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The Parkinson's Action Network (PAN) 14th Annual Forum

PRINCIPAL INVESTIGATOR:

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14. ABSTRACT This conference grant supported the Parkinson's Action Network (PAN)'s 14th Annual Research and Education Forum for Parkinson's patients, their families/caretakers and advocates held February 2 to 4, 2008 at the Hyatt Regency on Capital Hill, Washington, DC. This forum brought together some of the foremost doctors and scientists working on Parkinson's research to share their work with patients and leaders in the Parkinson's community. PAN's Research and Education Forum serves as a premier educational program for Parkinson's physicians, patients, researchers as well as leaders in the Parkinson's community. The primary goal of the Forum is to bring together these various stakeholders so that they can share information and learn about the latest developments in Parkinson's research. Through plenary sessions, workshops and networking opportunities, participants will learn about the latest research and discuss creative ideas for new research endeavors. Fundamental to the success of the Forum is the premise that visiting scientists and researchers can learn from each other and from Parkinson's patients and caregivers.					
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Introduction

The Parkinson's Action Network (PAN) held its **14th Annual Research and Education Forum** for Parkinson's patients, their families/caretakers and advocates from February 2 to 4, 2008 at the Hyatt Regency on Capitol Hill Hotel, Washington, DC. The Forum brought together some of the foremost doctors and scientists working on Parkinson's research to share their work with patients and leaders in the Parkinson's community. 300 Parkinson's patients and families/caretakers attended "live". An additional 300 people participated via the live web cast. We anticipate that hundreds more will access all or part of the web cast over the coming months. The web cast is available on PAN's website all year at <http://www.parkinsonsaction.org/2008-Forum-Webcast.html> Last year this feature received more than 2,000 "hits". We expect that number to grow this year as our outreach continues to grow.

Of the 300 participants, eight (8) were physicians, five (5) were researchers, ten (10) were leaders of other Parkinson's disease organizations throughout the country, ten (10) were corporate sponsors from pharmaceutical companies serving the Parkinson's community, and two hundred and sixty-seven (267) were Parkinson's patients and/or caregivers. 60 of the participants in the 2008 Forum were first time participants—this is approximately 20% of the Forum participants.

The U.S. Army's Medical Research and Material Command's grant of \$45,000 helped to support this important research and education program.

PAN's Research and Education Forum serves as a premier educational program for Parkinson's physicians, patients, researchers as well as leaders in the Parkinson's community. The primary goal of the Forum is to bring together these various stakeholders so that they can share information and learn about the latest developments in Parkinson's research. Through plenary sessions, workshops and networking opportunities, participants will learn about the latest research and discuss creative ideas for new research endeavors. Fundamental to the success of the Forum is the premise that visiting scientists and researchers can learn from each other and from Parkinson's patients and caregivers.

Body

This year's forum provided several informative panels including: researchers from several federally funded Parkinson's disease projects; leaders from the Neurotoxin Exposure Treatment Research Program (NETRP); and a panel of doctors and researchers who discussed FDA, Drug Development and the Critical Path.

Program sessions included:

