



HAPPY HOLIDAYS!



TSC ALERT

Edited by Vicky H Whittemore, PhD

December 2006

Welcome to the December 2006 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 2007 *TSC Alert* contact:

vwhittemore@tsalliance.org

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SAVE THE DATE

May 24-26, 2007

Tuberous Sclerosis Complex International Research Conference 2007 in Rome (Italy)

Venue: Grand Hotel Palazzo Carpegna, Rome, Italy

Information: <http://www.ptsroma.it/tsc2007/>

September 23-25, 2007

Tuberous Sclerosis Complex: From Genes to New Therapeutics

International TSC Conference organized by the Tuberous Sclerosis Alliance

Loews Annapolis Hotel, Annapolis, MD

More information coming soon!

September 11-14, 2008

International TSC Conference

Organized by the Tuberous Sclerosis Association, U.K.

Brighton, U.K.

More information coming soon!

REQUEST FOR INFORMATION

Online Registration Available for the NIH Town Hall Meeting on the Proposed Policy for Sharing of Data Obtained in NIH Supported or Conducted Genome-Wide Association Studies (GWAS) (NOT-OD-07-022)

National Institutes of Health

<http://grants.nih.gov/grants/guide/notice-files/NOT-OD-07-022.html>

Request for Information: NIH Plan to Reduce R01 Page Limit

The NIH is considering reducing the current 25 page limit for the Research Plan section of the research project grant (R01) application. A significant number of applicants and reviewers have suggested that NIH peer review could be improved by focusing less on experimental details and more on key ideas and the scientific significance of proposed projects. In addition, recruitment of qualified reviewers has become increasingly difficult, resulting in greater reviewer turnover and reduced consistency from one review meeting to the next.

To ensure that the NIH review process identifies the most promising scientific projects, we are evaluating the possibility of shortening the Research Plan section and focusing it more on ideas and significance. A committee has been formed at NIH to gather additional information from the external community and explore possible options. We would like your opinion, as an applicant and/or reviewer, of this potential change.

Responses must be submitted not later than January 5, 2007

The full text of this Request for Information, including specific questions and the instructions for submitting your opinions, is available at

<http://grants.nih.gov/grants/guide/notice-files/NOT-OD-07-014.html>

FUNDING OPPORTUNITIES

Understanding and Treating Tuberous Sclerosis Complex (R01) (PAS-06-205)

National Institute of Neurological Disorders and Stroke

National Cancer Institute

National Institute of Arthritis and Musculoskeletal and Skin Diseases

National Institute of Diabetes and Digestive and Kidney Diseases

National Institute of Mental Health

Tuberous Sclerosis Alliance

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PAS-06-205.html>

Understanding and Treating Tuberous Sclerosis Complex (R21) (PAS-06-206)

National Institute of Neurological Disorders and Stroke

National Cancer Institute

National Institute of Arthritis and Musculoskeletal and Skin Diseases

National Institute of Diabetes and Digestive and Kidney Diseases

National Institute of Mental Health

Tuberous Sclerosis Alliance

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PAS-06-206.html>

Pathway to Independence Awards

National Institutes of Health

The NIH Pathway to Independence Award is an innovative, new program that will provide an opportunity for promising postdoctoral scientists to receive both mentored and independent research support from the same award. NIH plans to issue between 150 and 200 awards for this program in the first year, and for the each of the next five years, amounting to approximately \$390 million. The actual number and distribution of awards made by the NIH Institutes and Centers will depend upon the quality of the applications received and the results of the scientific peer review process. The same standard submission dates for research career development awards will be used, please see <http://grants.nih.gov/grants/funding/submissionschedule.htm> for details.

For more information about this award, see:

http://grants.nih.gov/grants/new_investigators/pathway_independence.htm

Focal Cognitive Deficits in CNS Disorders (R03) (PA-07-034)

National Institute of Nursing Research

National Institute on Aging

Office of Behavioral and Social Science Research

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-034.html>

Focal Cognitive Deficits in CNS Disorders (R21) (PA-07-035)

National Institute of Nursing Research

National Institute on Aging

National Institute of Neurological Disorders and Stroke

National Institute of Child Health and Human Development

Office of Behavioral and Social Science Research

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-035.html>

Drug Discovery for Nervous System Disorders (R21) (PAR-07-049)

National Institute of Mental Health

National Institute on Aging

National Institute on Alcohol Abuse and Alcoholism

National Institute on Drug Abuse

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PAR-07-049.html>

Basic and Preclinical Research on Complementary and Alternative Medicine (CAM) (R01) (PA-07-007)

