

Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
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001. letter	Cindy Brownstein to Barbara Woolley re meeting attendees' information (partial) (1 page)	11/25/1998	P6/b(6)
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COLLECTION:

Clinton Presidential Records
First Lady's Office
Neera Tanden (Subject Files)
OA/Box Number: 14313

FOLDER TITLE:

Advocates for Epilepsy (Epilepsy Foundation) [Informational Packet]

2012-0057-S

kc642

RESTRICTION CODES

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

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

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

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

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

"Advocates for Epilepsy"

Epilepsy Foundation

A National Advocacy Project for Epilepsy Research

Advocates for Epilepsy

Epilepsy Foundation

Spring 1998

ROD R. BLAGOJEVICH
5TH DISTRICT ILLINOIS
COMMITTEE ON
NATIONAL SECURITY
COMMITTEE ON
GOVERNMENT REFORM
AND OVERSIGHT

Congress of the United States
House of Representatives
Washington, DC 20515-1305

February 24, 1998

Advocates for Epilepsy
4230 Greenfield Lane
Lake in the Hills, IL 60102

Dear Nancy and Debbie:

I wanted to write and thank you for including me in Advocates For Epilepsy's Town Hall Meeting last month. It was an incredibly informative evening and a model which should be followed in communities across the nation. It was a most effective way to spread your message.

I am grateful for the opportunity to have learned more about epilepsy - both from the medical perspective and from the personal perspective of the family members who told their individual stories.

I am thrilled that you had the opportunity to testify at the Congressional Appropriations Committee the following week. I pledge to do whatever I can to help you to increase funding for research into this devastating condition, and I would encourage all your volunteers to contact their own legislators on this issue.

I look forward to working with you in the future and wish you every success in this important mission.

Sincerely,

Rod R. Blagojevich
Rod R. Blagojevich
Member of Congress

RB/cmd

Town Hall Meeting

Approximately 175 people attended a town hall event in Schaumburg, Illinois in January.

This was a very exciting evening with area legislators and parents. Dr. Michael Chez, and Dr. Michael Smith, Chicago area Epileptologists, presented their viewpoints and information for those officials who were not familiar with epilepsy. David Axelrod Political Consultant, and parent of a child with epilepsy, moderated the event. Barbara Dershin, President of the Epilepsy Foundation of Greater Chicago, spoke to the audience about the campaign steps that were planned for the spring months, encouraging everyone to contact their legis-

lator by mail, phone, or in a personal visit. Nancy Monica and Debbie Flader who Co-Chair AFE spoke briefly of their personal stories on how they got involved with AFE. Parents had the opportunity to speak directly to the legislators about how epilepsy affects their lives. Thank you to all who attended, and a special thanks to those who shared their stories.

For more information on how to set up your own town hall event, contact Nancy Monica at (847) 669-1260.

Parents had the opportunity to speak directly to the legislators about how epilepsy affects their lives.

Visit us at the Olivia Waddell Website at <http://www.datasync.com/~josw/epilepsy.htm>

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**EPILEPSY
FOUNDATION**

212 456 2818
Neera Tandem
[001]

NATIONAL OFFICE4351 GARDEN CITY DRIVE
LANDOVER, MD 20785-2267

November 25, 1998

Barbara Woolley, Associate Director
Office of Public Liaison
The White House
via fax - 202-456-6218

Dear Ms. Woolley:

I am providing the following Social Security numbers, birth dates, and affiliations of the five individuals who will participate in the epilepsy meeting with the First Lady's staff.

Cindy Brownstein

Interim Chief Executive Officer, Epilepsy Foundation

P6/(b)(6)

P6/(b)(6)

Alexandra K. Finucane, Esq.

Vice President for Legal and Government Affairs, Epilepsy Foundation

P6/(b)(6)

P6/(b)(6)

Margaret Ann Scherer

Director of Communications, Epilepsy Foundation

P6/(b)(6)

P6/(b)(6)

Susan Landau AxelrodCo-chair of Advocates for Epilepsy & member of the Epilepsy Foundation of Chicago
Board of Directors

P6/(b)(6)

P6/(b)(6)

Ellen Riker

Marc Associates, representing the National Association of Epilepsy Centers

P6/(b)(6)

P6/(b)(6)

It is our understanding that the meeting is scheduled for Wednesday, December 2nd at 12:00 noon.
Please let us know exactly where the meeting will take place and whether parking is available
and/or if clearance is needed.