SATURDAY, FEBRUARY 2

8:00 – 9:00 am	Registration Check-in/Continental Breakfast
9:00 – 9:30 am	Welcome & Introduction Amy Comstock Rick, PAN Chief Executive Officer
9:30 – 11:30 am	Breakout 1: Introduction Advocacy Training Session Monica Billger, PAN Director of Outreach
	Breakout 2: Advanced Advocacy Training Mary McGuire Richards, PAN Deputy Chief Executive Officer
11:30 – 11:45 am	Break
11:45 – 1:15 pm	Box Lunch Plenary Session: “Food and Drug Administration (FDA), Drug Development, and the Critical Path” Moderator: Mary McGuire Richards Panel: Janet Woodcock, M.D., Deputy Commissioner, Chief Medical Officer, FDA, Christopher Milne, D.V.M., Assistant Director Tufts Center for the Study of Drug Development, Jeffrey Cossman, M.D., Chief Scientific Officer, The Critical Path Institute, Diane Dorman, Vice President for Public Policy, NORD
1:15 – 1:45 pm	Discussion: Mary McGuire Richards
1:45 – 2:00 pm	Break
2:00 – 3:00 pm	Introduction: Anne Udall, PAN Board of Directors Chair Keynote Speaker: Davis Phinney, Former Olympian and Professional Road Bicycle Racer
3:00 – 3:15 pm	Break (snacks available)
3:15 – 5:00 pm	Plenary Session: Emerging Therapies: Parkinson’s Treatments in the Pipeline Moderator: Dave Heydrick, M.D. Panel: Robert A. Hauser, M.D., M.B.A. Director, Parkinson's Disease & Movement Disorders Center Chair, Clinical Signature Interdisciplinary Program in Neuroscience, University of South Florida, Kent S. Allenby, MD, FACP Vice President, Drug Development, Kyowa Pharmaceutical
6:00 – 6:15 pm	Group Photo
6:15 pm	Cocktail Reception
7:00 – 8:30 pm	Louis Fishman Advocacy Awards Dinner

Keynote Speaker: Greg Simon, President, FasterCures
The Center for Accelerating Medical Solutions
Presentation of Awards: Anne Udall

SUNDAY, FEBRUARY 3

Times Subject To Change

8:00 – 9:00 am

Registration Check-in/Continental Breakfast

9:00 – 10:45 am

**Plenary Session: Federally Funded
Parkinson's Disease Research**

Moderator: Diane DiEuliis, Ph.D. Senior Policy Analyst, Office of Science and Technology Policy Executive Office of the President, Neurodegeneration Program Office, National Institute of Neurological Disorders and Stroke

Panel: Colonel Karl Friedl, U.S. Army Medical Research & Materiel Command's (USAMRMC), William K. Scott Ph.D., Miami Institute for Human Genomics, Caroline M. Tanner, M.D., Ph.D., The Parkinson's Institute

10:45 – 11:15 am

Discussion: Mary McGuire Richards

11:15 am – 11:30

Break

11:30 – 12:30 pm

Box Lunch

Introduction: Anne Udall

Keynote Speaker: Story C. Landis, Ph.D.,
Chair of the National Institutes of Health's
Stem Cell Task Force

12:30 – 12:45 pm

Break

12:45 – 2:45 pm

Plenary Session: Stem Cell Research in the States

Introduction: Amy Comstock Rick
Kim Love, President of Kimberly Love Consulting

2:45 – 3:00 pm

Break (snacks available)

3:00 – 4:15 pm

Advocacy Breakout Sessions

1.) Relationships & PD

~ Michael Church & Gretchen Garie Church

- 2.) Genetics and Parkinson's: "A Personal Story of Resilience and Hope ~ Linda O'Leary
- 3.) Yoga: A Health-Minded Way to Improve Movement & Enjoy a Better Quality of Life ~ Warren Spencer
- 4.) DBS Panel – A Patient's Perspective
~ Carol Meenen, Jackie Hunt Christensen,
Chris Kalhorn, M.D., Assistant Professor of
Neurosurgery at Georgetown University Hospital and
the Director of Movement Disorders Surgery

4:15 -4:30

Break

4:30 – 5:00 pm

**Plenary Sessions: Logistics &
Open Session Q&A**

6:00 pm

OPTIONAL Evening Activity

"Life is for the Living" Stem Cell Research: The
People, The Politics, The Science, The Hope
A documentary by Michael Rubyan

This project was directly relevant to the Department of Defense's Neurotoxin Exposure Treatment Research Program (NETRP) since Parkinson's Disease is a central focus of this program because of the importance of environmental factors, such as exposures to specific toxins, in the disease.

Conclusions

PAN's *14th Annual Research and Education Forum* provided hundreds of Parkinson's patients and their families/caretakers with important information about Parkinson's disease research. Parkinson's physicians, patients, researchers as well as leaders in the Parkinson's community came together for a 3-day program packed with plenary sessions, workshops and networking opportunities.

