

autism
BRAIN
NET



SFARI

SIMONS FOUNDATION
AUTISM RESEARCH INITIATIVE



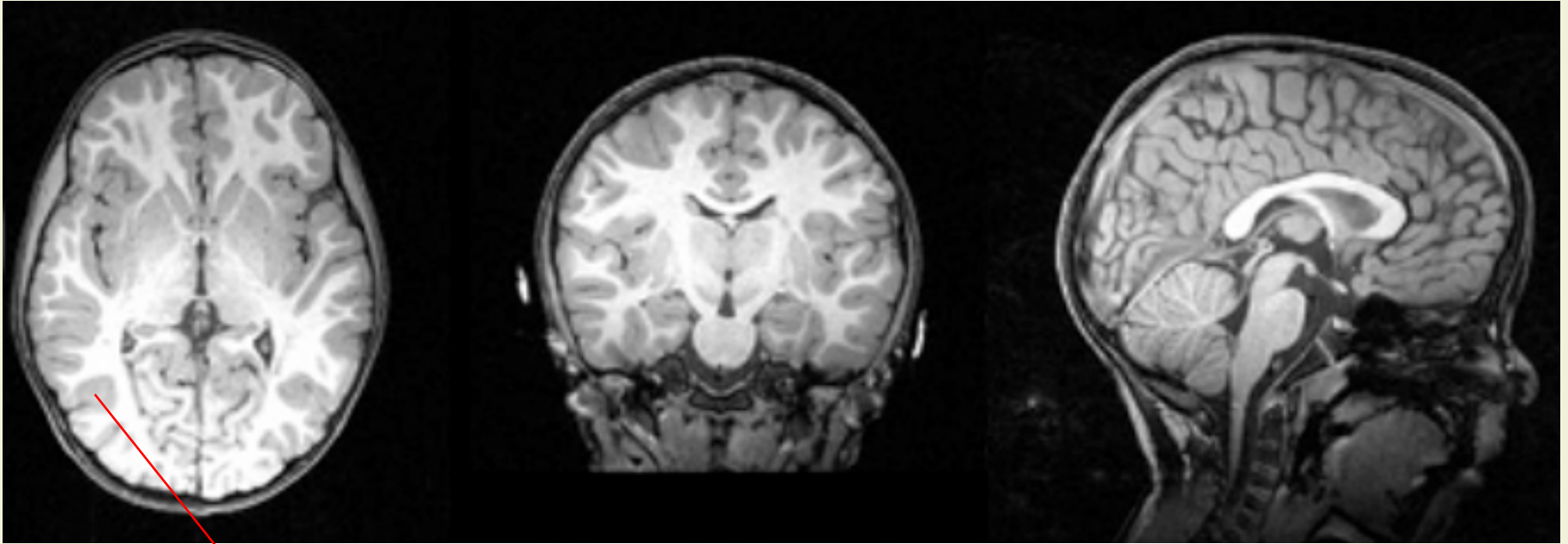
AUTISM SPEAKS®
It's time to listen.



AUTISM SCIENCE FOUNDATION

autism
**BRAIN
NET**

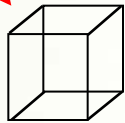
Resolution of MRI is too low to see neurons and networks



