

National Institutes of Health
National Institute of Neurological Disorders and Stroke

**REPORT OF THE WORKING GROUP
OF THE NATIONAL ADVISORY
NEUROLOGICAL DISORDERS AND
STROKE (NANDS) COUNCIL:**

**RECOMMENDATIONS FOR THE
UDALL CENTERS OF EXCELLENCE
IN PARKINSON'S DISEASE RESEARCH
PROGRAM**

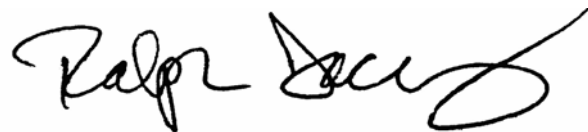
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Letter to NANDS Council from Dr. Ralph Dacey, Jr., MD, Working Group Chair

The Udall Center Program Evaluation Working Group of the National Advisory Neurological Disorders and Stroke (NANDS) Council developed and hereby submits this report on the Morris K. Udall Centers for Excellence in Parkinson's Disease Research Program (Udall Centers Program). This report and its accompanying Data Report (developed by Booz Allen Hamilton) are the results of an evaluation commissioned by the National Institute of Neurological Disorders and Stroke (NINDS) to objectively review the Udall Centers Program. This evaluation began in late 2005, after NINDS commissioned a feasibility study conducted by ORC Macro International. The investment in Parkinson's disease by the National Institutes of Health (NIH), and more specifically, NINDS, has led to further understanding of the disease's pathogenesis and treatment. This report presents recommendations for NINDS to implement in the Udall Centers Program so that the Institute can enhance its strong Parkinson's disease research portfolio.

The Working Group reviewed the evaluation Data Report in order to develop the recommendations in this report. The Working Group found that the Udall Centers Program significantly impacted the Parkinson's disease research field and therefore the NINDS should continue to support this Program. In its continued support of the Program, the Working Group recommends that NINDS establish a coordinating committee that promotes the clinical and translational research by the Centers, and also enhance training opportunities. The Working Group also emphasized the need for NINDS to conduct an ongoing evaluation of the Udall Program by developing metrics to aid in monitoring the Program. As the Parkinson's disease field evolves, it is important for NINDS to support the Centers research and provide guidance on research and collaboration between the Centers and with the external scientific community. As evaluations of this nature are imperative to NIH's management and support of scientific research, the Working Group provided some recommendations on conducting program evaluations based on their experience with this evaluation.



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1.0 Background of the Evaluation of the Udall Centers Program and the Working Group of the NANDS Council

The Evaluation of the Udall Centers Program

In 1997, the United States Congress passed the Morris K. Udall Parkinson's Disease Research Act and, on November 13, 1997, the President of the United States signed the Act into law. Prior to the passage of the Act, the National Institute of Neurological Disorders and Stroke (NINDS) established the Morris K. Udall Centers for Excellence in Parkinson's Disease Research Program. NINDS issued a Request for Applications (RFA) in 1997 and 1998, establishing 11 Udall Centers to conduct Parkinson's disease (PD) research.¹

In late 2003, member of a subcommittee of the National Advisory Neurological Disorders and Stroke (NANDS) Council² expressed interest in receiving information on the progress in PD research and PD knowledge gained by the Udall Centers Program. The Parkinson's Action Network, a non-governmental advocacy group, supported the review of the Udall Centers Program in 2004. One year later, NINDS issued a Request for Quotation (RFQ) for a comprehensive program evaluation of the Udall Centers Program and selected Booz Allen Hamilton (Booz Allen) as the independent contractor to conduct this evaluation.

Booz Allen's study team operationalized the plan set forth in an independent feasibility study³, developed data collection instruments, collected and analyzed data, and prepared the final Data Report⁴. Additionally, Booz Allen coordinated the efforts of the Working Group of the NANDS Council (see below) and facilitated the development of this recommendations report. The scope of the evaluation was the research foci, scientific progress and general activities of the Udall Centers funded through the 1997 and 1998 RFAs during the first five years of the program.

Description of the Udall Centers of Excellence in PD Research

The Udall Centers are located throughout the United States. Though the number and disciplines of the research staff vary by Udall Center, the Centers share similar organizational structures. Each Center has a Center Director – listed as the Principal Investigator on the grant application – who oversees Udall Center operations including administrative functions. The Director may also lead one or more individual research projects within the Udall Center.

¹ Of the 11 Centers that were established from the 1997 and 1998 RFAs, 10 still exist as Udall Centers. In addition to these 10, NINDS established another four Centers, including the Parkinson's disease – Data Organizing Center (PD-DOC).

² The NANDS Council's role is to advise NINDS on policy and procedures affecting its extramural research program and to provide a second level of review for all grant and cooperative agreement applications considered by NINDS. The Director of NINDS may also ask the NANDS Council members to offer expertise on program planning, review aspects of the intramural program, and provide clearance for special initiatives.

³ See Appendix A for the list of study questions developed by the feasibility study. Note that the feasibility study was conducted by Macro International.

⁴ The aggregated report prepared by Booz Allen is referred to as the Data Report. The Working Group reviewed this Data Report to determine their findings and recommendations for their Recommendations Report.

The Centers that received funding from the 1997 and 1998 RFAs typically included three to five projects and three to four cores. The Project/Core Directors (referred to as the Project/Core Leads to avoid confusion with the Center Directors) lead the research projects and cores that comprise the Udall Center. The projects vary in their research focus from basic to translational to clinical studies, both within and across Centers. The cores support the infrastructure of the Center and/or the projects and focus on areas such as training, administration, statistical analysis, or clinical and imaging science. In more recent years, the number of Udall Centers has increased and, as of July 2007, there were fourteen Udall Centers across the United States (including the Parkinson's Disease Data Organizing Center).

The Working Group of the NANDS Council

In 2005, the Director of NINDS, Dr. Story Landis, appointed individuals to a panel, organizing a Working Group of the NANDS Council.⁵ The Working Group, whose members were external to Booz Allen, guided and informed the evaluation of the Udall Centers Program. The Working Group provided guidance on data collection methods and reviewed the data for the purpose of providing specific recommendations on the Udall Centers Program.

The Working Group first convened via teleconference in 2005 and subsequently participated in several conference calls to discuss the evaluation approach. This group reviewed and made final decisions about the data collection instruments (i.e., the web-based survey and interview questions and protocols); discussed the use of a comparison group; and determined what individual data, besides the aggregated data in the Data Report, they needed to access. During the teleconferences, the Working Group established definitions for relevant terms used throughout the evaluation. These definitions included:

Basic Research	Pure research, without any constraint of practical application.
Translational Research	Applying ideas, insights, and discoveries generated through basic scientific inquiry to interventions, prevention, understanding mechanisms, and/or management of human disease.
Clinical Research	(a) Patient-oriented research. Research conducted with human subjects (or on material of human origin such as tissues, specimens and cognitive phenomena) for which an investigator (or colleague) directly interacts with human subjects. This area of research includes: Mechanisms of human disease Therapeutic interventions Clinical trials Development of new technologies (b) Epidemiologic and behavioral studies (c) Outcomes research and health service research

⁵ See Appendix A for Working Group member biographies, and Appendix C for member Conflict Statements.

