



TSC ALERT

Edited by Vicky H Whittemore, PhD

December 2005

Welcome to the December 2005 edition of *TSC Alert* – an online research newsletter for individuals interested in Tuberous Sclerosis Complex (TSC) research and clinical care. This online newsletter contains information of interest to the TSC research and health care community. Please forward this newsletter to colleagues who are interested in TSC. To be added/deleted to/from the mailing list for *TSC Alert* and/or to submit information for the January 2006 *TSC Alert* contact: vwhittemore@tsalliance.org

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Happy holidays! I'm writing you today with wonderful news that impacts everyone affected by tuberous sclerosis complex (TSC).

Over the past year, many of you worked tirelessly with the TS Alliance to secure increased funding for the TSC Research Program at the Department of Defense. We are truly excited to announce that just today **the Defense Appropriations Bill passed by Congress includes \$4.3 million for the DOD Tuberous Sclerosis Complex Research Program!** Once signed by the President, this will represent a \$1.1 million increase (34 percent) over last year's funding level, and the largest yearly increase secured since the inception of the program five years ago.

THANK YOU! This increase would not be possible without the efforts of everyone who contacted their Senators and Representatives to urge them to support this legislation. **Now is the time for you to contact them again to thank them for their vital support** -- a short email or card is fine.

On behalf of the TS Alliance staff and Board of Directors, best wishes for a wonderful holiday season.

Nancy Taylor, CEO

GRANT ANNOUNCEMENTS

UNDERSTANDING AND TREATING TUBEROUS SCLEROSIS COMPLEX

Participating Organizations

National Institutes of Health (NIH), (<http://www.nih.gov/>)

Tuberous Sclerosis Alliance (TS Alliance), (<http://www.tsalliance.org>)

Components of Participating Organizations

National Institute of Neurological Disorders and Stroke (NINDS), (<http://www.ninds.nih.gov>)

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), (<http://www.niddk.nih.gov/>)

National Institute of Mental Health (NIMH), (<http://www.nimh.nih.gov>)

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), (<http://www.niams.nih.gov>)

National Cancer Institute (NCI), (<http://www.nci.nih.gov>)

Letters of Intent Receipt Date(s): Not Applicable

Application Receipt Date(s): Standard dates apply, please see

<http://grants.nih.gov/grants/funding/submissionschedule.htm> for details

Peer Review Date(s): Standard dates apply, please see

<http://grants.nih.gov/grants/funding/submissionschedule.htm> for details

Council Review Date(s): Standard dates apply, please see

<http://grants.nih.gov/grants/funding/submissionschedule.htm> for details

Earliest Anticipated Start Date: April 2006

Additional Information To Be Available Date (Url Activation Date): Not Applicable

Expiration Date: March 2, 2008

RESEARCH ON AUTISM AND AUTISM SPECTRUM DISORDERS (PA-04-085)

National Institute of Mental Health (NIMH), (<http://www.nimh.nih.gov>)

National Institute on Deafness and Other Communication Disorders (NIDCD) (<http://www.nidcd.nih.gov>)

National Institute of Child Health and Human Development (NICHD) (<http://www.nichd.nih.gov>)

National Institute of Neurological Disorders and Stroke (NINDS), (<http://www.ninds.nih.gov>)

National Institute of Environmental Health Sciences (NIEHS) (<http://www.niehs.nih.gov>)

National Institute of Nursing Research (NINR) (<http://www.nih.gov/ninr>)

The purpose of this Program Announcement is to encourage grant applications for the support of research designed to elucidate the diagnosis, epidemiology, etiology, genetics, treatment, and optimal means of service delivery in relation to Autistic Disorder ("autism") and autism spectrum disorders (Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, Pervasive Developmental Disorder-Not otherwise specified, or "Atypical Autism").

This PA is meant to support the broad research goals of the Autism Research Matrix:

(<http://www.nimh.nih.gov/atuismi/xx/researchmatrix.pdf>).

