

# Autism Research at NICHD

February 25, 2010

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Development



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Moderator:

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Program Director, Healthy  
Tomorrows Partnership for  
Children Program

MCHB



# Extramural Funding Program

- Autism Centers of Excellence (ACE) program
- American recovery and reinvestment Act of 2009 (ARRA)
- Intellectual and Developmental Disabilities Research Centers (IDDRRC)
- Training program
- NICHD Brain and Tissue Bank

# Autism Centers of Excellence Program

# Trans-NIH Collaboration

- *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)
- National Institute on Deafness and Other Communication Disorders (NIDCD)
- National Institute of Environmental Health Sciences (NIEHS)
- National Institute of Mental Health (NIMH)
- National Institute of Neurological Disorders and Stroke (NINDS)

# Consolidation of CPEA and STAART

CPEA: Collaborative Programs of Excellence in  
Autism

1997-2007

Funded by NICHD & NIDCD

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STAART: Studies to Advance Autism Research  
and Treatment

2002/03-2007/08

Mandated by the Children's Health Act of 2000

Funded by the five Institutes of the NIH

Autism Coordinating Committee

# ACE Centers and ACE Networks

## Centers

Multidisciplinary research programs

Goal: Interdependent and interrelated subprojects

6 Centers (P50)

## Networks

Multiple sites focusing on a specific topic of research

Goal: Achieve optimal design and conduct of studies

5 Networks (R01)

# Common Requirements

- Data sharing via National Database for Autism Research
- Common Measures
- Annual meetings

# Common Measures

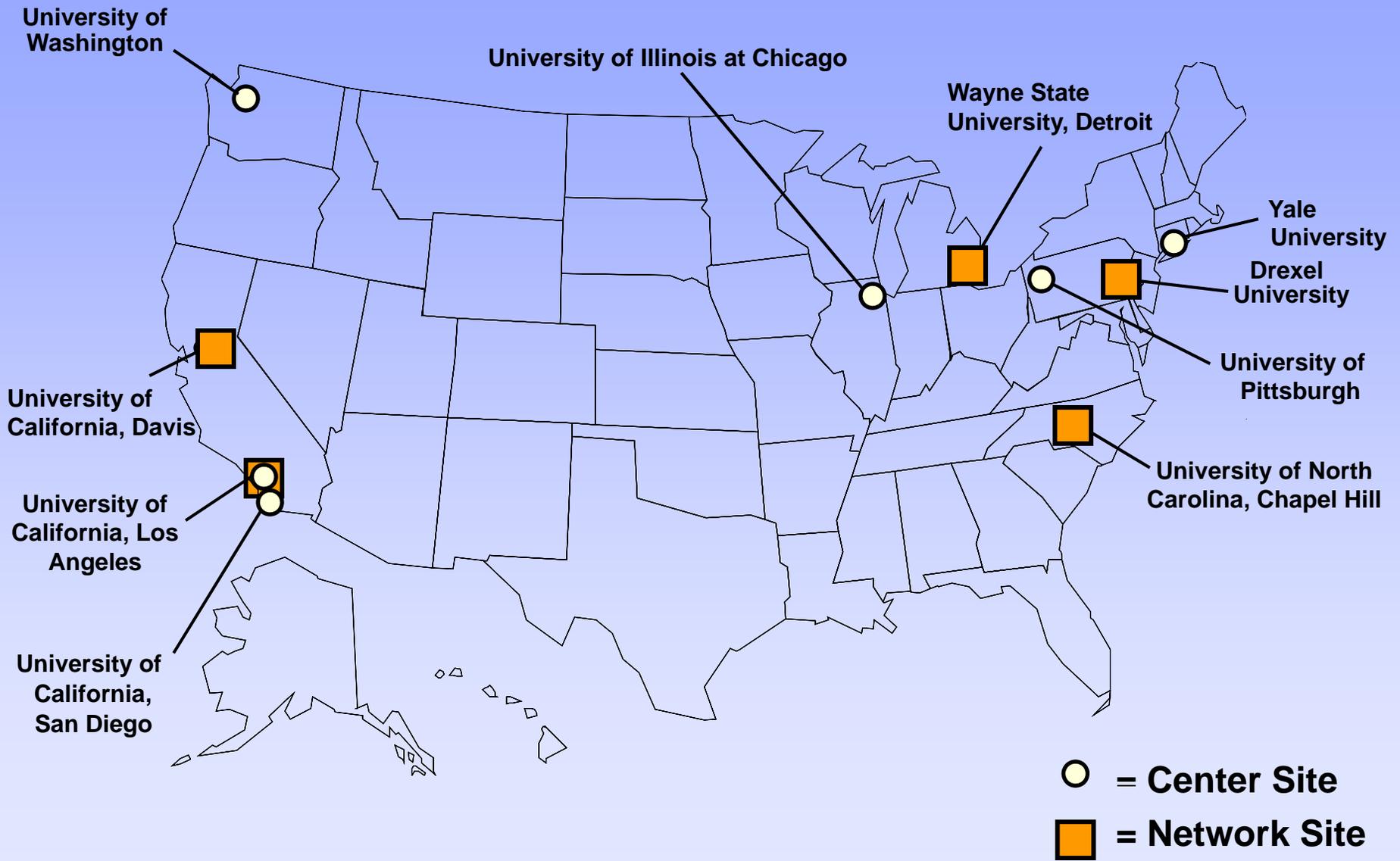
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- Medical/Family History
- Physical/Neurological Examination
- Karyotyping
- Autism Diagnostic Interview-revised
- Autism Diagnostic Observation Schedule
- IQ or developmental assessment measure with nonverbal and verbal components