Multidisciplinary

Research that brings experts from diverse disciplines, for example, scientists from different specialties (neurology, pediatrics, infectious disease, epidemiology, clinical trials, and a pharmacology) to address collectively a common complex problem.

The Working Group requested and received access to the identifiable data from the surveys and interviews/focus groups; all Working Group members signed confidentiality agreements pertaining to their receipt of these identifiable data.

In June 2007, the Working Group convened an in-person two-day meeting to review the collected data and develop recommendations for the Udall Centers Program. At the commencement of the meeting, Dr. Story Landis encouraged the Working Group to consider recommendations for future program evaluations. The Working Group's recommendations are included in this report.

Involvement of NINDS Staff

No NINDS leadership or staff had access to or reviewed the primary data collected by Booz Allen (with the exception of one Working Group member who was also an intramural researcher at NINDS). NINDS leadership and staff did not review the recommendations presented in this report prior to the report's distribution to the NANDS Council.

2.0 Findings of the Working Group of the NANDS Council

For the reasons listed below, the Working Group believes that NINDS should continue to support the Udall Centers Program.

1. The Udall Centers Program significantly impacted the Parkinson's disease research field.

Upon reviewing the Data Report, and examining the primary data collected by Booz Allen, the Working Group determined that the Udall Centers Program added value to the Parkinson's disease research field and increased visibility for Parkinson's disease.

2. The selection of applications with a range of investigator backgrounds was a strength of the process.

Upon review of the Udall Centers, the Working Group determined that the range of previous Parkinson's disease research experience did not appear to determine later levels of success. The Working Group noted that, while some Center Directors had not received funding for Parkinson's disease research from the NIH in the years preceding the Udall Center grant, the scientific output from these Centers included important research discoveries and significant scholarly publications.⁶ The Working Group concluded that the work of these Centers did contribute to the field of Parkinson's disease and believe that, when selecting applications, a range of investigator backgrounds should continue to be emphasized by the reviewers and no requirement of prior Parkinson's disease research experience should be imposed.

3. Substantial research training occurred throughout the Udall Centers.

Throughout the first five years of the Udall Centers Program, the Working Group saw evidence of a robust and substantive research training program. Udall Centers provided research training support to more than 100 individual trainees and ten of the 11 Centers reported an increase in the number of seminars, journal clubs and brainstorming workshops offered to research trainees.⁷ Overall, Udall Center Investigators who commented on the impact of Udall Center structure on trainee programs felt that the Udall Centers Program helped them attract more trainees, expose more young scientists to Parkinson's disease research, and develop more independent investigators in the field.

4. The Udall Centers engaged in multidisciplinary research.

The Working Group noted that, when it came to multidisciplinary research, Udall Center Investigators engaged in this form of collaboration and valued this approach to their scientific research. Udall Center Investigators collaborated by sharing materials – such as reagents, tissues, and animal models – and by collaborating on publications.⁸ Additionally, the Working Group noted that Udall Center Investigators engaged in multidisciplinary research within their

⁶ See Appendix D for further information on the past Parkinson's disease research experience of the Center Directors.

⁷ See Appendix E for further information on trainee numbers by Udall Center and research training activities.

⁸ See Appendix F for further information on Udall Center Investigators' collaborations.

Centers, with other Centers, and with non-Udall Parkinson's disease Investigators. The Working Group recognized that this was an activity recommended by NINDS and found that the Udall Centers successfully embraced this recommendation through several pathways.

5. The Annual Udall Center Meeting was beneficial for Udall Investigators.

The Working Group considered the Annual Udall Center Meeting to be a significant and beneficial activity for the Udall Center Investigators, as the majority of Udall Center Investigators found the annual meetings to be effective in helping them to reach their research goals and facilitate collaboration.⁹ Additionally, Udall Center Investigators commented that the annual meetings were helpful in exposing them to new areas of research and new discoveries, which in turn made them invaluable learning experiences. The Working Group also concluded that the participation of Non-Governmental Organizations is a positive aspect of the annual meetings.

6. NINDS Staff provided good support to the Udall Investigators.

The Working Group found that NINDS Staff provided excellent support to the Udall Investigators throughout the first five years of the Udall Centers Program. Udall Center Investigators who elaborated on their interactions with NINDS Staff praised them for their helpfulness, responsiveness and quality of advice. Additionally, when asked if NINDS Staff could improve the assistance it provides, the majority of Udall Center Investigators indicated that it needed no improvement.¹⁰ The Working Group concluded that, overall, NINDS provided consistent and sound support to the Udall Center Investigators.

⁹ See Appendix G for further information on the Udall Center Investigators' comments on the Annual Meeting.

¹⁰ See Appendix H for further information on Udall Investigators' responses about NINDS Staff improving the assistance it provides.

3.0 Udall Centers Program Recommendations

Prior to developing the recommendations for the Udall Centers Program, the Working Group stated its vision for the Udall Centers Program:

The primary goal of the Udall Centers Program is to develop new clinical treatments for Parkinson's disease. In an ideal world, the effort of the Udall Centers would be devoted entirely to translating existing knowledge about the biology of Parkinson's disease to clinical treatments. However, existing knowledge about the causes of Parkinson's disease limits the goal of developing clinical treatments because of a paucity of targets from basic science that are suitable for translational and clinical development. Therefore, it is recognized that basic science is currently a key component of the overall effort to develop clinical treatments. Nevertheless, particular emphasis should be placed on putting in place infrastructure and organization within the Centers to facilitate a rapid and vigorous translational process whenever an opportunity arises.

The Working Group recommends:

1. Develop a Coordinating Committee.

The WG recommends developing a Coordinating Committee that will provide input to Center Directors and NINDS toward achieving the goals of Udall Centers Program. The Coordinating Committee could consider promoting clinical and translational research, collaboration activities and training opportunities. The coordinating committee would be charged to promote collaboration and communication across Udall Centers, not within Centers.

Composition

- **Diverse scientific membership from the Parkinson's disease field** - These experts should be unaffiliated with NINDS and the Working Group recommends considering Parkinson's disease experts from the Department of Defense to be part of the Coordinating Committee.
- **Center Directors** - Cooperation from Center Directors will be central to moving the Udall Centers Program closer to its goals and, therefore, the Center Directors should be members of the Coordinating Committee (with the understanding that for some issues they will be conflicted out of the discussion).
- **NGO Representation** - In this role, Non-Governmental Organizations can help support new projects and potentially provide funding when there are gaps. While the involvement of NGOs may pose conflicts of interest in some cases, their participation in a number of the Coordinating Committee's activities would be helpful.

Responsibilities

- Promote cooperation and collaboration among the Centers and develop activities that promote these concepts.

- Promote translation of basic science findings into clinical applications.
- Promote training of future Parkinson's disease investigators.

Additionally, the Coordinating Committee should be involved in developing the language of the funding announcements (e.g., the committee could be responsible for ensuring the research emphasis within the funding announcement is compatible with current scientific trends and progress). The Working Group also determined that a report from the Coordinating Committee should be included in the annual report from NINDS to the Congress on the status of Parkinson's disease research.

