

Linking the autism community and researchers



share. research. discover.

One Child

Born: March 1993

Milestones:

- 1st words at 18 months
“no”, “shoe”, “Shaggy”
- 1st phrase at 24 months
“Don’t do that”

Parent Concerns:

- Language delay, poor eye contact, intense interest in a few things, challenging behaviors

Diagnosis: March 1996

- PDD-NOS (Changed to ASD in 2001)
- Mild Mental Retardation (dropped in 2000)



10,000+ Questions

Causes and Prevention:

- What caused my son to have autism?
- Will my future children have it?
- Can I lower the risks?
- What about the next generation (my grandchildren)?
- Will genetic research lead to effective treatments?



10,000+ Questions

Prognosis:

- Will he learn to talk, read, write?
- Will he have friends?
- Will he be able to work and live on his own?
- Will he be happy?
- Will he develop seizures?
- What other medical or mental health problems is he likely to develop?



Treatments/Therapies:

- Does he need speech and language therapy? OT?
- What kind of classroom or school does he need?
- Will behavioral therapy help?
- How can I help him eat and sleep better?
- How can I help him make friends?

Are there medications that will help? What are the side effects?

4 Answers

From Science and Medicine:

- Your son does not have Fragile-X
- 7-14% risk your future children will have ASD
- 10-20% risk your son will have seizures
- Speech and Language therapy might help



Now, a young adult

Age: 24 years old

Milestones:

- Received MD High School Diploma (age 20)
- Moved into supported residential setting (age 23)

Challenges:

- Intense interest in a few things, no close friends, no job
- Multiple hospitalizations for mood disorder
- Multiple medications

Diagnoses:

- Autism Spectrum Disorder (ASD)
- Bipolar Disorder



A Community-Powered Research Network

IAN RESEARCH

Over 56,000 Participants

- 17,000 children with ASD
- 5,000 adults with ASD
- 14,000 siblings
- 20,000 parents/guardians

IAN COMMUNITY

World-wide Resource

- 1.1 million visits per year
- 170 countries
- 12.4 million pages viewed

Established in 2006 with the mission to improve lives by accelerating research.



Key Contributions

- Network-led studies on priority topics
 - Bullying and discrimination
 - Caregiver Health and Well-being
 - Adult Transition Services
- Matched families with over 500 ASD studies
- Validated online parent-report of ASD dx
- Launched first online ASD biobank study
- First online RCT in children with ASD



15,000+ IAN Families

- ASD Research Priorities (Top 10)

Topic	Average Score (1-10)
1. Work/Employment Services	9.02
2. Social Skills/Interaction	8.73
3. Education	8.62
4. Sensory Issues	8.52
5. Mental Health Conditions	8.48
6. Transitioning to Independent Living	8.42
7. Community Services	8.19
8. Healthcare Access	8.08
9. Bullying/Discrimination	8.08
10. Speech & Language	8.02

