



## **TSC ALERT**

Edited by Vicky Holets Whittemore, Ph.D. & Cheryl Dunigan, Ph.D.

**September 15, 2003**

Welcome to the September 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 October 2003 *TSC Alert* contact: [Vicky.Whittemore@tsalliance.org](mailto:Vicky.Whittemore@tsalliance.org)

### **Table of Contents**

[Clicking on one of the headings takes you directly to that section of *TSC Alert*]

<b>GRANT ANNOUNCEMENTS:</b> .....	<b>1</b>
<b>NIH ANNOUNCEMENTS:</b> .....	<b>2</b>
<b>TSC TISSUE AVAILABILITY:</b> .....	<b>5</b>
<b>RESOURCES:</b> .....	<b>5</b>
<b>CLINICAL TRIALS/STUDIES:</b> .....	<b>5</b>
<b>NEW TSC PUBLICATIONS:</b> .....	<b>5</b>
<b>CONFERENCES:</b> .....	<b>9</b>
<b>ARCHIVED ISSUES OF TSC ALERT:</b> .....	<b>10</b>

### **GRANT ANNOUNCEMENTS:**

#### **TUBEROUS SCLEROSIS ALLIANCE: Letter of Intent Deadline Announced**

Letters of Intent (LOIs) will be accepted until **November 15, 2003**. Invited applicants will be selected from the submitted LOIs and asked to submit a complete application, due January 15, 2004. Funding to begin July 1, 2004.

Focus: Research related to the Tuberous Sclerosis Complex (TSC). Researchers focused on preclinical and clinical studies relevant to TSC are particularly invited to apply. LOIs describing other areas of research relevant to TSC will also be considered.

See the separate attachment that contains the complete RFA. Additional information can be obtained at: <http://www.tsalliance.org> or by calling Dr. Cheryl Dunigan at the TS Alliance at 1-800-225-6872.

### **CLINICAL STUDIES OF SAFETY AND EFFECTIVENESS OF ORPHAN PRODUCTS**

Availability of Grants; Request for Applications (Catalog of Federal Domestic Assistance No. 93.103), Food and Drug Administration, HHS Notice: Receipt dates for FYs 2004 and 2005.

<http://www.fda.gov/orphan/grants/2004RFA.htm>

## **NIH ANNOUNCEMENTS:**

### **MENTORED PATIENT-ORIENTED RESEARCH CAREER DEVELOPMENT AWARDS WITH EMPHASIS ON THE APPLICATION OF GENOMIC OR PROTEOMIC TECHNOLOGIES**

National Human Genome Research Institute and National Institute of Drug Abuse, National Institutes of Health

<http://grants1.nih.gov/grants/guide/rfa-files/RFA-HG-03-006.html>

### **REDUCING DISPARITIES IN THE TREATMENT OF EPILEPSY**

National Institute of Neurological Disorders and Stroke, National Institutes of Health

<http://grants.nih.gov/grants/guide/pa-files/PAS-03-164.html>

### **NINDS EXPLORATORY/DEVELOPMENTAL GRANTS FOR TRANSLATIONAL RESEARCH**

The NINDS uses the Exploratory/Developmental (R21) Grants to provide research support for new research projects in areas of high relevance to the mission of the [NINDS](#). Applicants may request a project period of up to two years with a combined budget for direct costs of up to \$275,000 for the two year period. For example, the applicant may request \$100,000 in the first year and \$175,000 in the second year. The request should be tailored to the needs of the project. Normally, no more than \$200,000 may be requested in any single year. See also full program announcement NIH Exploratory/Developmental Research Grant Award (R21): [PA-03-107](#)

As an Exploratory/Developmental mechanism, the R21 Grant is intended to support projects that: 1) assess the feasibility of a novel avenue of investigation 2) involve high risk experiments that could lead to a breakthrough in a particular field or 3) demonstrate the feasibility of new technologies that could have major impact in a specific area. To be eligible for consideration, proposals must be distinct from those traditionally submitted through the R01 mechanism. For example, projects designed to produce incremental advances in knowledge in a well-established area will not be considered. Proposals submitted under this mechanism should be limited to those with the potential for truly ground-breaking impact.