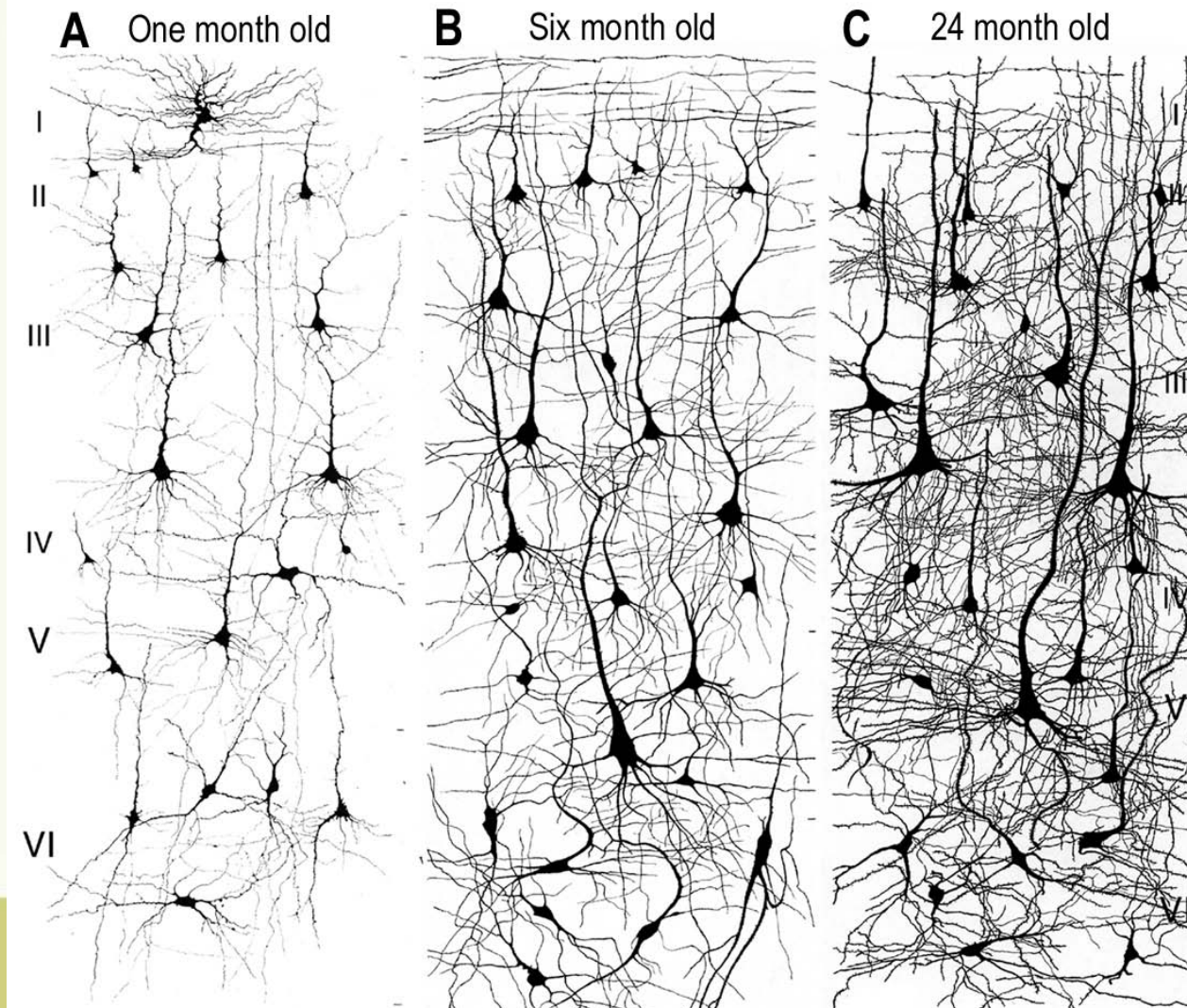
Voxel = 1 mm^3

Voxel = 50,000 neurons

Voxel = 100-300 million synapses



Resolution of MRI is too low to see neurons and networks





Neuropathology



Genetics



Neurochemistry



Based on findings from MRI, postmortem studies will require:

- A large number of clinically and genetically well-characterized brains for analysis
- Appropriate control brains for comparison
- Well organized cohorts to optimize research replication and complementarity.



Autism BrainNet





Autism BrainNet

Cyndi Schumann, Ph.D.

Matt Anderson, M.D., Ph.D.

Patrick Hof, M.D.

Carol Tamminga, M.D.



Autism BrainNet International



Oxford University



Olaf Ansorge, M.D

Autism BrainNet Web Site: AutismBrainNet.org

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24/7 HOT LINE
1-877-333-0999

autism BRAIN NET

Promoting Research into the Causes of Autism Spectrum Disorder

Although there is substantial evidence from neuroimaging studies that the brain of a child with autism is undergoing abnormal development, little is known about the underlying cellular, molecular and genetic mechanisms that lead to the onset of autistic symptoms.

[READ MORE +](#)

latest news

The Simons Foundation and Autism Speaks® forge a new alliance to foster postmortem brain research.

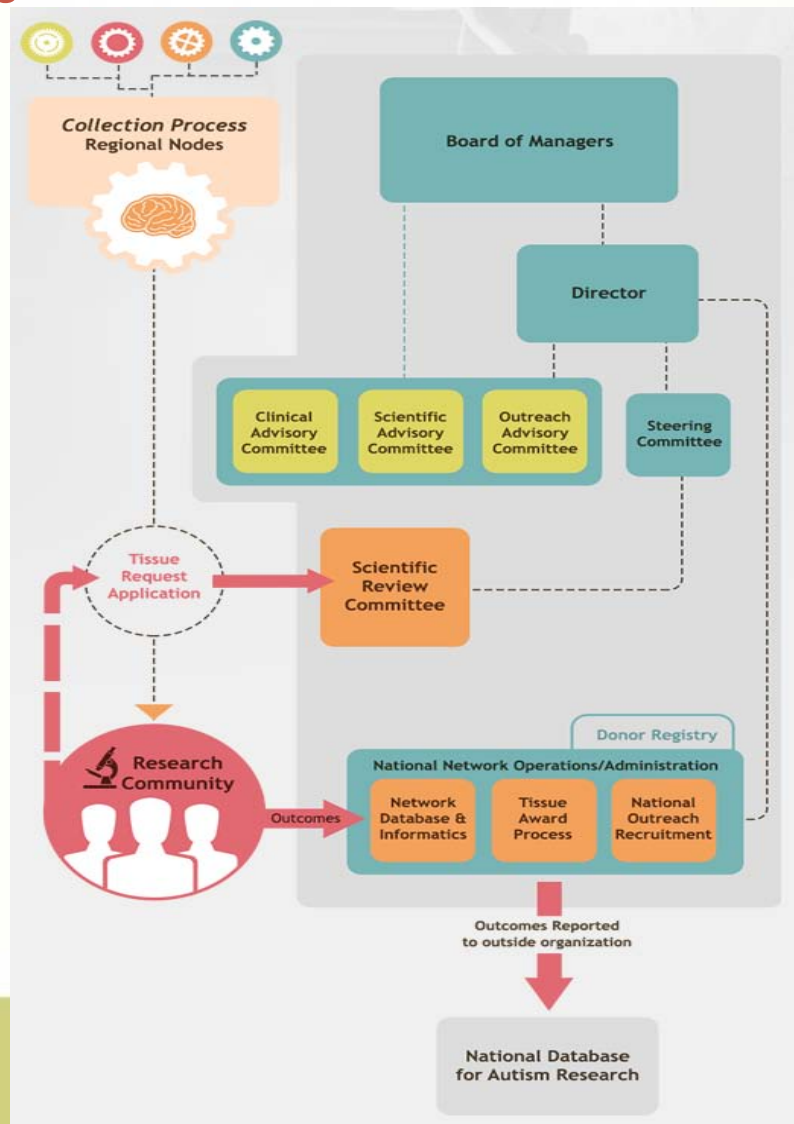
[READ MORE ->](#)