Appendices

PAN Board of Directors

Anne Udall, Ph.D., Chair/Founding Chair -- North Carolina

Dr. Udall is the Executive Director of The Lee Institute. She is the daughter of the late Representative Mo Udall.

John Rogers, Vice Chair-- Wisconsin

Mr. Rogers is President of Government Affairs for Whyte Hirschboeck Dudek Government Affairs, LLC. Mr. Rogers has been working on behalf of PAN since July of 2000. Mr. Rogers is a founding member of the Coalition for the Advancement of Medical Research (CAMR).

Lois Salisbury, Esq., Treasurer -- California

Ms. Salisbury is a lawyer and is the Director of the Children, Families, and Communities program at the David and Lucile Packard Foundation. Ms. Salisbury is a dedicated advocate on behalf of the Parkinson's community.

Deborah Brooks -- New York

Ms. Brooks joined The Michael J. Fox Foundation for Parkinson's Research in October 2000. Under her leadership, The Michael J. Fox Foundation has become the single largest funder of Parkinson's disease research outside of the U.S. government. Ms. Brooks is a member of the National Advisory Environmental Health Sciences Council of the National Institutes of Health (NIH) and the External Advisory Board for Emory University's Collaborative Center for Parkinson's disease Environmental Research.

Frank Carlucci -- Washington, D.C.

Mr. Carlucci has been a Managing Director of the Carlyle Group since 1989, Chairman since 1993 and Chairman Emeritus since January 2003. Mr. Carlucci was Secretary of Defense from November 1987 through January 1989, following his service as Assistant to the President for National Security Affairs under President Reagan. Before serving in these positions, Mr. Carlucci was Chairman and CEO of Sears World Trade, a business he joined in 1983. Mr. Carlucci preceded his affiliation with Sears World Trade, Inc. with a career in government service, which included Deputy Secretary of Defense (1980-82), Deputy Director of Central Intelligence (1978-80), U.S. Ambassador to Portugal (1975-78), Under Secretary of Health Education and Welfare (1973-75), Deputy Director of OMB (1970-72), and Director of the Office of Economic Opportunity (1969). Mr. Carlucci was a Foreign Service Officer from 1956 to 1980 and he served as an officer in the U.S. Navy from 1952 to 1954. Mr. Carlucci began his service to the PAN board in January 2005.

Robin Anthony Elliott -- New York

Mr. Elliott has been Executive Director of the Parkinson's Disease Foundation, Inc. since October 1996. Active in development, communications and not-for-profit management in New York City for more than 30 years, he has served as vice president for development and external affairs at Teachers College, Columbia University (1988-95) and (with the same title) at Hunter College, City University of New York (1982-88); as deputy to the Chancellor for University Relations at the City University of New York (1979-82); and as director of information and education at the Planned Parenthood Federation of America (1971-79). Mr. Elliott began his service to the PAN Board in March, 1998.

Morton Kondracke -- Washington, D.C.

Mr. Kondracke is the Executive Editor of the Capitol Hill newspaper Roll Call, a columnist, and commentator for the Fox News Channel. He is also the author of *Saving Milly: Love, Politics and Parkinson's Disease*; published in 2001. Mr. Kondracke serves on the Board of the Michael J. Fox Foundation for Parkinson's Research. His wife, Millicent Kondracke, lost her long struggle with Parkinson's disease in July 2004.

Barbara Kupperman -- Washington, D.C.

In addition to serving on PAN's Board, Mrs. Kupperman is also on the Board of Directors for the Institute for Spirituality and Health at George Washington University Medical School. Mrs. Kupperman has been involved in political and non-profit fundraising for over 30 years including her work with Senator Robert Dole, The National Journal, The Center for Strategic and International Studies, the Republican National Committee and the U.S. Committee for the Battle of Normandy Museum. Mrs. Kupperman is originally from Georgia but now resides in Washington, D.C. She was married to the late Robert H. Kupperman, who was diagnosed with Parkinson's disease 15 years ago. Mrs. Kupperman was elected to the PAN Board in July 2005.

