

**Report of Trans-National Institutes of Health Research
Conducted in Fiscal Year 2009**

Report to Congress

**National Institutes of Health
Department of Health and Human Services**

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Report of Trans-National Institutes of Health Research Conducted in Fiscal Year 2009

Report to Congress

I. Introduction

Section 402A(c)(2)(B) of the Public Health Service Act (PHS Act) (42 U.S.C. 282a(c)(2)(B)), added to the PHS Act by Section 103(a) of the National Institutes of Health (NIH) Reform Act of 2006, requires that the Secretary of Health and Human Services (HHS) submit an annual report to Congress identifying the percentage of funds made available by each national research institute and national center with respect to conducting or supporting research that involves collaboration between the institute or center and one or more other national research institutes or national centers (ICs). This third annual report provides the amount made available by each IC for conducting or supporting research that involves collaboration between that IC and one or more other ICs. This amount is expressed as the percentage of funds made available by each IC for the previous fiscal year (fiscal year 2009) for conducting or supporting trans-NIH Research. In addition, the House Report recognizes that there may be collaborative work between ICs that may not be fully demonstrated in budgetary data, such as planning meetings, conferences, and casual communication. Accordingly, this report provides narrative examples of inter-IC activities that fall under this category, such as collaborative conferences, workshops, Scientific Interest Groups, task forces, and educational campaigns.

II. Overview of Collaborations Within NIH

The NIH is composed of 27 Institutes and Centers, each having a distinct mission. However, leaders across the NIH recognize that scientific progress often comes at the interface of traditional boundaries. Therefore, there is considerable trans-NIH collaborative activity across IC boundaries at every level of NIH operations. Trans-NIH collaborative activities can be found in all disease areas and across basic, translational, and clinical research. These collaborations can be formal or informal and can involve sharing materials, specimens, or scientific expertise. Collaborations take place at any or all stages of a research project or program, including: 1) development of a concept, initiative, or plan; 2) funding; 3) conduct of the research; 4) management and administration of the project; and 5) measurement of results. Although some collaborations are the product of highly visible joint activities such as initiatives supported through the Common Fund and the NIH Blueprint for Neuroscience Research, the vast majority of collaborative activities take place day-to-day in the office and in the laboratory. This report includes the activities of the 24 NIH ICs with missions consistent with participation in trans-NIH research.

III. Scope of Report

Inclusions:

For the purposes of this report, a trans-NIH research collaboration is defined as a formally documented, science-based effort that includes two or more ICs. Within this defined cohort, two types of extramural collaborations are included in the budget figures presented in this report: 1) grants and contracts that are co-funded by two or more ICs, and 2) grants and contracts funded in response to collaborative program initiatives developed and announced by two or more ICs. Program initiatives of this type include Requests for Applications (RFAs), Requests for Proposals (RFPs), and Program Announcements (PAs). A qualifying feature of these extramural collaborative program initiatives is the formal participation by multiple ICs at the outset of the activity in developing and issuing the initiative. This is the first annual report to include collaborative activities supported by the American Recovery and Reinvestment Act of 2009 (ARRA). Intramural collaborative research projects also are included within the “Total Collaborative Activities” column in the Appendix 1 table.

This report also provides narrative examples of formally documented collaborative activities not fully demonstrated in the budgetary data, including conferences, workshops, Scientific Interest Groups, working groups, task forces, educational campaigns, and other major labor-intensive and time-consuming activities.

Exclusions:

Informal collaborations between ICs are excluded from this report, although they occur within all programs and at all levels. Also excluded are grants funded in response to “Parent Announcements.” These general announcements of guidelines for grant mechanisms (e.g., R01) do not address scientific areas and, therefore, are outside the scope of the collaborative program initiatives included in this report. The criteria for classification as a Parent Announcement (and therefore exclusion from this report) were broadened for the fiscal year (FY) 2009 report, resulting in an increased focus on collaborative research activities versus administrative activities to support these collaborations, such as announcements of administrative guidelines for grant applications. As in the previous reports, grants that provide shared resources have also been excluded from this report unless they are co-funded or funded in response to collaborative program initiatives.

Also excluded from this report are collaborative activities initiated through offices within the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI), unless the joint activity includes two or more ICs in addition to the DPCPSI office. This is consistent with this report’s definition of a trans-NIH collaboration and with NIH’s interpretation of the legislative language. Clearly, trans-NIH collaborations are central to the missions of all DPCPSI offices, and their efforts are critical to the synergy of inter-IC collaborations of all types. The five DPCPSI offices are:

- Office of Strategic Coordination (OSC), which oversees collaborative efforts across the NIH to plan, implement, and manage the programs funded via the NIH Common Fund. These programs are not included here because they are the subject of a separate report, the Common Fund Strategic Planning Report. All NIH ICs participate in these programs, and some ICs have contributed additional funds from their own appropriations. The IC funds are represented in this report, but the dollars appropriated to the Common Fund within the Office of the Director (OD) appropriation are not;
- Office of Behavioral and Social Sciences Research (OBSSR), which (a) leads the development of priorities for increasing the scope of and support for behavioral and social science research and training at the NIH; (b) coordinates research in the behavioral and social sciences across the 27 NIH Institutes and Centers (ICs); (c) develops and facilitates new initiatives in partnership with the ICs; (d) provides leadership in disseminating findings from behavioral and social sciences research and communicating the importance of such research in the acquisition, treatment, and prevention of disease and disability; and (e) advises key NIH officials on matters relating to behavioral and social science research;
- Office of Research on Women's Health (ORWH), which (a) advises the NIH Director and staff on matters relating to research on women's health; (b) serves as the focal point for women's health research and the study of sex/gender factors at NIH; (c) promotes, stimulates, and supports efforts to improve the health of women through biomedical and behavioral research on the roles of sex and gender in health and disease; (d) ensures that women are appropriately represented in clinical studies supported by NIH; and (e) develops opportunities for the recruitment, retention, re-entry, and advancement of women in biomedical careers and advancement of careers for men and women in women's health research;
- Office of Disease Prevention (ODP), which includes the Office of Dietary Supplements, Office of Medical Applications of Research, and Office of Rare Disease Research. ODP (a) provides overall coordination and guidance to the ICs concerning disease prevention and health promotion initiatives, policies, and activities; (b) collaborates in the formulation of research initiatives and policies that promote public health; and (c) stimulates, coordinates, and supports research on dietary supplements and on rare diseases; and,
- Office of AIDS Research (OAR), which has unique authorities to plan, coordinate, evaluate, and submit budget estimates for the NIH AIDS research program. OAR (a) coordinates the scientific, budgetary, legislative, and policy elements of the NIH AIDS research portfolio and sets the trans-NIH scientific priorities; (b) has established comprehensive trans-NIH planning, budgeting, and portfolio analysis processes to identify the highest priority areas of scientific opportunity, enhance collaboration, minimize duplication, and ensure that precious research dollars are invested effectively and efficiently; (c) prepares a Presidential by-pass budget; (d) identifies emerging scientific opportunities and public health challenges that require focused attention, and manages and facilitates multi-Institute and trans-Institute activities to address those needs; (e) fosters research by designating funds and supplements to jump-start or pilot

program areas; (f) sponsors reviews or evaluations of research program areas; (g) supports a number of initiatives to enhance dissemination of research findings to researchers, physicians, institutions, communities, constituency groups, and patients; and (h) facilitates international AIDS research and training.

The budget numbers exclude collaborative efforts coordinated through the NIH Clinical Center because the Clinical Center budget is funded through a mandatory contribution from the ICs as a standard percentage of the intramural IC budgets. However, it is important to note that the Clinical Center coordinates a range of trans-NIH activities, including the highly successful Bench-to-Bedside awards program. This program is supported through a number of OD offices in addition to voluntary contributions from 17 ICs. The Bench-to-Bedside awards program was created to speed translation of promising laboratory discoveries into new medical treatments by encouraging collaborations among basic scientists and clinical investigators. Since the Bench-to-Bedside program began over 11 years ago, 152 collaborative projects have received funding, representing partnerships among multiple NIH ICs.

Other trans-NIH activities coordinated through the Clinical Center include the Center for Neuroscience and Regenerative Medicine, which aims to discover methods to better intervene and prevent the long-term consequences resulting from traumatic brain injury. The Clinical Center's new Center for Interventional Oncology focuses on localized treatment and drug delivery by use of advanced imaging technologies, including cutting-edge magnetic resonance imaging, positron emission tomography, and computed tomography, combined with the capability to use all three technologies simultaneously to navigate a therapeutic device through the body.

Additional exclusions from this report include: (a) activities involving NIH collaboration with other agencies within HHS (these types of activities are included in the FY 2008 Intra-HHS Collaborations Report); (b) collaborations between individual NIH ICs and private sector partners; and (c) collaborations that are not supported through the ICs' budgets. The last category includes a number of major NIH efforts, such as the National Children's Study, the Special Statutory Funding Program for Type 1 Diabetes Research, and the Superfund program. These are collaborative efforts by design, jointly planned and managed by multiple ICs. However, as with activities supported through the Common Fund, the fact that they are not supported through the IC budgets precludes their inclusion in the totals and percentages that are presented in Appendix 1.