2. Utilize an RFA as the funding mechanism for the Udall Centers Program.

The Working Group recommends returning to the use of an RFA as the funding mechanism for the Udall Centers. In so doing, all applications for the Udall Centers Program will be submitted at the same time and this will allow for NINDS to view and evaluate the portfolio of potential Udall Centers as a whole. Additionally, the Working Group believes that NINDS should require a "Letter of Intent" to be submitted by the applicants prior to submission of the full application. NINDS Program Staff should respond to the letters of intent in an effort to promote timely feedback about the appropriateness of the proposed Center application and to improve communication between NINDS and applicants. Overall this will help NINDS to maintain the overall objectives of the Udall Centers Program and to keep the Program well-balanced.

In terms of the content of the RFA, the Working Group recommends that the wording should allow for researchers to pursue unexpected scientific discoveries and paths, as they arise. Additionally, the RFA should emphasize, if not require, that applicants should indicate his/her experience in management. This should include activities such as Department chair, Principal Investigator on a program project grant, director of a research group and/or professional organization, or coordinator of educational activities (particularly as a mentor of junior scientists). If applicants are explicit about management experience in their applications, study section members can focus on this issue during the review.

3. Improve the review process for Udall Center applications.

The Working Group believes that the review process must take into account the unique elements of the Udall Centers Program and the RFA in reviewing applications. To achieve this, the Working Group recommends NINDS:

- **Assess the responsiveness to the RFA** - NINDS program staff should review all applications received in response to the RFA to determine if they are responsive to the requirements and intent of the RFA, and if they have proposed an appropriate administrative structure. Any applications that are not responsive to the RFA should be returned to the applicant and not sent to the peer review committee.
- **Develop a separate study section** - NINDS should attempt to establish a repeating and consistent group of reviewers for the study section. The Working Group believes that a core group of reviewers that know the history and the evolution of the Udall Centers

Program would benefit the Program for the future. Additionally, consultants to Udall Centers should not serve as reviewers for the Center, or for other Centers competing in the same round of applications, and special care should be taken to avoid all conflicts of interest.

- **Accelerate review and funding timeframes** - NINDS should strive to review all applications and distribute funding to the successful applicants within six months.

4. Develop measures to monitor the progress of Udall Centers.

The Working Group recommends that NINDS develop specific metrics and measures by which to review the activities and scientific progress of the Udall Centers. To achieve this, NINDS should restructure the Progress Reports that are submitted annually by the Udall Centers. NINDS should develop a template-based Progress Report (for example a PDF that can be completed electronically) for the Udall Centers. In so doing, NINDS will establish future methods and data by which to assess the progress of the Udall Centers. The Progress Reports should specifically track and collect measurements on multiple areas such as:

- **Basic, translational, and clinical research and discoveries/accomplishments** - Udall Center Directors could be asked to report on the status of research projects, findings from the research, invention disclosures/patent applications, and any publications that arose from the research.
- **Outreach and educational efforts** - Udall Center Directors could report on the activities of the Outreach & Education Core, specifically addressing any meetings, classes or other interactions with the Parkinson's disease community.
- **Research trainees and training opportunities** - Udall Center Directors could report the number and names of research trainees, where the trainees went once they left the Udall Center, and any activities developed to further the training of junior scientists.

5. Establish a Center Administrator for each Udall Center.

The Working Group recommends that each Center have an administrator, separate from the Principal Investigator (Center Director) and Udall Center Investigators (Project/Core Directors). Each Center Administrator would be responsible for collecting standardized data from his/her respective Udall Center and the Center Administrators should meet annually to discuss ideas for improving Center management.

6. Improve the Annual Udall Center Meeting.

The Annual Meeting is a fundamental part of the Udall Centers Program, and although Udall Investigators found the meeting useful, the Working Group believes it can be enhanced. The Working Group suggests that the Center Directors themselves redesign the Annual Meeting and should consider the following when developing a new program:

- NINDS Staff should work with Center Directors to improve the efficiency and meaningfulness of the Annual Meeting so that it promotes the overall goals of the Udall Centers Program.
- Meeting content should be revised to address particular themes or to focus on fewer, but particularly promising, current research projects and/or discoveries.
- Junior investigators should be part of the Annual Meetings and should be encouraged, if not required, to present their scientific research and findings.
- The Annual Meeting should take place at Udall Centers, not at independent venues, and the location of the meeting should rotate each year.
- The participation of NGOs was seen as a positive aspect of the meeting.

7. Continue to develop and improve research training opportunities.

While the Working Group noted the development of many training opportunities within the Centers, the Working Group felt this could be enhanced. The Working Group recommends that NINDS:

- **Institute a cross-discipline training program** - The Working Group believes that the training of basic scientists in clinical aspects of Parkinson's disease, as well as the training of clinical scientists in basic research facets of the disease, could potentially be a unique feature of the Udall Centers Program. Each research trainee could have two mentors: one in basic research and one in clinical research.
- **Develop a Udall Center fellowship** - NINDS should develop a fellowship that will allow research trainees to travel to several Udall Centers and, thereby, receive a range of mentorship. This fellowship could promote and support the cross-discipline training program.
- **Emphasize translational research training opportunities** - NINDS should promote the development of translational research trainees by establishing incentives (e.g., Udall Centers that introduce MD-trainees to Parkinson's disease research could receive an additional \$100,000 in annual funding).

8. Continue to support and monitor the scientific outputs and the research foci of established Udall Centers.

The Working Group believes that NINDS should continue to support the Udall Centers Program, although there was variability in the scientific output of the centers based on the publication data. The Working Group noted that some Udall Centers are not performing as well as others and recommends that NINDS Staff review the work of the Udall Center Investigators on an ongoing basis and, in a timely manner, provide feedback and offer guidance to those Centers that are not meeting a performance standard.

The Working Group also discussed novel ways to increase the scientific output of the Udall Centers. One recommendation that emerged was for NINDS to establish a novel technologies grant, one to two years in duration that would be funded at the level of \$100,000. A second recommendation was to allow for the development and funding of pilot projects. The Working Group recommends that NINDS fund pilot projects up to \$50,000 for 12 months. By developing additional funding mechanisms to support innovative research, NINDS can assist Udall Centers in maximizing the impact of the Udall Center Investigators' research findings.

Additionally, the Working Group believes that the research focus of the Udall Centers should emphasize translational research. However, given the current state of the science, it is important to recognize that the basic research emerging from the Udall Centers generated a sizable amount of scientific output (as measured by scholarly publications) and led to advances in clinical research. NINDS Staff should promote viable translational research opportunities through the Udall Centers (by protecting/furthering the established infrastructure; by providing funding for specific research projects; and considering opportunities for partnership with, for example, the National Center for Research Resources' Clinical and Translational Science Awards program) but should also continue to recognize the value of substantive basic research in furthering the field of Parkinson's disease research.