# ACE Program

- Trans-NIH Collaboration
- Consolidation of CPEA and STAART
- ACE Centers and ACE Networks
- Common requirements
- Funding for the ACE program started in FY07 and FY08

# Autism Centers of Excellence (ACE): Center and Network Sites



# ACE Centers

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**Nancy Minshew**

University of Pittsburgh  
Information processing  
and learning

**Edwin Cook**

University of Illinois at  
Chicago  
Insistence on sameness

**Susan Bookheimer**

University of California,  
Los Angeles  
Communication deficits

**Bryan King**

University of Washington  
Protective versus risk  
factors

**Ami Klin**

Yale University  
Behavioral, brain, and  
molecular studies

**Eric Courchesne**

University of California,  
San Diego  
Early brain development

# ACE Networks

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## **Joe Piven**

University of North  
Carolina, Chapel Hill  
Early brain development

## **Diane Chugani**

Wayne State University  
Buspirone study

## **Daniel Geschwind**

University of California,  
Los Angeles  
Identification of autism  
susceptibility genes

## **Craig Newschaffer**

Drexel University  
Genes & environmental risk  
factors

## **Sally Rogers**

University of California,  
Davis  
RCT : intensive behavioral  
vs standard community-  
based interventions

# ACE Program Team

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Judith Cooper, Ph.D.  
NIDCD

Lisa Gilotty, Ph.D.  
NIMH

Deborah Hirtz, M.D.  
NINDS

Cindy Lawler, Ph.D.  
NIEHS

Alice Kau, Ph.D.  
NICHD

# Recovery Act Limited Competition

- Research to Address the heterogeneity in Autism Spectrum Disorders
- NIMH as leading Institute
- \$57 M commitment stated in RFAs
- Topic areas include:
  - Measurement Development
  - Biomarkers/Biological Signatures
  - Immune and Central Nervous Systems Interactions
  - Genetics/Genomics
  - Environmental Risk Factors
  - Pre-Clinical Treatment Development
  - Treatment and Intervention
  - Services Research

# Relevant ARRA projects

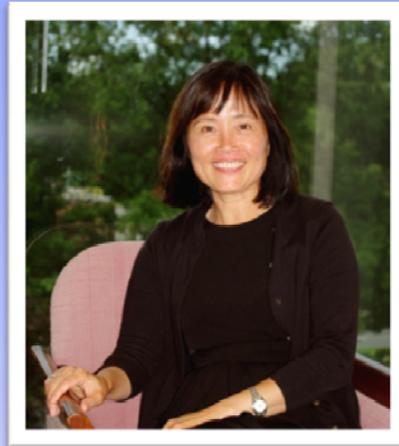
- Conducting early intervention in high-risk infants to prevent ASD
- Improving and streamlining screening and diagnosis of ASD at 18-24 months of age
- Testing a school-based, peer-led social skills intervention for adolescents with high functioning autism
- Developing a screening interview for research studies of ASD

