

*File Kennedy-Krieger*

NOTE TO: Carol Rasco  
FROM: Diana Fortuna *DF*  
CC: Jeremy Ben-Ami  
SUBJECT: Your question on the attached  
DATE: January 27, 1995

You had asked for an update on the advisory group that the Maternal and Child Health Bureau was convening in November. The purpose of the advisory group was to seek advice from grantees on how to restructure the University Affiliated Programs that do training in developmental disabilities. The impetus for your involvement was Gary Goldstein's letter to you expressing concern that MCHB was planning to cap individual awards under the program. As the largest grantee, Kennedy Krieger could have faced a major reduction under such a scenario.

According to James Pipai of MCHB, the advisory group convened in November and Kennedy Krieger participated. The plan to cap individual awards was ultimately dropped. The major change is that MCHB has decided to open the grant award process to previously unfunded programs, but no one is objecting to that (at least not yet). It is possible that Kennedy Krieger's award will be shaved back to some extent as new grantees are added, but it should not be a significant cut as they had feared in November.

After the November advisory group meeting, MCHB sent out draft guidance to grantees for comments, got a generally positive response, and made some changes to reflect those comments. The changes in the process will be announced in the Federal Register in a few days. Applications for grants are due in April.

Let me know if you have any further questions.

THE WHITE HOUSE  
WASHINGTON

STAN:

CAROL ASKED IF YOU  
COULD PROVIDE HER A BRIEF  
SYNOPSIS OF WHAT THE ISSUE  
HERE IS BY CONTACTING HHS

ROZ WILL HOLD THIS  
SCHEDULING REQUEST UNTIL SHE  
HEARS FROM YOU.

JED talked to  
Stan 11/3/95

cc: Ben-Ami  
orig: Roz tickler

look in  
files & check w/ Jeremy  
not clear if Carol would want  
to intervene - timing issues.

**FAX TRANSMITTAL COVER SHEET**

OCT 25 1994

**To:** Roslyn Miller

**Company:** The White House

**Fax #:** 202-456-2878

**Date:** 10/25/94

**# pages:**  (including this page)

**From:** Dr. Gary Goldstein

**Department:** President's Office

**Phone:** (410) 550-<sup>9483</sup>

**Transmitting Fax Number**  
**(410) 550-9524**

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**COMMENTS****Kennedy Krieger Institute**

Administration  
707 North Broadway  
Baltimore, Maryland 21205

**NOTE:**

If you do not receive the number of pages stated, or the pages are illegible, please call the sender at the number above as soon as possible.



Kennedy Krieger Institute

*Alana -  
See issue of  
adv. comm.  
on  
A comprehensive  
resource for children  
with disabilities  
4/26  
page &  
CR on  
status.  
Thanks,  
CAR*

Gary W. Goldstein, M.D.  
President

October 25, 1994

Ms. Carol Rasco  
Domestic Policy Advisor  
The White House  
West Wing, 2nd Floor  
Washington, DC 20500

ATTN: Roslyn Miller

Dear Carol,

I write to request an appointment with you to discuss upcoming changes in the funding of University Affiliated Programs. The Maternal and Child Health Bureau last week announced a total restructuring of the funding system for programs like the Kennedy Krieger Institute. These changes will be effective in the July 1, 1995 renewal of our grant support. I would like to have an opportunity to explain the impact of the proposed changes and get advice from you on how to proceed.

I will call your office in a few days to see if we can arrange a meeting in Washington.

Sincerely,

Gary W. Goldstein, M.D.

GWG:kah

NOV 29 1994

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr

CC: Jeremy Ben-Ami

SUBJ: Gary Goldstein's Concerns on Caps for UAP Training Funds

DATE: November 23, 1994

Last Friday, November 18th, I met with Gary Goldstein and two of his staff at the Kennedy Krieger Institute in Baltimore. At your direction, I was responding to his letter to you in which he expressed concerns that the Maternal and Child Health Bureau was going forward with a new way of funding their core training program in the developmental disability field that could have adverse effects.