IV. Percentage of Funds Made Available in Fiscal Year 2009 by Each National Research Institute or Center for Conducting Trans-NIH Research

Appendix 1 presents the percentage of funds made available by each research IC for the previous fiscal year (FY 2009) for conducting trans-NIH research. The figures presented in this table represent the sum of collaborative activities in three areas: extramural grants, extramural contracts, and intramural research projects. Section III of this report describes the categories of extramural grants and contracts that are included.

Intramural collaborations are identified through the NIH Intramural Database. As with extramural projects, reporting on intramural projects is limited to formal collaborations between two or more ICs. In each case, the total FY 2009 budget for a collaborative intramural research project is credited wholly to the lead IC because through this database it is not possible to apportion the effort or budget across multiple ICs. It is important to note that three of the ICs listed in Appendix 1 have no intramural research program.

As stated in Section III, the criteria for classification as a Parent Announcement (and therefore exclusion from this report) were broadened for the FY 2009 report to further exclude research support activities. This resulted in an overall decrease in the number of grants funded in response to collaborative program initiatives relative to the figures reported in the two previous annual reports. As also stated in Section III, this is the first annual report to include collaborative activities supported by ARRA. Collaborative research supported by ARRA contributed \$1,253,773,000 to the IC grand total shown in the “Total Collaborative Activities” column in Appendix 1.

V. Examples of Collaborative Work Between National Research Institutes and Centers

Appendix 2 highlights selected examples of collaborative activities across ICs that are not fully demonstrated in budgetary data. The activities are grouped within the following categories: (a) conferences, workshops, and meetings; (b) committees, working groups, and task forces; and (c) educational campaigns and clearinghouses. The list is intended to illustrate the range of types of collaborative activities, both extramural and intramural, and is not meant to be comprehensive. Therefore, the list provides information on just a few representative activities within each category. A complete list would be extremely large, since the NIH Scientific Interest Groups alone number over 100.

VI. Conclusion

NIH has a strong commitment to collaborative research, as evidenced by joint efforts at all levels. Although many inter-IC collaborative activities are typically not as visible as those supported through the Common Fund and through other high-profile trans-NIH collaborations, Appendix 1 illustrates that a significant percentage of the ICs’ budgets support these important activities. It also is clear that the focus and breadth of an IC’s mission affects the percentage of funds made available by an IC for conducting or supporting trans-NIH Research. The NIH appreciates the opportunity to offer specific examples of ongoing joint activities.

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Appendix 1: IC Collaborative Activity Summary – FY 2009

(\$000)

| Funding IC | Total IC Actual Obligations (Non-ARRA and ARRA Appropriations) | Total Collaborative Activities | Percent for Collaborative Activities |
|------------|--|--------------------------------|--------------------------------------|
| FIC | \$ 78,904 | \$ 55,018 | 69.7% |
| NCCAM | 141,023 | 58,648 | 41.6% |
| NCI | 5,706,458 | 776,440 | 13.6% |
| NCMHD | 237,416 | 58,533 | 24.7% |
| NCRR | 1,464,705 | 568,037 | 38.8% |
| NEI | 775,863 | 110,257 | 14.2% |
| NHGRI | 571,492 | 191,021 | 33.4% |
| NHLBI | 3,404,619 | 686,533 | 20.2% |
| NIA | 1,221,262 | 232,787 | 19.1% |
| NIAAA | 504,357 | 114,327 | 22.7% |
| NIAID | 4,879,967 | 857,295 | 17.6% |
| NIAMS | 591,962 | 143,356 | 24.2% |
| NIBIB | 352,726 | 132,469 | 37.6% |
| NICHD | 1,425,331 | 370,345 | 26.0% |
| NIDA | 1,169,669 | 299,597 | 25.6% |
| NIDCD | 475,780 | 76,331 | 16.0% |
| NIDCR | 447,149 | 110,204 | 24.6% |
| NIDDK | 2,085,278 | 380,331 | 18.2% |
| NIEHS | 736,828 | 156,452 | 21.2% |
| NIGMS | 2,346,064 | 304,365 | 13.0% |
| NIMH | 1,625,540 | 571,674 | 35.2% |
| NINDS | 1,794,818 | 445,585 | 24.8% |
| NINR | 158,844 | 59,133 | 37.2% |
| NLM | 366,685 | 17,752 | 4.8% |
| NIH | \$ 32,562,740 | \$ 6,776,489 | 20.8% |

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Appendix 2: Examples of Collaborative Activities Not Fully Demonstrated in the Budget Data

I. Conferences, Workshops, and Meetings

1. Advances in Optical Imaging and Biomedical Science

This June 1-2, 2009, symposium focused on high resolution imaging of complex biological systems and described advances at the theoretical, technical, and clinical levels that bridge technology and clinical diagnosis critical for ophthalmology and a growing number of medical fields. High resolution noninvasive functional imaging technology of significant diagnostic value includes laser scanning confocal/magnetic resonance/2-photon microscopy, optical coherence tomography, speckle microscopy, and adaptive optics.

Participating Institutes and Centers: NEI and NIBIB

Web site: http://www.nei.nih.gov/anniversary/symposia/optical_imaging.asp

2. Annual Symposium on Nonhuman Primate Models for AIDS

This annual conference is the leading forum for the exchange of the latest developments in AIDS research using nonhuman primates. Recent results in expensive human clinical trials of AIDS vaccines have highlighted the need for basic translational research in animal models. The October 28-31, 2009, meeting expanded to include a satellite meeting called “Exploiting Systems Biology in Nonhuman Primate Models for AIDS.” The scientific sessions included pathogenesis, immunology, virology, vaccines/prevention, and genetics/genomics.

Participating Institutes and Centers: NCRR, NIAID, and OAR

Web site: <http://nhp2009.hms.harvard.edu/>

3. Building the NIH Toolbox: Research in Cognition, Sensation, Emotion, and Motor Function

On October 27, 2008, the NIH Blueprint held a conference, which offered the public a first glimpse into the development of the NIH Toolbox, an assessment tool for motor,

cognitive, and emotional function as well as sensory status (e.g., vision, hearing, olfaction, etc). The overall purpose of the meeting was to garner interest from the scientific research communities regarding integration of the Toolbox into longitudinal and epidemiological studies and to receive feedback from the communities that would most likely use this assessment tool.

Participating Institutes and Centers: NCCAM, NCRR, NEI, NIA, NIAAA, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIEHS, NIGMS, NIMH, NINDS, NINR, and OBSSR

4. Decision Making in T1 Translational Research

The purpose of this February 10-11, 2009, workshop was to identify common problems encountered during the practice of T1 translational research and potential solutions to those problems. The workshop addressed the following topics: pathways of T1 translational research, use of team science, methods for incorporating advanced technologies and animal models into T1 translation, and the specific needs of early career investigators. The workshop report can be found at:

http://www.ncrr.nih.gov/publications/Decision_Making_in_T1_Translational_Research.pdf.

Participating Institutes and Centers: NCRR, NIA, and NCI

Web site:

http://www.ncrr.nih.gov/publications/Decision_Making_in_T1_Translational_Research.pdf

5. Future of Telehealth: Essential Tools and Technologies for Clinical Research and Care

This meeting, held on the NIH campus on June 25-26, 2009, brought together stakeholders from government agencies, academic institutions, health care organizations, and technology companies to review the state of telehealth science and technology, identify gaps in knowledge that can be addressed through targeted research and evaluation initiatives, and explore ways to leverage evolving information and communication technologies to broaden participation in biomedical and behavioral research and improve health outcomes in medically underserved communities. The workshop report can be found at:

http://www.ncrr.nih.gov/publications/clinical/Future_of_Telehealth_Final_Report_June_25-26_2009.pdf

Participating Institutes and Centers: NCRR, NIBIB, NLM, and NCMHD

Web site: <http://www.internet2.edu/health/library/NIH2009/>

6. GEI/NCI Meeting on “The Challenge of Mapping GWAS Signals”

This March 24-25, 2009, meeting addressed how Genome-wide Association Study (GWAS) signals should be followed up by sequencing and genotyping.

Participating Institutes and Centers: NHGRI, NCI, NIMH, NIDDK, NIGMS, NEI, NIDCD, NCBI, NHLBI, NIA, and NINDS.

Web site: <http://www.gei.nih.gov/genetics/meetings/mapping/index.asp>

7. How to Add Genetics to Your Studies

On May 26, 2009, NIH sponsored a preconference workshop at the 17th Society for Prevention Research Annual Meeting. The overall purpose of the workshop was to provide information about the theory and mechanics of conducting genetic studies in human populations, enabling participants to understand better the types of questions that can be addressed in genetic studies, how to collect DNA in their own studies, and the appropriate methods for analyzing genotypic data. A secondary purpose of the workshop was to build linkages between experts in molecular and behavioral genetics with prevention scientists so they may serve as resources for one another in future collaborations.

