

# **Why Invest in Programs for Adolescents and Adults with Autism?**

Clarence E. Schutt, Ph.D.



# Why invest now?

The number of adults is growing fast.

Autism is a poorly-studied *medical* condition.

The nexus of services shifts from schools at age 21 to the States.

The number of trained physician-scientists is shockingly low.

# **The Science of Autism**

What have we learned?

What does it mean for adults?

# What have we learned - I.

Heterogeneity is confirmed by genetics

(copy number variation, X-linked mosaicism, weak GWAS signals, chromatin remodeling)

‘Synaptic Plasticity’ is a core process affected in autism

(mGluR5, NRXN:NLGN, TSC1/TSC2, UBE3A, SHANK3)

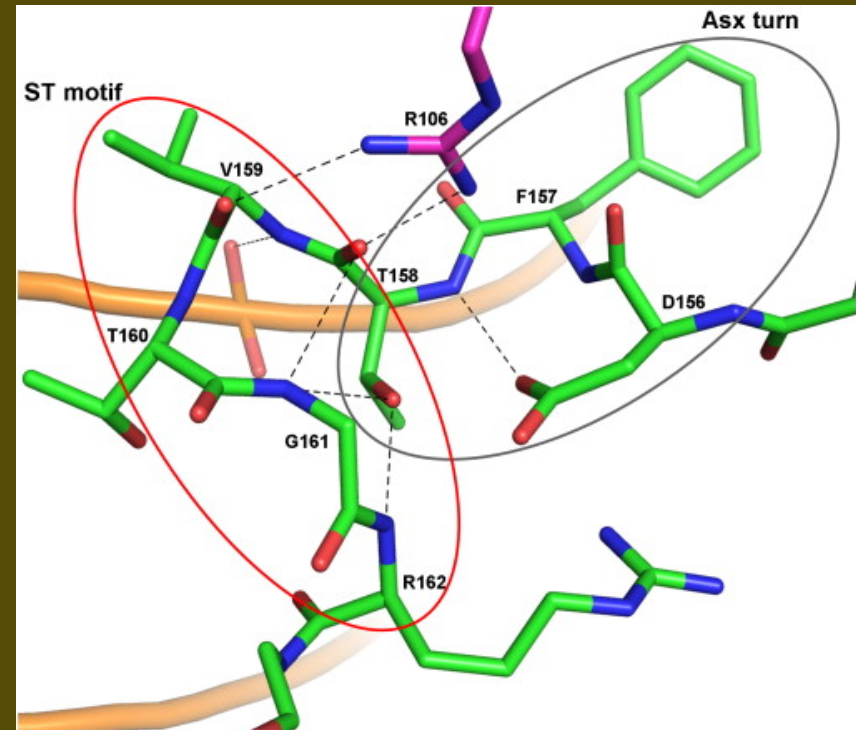
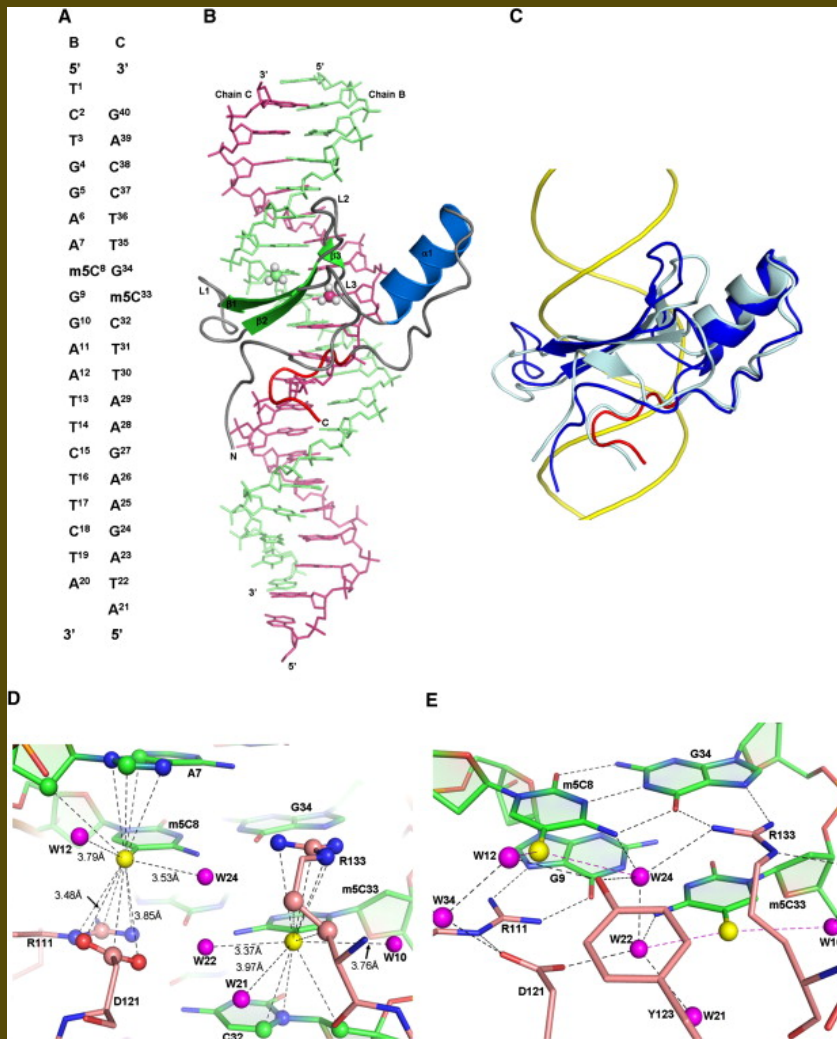
# What have we learned - II.