For the complete Program Announcement: <http://grants1.nih.gov/grants/guide/pa-files/PA-04-085.html>

RESEARCH ON PSYCHOPATHOLOGY IN INTELLECTUAL DISABILITIES (MENTAL RETARDATION) (PA-01-028)

National Institute of Mental Health (NIMH), (<http://www.nimh.nih.gov>)

NIMH invites research grant applications for research designed to elucidate the epidemiology, etiology, treatment, and prevention of mental disorders, including emotional and behavioral problems, in persons of any age with intellectual disabilities (mental retardation). This announcement uses the term "intellectual disabilities" to designate conditions that in the past have been referred to with the term "mental retardation", thus these two terms are to be understood as equivalent. For the complete Program Announcement:

<http://grants2.nih.gov/grants/guide/pa-files/PA-04-044.html>

NIH DIRECTOR'S PIONEER AWARD PROGRAM (DP1) (RFA-RM-06-005)

Letters Of Intent Receipt Dates: Not applicable

Application Receipt Date(s): February 27, 2006

<http://grants.nih.gov/grants/guide/rfa-files/RFA-RM-06-005.html>

NEW TSC PUBLICATIONS

[No authors listed] (2005) [The efficacy of topiramate (topamax) in the treatment of resistant epilepsy in children.] Zh Nevrol Psikhiatr Im S S Korsakova 105(11):21-3 [Article in Russian]

Astrinidis A, Senapedis W, Henske EP (2005) Hamartin, the Tuberous Sclerosis Complex 1 (TSC1) gene product, interacts with Polo-like kinase 1 (PLK1) in a phosphorylation-dependent manner. Hum Mol Genet 2005 Dec 8 [Epub ahead of print]

Cross JH (2005) Neurocutaneous syndromes and epilepsy-issues in diagnosis and management. Epilepsia 46 Suppl 10:17-23

Ferrando-Miguel R, Rosner M, Freilinger A, Lubec G, Hengstschlager M (2005) Tuberin - A New Molecular Target in Alzheimer's Disease? Neurochem Res 30(11):1413-1419

Finlay GA, Thannickal VJ, Fanburg BL, Kwiatkowski DJ (2005) Platelet-derived growth factor-induced p42/44 mitogen-activated protein kinase activation and cellular growth is mediated by reactive oxygen species in the absence of TSC2/tuberin. Cancer Res 65(23):10881-90

Folpe AL, Mentzel T, Lehr HA, Fisher C, Balzer BL, Weiss SW (2005) Perivascular Epithelioid Cell Neoplasms of Soft Tissue and Gynecologic Origin: A Clinicopathologic Study of 26 Cases and Review of the Literature. Am J Surg Pathol 29(12):1558-1575

Hawley JA (2005) Interaction of exercise and diet to maximise the training adaptation. Asia Pac J Clin Nutr 14 Suppl:S35

Jozwiak J, Jozwiak S, Oldak M (2005) Molecular activity of sirolimus and its possible application in tuberous sclerosis treatment. Med Res Rev 2005 Dec 2 [Epub ahead of print]

Kimball SR, Jefferson LS (2006) Signaling Pathways and Molecular Mechanisms through which Branched-Chain Amino Acids Mediate Translational Control of Protein Synthesis. J Nutr 136(1):227S-31S

Quigg M, Miller JQ (2005) Clinical findings of the phakomatoses: tuberous sclerosis. Neurology 65(10):E22-3

Santos TM, Han S, Bowser M, Sazani K, Beauchamp RL, Murthy V, Bhide PG, Ramesh V (2005) Alternative splicing in protein associated with Myc (Pam) influences its binding to c-Myc. J Neurosci Res 2005 Dec 8 [Epub ahead of print]

Tigas S, Carroll PV, Jones R, Bingham E, Russell-Jones D, Powell M, Scobie IN (2005) Simultaneous Cushing's disease and tuberous sclerosis; a potential role for TSC in pituitary ontogeny. Clin Endocrinol (Oxf) 63(6):694-5