NINDS also supports R21 Exploratory/Developmental Projects in Translational Research to support research projects intended to discover potential targets for therapeutic intervention, to identify candidate therapeutics, or to develop assays, animal models, devices, or technologies for screening or developing therapeutics. Such projects, if successful, should lead directly to a therapy development project for a particular neurological disorder. For additional Information, see: [PAR-02-138.html](#)

### **NCI WOULD LIKE TO SPEAK WITH PATIENTS, FAMILY CAREGIVERS, AND PHYSICIANS**

The National Cancer Institute (NCI) Office of Education and Special Initiatives is looking for patients, family caregivers, and physicians who are interested in participating in telephone focus

groups and in-depth interviews. This research will ensure that new NCI palliative care-related educational products meet the needs of a diverse audience. Flyers in English and Spanish are available that describe those who may qualify to participate. If you have any questions, or would like copies of the flyers for dissemination, please contact Melinda Moyer at ORC Macro at: [Melinda.K.Moyer@orcmacro.com](mailto:Melinda.K.Moyer@orcmacro.com) or 301-572-0475.

### **NCCAM ANNOUNCES NEW RESEARCH FELLOWSHIP PROGRAM**

The National Center for Complementary and Alternative Medicine (NCCAM), a component of the National Institutes of Health (NIH), announces the creation of a new NCCAM Director's Fellowship in Complementary and Alternative Medicine (CAM) Research, with funding by The Prince of Wales Foundation. The new fellowship program will add measurably to NCCAM's ongoing training activities by sponsoring outstanding research fellows to work in its Division of Intramural Research (DIR), based at the NIH in Bethesda, MD. A selection committee comprising leaders from the CAM and scientific communities will choose the recipient of the fellowship from a highly competitive international pool of applicants. Applicants must possess an M.D., D.O., Ph.D., D.C., D.M.D., N.D., D.V.M., or other equivalent degree, and have a record of excellence and promise in clinical and/or laboratory-based research -- preferably related to CAM.

The primary goal of the training program is to prepare the fellow for a career as an independent CAM investigator. The fellowship includes full salary, benefits, professional travel, and research support for 2 to 3 years. The fellow will undertake clinical, translational, and/or laboratory research in NCCAM's DIR. The DIR provides state-of-the-art research facilities as well as access to the extensive clinical research infrastructure of the NIH Clinical Center.

The Prince of Wales Foundation opened its Washington, DC, offices in 1997. It distributes funding each year to benefit a wide range of causes throughout the world, including supporting research in CAM and integrative health care.

For more information about the fellowship, applicants should contact:

Christopher Baron  
Human Resources Specialist  
Office of Human Resources, NIH  
31 Center Drive, Room 2C12  
Bethesda, MD 20892  
Email: [Baronch@mail.nih.gov](mailto:Baronch@mail.nih.gov)

**The deadline for receipt of applications is November 24, 2003.**

The National Center for Complementary and Alternative Medicine (NCCAM) is dedicated to exploring complementary and alternative healing practices in the context of rigorous science, training CAM researchers, and disseminating authoritative information to the public and professionals. For additional information, call NCCAM's Clearinghouse toll free at 1-888-644-6226 or visit the NCCAM Web site at <http://www.nccam.nih.gov>

### **LOAN REPAYMENT PROGRAM EXTENDED TO RESEARCHERS FUNDED BY NON-PROFITS**

The NIH has extended Loan Repayment Program eligibility to health professionals funded by nonprofit sources and non-NIH grants who are pursuing careers in the field of clinical, pediatric or health disparities research. **The current application cycle opens September 1 and closes December 31, 2003.**

This is a significant change from the first year of the LRP, when specific NIH grants were required for the submission of an application. The availability of loan repayment has the potential to ensure the recruitment and retention of highly qualified health professionals to our country's next generation of biomedical researchers, especially clinical investigators