9. Develop additional opportunities for multidisciplinary collaboration.

To further promote multidisciplinary collaboration, the Working Group recommends that NINDS:

- **Develop cores that serve multiple Udall Centers** - The Coordinating Committee, in collaboration with Udall Center Directors, could be charged to identify the needs of the Udall Centers and opportunities for inter-center cores, so as to promote collaboration.
- **Establish cores that could serve the wider research community** - Promoting collaboration with researchers external to the Udall Centers Program is an important endeavor and the Working Group believes that establishing cores to serve the wider research community should be pursued (to the extent it will not interfere with Udall Center research).
- **Use the Annual Meeting to promote multidisciplinary collaboration** - The Working Group believes that the Annual Meetings provides an important venue for Udall Center Investigators to share unpublished research findings and develop future multidisciplinary research projects.
- **Develop small workshop symposia** - The Working Group recommends developing smaller meetings (20 researchers or less) to provide an opportunity for Udall Center Investigators and non-Udall Parkinson's disease researchers to convene and discuss common discoveries/paths of research.

Additionally, the Working Group noted that Udall Center Investigators seemed unclear on the function of PD-DOC and encourages NINDS to clarify PD-DOC's role, responsibilities and relationship to the Udall Centers.

10. Require an Outreach & Education Core.

The Working Group recommends that each Udall Center develop an Outreach & Education Core – if it does not already contain one – to foster a stronger relationship with the Parkinson's disease community. This will benefit the community, as its members will learn about the Centers' scientific endeavors; simultaneously, it will allow the Centers to increase their understanding of the Parkinson's disease community and more closely link their research to the experiences of the patient.

11. Continue to provide support from NINDS Staff.

The Working Group believes that NINDS Staff has done an excellent job of supporting Udall Center Investigators. The Working Group believes that one way in which NINDS Staff could improve the support it provides is by developing a pre-application meeting to address questions and concerns from potential Udall Center applicants. Additionally, it would be helpful if the NINDS Program Staff who is responsible for overseeing the Udall Centers has both a good understanding of the Program and also runs the Parkinson's disease portfolio. In so doing, the Program Staff can see how the Udall Center Program fits into the larger whole.

4.0 Concluding Statement

The Working Group found that the efforts of the Udall Centers Program have positively impacted the Parkinson's disease research field and that the NINDS Program Staff has done an excellent job in fostering development within the Program. Nonetheless, the Working Group believes that there remain areas that could be improved with the Udall Centers Program, particularly with regard to collaboration among the Centers and making productivity more uniformly high across the Centers. The Working Group also recognizes that bringing translational research to therapeutic ends requires the participation of the pharmaceutical and medical device industries. As the purpose of the Udall Centers is to research and develop potential therapies for Parkinson's disease, the Working Group views nurturing this relationship as an important step in furthering the goals of the Udall Centers Program. Overall, the Working Group found that the Udall Centers Program has been beneficial for the field of Parkinson's disease research and recommends that NINDS continue to support the program.

5.0 Program Evaluation Process Recommendations

In addition to the Udall Centers Program recommendations, the Working Group developed recommendations to help guide NINDS, and the NIH, in conducting program evaluations. The Working Group stated that both NINDS and Booz Allen respected the authority of the Working Group and that it did not feel pressure to make recommendations one way or another. The Working Group explained that their program evaluation recommendations resulted from their experience in this process and they wanted to provide insight for future evaluations on how to develop a comprehensive and successful program evaluation from the beginning.

The Working Group recommends that an Institute conducting an evaluation:

1. **Develop a Working Group of individuals with varying areas of expertise.**

The Working Group members felt that their breadth and diversity was a strength and recommended striving for a range of expertise in future Working Groups. The Working Group recommended including:

- **Subject Matter Experts** - Though not necessary, the Working Group believed it benefited from having subject matter experts involved in the discussion. However, if there are too many subject matter experts, the disease community may think the findings were steered by these members of the group and that the recommendations are not representative of an unbiased evaluation.
- Subject matter experts will be needed to address what the ten most important advances in the field of interest were over the last ten years (see below), but this information can be gathered ahead of time and made available to the Working Group during its deliberations.
- **NGO representative(s)**

2. **Include the Working Group from the very beginning and in subsequent discussions about process and methodology.**

The Working Group recommends that, in future program evaluations, the Working Group should be involved in developing the program evaluation from the very beginning and should be responsible for determining the research questions, measures, data sources and areas of interest. The Working Group also agreed that NGOs, along with the Working Group, should have more input on the design of the evaluation process. Additionally, the Working Group recommends:

- **Develop a formal charge to the Working Group** - The requesting NIH-Institute should develop a formal charge to the Working Group that clearly states the group's role and responsibilities. Additionally, the Working Group recommends that the charge should be appropriately transparent and made available to the public.
- **Hold an initial in-person Working Group Meeting** - The Working Group recommends holding an in-person Working Group meeting at the beginning of the evaluation process

so that members can create a work plan and develop a cohesive and coherent approach to guiding the evaluation. Additionally, this will allow the Working Group members to get to know one another, which will help facilitate discussion in later teleconferences.

- **Identify and address major issues at the initial Working Group Meeting** - At the initial meeting, the Working Group should identify major issues the group will need to address to move the program evaluation forward. Potential issues to consider include:
 - 1) How to select a meaningful and informative comparison group
 - 2) How to measure the success of a Center/Program
 - 3) How to evaluate and measure the value add of a Center Program versus funding individual investigators without a Center
 - 4) How to measure the impact of scientific output
 - 5) How to identify available metrics and determine which should be used
- **Establish the evaluation as an iterative process** - The Working Group should see data, and have a chance to request any missing data, prior to meeting as a group to develop recommendations.
- **Make methodological experts available to the Working Group** - From the beginning, the Working Group should have access to – and should consult with – evaluation methodology experts so that a feasible and informative program evaluation plan is developed.

3. Determine standards for measuring the success of the program.

The Working Group stated measuring success is an important issue and needs to be given critical thought by the Working Group at the very beginning of the evaluation. Additionally, the Working Group stated that the duality inherent to a program evaluation poses challenges for assessment, as the Working Group must consider both the success of a Center and the success, or impact, of the scientific output from the Centers. The Working Group recommends:

- **Consult subject matter experts** - By consulting subject matter experts, the Working Group can determine the current state of the science in the field of interest. These subject matter experts could indicate, for example, what the ten most important advances in the field were over the last ten years. Subsequently, this information can be used by the Working Group to measure the impact of the scientific output from the Program Investigators.
- **Utilize a self-evaluation for the Program Investigators** - The Working Group found it useful to survey Program Investigators on what they believed were their individual top five research discoveries. This information could then be compared to the subject matter experts' responses on the same topic.
- **Evaluate Program Investigators' publications** - The Working Group found Investigators' publications to be a useful tool in measuring and evaluating the scientific

output and success of the Centers. However, consensus surrounding how to evaluate publications does not exist and it is important for the Working Group to determine how it will assess publications (e.g., journal impact factor, ratio of expected citations to actual citation rate, Thomson Scientific percentile ranking).

4. Discuss and establish a meaningful and informative comparison group.

The Working Group felt that one of the more challenging tasks facing the group was the establishment of a meaningful and informative comparison group. The Working Group determined that it would be difficult to develop guidelines or criteria for a single, universal comparison group, as the unique features of each program evaluation will dictate the comparison group appropriate for that evaluation. Additionally, there might be need for multiple comparison groups in the same evaluation to answer different questions. The Working Group encourages future groups to address this issue from the very beginning of the evaluation process and reminds future Working Groups to consider both the advantages and disadvantages to developing multiple comparison groups for different study questions (e.g., the scientific outputs of successful applicants versus unsuccessful applicants, the future funding success of Program Investigators versus non-Program Investigators in the same field).