NICHD: Intellectual and  
Developmental Disabilities  
Branch

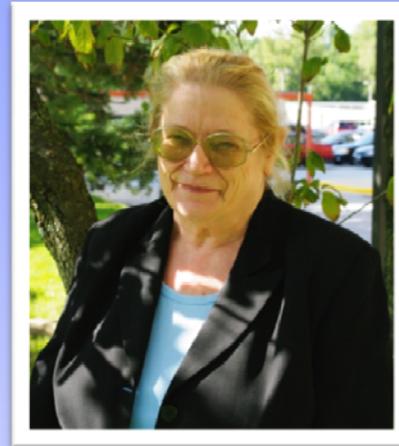
# IDD Branch Staff



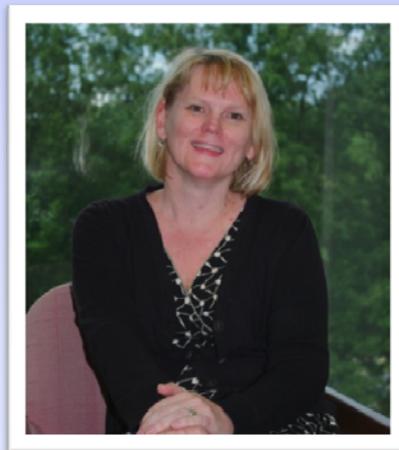
Melissa Parisi  
Branch Chief



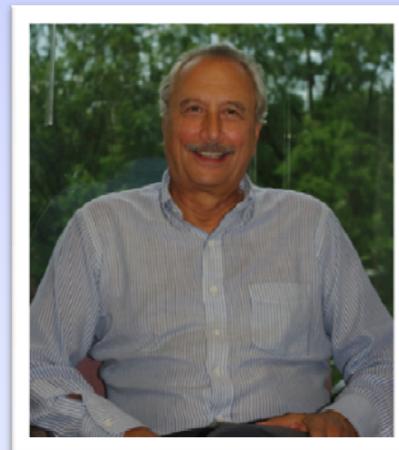
Alice Kau



Mary Lou Oster-Granite



Tiina Urv



Ljubisa Vitkovic

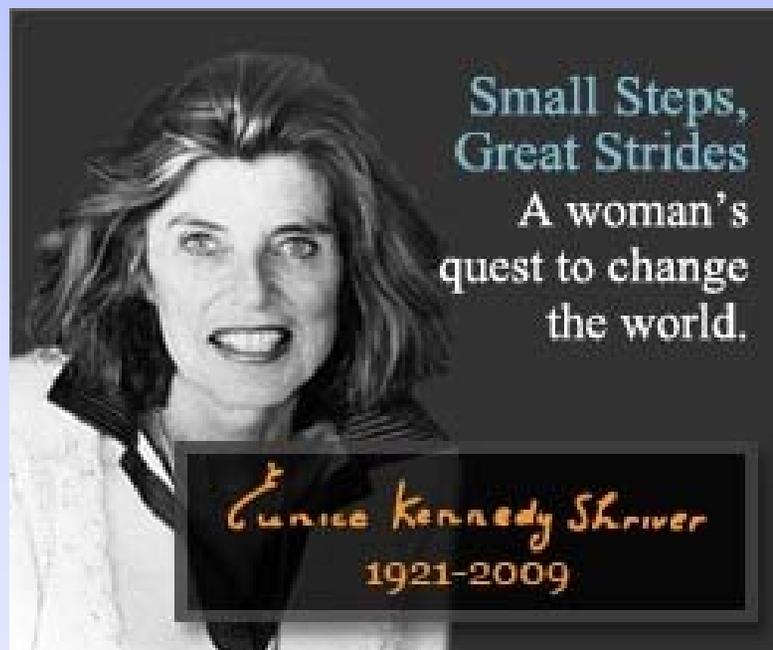
# IDD Branch Programs

- Autism Spectrum Disorders (ASDs)
- Eunice Kennedy Shriver IDD Research Centers (IDDRCs)
- Program on Fragile X syndrome (FXS) and associated disorders
- Rare Disease Cooperative Research Consortia (RDCRCs)
- Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers

# IDD Branch Programs

- Chromosome abnormalities, genetic/genomic syndromes, and epigenetic disorders
- Biochemical and metabolic disorders
- Newborn screening
- Research resources
- Branch-supported Training

