

**Report of Trans-National Institutes of Health Research
Conducted in Fiscal Year 2008**

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 2008

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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 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 second 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 2008) 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 the NIH Roadmap for Medical Research 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 cofunded 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. 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. These include 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. 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 major DPCPSI offices are:

- Office of Portfolio Analysis and Strategic Initiatives (OPASI), which oversees collaborative efforts across the NIH to plan, implement, and manage the NIH Roadmap for Medical Research. These programs are funded via the Common Fund and 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 to provide additional support for the Roadmap. 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 Diseases. 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 coordinates the scientific, budgetary, and policy elements of the NIH AIDS program. OAR prepares an annual comprehensive trans-NIH strategic plan and budget for all NIH-sponsored AIDS research, identifies emerging scientific opportunities that require focused attention, manages and facilitates multi-Institute activities in priority areas, sponsors reviews or evaluations of research program areas, tracks and monitors all NIH AIDS expenditures, and facilitates NIH involvement in international AIDS research activities.

Many of the collaborative activities reflected in Appendix 1 include one or more of these DPCPSI offices as active participants, even though for the purposes of this report the contributions of the DPCPSI offices are not reflected in the budget numbers.

The budget numbers do not include 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 10 years ago, 135 collaborative projects have received funding, representing partnerships among multiple NIH Institutes and Centers. Recently, the program expanded in scope to encourage partnerships between intramural and extramural NIH clinical researchers. Since 2006, 46 of 54 awards represent partnerships between intramural investigators from 14 ICs and 39 extramural grantee institutions.

Additional exclusions from this report are (a) activities involving NIH collaboration with other agencies within HHS (these types of activities are included in the FY 2007 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 latter 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 2008 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 2008) 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 2008 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.

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 Roadmap and 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.

Appendix 1

IC Collaborative Activity Summary - FY 2008 (\$ 000)

FUNDING IC	FY 2008 Enacted	Total Collaborative Activities	Percent for Collaborative Activities
FIC	\$ 66,912	\$ 46,148	69.0%
NCCAM	122,224	51,220	41.9%
NCI	4,830,647	837,623	17.3%
NCMHD	200,630	44,405	22.1%
NCRR	1,155,560	401,955	34.8%
NEI	670,664	120,909	18.0%
NHGRI	489,368	148,088	30.3%
NHLBI	2,937,654	570,478	19.4%
NIA	1,052,830	221,640	21.1%
NIAAA	438,579	106,229	24.2%
NIAID	4,583,344	977,675	21.3%
NIAMS	511,291	136,947	26.8%
NIBIB	300,233	138,758	46.2%
NICHD	1,261,381	390,063	30.9%
NIDA	1,006,022	238,423	23.7%
NIDCD	396,234	76,959	19.4%
NIDCR	392,233	97,192	24.8%
NIDDK	1,715,761	412,290	24.0%
NIEHS	645,669	147,991	22.9%
NIGMS	1,946,104	281,602	14.5%
NIMH	1,412,951	465,972	33.0%
NINDS	1,552,113	436,951	28.2%
NINR	138,207	60,709	43.9%
NLM	322,212	10,503	3.3%
IC Grand Total	\$ 28,148,823	\$ 6,420,729	22.8%

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Appendix 2

**Examples of Collaborative Activities not Fully Demonstrated
in the Budget Data**

I. Conferences, Workshops, and Meetings

**1. Manipulation of the Host Immune Response: Exploring the Crossroads of
Infectious Disease and Cancer**

Through an interdisciplinary symposium, leading scientists shared their research with the greater NIH community to foster interactions and forge future collaborations. In particular, the symposium highlighted the importance of connecting basic, translational, and clinical research and explored the commonality of host immune responses to cancer and infectious diseases.

Participating Institutes and Centers: NCI and NIAID

Web site: <http://guest.cvent.com/EVENTS/Info/Summary.aspx?e=192fc661-2f26-4f14-ad91-9b5b4814fd37>

2. Trans-NIH Systems Biology Conference

A trans-NIH systems biology meeting was held on June 26–27, 2008. Day 1 featured talks by 16 individuals who were instrumental in establishing a systems biology program at their host institution. Day 2 was a half-day meeting for the speakers and a smaller group of NIH scientists.