Here's the gist of their worry: For nearly 30 years, they have come to rely on the MCHB funds for a large part of their nationally acclaimed interdisciplinary training program. They now garner the largest of 32 such MCHB grants (see my app. A) and so feel particularly vulnerable if a cap is suddenly imposed that will cause disruption of their training efforts.

Although they have had access to James Pipai (301 443-2190) and his superior Woodie Kessel, MD, they feel those MCHB officials are playing their cards close to the chest. For a table of organization and other MCHB phone numbers, see app. B.. Thus, they do not know (and would like to know) if they intend to impose a cap, and if so at what level, and with what, if any, phase in time since they have had \$2 million in training funds since 1965 and it funds a big chunk of their regular staff and training stipends, and in turn permits them to send out professionals to the rest of the country that are regarded as some of the top-flight cross-disciplinary trained leaders.

Although the details of their recompetition for funds have not been released yet, they think it will be on a very fast track (Jan. solicitation of proposals, April deadline for submission, and July award).

Before I had this meeting, you asked me to get a memo from MCHB with their synopsis of the issue. I gave you a copy of that memo along with Gary's letter to you (but unfortunately did not make a copy for my files). If I recall the main point of Pipai's memo to me, it was that they planned to convene some type of advisory group in late November on this process.

We could find out more about that group and that process to see that it was appropriately sensitive to giving fair lead time and

avoiding any undue disruption of long-settled and effective training arrangements. Please advise.

I should add that I did nothing to raise Gary Goldstein's expectations that we could do anything if the process was fair, equitable and open.

However, this program, Little Rock, Memphis, Birmingham, Seattle and some of the other large programs could face very harsh consequences if new funding arrangements are suddenly sprung on them.

One final item Gary wanted me to share with you. Kennedy Krieger is thinking of developing a very ambitious multi-service program for the kids, non-disabled as well as disabled, in their very low-income immediate neighborhood, including their running a public school(s) on a contract basis. It all sounded very exciting. They are casting about for any source of federal funds -- research, capital or operating. They know they are sailing upstream, (and I underscored that point), but think they would fit very well with Administration priorities. Would you or Bill Galston have any ideas to offer them since teenage pregnancy prevention, violence prevention, strengthening families, etc are all part of their vision for this program?

NOV - 8 1994



## Kennedy Krieger Institute

November 1, 1994

*A comprehensive  
resource for children  
with disabilities*

Gary W. Goldstein, M.D.

President

Ms. Carol Rasco  
Domestic Policy Advisor  
The White House  
West Wing, 2nd Floor  
Washington, DC 20500

Dear Carol,

I hope to meet with you in the near future to discuss proposed changes in the mechanism of funding University Affiliated Programs by the Maternal and Child Health Bureau. The bureau has provided a substantial base of funding to the Kennedy Krieger Institute for the past twenty-five years in the form of an institutional award that supports our faculty and trainees. The Institute is the largest of thirty such training programs in the country and has consistently provided both extensive services and training opportunities for professionals in the field of developmental disabilities.

Last month Dr. Audrey Nora, Medical Director of the MCH Bureau, announced that the award process will change and will consist of an open competition for programs throughout the country. In addition, they stated that a decision has not yet been made about whether to place a financial cap on individual awards. A grant deadline of April 1, 1995 is anticipated and a decision about a financial cap will probably be made before that date.

The MCH Bureau grant to the Kennedy Krieger Institute is an extremely important financial base that allows our programs to succeed and grow. We now have an annual operating budget that exceeds \$60 million in services, training and research effort. The MCH award of \$1.7 million provides the basis for our success in obtaining additional funding which is translated into important services not only for our region but the rest of the country. My concern is that if the Bureau decides to place a cap on these awards, it is likely to be substantially less than our current funding. This would have an extremely detrimental effect on our ability to sustain and grow our services and training programs. I have no problem with open competition but am concerned about political pressures to have additional programs in the absence of enhanced funding to the MCH Bureau.