National Center for Complementary and Alternative Medicine

National Cancer Institute

Office of Dietary Supplements

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-007.html>

Development of Disease Biomarkers (R01) (PA-07-052)

National Institute of Diabetes and Digestive and Kidney Diseases

National Institute on Alcohol Abuse and Alcoholism

National Institute of Biomedical Imaging and Engineering

Office of Dietary Supplements

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-052.html>

Ancillary Studies of Kidney Disease Accessing Information from Clinical Trials, Epidemiological Studies, and Databases (R01) (PA-07-050)

National Institute of Diabetes and Digestive and Kidney Diseases

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-050.html>

Development of Assays for High Throughput Drug Screening (R01) (PA-07-054)

National Institute of Diabetes and Digestive and Kidney Diseases

National Cancer Institute

National Institute of Allergy and Infectious Diseases

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-054.html>

Neurologic Motor Speech Disorders and Speech Motor Control (R01) (PA-07-055)

National Institute on Deafness and Other Communication Disorders

National Institute on Aging

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-055.html>

Insulin Signaling And Receptor Cross-Talk (R01) (PA-07-058)

National Institute of Diabetes and Digestive and Kidney Diseases

National Institute on Aging

Application Receipt/Submission Date(s): Multiple dates, see announcement.

<http://grants.nih.gov/grants/guide/pa-files/PA-07-058.html>

Biobehavioral Methods to Improve Outcomes Research (R01) (PA-07-072)

National Institute of Nursing Research

National Cancer Institute

National Institute on Deafness and Other Communication Disorders

National Institute of Diabetes and Digestive and Kidney Diseases

National Institute of General Medical Sciences

Office of Behavioral and Social Science Research

Application Receipt/Submission Date(s): Multiple dates, see announcement.
<http://grants.nih.gov/grants/guide/pa-files/PA-07-072.html>

Research On Autism And Autism Spectrum Disorders (R01) (PA-07-085)

National Institute of Mental Health
National Institute of Child Health and Human Development
National Institute on Deafness and Other Communication Disorders
National Institute of Environmental Health Sciences
National Institute of Neurological Disorders and Stroke
National Institute of Nursing Research
Office of Dietary Supplements
Application Receipt/Submission Date(s): Multiple dates, see announcement.
<http://grants.nih.gov/grants/guide/pa-files/PA-07-085.html>

Center for Genomic and Phenomic Studies in Autism (U24) (RFA-MH-07-080)

National Institute of Mental Health
Application Receipt Date(s): January 26, 2007
<http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-07-080.html>

Ancillary Studies to Major Ongoing NIDDK and NHLBI Clinical Research Studies (R01) (PAR-07-024)

National Institute of Diabetes and Digestive and Kidney Diseases
National Heart, Lung, and Blood Institute
Application Receipt/Submission Date(s): Multiple dates, see announcement.
<http://grants.nih.gov/grants/guide/pa-files/PAR-07-024.html>

Drug Discovery for Nervous System Disorders (R01) (PAR-07-048)

National Institute of Mental Health
National Institute on Aging
National Institute on Alcohol Abuse and Alcoholism
National Institute on Drug Abuse
Application Receipt/Submission Date(s): Multiple dates, see announcement.
<http://grants.nih.gov/grants/guide/pa-files/PAR-07-048.html>

Dissemination and Implementation Research in Health (R01) (PAR-07-086)

National Institute of Mental Health
National Cancer Institute
National Heart, Lung, and Blood Institute
National Institute on Alcohol Abuse and Alcoholism
National Institute on Drug Abuse
National Institute on Deafness and Other Communication Disorders
National Institute of Dental and Craniofacial Research
National Institute of Nursing Research
Office of Behavioral and Social Science Research
Office of Dietary Supplements
Application Receipt/Submission Date(s): Application Submission/Receipt Dates(s): 05/24/2007, 01/24/2008, 09/24/2008, 05/22/2009
<http://grants.nih.gov/grants/guide/pa-files/PAR-07-086.html>

Chronic Illness Self-Management in Children and Adolescents (R01) (PA-07-097)

National Institute of Nursing Research
National Cancer Institute
National Institute of Child Health and Human Development
National Institute of Diabetes and Digestive and Kidney Diseases
Office of Dietary Supplements