Peter Thomas Lansbury, Jr., Ph.D. -- Massachusetts

Dr. Lansbury is a Research Associate in Neurology at the Center for Neurologic Diseases at Brigham and Women's Hospital in Cambridge, Massachusetts. He is also an Associate Professor of Neurology at Harvard Medical School and a Member of the Center for Biomedical Engineering at the Massachusetts Institute of Technology. Dr. Lansbury was named to the PAN Board in May 2004.

Mary Helen "Monnie" Lindsay, J.D. -- Nebraska

Ms. Lindsay has been the Nebraska state coordinator since 2005. She currently serves on the board of the local chapter of the American Parkinson's Disease Association (APDA). Lindsay also is a member of the Parkinson's Disease Working Group of the Collaborative on Health and the Environment and co-authored the Parkinson's community's suggested new definition of Parkinson's disease for the Department of Health and Human Services. She is a former attorney.

Cheryl Lynn Prescott -- Wisconsin

Ms. Prescott has served as a PAN Congressional Coordinator for the 5th Congressional District of Wisconsin since 2004. Her father, George Prescott, the former owner and chief executive officer of Prescott Supermarkets, Inc., announced his diagnosis of Parkinson's disease in 2001. Ms. Prescott is also on the Board of Directors of the Wisconsin Parkinson's Association, an organization of over 7,000 members and 60 support groups. She was elected to the PAN Board in October 2005.

J. Alexander "Andy" Salisbury -- North Carolina

Mr. Salisbury is a lawyer, working extensively with the energy and public utility industries representing electric utilities in state regulatory proceedings. His legal practice includes extensive work with the construction industry. Mr. Salisbury has Parkinson's disease and was named to the PAN Board in May 2004.

Joan I. Samuelson, Esq., Founder -- California

Diagnosed with Parkinson's in 1987, Ms. Samuelson left the practice of law to found the Parkinson's Action Network in 1991. She is a graduate of the University of California at Los Angeles (B.A. Public Service, 1972) and the Boalt Hall School of Law at the University of California at Berkeley (J.D., 1977). In December 1996, Ms. Samuelson was named one of the year's "Legal Eagles" by California Lawyer magazine, defined as one of 30 California lawyers "who made new law, set new policy, continued their exceptional work, or changed the course of national events." Ms. Samuelson also was a recipient of the California Federation of Business and Professional Women's Hall of Fame Award in 1993 and the Boalt Hall School of Law Alumni Association's Distinguished Service Award in 1996. In February 1997, she was honored by the American Society for Neural Transplantation for "outstanding efforts and support for research." Ms. Samuelson was the recipient of Research! America's 2000 advocacy award for "Exceptional Contributions as a Volunteer Advocate for Medical or other Health-Related Research. Ms. Samuelson also received the Parkinson's Institute 15th Anniversary Celebration and Gala Award for Achievement in October 2003.

Nathan Slewett -- Florida

Mr. Slewett is the Chairman of the Board of the National Parkinson's Foundation, Inc. Mr. Slewett was named the 1992-1993 Volunteer of the Year at the National Philanthropy Day Awards Luncheon hosted by the National Society of Fund Raising Executives.

Carol Walton -- New Jersey

Ms. Walton attended a Parkinson's Action Network Public Policy Forum in Washington, DC in 1994 and became an advocate for research. She spent a lot of time walking the halls of Congress - and helped to get the Morris K. Udall Parkinson's Research Act passed in 1997. During that forum she met Margaret

and Martin Tuchman who were also advocates and wanted to raise funds for research. They lived in New Jersey and offered Carol the opportunity to head their foundation. In 1999, Walton moved to New Jersey to start the Parkinson Alliance.

Peggy Willocks -- Tennessee

Ms. Willocks, PAN state coordinator for Tennessee since 2002 has been a leader of local support group for nine years. She initiated a young onset support group with emphasis on the newly diagnosed. Willocks also volunteers for APDA and the Parkinson's Disease Foundation (PDF). Willocks held a career in Public Relations and Education.