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**RESTRICTION CODES**

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2/9 Charlotte - would you pass on to Nina - Thanks per Evelyn

# California Consumer Protection Foundation

2213 Sixth Street, Berkeley, CA 94710 * (510) 704-8013
A Component Fund of The San Francisco Foundation

Evelyn Please have someone in Health - Clare - Nina - to call and meet with these people

Called 2/17 Requested their consensus statements

December 28, 1993



Mrs. Hillary Rodham Clinton
The White House
Washington, D.C.

Dear Mrs. Clinton:

We are writing to inform you that the Board of the California Consumer Protection Foundation recently awarded 7 grants totaling $157,770 to minority health coalitions (see attachment B) as a first step in our new initiative to support minority community participation in health reform.

Minority populations are the least likely to be heard in the impending state and national debates on health reform because they have the least amount of resources and are not as organized as other special interest groups. Health reform may affect them disproportionately because they have large numbers of uninsured, government insured and self-employed consumers. As an increasingly diverse state, the support of minorities may be a key factor in winning legislative and congressional approval.

In an attempt to increase private funding in this area, on January 27, 1994, we will be co-sponsoring a statewide forum in San Francisco for foundation representatives. Our co-sponsors are the James Irvine Foundation, the Henry J. Kaiser Family Foundation and The San Francisco Foundation.

The featured speaker at the forum will be Lucien Wolfin of the Center for Governmental Studies, who will present the findings of his just completed report, "California's Role in Health Reform". A panel, composed of California Consumer Protection Foundation health reform grantees, will respond to the findings, analyze the potential impact of health reform on low-income and minority communities, and discuss how their respective communities are organizing to meet the challenge. Representatives of the sponsoring foundations will also be available to discuss the grants they have made and the strategies and activities they are currently supporting to promote health reform.

You or your representatives are invited to attend. Your presence would obviously help attract a much wider audience of foundation executives. It may surprise you to know that even though health care for low-income and minority populations is a major concern of foundations, most are still reluctant to fund health reform. In fact, the four foundations sponsoring this forum are the only ones we know of in California who have made significant investments in this arena.

If you are unable to attend the forum in January, but are interested in future efforts, we would be happy to meet with you or your representative to discuss ways in which we could mutually support minority involvement in health reform and encourage other foundations to support the issue.

We look forward to hearing from you soon.

Sincerely,

Nelson Holl (pt)

Nelson J. Holl
Executive Director

Henry Izumizaki
CFO Board of Director

Associate, Urban
Strategies Council

- Giving grants to empower minority groups re Health Care Reform
- Asking them to reach out to small business + other groups
- Encouraging coalitions among diff racial & ethnic groups

**ATTACHMENTS:**

A. Information about the California Consumer Protection Foundation

B. Listing of and Description of our most recent health reform grants.

C. A Summary of the Foundation's position paper on Health Care Reform in Minority Communities

D. Health Care Reform in Minority Communities -- a position paper

# *California Consumer Protection Foundation*

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**Background**

The California Consumer Protection Foundation was established in 1991 by the Superior Court of the State of California to administer and distribute an approximately $4 million Consumer Trust Fund resulting from the settlement of a consumer class action lawsuit, *State of California v. Levi Strauss and Company*. The Levi Strauss Consumer Trust Fund will be entirely distributed over a five year period. Approximately $500,000 has been allocated for grants in 1994.

The Foundation is governed by a five member Board of Directors, appointed by the parties to litigation and approved by the court. It is incorporated as an independent 501(c)(4) with no remaining legal or financial connection with, or obligation to, Levi Strauss and Company. Thus, the "Levi Strauss Consumer Trust" designation is used for reference purposes only.

**Purpose**

The primary purpose of California Consumer Protection Foundation is, among other things, to further the interests of consumer protection in the State of California. The Foundation is a grant-making, not an operating, entity. The California Consumer Protection Foundation may also receive and administer other consumer trust funds.

By order of the Court, the Foundation shall give priority to:

a) projects or activities designed to safeguard the public in California against the creation or perpetuation of monopolies and against unfair or restrained competition in wholesale or retail sales, and

b) activities designed to benefit and protect low and moderate income consumers, especially in retail sales of goods and services.

Projects or activities which may be funded include research, study, education, publication and dissemination of consumer information, investigation, negotiation, lobbying, clearinghouse, administrative and/or legal representation or assistance, and other projects and activities that will directly and indirectly benefit the Levi Strauss consumer class.

In addition, the Board of Directors of the Foundation have established the following goals and priorities to provide greater focus and impact of the Levi Strauss Consumer Trust Fund.

**Foundation Goals**

1) Develop the organizational capacity of low-income and minority communities to engage in consumer protection activities.

2) Increase the responsiveness of business and government to the market and consumer protection needs of low-income, rural and minority communities.

3) Promote market diversity, hence consumer choice, in underserved low-income, rural and minority communities.

4) Increase the coordination, collaboration and communication between the public, private and non-profit sectors regarding consumer protection issues and needs.

5) Increase the participation and leadership of minorities in consumer education and advocacy, particularly among major consumer organizations.

**Foundation Priorities**

1) Enforcement of existing laws and regulations protecting consumers and/or challenging those which promote market segmentation, monopolies or unfair and anticompetitive practices in the marketplace. Activities may include research, monitoring, advocacy and litigation.

2) Consumer legislation which strengthens and increases consumer protections or increases access to goods and services, particularly for low-income, rural and minority populations. Activities may include research and publication, drafting proposed legislation, community organizing and education, and lobbying.

3) Consumer group or class action litigation focusing on specific industries or business practices. Activities may include research, discovery, case development, court representation or support briefs. Projects which involve the private bar are especially encouraged.

4) Areas in which the Foundation has an active interest including health reform and managed care transition, community reinvestment, and consumer fraud.

5) Identification of minority, rural and low-income consumer protection needs and issues.

6) Comprehensive, statewide or regional approaches addressing specific consumer problems or issues.

7) Consumer networks and coalitions which demonstrate active participation of grassroots and minority community organizations in planning and implementation. Activities may include seminars, conferences, network building, and technical assistance.

8) Broad-based consumer education targeting specific consumer issues and/or hard to reach populations. Projects should employ innovative, collaborative or comprehensive approaches to reach a wide audience.

9) Development of minority, low-income, rural and other disadvantaged consumer advocates through fellowships, training and technical assistance.

10) Projects or programs with a potential for matching support or long-term support from other funding sources.

B

# *California Consumer Protection Foundation*

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**HEATH REFORM GRANTS**
**AS OF NOVEMEBR 30, 1993**

**Asian American Health Forum, San Francisco ($10,000 - 6 months)**
1) To establish a network of A/PI groups in California to pro-actively participate in the implementation of health care reform. 2) To organize and conduct a statewide education and mobilization effort. 3) To conduct and disseminate a meaningful health reform policy analysis.

**Bay Area Black Consortium for Quality Health Care, Oakland ($6,720 - 6 months)**
To develop a plan for strengthening the Consortium's administrative capacity and organizational infrastructure to effectively reach, inform, and mobilize their constituencies to participate in the policy aspects of health care reform in local, regional and statewide settings.

**California Black Health Network, San Diego ($8,850 - 6 months)**
To conduct a organizational and management survey and develop a plan for the California Black Health Network to provide leadership in consumer activism around health care and health reform.

**California Rural Indian Health Board, Sacramento ($22,200 - 6 months)**
To plan and conduct one statewide and five regional, Indian specific forums on national health reform. Forums will engage tribal health professionals, tribal leaders and the community-at-large to develop a Native American consensus.

**Health Access of California, San Francisco ($50,000 - 12 months)**
To hire a Sacramento-based lobbyist and community strategist to represent low-income and minority health consumers, educate the media and increase the participation of minority community-based organizations in the health reform debates.

**Latino Issues Forum, San Francisco ($10,000 - 6 months)**
1) Develop an Clinton Health Plan impact report. 2) Convene a statewide conference. 3) Educate the media about potential impact on Latino consumers. 4) Expand health care seminars to include small business and Hispanic Chamber of Commerces. 5) Form a statewide Latino Health Care Task Force to work with other consumer and minority organizations. 6) Distribute the impact report.

**Western Center on Law & Poverty, Los Angeles ($50,000 - 12 months)**
To assist low-income health care consumers in advocating on their own behalf before state legislature and administrative agencies concerning managed care health care reform; to lobby and draft legislation to improve health care and delivery of services to low-income individuals.

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## Health Care Reform in Minority Communities: A Summary

In brief, the Foundation has found that the broader African American, Latino, Asian Pacific Islander and Native American communities were at differing levels of readiness to participate in the health reform debates and that health reform was also likely to impact them differently due to their community composition and organization. However, they were all seeking ways to educate their respective constituencies and develop networks and coalitions which would allow them to ultimately develop a multi-ethnic consensus and support for health reform. Many of these organizations already have the credibility and linkages within their respective communities to take advantage of free media opportunities and to organize community meetings, but lack the funding to mobilize such efforts around health reform.

