

Intellectual and Developmental Disabilities Research Center (IDDRC)

Tristram Smith PhD

Haggerty-Friedman Professor of Developmental/Behavioral Pediatric
Research

About IDDRCs

- “Centers of excellence” for research in intellectual and developmental disabilities
- Established in 1963 by Congress
- “Nation's first and foremost sustained effort to prevent and treat disabilities”
- U54 (cooperative agreement) funded by National Institute of Child Health and Development (NICHD)
- Next competition in **early 2018**

IDDRCs—must knock one off to get new one

1. CA: UC Davis MIND Institute
2. CA: UCLA Intellectual and Developmental Disabilities Research Center
3. DC: Children's National Medical Center, Washington, DC
4. KS: Kansas Intellectual and Developmental Disabilities Research Center
5. MA: Children's Hospital Boston Intellectual and Developmental Disabilities Research Center
6. MA: University of Massachusetts Medical School Intellectual and Developmental Disabilities Research Center
7. MD: Kennedy Krieger Institute Intellectual and Developmental Disabilities Research Center, Baltimore, MD
8. MO: Washington University in St. Louis Intellectual and Developmental Disabilities Research Center
9. NC: The Carolina Institute for Developmental Disabilities
10. NY: Rose F. Kennedy Center, Albert Einstein College of Medicine, Bronx, NY
11. PA: Children's Hospital of Philadelphia, University of Pennsylvania
12. TN: Vanderbilt Kennedy Center for Research on Human Development
13. TX: Baylor College of Medicine Intellectual and Developmental Disabilities Research Center
14. WA: Center on Human Development and Disability, University of Washington
15. WI: Waisman Center, University of Wisconsin-Madison

Structure of IDDRCs

- 3-6 cores, including ones for administration and clinical translation
 - Each must support ≥ 5 funded research projects, including ≥ 1 NICHD-funded project
- 1 or more high-impact research projects on one or more themes:
 - –omic Approaches
 - Outcome Measures
 - Multi-modal Treatment Approaches
 - Shared Resources Across IDDRCs
 - Public Health

Examples

- Baylor: largely focused on Rett Disorder
- UC Davis: largely focused on Fragile X and autism
- Wisconsin: Broader topics--
 - Developing nervous system and the etiology and treatment of developmental disabilities and neurodegenerative disorders.
 - Speech, language, communication, cognitive, and sensory processes
 - Affect and social interaction across the life span

Applying for IDDRC at Rochester

- Would create hub and infrastructure to catalyze IDD research
- Would elevate a larger initiative to establish URMC as the national leader in IDD care
 - Integrating research with health care delivery, education, policy, and advocacy
 - Comprehensive strategic plan under development by IDD Leadership Council convened by URMC CEO Mark Taubman

An Excellent Portfolio of NICHD Grants

5 R21 HD078744 02	IS JAUNDICE IN PREMATURE INFANTS A RISK FACTOR FOR AUTISM?	AMIN, SANJIV B	
1 R01 HD083369 01A1	5 R01 HD055191 08	COMMUNITY PARTNERSHIP FOR BREASTFEEDING PROMOTION AND SUPPORT DOZIER, ANN MARIE	
5 K24 HD064754 05	5 R01 HD069313 04	5 T32 HD057821 05	PEDIATRIC RESEARCH: BENCH TO BEDSIDE TO CURBSIDE SCHOR, NINA F
5 R01 HD064636 05	5 R01 HD075797 03	5 K12 HD068373 05	TRANSLATIONAL MOLECULAR PEDIATRIC RESEARCH SCHOR, NINA F
5 U10 HD068263 05	1 F31 HD082893 01	5 R01 HD060789 05	EMOTIONAL PROCESSES IN FAMILIES: NEW METHODS CAPTURING MULTIPLE LEVELS OF ANALYSIS STURGE-APPLE, MELISSA L et al.
5 R01 HD065425 05	5 R00 HD078482 04	5 R01 HD027206 23	COORDINATING INFORMATION IN SENTENCE PROCESSING TANENHAUS, MICHAEL KEHAS
	5 R01 HD076898 02	5 R01 HD073890 14	TIME COURSE OF SPOKEN WORD RECOGNITION TANENHAUS, MICHAEL KEHAS

Large portfolio of NIH-funded IDD-related research

- Autism spectrum disorder
- Rare and orphaned diseases
- Sensorimotor processing
- Environmental toxicants
- Neural circuitry

Preparation

- Pilot and feasibility funding
 - RFAs issued last Spring and Fall
- Information-gathering on ongoing research and other resources
 - Research meetings and town halls (Drs. Foxe and Smith)
 - Comprehensive assessment of all IDD programs and services at the University (IDD Leadership Council)
- Needs:
 - Signature research project to include in application
 - NICHD-funded animal study to support an animal behavior core

University of Rochester IDDRC—Possible Organization

Admin Core

CENTER DIRECTORS

*Tris Smith
&
John Foxe*

Scientific Cores

HUMAN CLINICAL
PHENOTYPING &
RECRUITMENT
Mruzek & Augustine

HUMAN
NEUROIMAGING &
NEUROPHYSIOLOGY
Aslin & Foxe

CELL & MOLECULAR
IMAGING
Majewska & Brown

ANIMAL BEHAVIOR &
NEUROPHYSIOLOGY
*Cory-Slechta &
Padmanabhan*

Candidate Projects

Batten's Disease
*Mink, Augustine,
Foxe*

Novel treatments for
lysosomal storage
disorders
*Noble, Proschel,
Mink, Foxe*

Gene-environment
interactions in IDD
*Mayer-Proschel &
Cory-Slechta*

Astrocyte dysfunction
in Vanishing White
Matter Disease
*Proschel &
Ghaemmaghami*

Clinical Partners

The Levine Autism
Center
Cole & Hyman

The Complex Care
Center
Tiffany Pulcino

Strong Center for
Developmental
Disabilities
*Hetherington &
Sulkes*

The Batten's Disease
Consortium
Mink & Augustine

The Clinical &
Translational
Science Institute
Bennett & Zand

The Institute for
Innovative
Transition
Mock

The Mary Cariola
Children's Center
Zandi