



# FOCUS ON RARE DISEASES



THE OFFICE OF RARE DISEASES NEWSLETTER

August 2007

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If you have any items of interest to add to the newsletter, please send them to [ord@od.nih.gov](mailto:ord@od.nih.gov) .  
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## HIGHLIGHTS OF THE OFFICE OF RARE DISEASES RESEARCH ACTIVITIES

### *Rare Diseases Clinical Research Network Update*

- **Notice of Intent to Publish a Request for Applications (RFA) for the Rare Diseases Clinical Research Network (RDCRN)**

A notice was published in the NIH Guide for Grants and Contracts on April 19, 2007 (<http://grants.nih.gov/grants/guide/notice-files/NOT-OD-07-062.html>). The Purpose of this Notice is to indicate the intent to publish an RFA to continue the Rare Diseases Clinical Research Consortia (RDCRC) Program and to inform potential applicants about the objectives of this cooperative agreement. The RFA will be open to current as well as new Consortia applicants. It is anticipated that this RFA will be published by December 2007 and approximately six awards will be made.

- **Upcoming Conference on Clinical Research for Rare Diseases (September 5, 2007)**

The upcoming educational seminar supported jointly by the NIH and the RDCRN, "Clinical Research for Rare Diseases: Opportunities, Challenges, and Solutions," will be held in Bethesda, Maryland on Wednesday, September 5, 2007. This one-day conference is focused on the methodology of clinical research in rare diseases. The target audience includes new investigators, trainees, junior faculty, and others interested in rare disease clinical research. Speakers will include expert clinical investigators who are actively engaged in rare disease research as well as members of the biopharmaceutical industry, the FDA, and NIH.

For more information, visit the web site at:  
<http://rarediseasesnetwork.epi.usf.edu/conference/>

*Please note the Conference is oversubscribed and the registration has closed. The proceedings of the conference are expected to be published.*

- **Clinical Protocols, DSMB, and Protocol Review**

In the past one and a half years more than twenty five clinical protocols have been approved by the Protocol Review Committees (PRC), Data Safety Monitoring Board (DSMB) and the NIH, and a few are under development. At this time twenty-five studies are included in ClinicalTrials.gov (<http://www.clinicaltrials.gov>) and twenty-three are actively recruiting patients.

#### **About the RDCRN**

Since Fiscal Year (FY) 2003 ORD, NCRR, NHLBI, NIDDK, NICHD, NIAMS, and NINDS have funded interdisciplinary clinical

research teams through the Rare Diseases Clinical Research Network. The RDCRN consists of 10 clinical research consortia with more than 70 sites and a Data and Technology Coordinating Center (DTCC). The RDCRN also collaborates with 30 patient advocacy groups that represent patients and families. The vast distribution of research locations across the United States makes investigational treatments more accessible to patients with rare diseases. This network conducts research on approximately 50 rare diseases. The goals of RDCRN are to:

- (1) Conduct clinical-translational research, including longitudinal studies, diagnostics, and therapeutic trials on multiple rare diseases;
- (2) Develop innovative tools to collect and manage geographically distributed clinical research data using standardized data elements;
- (3) Provide training to new clinical research investigators on rare diseases;
- (4) Improve access to information through the Web about rare diseases; and
- (5) Support demonstration projects.

For more information please go to:  
<http://rarediseasesnetwork.epi.usf.edu/>

#### ***Workshop on Spinal Cord Tumor Research***

The relatively infrequent occurrence of spinal cord tumors has made the study of these diseases difficult. Consequently, our understanding of the fundamental biology and optimal treatment of spinal cord tumors is limited, and these diseases continue to inflict considerable morbidity and mortality on both the pediatric and adult populations. As a first step to improve the outcome of patients with spinal cord tumors, the NIH Office of Rare Diseases, in coordination with

the National Cancer Institute and the National Institute of Neurological Disorders and Stroke, supported a workshop on February 12, 2007 to discuss the current understanding of these tumors. The overall goal of the meeting was to initiate a process to translate basic science research into improved clinical care for this group of patients. Workshop goals included 1) a review of current knowledge of the epidemiology of spinal cord tumors, 2) an