I would very much like to get together to discuss these issues before a final decision is made by MCH Bureau concerning financial caps on awards.

Sincerely,

Gary W. Goldstein, M.D.

GWG:kah

App. A

T. JACKSON  
 CASJRNMBNEDVBEFY9KALC.WKJ

**MEMBERSHIP DUES  
 CALCULATION TABLES  
 FY 1995**

		ADD CORE	ADD TRAINING INITIATIVE	ADD FRNS	MCH CORE	MCH SPRANS
<b><u>FULL UAP MEMBERS</u></b>						
1	BIRMINGHAM	AL			710,960	
2	ANCHORAGE	AK				
3	FLAGSTAFF	AZ				
4	LITTLE ROCK	AR			400,000	
5	LOS ANGELES (ucla)	CA			430,833	
6	LOS ANGELES	CA			658,561	
7	DENVER	CO				
8	SOUTH WINDSOR	CT				
9	NEWARK	DE				
10	WASHINGTON	DC			598,392	
11	MIAMI	FL			693,127	
12	ATHENS	GA				
13	HONOLULU	HI			400,000	
14	MOSCOW	ID				
15	CHICAGO	IL				
16	BLOOMINGTON	IN				
17	INDIANAPOLIS	IN			542,628	90,723
18	IOWA CITY	IA			400,000	
19	PARSONS	KS			565,087	
20	LEXINGTON	KY			397,270	
21	NEW ORLEANS	LA				
22	ORONO	ME				
23	BALTIMORE	MD			1,728,586	
24	BOSTON	MA			579,793	
25	WALTHAM	MA			701,716	
26	DETROIT	MI				
27	MINNEAPOLIS	MN				
28	HATTIESBURG	MS				
29	KANSAS CITY	MO				
30	MISSOULA	MT				
31	OMAHA	NE			406,600	
32	RENO	NV				
33	DURHAM	NH			400,000	
34	PISCATAWAY	NJ				
35	ALBUQUERQUE	NM			400,000	
36	BRONX	NY			585,399	
37	NEW YORK	NY				
38	ROCHESTER	NY			400,000	
39	VALHALLA	NY			473,600	90,669
40	CHAPEL HILL	NC			650,036	
41	MINOT	ND				
42	CINCINNATI	OH			621,765	
43	COLUMBUS	OH			989,836	
44	OKLAHOMA CITY	OK				
45	EUGENE	OR				
46	PORTLAND	OR			687,171	127,000
47	PACIFIC BASIN	HI				
48	PHILADELPHIA (at)	PA			400,000	
49	PHILADELPHIA	PA				
50	SAN JUAN	PR				
51	PROVIDENCE	RI				
52	COLUMBIA	SC				
53	VERMILLION	SD			416,000	
54	MEMPHIS	TN			913,669	
55	AUSTIN	TX				
56	LOGAN	UT				
57	BURLINGTON	VT				
58	RICHMOND	VA				