5. Request access to primary data and confidential information.

The Working Group believed it was important to have access to the primary data collected by the study team and recommends that confidential and sensitive information should be available to the Working Group upon request (e.g., unfunded grant applications, Progress Reports, INDs).

Working Group Members

- Bruce Bean, PhD
- Thomas Bird, MD
- Martha Bohn, PhD
- Don Cleveland, PhD
- Ralph Dacey, Jr., MD (Chair)
- Mark Hallett, MD
- Prisca Marvin, JD
- Richard Moxley, MD
- Harry Orr, PhD
- Creighton Phelps, PhD
- Amy Comstock Rick, Esq.

Appendices

Appendix A: Working Group Member Biographies

Ralph Dacey, Jr., MD (Chair)

*Professor and Chairman, Department of Neurological Surgery
Washington University*

Ralph G. Dacey, Jr., M.D., is the Henry G. and Edith R. Schwartz Professor and chairman of the Department of Neurological Surgery at Washington University School of Medicine in St. Louis, Missouri. He is also neurosurgeon-in-chief at Barnes-Jewish Hospital. He received his bachelor's degree at Harvard University and his medical degree at the University of Virginia. Dr. Dacey is secretary of the American Academy of Neurological Surgery, former chairman of the American Board of Neurological Surgery, and a past president of the Congress of Neurological Surgeons. His many honors include the international Grass Foundation award, which recognizes outstanding and continued contributions to research in neurosurgery.

Bruce Bean, PhD

*Professor of Neurobiology
Harvard Medical School*

Dr. Bean is Professor of Neurobiology at Harvard Medical School, where he does research on the electrical function of neurons in the central nervous system. He has previously held faculty positions at the University of Iowa and the Oregon Health Sciences University. He served on the National Advisory Neurological Disorders and Stroke Council from 2002 to 2006. He currently serves on the editorial boards of *Journal of Neurophysiology*, *Neuron*, and *Journal of General Physiology*. He received a BA from Harvard College and PhD from the University of Rochester.

Thomas Bird, MD

*Professor of Neurology, Medicine and Psychiatry
Head, Division of Neurogenetics
University of Washington School of Medicine*

Dr. Bird is a Professor of Neurology, Medicine and Psychiatry and Head of the Division of Neurogenetics at the University of Washington School of Medicine. Dr. Bird is also a research neurologist at the Geriatrics Research Education and Clinical Center with the VA Puget Sound Health Care System. Dr. Bird is the former Chief of Neurology Service at the Seattle VA Medical Center. Dr. Bird has been awarded the Wartenberg Award from the American Academy of Neurology (1992), the Met Life Alzheimer Research Award (1995), the Jacoby Award from the American Neurological Association (2001), and the Middle ton Research Award from the Department of Veteran Affairs (2005). Dr. Bird received a fellowship in medical genetics and completed his neurology residency at the University of Washington. He received a BA from Dartmouth College and an MD from Cornell University.

Martha Bohn, PhD

Medical Research Institute Council Professor, Department of Pediatrics & Department of Molecular Pharmacology and Biological Chemistry, Feinberg School of Medicine, Northwestern University

Dr. Bohn is the Medical Research Institute Council Professor in the Department of Pediatrics and the Department of Molecular Pharmacology and Biological Chemistry at the Feinberg School of Medicine, Northwestern University. She is Director of the Neurobiology Program at Children's Memorial Research Center (CMRC). Dr. Bohn served as Interim Director of the CMRC from 2001-2003. Dr. Bohn received her AB degree in Chemistry from Cornell University and her PhD degree in Neuroscience from the University of Connecticut in 1979. She has held faculty positions at Cornell Medical College, the State University of New York at Stony Brook, and the University of Rochester Medical Center. Dr. Bohn serves on the editorial boards for *Experimental Neurology*, and *Gene Therapy and Molecular Biology*. She has served as President for the American Society for Neural Transplantation and Repair and President for the Chicago Chapter of the Society for Neuroscience. She has also served on many advisory boards for scientific societies, the National Science Foundation and the National Institutes of Health. She served from 2001—2005 as a member of the NIH Recombinant DNA Advisory Committee that reviews all gene therapy clinical protocols and advises on policy related to the gene therapy field. Dr. Bohn also received an outstanding performance award from the National Science Foundation where she was Program Director for Developmental Neuroscience for two years. Dr. Bohn's research is focused on understanding development of the brain and generating novel therapies for neurodegenerative diseases, such as Parkinson's and Lou Gehrig's diseases. Her research program is supported by grants from the National Institutes of Health, the Chicago Biomedical Consortium, the State of Illinois Regenerative Medicine Institute, the Illinois Excellence in Academic Medicine Program and the Department of Defense. Dr. Bohn has lectured extensively and has published over 100 articles in scientific journals and books. She is also involved in several translational research projects aimed at translating novel gene therapies to the clinic for Parkinson's disease. Dr. Bohn recently established a viral vector translational resource center to facilitate the translation of basic science to the clinic in the field of gene therapies for neurodegenerative diseases and injuries to the nervous system.

Don Cleveland, PhD

Professor of Medicine, Neuroscience and Cellular and Molecular Medicine, University of California of San Diego

Dr. Cleveland is a Professor of Medicine at the Ludwig Institute for Cancer Research at the University of California of San Diego. Dr. Cleveland's research laboratory is focused on two general areas: 1) how spindles are assembled and chromosomes faithfully moved into each daughter cell just prior to division, and 2) the molecular genetics of axonal growth and mechanisms of human motor neurons disease, especially the disease familiarly known as Lou Gehrig's disease, or ALS. Dr. Cleveland received his Ph.D. from Princeton in 1977 and completed his postdoctoral fellowship at the University of California, San Francisco. He later joined the faculty at Johns Hopkins University School of Medicine where he was a Professor in the Department of Biological Chemistry. In 1995, Cleveland joined the University of California,

San Diego (UCSD), School of Medicine. Dr. Cleveland has received several awards and honors including election to both the National Academy of Sciences and the American Academy of Arts and Sciences in 2006. He has been the editor of the *Journal of Cell Biology* since 1999.

Mark Hallett, MD

*Chief, Human Motor Control Section,
National Institute of Neurological Disorders and Stroke, NIH*

Dr. Hallett is Chief of the Human Motor Control Section, NINDS, NIH, where he does research on the physiology of human movement and the pathophysiology of movement disorders. The work in the Laboratory currently includes studies on focal dystonias, Tourette's syndrome, Parkinson's disease, and psychogenic movement disorders. He is currently Editor-in-Chief of *Clinical Neurophysiology* and is one of the Associate Editors of *Brain*. He is past President of the American Association of Neuromuscular and Electrodiagnostic Medicine and the Movement Disorder Society, and past vice-president of the American Academy of Neurology. Dr. Hallett obtained his M.D. at Harvard University and trained in Neurology at Massachusetts General Hospital. He had fellowships in Neurophysiology at the National Institutes of Health and at the Institute of Psychiatry in London. From 1976 to 1984, Dr. Hallett was the Chief of the Clinical Neurophysiology Laboratory at the Brigham and Women's Hospital and Associate Professor of Neurology at Harvard Medical School. From 1984, he has been at the National Institute of Neurological Disorders and Stroke where he also served as Clinical Director of NINDS until July 2000.