assessment of the pathological classification of spinal cord tumors, 3) a definition of key aspects of clinical diagnosis and standardized treatment, 4) a cataloging of the current private and public databases available for the study of spinal cord tumors, 5) a presentation of developmental neurobiology and its role in patient treatment, 6) an assessment of animal models of central nervous system tumors

with respect to applications to human research, and 7) a recognition of the importance of patients and their advocates in the research process. Research priorities for each of these disciplines were identified as well as areas for future inter-disciplinary research collaborations. A summary of this workshop will be published in the *Journal of the National Cancer Institute*.

### ***Expanding Research in Systemic Amyloidosis***

Systemic amyloidosis is a rare disease that affects multiple organ systems and requires research attention by multiple NIH ICs. In response to Congressional interest, the ORD supported a number of amyloidosis-related conferences with NIH ICs and held workshops on amyloidosis research.

In June 2006, ORD convened the “Systemic Amyloidosis Focus Group Workshop,” a meeting of international researchers and NIH institute staff. The workshop participants identified research needs and scientific opportunities in the study of amyloidosis and steps to increase our understanding of the various forms of systemic amyloidosis in order to improve the prevention and treatment of this devastating disease. A workshop summary report entitled,

“Challenges and Opportunities for Systemic Amyloidosis Research,” was published in June 2007 in the journal, *Amyloid*.

A month after the 2006 focus group workshop, the National Institute of Diabetes, and Digestive and Kidney Diseases reissued a broad-based program announcement indicating interest in research applications targeting diseases caused by protein misfolding or misprocessing. The National Institute on Aging joined NIDDK. Plans are also underway to issue a multi-institute program announcement in late fall/early winter focusing interest in applications specifically on research relevant to systemic amyloidosis based on the recommendations of the focus group workshop.

### ***Collaboration, Education, and Test Translation Program for Rare Genetic Diseases (CETT)***

In the two years since ORD initiated the Collaboration, Education and Test Translation for Rare Genetic Diseases (CETT) Program, nearly two dozen new tests for rare genetic diseases have either become available or are in development. The CETT Program is a pilot project of ORD, designed to move tests for rare genetic diseases from the research laboratory to clinical settings by

establishing collaborations among clinicians, researchers, laboratories and patient advocates.

As a result of the CETT Program, testing is available for the following rare diseases: Cornelia de Lange Syndrome (University of Chicago); Joubert Syndrome (Prevention Genetics); Cherubism (Toronto’s Hospital for

Sick Children); X-linked Chondrodysplasia Punctata (University of Chicago); Kallman Syndrome (GeneDX); Progressive Familial Intrahepatic Cholestasis (Baylor College of Medicine); Russell Silver (Emory University); Mucopolysaccharidosis Type VI Maroteaux-Lamy (Emory University); Niemann Pick A/B (Emory University); X-Linked Periventricular nodular heterotopia (Harvard University); Primary Ciliary Dyskinesia (University of North Carolina at Chapel Hill); Infantile Neuroaxonal dystrophy (Oregon Health and Science University); and Multiple acyl-CoA dehydrogenation deficiency (University of Colorado at Denver).

Tests that are in development and available soon include: Arginase Deficiency (University of California at Los Angeles); Allan Herndon Dudley – MCT 8 (University of Chicago); 9q34 deletion (Emory University); Epimerase GALE (Emory University); PXE (GeneDX); Familial Focal Segmental Glomerulosclerosis – NPHS2, ACTN4, TRPC6 (Toronto's Hospital for Sick Children); Arrhythmogenic Right Ventricular Cardiomyopathy – DSG2, DSP, PKP2 (Toronto's Hospital for Sick Children); X-linked Recessive Brachytelephalangic

Chondrodysplasia Punctata – ARSE (GeneDX); Bilateral Frontoparietal Polymicrogyria – GPR56 (University of Chicago); and Autosomal Recessive Agammaglobulinemia – IGHM (Correlagen).

