THE FEDERAL agencies had given their approval. Jacob's therapists prepared evaluations, to measure changes that might come later. Vivian Kahn Adler, the speech therapist, noted deterioration in recent months. When she started, "he used at least five different sounds — 'hi,' 'more,' 'ma.' At that age it was very encouraging; he was a baby. Now he's not

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using many." She didn't know why Jacob had lost speech. It could be physical — his breath support had weakened. Or maybe, she said, cognitive. She was trying to get him to communicate by gazing at the food he wanted on his tray. During her Dec. 18 lesson, he sneezed and his head fell on his chest; he couldn't lift it. His eyes were crossed now, too. "A lot of kids you feel are stuck at the 3- to 6-month level," Adler said. "With Jacob, I feel there's a bright little kid in there. Sometimes he can wave. It'll take a while. If you don't have patience, you'll miss that wave."

The researchers decided the Sontags or Karlins would go first. They'd worked the hardest and raised the most money. At a diner, they flipped a coin. Jacob won. Jordana felt like a pioneer. She was hearing from families from around the world. "I feel great," she said, "like we've spared them the pain of all the fighting we've been through. I saw a video this family in Canada sent of their baby — his name's Jacob, too. He's 5 months, lifting his head, looking around. Can you imagine what this could do for him?"

SURGERY WAS TO BE done in two phases. On Friday, Jan. 2, at 8 A.M., Duncan used an air drill to cut a 9-millimeter hole in Jacob's skull. A tube was lowered into the ventricle; then a plastic, egg-shaped reservoir was attached to the tube and imbedded below the scalp, making a bump over Jacob's forehead. The reservoir would remain to facilitate future injections. This took less than an hour. Then Jacob was to be observed that weekend for signs of infection, and on Monday the genes would be implanted.

It was not to be. Sunday night he had a 103-degree fever, and Richard slammed

the nearest table. "Twelve hours away!" he said. Duncan came to the hospital past midnight to get a sample of Jacob's brain fluid to test for infection. While Richard held his son, a young doctor assisting Duncan put the syringe into the reservoir to withdraw a specimen. Jacob's brain fluid came rushing out, splashing on the floor. Richard's eyes widened; brain surgery wasn't like he'd envisioned. Duncan felt Jacob just had the flu, but didn't want to take chances. He said he'd have to consult Seashore before deciding when to proceed.

"If Dr. Seashore makes the call," Richard moaned, "we'll be waiting another year." At 10 the next morning, Leone wheeled in a cart with a black plastic container. Richard could not stop staring. The genes they had been waiting so long for, the genes that could change their son's life, had arrived, in an ice bucket that looked borrowed from a Motel 6.

For days, Jacob was too sick with flu for the injection. On Jan. 9 at 6 A.M., Jordana was watching him sleep when she noticed his pinkie finger tremble, then his arms, then the whole body. His eyes opened wide and she thought he was dying. The nurses could not stop the seizure and moved him to intensive care. Would there be anything left of him to save?

Not until Jan. 22 was he strong enough. The actual procedure was so simple that it was done in an examination room. Jacob was laid on his stomach, screaming, Richard and Jordana holding him down. Duncan took a syringe and inserted it into a pin in Jacob's scalp that looked like the needle used to blow up a football. With his left hand he injected the syringe's fluid and with his right thumb he pumped the implanted reservoir 16 times. After 14 months, it was over in three minutes.

The new genes were floating down the river Jacob.

"RICHARD AND I HAVE this joke," Jordana said. "Jacob will sit up and say, 'I don't know about this gene therapy.'" Jordana's mother urged, "Keep your camera out for when he lifts his head." They upped physical therapy to five days a week to capitalize on any improvement and thought they saw a million little things. "I was feeding him," said Jordana. "He put his hand on the spoon three or four times. He's done that before, but it was like right on my hand." When Richard held him, Jacob seemed to lift his head off Richard's chest more to look around. "Every day is exciting," said Jordana. "Lots of hope."

What was not encouraging was Jacob's sleeping patterns. He was constantly waking at night now and often would not go back to bed. "We're exhausted," said Jordana in mid-February. "We haven't had a good night's sleep in a month and a half." Their pediatrician prescribed a sedative for Jacob, but Jordana resisted. "We didn't want to do that," she said. "I hate giving in to this disease." For his part, Richard had surrendered. His attitude was, "Get the chloral hydrate!" The researchers told the Sontags his wakefulness might be positive, a sign gene therapy was working. They reasoned the new genes had so stimulated his brain, a sensory rush was keeping him awake.

Or it could be that Jacob was experiencing the classic sleep problems of an aging Canavan child.

Exhausted, Jordana no longer cared. The researchers didn't have to get up with him at 4 A.M. On Feb. 20, she was in tears. "Jacob did not sleep at all," she said. "I'm sorry we did the procedure. The only thing we got out of all this — he can't sleep! It's so cruel."