Participating Institutes and Centers: NIAAA, NIDA, NIMH, and NCI

8. Imaging the Pancreatic Beta Cell (Fourth Workshop)

This meeting, held on April 6-7, 2009, explored progress in the field of imaging pancreatic islet cell mass, function, and inflammation in endogenous or transplanted pancreatic islets and/or beta cells *in vivo*, and fostered the development of clinically useful imaging approaches for monitoring aspects of beta cell function in people with type-1 and type-2 diabetes and in those at risk for diabetes.

Participating Institutes and Centers: NIDDK, NIA, NIAID, and NIBIB

Web site: <http://www3.niddk.nih.gov/fund/other/imageislet/>

9. Influenza Dynamics and Evolutionary Analysis (IDEA) Workshop

On June 24-26, 2009, FIC hosted the inaugural Influenza Dynamics and Evolutionary Analysis (IDEA) workshop. The workshop brought together researchers from all six major continents, including virologists, evolutionary biologists, and representatives from the public and private sectors. The first one and a half days of the workshop consisted of oral presentations by participants on a wide range of topics relating to the study of

influenza virus evolution. The remainder of the workshop included an interactive demonstration of the latest epidemiological and phylogenetic methodologies and analysis of the participants' own virological data.

Participating Institutes and Centers: FIC, NIAID, and NLM

Web site: <http://origem.info/misms/DC/>

10. Neuroimaging in Obesity Research

On October 27-28, 2008, NIH held a trans-NIH workshop to evaluate the use of neuroimaging approaches for studying aspects of brain function that regulate energy balance, hunger, satiety, and food craving. The workshop brought together obesity and neuroimaging researchers to share their experiences using neuroimaging to study brain involvement in obesity, to explore what aspects of obesity research are best suited for neuroimaging studies, and to define best practices for using neuroimaging to study the role of the brain in obesity.

Participating Institutes and Centers: NIDDK, NIDA, NIA, NIMH, NIBIB, NCCAM, and OBSSR

Web site: <http://www3.niddk.nih.gov/fund/other/neuroimaging2008/index.htm>

11. New Horizons in Brain Imaging: A Focus on the Pacific Rim

NIH sponsored a conference on April 13-15, 2009, to discuss current advances in neuroimaging and to foster collaborations between scientists from nations along the Pacific Rim. Travel stipends were provided to students from Pacific Rim countries to attend the conference and to meet with neuroimaging researchers.

Participating Institutes and Centers: NIAAA and NIMH

12. NIDA Cost-Effectiveness Evaluation in Addiction Treatment Clinical Trials Workshop

This July 30-31, 2009, workshop was designed to advance the use and usefulness of economic evaluation in addiction treatment clinical trials, specifically Clinical Trials Network trials, by bringing together a select multidisciplinary group of health economists, addiction treatment clinicians and researchers, biostatisticians, and providers.

Participating Institutes and Centers: NIDA and NHLBI

13. NIH Blueprint for Neuroscience Research Workshop on “Harnessing Neuroplasticity for Human Applications”

On April 21-22, 2009, NIH convened a workshop that brought together leading researchers in the area of neural circuit retraining to discuss cutting edge advances and gaps in research. The results of the workshop will be used to inform the development of future initiatives in this area of research. The workshop report can be found at: http://www.neuroscienceblueprint.nih.gov/blueprint_basics/harnessing_neuroplasticity_workshop_report.htm.

Participating Institutes and Centers: NCCAM, NCRR, NEI, NIA, NIAAA, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIEHS, NIGMS, NIMH, NINDS, NINR, and OBSSR

14. NIH Conference on “Sleepiness and Health-Related Quality of Life”

On April 13-14, 2009, NIH convened a conference for the public to showcase advances in understanding how sleepiness interacts with health related quality of life indicators. The meeting brought together behavioral and neurobiological researchers at many levels and showcased many of the research directions now under way. Conference sessions focused on various topics, including the effects of acute alcohol on sleep and performance, the neural mechanisms underlying alcohol-related sleep disturbances, and the treatment and health outcomes of alcohol dependent individuals who suffer from insomnia.

Participating Institutes and Centers: NHLBI, NIAAA, NINDS, and NICHD

Web site: <http://www.nhlbi.nih.gov/meetings/workshops/sleep-hqol-agenda.htm>

15. NIH Summit: The Science of Eliminating Health Disparities

This conference, which took place on December 14-18, 2008, highlighted the research progress of the NIH on health issues among racial/ethnic minority and medically underserved populations.

Participating Institutes and Centers: All NIH ICs

Web site: <http://www.blsmmeetings.net/2008healthdisparitiessummit/>

16. NIMH Workshop on New Perspectives in the Translational Neuroscience of Late-Life Mental Disorders

This workshop, held on February 2-3, 2009, brought together basic and clinical researchers interested in topics of aging and mental health to identify key research

questions relative to future translational neuroscience studies on the causes of mental disorders in older adults and on charting mental illness trajectories so as to determine when, where, and how to intervene.

Participating Institutes and Centers: NIMH and NIA

Web site: <http://www.nimh.nih.gov/research-funding/scientific-meetings/2009/new-perspectives-in-the-translational-neuroscience-of-late-life-mental-disorders.shtml>

17. Opioid Prescribing to Adolescents in Dental Settings

The Monitoring the Future Study, a survey of 50,000 high school students, showed that in the past 5 years, 1 in 10 twelfth graders have experimented with hydrocodone for purposes other than a medical indication. Many opioid analgesic prescriptions for adolescents come from dentists. On February 23, 2009, NIDA convened a meeting of dental experts to discuss whether current opioid analgesic prescribing patterns reflect best practices and, if so, what research is needed to determine the best methods to minimize abuse of these drugs. A meeting summary can be found at: <http://www.drugabuse.gov/whatsnew/meetings/Dental/index.html>.

Participating Institutes and Centers: NIDA and NIDCR

Web site: <http://www.seiservices.com/NIDA/1014045/>

18. Opportunities for Strengthening the Research Enterprise in Sub-Saharan Africa (SSA) at the NIH

A summit on Sub-Saharan Africa (SSA) was held at the NIH on November 4-5, 2008. This seminal meeting provided a forum for discussing key opportunities for expanding training and research activities between NIH and SSA institutions, with the goal of identifying prospects for enhancing NIH research while working to stimulate the scientific research enterprise in SSA, bolstering the growth of centers of excellence in SSA, and encouraging the training and development of a cadre of African investigators able to advance a research agenda for the region.

Participating Institutes and Centers: FIC, NCI, NHGRI, CC, CIT, NCCAM, NCMHD, NCRR, NEI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NLM, NINDS, NIDDK, NIEHS, and OD

19. Personal Genomics Workshop: Establishing the Scientific Foundation for Using Personal Genome Profiles for Risk Assessment, Health Promotion, and Disease Prevention

This December 17-18, 2008, workshop explored the type of scientific foundation that is crucially needed to make the promise of personal genomics a reality. The workshop participants examined how the integration of genomics into personalized health can follow an evidence-based process. The process for using genomic applications in personalized health care (e.g., pharmacogenomics, early detection markers, testing in clinical trials) was discussed.

Participating Institutes and Centers: NCI, NHGRI, NHLBI, OBSSR, and CDC

Web site: <http://cancercontrol.cancer.gov/od/phg/workshop.html>

20. Promoting Generalization in Stroke Rehabilitation

While patients with stroke clearly benefit from rehabilitation interventions, optimal therapy protocols and their underlying mechanisms are not fully understood. This June 3-4, 2009, workshop was organized by NINDS to discuss how methods and principles that have been shown to work for one type of rehabilitation could be tested in the context of cognitive rehabilitation following a stroke. In particular, the meeting explored the theory of generalization, or how skills learned in one type of rehabilitation setting may be expanded to other areas of function.

Participating Institutes and Centers: NINDS, NICHD, NIA, NIDCD, VA, and AHA

21. Safe and Effective Instruments and Devices for Use in the NICU

On February 11, 2009, researchers met to discuss the challenges and opportunities for developing safe and effective devices and instruments for use in the neonatal period. Topics of discussion included: cardiopulmonary issues, cerebral oxygenation and imaging, metabolic monitoring, and sepsis.

Participating Institutes and Centers: NICHD, ORDR, and NHLBI

22. Sixth Inter-Institute Workshop on Biophotonics

This meeting was held on September 15-18, 2009, to discuss the latest developments in biophotonics at tissue, cell, and molecular levels. The goal of the meeting was to review multimodality imaging, development of molecular contrast agents, women's health

issues, and multidisciplinary networks of scientists, as well as European, American, and Asian networks and science-industry partnerships.