The CETT Program has expanded to include molecular and biochemical testing. At a 2007 meeting, guidelines were established for clinical test report forms, templates for educational materials and for public database capabilities. Turnaround time (TAT) for test results was one focus of the meeting, with participants recommending a 2-4 week TAT for samples of 5 amplicons or less; and a 4-8 week TAT for all other samples. Tests for additional family members should be completed in less than three weeks, the recommendations noted. Another focus was on variants of unknown significance. In such cases, appropriate databases are to be searched for previous findings, the specific nature of the changes are to be reported, and recommendations should be made as to whether testing of family members is warranted.

For more information, see the CETT Program web site at [www.CETTProgram.org](http://www.CETTProgram.org) or by email at [info@CETTProgram.org](mailto:info@CETTProgram.org)

### *Inventory of Biospecimen Repositories*

This Web-based database, constructed by the RAND Corporation under a contract with ORD, should be fully operational in 2007/2008. The database will list existing repositories in the United States and overseas. Feedback from researchers over time will identify collection, storage, and delivery issues that can impede research on rare diseases. The Web-based site for data entry by biospecimen repositories has been

pre-tested. In the near future, ORD plans to expand the information gathered and add international repositories. ORD also plans updates on an annual basis or when changes occur in the repositories to ensure that information is up to date.

## *National Disease Research Interchange*

Since 2002, ORD has worked with the National Disease Research Interchange (NDRI) to remedy unmet research needs for rare diseases human tissues. The NDRI program has received 2321 tissues from 246 donors affected by 101 rare diseases. Tissues must meet research specifications and can come from transplant, autopsy, and surgical donations from donors across the nation. In addition to matching tissues to researchers already registered with the NDRI, NDRI banks rare diseases samples and informs researchers of their availability through an on-line catalog.

NDRI also works with patient advocacy groups through the Rare Disease

Biospecimen Alliance as a means of encouraging tissue donations. NDRI is currently partnering with 10 organizations. Direct donations help families to fulfill their desire to advance medical research by donating tissues and are of critical importance to biomedical researchers. Also, currently NDRI has 800 paraffin blocks available for approximately 30 rare diseases and banked DNA, plasma, and cell lines from 51 donors.

All of these efforts are ongoing and the rare diseases program is growing rapidly. For donations or questions, call 1-800-222-NDRI (6374) or visit the NDRI Web site at <http://www.ndriresource.org/>.

### *Genetic and Rare Diseases Information Center*

The Genetic and Rare Diseases Information Center (GARD) provides rare diseases information to patients and their families, health professionals, researchers, and the public. Since 2002, GARD has responded to more than 19,000 inquiries for almost 5,000 rare and/or genetic diseases. For more information go to:

[http://rarediseases.info.nih.gov/html/resources/info\\_cnr.html](http://rarediseases.info.nih.gov/html/resources/info_cnr.html).

Later this year, as part of the ORD Web site redesign, GARD will post Q's and A's about specific rare diseases on the ORD Web-site and will have an expanded Web-based presence to permit individuals with questions to access information instantaneously on the ORD Web site or type in their questions. Answers will be posted on the Web site under the strictest privacy policies and without any individual identifiers.

## *WHO Uses Web-Based Approach to Revise Global Disease Standards*

The World Health Organization is launching a major online project to revise the global standard for medical and health statistics - the International Classification of Diseases (ICD). For the first time, WHO is inviting stakeholders to participate in the ICD revision through an Internet platform. This update is vital in order to keep up with recent progress in medicine and the use of

information technology in the field of health, and to improve the basis for international comparisons. The last version of ICD was adopted in 1990 by all WHO Member States, which have formally agreed to use it as a standard to report diseases and deaths. A steering group is in place to oversee emerging diseases and scientific developments. These developments,

combined with advances in service delivery and health information systems, require a revision of this global classification system. One major need is to improve the relevance of the ICD in primary care settings (clinics, doctors' offices and frontline health services), as that is where most people are treated. Another key driver is the development of computerized health information systems that require classifying electronic patient records according to the ICD.

The design of the ICD has a direct impact on health care, as it influences public health programmes, prevention, reimbursement and treatment. Countries use it to compile basic health statistics and to monitor health spending. To compare findings between countries, a common standard is needed. For example, a comparison of life expectancy from the beginning of the 20th century to today was possible thanks to mortality data using ICD.