The NIH Loan Repayment Programs can offer repayment of up to \$35,000 per year of qualified educational loan debt and cover the tax liability of the loan payments. Complete program information and online applications are available at the NIH Loan Repayment Programs Website: [www.lrp.nih.gov](http://www.lrp.nih.gov)

**MIDCAREER INVESTIGATOR AWARD IN PATIENT-ORIENTED RESEARCH (K24):  
ADDENDUM**

National Institute for Biomedical Imaging and Bioengineering  
<http://grants.nih.gov/grants/guide/notice-files/NOT-EB-03-008.html>

**UPDATE ON NIBIB POLICIES ON THE K-SERIES CAREER DEVELOPMENT AWARDS**

National Institute for Biomedical Imaging and Bioengineering  
<http://grants.nih.gov/grants/guide/notice-files/NOT-EB-03-009.html>

**NIBIB POLICIES AND PROCEDURES FOR INSTITUTIONAL TRAINING GRANT (T32)  
APPLICATIONS**

National Institute for Biomedical Imaging and Bioengineering  
<http://grants.nih.gov/grants/guide/notice-files/NOT-EB-03-010.html>

**POPULATION RESEARCH INFRASTRUCTURE PROGRAM**

National Institute of Child Health and Human Development  
<http://grants.nih.gov/grants/guide/rfa-files/RFA-HD-03-026.html>

**DEVELOPING TRANSLATIONAL RESEARCH ON MECHANISMS OF EXTINCTION  
LEARNING**

National Institute of Mental Health  
National Institute on Drug Abuse  
<http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-04-005.html>

**MODEL VALIDATION FOR ANTIEPILEPTOGENIC AND RESISTANT EPILEPSY  
THERAPIES**

National Institutes of Neurological Disorders and Stroke  
<http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-04-002.html>

**CENTERS OF BIOMEDICAL RESEARCH EXCELLENCE (COBRE)**

National Center for Research Resources  
<http://grants.nih.gov/grants/guide/rfa-files/RFA-RR-03-014.html>

## TSC TISSUE AVAILABILITY:

Please contact the Brain and Tissue Bank if you are interested in obtaining donated tissue from individuals with TSC for your research. You may contact them by phone at: 1-800-847-1539 or via e-mail at [btbumab@umaryland.edu](mailto:btbumab@umaryland.edu) Additional information can be found on their Web site at: <http://som1.umaryland.edu/BTBank/main.html>

## RESOURCES:

The Tuberous Sclerosis Alliance provides several publications for individuals with TSC and their families, as well as for health care professionals. You can access the TS Alliance Fact Sheets that provide information on all aspects of the disease on the website at <http://www.tsalliance.org>

The most recent Fact Sheet to be produced is on Infantile Spasms in Children with TSC and can be accessed at: <http://www.tsalliance.org/Fact%20Sheets/infantile%20spasms.pdf>

## CLINICAL TRIALS/STUDIES:

### **TS ALLIANCE AND LAM FOUNDTION: RAPAMYCIN CLINICAL TRIAL FOR RENAL AND LUNG INVOLVEMENT IN TSC AND LAM**

Patients with TSC and/or LAM are being enrolled in a clinical trial to study the effect of rapamycin on tumor growth in these two diseases. **Contact:** Dr. Frank McCormack at [frank.mccormack@uc.edu](mailto:frank.mccormack@uc.edu); or 513-558-4831, Dr. John Bissler at [john.bissler@chmcc.org](mailto:john.bissler@chmcc.org), or Dr. David Franz at [david.franz@chmcc.org](mailto:david.franz@chmcc.org).

### **NHLBI: LYMPHANGIOLEIOMYOMATOSIS (LAM) PROTOCOL**

The Tuberous Sclerosis Alliance encourages women with TSC and physicians who have patients with TSC, whether or not they have been diagnosed with LAM, to participate in this worthwhile study. Studies such as this are the first step in understanding this devastating disease and we are fortunate that the NHLBI has initiated a protocol aimed at understanding the pathogenesis of LAM. If you are interested in further information or have any questions, you may contact NHLBI at 1-877-NIH-LUNG (1-877-644-5864). Choose # 3 from the menu items after dialing. This is a toll free number.