Yu W, Fraser RB, Gaskin DA, Fernandez CV, Wright JR Jr (2005) C-Kit-positive metastatic malignant pigmented clear-cell epithelioid tumor arising from the kidney in a child without tuberous sclerosis. Ann Diagn Pathol 9(6):330-4

Zacharek SJ, Xiong Y, Shumway SD (2005) Negative Regulation of TSC1-TSC2 by Mammalian D-Type Cyclins. Cancer Res 65(24):11354-60

Zaroff CM, Morrison C, Ferraris N, Weiner HL, Miles DK, Devinsky O (2005) Developmental outcome of epilepsy surgery in tuberous sclerosis complex. Epileptic Disord 7(4):321-326

CONFERENCES

March 9-10, 2005

PKD/TSC Research Workshop

Chicago, IL

More information coming soon!

March 9 – 11, 2006

American Society for Experimental Neurotherapeutics: Eighth Annual Meeting

Omni Shoreham Hotel, Washington, DC

Abstract deadline: January 6, 2006

For more information: ASENT Executive Office at 414-273-8290 or e-mail: info@asent.org

March 31 – April 2, 2006

LAM Foundation 2006 Research Conference

Hilton Netherlands Cincinnati Hotel

Cincinnati, OH

<http://lam.uc.edu>

CANCELLED! May 3-5, 2006

TSC International Research Conference 2006

Berlin, Germany

Due to financial concerns, this conference has been cancelled!

May 10-14, 2006

1st East Mediterranean Epilepsy Congress

Sharm El Sheikh, Egypt

www.epilepsysharm2006.com

SAVE THE DATE! May 11-12, 2006

Hamartoma Syndromes and Insulin Signaling

Lister Hall, National Institutes of Health, Bethesda, MD

More information coming soon!

July 2-6, 2006

7th European Congress of Epileptology

Helsinki Fair Centre, Helsinki, Finland

<http://www.epilepsyhelsinki2006.org>

July 8-12, 2006

UICC World Cancer Congress 2006

Washington Convention Center, Washington, DC

<http://www.2006conferences.org/u-program.php>

Submit abstracts to UICC 2006 through the official conference website at

http://2006.confex.com/2006/uicc/index_UICC.epi

All abstracts must be submitted electronically.

For more information about abstract submission, please see

<http://www.2006conferences.org/u-abstracts.php>

SAVE THE DATE! July 14-16, 2006

National TSC Conference

Organized by the Tuberous Sclerosis Alliance

[Indian Lakes Resort](#)

Chicago, Illinois
<http://www.tsalliance.org>

July 27-30, 2006

6th Asian & Oceanian Epilepsy Congress

Kuala Lumpur Convention Centre

Kuala Lumpur, Malaysia

www.epilepsykualalumpur2006.org

August 2-4, 2006

10th European Conference on Epilepsy & Society

Copenhagen, Denmark

For more information: <http://www.epilepsyandsociety.org>

September 10-14, 2006

XXVIIIth International Congress of Clinical Neurophysiology

Edinburgh, UK

www.iccn2006.com

October 30 – November 2, 2006

World Congress on Autism

Cape Town, South Africa

Call for Papers closes 30th September 2005

Early Bird Registration Closes June 30th 2006

Please visit www.autismcongress.com

March 2007

NINDS Epilepsy Conference

Follow-up to 2000 Conference "Curing Epilepsy: Focus on the Future"

<http://www.ninds.nih.gov>

July 8-12, 2007

27th International Epilepsy Congress

Suntec Singapore International Convention and Exhibition Center

Singapore

For more information: www.epilepsycongress.org

NEWS

NIH announces the opening of the 2006 NIH Director's Pioneer Award

program. <http://www.nih.gov/news/pr/nov2005/od-28.htm>

TSC INFORMATION

For information about TSC, visit the TS Alliance Web site at: <http://www.tsalliance.org> or contact the TS Alliance at info@tsalliance.org or by telephone: 1-800-225-6872 or 301-562-9890.