Participating Institutes and Centers: NICHD, NHLBI, NCI, NINDS, NIBIB, NIMH, NEI, ORWH, and ORDR

23. Symposium on “Neuropathic Cancer Pain”

The Symposium, held on April 27, 2009, was designed to bring together a multidisciplinary group of researchers, clinicians, and patient advocates to build upon knowledge and understanding of the role of pain and pain management in clinical care. A group of experts presented their latest research and addressed gaps in knowledge for the critical focus areas that included defining pain through the patient’s eyes, assessment and outcome measures of neuropathic pain, evidence-based treatments, behavioral research, emerging therapeutic models, and future research directions.

Participating Institutes and Centers: NCI and Institutes of the NIH Pain Consortium (<http://painconsortium.nih.gov/members.html>)

Web site: <http://www.cancer.gov/researchandfunding/neuropain2009>

24. The Central Nervous System and Glycemic Control

The central nervous system is extremely important in regulation of glucose levels. A workshop held September 14-16, 2009, and comprised of researchers working in the areas of diabetes and central nervous system homeostatic mechanisms, focused on research opportunities, needs of relevant research communities, and the development of collaborations between diabetes and neuroscience researchers to understand better how glucose levels and neural systems are related.

Participating Institutes and Centers: NINDS, NIDDK, NHLBI, NEI, and NICHD

25. The Inclusion of Adolescents in HIV Biomedical Prevention Clinical Trials

This June 17-19, 2009, meeting focused on examining the feasibility of and barriers to the enrollment of adolescents in clinical trials to test new HIV biomedical prevention technologies, such as HIV vaccines, microbicides, and pre-exposure prophylaxis. The goal of the meeting was to develop a set of preliminary recommendations for inclusion of adolescents in these trials and to inform drug development and licensure processes that would be used while obtaining efficacy data in adult studies. The meeting participants represented various domestic and international experts from academia, industry, HIV-affected communities, and the Federal Government.

Participating Institutes and Centers: NICHD, NIAID, NIMH, NIDA, and OAR

Web site: <http://www.nichd.nih.gov/about/meetings/2009/061909.cfm>

26. The Promise of Induced Pluripotent Stem Cells (iPSCs) Workshop

On May 4, 2009, the NIH Stem Cell Implementation Committee and Task Force sponsored a workshop entitled “The Promise of Induced Pluripotent Stem Cells (iPSCs).” The workshop provided a forum to discuss cutting-edge iPSC research and to illuminate the central issues that currently challenge the field. Nine invited speakers focused on four topics, including comparison of iPSCs with embryonic stem cells, iPSC research on cardiovascular disorders, nervous system disorders, and diabetes.

Participating Institutes and Centers: NHLBI, NIDCD, NIDDK, NIMH, NINDS, and OD

Web site: <http://stemcells.nih.gov/news/ipscworkshop.htm>

27. Trans-NIH American Indian and Alaska Native Health Communications and Information Work Group

Formed in 2005, the Work Group, led by NIAMS, provides a forum for health education and communications staff from across NIH to share strategies and learn effective approaches to develop and disseminate health information designed for American Indian and Alaska Native communities. For the past year and a half, the Work Group has distributed quarterly health information mailings to Community Health Representatives (CHRs) to increase their awareness of the availability of free, science-based health information materials from the NIH. The Work Group also sponsors annual workshops for NIH employees interested in outreach to Native populations. The fourth workshop in the series, conducted in May 2009, focused on the role of CHRs in health research and education.

Participating Institutes and Centers: NIAMS, NCI, NEI, NHGRI, NHLBI, NIA, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIGMS, NINDS, NLM, NCRR, and ORWH

Web site:

http://www.niams.nih.gov/News_and_Events/Announcements/2009/AI_AN_workshop.asp

28. Workshop: Developmental Aspects of the Upper Airway

The March 5-6, 2009, workshop convened extramural experts from many disciplines (neonatology, pediatrics, otolaryngology, plastic surgery, bioengineering, imaging, sleep disorders, lung development, and genetics) to review the state of the science in pediatric upper airway disorders; make recommendations to the Institutes to fill knowledge gaps; prioritize new research directions; and capitalize on scientific opportunities. Participants

made recommendations that could facilitate translation of basic research findings into practice to improve diagnosis, treatment, and prevention of airway compromise in children.

Participating Institutes and Centers: NHLBI, ORDR, NICHD, and NIDCR

29. Workshop on Clinical Trial Endpoints for Acute GVHD after Allogeneic HCT, and the Identification of Future Scientific Directions Needed to Advance the Prevention of Acute GVHD

Graft-versus-host disease (GVHD), a frequent complication of allogeneic hematopoietic stem cell transplantation, is associated with substantial morbidity and mortality. This 2-day workshop, held May 19-20, 2009, addressed both clinical and basic research aspects of this topic. The goal was to obtain expert recommendations on future research directions to further understanding of acute GVHD biology.

Participating Institutes and Centers: NHLBI, NCI, NIAID, and ORDR

30. Workshop on “Genetics of Temporomandibular Joint Disorder and Comorbid Chronic Pain Conditions: Current Status and Next Steps”

This workshop was led by NIDCR and was held on June 10-11, 2009. The purpose of the meeting was to gather input from the pain and the genetic communities about the best approaches and needs of researchers to advance this field. The meeting provided a forum for addressing etiology and phenotypes of pain and how to use previous successes with genetics and genome-wide association studies as a tool in the study of susceptibility, development, and persistence of chronic pain conditions.

Participating Institutes and Centers: NIA, NIAMS, NIDCD, NIDCR, NIDA, NIDDK, NINDS, NINR, ORWH, and ORDR

II. Committees, Working Groups, and Task Forces

1. ARRA Sequencing Coordination Committee

This trans-NIH Committee was established to coordinate sequencing activities related to the American Recovery and Reinvestment Act (ARRA), including a voluntary coordinated review of ARRA sequencing grants. Within the committee, two working groups (NIH Sequencing Data Sharing Policy and Technical Working Groups) are developing a trans-NIH data-sharing policy for sequence and related data.

Participating Institutes and Centers: CC, CIT, CSR, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIEHS, NIGMS, NIMH, NINDS, NLM, and OD

2. Asthma Phenotypes Task Force

This task force develops definitions for specific asthma phenotypes and promotes a phenotype checklist for use in describing research study populations.

Participating Institutes and Centers: NHLBI, NCMHD, and NIAID

3. Barriers to Clinical Research

The NIH Intramural Working Group (IWG) launched this initiative to identify and reduce barriers to efficient and effective NIH-sponsored clinical research. The Medical Executive Committee was charged by the IWG with executing this initiative; its initial focus has been to address barriers to clinical research in the NIH Intramural setting. In fall 2008, the IWG proposed the appointment of an Intramural Clinical Research Steering Committee (ICRSC), a new advisory committee reporting to the NIH Deputy Director for Intramural Research, to coordinate and oversee implementation of procedures to address issues. The ICRSC is specifically charged with providing guidance in the following areas:

1. Standards and strategies for the development, review, and implementation of human subjects protocols, including institutional review board operations, support, and accountability, and ethical interactions with the pharmaceutical industry (including technology transfer).
2. Standards and strategies for the development, review, and implementation of human subjects research more broadly, including the scientific review of protocols and the Board of Scientific Counselors review of clinical programs.

Participating Institutes and Centers: NIAID, NIAMS, NHLBI, NIDDK, NCI, NIMH, NHLBI, NHGRI, NIAAA, NIDCD, NIEHS, CC, NICHD, NINDS, NEI, NIMH, NIAAA, NIDCR, and NIDA

4. Clinical Guidelines for Cardiovascular Risk Reduction in Adults

The NHLBI has convened an expert panel to review and update the scientific evidence regarding the assessment and management of cardiovascular (CV) risk factors. This effort will focus on developing comprehensive integrated guidelines across all CV risk factors that will be applicable to “real world” scenarios faced by individuals and clinicians.

Participating Institutes and Centers: NHLBI, NINDS, NIDDK, and DNRC

Web site: http://www.nhlbi.nih.gov/guidelines/cvd_adult/index.htm

5. Collaboration for the Osteoarthritis Imaging Initiative

The Osteoarthritis Initiative (OAI), a collaboration between NIAMS and pharmaceutical companies, has created a public repository of human OA data, radiological information, and biological specimens. This public resource contains a large collection of clinical magnetic resonance imaging (MRI) images of joint disease progression. NCI, using advanced image transfer and storage technology, assisted NIAMS in making their osteoarthritis images network accessible in a detailed, query-able manner. It did so by creating a demonstration project whereby OA images were accessible to any researcher on the Internet.