Participating Institutes and Centers: NIDDK, NCI, and NHLBI

3. NIH Mitochondria Minisymposium 2008: Mitochondria and their Proteomics

On January 9-11, 2008, the 3rd International NIH Mitochondria Minisymposium was held. The meeting had platform talks and poster sessions, as well as a plenary session by Douglas C. Wallace of the University of California-Irvine, a member of the National Academy of Sciences. Sessions centered on specific subsections of mitochondria as well

as “global concerns” of mitochondria, including clinical aspects of mitochondrial metabolism (and mitochondria from eukaryotes other than *H. sapiens*).

Participating Institutes and Centers: ODS, ORD, OIR, NCI, NEI, NHLBI, NIA, NIAAA, NIDA, NIDDK, NIEHS, NIMH, NINDS, and NINR

4. Image-Guided Interventions Workshop

This workshop was held on March 10-11, 2008, in conjunction with the National Center for Image-Guided Therapy (NCIGT) at Brigham & Women’s Hospital, Boston. The workshop achieved its aim of highlighting the current developments in the field of IGT and identified needs essential to move the field forward.

There was agreement among the IGT community that the lack of translation and validation studies hinders movement of new image-guided technologies into the clinic. The workshop also resulted in the identification of key needs: better surrogate markers and patient follow up; development of new chemotherapeutic agents; real time display; better probes for imaging and cell survival; better drug delivery methods, organized data collection from sites using various IG procedures to observe techniques being used successfully; development of truly intra-operative MRI to increase efficiency and aid patient safety; and data collection and validation/standardization methods.

Participating Institutes and Centers: NCI, NIBIB, and NCRR

5. Workshop for Next-Generation Methods of Peptide Identification

This workshop brought together bioinformatics researchers in the proteomics community to assess needs, strategies, and solutions for peptide identification by mass spectrometry.

Participating Institutes and Centers: NCI, NLM (NCBI), and NIST/DOC

6. “Cancer Research at Other NIH Institutes: Who is Doing What?”

This forum, sponsored by the NCI Trans-Extramural Awareness Group, was held September 16, 2008. Representatives from several ICs met to discuss a wide range of research topics related to their specific disease interest and cancer.

Participating Institutes and Centers: NCI, NIDA, NIDCR, NIAID, NICHD, NIAAA, NINDS, and CSR

7. Navigating the Translational Researcher through a Complex of Animal and Biological Resources

On August 19-20, 2008, a working group meeting was held in Seattle, Washington. The purpose of this meeting, entitled “Animal Models, Informatics and Access,” was to establish shared understanding and language between the disease models (life sciences) and the computational sciences communities. Discussion focused on life sciences-based data-use problems and existing technologies that might help bridge the gap between the disciplines. Finally, participants worked toward identifying unmet needs for which new technologies must be developed. The overall purpose of this activity is to promote a knowledge-base-driven resource to link and share NIH-supported disease models.

Participating Institutes and Centers: NCRR, NCI, NIDDK, NHLBI, NIA, NIAID, NIMH, NINDS, NINR, and OD

Web site:

http://www.ncrr.nih.gov/publications/comparative_medicine/animal_models_informatics_and_access.asp

8. Directors Regional Meeting on Aging Research

The purpose of this meeting on March 11, 2008, was to provide information on existing opportunities for research and training in the fields of aging and complementary and alternative medicine; provide hands-on technical assistance in grant writing; solicit advice on the design of new research opportunities; and gain strategies for recruiting under-represented students and investigators to aging and complementary and alternative medicine research.

Participating Institutes and Centers: NIA and NCCAM

9. The Role of Vascular Co-Morbidity in Neurodegenerative Diseases Resulting in Dementia and the Role of Vascular Factors in Other Cognitive, Affective, and Movement Disorders in Older Persons

This workshop was held on June 12-14, 2008, to examine the role of vascular changes in the development of neurodegenerative dementias, other cognitive conditions, and age-related motor and affective disorders.

Participating Institutes and Centers: NIA and NINDS

10. Pain in the Elderly

An exploratory workshop was held June-July 2008 to identify new opportunities that may promote understandings of the mechanisms, treatment, and management of pain in the aged. Topics ranged from basic research, including molecular, genetic, cellular, and circuitry mechanisms underlying pain perception and sensitivity in the elderly, to social and behavioral aspects of pain measurement, management, and intervention in elderly populations.