## NEW TSC PUBLICATIONS:

### **TSC RESEARCH SPOTLIGHT:**

**Yu J, Astrinidis A, Howard S, Henske EP (2003) Estradiol and Tamoxifen Stimulate Lymphangiomyomatosis-Associated Angiomyolipoma Cell Growth and Activate Both Genomic and Non-Genomic Signaling Pathways.** Am J Physiol Lung Cell Mol Physiol. 2003 Aug 15 [Epub ahead of print]. <http://ajplung.physiology.org/cgi/reprint/00204.2003v1>

Lymphangiomyomatosis (LAM) is a progressive lung disease affecting almost exclusively women. The reasons for this strong gender predisposition are poorly understood. Renal angiomyolipomas occur in 50-60% of sporadic LAM patients. The smooth muscle cells of pulmonary LAM and renal angiomyolipomas are nearly indistinguishable morphologically. Here, Yu and collaborators report

the first successful cell culture of a LAM-associated renal angiomyolipoma. The cells carried inactivating mutations in both alleles of the *TSC2* gene, and expressed estrogen receptor alpha, estrogen receptor beta, and androgen receptor. To elucidate the cellular pathways through which steroid hormones influence LAM pathogenesis, they treated the cells with both estradiol and tamoxifen. Cell growth was stimulated by estradiol, associated with phosphorylation of p44/42 MAPK at 5 min and an increase in c-myc expression at 4 hrs. Tamoxifen citrate also stimulated cell growth, associated with increased phosphorylation of p44/42 MAPK and expression of c-myc, indicating that tamoxifen has agonist effects on angiomyolipoma cells. This response to tamoxifen in human angiomyolipoma cells differs from prior studies of Eker rat leiomyoma cells, possibly reflecting cell type or species differences in cells lacking tuberin. Their data provide the first evidence that estradiol stimulates the growth of angiomyolipoma cells, that tamoxifen has agonist effects in angiomyolipoma cells, and that estradiol and tamoxifen impact both genomic and nongenomic signaling pathways in angiomyolipoma cells. The responsiveness of angiomyolipoma cells to estradiol may be related to the underlying reasons that lymphangiomyomatosis affects primarily women.

#### **NEW PUBLICATIONS:**

[No authors listed] (2003) Tuberous sclerosis associated with multiple speckled lentiginous nevi. *J Eur Acad Dermatol Venereol* 17(5):616-617

Antel SB, Collins DL, Bernasconi N, Andermann F, Shinghal R, Kearney RE, Arnold DL, Bernasconi A (2003) Automated detection of focal cortical dysplasia lesions using computational models of their MRI characteristics and texture analysis. *Neuroimage* 19(4):1748-1759

Aoki K, Yamaguchi A, Shimizu K, Hirayama A, Fukui Y, Samma S. [Non-ischemic tumor enucleation for renal angiomyolipoma: a case report.] *Hinyokika Kyo* 49(7):397-9 [Article in Japanese]

Ballou LM, Jiang YP, Du G, Frohman MA, Lin RZ (2003) Ca(2+)- and phospholipase D-dependent and -independent pathways activate mTOR signaling. *FEBS Lett* ;550(1-3):51-6

Baram TZ (2003) Treatment of infantile spasms: the ideal and the mundane. *Epilepsia* 44(8):993-4

Barker KT, Houlston RS (2003) Overgrowth syndromes: is dysfunctional PI3-kinase signalling a unifying mechanism? *Eur J Hum Genet* 11(9):665-70

Bermudez H, Guillonneau B, Gupta R, Adorno Rosa J, Cathelineau X, Fromont G, Vallancien G (2003) Initial experience in laparoscopic partial nephrectomy for renal tumor with clamping of renal vessels. *J Endourol* 17(6):373-8

Beugnet A, Wang X, Proud CG (2003) The TOR-signaling and RAIP motifs play distinct roles in the mTOR-dependent phosphorylation of initiation factor 4E-binding protein 1 in vivo. *J Biol Chem* Aug 11 [Epub ahead of print] <http://www.jbc.org/cgi/reprint/M308573200v1>