ATP
AUTISM TRANSLATIONAL PROGRAM

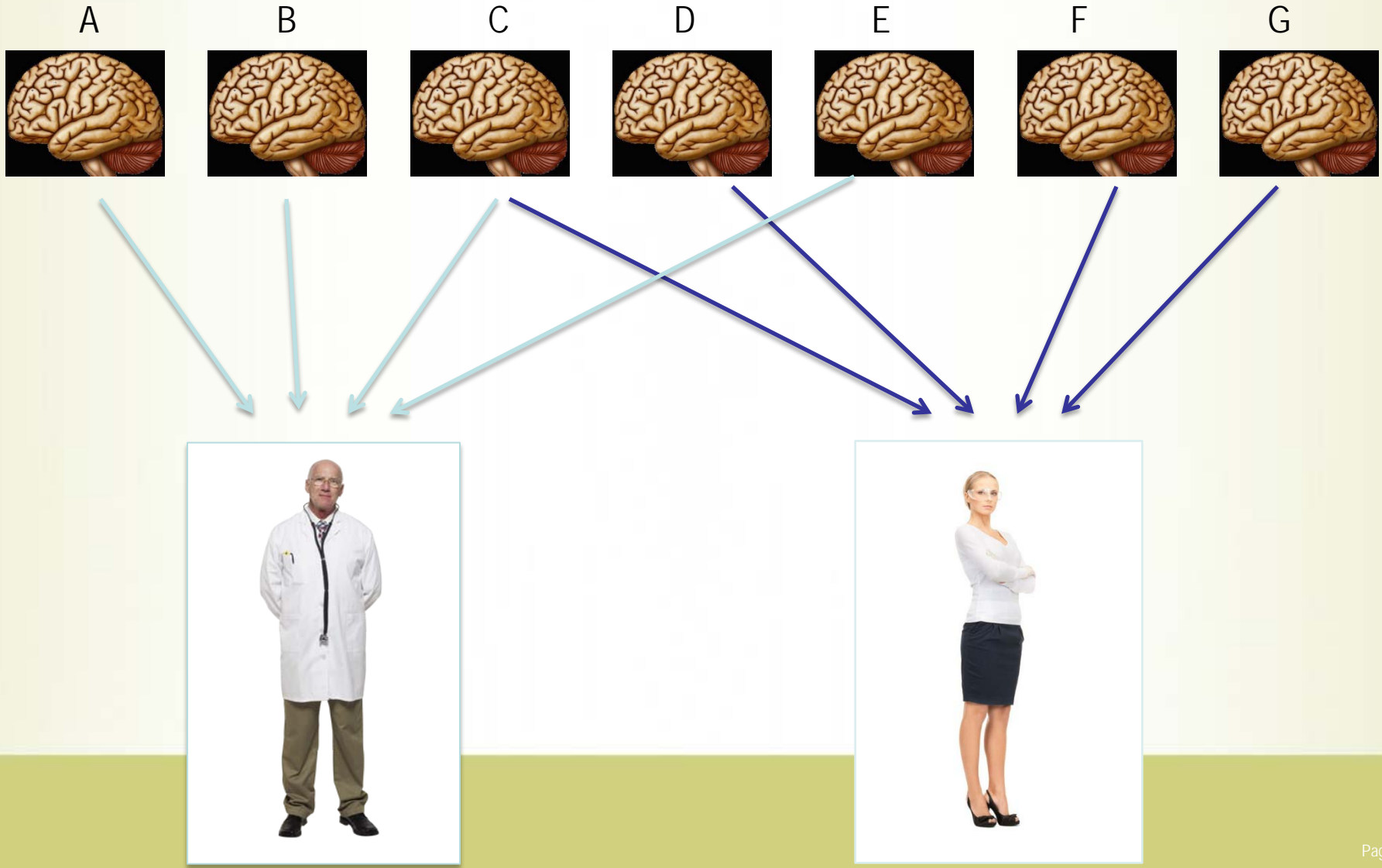
autism BRAIN NET

This initiative is supported by:

AutismBrainNet Organization



Development of cohorts of research brains

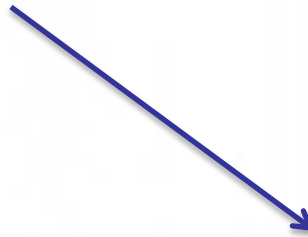
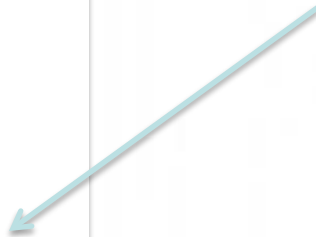