Previous ICD revisions were based on annual revision conferences attended by a limited number of selected experts. This Internet-based revision process provides wider scientific input, greater transparency and better exchange with the wide range of users, making the final ICD revision more useful. The Internet platform will also allow testing of the new classification before WHO Member States accept it as a global standard.

Since the endorsement of the tenth revision by the World Health Assembly in 1990, ICD 10 has become the international standard diagnostic classification for all general epidemiological and many health management purposes. These include the analysis of the general health situation of population groups and monitoring of the incidence and prevalence of diseases and other health problems in relation to variables such as the characteristics and circumstances of the individuals affected.

The categories are also useful to support decision making, reimbursement systems and for independent documentation of medical information. ICD 10 is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and hospital records. In addition to enabling the storage and retrieval of diagnostic information for clinical and epidemiological purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics by WHO Member States.

These Groups are composed of renowned international health leaders and chaired by:

- Mental Health: S. Hyman (USA)
- External Causes: J. Harrison (Australia)
- Rare Diseases: S. Ayme (France)
- Internal Medicine: K. Sugano (Japan)

### ***International Conference on Rare Diseases and Orphan Drugs in Brussels (ICORD 2007)***

The ICORD 2007 Annual Meeting will be held September 14-15 in Brussels. The Research Directorate General of the European Commission (EC) has organized a conference on rare diseases research on September 13, 2007 in Brussels. The meeting

will be open to all who are interested. It will focus on the areas that were identified as important for improved global collaboration at the 2006 Madrid meeting. Link: [http://www.icord.info/brussels\\_2007.php](http://www.icord.info/brussels_2007.php)

International Conferences for Rare Diseases and Orphan Drugs (ICORD) aims to improve health care and treatments, through global collaboration, for the benefit of patients with rare diseases. In the ICORD collaboration there are at present representatives of universities, patient organizations, and the pharmaceutical industry as well as agencies, mainly representing Europe and the United States. The aim is to broaden the representation to involve a larger part of the global rare diseases community.

The 1st ICORD meeting was held in Stockholm (ICORD 2005), with support from the Karolinska Institutet in Stockholm, the U.S. National Institutes of Health and the Research Directorate General of the European Commission.

ICORD 2006 was a one-day meeting held on October 25 in Madrid, Spain that identified important areas for future action and included the planning of upcoming ICORD conferences. Seven working groups were formed. The overall aim of these working groups is to stimulate constructive international collaborations that can result in true advantages for patients with rare diseases. Each working group will take steps during the subsequent year to move in the direction of improved international collaboration in their respective field. The working groups will present at annual ICORD meetings the steps that have been taken, highlighting the advantages or improvements in international collaboration. Link: <http://www.icord.info/index.php>

### ***Fiscal Year 2006 Biennial Report on Rare Diseases Research Activities***

Patients with rare diseases continue to benefit from the treatment applications realized by the emphasis the NIH places on both its basic and clinical intramural and extramural research programs. The ORD will contribute to the annual and biennial reports on rare diseases research as required by the NIH Reauthorization Act of 2007.

The FY 2006 biennial report will provide an overview of ongoing research in extramural and intramural programs, recent scientific advances, new or planned research initiatives,

and related activities such as scientific workshops and symposia, public and professional education and training, and information development and dissemination. Many advances presented are the direct result of years of rare diseases research sponsored by NIH.

For your information, the FY 2004 biennial report is available at: [http://rarediseases.info.nih.gov/html/reports/fy2004/FY2004\\_index.html](http://rarediseases.info.nih.gov/html/reports/fy2004/FY2004_index.html)

## *Scientific Conferences*

Every year, the ORD collaborates with NIH Institutes and Centers (ICs) and other Federal agencies to stimulate rare diseases research by supporting scientific conferences where research is lagging or to identify scientific opportunities. The outcomes of these scientific conferences have included:

- The establishment of research priorities;
- The development of collaborative research protocols;
- The setting of criteria for diagnosing and monitoring rare diseases;
- The identification of new research endeavors; and
- The publication of research findings in the scientific literature.