Application Receipt/Submission Date(s): Multiple dates, see announcement.
<http://grants.nih.gov/grants/guide/pa-files/PA-07-097.html>

Chronic Illness Self-Management in Children and Adolescents (R03) (PA-07-098)

National Institute of Nursing Research
National Cancer Institute
National Institute of Child Health and Human Development
National Institute of Diabetes and Digestive and Kidney Diseases
Office of Dietary Supplements

Application Receipt/Submission Date(s): Multiple dates, see announcement.
<http://grants.nih.gov/grants/guide/pa-files/PA-07-098.html>

Chronic Illness Self-Management in Children and Adolescents (R21) (PA-07-099)

National Institute of Nursing Research
National Cancer Institute
National Institute of Child Health and Human Development
National Institute of Diabetes and Digestive and Kidney Diseases
Office of Dietary Supplements

Application Receipt/Submission Date(s): Multiple dates, see announcement.
<http://grants.nih.gov/grants/guide/pa-files/PA-07-099.html>

James S. McDonnell Foundation 21st Century Science Initiative - 2007

Research Award Application Deadline: 5:59 PM CST on Monday March 12, 2006

The James S. McDonnell Foundation (JSMF) announces updated program descriptions and application guidelines for its 21st Century Science Initiative Research Awards. The 21st Century Research Awards support investigator-initiated research in two (2) topical areas: Studying Complex Systems and Brain Cancer Research*. Program information, application guidelines, and proposal preparation instructions are available at: <http://www.jsmf.org/apply/research>. No geographic restrictions; international applications are encouraged.

***PLEASE NOTE:** Beginning in 2007 Research Awards will no longer be funded in the topical area Bridging Brain, Mind, and Behavior. To support research spanning mind/brain JSMF will post guidelines for a completely new award category The James S. McDonnell Scholar Awards in January 2007. Deadline for applications for JSM Scholars is expected to be early April 2007.

New Guideline Effective January 1, 2007: Institutions sponsoring an application on behalf of a particular principal investigator to JSMF programs (Research Awards or Collaborative Activity Awards) can only submit ONE application every 3 years ON BEHALF OF THE NAMED PRINCIPAL INVESTIGATOR. When an investigator submits a letter of inquiry to the Collaborative Activity Award or a proposal for a Research Award in CY 2007 and the proposal is not funded, the next period of eligibility for that particular investigator and the proposal would begin in CY 2010. This policy is not intended to limit the number of applications from an institution. The intent of the policy is to encourage investigators and institutions to carefully consider the goodness of fit between a proposal and the goals of JSMF programs prior to submitting. Information on the Foundation's 21st Century Collaborative Activity Awards is also available on the website.

Robert Wood Johnson Executive Nurse Fellows Program 2007

Application deadline: February 1, 2007

The Robert Wood Johnson Executive Nurse Fellows Program is an advanced leadership program for nurses in senior executive roles in health services, public health and nursing education who aspire to help lead and shape the U.S. health care system. The three-year fellowships allow participating nurses to remain in their current positions while they gain the experiences, insights, competencies and skills necessary to advance in executive leadership positions in a health care system that is undergoing unprecedented change. The program is designed to give nursing and nurses a more influential role across many sectors of the economy. UP to 20 fellowships will be awarded in 2007.

The complete call for applications is available on the Foundation's Web site at: www.rwjf.org/cfp/executivenursefellows and the programs' web site at: www.enfp-info.org or by calling (415)502-6451.

NEW TSC PUBLICATIONS

Abraham R, Pagano F, Gomella LG, Baffa R (2007) Chromosomal deletions in bladder cancer: shutting down pathways. *Front Biosci* 12:826-38

Avila NA, Dwyer AJ, Rabel A, Moss J (2006) Sporadic Lymphangiomyomatosis and Tuberous Sclerosis Complex with Lymphangiomyomatosis: Comparison of CT Features. *Radiology* 2006 Nov 14 [Epub ahead of print]

Chang CC, Hsu HH, Kuo SW, Lee YC (2006) Bronchoscopic gluing for post-lung-transplant bronchopleural fistula. *Eur J Cardiothorac Surg* 2006 Nov 30 [Epub ahead of print]

Chen F, Bando T, Fukuse T, Omasa M, Aoyama A, Hamakawa H, Fujinaga T, Shoji T, Sakai H, Hanaoka N, Wada H (2006) Recurrent lymphangiomyomatosis after living-donor lobar lung transplantation. *Transplant Proc* 38(9):3151-3