Participating Institutes and Centers: NIA, NCCAM, and NIDA

11. Symposium on Sex Differences in Drug Abuse

This symposium was held at the Second Annual Meeting of the Organization for the Study of Sex Differences in New Orleans, Louisiana. The presentations by NIH-supported investigators focused on 1) the role that reproductive and stress hormones play in mediating sex differences in drug and alcohol dependence, and 2) research that addresses stages of the life cycle.

Participating Institutes and Centers: NIAAA and NIDA

12. Preventing Alcohol, Tobacco, and Other Substance-exposed Pregnancies: A Community Affair

This symposium, held on September 23-24, 2008, explored the most effective approaches for informing the public about the potential harm caused by risky drinking and other substance use during the childbearing years and, in particular, the importance of abstaining from any and all drinking and smoking during pregnancy. This symposium was a starting point in a national effort to change the common misperception that alcohol and/or tobacco use during pregnancy is safe. Target audiences of this symposium included general health care providers, addiction prevention and treatment professionals, health policymakers, Fetal Alcohol Spectrum Disorder and other addiction researchers, social marketing professionals, and the general public.

Participating Institutes and Centers: NIAAA and NICHD

13. Genetics of Sarcoidosis Workshop

This meeting on July 25, 2008, brought together investigators to review the studies conducted in the last 10 years in sarcoidosis genetics and to define short- and long-term scientific goals.

Participating Institutes and Centers: NHLBI, NIAID, and ORD

14. Workshop on Transforming Regenerative Medicine: An Interdisciplinary Approach

This May 19-20, 2008, meeting brought together leaders in the multiple fields that constitute regenerative medicine to explore strategies for better coordination of biological knowledge, engineering technologies, clinical needs, and resources in order to advance the field of regenerative medicine.

Participating Institutes and Centers: NCRR, NIDDK, NEI, CSR, NIDCD, NIGMS, NIH/OD, NIBIB, NIA, NIDCR, NHLBI, NINDS, NIEHS, NCI, NIAMS, and NIDA

15. Roundtable: “Understanding the Role of Genomics in Health Disparities: Toward a New Research Agenda”

This activity convened a group of experts whose work is important to understanding the social, environmental, and genomic causes of health disparities. The meeting investigated the role of genomics in racial and ethnic health disparities. Specifically, the meeting addressed what we know now and what we need to learn about the role of genomics in racial and ethnic health disparities to inform the ICs’ research programs.

Participating Institutes and Centers: NHGRI, NCMHD, and NCI

16. Third International Conference on HIV Treatment Adherence

This conference, convened on March 17-18, 2008, focused on understanding and enhancing patient adherence to HIV treatment regimens by highlighting the most current HIV treatment adherence research, programs, and perspectives from more than 20 countries. The primary goal of the conference was to spur the rapid translation of scientific advances into clinical and community practice by strengthening the dialogue between government agencies, treatment providers, and researchers.

Participating Institutes and Centers: NIMH and NIDA

Web site: <http://www.iapac.org/AdherenceConference01.html>

17. Workshop on “Imaging Imagining: The Mirror System and Beyond - Neural Representation of the Self and Others”

The discovery of neurons that respond to both one’s own actions and the actions of others has been proposed as the basis for understanding critical aspects of social interactions such as intentionality and empathy. Because of the implications for both substance abuse and mental health, NIDA and NIMH conducted a workshop on February 21-22, 2008, to address gaps and opportunities in this rapidly developing field. This workshop consisted

of four sessions: 1) Imaging Cognitive-Emotion Interaction; 2) Imaging Thought and Intention of Self and Others; 3) Imaging Development and Clinical Abnormalities of Social Cognition; and 4) The Role of Imaging Imagining for Drug Abuse and Mental Health Research.