These scientific conferences have contributed greatly to the exchange of ideas and information among basic and clinical investigators, patient advocacy groups, NIH staff, and the pharmaceutical, biotechnology, and medical devices industry.

The ORD has attached a list of the most recent conferences supported by the ORD with this issue of the newsletter and will do so with each future issue. For additional information on the scientific conferences program including the agenda, conference participants, and a report of the meeting, please visit the ORD website at: <http://rarediseases.info.nih.gov/html/workshops/sicon.html>

## *Revitalization of the Coalition of Patient Advocacy Groups, CPAG*

The RDCRN's Coalition of Patient Advocacy Groups, (CPAG) is meeting once again to promote collaboration between the voluntary patient support groups and the individual consortia of the RDCRN. The purpose of CPAG participation in the RDCRN is to support their common interest in the RDCRN and to provide a mechanism for feedback between the patients and the clinics. On July 8, 2007, CPAG's three new co-chairs were announced. They are:

- Christina Cornell, Vasculitis Foundation,
- Janalee Heinemann, Prader-Willi Syndrome Association, and

- Michele Manion, Primary Ciliary Dyskinesia (PCD) Foundation Foundation.

A meeting of CPAG will take place Tuesday, September 4, 2007 to coincide with the conference on "Clinical Research for Rare Diseases: Opportunities, Challenges, and Solutions," that will be held in Bethesda Maryland on Wednesday September 5, 2007.

## *FDA Office of Orphan Products Development*

The Office of Orphan Products Development (OOPD) is dedicated to promoting the development of products that demonstrate promise for the diagnosis and/or treatment of

rare diseases or conditions since 1982. The OOPD interacts with the medical and research communities, professional organizations, academia, and the

pharmaceutical industry, as well as rare disease groups. The OOPD administers the major provisions of the [Orphan Drug Act](#) (ODA) which provide incentives for sponsors to develop products for rare diseases. The ODA has been very successful - more than 200 drugs and biological products for rare diseases have been brought to market since 1983. In contrast, in the decade prior to 1983 fewer than ten such products came to market. In addition, the OOPD administers the [Orphan Products Grants Program](#) which provides funding for clinical research in rare diseases.

The Office of Orphan Products Development welcomes its new Director, Tim Coté, MD, MPH. Dr. Coté arrives in September and

brings with him a wealth of experience, skill, and ideas for the future of OOPD.

For an update on recent orphan product designations and orphan product approvals please visit the OOPD/FDA website at <http://www.fda.gov/orphan/>.

### ***The Center for Business Intelligence (CBI) 2nd Annual Rare Disease Leadership Summit***

#### **CBI's 2nd Annual Rare Disease Leadership Summit**

Financial, Clinical, Marketing and Reimbursement Considerations for Successful Orphan Drug Development  
December 5 - 6, 2007  
Washington, DC

This important annual summit focuses on the unique challenges and opportunities associated with rare disease research and orphan product development. Since January 2008 marks the 25th anniversary of the Orphan Drug Act, we are proud to announce that the newly appointed Director of the FDA Office of Orphan Products has been confirmed and will address the summit on the status of the Orphan Drug Act. Distinguished Faculty also includes Stephen Groft,

Pharm.D., Director, Office of Rare Diseases, NIH and Diane Edquist Dorman, Vice President, Public Policy for NORD. This year's meeting promises to further the thought-provoking discussions that were generated at last year's meeting and to update recent developments in the field.

For more information or to register, please call: 781-939-2438; fax: 781-939-2490; email: [cbireg@cbinet.com](mailto:cbireg@cbinet.com) or visit our website at: [www.cbinet.com/raredisease](http://www.cbinet.com/raredisease)  
*Mention Promo Code: NAC392 and Save \$400 off your registration fee!*

*(Offer is applicable for the standard price for the full conference and workshop registration only and can not be combined with other discounts or applied to a current registration)*

***Social Security Administration  
Compassionate Allowances***

The Social Security Administration is seeking ways to meet the needs of the most severely disabled in our society.