59	SEATTLE	WA		907,382	142,139
80	MOROANTOWN	WV		416,000	
81	MADISON	WI		559,834	
SUB-TOTAL				18,034,345	450,531

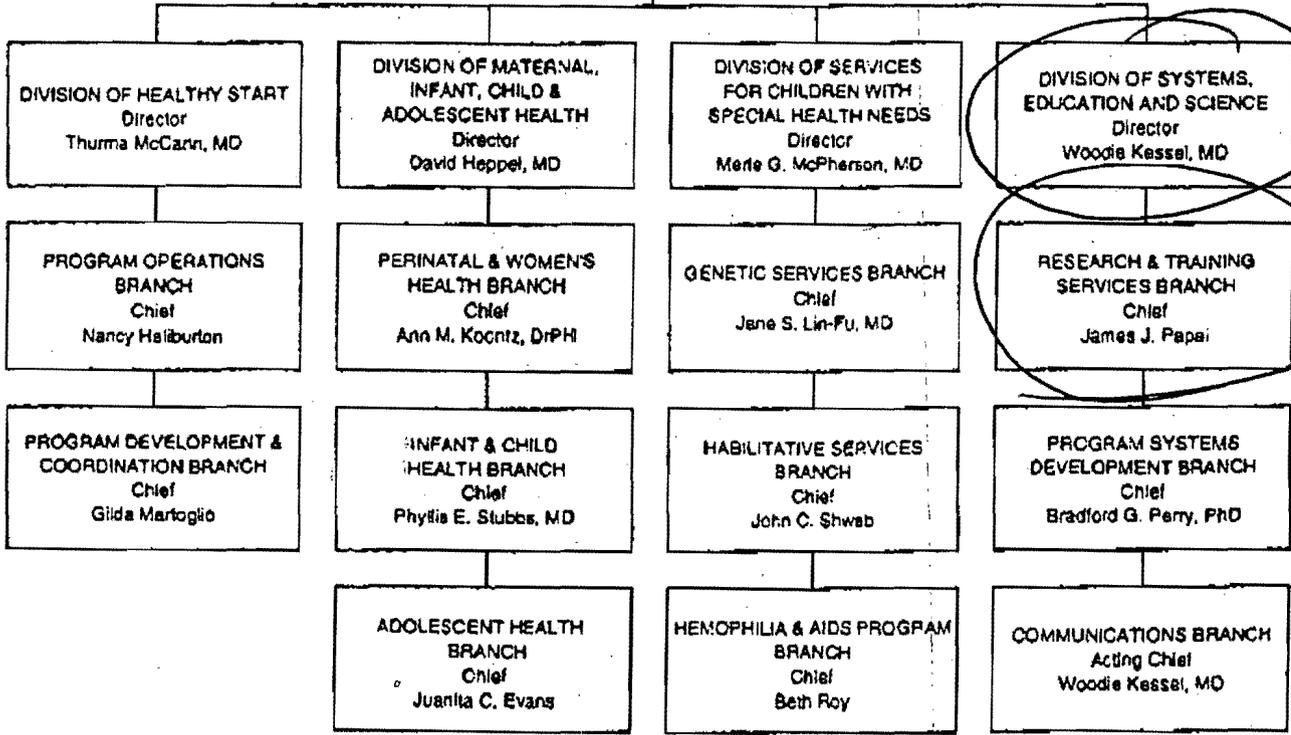
**MATERNAL AND CHILD HEALTH BUREAU**

Health Resources & Services Admin  
 Administrator

OFFICE OF PROGRAM SUPPORT  
 Director  
 Eamon M. Magee

OFFICE OF THE DIRECTOR  
 DIRECTOR  
 Audrey H. Nora, MD, MPH  
 Acting Deputy Director  
 Florence Fiori, DrPH

CIRO V. SUMAYA,  
 M.D., MPHTM



**MATERNAL AND CHILD HEALTH BUREAU**  
 5600 Fishers Lane  
 Rockville, Maryland 20857  
 Area Code (301)

Audrey H. Nora, M.D., M.P.H.	Room 18-05	443-2170
Florence Fiori, Dr.P.H.	Room 18-05	443-2170
Eamon M. Magee	Room 18-05	443-9657
Carol Galaty	Room 18-20	443-2778
Woodie Kessel, M.D.	Room 18A-55	443-2340
James J. Papai	Room 18A-55	443-2190
Bradford G. Perry, Ph.D.	Room 18A-55	443-3163
Merle G. McPherson, M.D.	Room 18A-27	443-2350
Jane S. Lin-Fu, M.D.	Room 18A-20	443-1080
John C. Shwab	Room 18A-18	443-2370
Beth Roy	Room 18A-19	443-9051
David Heppel, M.D.	Room 18A-30	443-2250
Ann M. Koontz, Dr.P.H.	Room 18A-38	443-5720
Phyllis E. Stubbs, M.D.	Room 18A-39	443-6600
Juanita C. Evans	Room 18A-39	443-4026
Thurma McCann, M.D.	Room 200 Twinbrook	443-0509
Nancy Haliburton	Room 200 Twinbrook	443-8283
Gilda Martoglio	Room 200 Twinbrook	443-8427

THE WHITE HOUSE  
WASHINGTON

Nancy Van Zant  
Kennedy Krieger Institute  
707 North Broadway  
Baltimore, MD 21205

THE WHITE HOUSE

Carol H. Rasco

Nancy-

Thanks so much  
for forwarding  
the Exceptional

Parent. It's always  
terrific to hear  
from Kennedy Krieger.  
I look at my Kennedy  
wall picture daily!