While many minority health coalitions have already developed position statements, particularly in regards to the transition of Medi-Cal to a managed care system, it is invariably a non-profit, community-based position which states an ideal with little indication of priority or compromise. The positions have not been broadly circulated to secure the backing of private health providers, business interests and the general public in minority communities.

Hence, the general principles for a multi-cultural perspective in health reform thus far elaborated by minority health coalitions may or may not accurately reflect what minorities can or should expect from health reform. They also provide little guidance for minority representatives when it comes to negotiating what is or is not actually acceptable to minority groups.

As health reform will probably require considerable trade-offs and numerous sacrifices, minority communities need to know where they are willing to compromise and be able to respond appropriately when the opportunity presents itself This cannot be accomplished without creating a community infrastructure and communications network which facilitates informed discussion, organized debate and hopefully broad-based consensus.

While we do not expect health advocates, health providers, business interests and consumers to agree on all aspects of health reform within their own communities, much less across racial and ethnic lines, it

is important to know what they do or do not agree on within their own communities before they can come to terms with others. This will help to avoid, or at least reduce, the all or nothing confrontations which have come to epitomize many public policy issues while minimizing fractious debates about who represents minority interests.

The Foundation has attempted to engage a response to these findings and support minority coalitions on their own turf, at their own level of development, and according to their own needs and aspirations. Given the immediacy of healthy reform, we believe it is preferable to support existing regional or statewide networks with expertise in health policy to lead the effort. In addition, we are willing to support mainstream health coalitions who have demonstrated an ability and willingness to work collaboratively with minority health coalitions.

D

# *California Consumer Protection Foundation*

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## HEALTH CARE REFORM IN MINORITY COMMUNITIES

### BACKGROUND

At the last annual Board Retreat, the California Consumer Protection Foundation Board determined that access to health care is a fundamental consumer issue for low income and minority communities.

Under the Clinton administration passage of comprehensive health reform is more likely than it has been in decades, largely because it has been purposefully characterized and structured as a middle-class issue. Thus, low-income, minority groups have had very little input and influence on the national proceedings.

As the Clinton plan is unveiled, there still are concerns that too many uncompromising and uncoordinated special interests will stall or derail passage of the major legislation.

Currently, mainstream health advocates are urging foundations to support their research, analysis and advocacy efforts and to support increased involvement of minority communities in the process. A fundamental question, however, is whether to fund mainstream groups to assist or represent minority communities or fund minority communities directly, or both.

On June 6, 1993, a subcommittee of the Board composed of Henry Izumizaki and Richard Craswell, and Foundation staff met with five health care advocates to discuss how the Foundation could assist minority communities to participate in the health care reform debate. Particular attention was paid to inviting minority health care advocates with statewide and/or national linkages. What follows summarizes the observations and recommendations of the participants, among them:

Tessie Guillermo, Executive Director - Asian American Health Forum
Adelbert (Bert) Campbell, Executive Director - Bay Area Black Consortium for Quality Health Care
Jacque Fuller, Representative - California Black Health Network
Carmella Castellano, Coordinator - Latinos for a Healthy California
Maryann O'Sullivan, Executive Director - Health Access

In addition, staff consulted with Jim Crouch, Executive Director of California Rural Indian Health Board, by phone to ascertain his views on the Native American community.

**The Clinton Plan**

Recently, 40 minority representatives were given the opportunity to review the Clinton Plan draft and provide comments. One of those attending was Tessie Guillermo of the Asian American Health Forum. In all, there were about 30 African Americans, 10 Latinos and 2 Asian Americans attending who, in the brief time they had to review and comment, quickly developed a written response and recommendations which they submitted to administration staff.

A major concern of the minority reviewers is the lack of adequate consumer protections and remedies against discrimination and weaknesses in the quality assurance program and process, particularly as it relates to cultural and linguistically appropriate services.

Another key issue is the future of community and public health services which have historically served special populations. Many health advocates fear a near total collapse of the community and public health system if it is unable to compete effectively with private providers.

These concerns are further exacerbated by the plan allowing the states too much latitude in implementing the plan locally and regionally. As a result, states with small or disorganized minority populations might ignore them in favor of a majority, mainstream program. Similarly, low-income and minority populations who have traditionally relied on public and community-based health care, have the most to lose if these services are reduced or eliminated as a result of "managed" competition.

While minority representatives have numerous concerns about the draft plan, they also concede that it is in their best interest to pass the major legislation as well. Thus, they are prepared to accept incremental implementation of the plan. They further believe that the administration is now actively seeking their support to help them sell the plan to the nation as a whole. Consequently, they will try to affect the Clinton plan as much as they can, but are willing to temper their demands to promote congressional support. In which case, much of the actual debate over implementation will take place on a state and local level.

On one hand, allowing the states more latitude in deciding how the plan would be implemented accommodates the demographic and political differences among the states, while shifting a major political problem from the federal government to the state level. On the other, it allows ethnically diverse states like California to develop systems which would probably not be politically or economically feasible in other states, but may serve as models for other states to draw on.

While most minority groups have staked out a position on cultural sensitivity and relevance, few have the broad-based support of public and private interests, i.e., the positions tend to reflect the views of community-based organizations serving low-income populations. On the otherhand, the cost limitations of universal health coverage will require that some negotiated give and take must occur between and among numerous interest groups. Whether there is an informed, educated and organized response from minority communities, either separately or jointly, may be a determining factor in many key implementation issues. Worse than no response is a disorganized response for it may seriously jeopardize any meaningful reform.

Should congress take too long, many states are prepared to enact their own reforms. In fact, California has already started. The extent to which minority consumers have a voice in the numerous and complex details of health reform on both the national and state level, as compared to heavily financed business and professional groups, will depend largely on how organized they are as consituent groups that elected officials cannot ignore.

## The Transition of Medi-Cal to Managed Care

While minority groups are only now being included in the national debate, they have been more involved in the State's effort to transition Medi-Cal clients to managed care. How well they have been able to influence that process is an early indication of what may need to occur in relation to the Clinton plan.

According to health care advocates, the State has virtually adopted all of their recommendations regarding cultural relevance and providing quality assurance standards for the transition and treatment of Medi-Cal clients, but the State has put no money behind those recommendations.

Considerable follow-up and monitoring will be needed to insure adequate resources are provided to implement recommended reforms. Also, community care clinics who currently serve Medi-Cal patients need to be monitored and evaluated to determine whether they can survive financially under managed care.

Finally, the Medi-Cal/managed care debates were of little interest to and had little impact on the broader community. Thus, the community coalitions that arose to challenge the Medi-Cal transition mainly attracted advocates for the poor. Given the stakes involved in national health reform, these coalitions could find themselves opposed by every other special interest unless they can build bridges with other constituent groups, such as business and labor.

## The Asian Pacific American Experience

Within the Asian Pacific Islander American (API) community there are only a few national health organizations. While they have been fairly successful in advocating the interests of low-income Asians in the Medi-Cal managed care transition, Asian American Health Forum (AAHF) and Association of Asian Pacific Community Health Organizations (AAPCHO) have had less success with presenting an API perspective in national reform, largely as a result of community disorganization.

For example, representatives from 11 local and national coalitions, involving more than 80 community-based organizations, have been meeting ad-hoc for two years to pull together a coordinating body. However, the statewide organizing effort has been hampered by the varying missions of local coalitions and member organizations who are involved in everything from employment to civil rights. However, they recently recieved funding from Pacific Bell to conduct planning process to formalize their statewide mission and structure.

Even if a statewide network of community-based agencies were formed, its role in the health reform effort might be clouded by a lack of focus specifically on health reform and the non-involvement of the private and public sectors. For the most part, private health providers and business and civic groups in the API community have taken a wait and see attitude. API health advocates fear that the lack of coordination and consensus among public, private and community interests will reduce what little influence they do have to insure that API health care needs are adequately addressed in the national and state debates on comprehensive reform.

API health advocates maintain that they lack the organizational resources (not expertise) to provide expert analysis of various health reform proposals, and a community infrastructure to circulate current information broadly and provide a forum for organized debate and consensus. Mostly they cite the lack of financial support.

## The African American Experience

A key health organization in the African American (AA) community is the California Black Health Network, which currently has three affiliate chapters: Los Angeles Leadership Council, San Diego Association of Health Professionals and the Bay Area Black Consortium for Quality Health Care. They are also trying to revive a chapter in Sacramento and would like to initiate one in Fresno.

While the Health Network includes public, private and community health providers, it has yet to educate and involve the broader AA community. According to Bert Campbell, Executive Director of the Bay Area Black Consortium, they have a hard enough time trying to convince private practitioners that health reform is more than a professional or economic issue, but rather a public health issue that they need to be more involved in.

For the most part, African Americans are already involved in high level health policy. But, AA health advocates maintain there is a need to "get down to earth", particularly as it pertains to what may happen to private practitioners serving the community when HMO's and managed care takes over. There is also a need to broaden the network to involve community groups, civil rights organizations and churches, not only to support reform, but to also consider what the impact will be on local communities.

