

Center for Clinical and Translational Science CCTS Digest 1.29.16 | <u>www.uab.edu/ccts</u>



### In This Issue



## Partner Network:

While we invite you to take part in all of our programs, items featuring this icon may be of particular interest. Look for the symbol throughout the Digest. Have news you'd like to share? Send it to: ccts@ uab.edu

# Rare Diseases Day is One Month Away: February 29



Olympic sprinter Priscilla Lopes-Schliep (left) and Jill Viles (right) have a genetic mutation in common. It causes one's muscles to overdevelop, while the other's waste away.

**Rare Disease Day** is recognized worldwide this year on Monday, February 29, as a day to raise awareness of rare diseases. Here at UAB, the CCTS is proud to sponsor the <u>Rare Disease Genomics Symposium</u> on Friday, February 26, 8 am-3:30 pm at Children's of Alabama's Bradley Lecture Center (4th Floor, Children's Harbor Building). Registration is \$15 and you can do so online today.



A recent story on the radio podcast "This American Life" featured a story of a woman who had to convince her own parents that she--and her father--had a rare disease. After a childhood of not understanding why her limbs would stop working, suddenly, and her muscles seemed too weak to support her own weight, Jill Vines, (pictured above, right) began doing her own research and came across a medical journal describing an extremely rare type of muscular dystrophy called Emery-Dreifuss.

"And then looking at the pictures, it was a very startling thing to realize, I'm seeing my dad's arm-just an instantaneous lock on something that's in your visual memory," Vines says in the interview, conducted by David Epstein. Epstein is the author of a book called "The Sports Theme," on the intersection of athelticism and genetics.

Vines wound up saving her father's life when she told him about her theory and he admitted that in addition to the muscle wasting, he experienced cardiac issues common among Emery-Dreifuss patients. He went to a cardiac clinic where he learned that his heart rate was only 30 beats per minute. He had a pacemaker put in immediately.

This is just the tip of this tale's iceberg, because Vines continued her research and her fight, arguing with neurologists and genetic experts that she had this rare disease. And further, she posited, a female professional athlete who was so muscular she had been tested for performance-enhancing drugs at a higher rate than most, had a genetic mutation in common with herself.

Priscilla Lopes-Schliep is an Olympic bronze medalist sprinter from Canada. She is so muscle-bound that she has been accused throughout her career of taking steroids. Someone once posted a photo online featuring a male bodybuilder's straining face atop her body.

"That was pretty messed up. And I was really pissed about that. And I got tested," Lopes-Schliep tells Epstein. "I felt like I was targeted because I got tested so much for track and field. And I think a lot of people really honestly truly believed that I was taking steroids."

Vines learned of Lopes-Schliep after her father's death when her sister showed her a photo of the muscle-bound sprinter.

"It was just unmistakable," Vines said. "It's like a computer that can analyze a photograph and get a match and be 100% sure that's the same shoulder, that's the same upper arm, I see the same veins, I see them branching this way. You just know. And that's hard to convey-- how could you just know? But I knew we were very likely cut from the same cloth, a very, very, very rare cloth."

To learn more, read the full story as told on "<u>This</u> <u>American Life.</u>" ProPublica features the tale as told by Epstein, "The DIY Scientist, the Olympian, and the Mutated Gene" <u>on their website</u>, which features videos and photos of both women. It is an unique tale, as each story of individuals with rare disease is, and shows no matter how far the science advances in this area, there are always additional discoveries to be made.

# Seminars, Symposia and Conferences

\*\*\*PLEASE NOTE: The CCTS Forum for Wednesday, February 3, will NOT take place in order to better organize next month's event. Please look to future issues of the Digest for updates on the March event.\*\*\*

Thursday, February 4 Clinical Trials Office Research Seminar Theme: ClinicalTrials.gov "SAE Reporting" with Lee Powell

Noon-1pm PCAMS, 1924 7th Avenue South



Please join us remotely via GoToMeeting from your computer, tablet or smartphone: <u>https://global.gotomeeting.com/join/930891813</u> You can also dial in using your phone (267) 507-0008;Access Code: 930-891-813

Friday, February 6 First Friday Mentoring Lunch Noon-1pm PCAMS, 1924 7th Avenue South

Please RSVP so that we have enough food: ccts@uab.edu; 205-934-7442.

Tuesday, February 9 "Developing a Bioinformatics Environment for Immunoglobulin Repertoire Sequencing" Alexander F. Rosenberg, PhD, Research Assistant Professor Division of Allergy, Immunology and Rheumatology Director of Bioinformatics, Department of Medicine University of Rochester Medical Center, Rochester, NY 11:30am Shelby 105, 1825 University Blvd

Please <u>register to attend</u> no later than Thursday, 02/04/16 Lunch will be served. We look forward to seeing you there!

