

# Arkansas Children's Hospital Research Institute RESEARCH UPDATE



January 2012

## Bleeding Disorders and Thrombosis Team Research Activities

Arkansas Children's Hospital houses the only federally funded hemophilia treatment center in the state. The center is available to any age patient with bleeding disorders, a group of conditions in which the body's blood clotting process is diminished. The most common hereditary bleeding disorder is Von Willebrand disease, which affects 1% of the population. Hemophilia affects males and is found in 1 of 3,000 males. Abnormal blood clotting can lead to heavy and prolonged bleeding after an injury or trauma or bleeding into joints causing swelling and bone destruction. At this federally funded center, patients are able to participate in clinical studies and other research activities. The Bleeding Disorders and Thrombosis Team is a multidisciplinary group of physicians, scientists, and medical professionals overseeing clinical trials and data gathering to help its pediatric and adult patients.



**Research team members are collecting information on clinical diagnosis and treatment information of their patients. Information of ACH patients is gathered through a web-based system to generate information on a credit card flash drive (pictured above) for patients to have while away from home.**

Through its work, the ACH team is able to enroll qualified patients in clinical trials held at its site and other bleeding disorders clinics throughout the US and the world. Currently, Dr. Kimo Stine of ACH's Hematology/Oncology unit is starting a clinical trial involving patients undergoing extracorporeal membrane oxygenation (ECMO) treatment. Working with the Critical Care Medicine and Cardiovascular unit, he is studying the effects of changes in Factor XIII, a protein that stabilizes clotting, on bleeding risks for children undergoing coronary bypass. Dr. Stine has recently closed out a clinical study of hemophilia A patients, in which the missing Factor VIII was replaced through a self-infused intravenous medication containing a modified protein with an increased half life of the protein. The investigational drug may help self-infusing patients administer a longer lasting blood clotting factor before activity. Another study follows pediatric and adult patients that infuse a different blood clotting factor, a factor needed to prevent bleeding into joints. These patients infuse before activity as well, and the patients are followed through reported bleeds and bone radiographs.

Through funding from the Maternal and Child Health Bureau (MCHB) and the CDC, research team members are collecting information on clinical diagnosis and treatment information of their patients. The information is assessed to learn more about public health issues regarding this community. The ACHRI researchers have supported MCHB and CDC work to gather information about joint mobility, school and work attendance, and viral status, among other concerns for these patients. Through the American Thrombosis and Hemostasis Network (ATHN), the information of ACH patients is gathered through a web-based system to generate information on a credit card flash drive for patients to have while away from home. The project originated after Hurricane Katrina as a way to ensure patients and medical providers had the necessary information in cases of relocation after disasters.

The Bleeding Disorders and Thrombosis Team is also interested in studying treatment compliance and self esteem among its patients. The group is also exploring ideas for basic science research to improve patient

outcomes. With its state-wide patient base, the team is able to find patients for its clinical studies. However, some studies require frequent visits, and therefore travel may be a deterrent for some patient participation.

Joining Dr. Stine from Hematology/Oncology in the Bleeding Disorders and Thrombosis Team are David Becton, MD; Shelley Crary, MD; Lakeisha Harris, RN, Specialty Nurse for Bleeding Disorders; Brenda Parks, Administrative Assistant; and Bryce Warren, CRA, Business Administrator. The group also includes Melissa Hicks, PT, DPT, Physical Therapist; Eileen Turner, LCSW, ACSW, Social Worker; Erika Christensen, RDH, BS, Registered Dental Hygienist; and Nicholas Long, PhD, Behavioral Pediatrics. Collaborators include Dr. Larry Suva of Orthopedic Research and Dr. Jerry Ware of Biophysiology and Biophysics.

### President's Choice Publications of the Month

The following articles were selected as this month's feature publications.

- Frye RE, Sequeira JM, Quadros EV, James SJ, Rossignol DA. Cerebral folate receptor autoantibodies in autism spectrum disorder. *Mol Psychiatry*. 2012 Jan 10. doi: 10.1038/mp.2011.175. [Epub ahead of print]
- Goudie A, Carle AC. Ohio study shows that insurance coverage is critical for children with special health care needs as they transition to adulthood. *Health Aff (Millwood)*. 2011 Dec;30(12):2382-90.

ACHRI would like to know about your published findings. As your articles are published, please email or mail a copy to [Phaedra Yount](#) (mail slot 842). The number of publications by our researchers is reported to the hospital and ACHRI boards, so it is important that we receive an accurate count of the publications your research produces.