Prisca Marvin, JD

Prisca Chen Marvin, J.D., is a past Chairman of the Board of Trustees of the National Alliance for Autism Research (NAAR), a nonprofit advocacy group dedicated to funding and accelerating biomedical research focusing on autism spectrum disorders. In 2006, NAAR merged with Autism Speaks. She is a 1988 graduate of the Georgetown University Law Center and received her undergraduate degree in chemical engineering from the Massachusetts Institute of Technology. A registered patent attorney with specialization in chemical patents, Ms. Marvin was an associate with firms in Wilmington, Delaware, and Washington, DC. She is a member of the American Institute of Chemical Engineers and the American Intellectual Property Law Association. She is a member of the Delaware Bar, the District of Columbia Bar and the United States Supreme Court. She is the mother of a teenage daughter with autism and an Associate of the Yale Child Study Center at Yale University. Ms. Marvin is also an Advisory Board Member of REACH at the University of Iowa.

Richard Moxley, MD

*Professor of Neurology and Pediatrics, Division of Medicine
Director of Neuromuscular Disease Center
University of Rochester School of Medicine & Strong Memorial Hospital*

Dr. Moxley currently directs the Wellstone Center at the University of Rochester. He is a Professor of Neurology and Pediatrics in the Division of Medicine at the University of Rochester School of Medicine. He is also the Director of the Neuromuscular Disease Center at Strong

Memorial Hospital. Dr. Moxley received his B.A. from Harvard University in 1962. He then completed his M.D. from the University of Pennsylvania in 1966. He completed an Internship at Pennsylvania Hospital, Residency in Neurology at Harvard Medical Center, and a Fellowship in Medicine from Johns Hopkins University. His clinical disease specialties are neuromuscular disorder and child neurology. He is the co-leader of Clinical Measures of Disease Manifestations section of the ENMC International Working Group on Myotonic Dystrophy and PROMM and other Proximal Myotonic Syndromes. He also serves as Chairman on the Committee to Establish Duchenne Dystrophy Practice Parameters, and was a NIAMS Advisory Council member from January 2002 through September 2005.

Harry T. Orr, PhD

*The Edmond Wallace and Anna Marie Tulloch Professor in Genetics
Director, Institute of Human Genetics
Director, Institute of Translational Neuroscience
University of Minnesota Medical School*

Dr. Orr is a Professor in the Department of Laboratory Medicine and Pathology, and the Department of Biochemistry, University of Minnesota Medical School, Minneapolis, MN. Dr. Orr received his BS in Biology from Oakland University, Rochester, Michigan and a PhD in Neurobiology from Washington University. After a Postdoctoral Fellowship at Harvard University, Dr. Orr joined the faculty of the University of Minnesota in 1980. Dr. Orr has served on many NIH grant review panels including chair of the Mammalian Genetics Study section, 1999-2000. He served on research advisory panels for the Huntington Disease Society of America, The National Ataxia Foundation, The ALS Association, and the Dystonia Association. Dr. Orr was awarded a NIH Javits Investigator Award, NINDS (2004), the Milton Wexler Award for Research in Huntington's Disease, Huntington Disease Society of America (1999), a NIH MERIT Award, National Institute of Arthritis and Infectious Disease, (1995), the Kilby International Award-Scientific Excellence, Kilby Awards Foundation Dallas, TX (1995), the Weil Award in Neuropathology, Society for Neuropathology and Experimental Neurology (1992), a Young Investigator Award, American Society for Histocompatibility & Immunogenetics (1985), a Scholar Award from the Leukemia Society of America (1993), and a Scholar Award, from the Searle Foundation (1981). Dr. has served on the editorial boards of the American Journal of Human Genetics, Human Molecular Genetics, Experimental Neurology, PLoS Genetics, the Journal of Neuroscience, and The Journal of Clinical Investigation. His research program is now focused on understanding the pathogenesis of the neurodegenerative disease spinocerebellar ataxia type 1 (SCA1). This work spanned the range from cloning the SCA1 gene, to developing animal models of human disease, and is now directed at the identification of targets for potential therapies.

Creighton Phelps, PhD

*Director, Alzheimer's Disease Centers Program
National Institute on Aging, NIH*

Dr. Phelps received his Ph.D. in Neuroanatomy from the University of Michigan and after post-doctoral training at University College London was a faculty member at the University of Connecticut Health Center in Farmington, Connecticut and subsequently, Wright State

University School of Medicine in Dayton, Ohio. In 1985, Dr. Phelps joined the staff of the National Institute on Aging (NIA) where he was program director for neurobiology and neuroplasticity. In 1989 he joined the national office of the Alzheimer's Association in Chicago as Senior Vice President for Medical and Scientific Affairs. In 1992 Dr. Phelps returned to the NIA where he directs the Alzheimer's Disease Centers Program which funds research centers at 29 major U.S. Medical Schools and he is the project officer for the National Alzheimer's Coordinating Center (NACC) and the National Cell Repository for Alzheimer's Disease (NCRAD).

Amy Comstock Rick, JD

Chief Executive Officer, Parkinson's Action Network

Mrs. Rick is the chief executive officer of Parkinson's Action Network. Before joining PAN in 2003, she served as the sixth Director of the U.S. Office of Government Ethics, having accepted the nomination to the Senate-confirmed position in 1999. Prior to her appointment to the Office of Government Ethics, Mrs. Rick was Associate Counsel to the President in the White House Counsel's Office. Mrs. Rick began her federal service as an attorney at the U.S. Department of Education in 1988; she ended her tenure there in 1998 as Assistant General Counsel for Ethics. Mrs. Rick began her professional career at the law firm of Beveridge & Diamond. She received a Bachelor of Arts degree from Bard College and a Juris Doctor degree from the University of Michigan.

Appendix B: Study Questions

Study Question 1 – How were the initial 11 Udall Centers selected?

- Which components of the Udall PD Research Act of 1997 were included in the 1997 and 1998 RFAs issued by NINDS for specialized Centers of Excellence for PD research (later called Udall Centers)?
- To what extent were the grant applications received by NINDS (and those that were successful) responsive to the RFA?
- What role did NINDS program staff play in serving as a resource during the application process?
- In what ways could the process for selecting Udall Centers be improved?

Study Question 2 – How did NINDS administer the Udall Centers Program from FY 1998 – 2003?

- What level of NIH resources (funding and staff support) was allocated to the Udall Centers Program?
- To what extent did NINDS staff facilitate collaboration among Udall Center investigators?
- To what extent did NINDS staff find ways to meet the evolving scientific and resource needs of the Centers and address emerging priorities relevant to the Centers' research programs?
- Did all of the Udall Center awardees submit a competing continuation application five years later? If not, why not?
- In what ways could the administration of the Udall Centers Program be improved in the future?