A major impediment to the Health Network playing a larger role in health reform is the lack of resources. Currently, it has one part-time staff person. For the most part, the Health Network and the affiliated chapters are run by volunteers who have regular jobs. What funding they do have tends to be government grants restricted to demonstration or community health education projects. Thus, there is a limit to what can be accomplished by the Network and its affliliates without staff support and financial backing.

In contrast to the Asian Pacific American experience, the African American community already has a statewide organizational framework to involve health care professionals from the community, public and private sectors, though it may need some shoring up. On the otherhand, it is limited to health professionals who may or may not share the same perspective as consumers. Thus, whether

these same professionals are willing and able to take the lead in educating and organizing the general public is another question altogether.

**The Latino or Hispanic American Experience**

Thanks to foundations such as Kaiser Family and James Irvine, the Latino community is making considerable progress towards achieving consensus on a number of health reform issues and has established a basic framework for communication among diverse interests within the community. Two of the major statewide organizations are the Latino Coalition for a Healthy California and Latino Issues Forum.

While the Coalition focuses primarily on health policy issues, Latino Issues Forum is engaged in a wide range of issues which involve the broad-based participation of Latinos throughout the state. Thus, while the Coalition focuses on analyzing and developing health policy, the Forum acts a convenor of diverse Latino interests to consider various policy proposals and recommendations.

The Coalition's position paper, Latino Perspective on Access to Care and Health System Reform (endorsed by 22 Latino CBO's and many elected Latino officials) served as the basis and model for the Surgeon General's Hispanic/Latino Health Initiative. More recently, the Coalition played a key role in organizing the Surgeon General's Regional Meeting in Los Angeles.

Recently, the Coalition played a key role in addressing Latino community concerns surrounding the State Department of Health Service's plan to convert Medi-Cal into managed care. In the Final Strategic Plan, the Department of Health Services adopted the Coalition's Cultural Index of Accessibility to Care, which specifies standards to safeguard the needs of multi-lingual, multi-cultural populations in managed care systems, and sets forth requirements to be included in Medi-Cal contracts with health care providers.

When the Clinton Health Plan is unveiled, the Coalition and the Forum already know how they will proceed to analyze the proposals and begin educating their constituency to develop consensus positions.

While Latinos for a Healthy California and Latino Issues Forum, have managed to engage public, private and community interests in a constructive dialogue on health reform, they still are seeking ways to broaden their linkages and facilitate the flow of information. A high priority is to work with other coalitions and minority communities to consolidate health reform networks and positions.

In comparison to the API community and the AA community, the Latino community is not only well organized, but quite effective in developing broad based support and consensus without sacrificing its focus on health reform. This, perhaps has a lot to do with having two complementary structures, one to focus on health care analysis and the other to convene community interests. If there is a weakness, it is the fact that business and civic groups are not as involved as they could be.

As much as it works for the Latino community though, this structure may not apply to other ethnic groups. But, it is worth contemplating as a model worth replication, particularly from a foundation perspective.

## The Native American Experience

Roughly half of all Native Americans are "insured" by the Federal Indian Health Service. Eligibility is based on geography, i.e., their proximity to reservations. The other half, mostly urban Indians, are "not on the screen".

Under the Federal Indian Health Service, there is no defined benefits package; instead benefits differ from state to state and from county to county. Also, the Federal Indian Health Service is funded through the Department of Interior, rather than Health and Human Services.

Under the Clinton Plan, Indian Health Services would be mandated and funded like the veterans benefits. However, Native Americans would have to work through congressional health committees which they have rarely worked with.

For the most part there is not a lot of awareness of the potential benefits or pitfalls among Native Americans about the Clinton Plan. For example, would all Native Americans be included under Indian Health Services or would those living off the reservation be paying twice. First, by giving up their land and second by paying taxes. Or, would they be exempt, in which case the employer portion would also be exempt, making Native Americans desirable employees, but creating a double standard in the workplace.

Given their limited experience outside of the Department of Interior, and the political clout of other interest groups, Native Americans could, as they have been before, become the forgotten minority.

Fortunately, the State Tobacco Control Program has funded the creation of ethnic networks to promote tobacco cessation. This has allowed 20 Native American Health Projects, 10 of which are California Rural Indian Health Board (CRIHB) members, to at least meet on a regular basis. This network is perceived as a logical beginning point for broader community education and involvement around health reform.

## Inter-ethnic Collaboration

In June 1992, the Kaiser Family Foundation provided $10,000 to fund a one-day conference of over 45 minority health care professionals to discuss the impact of health reform on communities of color. The result was the formation of the California Pan-Ethnic Health Network (CPEHN) and a set of 13 guiding principles which can be utilized to evaluate various reform proposals, entitled A Multi-Cultural Approach to Health Care System Reform.

However, there is a question of who will be evaluating these proposals on behalf of minority communities and whether they have the involvement, support and trust of the broader community. More importantly, one has to recognize that there is a clear difference between the ideal, which can be articulated quite easily, and the practical solutions and trade-offs which are necessary when there is a cap on how much can be spent to implement any comprehensive health reform plan.

Since the publication of the principles, which remain the only comprehensive statement of African American, Asian, Latino and Native American communities on health care reform, 35 organizations have endorsed the document. It has also served as a basis for input to the Department of Health Services's Task Force on Multi-Cultural Competence, to the Governor and the Assembly and Senate Health Committees on the Medi-Cal/managed care conversion, and to the California Congressional delegation on the critical components of health care reform for the minority population.

Since the June 1992 meeting, CPEHN has continued to meet as a loosely organized steering committee, staffed by Carmella Castellano of Public Advocates/Latinos for a Healthy California. Over the summer they plan to look at structural issues, such as incorporation and staffing.

While CPEHN may serve as a coordinating body for people of color, at least community-based organizations, there is no money available for conferences, conference calls and mailings. What little subsidy Public Advocates can offer, primarily Carmella's time, is insufficient to mobilize and sustain a statewide effort.

Yet, it is precisely this type of infrastructure that is needed to insure that people of color are not in conflict with each other over key provisions of health care reform and that they have a forum, outside of the mainstream debate, to discuss differences and to develop broadly supported positions or concessions.

While advocacy is also inherent to the process of health reform, it is not the primary goal of minority health reform advocates at this juncture. Overwhelmingly, they seek to involve a cross-section of their respective communities in informed discussion and provide a structure for dialogue and compromise with other community interests.

To some extent, major funders like the Kaiser Family Foundation, Irvine and San Francisco have already paved the way by supporting key projects such as Health Access, Latinos Issues Forum and CPEHN.

According to minority representatives, two other specific areas where foundations could make a difference is:

1) Monitoring Medi-Cal Managed Care

While the Dept. of Health Services expressed a commitment to ensuring cultural competency of Medi-Cal providers, minority communities believe the implementation of managed care should be monitored and evaluated to determine how or if it may apply to the larger health care reform debate,

and to insure compliance with the established guidelines. There is also a need to educate consumers about their rights with respect to managed care transition.

2) Community/Public Health Care Delivery Management

As the Clinton plan will require community and public health providers to organize as health alliances to compete head to head with HMO's, there is considerable concern that many community and public health services will not be able to compete due to incompatible systems, excessive duplication and the inability to competitively market their services. Yet, many of these institutions are the most experienced at providing culturally competent services in ethnically diverse communities.

Thus, efforts need to be taken to evaluate their ability and readiness to make the transition, and if necessary, to support the development of model alliances or technical assistance programs and uniform operating procedures which emerging health care alliances can easily adopt to make the transition and enhance their competitive position as quickly as possible. Otherwise, while community and public health providers are struggling to consolidate, HMO's could come in and simply sign up all their patients, leaving only the undocumented and uninsured. Without sufficient patient premiums, these public and community programs would cease to exist.

## SUMMARY RECOMMENDATIONS

The health care advocates who attended the meeting offered the following recommendations, which are endorsed by the Foundation's Subcommittee on Health Reform:

1) Focus on organizational capacity building and community infrastructure to enhance the ability of communities of color to educate and involve a broad cross-section of their respective communities.

2) Require that any grants for capacity building and networking be tied to specific projects such and that they concentrate on models for improving public, private and community relations.

3) Encourage health reform grants that involve a broad cross-section of the community, i.e. public, private and community interests, and have statewide involvement or impact.

4) Require that health reform grantees not only collaborate within their own ethnic communities, but with other minority and mainstream networks as well.

5) Be ready to work with communities according to where they are in the process. Some communities are more organized than others. Many also have linguistic, cultural and generational issues they must overcome as well.

6) Be willing to work with specific organizations to develop proposals and/or proposal guidelines which respond to the organizational, social, cultural and political realities of their own communities, instead of dictating what they should be doing.

7) Recognize that health reform is a complex issue and that few organizations are professionally or experientially prepared to evaluate health reform proposals, communicate them to the public, and/or pull together a broad cross-section of the community. Therefore, we should fund proven organizations with established networks. However, some provision may be made to open the process to new coalitions or groups.

