



August 2008

CROWNING MOMENTS



Because of research, improved medications are available for Paige and other children with juvenile rheumatological diseases.

A toddler with a facial rash and swelling would concern any parent. At two, Paige had a butterfly rash across her nose and onto her cheeks. "It was bright red like she had been in the sun," says her mother Sherri, "and she was a little fussy." At a doctor's visit, the family was told that the child had an allergy. The family from Fulton in southwest Arkansas then made a trip to a dermatologist in Little Rock. A papule, appearing to be a clear blister, formed on Paige's finger, and she was referred to Dr. Paula Morris, a rheumatologist at ACH.

At this time, Paige was diagnosed with juvenile dermatomyositis, a condition characterized by skin inflammation, arthritis, and muscle weakness. Under Dr. Morris' care, Paige's disease was treated with medication. For Paige, the effects are mostly with the skin and not with her muscles. She keeps out the sun (sunscreen doesn't help protect her) to avoid relapses of the rash.

Indoor activities keep Paige, now 14, busy. "I've been in dance for three years and competing in pageants for two," says Paige. She has won many dance and pageant competitions. So far this year, she has been crowned with one national, five state, and four local titles. Paige is hoping to attend a mini-national pageant in Fayetteville in October to add another crown to display in her room among her ribbons, trophies, and sashes.

Though Paige does not participate in a research project, her physician Dr. Morris does. Since 2002, Dr. Morris has conducted funded research on medications for juvenile idiopathic arthritis, and these medications are often also used to treat other conditions such as juvenile dermatomyositis. Paige and Sherri both agree that improved medications have been one of the benefits of research in juvenile rheumatological diseases. "There is a big contrast in medications from 20 years ago to today," says Dr. Morris.

Reflecting this evolution, Dr. Morris was recently asked to participate in an international study of a medication for juvenile idiopathic arthritis. Now, ACH is 1 of 14 US sites in addition to 59 international sites for the study. Patients in the study are committed to coming to the Pediatric Clinical Research Unit at ACH every two weeks for two years. Each visit will last about half a day including the IV infusion of the medication.

Like Paige, Dr. Morris and her staff now have a crowning moment of their own. The ACH site was the first study site in the US (and the second throughout all worldwide sites) to complete the steps necessary through ACH's review and the sponsor's contract phases. "They were impressed by the site visit," Dr. Morris says of an inspection by the study sponsor. She adds, "They could have gone anywhere for the study but came here."

Sherri and Paige also have high praise. "She's just been wonderful," Sherri says of Dr. Morris. "If you need her, you can find her." She also adds of the nursing staff, "Pam Andrews and all the nurses get back to you."

The successes of Paige and Dr. Morris are something of which we can all be proud. These achievements are only the beginning of greater triumphs to come from them.

INTRODUCTIONS ARE IN ORDER

When the research institute opened in 1992 there were only a handful of researchers on campus. In fiscal year 2008 approximately 120 researchers prepared and submitted proposals for future research projects or actively participated in research. With this growth in the number of investigators on campus comes the challenge of ensuring that everyone is properly introduced to new researchers as they arrive on campus. Collaboration is the key to successful research, and a proper introduction is the key to collaboration.

Welcome Bradley Schaefer



G. Bradley Schaefer, M.D., is the new chief of genetics and metabolism in the College of Medicine's Department of Pediatrics and inaugural director of the Division of Genetics in the UAMS College of Medicine. In addition, he will continue as medical director for the Department of Genetic Counseling in the UAMS College of Health Related Professions, a position he held as an adjunct professor while at the University of Nebraska Medical Center. His research interests include the genetic causes of complex traits, specifically neurodevelopmental disorders like autism, mental retardation, and cerebral palsy; craniofacial disorders such as cleft lip/palate and craniosynostosis; and hearing loss. He is currently collaborating with Charlotte Hobbs at UAMS/ACHRI and Mark Mengel at UAMS, many investigators back at the University of Nebraska Medical Center, and John Bodensteiner, a pediatric neurologist in Phoenix.