Study Question 3 – What were the baseline characteristics of the individual Udall Centers prior to the start of the program (FY 1996 – 1998) in each of the following areas:

- Overall research experience of the institution, Center Director, and Project/Core Directors
- Previous PD research experience of the institution, Center Director, and Project/Core Directors
- Center Director's previous experience leading multidisciplinary research teams
- PD research areas to be pursued
- Breadth of the Center's organizational structure, and whether it includes basic, translational, or clinical research

Study Question 4 – To what extent did the individual Udall Centers implement the activities recommended by NINDS during their first five years?

- Offer research training relevant to PD
- Obtain adequate research support for Udall Center projects
- Promote multidisciplinary collaborations within and between Udall Centers
- Ensure effective day-to-day management and communications
- Emphasize strategic planning, including setting milestones, monitoring progress, and seek advisory committee input

Study Question 5 – To what extent did the individual Udall Centers and the Centers as a group achieve the following short-term research goals in the first five years:

- Integrated multidisciplinary program focusing on a set of interrelated scientific problems aimed at advancing PD research
- Early results leading to new hypotheses relevant to PD
- New procedures developed for sharing PD research findings and scientific techniques
- Recruitment of new faculty and trainees to PD research
- More multidisciplinary research relevant to PD
- Broader research and infrastructure support for projects relevant to PD

Study Question 6 – To what extent did the individual Udall Centers and the Centers as a group achieve the following long-term research goals during their first five years:

- Noteworthy research discoveries involving basic, clinical, and/ or translational research that are likely to advance the prevention, diagnosis, and/or treatment of PD
- New scientific tools developed and shared with other PD researchers (e.g., new models, technologies, databases, repositories, classification standards, research techniques)
- Increased number of independent research scientists conducting PD research
- Increased level of collaboration with other PD researchers and the broader PD community
- Increased institutional commitment to PD research

Study Question 7 – Why were some Udall Centers more successful than others?

- To what extent were specific Center characteristics related to their subsequent success in achieving program goals?
- Comparing more (or less) successful Centers, can “Centers with strong potential” be identified from their baseline characteristics? If so, what are the characteristics?
- To what extent were specific activities conducted by the Centers related to their subsequent success in achieving program goals?
- Comparing the approaches used by the more successful (and less successful) Centers during the first five years, can “best practices for Centers” be identified? If so, how was each practice usually implemented?

Study Question 8 – Were the Udall Center researchers more (or less) successful than a comparable group of PD researchers advancing PD research in:

- Generating new hypotheses relevant to PD
- Achieving noteworthy research discoveries
- Developing new scientific tools and sharing these tools with the PD research community

Study Question 9 – Were the Udall Center researchers more successful than a comparable group of researchers in collaborating with researchers at other institutions to advance PD research?

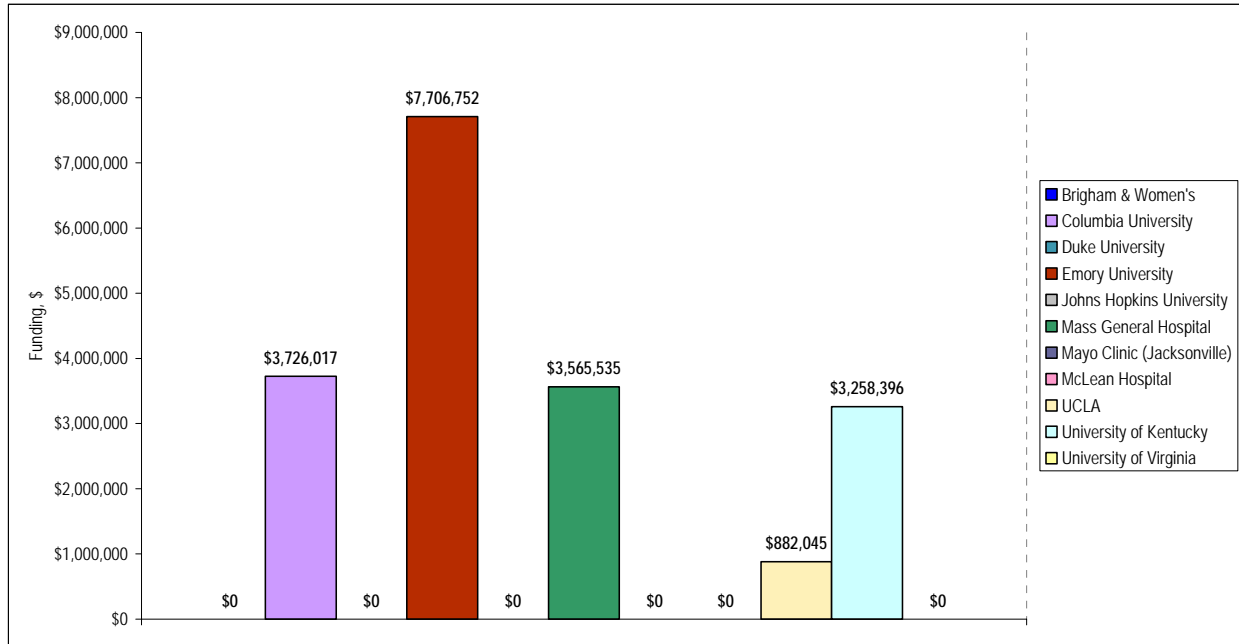
Study Question 10 – Were the Udall Center researchers more successful than a comparable group of researchers in increasing the number of new faculty and trainees (independent research scientists) conducting PD research?

Appendix C: Working Group Member Conflict Statements

- **Martha Bohn** – Dr. Bohn is a co-founder of MedGenesis Therapeutix and holds 3.6% equity in this company, however her only formal role is as a non-paid consultant. MedGenesis develops novel therapies for Parkinson’s Disease. Dr. Bohn also is a consultant for SanBio.
- **Amy Comstock Rick** – Ms. Comstock is the Chief Executive Officer for the Parkinson’s Action Network and in this capacity she makes recommendations about the structure and function of current Udall Centers and the future of the Program.
- **Mark Hallett** – Dr. Hallett is an employee of NINDS but is not involved in the Udall Center Program and does not anticipate any review of Udall Applications in the future.
- **Creighton Phelps** – Dr. Phelps has been involved with NINDS in the past and attends Udall Center Director Meetings to update NINDS on issues relevant to Parkinson’s Disease.
- **Thomas Bird** – Dr. Bird receives royalty payments from Athena Diagnostics Inc., a company involved with genetic tests for Parkinson’s Disease. He is also a Federal Employee with the Veteran’s Administration.

