



## about autism

### MEANINGFUL RESEARCH


Autism is a neurological disorder that knows no social, ethnic or racial boundaries. Once considered an extremely rare disorder, autism has now reached epidemic proportions. According to a recent government report 1 in every 150 children is thought to be autistic. It is currently predicted that every twenty minutes a child is diagnosed with autism and more children are diagnosed with autism than AIDs, cancer and diabetes combined. Unfortunately, we have no real answers as to what may be causing this current epidemic of children with autism or what can be done to help them.

Donated tissue may provide key information necessary to help the thousands of children who suffer with this devastating disorder.

### A PRECIOUS NEED

Participating autism organizations are working closely with scientists and clinicians throughout the country in an effort to find effective treatments for this devastating disorder. According to these experts, limited availability of tissue from children who suffer with autism is hampering research because without actual tissue, it is impossible to determine the basic biological defects responsible for this disorder.

In an effort to increase research, we are working in collaboration with the NICHD Brain and Tissue Bank for Developmental Disorders at the University of Maryland to support tissue donations.



## participating organizations

AUTISM RESEARCH INSTITUTE  
[www.Autism.com](http://www.Autism.com)

AUTISM SOCIETY OF AMERICA  
[www.Autism-Society.org](http://www.Autism-Society.org)

AUTISM ONE  
[www.AutismOne.org](http://www.AutismOne.org)

GENERATION RESCUE  
[www.GenerationRescue.org](http://www.GenerationRescue.org)

NATIONAL AUTISM ASSOCIATION  
[www.NationalAutism.org](http://www.NationalAutism.org)

SAFEMINDS  
[www.SafeMinds.org](http://www.SafeMinds.org)

UNLOCKING AUTISM  
[www.UnlockingAutism.org](http://www.UnlockingAutism.org)

# AUTISM RESEARCH OFFERS HOPE



## facts about tissue donation

AUTISM RESEARCH INSTITUTE  
AUTISM SOCIETY OF AMERICA  
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SAFEMINDS  
UNLOCKING AUTISM



## why donate?

### RESEARCH RELIES ON TISSUE DONATION

Human tissue donation is a precious gift. For some, tissue donation may be difficult to consider; whereas for others, there is a sense of comfort and satisfaction in knowing that they have been able to help advance the science in an effort to find answers to help end the autism epidemic.

In deciding whether or not to donate your loved ones' tissue, the following points are helpful to know.

- :: *Tissue donation is accepted by most major religions*
- :: *All additional costs incurred by the donation are covered by the tissue bank*
- :: *The procedure to recover tissue does not interfere with a traditional funeral service*

### ANYONE CAN BE A DONOR

Anyone, regardless of age, is invited to register as a tissue donor. The tissue bank is just as much in need of control tissue as tissue from those with autism. All donor information remains anonymous, and anyone who registers holds the right to withdraw from being a donor at any time.

It is very important that tissue be recovered within 24 hours because, after this time, the tissue has lost most of its usefulness for research purposes. Because of the irreplaceable nature of donated tissue, each lost donation is a 'blow' to research that is impossible to measure. Therefore, advanced registration is especially important in that it enables the intricate process of tissue recovery to occur in a timely manner.




## NICHD Brain & Tissue Bank

The NICHD Brain and Tissue Bank was established in 1991 by the National Institutes of Health to advance research on developmental disorders, including autism. To donate brain and systemic tissue (heart, kidney, colon, nerve and other tissues), it is recommended that you pre-register with the NICHD Brain and Tissue Bank for Developmental Disorders.

The NICHD Bank is the primary source of tissue for basic research on Autism Spectrum Disorders and has provided over 3000 tissue samples to more than 50 researchers, resulting in over 100 scientific publications and scientific meeting presentations.

Brain and tissue banks serve the critical role of collecting, preserving and distributing tissue to qualified scientific investigators who are dedicated to the improved understanding and development of effective treatments for developmental disorders, such as autism spectrum disorders.

NICHD BRAIN AND TISSUE BANK *for*  
DEVELOPMENTAL DISORDERS  
University of Maryland  
Department of Pediatrics  
655 West Baltimore St., 13-013 BRB  
Baltimore, MD. 21201-1559  
Toll free 800-847-1539  
Ph. 410-706-1755  
Fx. 410-706-0038  
btbumab@umaryland.edu  
www.btbankfamily.org



## how to register

Call the NICHD Bank at 1-800-847-1539 or 410-706-1755 (outside of the continental U.S.) with any questions you may have about pre-registration or tissue donation.

The decision to donate tissue is best made in advance rather than at a moment of crisis. Pre-registration also allows for the collection of information that is vital to the speedy recovery of tissue.

Alternatively, families may register with the Autism Tissue Program (ATP) for brain-only donations by calling 1-877-333-0999.

### TISSUE RECOVERY

The next of kin or family member should call the toll free number 1-800-847-1539 or 1-410-706-1755 (from outside the continental U.S.) if death is imminent or as soon as possible after a death. Calls are taken 24 hours a day. It is also important that medical and funeral personnel are aware of the desire to donate tissue.

Even if a person is not registered in advance, tissue donation may still be possible by calling the toll-free number 1-800-847-1539. The Brain and Tissue Bank will make every attempt within its means to ensure successful tissue recovery.