Participating Institutes and Centers: NIDA, and NIMH

18. “Can Physical Activity and Exercise Prevent Substance Use? Promoting a Full Range of Science to Inform Prevention”

The meeting was held on June 5-6, 2008, in Bethesda, Maryland. The purpose of the meeting was to provide a forum for scientists to share relevant research addressing the relationships between physical activity/exercise and biomedical and behavioral health, toward the aim of stimulating research to inform effective substance use prevention. Presenters raised a full range of potential neurobiological, developmental, social, and environmental processes associated with physical activity and the onset and progression of drug abuse.

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

Web site: <http://www.drugabuse.gov/whatsnew/meetings/exercise/index.html>

19. Spring 2008 Symposia Series on Mechanisms of Behavior Change

Mechanisms of behavior change (MOBC) generally refer to the underlying, basic psychological, social, and neurological processes that drive therapeutic change. This is a cross-cutting research area for NIH as the issues regarding behavioral change are common to various diseases, such as alcohol dependence, smoking, and obesity. In spring 2008, NIH sponsored a 3-part symposia series on MOBC to share findings and stimulate discussion in this research area.

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

20. Quantitative and Systems Pharmacology Workshop

The Quantitative and Systems Pharmacology Workshop, held on September 25-26, 2008, provided state-of-the-art knowledge and perspective about topics at the interface of systems biology and pharmacology to a highly diverse spectrum of researchers in academia, industry, and government. The Workshop addressed the question of where systems biology, modeling, and more quantitative measurements can be applied to advance pharmacology and drug discovery/action now and in the foreseeable future.

Participating Institutes and Centers: NIGMS, and NIBIB

21. Workshop on Measures of Psychosocial Stress

This January 2008 workshop, organized by OBSSR and several IC partners, included presentations by experts doing research on psychosocial stress as well as by investigators funded under the Exposure Biology Program of the NIH Genes, Environment and Health Initiative. The workshop offered the attendees the opportunity share ideas, identify opportunities for collaboration, and brainstorm a high-priority list of measures of psychosocial stress, all with an eye toward developing tools for use in large-scale epidemiologic studies.

Participating Institutes and Centers: NIDA, NCI, NIAAA, NIEHS, and OBSSR

II. Committees, Working Groups, and Task Forces

1. 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 Announcement PAR-08-138 (*Genetic Screens to Enhance Zebrafish Research*).

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/>

2. 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, NIGMS, NIDCD, NIDDK, NIEHS, NIMH, and NINDS

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

3. Genome-Wide Association Studies Workgroup

The goal of this workgroup is to develop and implement the genome-wide association studies (GWAS) policy. Currently, the group is focused on the implementation of policy designed to maximize the benefits of the numerous genome-wide studies and, at the same time, maintain the privacy and confidentiality of individual research participants.

Participating Institutes and Centers: All NIH ICs

Web site: <http://grants.nih.gov/grants/gwas/>

4. Trans-NIH Consortium on Enhancing Development of Genome-wide Association Methods

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

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

5. 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

6. Neurodegeneration Workgroup

The purpose of the Workgroup is to facilitate interaction of scientists working in neurodegeneration. The goal is to expand the group to include intramural scientists from several Institutes.

Participating Institutes and Centers: NINDS and NEI

7. NIH Chronic Graft Versus Host Disease Study Group

The NIH Intramural Chronic Graft Versus Host Disease (GVHD) Study Group was initiated in January 2003 with the goal of creating a high-quality multidisciplinary clinical and research program focusing on those challenges that can be uniquely addressed at the NIH. The main objectives are: establishing a multidisciplinary trans-NIH chronic GVHD clinic; creating a platform for developing chronic GVHD evaluation

tools; pursuing studies of chronic GVHD pathophysiology; developing new treatments; and providing leadership in the field—regional, national, and international.

Participating Institutes and Centers: NCI, ORD, NHLBI, NIAID, ORD, HRSA, and NNMC

Web site: <http://ccr.ncifcrf.gov/resources/gvhd/program.asp>

8. Microbicides Working Group

The Center for Cancer Research (CCR), NCI, is invigorating efforts towards the discovery and development of effective anti-HIV chemoprevention agents (microbicides). In June 2008, the CCR Center for Excellence in HIV and Cancer Virology hosted a broad spectrum of intramural and extramural investigators in an effort to coordinate CCR/NCI research plans with those at NIAID, NICHD, OAR, and extramural academic institutions and non-profit organizations. Seminars were presented on the current pipeline of anti-HIV chemoprevention agents and the significant hurdles that must be cleared for a useful agent to reach clinical utility. The day-long workshop helped to establish a foundation for greater interagency cooperation to enhance the development of effective anti-HIV chemoprevention agents (microbicides).