Plus, they were pushing

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him for any physical gain while the new genes were fresh. With Jacob screaming, his physical therapist put on his stiff leg supports and led him a few steps. Richard placed him on the floor, legs crossed in a yoga position, his head flopped on his chest, and pleaded, "Lift it — come on Boo," but the head did not budge.

On Feb. 24, Jacob turned 2. They celebrated quietly, the three of them. At one point, Richard left the room so Jordana would not see him cry.

That week, Jordana gave in. She explained her decision to medicate Jacob this way: "I think we're better off as a family if the baby sleeps." They began giving him Klonopin, a muscle relaxant. It was the turning point. The muscle relaxant relaxed the parents, too.

Jacob's stiffness decreased; he stopped grinding his teeth. "Jacob is doing phenomenal," Richard said in mid-April. "He is in a fabulous mood." Why? "He's stoned," said Richard. "It's hard to know how much is Klonopin or the gene therapy or physical therapy five times a week. There are so many variables."

Jordana's fantasy, that he'd sit up, hadn't happened. "Not yet," she said. "In the past, I'd be devastated. But I feel I don't have to worry now. We got him the gene therapy; we've done all we can. I guess if I had to choose between motor skills and the cognitive, I'd choose this. He'll hang out in bed with us. We just lay him flat and play with him. Everything is funny to him now. Richard brought him in the other morning. I said, 'Little Man.' He starts smiling. 'Hi, Little Man.' He says, 'Hi.' I heard him!"

Jordana did not wait for During's lab to call with the latest results; she phoned Philadelphia herself and wormed it out of the M.R.I. people. "They gave me an

unofficial report that Jacob has myelin!" she said on June 5. "They still have to do a comparison with the last M.R.I., but I have a feeling it's in the area that controls cognition."

Four days later, she left a message: "Wanted to let you know we received the report, and it says there have not been significant changes. He does have myelin, but it's the myelin he had prior to gene therapy."

JORDANA RETURNED to work part time. They sold the big house and moved to an attractive ranch house that was half the price. It was a nice fit, on one floor, easy for Jacob. All the rooms had furniture.

She was busy raising money for the Canavan Research Fund the families had founded. She spoke with rabbis and doctors about publicizing the new prenatal screening test for Canavan that was developed in the mid-1990's after Matalon's failure.

On June 19, the Sontags met with a lawyer about a "wrongful birth" lawsuit they had filed against the doctors Jordana used when she was pregnant with Jacob. In the lawsuit, Jordana claims she had repeatedly requested all relevant prenatal screening tests and had been given several but not the new one for Canavan. During the meeting, Jordana held Jacob and explained how they had struggled to enrich his life. So it wasn't until the end that the lawyer, Bruce Clark asked the awkward question, "You would have had an abortion had you known?"

"Absolutely," said Jordana. "Even with this little man in my arms, I would."

"It's not fair," said Richard. "Trapped in that body."

THE PREVIOUS YEAR, RICHARD had dismissed the National Tay-Sachs and Allied Diseases conference as too

touchy-feely, but this year they went and were the last to leave a seminar on how people with a disabled child can hold a marriage together. The therapist had couples take a personality test, and it turned out Richard was a "fixer" while Jordana was a classic "turtle." And when the turtle complained, the fixer felt he had to make everything all right, scaring the turtle instead of just giving that little turtle a hug. "I know this sounds totally ridiculous," Jordana would say later, "but it made perfect sense at the time."

The next day, the three Sontags were at a deli getting Jacob his matzoh-ball soup when Jordana realized she'd forgotten an appointment to visit a school for Jacob. "I know why," she told Richard. They had run into three families just back from a Little League game, all these messy, jumpy, little noodle boys, and here the Sontags were heading to some depressing handicapped school. "I don't know why you're feeling that way," Richard started, but Jordana cut him off. "We're not even away from this marriage seminar for 24 hours," she said, "and you're trying to fix everything, Mr. Fixer," which made Richard laugh. The turtle was out of her shell, snapping.

ON SEPT. 9, JACOB WENT to Yale for his second injection. He was home in two days. Thomas Jefferson University Hospital, in Philadelphia, where During and Leone now work, was also doing the procedure.

THAT MONTH, NINE THERAPISTS and social workers gathered to discuss the new program Jacob was starting at the Saint Agnes rehabilitation center, where the typical disabled child receives \$33,000 a year in government-financed services. Jacob's home

Continued on page 112



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CANAVAN

Continued from page 82

therapists were there to advise the school therapists who would be taking over.