Development of cohorts of research brains

Cases

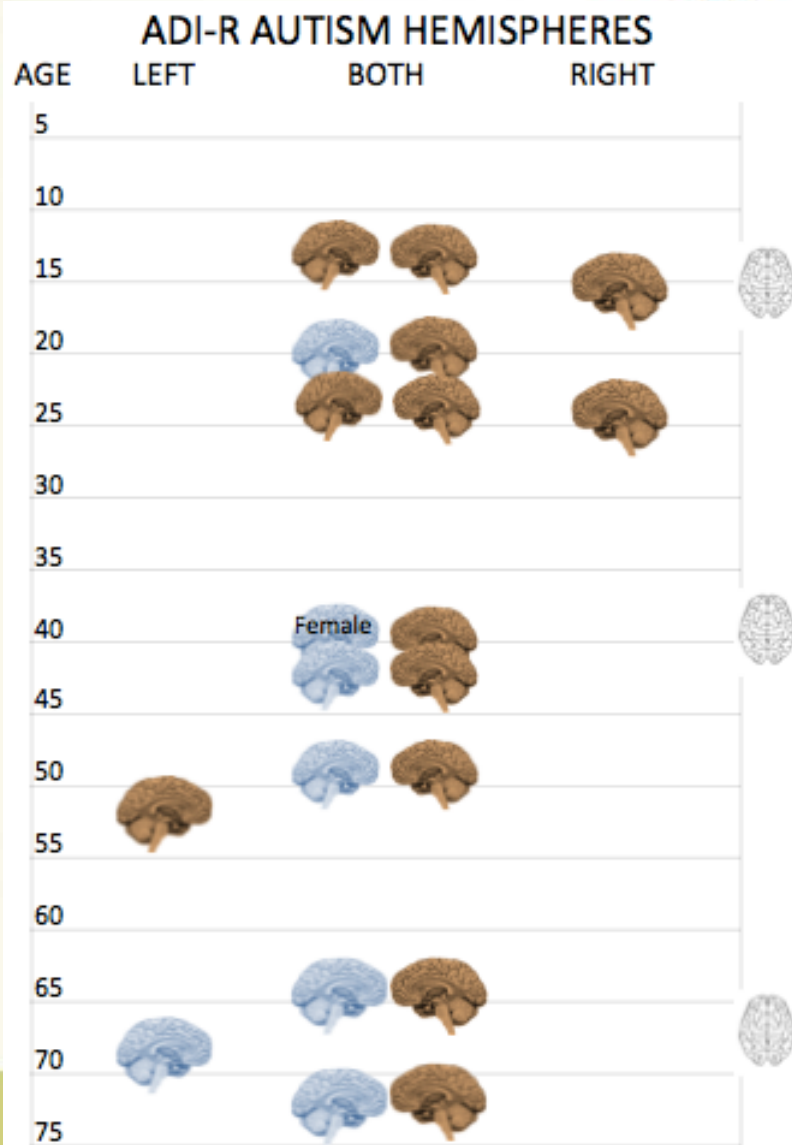
Controls





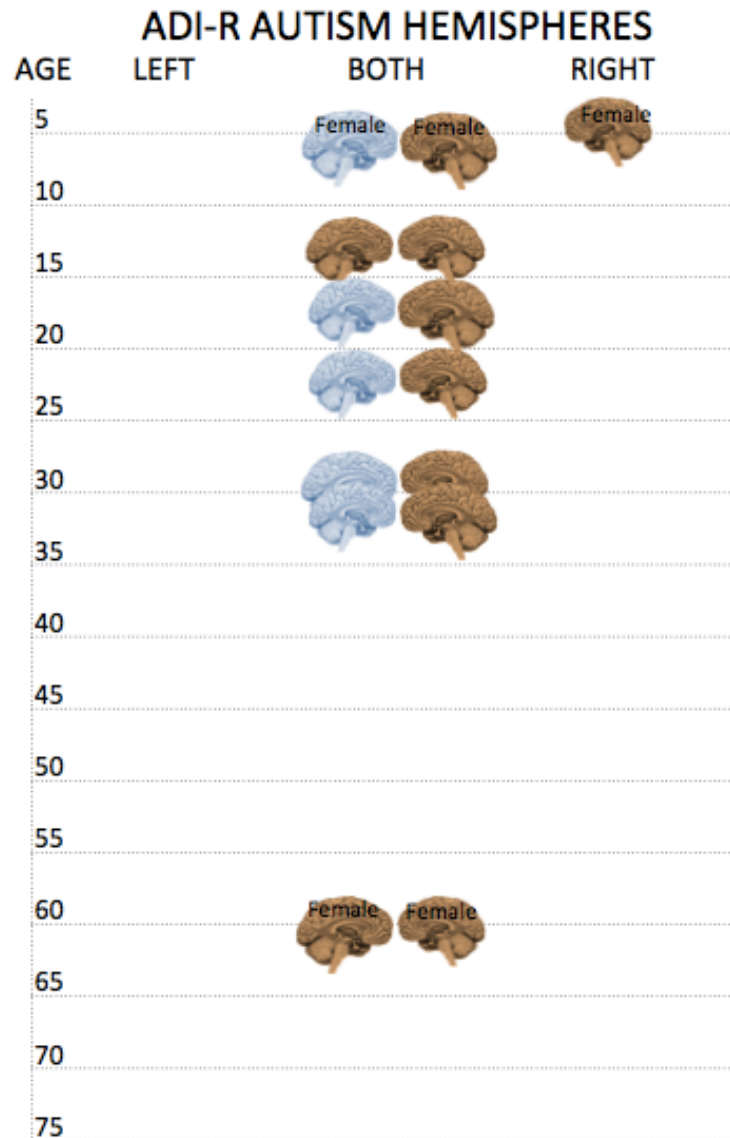
Development of cohorts of research brains

- ASD versus Age-matched Controls
- ASD versus Epilepsy versus Controls
- ASD with 16p11.2 deletion and Controls