Participating Institutes and Centers: NCI, NIAID, NICHD, and OAR/OD

9. 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 serve as a nidus for innovative intramural-extramural research partnerships. The Subcommittee will continue to function 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

10. NIH Scientific Directors' Subcommittee on Biorepository Practices and Guidelines

The NIH Scientific Directors' Subcommittee on Biorepository Practices and Guidelines within the Intramural Research Program (IRP) was formed to make recommendations to

the Scientific Directors concerning biorepository practices and policies within the NIH IRP. The Subcommittee was charged with a) determining the scope and current conditions of biospecimen storage across the IRP; b) identifying steps needed to meet “best practices” guidelines for biospecimen storage; c) evaluating use of local harmonized biorepositories versus creation of a centralized facility; d) evaluating inventory tracking systems that can be used to manage biospecimen collections and meet reporting requirements; and e) considering implementation for new specimen collections versus legacy collections.

Participating Institutes and Centers: NCI, NIAID, CC, NIDDK, NHLBI, NINR, NIDCD, NIMH, NHGRI, NIEHS, and NICHD

11. 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

12. Collaboration for the Osteoarthritis Imaging Initiative

The Osteoarthritis Initiative (OAI), a collaboration between the NIH’s NIAMS and pharmaceutical companies, has created a public repository of human OA data, radiological information, and biological specimens. Thus, the public resource developed a large collection of clinical MRI images of joint disease progression.

NCI, using advanced image transfer and storage technology developed by its Center for Biomedical Informatics and Information Technology (CBIIT) and specified by the Cancer Imaging Program (CIP), Division of Cancer Treatment and Diagnosis, was able to assist NIAMS in making their osteoarthritis images network accessible in a detailed, query-able manner (<http://ncia.nci.nih.gov>). It did so by creating a demonstration project whereby OA images were accessible to any researcher on the Internet. NCI CBIIT and CIP have offered NIAMS the opportunity to share its open-source open-access technology to extend its cross-disciplinary community at minimal cost and avoid redundant technology development.

Participating Institutes and Centers: NCI, NIAMS, and NIBIB

13. Synchrotron Program Officers Group

This group meets approximately twice a year to discuss and/or plan for the following: the needs of the biomedical research community for synchrotron radiation, the balance among the Nation's synchrotron radiation beamlines for the various structural biology techniques, the newest technologies, and cooperative (inter-IC and interagency) funding.

On April 27-28, 2008, NCRR and NIGMS convened an expert panel on the opportunities and capabilities for life sciences research at the National Synchrotron Light Source II (NSLS-II), which will be built by DOE/Biological and Environmental Sciences (BES) at Brookhaven National Laboratory. Representatives from NCRR, NIGMS, NIBIB, DOE, and NSF attended as observers. On September 11-12, 2008, DOE/BES held a follow-on workshop on Imaging and Spectroscopy opportunities at NSLS-II.

Participating Institutes and Centers: NCRR, NIGMS, NIBIB, NCI, NSF, and DOE

Web site: http://www.ncrr.nih.gov/publications/biomedical_technology/NSLS-II.pdf

14. 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

15. National Institutes of Health and National Aeronautics and Space Administration (NASA) Collaboration on Space-Related Health Research

After the development of a Memorandum of Understanding between the NIH and NASA, a meeting was held to discuss the drafting of a funding opportunity announcement (FOA) that would publicize the availability of the International Space Station (ISS) as a research environment and announce the NIH's willingness to consider investigator-initiated applications for biomedical research on the ISS that would benefit human health on Earth. This meeting gathered program staff from across the NIH to provide feedback on the FOA, gauge interest, and discuss feasibility with NASA officials.