Brugarolas JB, Vazquez F, Reddy A, Sellers WR, Kaelin WG (2003) TSC2 regulates VEGF through mTOR-dependent and -independent pathways. *Cancer Cell* 4(2):147-58

Caraballo RH, Fejerman N, Bernardina BD, Ruggieri V, Cersosimo R, Medina C, Pocięcha J (2003) Epileptic spasms in clusters without hypsarrhythmia in infancy. *Epileptic Disord* 5(2):109-13

Date H, Aoe M, Nagahiro I, Sano Y, Andou A, Matsubara H, Goto K, Tedoriya T, Shimizu N (2003) Living-donor lobar lung transplantation for various lung diseases. *J Thorac Cardiovasc Surg* 126(2):476-81

Eisermann MM, DeLaRaillere A, Dellatolas G, Tozzi E, Nabbout R, Dulac O, Chiron C (2003) Infantile spasms in Down syndrome-effects of delayed anticonvulsive treatment. *Epilepsy Res* 55(1-2):21-7

Figiel M, Maucher T, Rozyczka J, Bayatti N, Engele J (2003) Regulation of glial glutamate transporter expression by growth factors. *Exp Neurol* 183(1):124-35

Francois LL, Manel V, Rousselle C, David M (2003) Ketogenic diet as an alternative therapy for children with refractory epilepsy: about 29 children.] *Arch Pediatr* 10(4):300-6 [Article in French]

Govindarajan B, Mizesko MC, Miller MS, Onda H, Nunnally M, Casper K, Brat D, Cohen C, Arbiser JL (2003) Tuberous Sclerosis-associated Neoplasms Express Activated p42/44 Mitogen-activated Protein (MAP) Kinase, and Inhibition of MAP Kinase Signaling Results in Decreased in Vivo Tumor Growth. *Clin Cancer Res* 9(9):3469-75

Hamano S, Tanaka M, Mochizuki M, Sugiyama N, Eto Y (2003) Long-term follow-up study of West syndrome: Differences of outcome among symptomatic etiologies. *J Pediatr* 143(2):231-5

Harding M (2003) Immunophilins, mTOR, and pharmacodynamic strategies for a targeted cancer therapy. *Clin Cancer Res* 9(8):2882-6

Hengstschlager M, Rosner M, Fountoulakis M, Lubec G (2003) Regulation of PCNA and CAF-1 expression by the two tuberous sclerosis gene products. *Biochem Biophys Res Commun* 307(3):737-42

Inoki K, Li Y, Xu T, Guan KL (2003) Rheb GTPase is a direct target of TSC2 GAP activity and regulates mTOR signaling. *Genes Dev* 17(15):1829-34 [Epub 2003 Jul 17]

Jung YJ, Isaacs JS, Lee S, Trepel J, Neckers L (2003) IL-1beta mediated up-regulation of HIF-1alpha via an NFkB/COX-2 pathway identifies HIF-1 as a critical link between inflammation and oncogenesis. *FASEB J* Sep 4 [Epub ahead of print]  
<http://www.fasebj.org/cgi/content/abstract/03-0329fjev1>

Kis A, Yellon DM, Baxter GF (2003) Second window of protection following myocardial preconditioning: an essential role for PI3 kinase and p70S6 kinase. *J Mol Cell Cardiol* 35(9):1063-71

Lizcano JM, Alrubaie S, Kieloch A, Deak M, Leever SJ, Alessi DR (2003) Insulin-induced Drosophila S6 kinase activation requires phosphoinositide 3-kinase and protein kinase B. *Biochem J* 374(Pt 2):297-306

Nomura M, He Z, Koyama I, Ma WY, Miyamoto KI, Dong Z (2003) Involvement of the Akt/mTOR pathway on EGF-induced cell transformation. *Mol Carcinog* 38(1):25-32

Okano J, Shiota G, Matsumoto K, Yasui S, Kurimasa A, Hisatome I, Steinberg P, Murawaki Y (2003) Hepatocyte growth factor exerts a proliferative effect on oval cells through the PI3K/AKT signaling pathway. *Biochem Biophys Res Commun* 309(2):298-304