It isn't just the brain.

The medical sciences of physiology, neurology  
endocrinology & immunology will be central.

Autism throws out a challenge to science: what  
happens when communication between cells,  
organs, and individuals is impaired?

It's the whole body.



**MecP2:DNA (Ho et al., Mol. Cell, 29: 525-531, 2008)**

# Implications for Adults with Autism

There is great variation among persons labeled  
'autistic'.

Global systems (LC-NA) and cellular pathways  
(mTor-Akt) can be targeted.

We need to ask: What happens when  
neurodevelopmental disorders become 'chronic  
autism'?

# So what is needed?

Discovery starts with observations by medical doctors on large numbers of adults with autism.

Constant two-way communication between medical doctors & scientists.

One-stop center for medical care, social & life planning, and communication needs.



# Core Investment

Strong Clinic with Physician:Scientist  
Partnerships.

Training a New Generation of Medically-trained  
Specialists in Autism.

Communication Assessments  
(speech, motor, auditory, visual)

Policy Research to Drive the Legislative  
Process

# The Boston Globe

## MGH to target adult autism \$29m gift will fund specialized program

By Liz Kowalczyk, Globe Staff August 23, 2009

Massachusetts General Hospital is creating one of the first comprehensive programs in the nation to provide specialized medical care to adults with autism, a group whose numbers are poised to surge as tens of thousands of children diagnosed with the developmental disorder grow up.



The hospital plans to announce Tuesday that it will receive \$29 million, the fourth-largest gift in its history, from Nancy Lurie Marks and her family foundation in Wellesley, in part to add a major adult component to its pediatric autism program. The money will also allow the hospital to expand its services for children with autism, who now wait up to a year for an appointment, conduct extensive research, advocate for patients, and train physicians.

Foundation staff and autism specialists said many physicians are hesitant or unsure how to talk to and examine adult autistic patients. Their behavior can include rocking and repeating stock phrases - or not speaking at all - and that can lead to serious gaps in care and an over-reliance on psychiatric medications.

Autism "is treated as a childhood disorder but it's lifelong," said Clarence Schutt, director of the Wellesley foundation, which is a leading funder of autism research and whose grant to Mass. General is its largest ever.

Many adults with autism continue to see their pediatricians well into their 40s, while others go long periods without a physical or dental exam. Still others are misdiagnosed, with doctors missing complications such as sleep apnea or gastrointestinal pain because the patient cannot communicate the problem, doctors and families said.

NLM

FAMILY FOUNDATION

NLM

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