Questions? Please contact Dr. James Cimino, Director, Informatics Institute (<u>ciminoj@uab.edu</u>; 205.996.1958)

Thursday, February 11 UAB Informatics Institute Lecture "Demystifying Brain Injuries and Beyond: Informatics for Critical Care Medicine" Vignesh Subbian, PhD Instructor, Department of Electrical Engineering and Computing Systems University of Cincinnati

Noon-1pm Shelby 515 1825 University Blvd Please register to attend no later than Monday, 02/08/16 Lunch will be served. Questions? Please contact Dr. James Cimino, Director, Informatics Institute (ciminoj@uab.edu; 205.996.1958)

### Thursday, February 18

Professional Skills Development Series "Drug Discovery and Device Development- A Birmingham Partnership Making it Happen" Presented by: Maaike Everts, PhD Associate Professor, Department of Pediatrics, Infectious Diseases Associate Director Alabama Drug Discovery Alliance (and) Robert Hergenrother, PhD Director, Medical Technology Development, Director, AIMTech Southern Research

Goals:

- Educate about the drug discovery and device development process
- Describe the CCTS Drug Discovery program and the 'Alabama Drug Discovery Alliance,' as well as the local device development program 'AIMTech'
- Describe how to get support from either program

### 8-9:30 am

Pittman Center for Advanced Medical Studies (PCAMS) 1924 7th Avenue South

REGISTER: http://drugdiscoverydevicedevelopment.eventbrite.com



The PSDS program is also available via GoToMeeting. If you cannot join us in PCAMS, please join us from your computer, tablet or smartphone via https://global.gotomeeting.com/join/840329197 You can also join us by phone (long distance): +1 (224) 501-3412 Access Code: 840-329-197

Friday, February 26 Rare Disease Genomics Symposium



8:30am-3:30pm Bradley Lecture Center 4th Floor, Children's Harbor Building \$15 to attend To register, visit <u>ChildrensAL.org/genetics</u> Questions? Please contact Shaila Handattu at <u>hande@uab.edu</u>

### Friday, February 26

### UAB Sponsored Conference on Therapeutic Adherence

A national conference on therapeutic adherence sponsored by the UAB School of Medicine and our University Wide Interdisciplinary Research Centers (UWIRCS) at the Edge of Chaos (<u>http://theedgeofchaos.org/</u>). Please RSVP at <u>http://amc21adherenceconfernce.eventbrite.com</u>

The "Understanding and Improving Treatment Adherence: An Interdisciplinary Approach" conference will include several notable speakers (see below) didactic discussions, as well as breakout sessions. The published proceedings will highlight gaps in adherence research and collaborative funding opportunities. More details will be forthcoming.

Speaker	Торіс
Rivet Amico, PhD, University of Michigan	Conceptual models and behavioral frameworks in designing studies on adherence: How to employ models in needs assessment, intervention mapping, or continuous quality improvement
Elizabeth McQuaid, PhD, Brown University	Ethnic disparities and therapeutic adherence
	, Taxonomy of adherence research: How models of therapeutic adherence research fit within clinical settings
Jeffrey Curtis, MD, MS, MPH, UAB	Improving therapeutic adherence and utilization of large databases in therapeutic adherence research

Thursday, February 25 UAB Research Orientation Program Fourth Thursday of each month PCAMS, 1924 7th Avenue South

New to the UAB platform of education offerings for research is a program designed for young investigators and research staff that are new to research (possibly within the first 2

months of starting in research).

**Content:** A basic review of how to implement a sponsored or investigator initiated study including clinical, regulatory and financial aspects. Designed to provide a basic overview of implementing a study, familiarize attendees with the language, and hopefully provide guidance on avoiding pitfalls when starting out. Will provide basic tools and some of the necessary language in order to successfully conduct a research study.

Who should attend: New faculty, coordinators, budget and regulatory staff Cost: Free

**Registration:** Limited, so please REGISTER early by contacting Dharti K. Patel, Dpatel80@uab.edu

# **SAVE THE DATE:**

Friday, March 18

"Infusing Integrative Bioethics into Research Partnerships: Bioethical Dialogue on Respect and Power-Sharing

Presented at the Tuskegee University Kellogg Conference Center 9:30am-4:30pm

Wednesday, May 4 Center for Genomic Medicine Symposium Presented by: The University of Alabama at Birmingham and HudsonAlpha Institute for Biotechnology Jackson Center, Huntsville, AL 10am-3pm

Hear talks from specialists and gain the opportunity to ask questions of a distinguished panel of experts.