### Meet the Researcher

Richard Frye, MD, PhD, is the Director of Autism Research at ACHRI. He joined ACHRI in October and was previously at the University of Texas Health Sciences Center at Houston.

- **What are your research interests?** My primary research interest focuses on neurodevelopmental disorders including autism spectrum disorder, dyslexia, learning disabilities and developmental delays. I am especially interested in the medical-basis of these disorders and treatment trials. In addition, I have a significant interest in neuroimaging, including magnetoencephalography, diffusion tensor imaging and brain surface morphology.
- **What are your plans for research projects in the near future?** To build an integrated center that is focused on finding the causes of neurodevelopmental disorders, discovering treatments that will help children recover cognitive function, and to learning to prevent these disorders.
- **Anything else you would like people to know about you or your work?** We have a unique group at ACH that believes neurodevelopmental disorders such as autism can be treated in order to improve the lives of children with neurodevelopmental disorders. We are at a unique time in history when we may be able to make significant inroads into improving the lives of children who suffer from neurodevelopmental disorders.
- **Why do you think research is important?** Research is especially important in neurodevelopmental disorders because we are only beginning to understand the reasons why children have these disorders, and the only way to prevent and treat these disorders is to actively and vigorously pursue clinical, basic, and translational research.



**Please join ACHRI  
in welcoming  
Dr. Richard Frye**

### Upcoming Reception to Honor Ron Scott

In February, Ron Scott will retire after 20 years at Arkansas Children's Hospital of which the last 15 years have been at ACHRI as an Environmental Technician. Ron is familiar to researchers and staff on the second floor of the research building and to many throughout ACHRI and ACNC. We send Ron best wishes for an awesome retirement. To read a complete article describing Ron's service at ACH/ACHRI, [click here](#).

You are invited to attend Ron's retirement reception, which will be held February 13 from 2 to 4 pm in the South Campus Brandon North A/B.

### Sign up for Mobile Updates Regarding ACHRI's Currently Enrolling Studies

ACH needs volunteers for clinical trials. Join our mobile updates to stay informed about available studies. Text RESEARCH to 772937 Opt-in only. No spamming. Your info will never be shared. This is a free service. Standard text rates apply.

### UPDATE - Elevator Upgrade

Due to delays in the elevator upgrades, completion is expected by the end of January. Employees may take the stairs or they may enter ACHRI via the skywalk located on the 4th floor of the South Campus Medical Arts Building. From that point, stairs may be taken to access ACHRI's 2nd or 4th floors. The freight elevator is designated for animal and materials management purposes. Employees with handicaps that prevent them from using the stairs may receive authorization to use the freight elevator only after receipt of animal certification. If you have questions or concerns regarding this matter, please contact Blake Harrison at 364-2710 or Al Martin at 364-7519 (pager 405-0272).

### Dropbox and Similar "Cloud" Applications Are Not To Be Used for Confidential Information

Many individuals have discovered that services like Google Docs, Dropbox, and Mozy are simple ways to store backups, share files with others, and access files from anywhere. For most personal purposes these services, and the many services that are similar, are safe to use and provide a useful convenience. Always keep in mind that you truly do not have control of these files when they are placed in the cloud. Only place files that are appropriate, keeping local backups, since they could be lost or in some cases accessed by others. You must never, under any circumstances, place files containing ACH confidential information or patient information, in the cloud. If you have any questions pertaining to clinical information in the cloud please contact Erin Parker, the director of corporate compliance at x42875. If you would like to report a suspected breach or any other research issues in a confidential manner you can call the ACH compliance hotline at 1-877-384-4275. For more info about ACH corporate compliance, please visit <http://www.archildrens.org/about-ach/corporate-compliance.aspx>



### 2011 ACHRI Annual Report

ACHRI has just released its 2011 Annual Report, *We Believe*. The report reviews the successes of the last year and considers the exciting future of pediatric biomedical research. These stories are representative of the achievements of all of ACHRI's investigators and show the promise of research to improve the health, development, and well-being of children everywhere. The recent accomplishments by ACHRI's various research areas reflect our diverse research expertise, ranging from basic science to clinical and community-based research.

You can view the report online at <http://achri.archildrens.org/about/ACHRIAnnualReport2011.pdf>.

## Recent Grant Submissions

PI	Agency	Project Title	Project Period	Total Funding
Martin Ronis	NIH	Lipid Aldehydes and Ethanol- Induced Liver Damage	6/1/2013-5/31/2018	\$935,353

## ACHRI Researcher-Specific Announcements

Announcements that are specific to ACHRI/ACH Campus Researchers may be found at the Weekly Research Update page: <http://compoint/ACHRI/default.aspx>