Carol

3 June 1995



JUN - 2 1995

## Kennedy Krieger Institute

*Nancy Van Zant  
Vice President for  
External Relations*

May 30, 1995

*A comprehensive  
resource for children  
with disabilities*

Ms. Carol Rasco  
The White House  
West Wing, 2nd Floor  
Washington, DC 20050

Dear Carol,

I thought you would like to see this issue of Exceptional Parent with several contributions by Kennedy Krieger staff.

The cover picture is also one of our families.

It is always good to be in touch with you. I hope to see you in the coming months.

Sincerely,

Nancy Van Zant

NVZ:dt

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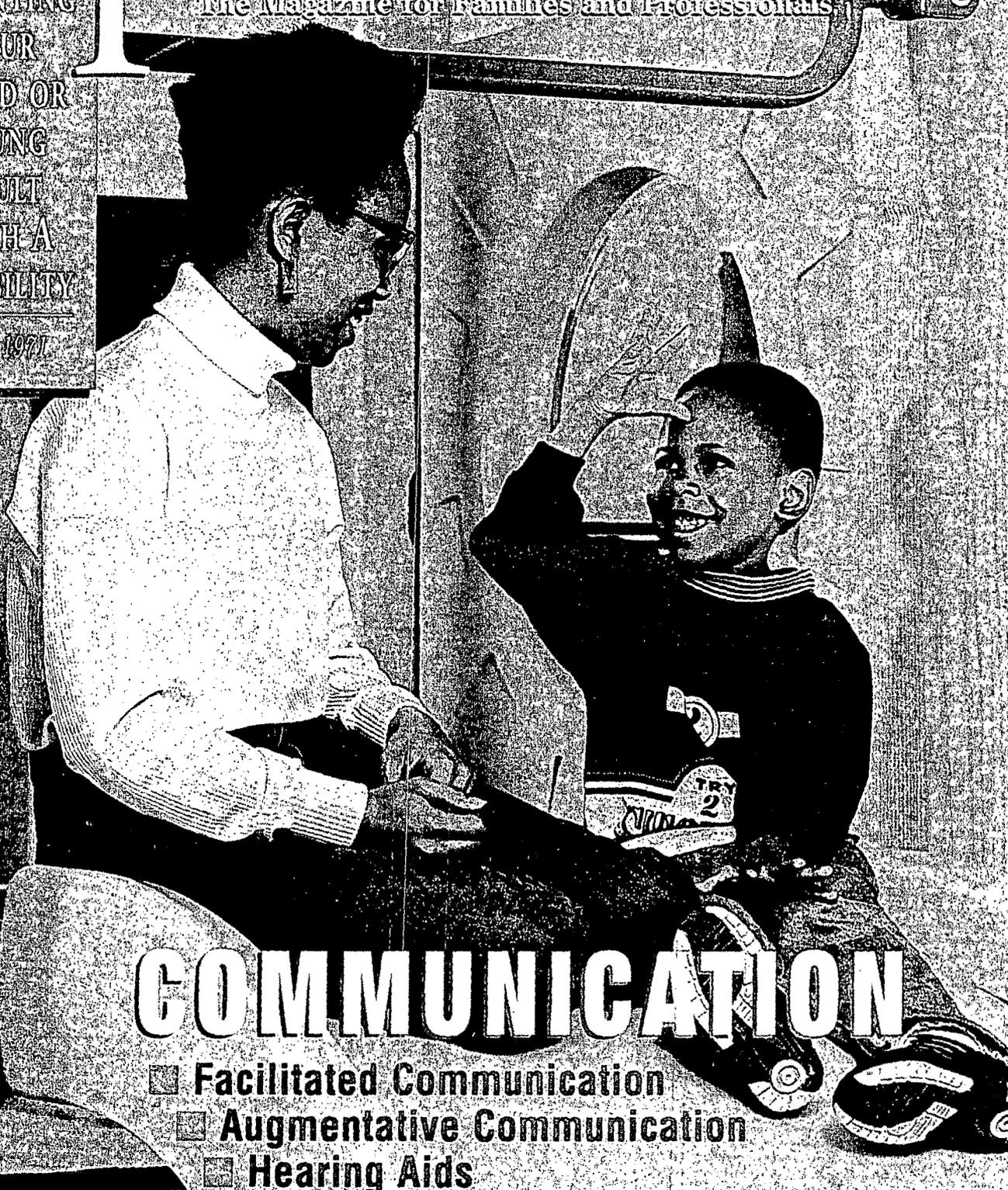
MAY 1995