- **ASD Research Priorities (2nd Tier)**

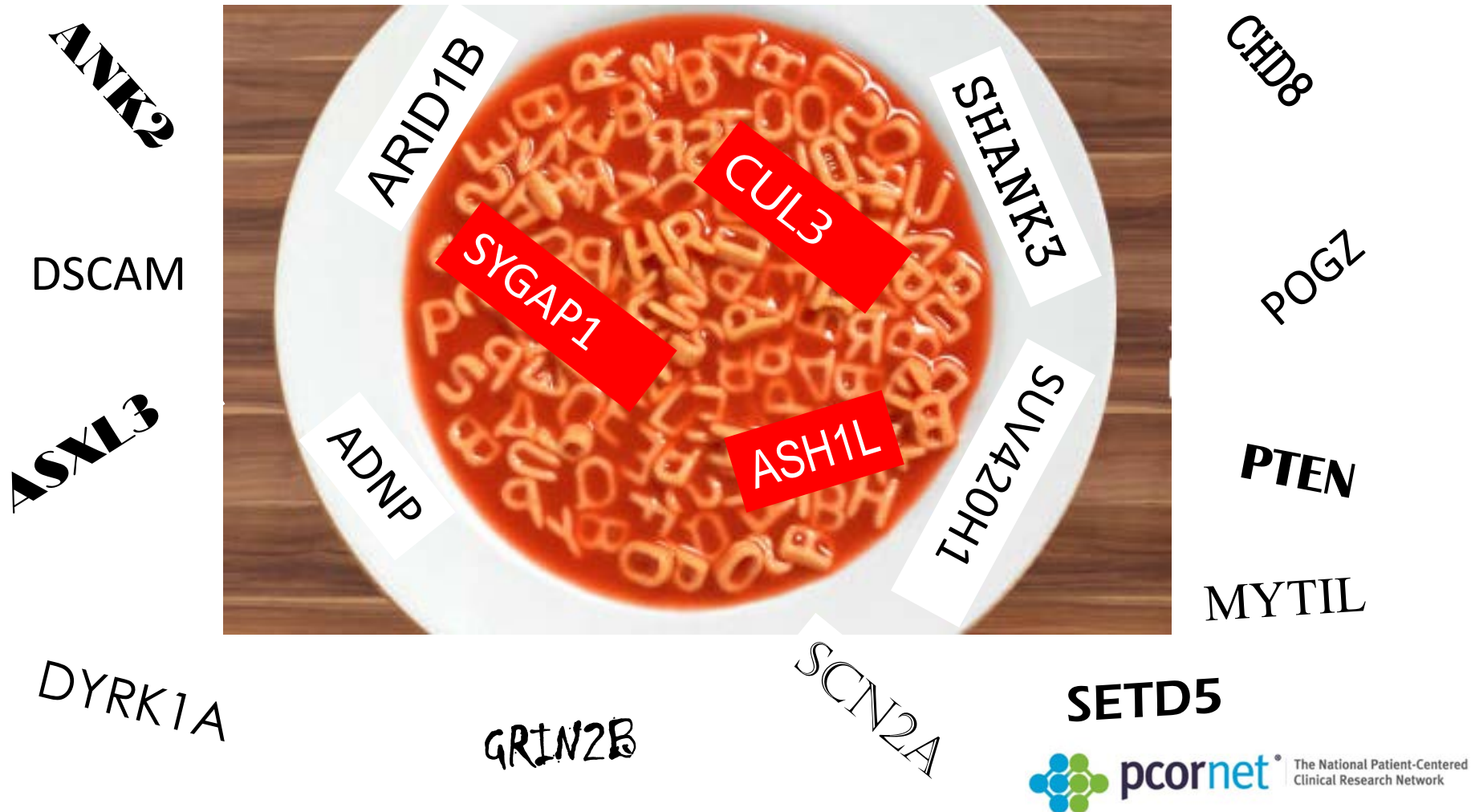
Topic	Average Score (1-10)
11. Self-Advocacy	7.75
12. General Adult Issues	7.67
13. Federal/State Assistance Programs	7.63
14. Behavior Therapies	7.58
15. Self-Injurious/Aggressive Behaviors	7.44
16. Family Stress	7.38
17. Medical Treatments	7.33
18. Sleep	7.15
19. Financial Effects of ASD	7.12
20. Suicide	7.04

- **ASD Research Priorities (3rd Tier)**

Topic	Average Score (1-10)
21. Genetic Causes	7.00
22. Motor Skills	6.85
23. Environmental Causes	6.69
24. Complementary Medications	6.33
25. Romantic Relationships	6.29
26. Elopement	6.21
27. Eating/Feeding	6.10
28. Digestion/Gut Issues	5.98
29. Special Diets	4.73

How do we integrate **genetic** **research** with **patient-centered** **outcomes** and **priorities**?

Family-friendly Communication



Focus on autism AND....

- Medical problems

- Sleep disturbances (50-80%)
- Epilepsy (11-39%)
- GI disorders (9-84%)
- Specific syndromes (10%)
- Motor disturbances
- Cerebellar pathology
- Sensory dysfunction
- Dysmorphic features



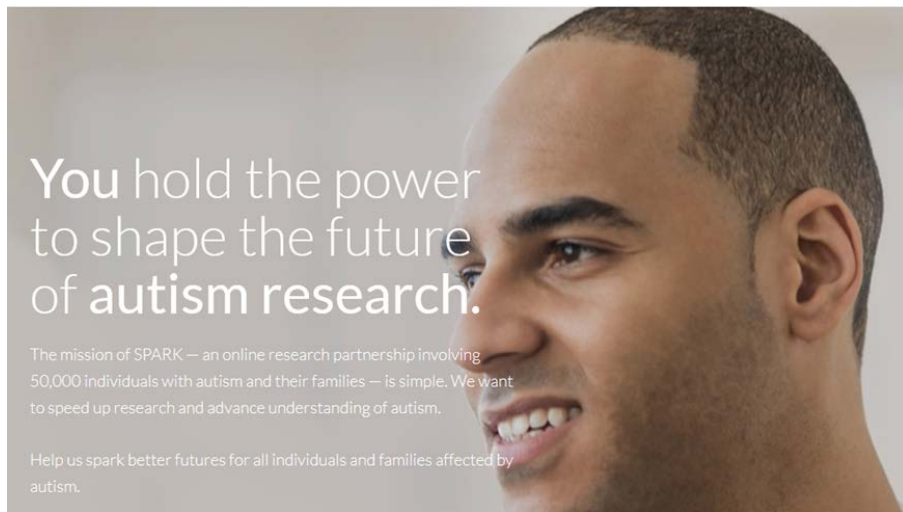
- Psychiatric problems

- Intellectual Disability (40-70%)
- ADHD (30-80%)
- Anxiety disorders (25-50%)
- Depression (2-52%)
- Bipolar disorder (7%)
- Gender dysphoria



Create Lasting Partnerships

- Families are key members of the research team
- Share information back with families



ian interactive autism network

LINKING THE AUTISM COMMUNITY AND RESEARCHERS

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