# *Eunice Kennedy Shriver IDD Research Centers (IDDRCs)*

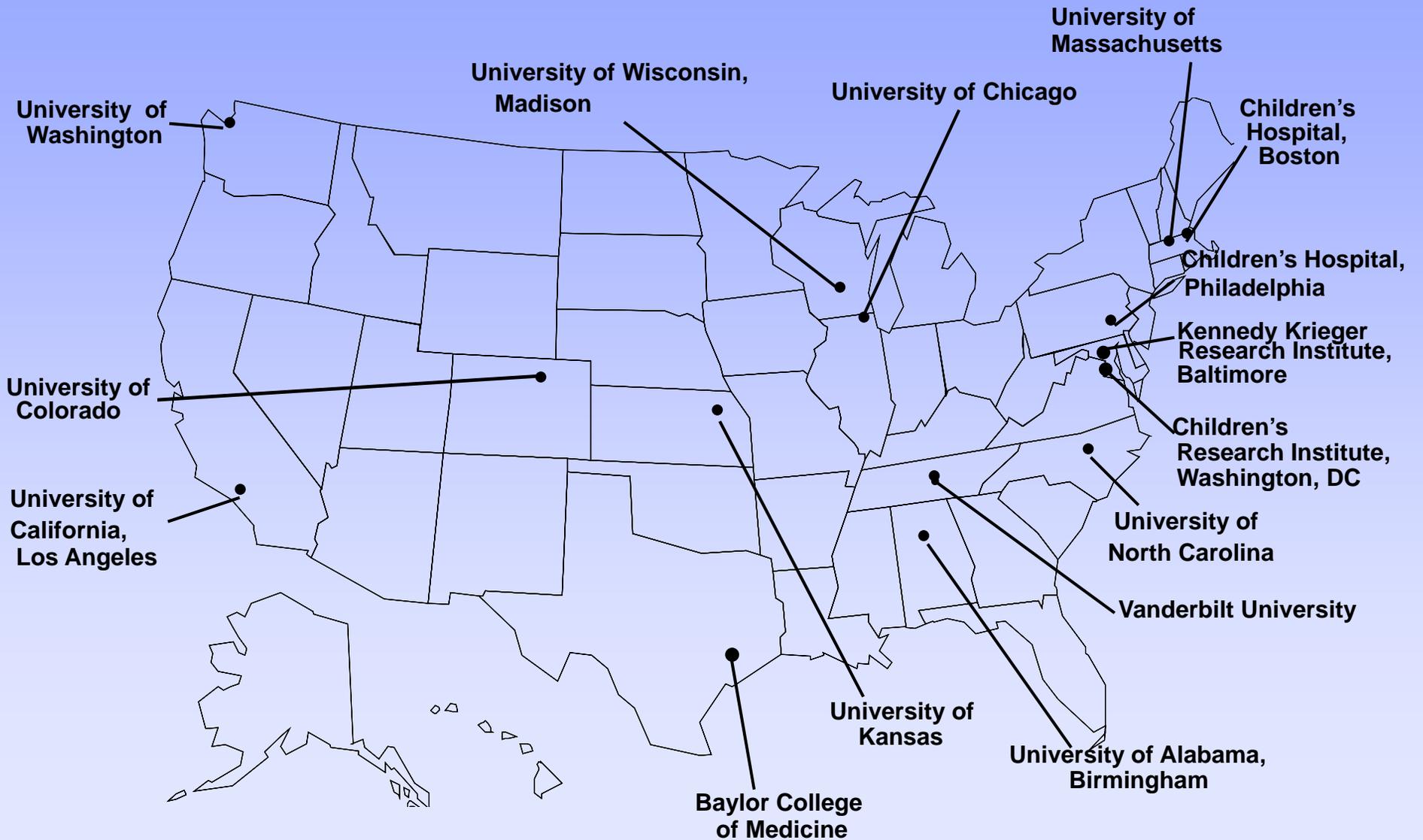


<http://www.eunicekennedyshriver.org/>

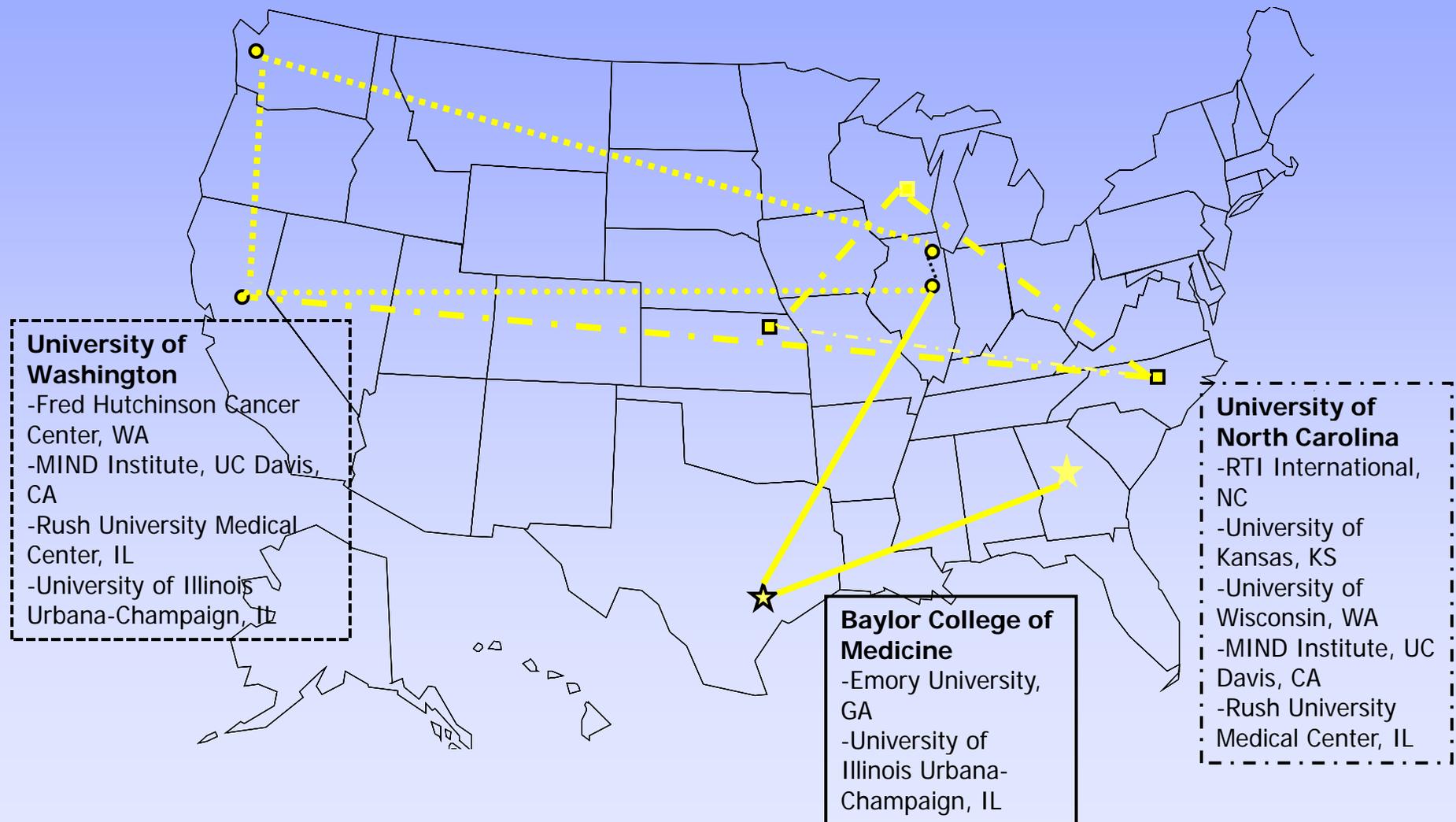
# IDDRCs: Highlights

- Integrated patient registries for Fragile X syndrome and other IDD conditions
- Synergy with related IDD programs for service, leadership, and training (UCEDDs, LENDs)
- Interdisciplinary Training Conference in Intellectual Disabilities

# IDDRCs: 15 sites in U.S.



# Fragile X Research Centers: a network of collaborating sites



# Research Resource

# NICHD Brain & Tissue Bank

- Funding began in 1991
- Research resource to increase knowledge of the etiology and pathogenesis of neurodevelopmental disorders
- Re-competed and re-awarded in August 2009 to University of Maryland
- Emphasis on acquisition of ASD tissues
- Laying the groundwork for establishing an international network of biobanks