If we can provide additional information, please give us a call on Monday.

Sincerely,

Cindy Brownstein
Interim Chief Executive Officer

ADVOCATES FOR EPILEPSY

MISSION

ADVOCATES FOR EPILEPSY (AFE) is a national grassroots effort whose members are dedicated to finding a cure for epilepsy and improving treatment options.

More research is desperately needed to reach this goal. Medical research has resulted in advances in the treatment of seizures but more needs to be done. Over 2.5 million people have epilepsy in the United States. It is not widely understood that approximately 500,000 individuals have intractable or uncontrolled seizures. The economic cost and emotional toll of epilepsy, particularly uncontrolled epilepsy can be devastating.

AFE works to increase epilepsy research funding through government and private sources and is directing its initial campaign to congress for increasing epilepsy funding through the National Institute of Health. AFE is striving to triple research dollars for epilepsy from approximately \$55 million in 1997 to a minimum of \$170 million. AFE has a goal of increasing research by an additional \$75 million for fiscal year 1999, making a total of \$130 million.



Advocates for Epilepsy

Epilepsy Foundation

A National Advocacy Project for Epilepsy Research

June 1, 1998

Ms. Neera Tanden
Associate Director for Domestic Policy
The First Lady's Office
1600 Pennsylvania Avenue, NW
Washington, DC 20502

Dear Ms. Tanden:

It was wonderful to have met you and I appreciate your time, energy and concern.

Epilepsy is a disease about which I knew nothing until my daughter had her first seizures 16 years ago. I am now close to an "expert", though this knowledge has contributed nothing toward helping to stop her recurrent seizures and the subsequent brain damage.

The fact remains that for a sizable population of people with epilepsy, including my daughter, life becomes a day-to-day struggle to survive seizures. And those days are often spent in drug-induced stupors. Under the cloud of five potent anti-convulsant medications which all negatively affect her mental status, Lauren also struggles to simply awaken in the morning and to get through each day with any measure of productivity.

I am so grateful that Mrs. Clinton was moved by my family's story. Her support could be a tremendous boost for people with epilepsy and their families.

We are at an exciting point now--for the first time ever we have political support for increased attention to epilepsy research. If Mrs. Clinton will contact Senator Specter and Representative Porter and express her own interest, this could be of monumental importance. Any input she might have with Dr. Varmus could significantly energize the movement.

I realize you are approached by different 'disease' groups daily. We do not wish to take resources away from any other needy constituency. But, as the chart I left with you indicates, there has been much disparity between the funding for other neurological disorders and the funding for epilepsy at NINDS.

We appreciate anything Mrs. Clinton can do to help close this gap, and to help our children.

Sincerely,

Susan Axelrod
Vice-Chair, Advocates for Epilepsy
8110 Woodside Lane
Burr Ridge, IL 60525
630-887-8781

Debbie Flader, National Co-Chair
2134 Baldwin Court
Hanover Park, IL 60103
(630) 830-1802
Fax: (630) 830-1878
E-mail: schniekes1@aol.com

Nancy Monica, National Co-Chair
4230 Greenfield Lane
Lake in the Hills, IL 60102
(847) 669-1260
Fax: (847) 669-1261
E-mail: snick1@hotmail.com

Susan Axelrod, Vice-Chair
8110 Woodside Lane
Burr Ridge, IL 60525
(630) 887-8781
E-mail: axelrodsm@aol.com

1998 Plan Overview

A minimum goal of AFE is to triple epilepsy research dollars distributed by the NIH (National Institute of Health) through NINDS (National Institute of Neurological Disease and Stroke) which is the primary funder of epilepsy research in the United States. Specifically, AFE is requesting an increase of \$75 million for fiscal year 1999, making a total of \$130 million.

The method for accomplishing this is to influence Congress and Senate specifically to add funding for epilepsy. To do this we have to convince the subcommittees for appropriations to appropriate dollars to meet our request.

Congressman John Porter of Illinois is the chairman of this committee for the House of Representatives. There are 13 Congressmen on the subcommittee, representing various states. These are primary targets to reach our goal. A list is attached.

Senator Arlen Specter chairs the Senate Appropriations Committee. A list of members is attached. These are primary targets as well.

Legislators only respond to people from their specific territories. Volunteer coordinators are being sought for each state.