Richard and Jordana took turns rocking their 2½-year-old and giving him a bottle. "He has been making tremendous strides," Richard said. Adler, the speech therapist, explained how much of her time was spent working on chewing and swallowing. She didn't say it, but most Canavan children wind up on feeding tubes. "He'll drink from a cup, but there's still spillage on the sides," she said. She warned that he sometimes choked on solids, "a bit of a safety issue." As if on cue, Jacob began gagging on a waffle Jordana was feeding him, coughing and turning red. The room went dead. "Breathe," said Jordana. There was a moan and Jacob's normal color returned.

"He never used to cough so well," said Nancy Wolff, his physical therapist. "This is good."

Someone asked if he could flip a switch, and his occupational therapist said no. When the center's medical director, Dr. Maria Pici, asked what gains he had made, the physical therapist said he could roll on his side if she helped. "If I give him minimal facilitation depending on his mood and I tell him, 'Jacob bring your arm over, bring your leg over,' and of course I'm aligning him, he can roll," Wolff said.

They asked what Jacob liked. "Human contact," said Wolff. "And silliness. He loves silliness."

"Gassy noises, he loves them," Richard said.

"He's there," his physical therapist said. "Definitely," his occupational therapist said.

Jacob's Oct. 21 report from Children's Hospital in Philadelphia showed no new myelin. While researchers kept the other children's results confidential, parents talked, and Jordana learned that none of the children's M.R.I.'s showed myelin. Or, as Jordana put it, "at least not yet." Still, she saw potential in another new development. Jacob's ophthalmologist had found evidence of new myelin in his eyes. It wasn't likely to help Jacob see better, but the doctor found it "fascinating."

Some families grew discouraged. One dropped out, and even Helene Karlin had mixed feelings. "I don't even want to talk to the other par-

ents," she said. "I don't want them to hear any discouraging note. They need to fight." There was another setback. The 5 percent risk from implanting the reservoir — it happened. In September, one child developed a serious complication and the reservoir was removed. Doctors sought to determine if there was brain damage.

SOME STORIES DO NOT END AS YOU expect. A year and a half ago, I could see the two central themes clearly. First, the curse of science: how a new medicine like gene therapy could seem to offer so much hope and yet cause so much pain, because it is still only promise. And second, the blessing of science: how the pursuit of new medicine could lead to a prenatal screening that would allow the Sontags to have a healthy baby the next time. I envisioned the story closing joyously, with Jordana giving birth to a new child.

What I witnessed instead was the hardships of the pioneer family. At the Sontags' meeting with the lawyer last summer, he asked if they would try to have another child. "We've only started to discuss that," Richard said softly.

Last month, Richard called as I was finishing the article. He was concerned I hadn't seen Jacob in weeks. "He's a whole new child," said Richard. "They love him at school," said Jordana.

On Nov. 5, I spent the day with Jacob. That morning at Saint Agnes, a well-staffed, bright, state-of-the-art rehab center, Jacob fell asleep while two speech therapists were having him practice eating a Ritz Bits cracker. In class, it took more than an hour to feed him a pureed lunch. His teachers and aides talked about how much he loved the computer, but when placed in front of it, he fell asleep again.

Then at home that night, Jacob was another child. His face lit up when Richard returned from work and kissed him hello. For two hours, the Sontags roughhoused. They called him Boo and Bubbles, Mr. Head and Little Man, and the noisier and louder and sillier they all grew, the more Mr. Stinky Butt beamed and his eyes shone. It was wonderful to see, and for once I stopped trying to guess how much was going on inside. This was medicine more remarkable than new genes, Klonopin or physical therapy five times a week — a parent's love. ■

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December 3, 1998

98 DEC 4 PM 12:55

William Jefferson Clinton
President
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500

Dear Mr. President:

I enjoyed seeing you last night at the DLC Annual Conference Dinner. Pursuant to our conversation last evening, I am following up on our discussion about convening a meeting to discuss the ramifications of the recent layoffs in the American work force.

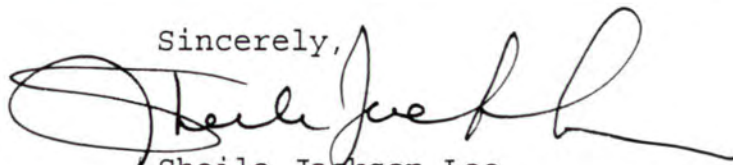
In recent days several major American companies have announced future layoffs in work force structure. Mr. President, as I am sure you are keenly aware, these proposed layoffs will have a tremendous impact not only on the businesses but on the communities and more importantly the individuals affected by these layoffs.

In writing this letter, I am proposing that you convene a meeting next week to address the impact of these layoffs. The Texaco Corporation, Boeing Corporation, the Exxon-Mobil Corporations, and the Kellogg Company have all announced major reductions in their respective work forces. It is estimated that Boeing will reduce its work force by 53,000 jobs during the next two years, while the Exxon-Mobil merger will result in another 9,000 layoffs. I along with several other members of Congress would appreciate the opportunity to meet with you to discuss the economic impact on the communities which we represent.

