




International Research Opportunities at the National Institute of Child Health and Human Development

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NICHD Mission

- NICHD supports both domestic and international research and training programs.
- NICHD supported research focuses on the process of human development to assure that every individual is born healthy and wanted, that women suffer no adverse consequence from the reproductive process, and that all children have the opportunity to fulfill their potential for a healthy and productive life unhampered by disease or disability.
- Research in Newborn screening and prevention of developmental disabilities has been an important aspect of NICHD programs




NIH Mechanisms that Support International Research Collaboration

- Investigator Initiated Research Grants (R01, R21) and Training Programs (D43)
- NICHD Initiated Programs
 - Program Announcements
 - Request for Applications
- Consultation through Conferences and Advisory Panels
- International Partnerships Including Linking with Established Research Networks
- Collaboration and Training in Intramural Research Laboratories




NICHD Extramural International Activities





NICHD Programs Related to Newborn Screening and Developmental Disabilities: A NBSS Approach

- Basic research on etiology of congenital conditions
- Development of screening technologies
- Development of clinical interventions
- Research on social, behavioral and educational interventions




NIH Institutes Relevant to Newborn Screening

- NINDS – developmental neurological disorders
- NIDDK – metabolic conditions
- NIBIB – point of care technologies
- NHGRI – genomics, linkages to conditions
- NHLBI – hemoglobinopathies and cardiomyopathies
- NIAMS – neuromuscular conditions
- NIDCD – hearing impairment
- NIEHS – environmental factors associated with congenital defects
- .nlm – NBS resource pages including Genetics Home Reference
- FIC – Genetics and informatics training
- ORD – rare diseases



Current or Planned NICHD Research Initiatives in Newborn Screening

- Innovative Therapies and Clinical Studies for Screenable Disorders
- Newborn Screening Translational Research Network
- Health Behavior and Disease Management Research for Newborn Screening



PA: Innovative Therapies and Clinical Studies for Screenable Disorders

Solicits research applications that are relevant to

- The basic understanding and development of therapeutic interventions for currently screened conditions and
- "High Priority" genetic conditions for which screening could be possible in the near future. High priority conditions are those for which the development of an efficacious therapy would make NBS amenable
- Application deadlines 3 times each year until 2009
- Available under www.grants.gov



Areas of Particular Relevance

- Basic investigation to optimize current treatment regimens
- Develop new therapeutic interventions for screenable conditions through multidisciplinary clinical trials
- Pre-clinical testing for safety, toxicity and efficacy in animal models
- Research on the natural history of conditions through longitudinal studies
- Identification of genetic and environmental factors that determine risk or modify disease onset, symptoms, progression or outcome.
- Determination of the influence of risk factors such as race, ethnicity and co-morbid medical conditions associated with treatment outcomes.



Future NIH Initiative: Newborn Screening Translational Research Network

- Tripartite network that links researchers with newborn screening programs and treatment centers to:
 - Validate screening technologies and therapeutic interventions for rare diseases
 - Increase access to dried bloodspots and other samples for research use
 - Perform longitudinal health outcomes research on individuals identified through newborn screening
 - Establish an informatics system to link researchers with potential human subjects for clinical trials
 - Develop informed consent and recommended research policies



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Advantages of a Newborn Screening Translational Research Network

- Links many sites together for more efficient collection of data for rare conditions
- Stimulates more rapid adaptation of fundamental research findings to clinical practice
- Can profit from international collaborations



Future NIH PA: Needs Assessment and Feasibility Studies for Health and Social Outcomes

- Interventions for increasing newborn screening literacy
- Informed consent and decision-making
- Examination of communication elements and psychosocial factors that influence unintended outcomes of newborn screening information
- Effects of newborn screening information on follow-up, family well-being and consequences for child health outcomes
- Development of health behavior and disease management interventions to enhance the outcome of therapeutic recommendations



Helpful addresses

- www.nih.gov NIH home page
- www.nichd.gov NICHD home page with information on initiatives and application procedures
- <http://crisp.cit.nih.gov/> provides listing of all funded NIH grants with abstracts and PI contact information
- <http://ghr.nlm.nih.gov/> National Library of Medicine Genetic Home Reference
- <http://grants1.nih.gov/grants/guide/index.html> information on latest NIH initiatives
- <http://www.grants.gov> new electronic application system



NICHD Contacts

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