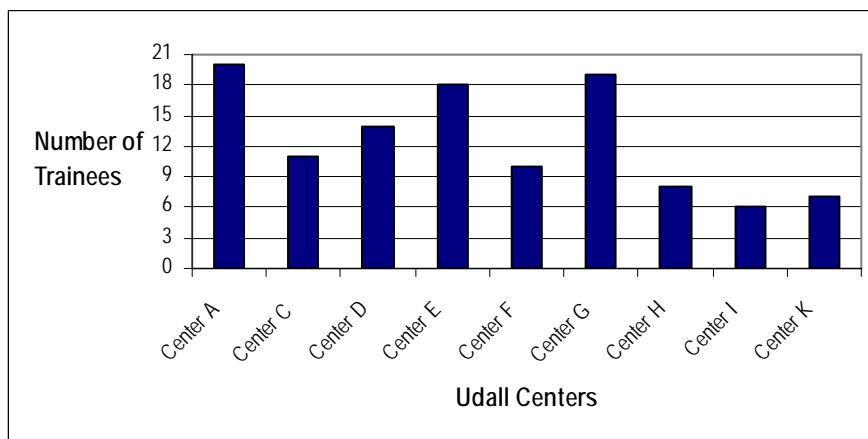
Appendix D: Center Directors' Past Parkinson's Disease Research Experience

**NIH Funding, by Center Directors, for Parkinson's Disease Research
Prior to Receiving Udall Center Funding**



Appendix E: Research Trainee Numbers and Research Training Activities

**Total Number of Individual Trainees at Each Udall Center*
During the First Five Years of the Program**



**No data available for Center B or Center J*

Research Trainees Program Development: Major Themes

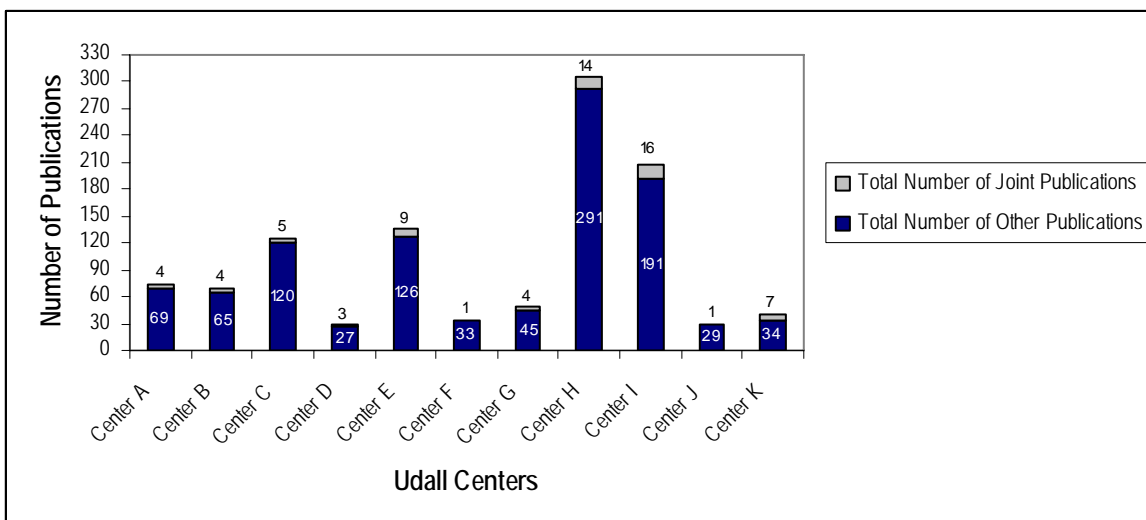
What program developments did the Udall Center structure allow your Center to create for research trainees?	# of Centers
Increased the number of seminars, journal clubs, and brainstorming workshops	10
Increased the number of post-doctoral trainees for basic and clinical research	8
Increased mentoring opportunities	7
Increased training opportunities for students	7
Enabled young scientists to start and develop their careers in PD research	4
Increased overall collaboration	3
Enabled young scientists to participate in PD meetings	2

Appendix F: Udall Center Investigators' Collaborations

Impact of Collaboration on Achieving Research Goals

Interview Results: Center Directors and Project/Core Leads	
Collaboration had a positive impact on research (21)	<ul style="list-style-type: none"> • Collaboration allowed us to make faster progress on our research, helped to unify our approach and re-directed our research (7) • Collaboration occurred: we received and/or shared materials, tissues, reagents, animal models, and discoveries (7) • Collaboration helped our knowledge base and technical resources; we exchanged protocols, had access to unpublished information, exchanged personnel, exchanged techniques, shared methods, and compared data results (5) • Collaboration outside of the Center was much more than it otherwise would have been without the Udall Center structure (2)
Collaboration had little impact on research (7)	<ul style="list-style-type: none"> • Collaboration hasn't helped research goals; wasn't relevant for the cores (5) • Collaboration helped us move toward our goals but the impact wasn't huge; would have happened absent of the Udall structure (2)
Collaboration had some impact on research (2)	<ul style="list-style-type: none"> • Collaboration occurred, but it was not on efforts toward primary research goals—it was outside of the initial goals (2)

Publication Collaboration Among Udall Centers



Appendix G: Udall Center Investigators' Comments on the Annual Meeting

Usefulness of Udall Annual Meetings and Impact of Udall Annual Meetings on Furthering Research

INTERVIEW RESULTS: Center Directors and Project/Core Leads	
How Useful Were the Annual Udall Center Meetings?	<ul style="list-style-type: none"> Elaborations and Impact of the Annual Udall Center Meeting on Research
Useful (33)	<ul style="list-style-type: none"> Allowed us to build relationships with others in the PD field, create a PD research community, and facilitate collaboration (25) Provided a venue for sharing techniques and methods, including student-post-doctoral exchanges (9) Provided a venue for discussing ideas, research discoveries, and new areas of research (8) Provided a venue for sharing reagents, materials, animals, and antibodies (8) Provided an incentive to prepare because they acted as deadlines (5) Increased involvement with PD community- volunteer organizations (clinical trial recruitment, understanding different perspectives, and understanding the disease) (4) Provided an opportunity to learn about the structure, research activities, and progress of the other Udall Centers and the diversity of the portfolio (4) Exposed us to colleagues in different disciplines (3) Provided a venue for discussing multi-institutional resource issues (e.g., brain banking, PD-DOC) (2) The meeting was useful but it did not help in furthering my research (1)
Not Useful (6)	<ul style="list-style-type: none"> It was difficult to meet people since they were often presenting or in subgroups; at the later meetings, there was more opportunity for interaction (2) They were too structured around the presentations by each Center and would have preferred to hear about the data results of pre-published work (1) There seemed to be opportunities for the Centers to posture among each other (1) The presentations were not all high-quality (1) They needed more structure for collaboration (1)

Appendix H: Udall Center Investigators' Responses Regarding Improving Assistance from NINDS Staff

Improving NINDS Assistance During the Pre-Award Timeframe

Could NINDS staff improve the assistance it provides to applicants during the pre-award period?	Center Directors	Project/Core Leads	Total
Yes	1	3	4
No	5	15	20

**Interviewees who provided a response of N/A were removed from the analysis.*

Improving NINDS Assistance During the Application Process

Could NINDS staff improve the assistance it provides to applicants during the application process?	Center Directors	Project/Core Leads	Total
Yes	1	3	4
No	5	24	29

**Interviewees who provided a response of N/A were removed from the analysis.*

Improving NINDS Assistance During the Post-Award Period

Could NINDS staff improve the assistance it provides to applicants during the post-award period?	Center Directors	Project/Core Leads	Total
Yes	2	0	2
No	5	17	22

**Interviewees who provided a response of N/A were removed from the analysis.*