Participating Institutes and Centers: NIAMS, NEI, NICHD, NIAID, NINR, NIAAA, NIMH, NCI, NIDA, NHLBI, NIBIB, NINDS, NIA, NIDCD, NCRR, NLM, NIDDK, NIDCR, OD, CSR, and NASA

Web site:

http://www.niams.nih.gov/News_and_Events/NIH_NASA_Activities/default.asp

16. Inter-Institute Imaging Group

This group meets monthly to enable discussion of scientific and programmatic issues in biomedical imaging. Topics range from anatomic imaging to functional and molecular imaging. Opportunities for collaborative efforts, ongoing programs and projects, and strategies for funding extramural imaging research are discussed.

Participating Institutes and Centers: NIBIB, CC, CSR, NCRR, NCI, NEI, NHLBI, NIA, NIAID, NIAMS, NICHD, NIDA, NIDCD, NIDCR, NIDDK, NIGMS, NIMH, NINDS; FDA, HHS/OS, and NIST/DOC

17. Down Syndrome Working Group

This trans-NIH working group is charged with coordinating ongoing research already supported by the NIH related to Down syndrome and with enhancing new, NIH-supported research efforts based on identification of areas of greatest scientific opportunity, especially as they relate to the development of future treatments.

Participating Institutes and Centers: NICHD, NCI, NHLBI, NIA, NIAID, NIMH, and NINDS

18. 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 these 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/>

19. 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, NCI, NIGMS, NICHD, NIA, NIAMS, NIMH, NIDA, NIAAA, NIBIB, NIDCD, NCCR, NCCAM, FIC, CC, OBSSR, OTT, ODP/ORD, and ORWH

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

20. Trans-NIH Bioethics Committee

This committee was established to contribute directly to NIH's policy development and decision-making process by serving as a forum for discussion and analysis on a range of issues related to the conduct and oversight of NIH-funded clinical research.

Participating Institutes and Centers: All NIH ICs

Web site: <http://crpac.od.nih.gov/tnbc.asp>

21. 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, and ORWH

22. NIH Resveratrol Clinical Research

This interest group was established as a trans-NIH effort to share information on the use of resveratrol in clinical trials as a therapeutic agent for inflammatory and neoplastic disease.

Participating Institutes and Centers: NIEHS, NIA, NIMH, NCI, NCCAM, NINDS, and NIDDK

23. Trans-NIH Sickle Cell Group

This group was established to accelerate research on Sickle Cell Disease across NIH, with a focus on developing new, more effective therapies.

Participating Institutes and Centers: NHGRI, NHLBI, NIDDK, ORD, FIC, and FNIH

Web site: <http://www.genome.gov/11509561>

24. NIH Obesity Research Task Force

The Task Force was established by the NIH Director as a trans-NIH effort to accelerate obesity research across the NIH.

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

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

25. 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

26. Systems Biology Scientific Interest Group

The SysBioSIG was created in 2003 to enhance the awareness of and encourage the development of systems biology within both the intramural and extramural NIH communities.

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

Web site: <http://www.nih.gov/sigs/sysbio>

27. 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/>

28. 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, and NINR

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

29. 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 (MDCC) 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. Strategic planning efforts by the MDCC

led to the development of an Action Plan for the Muscular Dystrophies (approved in December 2005), which contains specific research objectives appropriate to the missions of all MDCC member agencies and organizations and thus serves as a central focus for coordination of research.

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

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

30. NIH Public Trust Initiative

The mission of the NIH Public Trust Initiative is to enable the public to understand and to have full confidence in the research that NIH conducts and supports across the country and throughout the world. Specifically, the Public Trust Initiative seeks to provide the public information about how NIH conducts and supports research; opportunities to participate in priority setting and other NIH activities; opportunities to participate in clinical research; and access to, and understanding of, research results.

Participating Institutes and Centers: NINR, NICHD, NCI, NCRR, NIA, NIAAA, NIAID, NIAMS, NIBIB, NIDA, NIDCD, NIDCR, NIGMS, NIMH, NINDS, OBSSR, OTT, ODP/ORD, and ORWH

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

31. 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/>

32. Trans-NIH Working Group on Global Health and Climate Change

The Trans-NIH Working Group on Global Health and Climate Change is a cooperative effort among 16 ICs focused on the current and future role of NIH in climate-change-related research. NIH supports a wide variety of research projects that are relevant to the health effects of climate change. These projects represent an ongoing platform from which NIH can begin to evolve a coherent strategy, including the identification of gaps

and priorities for future investments. Activities that will support development of this strategy include in-depth portfolio analysis, literature surveys, an interagency discussion, and at least one public conference on climate change and global health.