Autism BrainNet Cohort Candidates

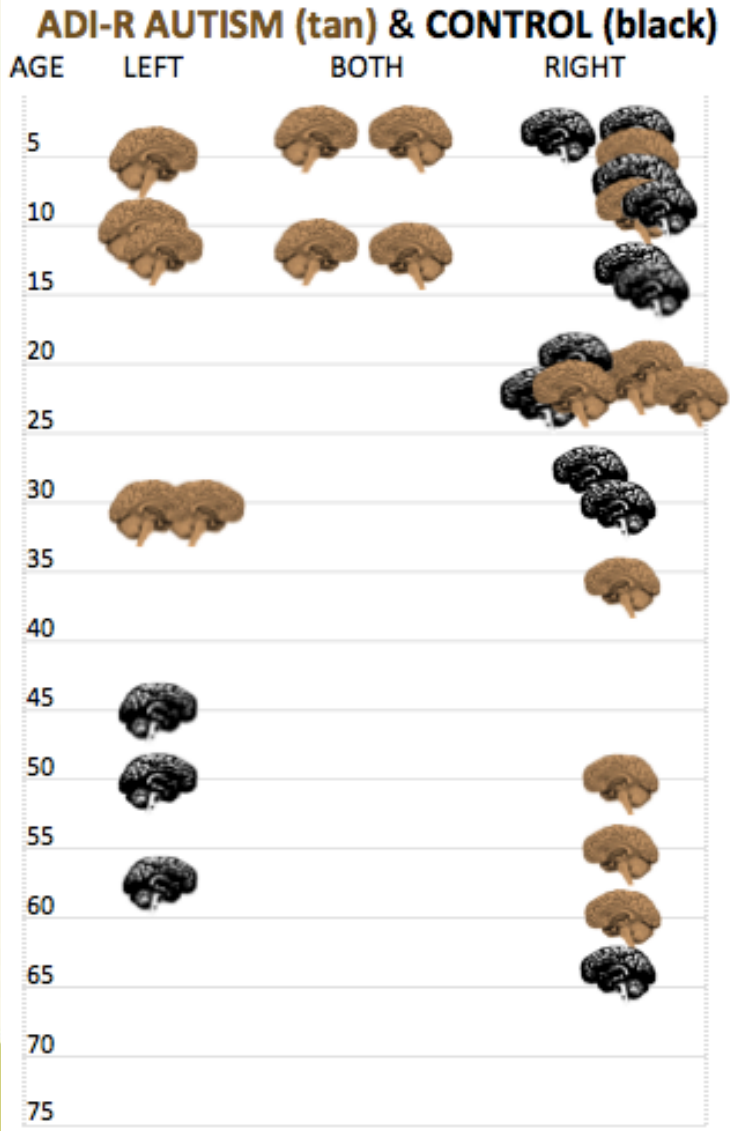
Formalin Fixed
Liquid Nitrogen Frozen



BEARS

Cohort Candidates

Formalin Fixed
Frozen



Autism BrainNet Celloidin Cohort

#	Age	Diagnosis	Sex	Laterality
1	4	Autism - ADI-R	M	L
2	4	Autism - ADI-R	M	R
3	4	Control	F	R
4	4	Control	F	R
5	5	Autism - ADI-R	F	L
6	5	Autism - ADI-R	F	R
7	7	Control	M	R
8	8	Autism - ADI-R	M	R
9	8	Control	F	R
10	11	Autism - ADI-R	F	L
11	13	Autism - ADI-R	M	L
12	14	Control	M	R
13	15	Control	F	R
14	20	Control	F	R
15	21	Autism - ADI-R	F	R
16	22	Autism - ADI-R	M	R
17	23	Autism - ADI-R	M	R
18	23	Control	M	R
19	28	Control	M	R
20	32	Autism - ADI-R	M	L
21	32	Autism/Fragile X	M	L
22	32	Control	M	R
23	36	Autism - ADI-R	M	R
24	48	Control	M	L
25	51	Control	M	L
26	52	Autism - ADI-R	M	R
27	52	Control	M	R
28	56	Autism - ADI-R	M	R
29	59	Control	M	L
30	60	Autism - ADI-R	M	R
31	64	Control	M	R



Need for Community Involvement

This will only be successful if the community is fully engaged and supportive. This will require a nationwide outreach effort to communicate the message that

It Takes Brains to solve autism.



It Take Brains to Solve Autism

Alison Singer

Autism Science Foundation

IACC Meeting

July 8, 2014





IACC Strategic Plan (2009-2013)

Question 2: How Can I Understand What is Happening?

Short-Term Objectives

4. Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research..

Focus Group Behavior Change

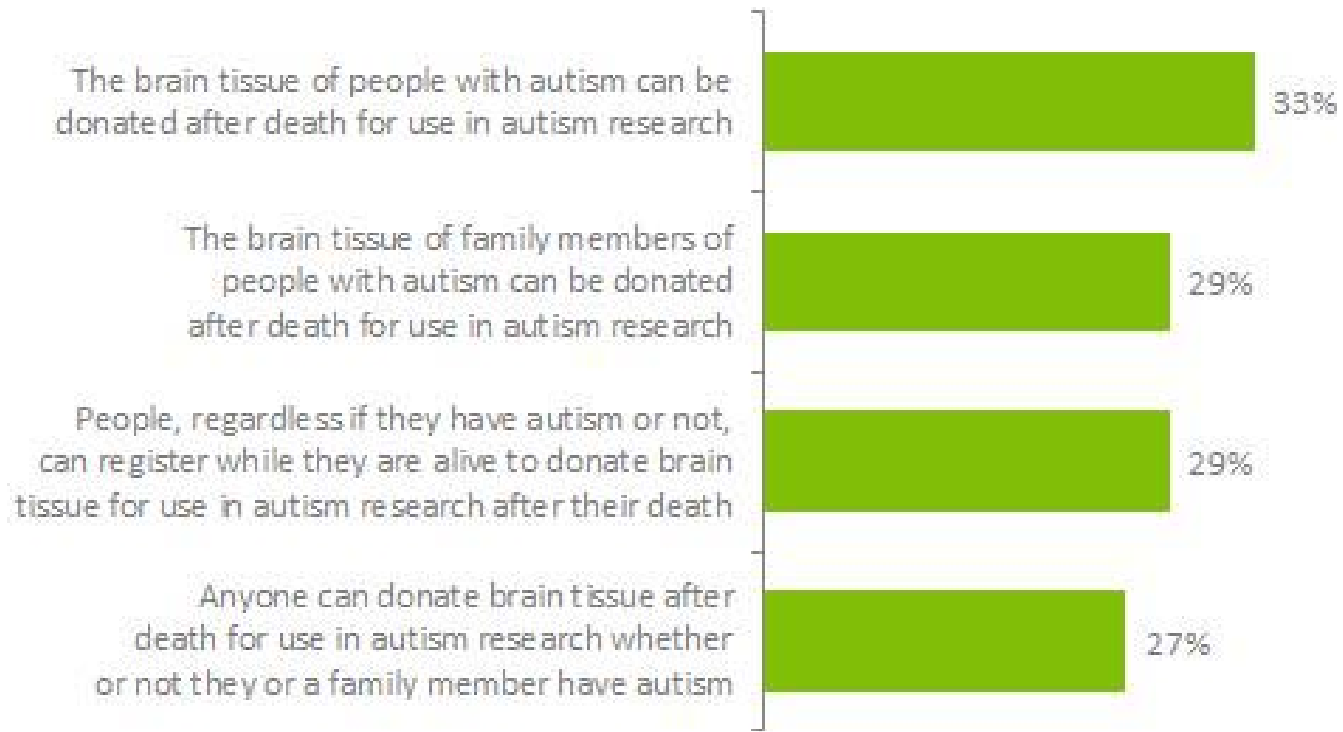
After seeing this campaign, I would [CHECK AS MANY AS APPLY]:	Group 1 Parents 3 – 10	Group 2 Parents 11 - 17	Group 3 Parents 18+	Group 4 Adults with Autism*
Probably do nothing	1			1
Think about the issue	3	4	2	3
Seek more information about brain tissue donation	1	3	3	
Go to the website listed in the advertising		2	3	1
Google brain tissue donation		4	2	1
Speak to someone about brain tissue donation at an autism walk or meeting	1	2	1	
Speak to a friend/family member about brain tissue donation	1	3	3	
Register myself to become a brain tissue donor		1		
Register my child with autism to become a brain tissue donor		1		
Talk to my child's doctor about brain tissue donation		2		