Participating Institutes and Centers: NCI, NIAMS, and NIBIB

Web site:

http://www.niams.nih.gov/Funding/Funded_Research/Osteoarthritis_Initiative/default.asp

6. Diabetes Mellitus Interagency Coordinating Committee

The Diabetes Mellitus Interagency Coordinating Committee (DMICC), authorized by Public Law 93-354, fosters collaborations between Federal agencies that conduct or support diabetes-related activities and provides a forum for members to share information and ideas to synergize Federal efforts to combat diabetes. In addition to NIH ICs, DMICC member organizations include non-NIH member representatives from the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, the Food and Drug Administration (FDA), the HHS Office of Minority Health, the Indian Health Service, the Veterans Health Administration of the Department of Veterans Affairs (VA), the U.S. Department of Agriculture, and the Department of Defense.

Participating Institutes and Centers: NIDDK, NCCAM, NCRR, NCMHD, NEI, NHLBI, NHGRI, NIAID, NIBIB, NICHD, NIDCR, NIEHS, NIGMS, NIMH, NINDS, NINR, NIA, NIAAA, NIDCD, NIDA, NLM, and CSR

Web site:

<http://www2.niddk.nih.gov/AboutNIDDK/CommitteesAndWorkingGroups/DMICC/Default.htm>

7. Electronic Biospecimen Management System

The goal of the project is to provide extensive repository management and tracking of clinical biospecimens to ensure compliance with congressionally mandated reporting requirements in the NIH Reform Act of 2006.

Participating Institutes and Centers: NIAID and NHLBI

8. Gene Therapy Consortium

This intramural workgroup focuses on the development of translational research in genetics and neuroscience. The intent is to develop the framework from which to undertake clinical trials and therapeutic interventions in heritable retinal and neurodegenerative disorders.

Participating Institutes and Centers: NEI, NHGRI, NIDCD, and NIDCR

9. Health Literacy Workgroup

This workgroup encourages empirical research through trans-NIH funding announcements on health literacy concepts, theory, and interventions as these relate to the HHS' public health priorities that are outlined in its HealthierUS and Healthy People 2010 initiatives. Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Participating Institutes and Centers: NCI, NHLBI, NIA, NIBIB, NIDCD, NIDCR, NIEHS, NIMH, NINR, NLM, and OBSSR

10. Knowledge Management and Health: Translational Applications for Semantic Abstraction Technologies

This project is a collaboration between the NHLBI and the NLM to develop advanced information management applications to support the development of clinical practice

guidelines. The underlying methodology is to extend and adapt Semantic MEDLINE, a biomedical information management system under development at the Lister Hill National Center for Biomedical Communications, NLM.

Participating Institutes and Centers: NLM and NHLBI

11. Muscular Dystrophy Coordinating Committee

The Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2001 (MD-CARE Act) authorized the establishment of the Muscular Dystrophy Coordinating Committee to coordinate activities relevant to the various forms of muscular dystrophy across NIH and other Federal agencies. The committee also includes members from patient organizations.

Participating Institutes and Centers: NINDS, NIAMS, NICHD, and NHLBI

Web site: http://www.ninds.nih.gov/find_people/groups/mdcc/index.htm

12. NIH Autism Coordinating Committee

In 1997, at the request of Congress, the NIH formed the Autism Coordinating Committee (NIH/ACC) to enhance the quality, pace, and coordination of efforts at the NIH to find a cure for autism. Since then, the NIH/ACC has been instrumental in the research into, understanding of, and advances in autism (e.g., the creation of several research centers and networks to enhance the coordination and focus of autism researchers throughout the country).

Participating Institutes and Centers: NIMH, NICHD, NIDCD, NINDS, NIEHS, NIAID, NINR, and NCCAM

Web site: <http://www.nimh.nih.gov/research-funding/scientific-meetings/recurring-meetings/iacc/nih-initiatives/nih-autism-coordinating-committee.shtml>

13. NIH Biomedical Information Science and Technology Initiative Consortium

The mission of this consortium is to make optimal use of computer science and technology to address problems in biology and medicine by fostering new basic understandings, collaborations, and transdisciplinary initiatives between the computational and biomedical sciences.

Participating Institutes and Centers: NIGMS, CC, CIT, CSR, FIC, NCI, NCRR, NCMHD, NEI, NHLBI, NHGRI, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDCR, NIDDK, NIEHS, NIMH, NINDS, NINR, NIA, NIDCD, NIDA, NLM, ODP, OER, OIR, OLPA, OM, DPCPSI, ORS, and OSP

Web site: <http://www.bisti.nih.gov/>

14. NIH Blueprint for Neuroscience Research

The NIH Blueprint for Neuroscience Research is a cooperative effort among the 16 NIH ICs and offices that support neuroscience research. By pooling resources and expertise, the Blueprint supports the development of new tools, training opportunities, and other resources to assist neuroscientists in both basic and clinical research.

Participating Institutes and Centers: NCCAM, NCRR, NEI, NIA, NIAAA, NIBIB, NICHD, NIDA, NIDCD, NIDCR, NIEHS, NIGMS, NIMH, NINDS, NINR, and OBSSR

Web site: <http://neuroscienceblueprint.nih.gov/>

15. NIH Cognitive and Emotional Health Project Steering Committee

The Cognitive and Emotional Health Project is an ongoing trans-NIH initiative to assess the state of epidemiologic research on demographic, social and biologic determinants of cognitive and emotional health in aging populations, and the pathways by which cognitive and emotional health may reciprocally influence each other.

Participating Institutes and Centers: NIMH, NIA, and NINDS

Web site: <http://trans.nih.gov/CEHP/>

16. NIH Extramural Program Management Committee Workgroup on Management and Monitoring of International Awards

This group aims to develop “Best Practices” or Standard Operating Procedures for management and oversight of NIH grant awards in developing countries. The Working Group consists of a steering committee and the following four subcommittees: tracking, financial and program administration, ethics, and institutional capacity.

Participating Institutes and Centers: NIAID, NICHD, NIMH, NHLBI, NCI, FIC, NIDCR, NIA, NCCAM, NEI, NIH CC, NIGMS, NHGRI, and OD

17. NIH International Tuberculosis Working Group

NIH tuberculosis (TB) research is coordinated through monthly meetings of the NIH International TB Working Group. NIH-funded domestic and international research includes studies to characterize drug resistance; the identification, preclinical

development, and clinical evaluation of new drugs, diagnostics, and vaccines; and studies of the epidemiology and transmission of TB, including research addressing HIV/TB co-infection and TB in high-risk populations. These meetings often are attended by experts from other agencies as well, including USAID, FDA, and CDC.

Participating Institutes and Centers: NIAID, NHLBI, NICHD, NIDA, NIGMS, and FIC

18. NIH Intramural Research Program (IRP) Promotion

The NIH Scientific Directors have created a committee whose charge is to “build awareness and improve the visibility of the NIH Intramural Research Program.” This will be achieved by:

- clearly explaining how the research done here improves people’s lives
- showcasing the talents of our scientists, clinicians, and professional staff
- providing information on how we are training the “next generation” of biomedical scientists
- promoting participation in clinical research studies done at the NIH Clinical Research Center

Participating Institutes and Centers: All NIH ICs

Web site: <http://iamintramural.nih.gov/>

19. NIH Molecular Genetics Testing Subcommittee

The NIH Molecular Genetics Testing Subcommittee of the NIH Medical Executive Committee was convened in January of 2008 to evaluate the recent history of molecular genetic testing and payment strategies at the NIH Clinical Center. A long-term goal is a trans-NIH molecular genetics testing facility to meet the needs of the Clinical Center patient population, contribute to the NIH training and education mission, and foster innovative intramural-extramural research partnerships. The Subcommittee continues to assist the Clinical Center in negotiating test prices with external commercial laboratories, to ensure optimal test ordering by users of the Clinical Center, and to advise the Clinical Center leadership on the evolving role of molecular genetic testing in clinical medicine and translational research.

Participating Institutes and Centers: NCI, NICHD, NEI, NINDS, NHGRI, NIAMS, and CC

20. NIH Neuroprosthesis Group (NPG)

The NPG is a working group of program officers across NIH with an interest in promoting neuroprosthesis and neuroengineering research. Activities include the

discussion of planning trans-NIH initiatives, co-funding grants and contracts and participating on joint site visits to mutually funded investigators.

Participating Institutes and Centers: NIBIB, NINDS, NICHD, NIDCD, and NIMH

21. NIH Obesity Research Task Force

Given the importance of the obesity epidemic as a public health problem, the NIH Obesity Research Task Force was established to accelerate progress in obesity research across the NIH. Co-chaired by the Directors of NIDDK and NHLBI, the Task Force has been instrumental in fostering trans-NIH collaboration in obesity research, including basic, clinical, and population studies. The Task Force also sponsors an NIH seminar series on obesity research topics.