Participating Institutes and Centers: FIC, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NIAID, NIAMS, NIBIB, NICHD, NIDCR, NIMH, NLM, and OD

33. Four Institute Gene Therapy Program

This program provides an interactive and synergistic environment where scientists and trainees from four different Institutes, and many different disciplines, work together toward the common goal of developing new therapeutic modalities for human disease. The essential goal of this program is to create a new cooperative and interactive program between Institutes to develop clinical gene therapy protocols with maximum efficiency and minimum duplication of efforts and resources. The program has been cited as a meritorious model for collaborative interactions between Institutes for clinical research as NIH enters the 21st century.

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

34. 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

35. 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

36. Trans-NIH Sarcoidosis Committee

This group coordinates sarcoidosis research activities across the NIH.

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

37. 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 and NIAID

38. Trans-NIH Sleep Research Coordinating Committee

NIH activities concerning sleep disorders research, education, and dissemination are coordinated through quarterly meetings of representatives from 12 NIH components for which the NHLBI National Center on Sleep Disorders Research serves as the lead office. The Committee identifies areas for potential coordination such as investigator-initiated grant applications, programmatic contacts for applicants, data resources, and the NIH Sleep Disorders Strategic Plan.

Participating Institutes and Centers: NHLBI, NIAAA, NIA, NIAMS, NCI, NICHD, NIDDK, NIDA, NIMH, NINDS, NINR, and ORWH

39. Pharmacogenetics Research Network

This is a program to study the pharmacogenetics of medicines used to treat various diseases.

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

40. 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 ORD

41. 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. A Steering Committee composed of representatives from across NIH was established to provide governance and direction.

A survey of intramural principal investigators identified the most significant barriers to performing clinical research at NIH. Focus groups, attended by principal investigators and research support staff, were then conducted to ascertain additional details about the barriers associated with clinical research and to discuss potential solutions. Further clarity on these issues was gained from interviews with a wide range of intramural NIH leaders including IC Clinical and Scientific Directors. Recommendations to address the issues identified are being developed and reviewed.

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

42. 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, NCRR, 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>

43. Trans-NIH Working Group for Research on Chronic Fatigue Syndrome

The mission of this group is to stimulate and support research on Chronic Fatigue Syndrome within the context of each IC; collaborate and coordinate research agendas of all ICs to issue on a regular basis joint Program Announcements and/or theme-related Requests for Applications; and plan and sponsor scientific symposia to foster awareness, provoke new scientific interest, and generate interdisciplinary collaboration among both the NIH and academic scientific community.

Participating Institutes and Centers: ORWH, NIA, NIAAA, NIAID, NIAMS, NICHD, NIDDK, NIEHS, NIMH, NINDS, NINR, NHLBI, NCRR, NCCAM, OBSSR, ODS, NCCAM, and CSR

Web site: <http://orwh.od.nih.gov/cfs.html>

44. 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 four subcommittees: 1) tracking, 2) financial and program administration, 3) ethics, and 4) institutional capacity.

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

45. Behavioral and Social Sciences Research Coordinating Committee

This committee was established to enhance information exchange, communication, integration, and coordination of behavioral and social sciences research/training activities at the NIH. The Committee facilitates and promotes (a) exchange of programmatic and scientific information of mutual interest and (b) planning and implementation of collaborative programmatic and scientific activities and initiatives. The NIH ICs participate in the Coordinating Committee through their appointment of a member and an alternate. Initiatives include sponsorship of a monthly seminar series and development of a trans-NIH program announcement on health disparities.

Participating Institutes and Centers: CSR, NCCAM, NCI, NCRR, NEI, NHGRI, NHLBI, NIA, NIAAA, NICHD, NIDA, NIDCD, NIDDK, NIDCR, NIGMS, NIMH, NINDS, NINR, NLM, OAR, OBSSR, ODP, and ORWH

46. 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

III. Educational Campaigns and Clearinghouses

1. Introduction to the Principles and Practice of Clinical Research

This 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.