Pre-Wave Online Survey;

N= 412 Sept 1 – Oct 2, 2013

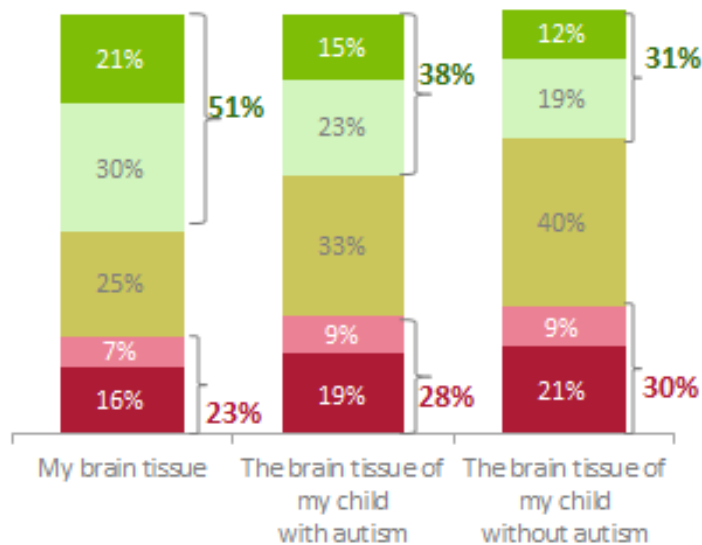
% Aware Prior to Survey



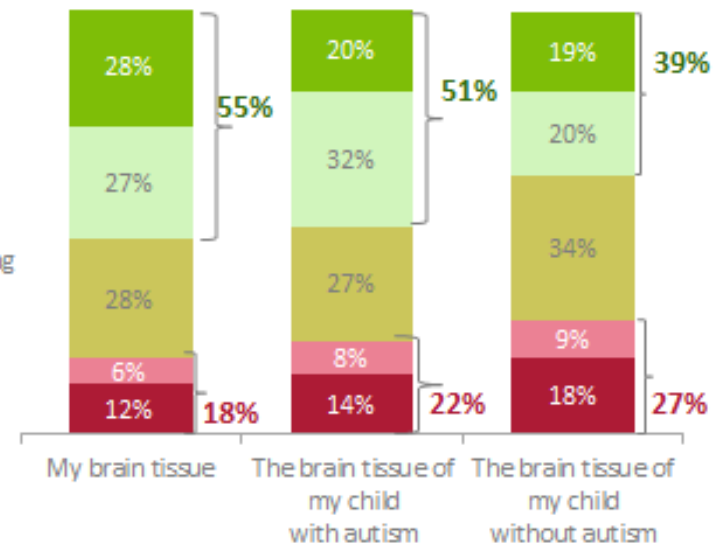


Willingness to Consider Registering

People with autism and their family members can donate brain tissue for autism research



Research using brain tissue is being overseen by a consortium of the Simons Foundation, the MIND Institute, Autism Speaks, and the Autism Science Foundation, as well as several major US university medical centers





Why Willing/Not Willing

- Would be Willing (55%)
 - Help other children (51%)
 - Support research (38%)
- Undecided (25-40%)
 - Wasn't aware (33%)
 - Haven't thought about it enough; need more info (27%)
- Are Unwilling (18-30%)
 - Unethical (28%)
 - Don't want to think about this topic while my child is alive (22%)



THE MATTHEWS,
FROM BEACON, NY,
CHRISTINE, MARK
AND THEIR SONS
MARK JR., TIMOTHY
AND CASEY.
CASEY, AGE 14,
HAS AUTISM.

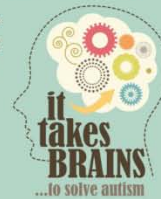
IT TAKES BRAINS TO SOLVE AUTISM

The Matthews never saw themselves as a “super” family, yet when they bonded together to support their autistic son Casey, they were indeed super. And now the Matthews and families like them around the world are being looked upon as super heroes. Why?