# Training

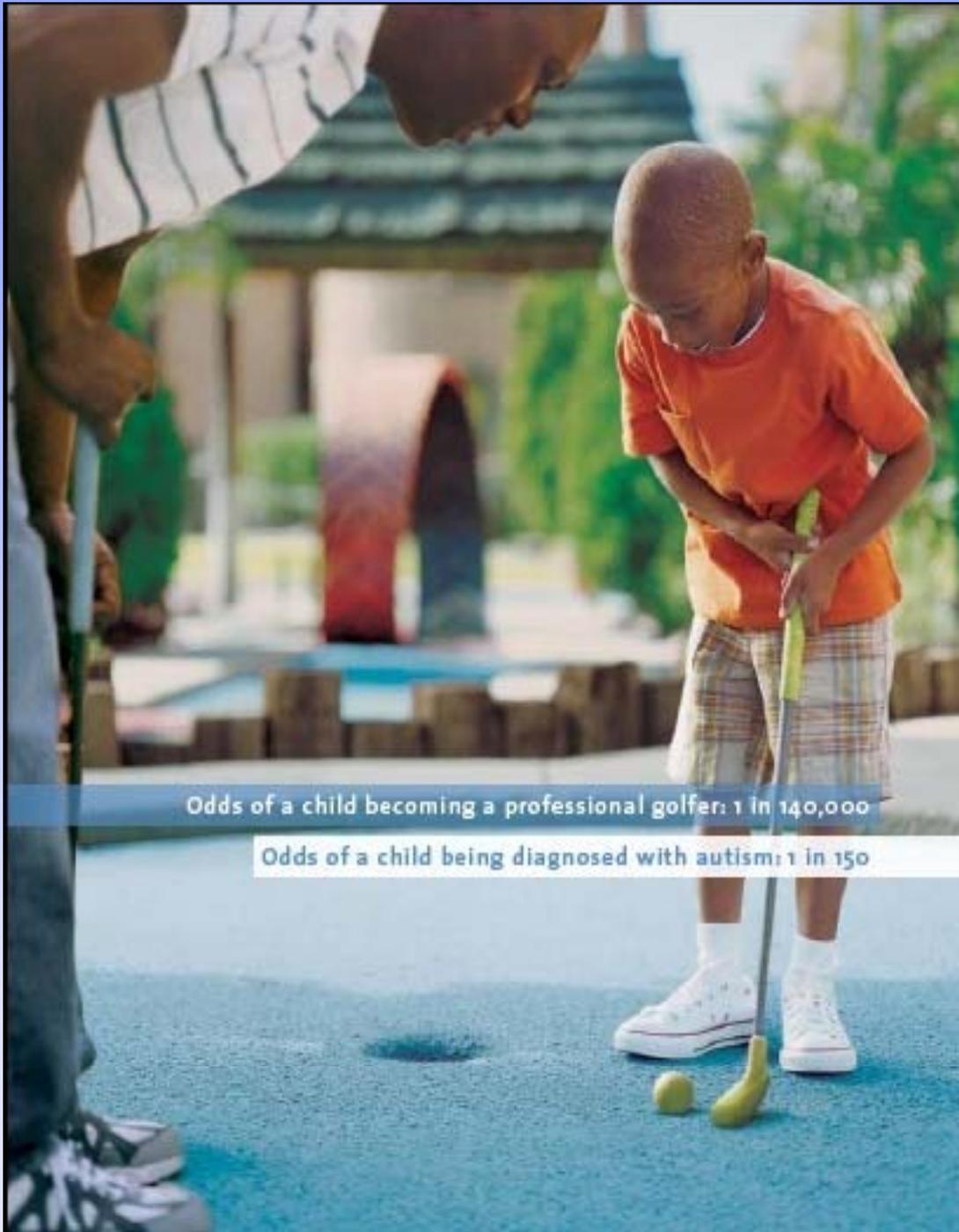
# Training the Next Generation of Investigators

## IDD Training efforts:

- Individual pre- and post-doctoral fellowships (17)
- Ks: Career development awards (20)
- T32: Institutional training programs, many interdisciplinary (9)
- Training components within Cooperative Research Centers (4)

# Autism Research Future Directions

- Identification of risk factors to allow early diagnosis and intervention
- Progress in understanding genetic and environmental contributions to ASDs
- Expand the capacity of NICHD Brain and Tissue Bank for IDD to include more ASD samples



Odds of a child becoming a professional golfer: 1 in 140,000

Odds of a child being diagnosed with autism: 1 in 150



**AUTISM SPEAKS™**  
It's time to listen.

Courtesy of Autism Speaks

# 6 critical questions from a parent's perspective: Framing the IACC Strategic Plan

- When should I be concerned?
- How can I understand what is happening?
- What caused an ASD to happen and can it be prevented?
- Which treatments and interventions will help with ASDs?
- Where can I turn for ASD-related services?
- What does the future hold?

# Discussion

- Developing an integrated view of a common mission towards ASD
- Identifying opportunities for collaboration

An aerial photograph of a volcanic crater. The crater's rim is a thick, dark green forest. The interior of the crater is a mix of brown and grey volcanic rock, with a central lake. The sky is blue with white clouds. The text "THANK YOU" is centered in the middle of the image.

**THANK YOU**