

Global Scope of the NICHD Brain and Tissue Bank for Developmental Disorders

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Introduction

The NICHD Brain and Tissue Bank was established in 1991 to collect, store and distribute human tissue to further medical research with a special focus on developmental disorders. The Bank has recovered tissue from over 3000 individuals primarily from the USA, but also from Australia, Canada, England, New Zealand, South Africa and Spain. Tissues have been collected from individuals with over 400 different disorders and from controls ranging from neonatal to greater than 100 years of age. Medical records and neuropathology reports for individuals with disorders are available to researchers in strict compliance with privacy rules. Both brain and systemic tissues are collected and stored at -80°C and in 10% formalin (>88,000 samples). Researchers must secure institutional approval for research with human tissue and sign a Material Transfer Agreement. To date 726 researchers in 20 countries have received over 28,000 tissue specimens. The frozen tissue is suitable for isolation of high quality RNA. RNA integrity numbers (RIN) for brain in two separate laboratories range from 6.8 +/- 1.6 (n=31) to 8.96 +/- 0.48 (n=52) indicating that the great majority of tissue samples are suitable for molecular biological studies. RIN values are minimally affected by post-mortem interval (up to 24 hours) and time in storage at -80°C. The pH of 39 brain samples was 6.52 +/- 0.25. Researchers have published over 400 scientific papers and 300 abstracts using tissue from the Bank. For availability of tissue, Tissue Request Form and Material Transfer Agreement go to www.bibank.org. (NICHD contract # HHSN275200900011C, Ref. # NO1-HD-9-0011)

Goals and Purposes

The NICHD Brain and Tissue Bank for Developmental Disorders serves an intermediary between families that are supportive of medical research through donated human tissue and researchers who are in need of the tissue. The Bank works closely with dozens of support groups, physicians and researchers. The Bank sends representatives to national meetings of support groups and scientific sessions sponsored by the Society for Neuroscience, Leukodystrophy and Tuberos Sclerosis. The Bank writes short articles for support group newsletter and is cited on the web sites of support groups. The Bank collects both brain and systemic tissue, depending on the tissue affected. The Bank works closely with researchers to collect additional tissues as needed and adjusts the collection procedure to support unique research protocols.

NICHD BRAIN AND TISSUE BANK
Recipients of Tissue Worldwide

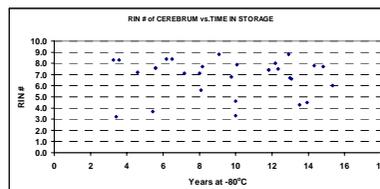
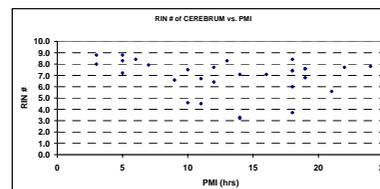
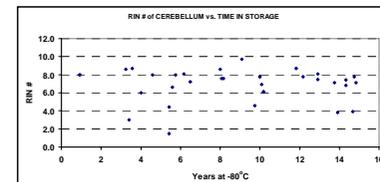
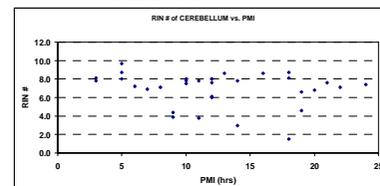


Publications Based on Tissue From the NICHD Brain and Tissue Bank

Topic	# of Papers
Adrenoleukodystrophy	8
Adrenoleukodystrophy / Multiple Sclerosis	1
Adrenomyeloneuropathy	1
AIDS	1
Alexander Disease	11
ALS	3
Alzheimer's Disease	16
Alzheimer's Disease/Down Syndrome	1
Angelman Syndrome	1
Ataxia	2
Ataxia Telangiectasia	5
Autism	60
Autism/Rett Syndrome	5
Autoimmune	1
Battens Disease	2
Beckwith-Wiedemann Syndrome	1
Cancer	7
Dementia	3
Developmental Studies	137
Down Syndrome	14
Dystonia	6
Epilepsy	11
Forensic Pathology	2
Fragile X	9
HIV	3
Krabbe's Disease	1
Laron Syndrome	2

Topic	# of Papers
Leukodystrophy	1
Lissencephaly	1
Mucopolysaccharidosis	1
Multiple Sclerosis	6
Muscular Dystrophy	4
Neurodegeneration	1
Neurofibromatosis	4
Neuropathy	6
Pain	1
Parkinson's Disease	15
Peripheral Neuropathy	1
Prader-Willi Syndrome	16
Rett Syndrome	16
Rett Syndrome/Angelman Syndrome	1
Schizophrenia	7
Scleroderma	1
Smith-Lemli-Opitz Syndrome	1
Spinal Muscular Atrophy	1
Sturge Weber Syndrome	2
Sudden Infant Death Syndrome	16
Tay-Sachs Disease	2
Thymidine Phosphorylase Deficiency	2
Tuberos Sclerosis	5
Vanishing White Matter Disease	2
Walker-Warburg Syndrome	1
Wilms Tumor	1
Total	443

Results – RIN#



Tissue	RIN#	n	Tissue	RIN#
Cerebellum	6.8 ± 1.9	33	Liver	5.1 ± 1.6
Cerebrum	6.8 ± 1.6	34	Lung	5.4 ± 1.9
Cerebrum (Lab 2)	9.2 ± 2.2	78	Psoas	6.5 ± 1.6
Heart	6.2 ± 1.7	10	Testis	6.8 ± 1.5
Kidney	5.2 ± 1.9	24		
	(ave ± std. dev)			(ave ± std. dev)

Conclusion

The NICHD Brain and Tissue Bank for Developmental Disorders located at the University of Maryland, Baltimore source of human tissue from a wide range of developmental disorders. The brain and systemic tissue has been used by 726 researchers to generate 443 publications. The data presented indicate that approximately 80% of the brain samples yield high quality RNA and that in the remaining cases, a low RIN value is not associated with PMI (up to 24 hrs) or length of time in storage at -80°C. Systemic tissue yields somewhat lower RIN values.