You will have the chance to tour the innovative HudsonAlpha facility, enjoy a networking lunch with your peers and discuss with colleagues over cocktails at the evening social.

Registration is free of charge. Agenda and registration information to follow.

Funding Opportunity: REACT RFA

# **Rehabilitation** Research Resource to Enhance Clinical Trials

# **Request for Applications for Pilot Studies**

The NIH national Rehabilitation Research Resource to Enhance Clinical Trials (REACT), based at the University of Alabama at Birmingham (UAB), invites letters of intent for pilot studies that address novel scientific questions related to medical rehabilitation and that will lead to more definitive clinical trials.

The central goal of the REACT Center Pilot Studies Program is to catalyze the success of medical rehabilitation researchers and interdisciplinary teams by providing consultation, seed funds, key expertise and resources for the conduct of innovative pilot projects, early-stage proof-of-concept studies, and futility studies needed to shape more definitive clinical trials.

**Eligibility.** This program supports full-time faculty investigators in biomedical, behavioral, clinical and social sciences at academic institutions in the US who are eligible to receive NIH funding. We encourage applications from interdisciplinary research teams, underrepresented minority applicants and faculty at all ranks.

Application Procedure. This funding mechanism involves a two-phased application process (see Key Dates for details). For the pre-application phase, applicants are requested to submit the following documents as a single PDF file to <u>REACTCenter@uab.edu</u> no later than February 15, 2016 at 5:00 PM Central Time:

 Letter of Intent (limited to 2 pages, excluding references) to include:

excluding references), to include: Investigative Team, Specific Aims, Significance & Innovation, Approach, and Plan for seeking future extramural funding for a clinical trial.

- Description of REACT resources that may be sought to support the pilot study (limited to ½ page). See website
  for description of resources available.
- 3. NIH Biosketches of the PI and co-investigators.

Pre-applications selected for Phase 2 full application will be expected to submit a 6-page proposal, as well as a budget and budget justification.

**Criteria for Review.** Emphasis will be placed on scientific merit and likelihood that the work will advance to a more-definitive clinical trial. Applications responsive to this RFA should focus on medical rehabilitation of a broad range of chronic diseases and acute conditions, e.g., muscle, bone, or joint diseases; neurodegenerative or neurodevelopmental diseases; traumatic injury (e.g., SCI, TBI); stroke; cancer; aging/frailty; or post-surgical rehabilitation.

Funding. It is anticipated that up to four pilot studies will be awarded. Applicants may request up to \$40,000 direct costs. Awards are limited to 12 months in duration. Indirect costs are capped at 47% (UAB federally negotiated rate).

Questions? Application guidelines and answers to Frequently Asked Questions (FAQs) are available on the REACT website: <a href="https://react.center/funding/">https://react.center/funding/</a>. For additional questions, contact Mr. Jeff Foster at (205) 996-6086 or email REACTCenter@uab.edu.

The REACT Center is supported by NIH grant 1P2CHD086851.

Click for PDF of announcement; visit the REACT website.

# Announcing the CCTS Research Voucher Program Accelerate Discovery with CCTS Research Vouchers

The <u>CCTS Research Voucher Program</u> provides direct research support to investigators throughout the partner network. Investigators may use vouchers to offset expense(s) for clinical and translational research services, including clinical research units, sample handling and biospecimen storage, necessary laboratory tests, study design and methodology, database handling, informatics and other CCTS-related resources across the Partner Institutions.

ICYMI: Our January 6 Forum topic focused on the Voucher Program-click to review the presentation.

#### Key Dates

Letter of Intent Due Date	February 15, 2016
	5:00 PM CT
Invitation to Submit Full Application	March 7, 2016
Full Application Due Date	April 18, 2016
	5:00 PM CT
Review Process Completed	May 23, 2016
Start Date of Awards	June 20, 2016

Apply for up to \$5,000 (direct) in research support to facilitate the rapid and efficient implementation of a study by working closely with shared facilities using state-of-the-art methodologies.

Applications must outline:

-Experimental need

-What will be enabled by the investment (e.g., manuscript, grant application, additional aims)

-Provide a budget with justification

Proposals which seek to use CCTS Resources will be given special consideration. All lines of investigation supported by the CCTS Research Voucher Program require appropriate regulatory approvals (IRB, IACUC, as applicable) in advance of award and study implementation.