SUMMARY: Under titles II and XVI of the Social Security Act (the Act), we pay benefits to individuals who meet our rules for entitlement and have medically determinable physical or mental impairments that are severe enough to meet the definition of disability in the Act. The rules for determining disability can be very complicated, but some individuals have such serious medical conditions that their conditions obviously meet our disability standards. To address these individuals' needs, we strive to provide not only responsive, but also compassionate, public service that ensures the most severely disabled in our society who meet the Act's requirements are awarded benefits quickly. To that end, we are investigating methods of making "compassionate allowances" by quickly identifying individuals with obvious disabilities. The purpose of this notice is to give you an opportunity to send us comments about what standards we should use for compassionate allowances, methods we might use to identify compassionate allowances, and suggestions for how to implement those standards and methods.

DATES: To be sure that your comments are considered, we must receive them by October 1, 2007.

ADDRESSES: You may give us your comments by: Internet through the Federal eRulemaking Portal at <http://www.regulations.gov>; e-mail to [regulations@ssa.gov](mailto:regulations@ssa.gov); telefax to (410)

966-2830; or letter to the Commissioner of Social Security, P.O. Box 17703, Baltimore, MD 21235-7703. You may also deliver them to the Office of Regulations, Social Security Administration, 960 Altmeyer Building, 6401 Security Boulevard, Baltimore, MD 21235-6401, between 8 a.m. and 4:30 p.m. on regular business days.

Comments are posted on the Federal eRulemaking Portal, or you may inspect them on regular business days by making arrangements with the contact person shown in this preamble.

**FOR FURTHER INFORMATION CONTACT:**

James Julian, Director, Office of Compassionate Allowances and Listings Improvements, Social Security Administration, 4470 Annex Building, 6401 Security Boulevard, Baltimore, MD 21235-6401, (410) 965-4015. For information on eligibility or filing for benefits, call our national toll-free number 1-800-772-1213 or TTY 1-800-325-0778, or visit our Internet Web site, Social Security Online, at <http://www.socialsecurity.gov>.

**SUPPLEMENTARY INFORMATION: Electronic Version**

The electronic file of this document is available on the date of publication in the Federal Register at <http://www.gpoaccess.gov/fr/index.html>.

Sequential Evaluation Process for Determining Disability

We use a five-step "sequential evaluation process" to decide whether

an individual is disabled, but will stop at any point in the process at which we are able to make a disability determination. At step one, we determine whether an individual is currently engaged in substantial gainful activity. If not, we then move to step two and determine whether the individual has a “severe” impairment or combination of impairments significantly limiting the ability to perform basic work activities. At step three, we compare the individual’s impairment(s) to those in the Listing of Impairments in appendix 1 of subpart P of part 404 of our regulations (listing). If the impairment does not meet or

equal in severity a listing, at step four, we assess the individual’s residual functional capacity to determine if the individual can do any past relevant work. Finally, at step five, we determine whether other work exists in significant numbers that such an individual can perform, considering the individual’s residual functional capacity, age, education, and work experience. We use different sequential evaluation processes for children and for individuals already receiving benefits when we determine whether they are still disabled. See §§ 404.1594, 416.924, 416.994, and 416.994a of our regulations.

### ***About ORD***

The Office of Rare Diseases (ORD) was established in 1993 within the Office of the Director of the NIH, the Nation's medical research agency. Public Law 107-280, the [Rare Diseases Act of 2002](#), established the office in statute. The goals of ORD are to stimulate and coordinate research on rare diseases and to respond to the needs of patients who have any one of the almost 7,000 rare diseases known today.

Definition of rare diseases: (Orphan Drug Act as amended in 1984 by P.L. 98-551 to add a numeric prevalence threshold to the definition of rare diseases.)

*“...the term, rare disease or condition means any disease or condition which (a) affects less than 200,000 persons in the U. S. or (b) affects more than 200,000 persons in the U.S. but for which there is no reasonable expectation that the cost of developing and making available in the U. S. a drug for such disease or condition will be recovered from sales in the U. S. of such drug.”*

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