## FUNDING RECOMMENDATIONS

The CCPF Health Reform Subcommittee recommends that the Board of the Foundation adopt a funding goal of $50,000 to $60,000 for remainder of 1993, largely to provide 5-6 small grants for health reform and Medi-Cal/managed care transition. For 1994 and 1995, the Subcommittee would like to recommend a funding goal of $150,000 to $200,000 a year (out of a total $500,000 in 1994 and $1 million per year grants budget in 1995), which we would try to make on a matching basis with other foundations.

**Note: These recommedations were approved by the CCPF Boad Directors on July 21, 1993 as general guidelines for its support of health reform in minority community.**

February 16, 1994

Elihu H. Estey, M.D.
Professor of Medicine
University of Texas
Texas Medical Center
1515 Holcombe Boulevard
Houston, TX 77030

Dear Dr. Estey:

Thank you for your letter regarding the reform of our nation's health care system and your concerns of those suffering from acute myelogenous leukemia. The need for continued clinical research in our academic centers is fully realized by the Administration.

Since January of 1993, our office has been hard at work on a health care reform initiative that we hope will be passed into law before the end of the 103rd Congress. Your thoughts, and those of many Americans like you, have been of great value in the formulation of the comprehensive health reform that President Clinton introduced to Congress on October 27, 1993.

The tremendous advancements in cancer research have been made through dedicated professionals such as yourself. It is through this research that lives will be saved and in the long run, reduce health care costs. Advancing research and technology increases the potential for more effective, low cost treatments. The development of new medications and innovations in the way we receive health care will lead to increased efficiency in the health care system and a higher standard of living for all Americans.

The Health Security Act is based on the following six principles: security, savings, quality, choice, simplicity and responsibility. It is imperative that all Americans become involved in the debate which will continue to shape the policies that affect our nation and each of us personally.

Thank you again for your interest and suggestions.

Regards,

Ira C. Magaziner
Senior Advisor to the President
for Policy Development

February 7, 1994

leave in

Elihu H. Estey, M.D. → Professor of Medicine
~~Texas Medical Center~~ The University of Texas
1515 Holcombe Boulevard ~~M.D. Anderson Cancer Center~~
Houston, TX 77030

Dear Dr. Estey: add space

Thank you for your letter regarding the reform of our nation's health care system and your concerns of those suffering from acute myelogenous leukemia. The need for continued clinical research in our academic centers is fully realized by the Administration. Since January of 1993, our office has been hard at work on a health care reform initiative that we hope will be passed into law before the end of the 103rd Congress. Your thoughts, and those of many Americans like you, have been of great value in the formulation of the comprehensive health reform that President Clinton introduced to Congress on October 27, 1993.

add space

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Thank you again for your interest and suggestions.

Regards,

Ira C. Magaziner
Senior Advisor to the President
for Policy Development

ICM:pr

ask Lynn for language on medical research to add to the 2nd page. M.

THE WHITE HOUSE

WASHINGTON

Elihu H. Estey, M.D.
Texas Medical Center
1515 Holcombe Boulevard
Houston, TX 77030

THE UNIVERSITY OF TEXAS
MD ANDERSON
CANCER CENTER

KM.

Elihu H. Estey, M.D.
Professor of Medicine
Dept. Hematology
Leukemia Section
(713) 792-7544 Office
(713) 794-4297 Fax

400

October 1, 1993

Mr. Ira Magaziner
Senior Advisor to The President
Domestic Policy
1600 Pennsylvania Ave. Northwest
Washington, D.C. 20500

Dear Mr. Magaziner:

Enclosed please find a letter that I have sent to Mrs. Hillary Rodham Clinton. The letter expresses my concern that her otherwise laudable effort to reform American medicine will jeopardize clinical research in acute myelogenous leukemia. I would appreciate any thoughts that you may have on this matter.

Sincerely,

Elihu H. Estey, M.D.

Enclosures

EHE/skk

THE UNIVERSITY OF TEXAS
MD ANDERSON
CANCER CENTER

Elihu H. Estey, M.D.
Professor of Medicine
Dept. Hematology
Leukemia Section
(713) 792-7544 Office
(713) 794-4297 Fax

September 29, 1993

Mrs. Hillary Rodham Clinton
Head of Health Care Reform
1600 Pennsylvania Ave. Northwest
Washington, D.C. 20500

Dear Mrs. Clinton:

I am a 47-year old oncologist at the University of Texas M.D. Anderson Cancer Center in Houston where I specialize in treatment of acute myelogenous leukemia (AML). As I believe you can see from the attached CV, I have achieved an international reputation in this field.

I wholeheartedly support the overall tenor of your proposed health care reforms. In particular I am convinced that, in my limited practice arena, substantial savings in costs can be realized without harming patients. Indeed some measures that would reduce costs would also be medically beneficial. For example, providing incentives for AML patients to be treated and followed-up outside rather than inside the hospital (the opposite of the current practice) would not only save money but would also reduce the risk of "nosocomial", i.e. hospital-acquired, infections. It is widely accepted that, although infections are an inevitable consequence of chemotherapy of AML, nosocomial infections are more difficult to treat than outpatient-acquired infections.

While thus being an ardent proponent of health care reform, I fear that reform may harm my field, clinical research in AML, as conducted in major academic centers such as M.D. Anderson. This anxiety has impelled me to write you. Eighty percent of patients with AML will die of their disease if given the therapy that most patients currently receive from most practicing oncologists. This statistic is based on experience with thousands of patients and is thus not open to serious doubt. Indeed our knowledge of prognosis is such that large groups of AML patients can be readily identified for whom there is no possibility of cure with conventional therapy. Given these facts I believe the only acceptable treatment for the vast majority of patients with AML is investigational therapy. By this, of course, I mean therapy undertaken as part of a formal clinical research trial and conducted in recognized academic centers

that can be fairly said to have expertise in managing AML and the complications of chemotherapy for AML. In short, the standard of care should be investigational treatment. Having devoted 15 years of my life to such clinical research, I believe I and many fellow clinical researchers bring the same enthusiasm and dedication to our field as you, your husband, and his administration bring to yours. Indeed clinical research in AML and probably in general has the same leitmotif of "change" that President Clinton has adopted for his administration. Most of our clinical trials are unsuccessful but this does not absolve us of the responsibility to keep trying and to be dissatisfied with the status quo.

What I fear, however, is that reform will enshrine the status quo in the treatment of AML. This will result if cost becomes the sole determinant of where a patient with AML is treated. While realizing the imperative of cost containment as mentioned above, I doubt that good clinical research can be made to be as cheap as administration of conventional therapy, the same therapy that fails to cure 80% of patients with AML. Yet there can be no denying the desire of some insurance companies to avoid incurring the costs of clinical research. Not infrequently patients have informed me that their insurance will cover the costs of conventional but not investigational therapy thus effectively forcing patients to choose between therapy known to be useless for a fatal disease or exhausting their savings, if they have savings at all. Such a policy if adopted on a general basis by HIPCs would be a moral and scientific disaster. I believe it is the responsibility of the U.S. government to avert this disaster by ensuring that treatment of AML is not solely or even primarily determined by cost. Indeed I believe the correct policy is, as far as possible, to mandate that treatment for diseases that are largely incurable today be investigational in nature and be conducted in a clinical research setting in recognized academic centers. Only by adopting this policy will there be the prospect that these diseases will not remain incurable tomorrow.

Sincerely,

Elihu Estey

Elihu H. Estey, M.D.

Enclosure

EHE/skk

cc: Ira Magaziner, Senior Advisor to the President for Domestic Policy
Joycelyn Elders, Surgeon General
Senator Phil Gramm
Senator Kay Bailey Hutchenson
Congressman Michael Andrews

# Withdrawal/Redaction Sheet
## Clinton Library

| DOCUMENT NO. AND TYPE | SUBJECT/TITLE | DATE | RESTRICTION |
|---|---|---|---|
| 001. resume | [Personally Identifiable Information] [partial] (1 page) | 10/00/1993 | b(6) |

**COLLECTION:**
Clinton Presidential Records
Chief of Staff
Harold Ickes (Health Care Files)
OA/Box Number: 8104

**FOLDER TITLE:**
Healthcare '94 General [4]

2022-0433-S
rs3717

**RESTRICTION CODES**

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

**P1 National Security Classified Information [(a)(1) of the PRA]**
**P2 Relating to the appointment to Federal office [(a)(2) of the PRA]**
**P3 Release would violate a Federal statute [(a)(3) of the PRA]**
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**b(1) National security classified information [(b)(1) of the FOIA]**
**b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]**
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**b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]**
**b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]**
**b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]**
**b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]**
**b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]**