Participating Institutes and Centers: NIDDK, NHLBI, NEI, NCI, NHGRI, NIA, NIAAA, NIAMS, NIBIB, NICHD, NIDCR, NIDA, NIEHS, NIMH, NINDS, NINR, NCCAM, NCMHD, NCRR, FIC, CSR, OBSSR, ODS, ODP, ORWH, and DNRC

Web site: <http://obesityresearch.nih.gov>

22. NIH Pain Consortium

The NIH Pain Consortium was established to enhance pain research and promote collaboration among researchers across the many NIH ICs that have programs and activities addressing pain. These activities include research on sensory and basic mechanisms, as well as the emotional and biobehavioral aspects of pain. Age, sex, hormones, gender, ethnicity, and genetics all play a role in pain response and perception. The hope is that through increased knowledge of basic pain mechanisms, better pain management will result.

Participating Institutes and Centers: NINR, NINDS, NIDCR, NIDA, NCCAM, NCI, NIGMS, NICHD, NIA, NIAMS, NIMH, NIAAA, NIBIB, NIDCD, NCRR, NEI, FIC, CC, OBSSR, OTT, ORDR, and ORWH

Web site: <http://painconsortium.nih.gov>

23. NIH Population Modeling Special Interest Group (POPMOD SIG)

This group of 13 ICs convened to raise awareness across NIH of the various population modeling programs supported by the NIH. Population modeling includes disease and disorder modeling, which predicts the impact of disease control efforts to a defined population. In addition the group is exploring ways to integrate population modeling

efforts with basic science modeling efforts to promote mechanism-based disease prediction population models.

Participating Institutes and Centers: NIBIB, FIC, NCI, NHLBI, NIA, NIAAA, NICHD, NIDA, NIDCR, NIDDK, NIGMS, NIMH, and OD

24. NIH Proteomics Interest Group (ProtIG)

ProtIG is an NIH Special Interest Group that organizes seminars and workshops in relevant areas of proteomics, including talks on separation and protein identification methods, determination of posttranslational modifications, protein-protein interactions, and bioinformatics and data management. A monthly seminar series is held to foster interaction among the ICs and research community.

Participating Institutes and Centers: NCI, NHLBI, NIAID, NIMH, NCBI, NIAMS, NIDDK, NHGRI, NICHD, NINDS, NCRR, NIAAA, and NIEHS

Web site: <http://proteome.nih.gov>

25. NIH Sequencing Data Sharing Policy Working Groups

The Data Release Policy Working Group will: (a) develop a statement describing the objective/rationale for an NIH-wide policy for the release of genomic sequence data; (b) state the over-arching principles upon which this policy will rest; (c) define the types of projects to which an NIH-wide sequence data release policy will apply; and (d) address issues pertaining to identifiability of human sequence data. The Data Release Technical Working Group will describe the technical issues that need to be taken into account in the development of an NIH-wide policy for the deposition and release of data from sequencing projects, specifically including those using “next-generation” sequencing instruments.

Participating Institutes and Centers: NIDCR, NHGRI, NIAID, NIMH, NHLBI, NCBI, NIDDK, NIA, NIDA, NCI, and NINDS

26. NIH Stem Cell Task Force

The purpose of the Task Force is to enable and accelerate the pace of stem cell research by identifying rate-limiting resources and developing initiatives to overcome barriers to progress.

Participating Institutes and Centers: NINDS, NIDCD, NIDDK, NHLBI, NCI, NCRR, NEI, NICHD, NIDCR, NIGMS, OTT, OER, and OSP

Web site: <http://stemcells.nih.gov/policy/taskforce/>

27. NIH Task Force on the Future of Emergency Care

In response to a set of 2006 reports from the Institute of Medicine's Committee on the Future of Emergency Care in the United States Health Care System, the NIH created a Task Force on the Future of Emergency Care to review research and research training opportunities relevant to acute illness in the prehospital and Emergency Department (ED) setting. The NIH convened a series of roundtables with emergency medicine research experts in 2008 and 2009, focusing on research opportunities and needs. The roundtables were guided by the responses to a Request for Information, released on June 2008, which solicited input from the greater extramural research community.

Participating Institutes and Centers: NINDS, CIT, CSR, CC, NCI, NCRR, NCMHD, NHLBI, NHGRI, NIA, NIAAA, NIAID, NIBIB, NICHD, NIDCR, NIDDK, NIDA, NIEHS, NIGMS, NIMH, NINR, NLM, and OD

Web site: <http://grants.nih.gov/grants/guide/notice-files/NOT-NS-08-021.html> (Request for Information Notice)

28. Participant Protection and Data Management Steering Committee (PPDM)

The NIH Genome-Wide Association Studies (GWAS) Participant Protection and Data Management Steering Committee (PPDM) advises the Senior Oversight committee of the programmatic and policy needs and opportunities related to ensuring robust policies and mechanisms for providing privacy and other research protections to the interests of individuals whose data reside within the NIH GWAS data repository. The PPDM serves as the principal trans-NIH committee to promote communication across the ICs and to initiate the development and ongoing review of specific policies and procedures related to issues of participant protection in GWAS data submission, data management, and data distribution.

Participating Institutes and Centers: All NIH ICs with a Data Access Committee (currently NIGMS, NCI, NEI, NIAID, NINDS, NHGRI, NHLBI, NIDDK, NIA, NIDA, NIDCR) and other expertise from OER, OHSR, and OGC

29. Public Health Genomics Interest Group (PHGIG)

This monthly seminar series, led by NCI's Cancer Control and Population Sciences Division, facilitates the exploration of ongoing, planned, and future initiatives led by the NIH and other groups designed to accelerate the process for integrating advances in genomics and related fields into practice.

Participating Institutes and Centers: All NIH ICs

Web site: <http://cancercontrol.cancer.gov/od/phg/seminar.html>

30. Specimen Resource Locator Working Group

The purpose of this group is to develop a single system for researchers to locate biorepositories. The initiative is also open to all ICs and involves biorepository vendors who supply software to the NIH. The project is being developed within the scope of the BigHealth and caBIG initiatives.

Participating Institutes and Centers: NCI, NIDDK, and ORDR

31. Translational Research Interest Group

The purpose of this group is to bring physicians and scientists from various disciplines together to discuss: 1) efficient ways to accelerate the application of biomedical research discoveries to better help patients and 2) the translation of clinical research observations into the development of improved preclinical disease models. This intramural scientific interest group coordinates seminars and workshops to help bridge the gap between laboratory research and clinical applications.

Participating Institutes and Centers: NIAID, NCI, NICHD, CC, NIGMS, NIMH, NHLBI, NCR, NIDA, NINDS, NIAAA, CSR, NHGRI, NIA, NINR, NLM, NEI, NIEHS, NIBIB, NIDCR, NIDDK, and FDA/CDER

Web site: <http://sigs.nih.gov/trig/Pages/default.aspx>

32. Trans-NIH Angiogenesis Program (TARP) Steering Committee

The TARP was established to encourage and facilitate the study of the underlying mechanisms controlling blood vessel growth and development; identify specific targets and to develop therapeutics against pathologic angiogenesis in order to reduce the morbidity due to abnormal blood vessel proliferation in a variety of disease states; better understand the process of angiogenesis and vascularization to improve states of decreased vascularization; encourage and facilitate the study of the processes of lymphangiogenesis; and achieve these goals through a multidisciplinary approach, bringing together investigators with varied backgrounds and varied interests.

Participating Institutes and Centers: NICHD, NHLBI, NCI, NIDDK, NEI, and NINDS

Web site: <http://www.tarp.nih.gov/index.html>

33. Trans-NIH Bioethics Committee (T-NBC) Human Data and Specimen Subcommittee (DSC)

This Committee/Subcommittee is charged with developing NIH policy to guide the collection, storage, sharing, distribution and use of human specimens and/or data to advance basic/clinic biomedical and behavioral research that is translated into discoveries to improve health care. Drafted policy is reviewed for technical issues by NIH sibling agencies through the Trans-HHS Taskforce on Harmonization of Ethical and Legal Policies Related to the Use of Human Specimens and Data in Research (HELPS).

Participating Institutes and Centers: All NIH ICs and OD

34. Trans-NIH Biomedical Informatics Coordinating Committee

The Trans-NIH Biomedical Informatics Coordinating Committee was established in the spring of 2007 to improve communication and coordination of issues related to clinical and bio-informatics at NIH. The Committee provides a forum for sharing information about NIH informatics programs, projects, and plans, including their relationship to activities of other Federal agencies and non-Government organizations. At the Director's request, it coordinates NIH's input into external informatics forums and initiatives, including those related to information technology standards development.

Participating Institutes and Centers: NIAID, NIGMS, NHLBI, NCI, NIEHS, NIAAA, NIDDK, CC, NIBIB, NCCR, NLM, NINR, NHGRI, OER, OSPA, NIMH, CIT, FIC, NINDS, NIDCD, NIDCR, CSR, NICHD, and NIAMS

35. Trans-NIH Brain Tumor Committee

The mission of this committee is to advance basic, translational, and clinical brain tumor research by facilitating trans-Institute and cross-Division collaborations and promoting communication with the brain tumor advocacy and research communities. Strategies in support of the mission include: organizing meetings focused on brain tumor research; identifying opportunities for collaboration, including leveraging of relevant resources and expertise; developing integrated collaborative approaches that capitalize on the unique strengths of different ICs; prioritizing brain tumor research initiatives; improving accessibility to, and promoting sharing of information about NIH brain tumor-related activities, opportunities, and resources; and enhancing interactions with brain tumor advocacy groups.