Choi JS, Zheng LT, Ha E, Lim YJ, Kim YH, Wang YP, Lim Y (2006) Comparative genomic hybridization array analysis and real-time PCR reveals genomic copy number alteration for lung adenocarcinomas. *Lung* 184(6):355-62 [Epub 2006 Nov 3]

Deonna T, Roulet E (2006) Autistic Spectrum Disorder: Evaluating a Possible Contributing or Causal Role of Epilepsy. *Epilepsia* 47(s2):79-82

Gan B, Yoo Y, Guan JL (2006) Association of focal adhesion kinase with tuberous sclerosis complex 2 in the regulation of s6 kinase activation and cell growth. *J Biol Chem* 281(49):37321-9 [Epub 2006 Oct 16]

Goh S, Weiss WA (2006) Genotype-phenotype correlations in tuberous sclerosis: Who and how to treat. *Ann Neurol*. 2006 Nov 21 60(5):505-507 [Epub ahead of print]

Guertin DA, Stevens DM, Thoreen CC, Burds AA, Kalaany NY, Moffat J, Brown M, Fitzgerald KJ, Sabatini DM (2006) Ablation in Mice of the mTORC Components raptor, rictor, or mLST8 Reveals that mTORC2 Is Required for Signaling to Akt-FOXO and PKCalpha, but Not S6K1. *Dev Cell* 11(6):859-71

Jansen AC, Sancak O, D'Agostino MD, Badhwar A, Roberts P, Gobbi G, Wilkinson R, Melanson D, Tampieri D, Koenekoop R, Gans M, Maat-Kievit A, Goedbloed M, van der Ouweland AM, Nellist M, Pandolfo M, McQueen M, Sims K, Thiele EA, Dubeau F, Andermann F, Kwiatkowski DJ, Halley DJ, Andermann E (2006) Unusually mild tuberous sclerosis phenotype is associated with TSC2 R905Q mutation. *Ann Neurol* 2006 Nov 21 60(5):528-539 [Epub ahead of print]

Juvet SC, McCormack FX, Kwiatkowski DJ, Downey GP (2006) Molecular Pathogenesis of Lymphangiomyomatosis: Lessons Learned from Orphans. *Am J Respir Cell Mol Biol* 2006 Nov 10 [Epub ahead of print]

Kaur S, Lal L, Sassano A, Majchrzak-Kita B, Srikanth M, Baker DP, Petroulakis E, Hay N, Sonenberg N, Fish EN, Platanias LC (2006) Regulatory effects of mTOR-activated pathways in type I and II interferon signaling. *J Biol Chem* 2006 Nov 17 [Epub ahead of print]

Li W, Petrimpol M, Molle KD, Hall MN, Battegay EJ, Humar R (2006) Hypoxia-Induced Endothelial Proliferation Requires Both mTORC1 and mTORC2. *Circ Res* 2006 Nov 16 [Epub ahead of print]

Robyr R, Bernard JP, Roume J, Ville Y (2006) Familial diseases revealed by a fetal anomaly. *Prenat Diagn* 2006 Dec 1 26(13):1224-1234 [Epub ahead of print]

Selle B, Furtwangler R, Graf N, Kaatsch P, Bruder E, Leuschner I (2006) Population-based study of renal cell carcinoma in children in Germany, 1980-2005: more frequently localized tumors and underlying disorders compared with adult counterparts. *Cancer* 2006 Nov 15 [Epub ahead of print]

Sharp FR, Xu H, Lit L, Walker W, Apperson M, Gilbert DL, Glauser TA, Wong B, Hershey A, Liu DZ, Pinter J, Zhan X, Liu X, Ran R (2006) The future of genomic profiling of neurological diseases using blood. *Arch Neurol* 63(11):1529-36

Uritani M, Hidaka H, Hotta Y, Ueno M, Ushimaru T, Toda T (2006) Fission yeast Tor2 links nitrogen signals to cell proliferation and acts downstream of the Rheb GTPase. *Genes Cells* 11(12):1367-79

Weimbs T (2006) Regulation of mTOR by Polycystin-1: Is Polycystic Kidney Disease a Case of Futile Repair? *Cell Cycle* 2006 Nov 1 5(21) [Epub ahead of print]

York B, Lou D, Noonan DJ (2006) Tuberin nuclear localization can be regulated by phosphorylation of its carboxyl terminus. *Mol Cancer Res* 4(11):885-97