# CURRICULUM VITAE

| | |
|---|---|
| Name: | Elihu H. Estey, M.D. |
| Present Title and Affiliation: | Professor<br>Internist<br>Department of Hematology<br>Division of Medicine<br>UT MD Anderson Cancer Center<br>Houston, Texas 77030 |
| Birthdate and Place: | (b)(6) |
| Citizenship: | United States |
| Social Security Number: | |
| Home Address: | 1902 Sunset<br>Houston, Texas 77005<br>(713) 522-0149 |
| Office Address: | The University of Texas<br>M.D. Anderson Cancer Center<br>Department of Hematology - 61<br>1515 Holcombe Boulevard<br>Houston, Texas 77030<br>(713) 792-7305 |
| Marital Status: | Married<br>Cynthia L. David, M.D.<br>No children |
| Licensure: | TX F5200 |
| Education: | A.B., Yale University<br>New Haven, Connecticut (1968)<br>M.D. Johns Hopkins University<br>Baltimore, Maryland (1972) |
| Post Graduate Training: | |
| 1978-1980 | Fellow, Department of<br>Developmental Therapeutics, |

| | |
|---|---|
| | UT MD Anderson Hospital and Tumor Institute, Houston, Texas |
| 1976-1978 | Chief Resident in Neurology, New York University-Bellevue Medical Center, New York, New York |
| 1975-1976 | Resident in Neurology, New York University-Bellevue Medical Center, New York, New York |
| 1974-1975 | Senior Resident in Medicine, New York University-Bellevue Medical Center, New York, New York |
| 1973-1974 | Junior Resident in Medicine, New York University-Bellevue Medical Center, New York, New York |
| 1972-1973 | Intern in Medicine, New York University-Bellevue Medical Center, New York, New York |

Specialty Boards:

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| 1975 | American Board of Internal Medicine |
| 1982 | Subspeciality - Medical Oncology |

Military or Government Service: None

Academic and Professional Appointments:

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| 1993-present | Professor of Medicine, Internist, Department of Hematology, Division of Medicine, University of Texas, M.D. Anderson Cancer Center, |

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|---|---|
| | Houston, Texas |
| 1984-1993 | Associate Professor of Medicine, Associate Internist, Department of Hematology, Division of Medicine, University of Texas, M.D. Anderson Cancer Center, Houston, Texas |
| 1987-1989 | Member, Graduate School of Biomedical Sciences, The University of Texas Health Science Center, Houston, Texas |
| 1983-1984 | Cancer Expert, Investigational Drug Branch, Division of Cancer Treatment, National Cancer Institute, Bethesda, Maryland |
| 1980-1983 | Assistant Professor of Medicine, Assistant Internist, Department of Developmental Therapeutics, The University of Texas System MD Anderson Hospital and Tumor Institute, Houston, TX |

Administrative Responsibilities:

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|---|---|
| 1990-present | Co-clinical Director Leukemia Service |
| 1989-present | Chairman, Department of Hematology Acute Leukemia Clinical Planning Conference |
| 1988-present | Member, Surveillance Committee (Institutional Review Board) |
| 1989-1992 | Member, Infection Control |

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| | Committee |
| 1990-1992 | Member, Brown Foundation Award Selection Committee |

Local, State, National, International Committees:

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| 1993 | Member Adria Laboratories Physician Advisory Board |

Editorial Boards: None

Honors and Awards:

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| 1993 | Invited Author MKSAP Syllabus: Acute Myelogenous Leukemia |
| 1993 | Invited Speaker, Acute Leukemias - Pharmacokinetics and Management of Relapsed and Refractory Disease; Münster Germany |
| 1993 | Invited Speaker, Haematology Society of Australia, Melbourne, Australia, "New Approaches to Utilizing Cytotoxins in AML/MDS" |
| 1993 | Invited Speaker, Westmead Hospital, Sydney, Australia, "Evolution of the Current AML Clinical Trial Program at M.D. Anderson" |
| 1993 | Invited Speaker, New Zealand Society for Haematology "Treatment of AML/MDS at M.D. Anderson Hospital |
| 1993 | Invited Speaker, University of Pittsburgh School of Medicine, Pittsburgh, PA "Treatment of AML at M.D. Anderson Hospital" |

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| 1993 | Invited Speaker, Cleveland Clinic, Cleveland, Ohio "Treatment of AML at M.D. Anderson Hospital |
| 1993 | Invited Speaker, Ontario Cancer Institute/ Princess Margaret Hospital, Toronto, Ontario, Canada: "Treatment of AML at M.D. Anderson Hospital" |
| 1993 | Invited Speaker, McMaster University, Hamilton, Ontario Canada: "Treatment of AML at M.D. Anderson Hospital" |
| 1993 | Organizing Committee + Invited Speaker "Leukemia: The Next Questions", Houston, Texas |
| 1992 | Invited Speaker "Leukemia 1992 2nd International Course, Recent Progress in Biology and Clinical Research in Adult Leukemia" - Genoa, Italy |
| 1992 | Invited Speaker, International Conference on Growth Factors in Cancer Therapy - Vanderbilt University, Nashville, TN |
| 1992 | Invited Speaker, "Lymphoma, the Next Questions" - Orlando, FL |
| 1991 | Invited Speaker, Apheresis Workshop University of Texas M.D. Anderson Cancer Center, Houston, Texas |
| 1991 | Invited Speaker, Acute Leukemias - Pharmacokinetics and Management of Relapsed and Refractory Disease; Muenster, Germany |
| 1990 | Invited Speaker, Symposium |

"Leukemia: The Next Questions"; Houston, Texas

1990 Invited Speaker, Conference on 2-chlorodeoxyadenisone, Scripps Clinic and Research Foundation, La Jolla, CA.

1990 Invited Speaker, Symposium "Clinical Perspectives on Granulocyte-Macrophage Colony Stimulating Factors" Hahnemann University, Philadelphia, PA

1990 Invited Speaker "NCI-EORTC Meeting on Neoplasia in the Elderly" Venice, Italy

1990 Invited Speaker Symposium "Hematopoietic Growth Factors in Oncology" University of Arkansas for Medical Sciences, Little Rock, AR

1989 Invited Speaker, Second International Symposium "Acute Leukemias: Prognostic Factors and Treatment Strategies", Muenster, Germany

1989 Invited Speaker, UCLA Symposia on Molecular and Cellular Biology; "Acute Myelogenous Leukemia", Lake Lanier, Georgia

1989 Invited Speaker, BICON - 2nd Biennial Conference on Chemotherapy of Infectious Diseases and Malignancies, Montreux, Switzerland

1989 Invited Speaker, 5th European Conference on Clinical Oncology, Satellite Symposium: "Intron-A/GM-CSF", London, England

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| 1989 | Invited Speaker, St. Elizabeth's Hospital, Boston, Massachusetts, "GM-CSF in AML" |
| 1987 | Invited Speaker, Thomas Jefferson University School of Medicine, Philadelphia, Pennsylvania, "Therapy of AML" |
| 1986 | Invited Speaker, Rush-Presbyterian Medical Center, Chicago, Illinois, "High-dose Ara-C Therapy of AML" |
| 1986 | Leukemia Research Foundation Award for work on "Topoisomerase II - Mediated DNA Cleavage as a Predictor of Clinical Response in Human Adult Leukemia" |
| 1985 | Invited Speaker, Brook Lodge Symposium on "CYTOSAR-U Sterile Powder: Therapeutic Biological Effects", Kalamazoo, Michigan |
| 1983-1985 | Special Fellow, Leukemia Society of America |

Society Memberships:

American Society of Hematology
American Society of Clinical Oncology
American Association of Cancer Research
Harris County Medical Society
Texas Medical Association

Grant Support for the Past Five Years:

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|---|---|
| 05/1/93 - 05/1/94 | Argus Pharmaceuticals, Inc., "Phase I Study of AR-623 (Liposomal Tretinoin) in Patients |

with Hematologic Malignancies".
**Elihu H. Estey, Principal Investigator**
Total Direct Cost of Project: $ 68,500

11/1/92 - 11/1/95

University of Texas MD Anderson Cancer Center Physicians Referral Service (PRS) Clinical Research Grant "Bayesian Statistical Methods for Design and Analysis of Clinical Trials in AML".
**Elihu H. Estey, Principal Investigator**
Total Direct Cost of Project: $ 36,000

11/1/92 - 11/1/95

University of Texas MD Anderson Cancer Center Physicians Referral Service (PRS) Clinical Research Grant "Minimal Residual Disease in Acute Myelogenous Leukemia".
K-S. Chang, Principal Investigator
**Elihu H. Estey, Co-Investigator**
Total Direct Costs of Project: $65,000

5/26/92 - 6/30/96

PO1-CA55164, years 1-4, Therapy of AML
Albert Deisseroth, Principal Investigator
Project 1, "Clinical Trials of Growth Regulatory Molecules and Chemotherapy to Reduce Leukemia Burden".
**Elihu H. Estey, Project Director**
Total Direct Costs of Project: $159,940

6/1/91 - 7/31/96

RO1-CA32839, years 9-13, "Cellular Pharmacology in Cancer Chemotherapy".
William Plunkett, Principal Investigator
**Elihu H. Estey, Co-Investigator**
Total Direct Costs: $685,478