Participating Institutes and Centers: NCI and NINDS

36. Trans-NIH Consortium on Enhancing Development of Genome-wide Association Methods (ENDGAME)

This Consortium develops computational methods for genome-wide association studies.

Participating Institutes and Centers: NHLBI, NIEHS, NCI, NHGRI, and NIGMS

Web site: <http://riskfactor.cancer.gov/tools/pharmaco/gen/endgame.html>

37. Trans-NIH Coordinating Committee for Lymphatic Research

The Trans-NIH Coordinating Committee for Lymphatic Research was established in 2002 to stimulate and coordinate research efforts in lymphatic biology and its diseases through the use of initiatives and working groups across the NIH.

Participating Institutes and Centers: NHLBI, NCI, NIAID, NEI, NIDDK, NINR, NCRR, NICHD, NIAMS, CSR, and ORDR

38. Trans-NIH Diabetes Complications Working Group

This working group meets to discuss the status of current projects and potential ideas for future projects about complications of diabetes mellitus.

Participating Institutes and Centers: NIDDK, NHLBI, NEI, and NIMH

39. Trans-NIH Endocrine Group

The Trans-NIH Endocrine Group meets once every two months to discuss topics related to endocrine research. The topics include scientific discussions and review and program issues in this area, as well as facilitating extramural endocrine research.

Participating Institutes and Centers: NIA, NIAAA, NIDDK, NICHD, CSR, and NCI

40. Trans NIH Fragile X Research Group

The charge of this trans-NIH working group is to develop comprehensive recommendations for specific, high-priority research objectives for Fragile X Syndrome (FXS) and the associated disorders of FXTAS and FXPOI. The working group is composed of scientific experts from the research and clinical communities, along with representatives of affected individuals and family members, other pertinent Federal agencies and invested NIH ICs. The recommendations are designed to be used by the NIH and FXS, FXTAS, and FXPOI research communities and to be shared with other

Federal agencies to facilitate coordinated research activities that will lead to timely detection, diagnosis, treatment, and prevention of the targeted disorders.

Participating Institutes and Centers: NICHD, NIDDK, NIA, NIMH, NCRR, NINDS, and ORDR

Web site:

http://www.nichd.nih.gov/publications/pubs_details.cfm?from=&pubs_id=5729

41. Trans-NIH Global Health Research Working Group

The Working Group was established to explore, develop, and oversee specific actions the NIH could take to support ICs' international research engagements. The group meets quarterly and convenes advisory subgroups, as needed, to analyze issues and develop recommendations for individual IC or cross-NIH consideration.

Participating Institutes and Centers: CC, CSR, FIC, OAR, NIA, NCCAM, NCI, NCRR, NIAID, NIBIB, NICHD, NHGRI, NEI, NHLBI, NIAMS, NIDA, NIDCR, NIDDK, NIEHS, and NLM

42. Trans-NIH Hydrocephalus Working Group

This group focuses on hydrocephalus and related disorders, such as neural tube defects, that often lead to hydrocephalus. The group meets twice a year to share information and identify research priorities and opportunities for collaboration across NIH and with industry and private organizations.

Participating Institutes and Centers: NINDS, NICHD, and NIBIB

43. Trans-NIH Nanotechnology Task Force: Health Implications Working Group

The NIH Director established the Trans-NIH Nanotechnology Task Force in April 2006 and charged it with developing an NIH-wide scientific and policy vision for nanotechnology. A subset of the Task Force is the Health Implications Working Group, which was established to develop and assist in coordinating a trans-NIH plan to determine the fundamental interactions of engineered nanomaterials with biological systems and the physicochemical principles that may be exploited to maximize biocompatibility and biomedical application of nanotechnology.

Participating Institutes and Centers: FIC, NCI, NCMHD, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDA, NIDCD, NIDDK, NIDCR, NIEHS, NIGMS, NIMH, NINDS, NINR, and NLM

Web site: <http://www.nih.gov/science/nanotechnology/index.htm>

44. Trans-NIH Sarcoidosis Committee

This group coordinates sarcoidosis research activities across the NIH.

Participating Institutes and Centers: NHLBI, NIAMS, NEI, NIDDK, NINDS, NINR, ORDR, and ORWH

45. Trans-NIH Women's Health Research Group

The Trans-NIH Women's Health Research group is organized to support and encourage research in women's health issues at the basic, translational, and clinical levels to include the biology and diseases status of different organ systems. The committee organizes a monthly symposium series and a mentoring program for fellows supported to perform research studies focusing on women's health diseases.

Participating Institutes and Centers: NIEHS, NCI, NEI, NICHD, NIDDK, NHLBI, NLM, and ORWH

46. Trans-NIH Xenopus Coordinating Committee

The Trans-NIH Xenopus Initiative was established in 1999 for the creation of critical community-wide resources for Xenopus models that would aid in the understanding of embryonic development, organogenesis, oncogenesis, and cell biological processes. This initiative includes genomic and genetic resources, scientific meetings, and research program announcements.

Participating Institutes and Centers: NICHD, NCI, NEI, NCRR, NIDCR, NIGMS, NIDCD, NIDDK, NIEHS, NIMH, and NINDS

Web site: <http://www.nih.gov/science/models/xenopus/>

47. Trans-NIH Zebrafish Coordinating Committee

The Trans-NIH Zebrafish Coordinating Committee was established in 1997 to promote the use of zebrafish to study vertebrate development and disease. The initiatives include NIH-sponsored courses and meetings, zebrafish genomic and genetic resources, selected reports and publications, and research initiatives such as Program Announcements PAR-08-138 (*Genetic Screens to Enhance Zebrafish Research*) and PAR-08-139 (*Enhancing Zebrafish Research with Research Tools and Techniques*).

Participating Institutes and Centers: NICHD, NIDDK, NCI, NEI, NHLBI, NIA, NIAAA, NIAMS, NIDCD, NIDCR, NIDA, NIEHS, NIMH, and NINDS

Web site: <http://www.nih.gov/science/models/zebrafish/>

48. U.S.-India Joint Working Group on Prevention of Sexually Transmitted Infections (STIs) and HIV/AIDS

This bilateral program between the United States and India was established in June 2006 with the signing of a Joint Statement on the Prevention of STIs and HIV. The program aims to facilitate successful U.S. and Indian research collaborations involving trans-NIH efforts.

Participating Institutes and Centers: NIAID, FIC, NHLBI, NIAAA, NIAID, NICHD, NIMH, NCI, NIDA, and OAR

III. Educational Campaigns and Clearinghouses

1. AIDSinfo

NLM manages *AIDSinfo*, an HHS project that offers the latest Federal Government approved information about HIV/AIDS medical practice guidelines and clinical trial research in treatment and prevention for health care providers, researchers, people affected by HIV/AIDS, and the general public. The medical practice guidelines are developed by working groups under the auspices of the Office of AIDS Research Advisory Council. These working groups include pharmacists, physicians, researchers, and HIV treatment advocates from across the country. InfoSIDA, a Spanish-language version, features a customized Home page and Spanish language services.

Participating Institutes and Centers: NLM, NIAID, and OAR

2. “Are You at Risk for Oral Cancer? What African American Men Need to Know”

Designed to promote early detection of oral cancer among African American men, this campaign consists of a brochure, posters, and a card describing the oral cancer exam. All materials are currently available on NIDCR’s Web site; printed copies are also available. NIDCR and NCI are now preparing campaign kits for distribution to NCI community-based cancer networks that reach African Americans. The kits were also distributed to health organizations, African American community groups, and churches around the country in FY 2009.

Participating Institutes and Centers: NIDCR and NCI

3. Children and Clinical Studies Educational Web Resource

Children and Clinical Studies is a Web-based educational tool designed to equip parents and children with the information they need to understand clinical research and make informed decisions about participating in a pediatric study. The site combines text, graphics, and documentary films of experts, parents, and children sharing their experiences with pediatric clinical research.

Participating Institutes and Centers: NHLBI, NCRR, and NICHD

Web site: <http://www.nhlbi.nih.gov/childrenandclinicalstudies/index.php>

4. ClinicalTrials.gov (Registry of Clinical Research)

ClinicalTrials.gov was established in 2000, in part, pursuant to the Food and Drug Modernization Act of 1997, P.L. 105-115, to provide a public resource of information on clinical research. ClinicalTrials.gov currently contains registration information for more than 82,000 trials sponsored by the NIH, other Federal agencies, and private industry. Studies listed in the database are conducted in all 50 States and in 170 countries.

