

COMMUNITY PARTNERED RESEARCH MODELS: THE UCLA-HELP GROUP ALLIANCE AND SPARK

Amanda Gulsrud, Ph.D.
Assistant Professor in Psychiatry
Clinical Director, CAN Clinic



CENTER FOR AUTISM RESEARCH AND TREATMENT

Community Partnered Research

- ◆ **UCLA Center for Autism Research and Treatment (CART)**
 - ◆ Strong foundation in community-based participatory research (CPPR)
 - ◆ CPPR communities are actively engaged in the research process through partnerships with academic institution:
 - ◆ Community members as study partners, not just subjects
 - ◆ Community knowledge helps understand health problems and to design activities to improve these problems
 - ◆ Community learns how research is done and what comes out of it
- ◆ **Emphasis on under-resourced and under-represented communities**
 - ◆ African American and Latino communities in Los Angeles are largely under-represented in research

Partnering in South Los Angeles

- ◆ ASD occurs in all racial, ethnic, and social groups...BUT
 - ◆ African American and Latino children are more likely to be diagnosed later
 - ◆ Autism can be reliably diagnosed at two years of age (and sometimes younger)
 - ◆ The average age of diagnosis for African American and Latino children is **~6-8 years**
- ◆ Most current intervention studies in autism have only included predominantly white, middle class populations (Lord, Wagner, Rogers, Szatmari, Aman, Charman et al., 2005).



Barriers to Participation in Research

- ◆ Access Barriers
 - ◆ Location
 - ◆ Limited availability of service providers
 - ◆ Service cost
 - ◆ Family stressors
- ◆ Predictors of Attrition and Treatment Dissatisfaction
 - ◆ Time commitment (waitlist, length of intervention)
 - ◆ Few incentives for attendance
 - ◆ Mismatched expectations
 - ◆ Lack of cultural understanding

Community Partnerships

- ◆ **Community-Academic Partnerships**
 - ◆ UCLA- Help Group Research Alliance
 - ◆ Non-public school for individuals with ASD
 - ◆ Health African American Families
 - ◆ Grassroots effort in South LA
 - ◆ Fiesta Educativa
 - ◆ Nonprofit parent-run organization
 - ◆ *Promotoras de Salud*
 - ◆ Local Regional Centers and LAUSD



Genetics: A Case for CPPR

- ◆ We can work within trusted and established community- partnerships to help communicate complex topics
- ◆ Communities that may be skeptical or weary of research can learn about and ask questions in a supportive and culturally-inclusive environment
- ◆ Partnerships help to identify families who may never have had the opportunity to participate in the past, especially families who are low-resource

What Causes ASD?

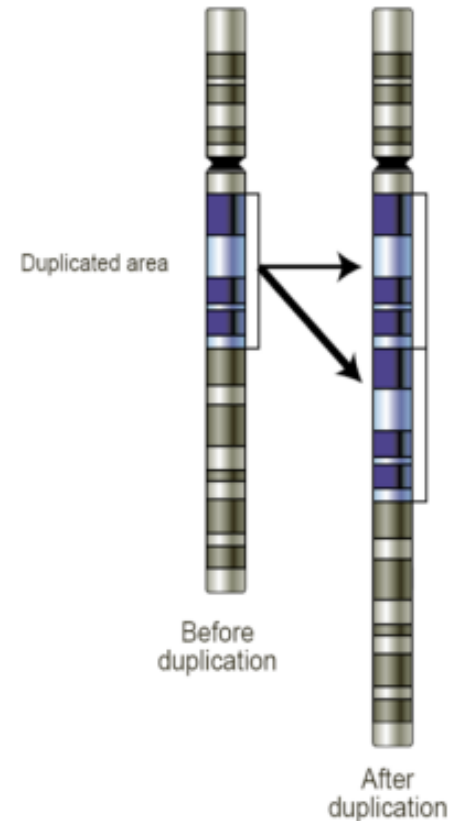


- ◆ No one cause of autism has been identified
- ◆ Most cases involve a complex and variable combination of genetic risk and environmental factors that influence early brain development
- ◆ Autism occurs at similar rates across all ethnic and racial groups, yet most of the information we know is based upon Caucasian participants

Genetics of Autism

- ◆ About 20% of individuals with ASD have identifiable genetic disorders
- : ◆ 60% monozygotic twin concordance
 - ◆ With BAP 90% concordance
- ◆ 20% chance of having a second child with ASD
- ◆ Several single gene disorders show high rates of autism:
 - ◆ Fragile X syndrome: 1-2%
 - ◆ Tuberous Sclerosis: <1% (30-50% have autism)
 - ◆ Rett syndrome: <1%

Copy Number Variants in 10-20%



But there is still much that we
do not know.....

What is SPARK?

- ◆ A landmark online research partnership designed to facilitate research that speeds up our understanding of the causes of autism and how autism impacts all those affected¹
- ◆ This first of its kind study will be done entirely online to encourage all in the autism community to participate, with the goal of establishing the largest online autism research cohort
- ◆ SPARK will collect unique information from individuals affected by autism to equip researchers with the information they need to deliver treatment and scientific advances as rapidly as possible
- ◆ SPARK is sponsored by the Simons Foundation Autism Research Initiative (SFARI)

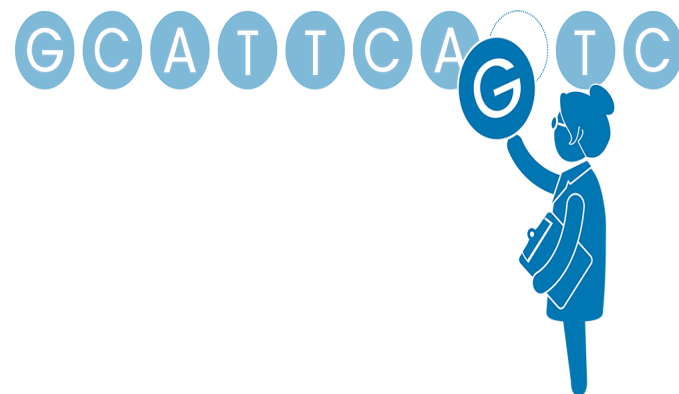
SPARK

Igniting autism research
Improving lives



Why Now?

- ◆ Autism is known to have a **strong genetic component**, but there is no singular cause of autism, and there is still so much we don't know.
- ◆ **Knowledge gained** through scientific research like SPARK can be **empowering** to individuals affected by autism.
- ◆ **More research is needed** to better understand the causes of autism to develop effective treatments and better tools for the everyday challenges autism brings.



To Learn More

◆ Visit:

◆ www.SPARKforAutism.org/UCLA

◆ Or the UCLA CART Booth



Thank you!