9/1/90 - 8/31/92

RO3-CA53311, years 1-2, "Biochemical Modulation to Increase Leukemia Response"
Varsha Gandhi, Principal Investigator
**Elihu H. Estey, Co-Investigator**
Total Direct Costs: $74,479

| | |
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| 9/1/92 - 8/31/95 | RO1-CA57629, years 1-3 "Biochemical Strategies to Increase Leukemia Response." Varsha Gandhi, Principal Investigator **Elihu H. Estey, Co-Investigator** Total Direct Costs: $273,633 |
| 6/1/91 - 6/1/92 | Cancer Fighters of Houston Inc. $30,000 for "IL-2 as Post-Remission Therapy of AML" **Elihu H. Estey, Principal Investigator** |

Patents Granted:

None

Teaching Experience:

| | |
|---|---|
| 1993 | Lecturer, Medical Oncology Board Review Course co-sponsored by American College of Physicians and MD Anderson, "Treatment of AML" |
| 1993 | Thesis Adviser to Xudong Xu candidate for Master of Public Health Degree at University of Texas Health Science Center at Houston |
| 1993 | Lecturer, 15th Annual M.D. Anderson Pharmacy Symposium on Cancer Chemotherapy, Houston |
| 1993 | Lecturer, The Acute Leukemias to Leukemia Research Nurses at "Leukemia, The Next Questions" meeting in Houston |
| 1992 | Lecturer, Oncology Board Review Course, University of Texas Medical School Houston, "Treatment of Acute Leukemia" |
| 1991 | Lecturer, Houston Cytogenetics Journal Club |
| 1989-1992 | Lecturer for Schering-Plough Preceptorships held at University of Texas, M.D. Anderson Cancer Center |

| | |
|---|---|
| 1980-present | Attending physician Leukemia Service, University of Texas, M.D. Anderson Cancer Center. Responsible for instruction of oncology fellows, and "inservices" to nursing staff. |

## BIBLIOGRAPHY

A. Published Articles


1. Lieberman A, Kupersmith M, **Estey E,** and Goldstein M: Treatment of Parkinson's disease with bromocriptine. New England Journal of Medicine 295:1400-1404, 1976.

2. Lieberman A, **Estey E,** Kupersmith M, Gopinathan G, and Goldstein M: Treatment of Parkinson's disease with lergotrile mesylate. Journal of the American Medical Association 238:2380-2382, 1977.

3. Lieberman A, **Estey E,** Gopinathan G, Ohashi T, Sauter A, and Goldstein M: Comparative effectiveness of two extracerebral DOPA decarboxylase inhibitors in Parkinson's disease. Neurology 28:964-968, 1978.

4. **Estey E,** Lieberman A, Pinto R, Meltzer M, and Ransohoff J: Cerebral Arteritis in Scleroderma. Stroke 10:595-597, 1979.

5. Lieberman A, Gopinathan G, **Estey E,** Kupersmith M, Goodgold A, and Goldstein M: Lergotrile in Parkinson's disease: further studies. Neurology 29:267-272, 1979.

6. Lieberman A, Kupersmith M, Gopinathan G, **Estey E,** Goodgold A, and Goldstein M: Bromocriptine in Parkinson's disease: further studies. Neurology 29:363-369, 1979.

7. Lieberman A, Ruoff M, **Estey E,** Seidman I, Lieberman I, and Wise A: Irreversible pulmonary toxicity after a single course of BCNU. American Journal of the Medical Sciences 279:53-56, 1980.

8. **Estey E,** Weaver S, Ho D, and Bodey G: Clinical pharmacology of moxalactam in patients with malignant disease. Antimicrobial Agents and Chemotherapy 19:639-644, 1981.

9. **Estey E,** Weaver S, LeBlanc B, Brown N, Ho D, and Bodey G: Clinical pharmacology of ceforanide. Clinical Pharmacology and Therapeutics 30:398-404, 1981.

10. **Estey E,** Keating M, McCredie K, Bodey G, and Freireich E: Causes of initial remission failure in acute myelogenous leukemia. Blood 60:309-315, 1982.

11. **Estey E,** Keating M, McCredie K, Bodey G, and Freireich E: Phase II trial of mitoxantrone in refractory acute leukemia. Cancer Treatment Reports 67:389-390, 1983.

12. Fainstein V, Bodey G, McCredie K, Keating M, **Estey E,** Bolivar R, and Elting L: Coagulation abnormalities induced by beta-lactam antibiotics in cancer patients. Journal of Infectious Diseases 148:745-750, 1983.

13. Kantarjian H, Saad M, **Estey E,** Sellin R, and Samaan N: Hypercalcemia in disseminated candidiasis. American Journal of Medicine 74:721-724, 1983.

14. **Estey E,** Maksymiuk A, Smith T, Fainstein V, Keating M, McCredie K, Freireich E, and Bodey G: Infection prophylaxis in acute leukemia: Comparative effectiveness of sulfamethoxazole and trimethoprim, ketoconazole, and a combination of the two. Archives of Internal Medicine 144:1562-1568, 1984.

15. **Estey E,** Keating M, Smith T, McCredie K, Legha S, Walters R, Bodey G, and Freireich E: Prediction of complete remission in patients with refractory acute leukemia treated with AMSA. Journal of Clinical Oncology 2:102-106, 1984.

16. Andersson B, Cogan B, Keating M, **Estey E,** McCredie K, and Freireich E: Subacute pulmonary failure complicating therapy with high-dose ara-C in acute leukemia. Cancer 56:2181-2184, 1985.

17. Maddox A-M, Keating MJ, McCredie KB, Estey EH, and Freireich EJ: Phase I evaluation of intravenous difluoromethylornithine - a polyamine inhibitor. Invest New Drugs 3:287-292, 1985.

18. Kantarjian H, Keating M, Walters R, **Estey E,** McCredie K, Smith T, Dalton W, Cork A, Trujillo J, and Freireich E: Acute promyelocytic leukemia: M.D. Anderson Hospital Experience. American Journal of Medicine 80:789-797, 1986.

19. Iacoboni S, Plunkett W, Kantarjian H, **Estey E,** Keating M, McCredie K, and Freireich E: High-dose cytosine arabinoside: Treatment and cellular pharmacology of chronic myelogenous leukemia blast crisis. Journal of Clinical Oncology 4:1079-1088, 1986.

20. **Estey E,** Hoth D, Simon R, Marsoni S, Lleyland-Jones B, and Wittes R: Therapeutic results in phase I trials of anti-neoplastic agents. Cancer Treatment Reports 70:1105-1115, 1986.

21. Kantarjian H, **Estey E,** Plunkett W, Keating M, Walters R, Iacoboni S, McCredie K, and Freireich E: Phase I-II clinical and pharmacologic studies of high-dose cytosine arabinoside in refractory leukemia. American Journal of Medicine 81:387-394, 1986.

22. Bakic M, Beran M, Andersson B, Silberman L, **Estey E,** and Zwelling L: The production of topoisomerase II-mediated DNA cleavage in human leukemia cells predicts their susceptibility to 4'-[9-acridinylamino] methanesulfon-m-aniside [m-AMSA]. Biochemical and Biophysical Research Communications 134:638-645, 1986.

23. **Estey E,** Adlakha RC, Hittelman WN, and Zwelling LA: Cell cycle stage-dependent variations in drug-induced topoisomerase II-mediated DNA cleavage and cytotoxicity. Biochemistry 26:4338-4344, 1987.

24. **Estey E,** Plunkett W, Dixon D, Keating M, McCredie K, and Freireich EJ: Variables predicting response to high-dose cytosine arabinoside therapy in patients with refractory acute leukemia. Leukemia 1:580-583, 1987.

25. **Estey EH**, Keating MJ, Dixon DO, Trujillo JM, McCredie KB, and Freireich EJ: Karyotype

is prognostically more important than the FAB system's distinction between myelodysplastic syndrome and acute myelogenous leukemia. Hematologic Pathology 1(4):203-208, 1987.

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27. **Estey EH**, Keating MJ, McCredie KB, and Freireich EJ: Continuous-infusion amsacrine in patients with refractory acute myelogenous leukemia. Cancer Treat Rep 71:1113-1114, 1987.

28. Zwelling L, **Estey E**, Silberman L, Doyle S, and Hittelman W: The effect of cell proliferation and chromatin conformation on intercalator-induced protein-associated DNA cleavage in human brain tumor cells and human fibroblasts. Cancer Res 47:251-257, 1987.

29. Plunkett W, Liliemark JO, Adams TM, Nowak B, **Estey E,** Kantarjian H, and Keating MJ: Saturation of 1-ß-D-arabinofuranosylcytosine 5'-triphosphate accumulation in leukemia cells during high-dose 1-ß-D-arabinofuranosylcytosine therapy. Cancer Research 47: 3005-3011, 1987.

30. Bakic M, Chan D, Andersson BS, Beran M, Silberman L, **Estey E,** Ricketts L, and Zwelling LA: Effect of 1-beta-D-arabinofuranosylcytosine on nuclear topoisomerase II activity and on the DNA cleavage and cytotoxicity produced by 4'-(9-acridinylamino) methane-sulfon-m-anisidide (m-AMSA) and etoposide in m-AMSA-sensitive and -resistant human leukemia cells Biochem. Pharmacol. 36:4067-4077, 1987.