Participating Institutes and Centers: NLM, NCI, NEI, NHLBI, NHGRI, NIA, NIAAA, NIAID, NIAMS, NICHD, NIDCD, NIDCR, NIDDK, NIDA, NIEHS, NIGMS, NIMH, NINDS, NINR, NIBIB, CC, NCCAM, and OD

Web site: www.ClinicalTrials.gov

5. Evolution in Medicine Curriculum Supplement Committee

This is a trans-NIH effort to work with a contractor with education curriculum publication experience to develop a one-week-long curriculum supplement for high school biology classes studying evolution. The goal will be to provide students with examples of how evolution impacts modern biomedicine.

Participating Institutes and Centers: NIGMS, NIDCR, NEI, NINDS, NHLBI, NIAID, NIDA, NIA, NCI, NCRR, and OSE

6. Introduction to the Principles and Practice of Clinical Research

This activity, established at the NIH Clinical Center, is a study curriculum on how to effectively conduct clinical research. Most medical schools lack a formal course in training for clinical research, and investigators have relied on mentors to learn how to conduct clinical trials. The program trains researchers in how to design a successful clinical trial by focusing on epidemiologic methods, study design, protocol preparation, patient monitoring, quality assurance, and FDA issues. Other areas covered include data management and ethical issues, including protection of human subjects.

Participating Institutes and Centers: CC, NCCAM, NEI, NIA, NIMH, NIAID, and NCI

Web site: <http://www.cc.nih.gov/training/training/ippcr.html>

7. MedlinePlus and MedlinePlus en español

MedlinePlus and *MedlinePlus en español* are health information portals that bring together NIH and other government and authoritative health information for patients,

families, and professionals. MedlinePlus links to over 5,200 consumer health Web documents in English, and almost 750 in Spanish, from nearly every NIH IC.

Participating Institutes and Centers: NLM, OD, NCI, NEI, NHLBI, NHGRI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDCD, NIDCR, NIDDK, NIDA, NIEHS, NIGMS, NIMH, NINDS, NINR, NCCAM, NCMHD, and CC

Web site: <http://medlineplus.gov>, <http://medlineplus.gov/salud>

8. National Asthma Education and Prevention Program

This program seeks to enhance the quality of life for patients with asthma and decrease asthma-related morbidity and mortality by improving asthma awareness, diagnosis, and treatment.

Participating Institutes and Centers: NHLBI, NIAID, and NIEHS

Web site: <http://www.nhlbi.nih.gov/about/naepp/index.htm>

9. National Eye Health Education Program Partnership

The Partnership was established by the NEI to promote collaboration on eye health education for higher risk audiences, including people with diabetes, people over age 60, and people with a family history of eye disease.

Participating Institutes and Centers: NEI, NIDDK, and NIA

Web site: <http://www.nei.nih.gov/nehep>

10. NIH MedlinePlus Magazine

The *NIH MedlinePlus Magazine* is a trans-NIH collaboration to aid the translation of NIH-sponsored research results for the benefit of patients, families, and the general public. Articles are written in plain language with the assistance of IC investigators and communications staff. The magazine contains no advertising and is distributed free of charge to doctors' offices and hospitals throughout the country.

Participating Institutes and Centers: All NIH ICs

11. NIH Osteoporosis and Related Bone Diseases—National Resource Center

This information clearinghouse provides patients, health professionals, and the public with an important link to resources and information on metabolic bone diseases. The mission is to expand awareness and enhance knowledge and understanding of the prevention, early detection, and treatment of these diseases, as well as strategies for coping with them.

Participating Institutes and Centers: NIAMS, NIA, NICHD, NIDCR, NIDDK, and ORWH

Web site: http://www.niams.nih.gov/Health_Info/Bone/

12. SciLife

SciLife is an annual event that provides free information, resources, and organizational tools to help high school students and their parents plan for college and explore career options in the health and medical sciences. The NIH Office of Science Education (OSE) joins forces with area leaders in science education to offer the program to people in the Washington, D.C., metropolitan area.

Participating Institutes and Centers: NHGRI, NIAID, NIDDK, and OSE

13. Trans-NIH American Indian and Alaska Native Health Communications and Information Workgroup

The workgroup, which includes participants from health education and communications staff from across the NIH, has formed a partnership with the Indian Health Service to disseminate NIH health information to approximately 1700 community health representatives.

Participating Institutes and Centers: NIAMS, NCI, NEI, NHGRI, NHLBI, NIA, NICHD, NIDA, NIDCR, NIDDK, NIGMS, NLM, NCRR, and ORWH

14. Trans-NIH Communications Group on Common Diseases

This Group aims to develop and implement a cohesive communications plan to inform and educate both the public and health professionals about the genetics of common disease and traits. The Group's plan includes developing Web-based information regarding how to understand the implications of data generated by genome-wide association studies, how to interpret such data, and how to use it in personalized health care. As a first step, the Group is collecting empirical data regarding the views of

consumers and health professionals and conducting a scientific literature review and an environmental scan that will inform the work of the Group.

Participating Institutes and Centers: NHGRI, NCI, NHLBI, NIAID, NIDA, NIDCR, NIDDK, NIEHS, NIMH, NINDS, NLM, OCPL, OIR, OSP, CDC, and HHS

15. Trans-NIH Working Group on Genetics for the Public

The mission of this working group is to foster trans-NIH discussions of strategies to improve genetics education for the public, including information about genetic and genomic research. The Group has developed a pamphlet and 2-page fact sheet entitled “Genetic Testing: What it Means for You and Your Family,” now posted on the NHGRI health Web pages <http://www.genome.gov/19516567>.

Participating Institutes and Centers: NHGRI, ORD, NLM, NICHD, NCI, OD, NIAMS, and NINR

16. We Can! “Ways to Enhance Children’s Activity and Nutrition”

We Can! is a national program designed for families and communities to help children maintain a healthy weight.

Participating Institutes and Centers: NHLBI, NIDDK, NICHD, and NCI

Web site: <http://www.nhlbi.nih.gov/health/public/heart/obesity/wecan/index.htm>

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Appendix 3: Key to Acronyms

AHA – American Heart Association

CC – Clinical Center

CDC – Centers for Disease Control and Prevention, HHS

CDER –Center for Drug Evaluation and Research, FDA

CIT – Center for Information Technology

CSR – Center for Scientific Review

DNRC – Division of Nutrition Research Coordination

DPCPSI – Division of Program Coordination, Planning, and Strategic Initiatives, OD

FDA – Food and Drug Administration, HHS

FIC – Fogarty International Center

HHS – Department of Health and Human Services

IC – NIH Institute or Center

NCBI – National Center for Biotechnology Information, NLM

NCCAM – National Center for Complementary and Alternative Medicine

NCI – National Cancer Institute

NCMHD – National Center on Minority Health and Health Disparities

NCRR – National Center for Research Resources

NEI – National Eye Institute

NHGRI – National Human Genome Research Institute

NHLBI – National Heart, Lung, and Blood Institute

NIA – National Institute on Aging

NIAAA – National Institute on Alcohol Abuse and Alcoholism

NIAID – National Institute of Allergy and Infectious Diseases

NIAMS – National Institute of Arthritis and Musculoskeletal and Skin Diseases

NIBIB – National Institute of Biomedical Imaging and Bioengineering

NICHD – *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

NIDA – National Institute on Drug Abuse

NIDCD – National Institute on Deafness and Other Communication Disorders

NIDCR – National Institute of Dental and Craniofacial Research

NIDDK – National Institute of Diabetes and Digestive and Kidney Diseases

NIEHS – National Institute of Environmental Health Sciences

NIGMS – National Institute of General Medical Sciences

NIMH – National Institute of Mental Health

NINDS – National Institute of Neurological Disorders and Stroke

NINR – National Institute of Nursing Research

NLM – National Library of Medicine

OAR – Office of AIDS Research, DPCPSI, OD

OBSSR – Office of Behavioral and Social Sciences Research, DPCPSI, OD

OCPL – Office of Communications and Public Liaison, OD

OD – Office of the Director, NIH

ODP – Office of Disease Prevention, DPCPSI, OD

ODS – Office of Dietary Supplements, ODP, DPCPSI, OD

OER – Office of Extramural Research, OD

OGC – Office of the General Counsel, HHS

OHSR – Office of Human Subjects Research, OIR, OD

OIR – Office of Intramural Research, OD

OLPA – Office of Legislative Policy and Analysis, OD

OM – Office of Management, OD

ORDR – Office of Rare Diseases Research, ODP, DPCPSI, OD

ORS – Office of Research Services, OM, OD

ORWH – Office of Research on Women’s Health, DPCPSI, OD

OS – Office of the Secretary, HHS

OSE – Office of Science Education, OSP, OD

OSP – Office of Science Policy, OD

OSPA – Office of Science Policy Analysis, OSP, OD

OTT – Office of Technology Transfer, OIR, OD

USAID – U.S. Agency for International Development

VA – Department of Veterans Affairs