Yoshida S, Hayashi T, Ishii N, Yoshinaga A, Ohno R, Terao T, Watanabe T, Yamada T, Osada H (2006) Bilateral renal angiomyolipoma coexistent with pulmonary lymphangioliomyomatosis and tuberous sclerosis. *Int Urol Nephrol* 2006 Nov 16 [Epub ahead of print]

Zafeiriou DI, Ververi A, Vargiami E (2006) Childhood autism and associated comorbidities. *Brain Dev* 2006 Nov 3 [Epub ahead of print]

Zarogiannis S, Hatzoglou C, Molyddas PA, Gourgoulisanis K (2006) Lymphangioliomyomatosis. *Eur Respir J* 28(6):1284

CONFERENCES & SEMINARS

February 1-2, 2007

National Coalition for Health Professional Education in Genetics (NCHPEG) and Genetics Resources on the Web (GROW) 10th Annual Meeting: Pharmacogenomics

Hyatt Regency Bethesda, Bethesda, MD

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

March 29-30, 2007

Curing Epilepsy 2007: Translating Discoveries into Therapies

Natcher Conference Center, Bethesda, MD

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

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

April 19-22, 2007

2007 LAM International Research Conference

The LAM Foundation

Cincinnati, OH

<http://www.thelamfoundation.org>

May 9-12, 2007

68th Annual Meeting of the Society for Investigative Dermatology

The Century Plaza Hotel, Los Angeles, CA

For more information: www.sidnet.org

May 24-26, 2007

Tuberous Sclerosis Complex International Research Conference 2007 in Rome (Italy)

Venue: Grand Hotel Palazzo Carpegna, Rome, Italy

Information: <http://www.ptsroma.it/tsc2007/>

September 23-25, 2007

Tuberous Sclerosis Complex: From Genes to New Therapeutics

International TSC Research Symposium organized by the Tuberous Sclerosis Alliance

Loews Annapolis Hotel, Annapolis, MD

More information coming soon on the TS Alliance website at www.tsalliance.org

September 11-14, 2008

International TSC Conference

Organized by the Tuberous Sclerosis Association, U.K.

Brighton, U.K.

More information coming soon!

NEWS

Early Career Scientist Award to Kevin Ess, MD, PhD

Kevin Ess, MD, PhD, Assistant Professor of Neurology, Vanderbilt University, was awarded a Milken Family Foundation Early Career Scientist Award at the recent American Epilepsy Society meeting in San Diego. This award provides funding for a grant entitled "GABAergic Interneurons in Tuberous Sclerosis Complex." Congratulations, Kevin!

A SCIENCE article by NIH Director about NIH Funding in the Post-Doubling Era

An article by NIH Director Dr. Zerhouni appeared in the November 17 issue of SCIENCE, entitled, "NIH Funding in the Post-Doubling Era: Realities and Strategies." You can access the article directly from the [NIH home page \(www.nih.gov\)](http://www.nih.gov), under the "In The News" section on the left side of the page. Please feel free to share it with colleagues.

New Guideline for the Diagnostic Assessment of Children with Continuous Seizures

ST. PAUL, Minn – A new guideline developed by the American Academy of Neurology and the Child Neurology Society aims to help physicians diagnose the causes of status epilepticus, a state of continuous seizures, in children, many of whom have epilepsy. The guideline is published in the November 14, 2006, issue of Neurology, the scientific journal of the American Academy of Neurology.

Status epilepticus is the medical term for a seizure, or series of seizures, that lasts more than 30 minutes. It includes two or more continuous seizures if there is not full recovery of consciousness in between. Status epilepticus is a life-threatening emergency that requires hospital evaluation and treatment for control. Status epilepticus annually affects an estimated 31,600 children under the age of 18 in the United States. It is most common in infants and toddlers.

To develop the guideline, the authors reviewed the major available scientific studies on the topic.

The guideline recommends physicians consider anti-epileptic drug (AED) levels when a child with treated epilepsy develops status epilepticus.

“If a child with epilepsy has continuous seizures, it is possible that AED levels are low, because of inadequate dosing, non-compliance or withdrawal of the AED,” said lead author James Riviello, MD, with Children’s Hospital and Harvard Medical School in Boston, Massachusetts, and a member of the American Academy of Neurology and Child Neurology Society. “Data show low AED levels in 32 percent of children who develop status epilepticus, but this may not necessarily have caused the status epilepticus.”