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32. Walters RS, Kantarjian HM, Keating MJ, **Estey EH**, McCredie KB, and Freireich EJ: Intensive treatment of acute leukemia in adults 70 years of age and older. Cancer 60:149-155, 1987.

33. Walters RS, Kantarjian HM, Keating MJ, **Estey EH**, McCredie KB, Freireich EJ, Stass SA: T-cell receptor gamma chain gene rearrangement in acute myelogenous leukemia - evidence for lymphoid lineage prematurity. Hematol Pathol 1:93-93, 1987.

34. Walters RS, Kantarjian HM, Keating MJ, Plunkett WK, **Estey EH**, Andersson B, Beran M, McCredie KB, Freireich EJ: Mitoxantrone and high-dose cytosine arabinoside in refractory acute myelogenous leukemia. Cancer 62:677-682, 1988.

35. Hittelman WN, Agbor P, Petkovic I, Andersson B, Kantarjian H, Walters R, Koller C, **Estey E,** Keating M, and Beran M: Detection of leukemic clone maturation in vivo by premature chromosome condensation. Blood 72:1950-1960, 1988.

36. **Estey E,** Smith TL, Keating MJ, McCredie KB, Gehan EA, and Freireich EJ: Prediction of survival during induction therapy in patients with newly diagnosed acute myeloblastic leukemia. Leukemia 3:257-263, 1989.

37. Heinemann V, **Estey E,** Keating MJ, and Plunkett W: Patient-specific dose rate for continuous infusion high-dose cytarabine in relapsed acute myelogenous leukemia. J Clin Oncol 7:622-628, 1989.

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D. Abstracts

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

17-Feb-1994 05:19pm

TO: (See Below)

FROM: Jeffrey L. Eller
Office of Media Affairs

SUBJECT: First Lady Transcript from H.I.H

SPEECH BY FIRST LADYHILLARYCLINTON
TO THE STAFF OF THE NATIONAL INSTITUTES OF
HEALTH
BETHESDA,MARYLAND
APPROXIMATELY 12:30 P.M. EST
THURSDAY, FEBRUARY 17, 1994
TRANSCRIPT BY: FEDERAL NEWS SERVICE
620 NATIONAL PRESS BUILDING
WASHINGTON,DC 20045

MS. CLINTON: Thank you very much. Thank you.

It is a real thrill for me to be here and I want to start by acknowledging how much I appreciated the session I had this morning. As I told Doctor Varmus on my way in, I was only sorry my daughter could not have been with me because she would have understood far more than I did. She's been studying genetics in her biology class and I sat on the floor with her for a few hours a couple of weeks ago while on a great poster board she was describing the retro-virus functions that Doctor Varmus was explaining to me and my contributions since I didn't understand anything about it was to help her color in the various parts while she tried desperately in that wonderful tone that thirteen-year-olds take to their parents to explain to me very patiently all those things that she had been learning about transcriptes (sp) and stuff that I'd never heard of before. So this was a special treat for me and I will take it back to her.

I'm also honored to be on the same platform as the three people who are here with me. The three that are here, Secretary Shalala and
Secretary Lee and Doctor Varmus , are appointments that really mark for the first time that a President has chosen three people from research universities for top positions

at HHS. As many of you know, Secretary Shalala served as the President of the University of Wisconsin and also on at least one board affiliated with NIH. Doctor Lee and Doctor Varmus come from the University of California at San Francisco and Doctor Lee has had a -- in working to improve health care in all of its aspects here in our country.

But I would like to offer special thanks to Doctor Varmus who agreed to leave warmer if not sunnier California to come back to NIH to take the helm. He is not only the first Nobel laureate to head these institutes, he is also a strong and able leader whose ideas abouthealthcare have been invaluable to this administration and will continue to be as we move to implement many of the ideas that you and he have brought to this administration. So we are very grateful that he is

providing the leadership that we knew we would count on when he agreed to take this position.

This institution is truly at the epicenter of our nation's bio- medical research efforts. For more than a century, NIH has been a pillar of scientific achievement paving the way to fundamental discoveries that have revolutionized our understanding of biology and the practice of medicine and improved the lives of people all over our globe. Eighty three scientists affiliated with NIH have gone on to win Nobel prizes. And at least thirty five thousand scientists are supported by NIH at any given time. Among the list of scientific and medical breakthroughs, although far too long to be exhausted, you know as well as I, and I want the country to know, are those affecting heart disease and cancer and strokes and schitzophrenia.
Those are just a few of the diseases that are less frightening, less threatening, less deadly today because of basic and clinical research done right here at NIH and at research universities across the country.

I'd like to take a moment to note that just this last week the scientific community lost one of its great leaders, Howard Temmon (sp). Professor Temmon was at the University of Wisconsin,a close friend of Secretary Shalala's, Phil Lee's and Harold Varmus's. His dogged pursuit of the enzyme reverse transcriptase won him a Nobel Prize in medicine and exemplified the important work you and your colleagues do in finding cures and treatments for diseases. No one would have called Dr. Temmon an AIDS researcher; yet, his work led directly to the quick identification of the AIDS virus. No one would have called him a bioengineer; yet, his work led to the birth of the biotechnology industry. What his colleagues and all of you here in this auditorium who counted yourselves among them did call him was a bench scientist -- words of very high praise -- whose work opened doors and saved lives. His death robs us of one of our most talented scientists, one of our country's best teachers, and one of our most passionate advocates of basic research.

Today, as our nation attempts to fix a health care system that badly needs repair, the work of scientists like Dr. Temmon and yourselves is more important than ever. That's because medical research andhealthcare reform go hand in hand. I am not a scientist. But even as a lay person, before I ever became involved with health care reform, I knew that scientific research is about exploration, discovery and pushing the boundaries. I knew that science is a tool we use to evolve and survive as a species. And I also know that it's not just the contribution of the great researchers that count, it's the endless hours that researchers in labs, big and small,

devote to studying everything from the common cold to genetic coding that will lead to the kinds of breakthrough research that we all count on.

Without basic research, we would never have been able to beat diseases like hepatitis or polio; we would never have benefited from vaccines and drug treatments and new diagnostic and surgical techniques that save thousands of lives every year. In short, without basic biomedical research, we would never have achieved the quality of health care or the quality of life that most Americans enjoy.

The United States has no rival in basic biomedical research, because of our government's investment in NIH and in our nation's great research universities and because of the brilliant research and development found in our private sector as well. And yet we know that the research in and of itself would not be what we see and feel every day, were it not for the use that it has been put to.

Today I saw firsthand the evidence of this, when I met a seven- year-old girl named Ashante DiSilva (ph). Nearly three and a half years ago she was in this hospital to receive the world's first gene therapy, to treat her ADA deficiency, a genetic deficit that destroys the immune system and leaves a person vulnerable to countless infections. Before her treatment, her life was one of confinement and fear; today she is healthy and living a full life.

From the discovery in 1944 that genes are made of DNA, to the breaking of the DNA code in 1961, to the explanation of retroviruses in 1970, to the cloning of DNA in 1983, scientists at NIH put the pieces of the puzzle together that made Ashante's (ph) treatment possible and made it possible for me to see her in the company of a very happy father this morning.

That's why the president believes so strongly in the need for continued investment in basic science and biomedical research and training. And that's why he also believes it is essential that we preserve the mission of the academic health centers which train young scientists and doctors and help treat some of the most vexing diseases facing mankind.

For much of the past decade, biomedical research has been neglected and underfunded and even unappreciated, and the president intends to fix that. He intends to fix it by reaffirming our nation's commitment to basic biomedical research and training and by fixing ourhealthcare system overall. It is that dual commitment that brings me in part to you today.

In 1945 in his landmark report, Dr. Vannevar Bush said that progress in the war against disease depends upon a flow of new scientific knowledge. New products, new industries and more jobs require continuous additions to knowledge of the laws of nature and the application of that knowledge to practical purpose. In keeping with that philosophy, the Clinton administration has provided new resources in the past year for the research enterprise here at NIH. In fiscal 1994, the president and Congressincreased the NIH budget by $631 million over fiscal 1993. In the face of fierce spending restraints agreed to with Congress, the president has proposed another $517 million increase for fiscal 1995, most of it for basic research.

The president also believes in establishing priorities for research that will provide direction without tying hands. There are significant new funds for AIDS research, 21 percent more last year and another 6 percent increase this year. There is a stronger commitment to breast cancer research, including funding for hundreds of new projects in this area. And there will be an 18 percent increase for the genome project in the fiscal 1995 budget.

Without these kinds of expanded investments in medical research, we cannot have a health care system that gives us the kind of health care we want and expect as a nation. Key elements of reform -- quality, prevention and savings -- simply cannot be achieved without continuing and strengthening our research efforts. The president's approach to reform reflects the vital intersection between research and high-quality, affordable health care.