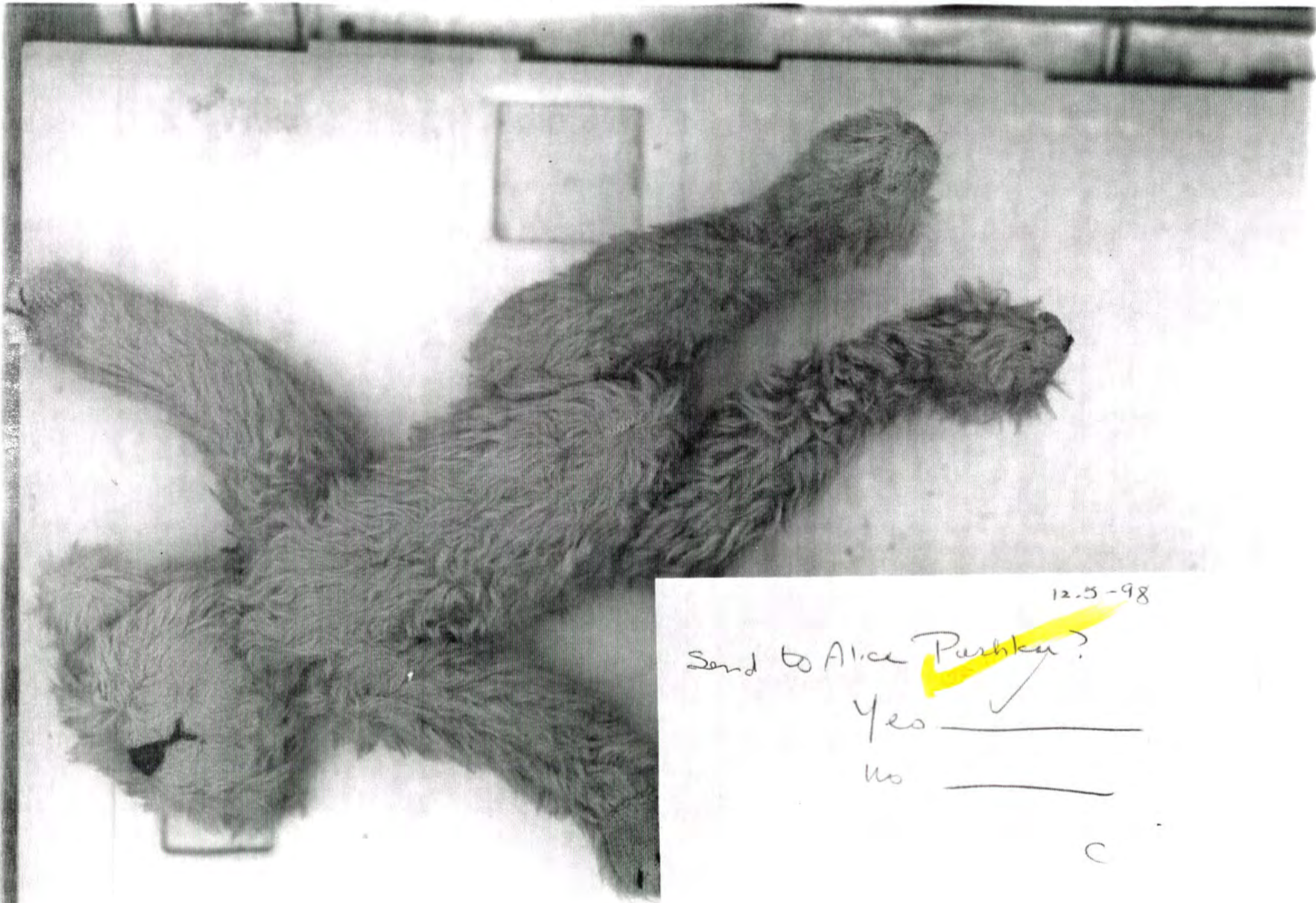
These proposed reductions have greatly increased the anxiety level among our constituents. The impact on Houston will be enormous, as Houston is home to some 17,000 employees of the Exxon and Mobil Corporations. The layoffs coupled with the lingering Asian economic crisis, represent a threat to the continuing prosperity enjoyed under your administration. I believe that in convening a meeting, we can begin to construct solutions to these pending layoffs.

Mr. President, thank you for your attention to this request. I look forward to hearing from you and if I can be of any assistance to you please do not hesitate to contact me or my chief of staff, Kathi Wilkes.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Sheila Jackson Lee', with a large, stylized initial 'S' and a long, sweeping horizontal line extending to the right.

Sheila Jackson Lee
Member of Congress



12.5-98

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