- Pacios Cantero J, Perez Robledo J, Moreno Azcoita M (2003) Wunderlichacute;s syndrome due to rupture of a renal angiomyolipoma. *Rev Esp Enferm Dig* 95(7):497-499 [Article in English, Spanish]
- Patel PH, Thapar N, Guo L, Martinez M, Maris J, Gau CL, Lengyel JA, Tamanoi F (2003) Drosophila Rheb GTPase is required for cell cycle progression and cell growth. *J Cell Sci* 116(Pt 17):3601-10
- Patel S, Lipina C, Sutherland C (2003) Different mechanisms are used by insulin to repress three genes that contain a homologous thymine-rich insulin response element. *FEBS Lett* 549(1-3):72-6
- Peralba JM, DeGraffenried L, Friedrichs W, Fulcher L, Grunwald V, Weiss G, Hidalgo M (2003) Pharmacodynamic Evaluation of CCI-779, an Inhibitor of mTOR, in Cancer Patients. *Clin Cancer Res* 9(8):2887-92
- Porter BE, Judkins AR, Clancy RR, Duhaime A, Dlugos DJ, Golden JA (2003) Dysplasia: A common finding in intractable pediatric temporal lobe epilepsy. *Neurology* 61(3):365-368
- Ruggieri VL, Arberas CL (2003) [Behavioural phenotypes. Biologically determined neuropsychological patterns.] *Rev Neurol* 37(3):239-53 [Article in Spanish]
- Ryu JH, Swensen SJ (2003) Cystic and cavitary lung diseases: focal and diffuse. *Mayo Clin Proc* 78(6):744-52
- Shao Y, Zhong DR, Li XH (2003) [Differences in morphology and immunohistochemistry between hepatic angiomyolipoma and renal angiomyolipoma.] *Zhonghua Yi Xue Za Zhi* 83(13):1142-5 [Article in Chinese]
- Tachataki M, Winston RM, Taylor DM (2003) Quantitative RT-PCR reveals tuberous sclerosis gene, TSC2, mRNA degradation following cryopreservation in the human preimplantation embryo. *Mol Hum Reprod* 9(10):593-601
- Taveira-DaSilva AM, Stylianou MP, Hedin CJ, Kristof AS, Avila NA, Rabel A, Travis WD, Moss J (2003) Maximal oxygen uptake and severity of disease in lymphangioliomyomatosis. *Am J Respir Crit Care Med* Sep 4 [Epub ahead of print]
- Van Splunder J, Stilma JS, Evenhuis HM (2003) Visual performance in specific syndromes associated with intellectual disability. *Eur J Ophthalmol* 13(6):566-74
- Verhaaren HA, Vanakker O, De Wolf D, Suys B, Francois K, Matthys D (2003) Left ventricular outflow obstruction in rhabdomyoma of infancy: Meta-analysis of the literature. *J Pediatr* 143(2):258-63
- Watanabe Y, Oki S, Migita K, Isobe N, Okazaki T, Nabika S (2003) [A case of subependymal giant cell astrocytoma not associated with tuberous sclerosis.] *No Shinkei Geka* 31(5):543-8 [Article in Japanese]
- Yoshino K, Tokunaga C, Hara K, Yonezawa K (2003) [mTOR complex as an integrating controller of cell growth.] *Tanpakushitsu Kakusan Koso* 48(10):1378-85 [Article in Japanese]

Yu J, Astrinidis A, Howard S, Henske EP (2003) Estradiol and Tamoxifen Stimulate Lymphangiomyomatosis-Associated Angiomyolipoma Cell Growth and Activate Both Genomic and Non-Genomic Signaling Pathways. *Am J Physiol Lung Cell Mol Physiol*. 2003 Aug 15 [Epub ahead of print]. <http://ajplung.physiology.org/cgi/reprint/00204.2003v1>

Zhang SX, Gozal D, Sachleben LR Jr, Rane M, Klein JB, Gozal E (2003) Hypoxia induces an autocrine-paracrine survival pathway via platelet-derived growth factor (PDGF)-B/PDGF- $\beta$  receptor/phosphatidylinositol 3-kinase/Akt signaling in RN46A neuronal cells. *FASEB J* 17(12):1709-1711