In 1998 state coordinators will recruit volunteers to work in their state to reach legislators with our story and to make them aware of our common goal.

Training will be provided by AFE, EFA, and your local affiliate.

National Campaign Coordinators:

Debbie Flader (630)830-1802
Fax: (630)830-1878
E-Mail - schniekes1@aol.com

Nancy Monica (847)669-1260
Fax: (847)669-1261
E-Mail - snick1@hotmail.com

For other information:

Barbara Dershin (312)986-3251
Fax: (312)939-0391
E-Mail - barb.dershin@iarf.org

Julie Ward
E-Mail - (IN:WARDJULIE@efa.org)

Subcommittee on Labor, Health and Human Services, and Education

John Edward Porter (IL 10)
115 N. Arlington Heights Rd.
Arlington Heights, IL 60004-3945
(708)392-0303

C.W. Bill Young (FL 10)
801 W. Bay Drive, Room 606
Largo, FL 33770-3249
(813)581-0980

Ernest J. Istook, Jr. (OK 5)
5400 Grand Blvd., Suite 505
Oklahoma City, OK 73112
(405)942-3636

Henry Bonilla (TX 23)
111 East Broadway
Room 101
Del Rio, TX 78840
(210)774-6547

Dan Miller (FL 10)
2424 Manatee Ave., Suite 104
Bradenton, FL 34205
(941)747-9081

Jay Dickey (AR 4)
100 Reserve Suite 201
Hot Springs, AR 71901
(501)623-5800

Roger F. Wicker (MS 1)
8625 Highway 51 North
Southaven, MS 38671
(601)844-5437

Anne M. Northup (KY 3)
Mazzoli Federal Building
600 Martin Luther King Dr., Suite 216
Louisville, KY 40202
(502)582-5129

David R. Obey (WI 7)
317 First St.
Wassau, WI 54401-5498
(715)842-5606

Louis Stokes (OH 11)
3645 Warrenville Center Rd., Suite 24
Shaker Heights, OH 44122
(216)522-4900

Steny H. Hoyer (MD 5)
6500 Cherrywood Lane, Suite 310
Greenbelt, MD 20770
(301)474-0119

Nancy Pelosi (CA 8)
450 Goldengate Ave.
San Fransico, CA 94102-3460
(415)556-4862

Nita M. Lowey (NY 18)
222 Mamaroneck Ave., Suite 310
White Plains, NY 10605
(914)428-1707

Rosa L. DeLauro (CT 3)
One Century Towers
255 Church St.
New Haven, CT 06510
(203)562-3718

CONTACTING YOUR LEGISLATOR

A personal visit with a Member of Congress or U.S. Senator is an effective way to emphasize your interest in advocating for Epilepsy Research. Some steps to follow to urge support are listed below:

- 1.) Identify your local congress person.
- 2.) Call for an appointment, to meet with him/her locally. If the senator or congressman is not available, meet with the legislative aid. State that you would like to meet to discuss the need for increased funding for Epilepsy Research and identify persons who will attend, noting whether they are constituents. (Note - you may meet with a staff member.)
- 3.) Bring the AFE packet supplied to you by your State Coordinator.
- 4.) Present your personal story of "living with epilepsy". Relate the lack of research dollars to your personal story. Display epilepsy graph.
- 5.) Ask your senator/congressman for support in increased funding to epilepsy research by \$75 million in 1998. Ask your senator/congressman how he/she can help.
- 6.) Leave an AFE packet with your senator/congressman. (Take out the report form for yourself.)
- 7.) Follow-up with a thank you letter.
- 8.) At the end of your meeting fill out the report form from the folder and return to AFE.

Here's How I Can Help

----- State Coordinator

----- PR Coordinator / Committee

----- Local Volunteer

----- Letter Writing

Name -----

Address -----

Phone -----

E-Mail -----

ADVOCATES FOR EPILEPSY

Contact Report Form

After your initial visit with your Member of Congress, AFE would like the following feed-back.

1. Specifically, whom did you meet with? (Please include name, address and phone).
2. If you met with a legislative aide, or other staff member, what is the name of the Member of Congress?
3. Please summarize details of your meeting. (Did you find your Member of Congress helpful?)
4. Action plan. Please list any action your Member of Congress has promised to take.

Please send to:
Debbie Flader, 2134 Baldwin Ct., Hanover Park, IL 60103