They have all been united by one brave and heroic act...pledging to donate the brain tissue of their sons and daughters for when they are sadly no longer with us. It's difficult to think about, but the reality is that brain tissue is urgently needed for the scientific research that will help thousands of people with autism.

Join forces with the Matthews and other super hero families to help ensure a brighter future for all. Because it takes brains to solve autism.

Visit TakesBrains.org to learn more and see how your entire family can help build a better tomorrow.



This initiative
is guided by:



UC DAVIS
MIND INSTITUTE



SFARI | SIMONS FOUNDATION
AUTISM RESEARCH INITIATIVE

THE MATTHEWS,
CHRISTINE, MARK & THEIR
SONS MARK, JR., TRISTYAN
& CASEY.

CASEY, AGE 14,
HAS AUTISM.



IT TAKES BRAINS

...to solve autism



Meet the Matthews

IT TAKES BRAINS is the outreach program of the [Autism BrainNet](#), a new network of research institutions that will collaborate on groundbreaking brain research. Brain study is the key to solving autism, and our mission is to urge families to make the heroic decision to register for brain tissue donation.

[Read More -](#)



Q&A

Topics include:

- THE FACTS
- REGISTRATION
- DONATION



RESEARCH

Studies focusing on differences in brain structure, development, and genetic function will transform the understanding and treatment of autism.

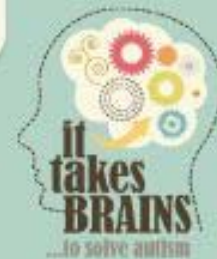


SIGN UP

REGISTER TO DONATE brain tissue and ensure a brighter future for all.



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Q&A **RESEARCH** **SIGN UP**

it takes BRAINS
...to solve autism

QUESTIONS & ANSWERS

THE FACTS

REGISTRATION PROCESS


DONATION PROCESS

- Q:** Why should my family consider donation?
- Q:** Why is there a shortage of brain tissue and how severe is the shortage?
- Q:** Why do scientists need to study brain tissue to solve autism?
- Q:** Why can't scientists use MRIs, EEGs, or other imaging methods to study brain tissue?
- Q:** Does registering as a donor mean that medical treatment will be altered?
- Q:** What are the various religious points of view on brain donation?

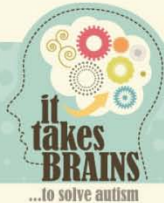
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Q&A RESEARCH SIGN UP



QUESTIONS & ANSWERS

THE FACTS

REGISTRATION PROCESS

DONATION PROCESS


Q: Why should my family consider donation?

Q: Why is there a shortage of brain tissue and how severe is the shortage?

Q: Why do scientists need to study brain tissue to solve autism?





Q: Why can't scientists use MRIs, EEGs, or other imaging methods to study brain tissue?

A: *Currently, scientists can study the living brain by using imaging techniques and observing the electrical activity of the brain. Unfortunately, although research conducted using imaging techniques gives scientists some valuable information about brain structure and function, these methods only get us part of the way to the answers we seek. They do not allow scientists to see individual brain cells or study the very small molecular structures within the brain. Further, imaging techniques do not give scientists the information needed to understand the effects that genetic differences have on brain tissue. The only way to study brain structure and the structure of brain molecules is to examine the whole brain after death. These studies allow scientists to investigate particular pathways and look at the individual neurons of the brain to help understand both normal and abnormal brain development and activity. Similarly, the only way to see how gene expression occurs in different parts of the brain is to study the brain tissue itself.*



Q: Does registering as a donor mean that medical treatment will be altered?

Q: What are the various religious points of view on brain donation?

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The screenshot shows the TakesBrains.org website interface. At the top, there are navigation links for Q&A, RESEARCH, and SIGN UP. The main header features the 'it takes BRAINS ...to solve autism' logo. The article title is 'RESEARCH: What Have Scientists Learned? What Do They Hope to Learn?'. The article text discusses brain tissue research findings and future research goals. The footer includes logos for Autism Science Foundation, UC Davis Mind Institute, Autism Speaks, and SFARI, along with contact and privacy information.

Q&A RESEARCH SIGN UP

it takes BRAINS ...to solve autism

RESEARCH

What Have Scientists Learned? What Do They Hope to Learn?

What have scientists learned about autism from brain tissue research and what do they hope to learn? Researchers learned that there are important cell differences in the brains of people with autism. For example, researchers have discovered that:

- Children with autism have different underlying brain structures compared with typically developing children, including an overabundance of nerve cells in an area of the brain involved in social and communication skills.
- Genes involved in cell connectivity tend to be expressed at lower levels in autism brains, and genes related to immune cells at higher levels, than in control brains.
- The brains of autistic people have fewer oxytocin receptors than the brains of unaffected people. Oxytocin is a hormone that has an influence on social behavior.
- There appear to be structural difference in the brains of people with autism, including differences in the number and size of neurons and the presence of inflammation.