This activity was established at the NIH Clinical Center, the clinical research hospital of the NIH. 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 are 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>

2. 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>

3. 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: OSE, NIGMS, NIDCR, NEI, NINDS, NHLBI, NIAID, NIDA, NIA, NCI, and NCRR

4. 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/naep/index.htm>

5. 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>

6. 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/

7. “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 will be available by the end of 2008. NIDCR and NCI are now preparing campaign kits for distribution to NCI community-based cancer networks that reach African Americans. The kits also will be distributed to health organizations, African American community groups, and churches around the country in FY 2009.

Participating Institutes and Centers: NIDCR and NCI

8. 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

9. 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 will include 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

10. 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 4,700 consumer health Web documents in English, and almost 700 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>

11. 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: NLM, NINR, NIEHS, NIDDK, NIAMS, NIAAA, NEI, NCCAM, NIBIB, and FIC

12. ClinicalTrials.gov (Registry of Clinical Research)

ClinicalTrials.gov was established, in part, pursuant to the Food and Drug Modernization Act of 1997, Pub. L. 105-115, to provide a public resource of information on clinical research. ClinicalTrials.gov offers up-to-date information about federally and privately supported clinical trials for a wide range of diseases and conditions. ClinicalTrials.gov currently contains registration information for more than 60,000 trials sponsored by the NIH, other Federal agencies, and private industry. Studies listed in the database are conducted in all 50 States and in 157 countries. The system was significantly expanded in FY 2008 pursuant to the Food and Drug Administration Amendments Act of 2007, Pub. L. 110-85, to accept more information about each trial, including summary statistics describing the results of certain registered trials. Results reporting is required for certain studies of approved FDA-regulated drugs, biological products, and devices.

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

13. Undiagnosed Diseases Program

An inter-Institute initiative, this program is sponsored by the NIH Office of Rare Diseases, the NHGRI, and the NIH Clinical Center. The goals of the program are to provide answers to patients with mysterious conditions that have long eluded diagnosis, and to advance medical knowledge about rare and common diseases.

Participating Institutes and Centers: All NIH ICs

Web site: <http://rarediseases.info.nih.gov/Undiagnosed>

14. 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. In 2007, the Group 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

15. 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>

16. 2008 NIH Summer Institute on Health Services Research: Cross-Systems Research to Improve Health Outcomes

This educational program, held in the summer of 2008, provided training in conceptual, methodological, and practical issues involved in planning and carrying out cross-systems health services research. The program included lectures, seminars, and small group discussions in research design relative to social work as it relates to health services; discussion sessions on methodological approaches and interventions; and consultation on the development of research interests and advice on preparing and submitting research grant applications to the NIH.

Participating Institutes and Centers: NCI, NHLBI, NIA, NIAAA, NICHD, NIDA, NIMH, NINR, OD, and OBSSR

Appendix 3

Key to Acronyms

CC - Clinical Center

CCR - Center for Cancer Research, NCI

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, NIDDK

DOC - Department of Commerce

DOE - Department of Energy

DPCPSI - Division of Program Coordination, Planning, and Strategic Initiatives

FDA - Food and Drug Administration, HHS

FIC - Fogarty International Center

FNIH - Foundation for the NIH

HHS - Department of Health and Human Services

HRSA - Health Resources and Services Administration

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

NICHHD - 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

NIST - National Institute of Standards and Technology, DOC

NLM - National Library of Medicine

NNMC - National Naval Medical Center

NSF - National Science Foundation

OAR - Office of AIDS Research, OD

OBSSR - Office of Behavioral and Social Sciences Research, OD

OD - Office of the Director, NIH

ODP - Office of Disease Prevention, OD

ODS - Office of Dietary Supplements, ODP, OD

OER - Office of Extramural Research, OD

OIR - Office of Intramural Research, OD

OLPA - Office of Legislative Policy and Analysis, OD

OM - Office of Management, OD

OMAR - Office of Medical Applications of Research, ODP, OD

ORD - Office of Rare Diseases, ODP, OD
ORS - Office of Research Services, OM, OD
ORWH - Office of Research on Women's Health, OD
OSE - Office of Science Education, OSP, OD
OSP - Office of Science Policy, OD
OTT - Office of Technology Transfer, OIR, OD
OS - Office of the Secretary, HHS
USAID - U.S. Agency for International Development