# EXCEPTIONAL PARENT

The Magazine for Families and Professionals

PARENTING  
YOUR  
CHILD OR  
YOUNG  
ADULT  
WITH A  
DISABILITY

Since 1971



## COMMUNICATION

- Facilitated Communication
- Augmentative Communication
- Hearing Aids
- Using the Telephone

THE WHITE HOUSE  
WASHINGTON

February 16, 1996

Lainey Lebow-Sachs  
Senior Vice-President  
for External Relations  
Kennedy Krieger Institute  
707 North Broadway  
Baltimore, MD 21205

Dear Ms. LeBow-Sachs:

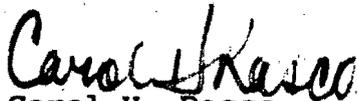
Thank you for your letter. Mrs. Clinton plans to donate all net proceeds after taxes from her book, It Takes a Village: And Other Lessons Children Teach Us to charities that support children and families, specifically children's hospitals. Mrs. Clinton is soliciting advice from the National Association for Children's Hospitals and Related Institutions (NACHRI). NACHRI has developed a criteria for hospitals that wish to be considered.

To find out how to apply for donations, you should feel free to contact Melissa Lee at:

NACHRI  
401 Wythe Road  
Alexandria, VA 22314  
(703)684-1355

Thank you again for your letter. I wish you the best of luck in your new job.

Sincerely,



Carol H. Rasco  
Assistant to the President  
for Domestic Policy



## Kennedy Krieger Institute

January 18, 1996

*A comprehensive  
resource for children  
with disabilities*

Ms. Carol Rasco  
Domestic Policy Advisor  
The White House  
West Wing, 2nd Floor  
Washington, DC 20500

Dear Ms. Rasco,

On January 2, 1996, I joined the staff at the Kennedy Krieger Institute as the Senior Vice President for External Relations. Gary W. Goldstein, M.D., President of the Institute, suggested that I contact you and ask for your assistance.

According to reports in the media about Hillary Clinton's book, "It Takes a Village: And Other Lessons Children Teach Us", Mrs. Clinton plans to donate proceeds from the publication to children's hospitals. The children at Kennedy Krieger would like to be a recipient of the royalties.

Dr. Goldstein told me that you visited the Institute in 1994, and he describes you as a devoted advocate for children with disabilities. Although we have sent a letter to the First Lady requesting that we be considered a recipient, I hope you will support our request by sharing information about Kennedy Krieger with her.

As you know, there are thousands of children nationwide with disorders of the brain who want and deserve the chance to live and thrive in the community. Helping children reach their fullest potential and participate in family, school and community life is the thrust of the Institute's mission. I hope that you will take this message to Mrs. Clinton and become the advocate for the more than 10,000 children that we serve each year.

I have attached a copy of the letter that we sent to the First Lady. If you need additional information, please call me at (410) 550-8338.

Sincerely,

Lainy LeBow-Sachs  
Senior Vice President  
for External Relations

LLS:dt