The guideline also recommends an EEG, a test of electrical activity of the brain, be considered in a child with status epilepticus. “An EEG may be helpful in determining whether there are generalized or focal abnormalities or when there is suspicion that the continuous seizures are non-epileptic,” said Riviello.

According to the guideline, physicians should also consider infectious, toxicology and metabolic studies in children with status epilepticus when there are clinical indicators for concern or when the initial evaluation doesn’t reveal the cause of the continuous seizures. Neuroimaging may also be considered, after the child with status epilepticus is stabilized, if there are clinical indications or if the cause of the seizures is unknown.

The status epilepticus guideline is endorsed by the American Academy of Pediatrics, the American College of Emergency Physicians, and the American Epilepsy Society. A guideline to treat status epilepticus is currently under development by the Epilepsy Foundation of America.

The American Academy of Neurology, an association of more than 19,000 neurologists and neuroscience professionals, is dedicated to improving patient care through education and research. A neurologist is a doctor with specialized training in diagnosing, treating and managing disorders of the brain and nervous system such as stroke, Alzheimer’s disease, epilepsy, Parkinson disease, and multiple sclerosis. For more information about the American Academy of Neurology, visit www.aan.com

The Child Neurology Society is the professional organization representing more than 1,500 child neurologists. For more information about the Child Neurology Society, visit www.childneurologysociety.org

TSC CLINICAL TRIALS AND STUDIES

1. Sirolimus in Treating Patients with Angiomyolipoma of the Kidney

Official Title: Phase II Study of Sirolimus in Patients with Angiomyolipoma of the Kidney Secondary to Tuberous Sclerosis or Lymphangioleiomyomatosis

Study Purpose:

Rationale: Drugs used in chemotherapy, such as sirolimus, work in different ways to stop the growth of tumor cells, either by killing the cells or by stopping them from dividing.

Purpose: This phase II trial is studying how well sirolimus works in treating individuals with angiomyolipoma of the kidney.

Eligibility:

Ages Eligible for Study: 18 Years - 65 Years

Genders Eligible for Study: Both

Location and Contact Information:

Please refer to this study by ClinicalTrials.gov identifier NCT00126672

Connecticut

Connecticut Children's Medical Center, Hartford, Connecticut, 06106, United States; Recruiting Francis J. DiMario, MD 860-545-9460

Massachusetts

Massachusetts General Hospital, Boston, Massachusetts, 02114, United States; Recruiting Elizabeth Thiele, MD, PhD 617-726-6540

New York

New York University Medical Center, New York, New York, 10016, United States; Recruiting Daniel K. Miles, MD 212-263-8318

Ohio

Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, 45229-3039, United States; Recruiting David Franz, MD 513-636-4222 david.franz@chmcc.org

Pennsylvania

University of Pennsylvania Medical Center, Philadelphia, Pennsylvania, 19104-4283, United States; Recruiting Peter Crino, MD, PhD 215-349-5312

Texas

University of Texas Southwestern Medical Center at Dallas, Dallas, Texas, 75390, United States; Recruiting Arthur I. Sagalowsky, MD 214-645-8797 arthur.sagalowsky@utsouthwestern.edu

Study chairs or principal investigators: Sandra Dabora, MD, PhD, Study Chair, Brigham and Women's Hospital

For more information about this clinical trial, visit:
<http://www.cancer.gov/clinicaltrials/DFCI-04298>

2. Siblings Wanted for a Modifier Gene Research Study



The Herscot Center for Tuberous Sclerosis Complex and the Center for Human Genetic Research at the Massachusetts General Hospital are trying to identify additional genes that play a role in neurological problems in TSC.

We would like to enroll TSC siblings over 2 years of age that differ in their expression of
autism or infantile spasms or uncontrollable seizures

Participants will have:

- clinical evaluation by a neurologist specialized in TSC (Dr. Elizabeth Thiele)
- blood drawn
- brain MRI
- EEG
- neuropsychological testing (only for siblings differing in autism)

The whole study will take about 2 days to complete. There is no direct cost to the participants.

Travel and lodging will be reimbursed for participants who live more than 2 hours away from Boston.

For more information contact Susana Camposano 617-726 0240 (M-F, 8-5),
scamposano@partners.org

3. TSC and TSC/LAM Protocols at the National Institutes of Health

The Clinical Research Nurses can be reached toll-free at 1-877-NIH-LUNG, # 3 on the menu or locally through 301-496-3632.

TSC INFORMATION

For information about TSC and the Tuberous Sclerosis Alliance, 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.