The president's approach will provide health security for every citizen, beginning with private health insurance coverage that guarantees comprehensive benefits. That means that every citizen can take full advantage of the breakthroughs you achieve here, breakthroughs that not only save lives but save money, so that in the future we will not wake up, as we did this morning, to front page articles about how insurance companies determine arbitrarily who is entitled to the kinds of treatments and breakthroughs you work hard to provide to American citizens and those people around the globe.

Those of you in the medical profession know all too well the impact that a chronic illness can have on a family, or a pink slip that results in a lost job and a loss of health benefits, or a preexisting condition that isn't covered by most health plans. Several of you in the presentations I heard this morning mentioned the Lasker (sp) Awards, and in particular, the work and comment that Dr. Nancy Wexler (sp) made to me that made such a very big

impression on me, which was reiterated by several of you today, that at the rate you are going with the work you are doing, we will soon discover we all have preexisting conditions and are all totally uninsurable. (Laughter.) So if there is no other reason for the research and scientific community to support universalhealthcare for all Americans, do it out of self-interest so that you, too, will have insurance when we reach the point where we know everything there is to know about what diseases we are genetically predisposed to incurring.

A few months ago, a scientist pointed out to me that this kind of work that you are doing will obviously impact not just in the future but on the daily basis on the young children that I saw, like Ashante (ph), and that part of what I would try to do is to spread that word as I travel around the country. And so when I speak, I speak not only about the insurance industry, although that's usually what gets the coverage, but I speak also about the need for research and the support of basic research and clinical work that will lead to the ultimate preventive health care, the elimination, or certainly the amelioration of many of the diseases that afflict us now.

If we are able to match our research progress with the reforms in our health care system, then we will be able to maximize the positive impacts of the work that you are engaged in, because health security not only means guaranteeing comprehensive benefits throughout a person's life, it also means emphasizing early diagnosis and prevention of diseases. And I saw today, very graphically illustrated with family trees, how learning more about the genetic underpinnings of diseases like colon cancer will not only be able to serve as an early warning signal to those individuals who carry the gene, but also as a great relief to those members of the same family who do not, and that the obvious impact of bringing this work into the lives and the doctors' offices and the hospitals of America will be to provide real security and also real information about future health challenges to all of us.

Now, as we move forward in this health care debate, we have to recognize that without comprehensive benefits that include preventive care that do what insurance plans today will not, namely, pay for child immunizations or sonograms for pregnant women or clinical trials for experimental drugs, then many of the benefits that you are working to extend to Americans will remain out of reach.

Listen carefully as the debate goes forward and as it often breaks between those who argue they are for universal access versus those who argue they are for universal coverage. We all have access right now to everything you have done to improve health care in the last decades but we all cannot afford it, we all do not

have insurance policies that will pay for it. So merely having access is like being able to go right now to our nearest car dealership and buy the most expensive car on the lot. Every one of us in America has that right. The fact is, most of could not afford, realistically, to do so.

The President's approach is the only one that covers clinical trials in the basic benefits package. So no longer will some be eliminated because of the insurance coverage they have if they are candidates for clinical trials that you are conducting or those with whom you work. If we can more effectively put your knowledge and wisdom to use preventing diseases or detecting them early enough to treat, we can also begin to rein in the rising costs of American health care. We will spend more than a trillion dollars this year and much of that will go for sick care, not health care. Despite the remarkable work done at NIH on behavioral research for example, we spend billions to treat the symptoms of disease and comparatively little to prevent it.

Another critical part of the President's approach is Title 3 of the Health Security Act, known as the Public Health Initiative. This maps out a vigorous plan of investment in public health and bio- medical research that will ensure that all Americans truly do have access to top quality medical care that NIH research makes possible. The President's approach will promote research services that will help answer important questions about the effectiveness of treatment and patient outcomes. This will be very useful to doctors and hospitals as well as academic health centers and research institutions training future doctors and scientists.

The president's approach also helps strengthen academic health centers by requiring that all health plans contract with academic health centers for the treatment of rare and specialized diseases. And I want to emphasize this point. Many people are concerned about change in ourhealthcare system. I am concerned about what will happen if we fail to change.

I am particularly concerned that with the trends that are pushing more employers into managed care arrangements in order to save costs because they bear a disproportionate share of the costs under the way our system currently operates, they are acceding to demands that they eliminate from their coverage access to academic health centers. So that those who are employed or who are enrolled in such plans, which now are increasingly a majority of all Americans who receivehealth insurance through their employment, will not have the option of going to the academic health centers that you work with if they expect to have their insurance cover such treatment.

This is particularly important that we pay attention to this and work very hard to achieve the president's approach, which is to require all plans that provide health insurance coverage to contract with such academic health centers in order to preserve and protect the critical mission of these centers.

Academic health centers also will be crucially important in serving as the quality foundation for health care reform, helping to disseminate information out into clinical practice. And I have to say that one of those things that has surprised me in the past year is how difficult it often is to get information into the daily practice settings of the majority of physicians in our country. And providing some bridge between what you do and the academic health centers do through these quality foundations that will be established, we believe, will more quickly disseminate the information you are compiling and analyzing so that it can actually be put into practice.

Above all,healthcare reform is not about government control, about the government making decisions best left to doctors or scientists or patients. Reform is about revamping a system so that private health plans truly compete, not over which insurer can do the best job of screening out high-risk families, but over which can deliver the highest quality care at the best price.

One of the great attacks that is going on about the president's approach is to try to argue that it is government-dominated or government control. And that always amuses me because what we have in our country now is a mixed system in which we have government-financed and -supported institutions like NIH; we have those like the academic health centers that receive funding from private sources and government sources, both state and federal; and we have purely private health care institutions. We intend to maintain that mix, but we intend to try to provide better support and better functioning of the health care plans in the private sector so that they can truly compete with one another, not in the ways they have competed in the past, which is to try to eliminate people from health care coverage, but by actually providing health care to people.

Reform is our opportunity for progress. It is our chance to succeed where past generations have failed. It is our chance to improve the health of individual Americans and protect the integrity of our entire health care system. If we can find a vaccine for polio, if we can discover the structure of DNA, surely we ought to be able to make the political decisions necessary to fix and treat a health care system that needs our help.

As scientists, you are well schooled in the art of perseverance. You know what patience and fortitude it takes to solve the riddles of disease and to unlock the mysteries of nature and the universe. You know how important it is to push ahead until you do succeed. Well, that is exactly the attitude we take with us into this health care debate. We do not expect it to be easy. We are well aware of the history, starting with Franklin Roosevelt, of presidents, both Democratic and Republican, who have understood what was at stake and attempted to move toward real health security. And we know full well that there are many interests arrayed against the changes that we believe will provide a better and more secure footing, not only for individual health care status but for the institutions like NIH that are so vital to our overall health care status in our country.
It always is easier to maintain the status quo, which is what has happened repeatedly in our efforts to reform health care in the past. This time, however, maintaining the status quo cannot be an acceptable alternative. We know that we have the finest doctors and researchers and scientists and hospitals and nurses in the world. But we also have the stupidest financing system for health care in the world, and the stupidity of that system threatens the quality of all that you do and are engaged in doing to try to improve the health of both individuals and a nation.

We are facing challenges from those who do not believe in research or do not believe in the government's role in research. We are facing challenges from those who believe that the billions of dollars we spend on the paperwork health care system are justifiable. And we are facing challenges of trying to explain to Americans why what they hold dear with their health care system and what they hope for with the breakthroughs that you are on the brink of giving them every day, are in danger unless we have the courage to change.

We have to fight off those who would undermine our commitment to basic research, who would engage in gimmicks like balanced budget amendments that would decimate many of the functions that we believe are important to investing in the future -- health care for all of us at an increasingly higher level of scientific understanding and the better delivery system that comes with that.

What we hope you will do, as scientists and researchers and doctors, is to take a stand on behalf of what you know and what you care about, and that is the commitment you have given your lives to of improving health, of unlocking the mysteries that surround disease, of helping to cure and prevent all that ails each of us as we move through our lives. And if you bring that

commitment to this challenge, your voices will be heard loudly. You have more credibility than many of the forces arrayed against the changes that we seek to benefit all of us. With your help we can, in Louis Pasteur's words, ''extend the frontiers of life'' and make our fellow citizens and our nation healthier, happier and more secure.

Thank you very much. (Applause.)

END

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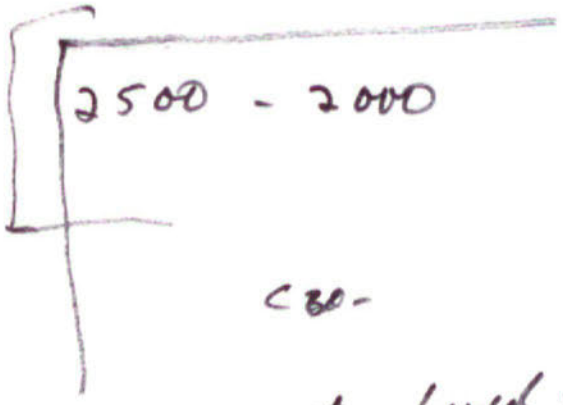


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