Voucher Ideas (not an exhaustive list):

- I would like to use CRSP and the Clinical Research Unit to recruit, consent and collect blood specimens from a few participants to generate preliminary data for an R01.

- I need extended biostatistics consultation / methodologic assistance from USA's Translational Research Services Unit, which will inform the research strategy of an investigator-initiated clinical trial.

- I would like to image a few healthy controls at Auburn University's MRI Research Center to establish study feasibility for a potential career development award.

- I need help to develop a REDCap database to aid in the collection, management and archival of clinical research data.

Please visit <u>CCTS Research Commons</u> to learn more about available CCTS resources and capacities across the <u>Partner Network</u>. If you have any questions about eligible opportunities.

Research Voucher Requests will be accepted electronically as <u>a single PDF</u> by CCTS Research Commons (<u>ccts@uab.edu</u>) on a rolling basis. Applications will be reviewed by the CCTS Executive Council for scientific merit, mission alignment, appropriateness of the budget and justification of need.

Questions? Contact the CCTS--call: 205-934-7442 or email: ccts@uab.edu

# ACTS Translational Science 2016 Travel Awards Deadline Extended \*Due January 31\*



The Center for Clinical and Translation Science (CCTS) is pleased to offer travel awards to investigators and trainees across the <u>CCTS Partner Network</u> who are interested in presenting their work at the upcoming <u>ACTS Translational Science</u> <u>Meeting</u>.

Available for investigators and teams at all levels of career development, with special emphasis on junior faculty, postdoctoral fellows, and graduate students. Requires an abstract submission as a presenter at theTranslational Science 2016 Meeting, taking place April 13-15, 2016, at the Omni Shoreham Hotel in Washington, DC.

What You Will Experience at ACTS:

- Translational Science 2016 will offer more continuing education than ever before!
- Hear dedicated plenary sessions, view abstracts during expanded poster-hall viewing hours with dedicated oral presentation time, and over thirty 60-minute breakout sessions covering the following topic areas:
- Translational Science in the Digital Age
- Dissemination and Implementation Science
- Team Science
- Learning and Development Science
- Innovation and Entrepreneurial Science
- Integrity & Conduct of Clinical and Translational Science
- Translational Science Acceleration
- Informative Examples of Translational Science
- The Translational Science Meeting spotlights cutting-edge achievements in clinical and translational investigation, research impact, networking and scientific community, exposure to novel methods, best practices and important resources, and career development programs.

Learn more about the meeting and <u>REGISTRATION INFORMATION</u> for Translational Science 2016.

Travel awards of up to \$1,000 will be available from the CCTS to match funds from the researcher's department.

Please submit the following materials to the CCTS to apply for your travel award:

• Copy of submitted abstract

• Letter from the Chair of your Department specifying they will provide matching funds in the amount of \$1,000 towards travel.

Please submit your application for a travel award to Angie Schmeckebier/CCTS Research Commons at <u>ccts@uab.edu</u> no later than January 31, 2016.

# BIOSTATISTICS & BIOREPOSITORY\*(\*new!)

### Mondays

Epidemiology/Biostatistics Clinic in The Edge of Chaos

This clinic provides the UAB community access to epidemiology and biostatistics resources. Available most **Mondays, 10am-2pm** in The Edge of Chaos (Lister Hill Library, 4th floor). Check the Edge of Chaos calendar for confirmation of meeting dates and times.

## **UAB CCTS Biostatistics & Biorepository Clinics**

Biostats: Weekly on Wednesdays, 11:30am-1pm Biorepository: First Wednesday of each month, 11:30am-1pm PCAMS Building 1924 7th Avenue South

We've expanded our Biostats Clinic to include members of our CCTS Biorepository Team. On the **FIRST WEDNESDAY** of each month, experts from our <u>CCTS Core</u> <u>Lab</u> will join the CCTS Biostats experts to **answer questions and provide consultative services on any aspect of specimen collection, specimen management, specimen processing and biorepository needs.** 

<u>The Biostatistics & Biorepository Clinics</u> are open to all faculty members, postdocs, fellows, residents, and students. Attendees are invited to bring statistical and methodological questions about on-going research projects, projects being planned, manuscripts in progress, responses to peer reviewers, and published articles. They are also invited to bring their laptops. Assistance will be provided by members of the <u>CCTS BERD & Biorepository group</u>s. A light lunch is served.

## **BERD Design Consultation Available Today**

If you can't visit the clinic, please contact the **BERD** or the **Core Lab** at your convenience by emailing <u>ccts@uab.edu</u>, calling (205) 934-7442, or connecting through <u>Research Commons</u> on the <u>CCTS home page</u>.

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