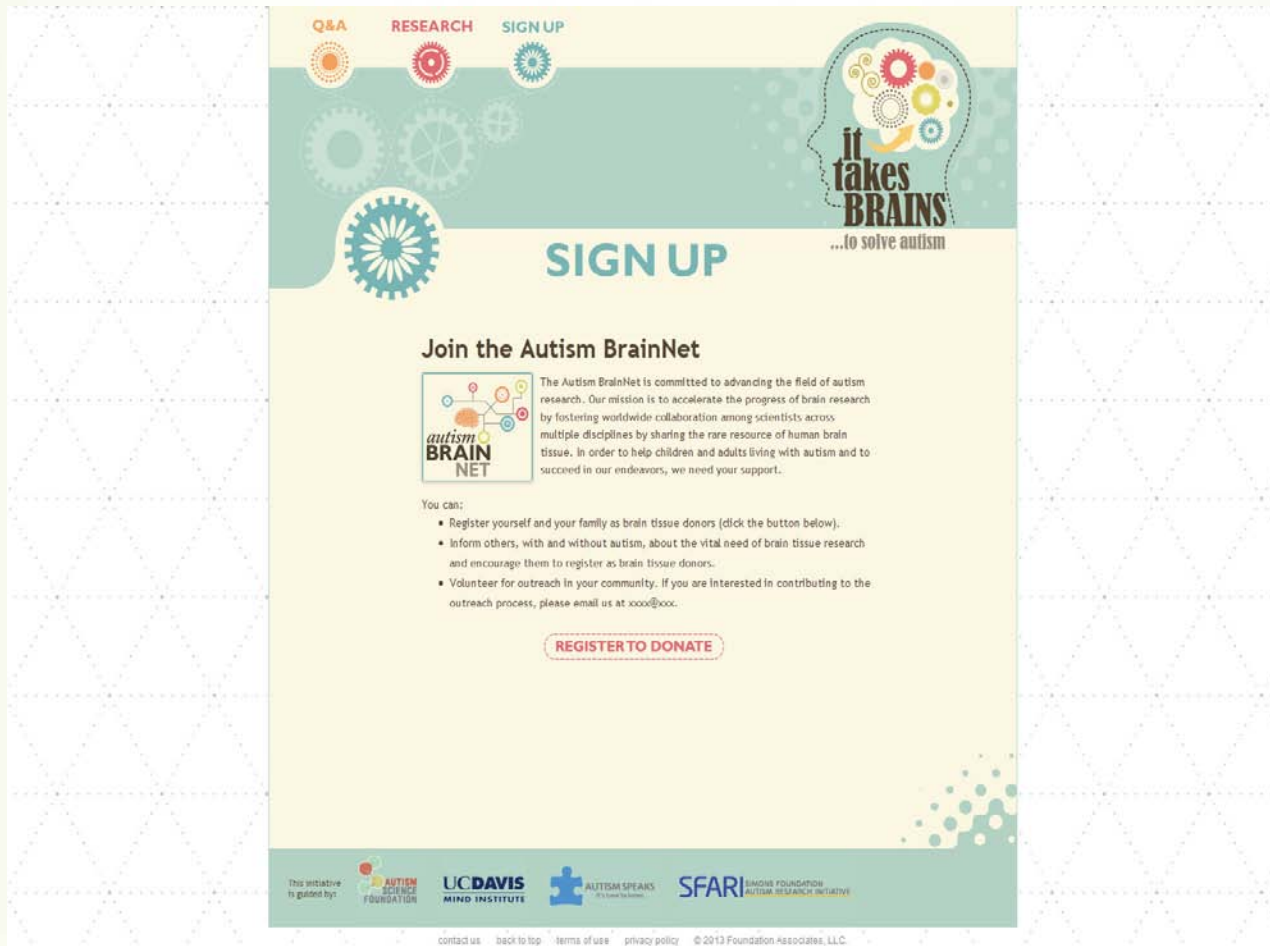
Scientists hope to study the genetic functioning of brain cells and to understand the role of epigenetics (the modifying of gene behavior and the turning on and off of individual genes) in autism. They also need to study gene expression and changes specific to neurons, which can be seen only by examining brain tissue.

Brain research may also lead to the development of ways to influence the way the brain develops its connections in early childhood in order to reduce some of the difficulties experienced by people with autism. Scientists may also come to a better understanding of how brain structure relates to the special skills of some autistic people.

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The screenshot displays a website banner for 'it takes BRAINS ...to solve autism'. At the top, there are navigation links for 'Q&A', 'RESEARCH', and 'SIGN UP', each accompanied by a gear icon. The main heading 'SIGN UP' is prominently displayed in a large, teal font. Below this, the text 'Join the Autism BrainNet' is followed by a brief description of the organization's mission: 'The Autism BrainNet is committed to advancing the field of autism research. Our mission is to accelerate the progress of brain research by fostering worldwide collaboration among scientists across multiple disciplines by sharing the rare resource of human brain tissue. In order to help children and adults living with autism and to succeed in our endeavors, we need your support.' A list of actions users can take is provided, including registering as donors, informing others, and volunteering for outreach. A red button labeled 'REGISTER TO DONATE' is positioned below the list. The footer of the banner features logos for the Autism Science Foundation, UC Davis Mind Institute, Autism Speaks, and SFARI (Simons Foundation Autism Research Initiative), along with contact information and a copyright notice for 2013 Foundation Associates, LLC.

Q&A RESEARCH SIGN UP

it takes
BRAINS
...to solve autism

SIGN UP

Join the Autism BrainNet

The Autism BrainNet is committed to advancing the field of autism research. Our mission is to accelerate the progress of brain research by fostering worldwide collaboration among scientists across multiple disciplines by sharing the rare resource of human brain tissue. In order to help children and adults living with autism and to succeed in our endeavors, we need your support.

You can:

- Register yourself and your family as brain tissue donors (click the button below).
- Inform others, with and without autism, about the vital need of brain tissue research and encourage them to register as brain tissue donors.
- Volunteer for outreach in your community. If you are interested in contributing to the outreach process, please email us at xxxx@xxx.

[REGISTER TO DONATE](#)

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You Can Register Right Now!



**IT TAKES
BRAINS**
...to solve autism

It Takes Brains is the outreach program of the Autism BrainNet, a new network fostering worldwide collaboration of scientists conducting groundbreaking brain research.

Learn about it
TakesBrains.org