Zhou C, Gehrig PA, Whang YE, Boggess JF (2003) Rapamycin inhibits telomerase activity by decreasing the hTERT mRNA level in endometrial cancer cells. *Mol Cancer Ther* 2(8):789-95

## CONFERENCES:

For a complete listing of conferences, visit the TS Alliance website at: <http://216.33.101.121/Research/upcoming%20conferences.asp>

### October 1, 2003

#### **Tuberous Sclerosis Complex Symposium**

Satellite Conference in conjunction with the Child Neurology Society Meeting

Sponsored by the TS Alliance, NINDS, NIH and CNS

Loews Miami Beach Hotel, Miami Beach, FL

Advance registration REQUIRED: You must register on-line or by FAX/mail on or before September 15, 2003. Limited to first 250 registrants.

[http://www.childneurologysociety.org/events/evt\\_001.asp](http://www.childneurologysociety.org/events/evt_001.asp)

### October 22-23, 2003

#### **Second Meeting of the Secretary's Advisory Committee on Genetics, Health and Society**

Loews l'Enfant Plaza Hotel, Washington, DC

For directions and to make online lodging reservations, visit

[http://www.loewshotels.com/hotels/washington\\_lenfant/default.asp](http://www.loewshotels.com/hotels/washington_lenfant/default.asp).

An agenda will be posted online in the coming weeks at

<http://www4.od.nih.gov/oba/sacghs/sacghsmtg.htm>

Individuals who wish to provide public comment may do so in writing and/or orally during the meeting. If you wish to provide public comment, please contact Amanda Sarata by email at [sarataa@od.nih.gov](mailto:sarataa@od.nih.gov) or by phone at 301-496-9838 and indicate whether you would like to provide oral and/or written comments, whether you will be speaking on behalf of a particular organization, and if so, your affiliation to that organization. We ask that you please submit written comments by Wednesday, October 1.

For the October meeting in particular, the Committee would welcome public comment on:

\* The adequacy of the education and training of health professionals in genetics and the genetics workforce and whether current efforts to prepare health professionals to use genetic technologies are adequate and, if not, what the gaps are and how should they be addressed; and

\* The role, current activities, and plans of the Federal regulatory agencies to assure the safety and appropriate marketing of genetic tests.

Viewing Options: The meeting is open to the public and pre-registration is not required. Seating will be available on a first-come-first-serve basis. The meeting will also be Web cast. Information on how to gain access to the Web cast will be available on the day of the meeting at

<http://www4.od.nih.gov/oba/sacghs/sacghsmtg.htm>

#### **October 22-25, 2003**

##### **National Association for the Dually Diagnosed Annual Conference**

Holiday Inn – Chicago Mart Plaza, Chicago, IL

<http://www.thenadd.org/content/conferences/20thannualspk.shtml>

#### **March 26-28, 2004**

##### **LAM Foundation Research Conference**

The Westin, Downtown Cincinnati, OH

More information coming soon!

#### **February 20-22, 2004**

##### **The 1st Pan African & Pan Arab International Pediatric Epilepsy Conference**

Cairo, Egypt

The conference program and online registration is available at:

<http://www.enps-eg.com/Conference/Conferencehome.htm>

#### **Save the date!!! September 16-18, 2004**

##### **Tuberous Sclerosis Association International Research Conference**

Queens College, Cambridge UK

(More information coming soon!)

## **ARCHIVED ISSUES OF TSC ALERT:**

#### **December 2002 TSC Alert**

<http://www.tsalliance.org/research/tsc%20alert.asp>

#### **January 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alert012203.asp>

#### **February 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alert021003.asp>

#### **March 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alert030403.asp>

#### **April 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alert040103.asp>

**May 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alertdefault.asp>

**June 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alert060103.asp>

**July 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alertdefault.asp>

**August 2003 TSC Alert**

<http://www.tsalliance.org/Research/TSC%20Alertdefault.asp>