When asked why research is important, Dr. Schaefer says, "Identifying the cause of a particular condition is the launching point for defining outcomes, prognosis, and treatment. Also, for most families, just knowing 'why' is greatly empowering."

PRESIDENT'S CHOICE

Stop by the bulletin board located in the first-floor lobby of the ACHRI building to see this month's President's Choice publications. The following articles were selected as this month's feature publications.

- Sheree L. Boulet, Quanhe Yang, Cara Mai, Russell S. Kirby, Julianne S. Collins, James M. Robbins, Robert Meyer, Mark A. Canfield, Joe Mulinare, for the National Birth Defects Prevention Network. Trends in the Postfortification Prevalence of Spina Bifida and Anencephaly in the United States. *Birth Defects Research* (Part A) 82:527–532 (2008).
- S. Jill James, Stepan Melnyk, Stefanie Jernigan, Amanda Hubanks, Shannon Rose, David W. Gaylor. Abnormal Transmethylation/transsulfuration Metabolism. and DNA Hypomethylation Among Parents of Children with Autism. *J Autism Dev Disord*. 2008 May 30. [Epub ahead of print].

ACHRI would like to know about your published findings, as your articles are published, please email or mail a copy to [Phaedra Yount](mailto:Phaedra.Yount@uams.edu) (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. To see all recent publications by ACHRI researchers and their collaborators, please visit the [publications web page](#).

WHO DO YOU CALL WHEN YOU NEED STATISTICAL SERVICES?

For questions and requests regarding statistical services and reviews, please e-mail achbiostat@uams.edu. If you are currently working on a project with an individual in the statistics group, please copy achbiostat@uams.edu on your email correspondence with that individual.

GOT HIPAA?

Do you have a human subject research project that you have been working on for years? Or did you start your project last week? Either way, HIPAA is an important part of your study.

If your project began on or before 2003 (the implementation of the HIPAA privacy rule), take a moment to revisit your current HIPAA process. If you have a combined informed consent and your study started before 2003 you should contact us to verify that you have all of the required elements. If you are not collecting the HIPAA authorizations correctly, there could be issues when you try to use your data.

If you are starting a new project take a moment to read the [ACH policy N05](#) and [IRB policy 13.3](#).

If you have your participants sign the correct forms now, you will avoid issues in the future.

If you have any HIPAA questions, please contact Margie Brackeen in the ACHRI Human Subject Protections Area at 364-3586 or brackeenmargiei@uams.edu.

RECENT AWARDS AND SUBMISSIONS

Awards				
PI	Agency	Project Title	Project Period	Total Funding
Sadia Malik	NIH	Maternal Smoking, DNA Repair Polymorphisms and the Risk of Septal Heart Defects	7/10/08-6/30/13	\$649,350
Shanmugam Nagarajan	NIH	Role of Fcγ Receptors in Atherosclerosis	6/1/08-5/31/13	\$1,787,500
Submissions				
PI	Agency	Project Title	Project Period	Total Funding
Charlotte Hobbs	CDC	AR Centers of Excellence for Surveillance, Research Services, and Evaluation Aimed at Birth Defects	12/1/08-11/30/13	\$5,593,000
Laura James	NIH	Identification of New Mechanistic Biomarkers of Adverse Responses to Acetaminophen in Children and Adolescents	4/1/08-3/31/13	\$2,575,460
Robert Wolfe	NIH	Substrate Cycling in Energy Metabolism Competitive Renewal	4/1/09-3/31/14	\$1,837,500

NEW INDUSTRY-SPONSORED PROJECTS

Clinical Trials	Agency	Project Period	Total Cost
Kimo Stine	Schering Plough	7/08 - 6/10	\$32,300
George Fuchs	Ception	7/08 - 6/10	\$78,482
Kimo Stine	Bayer	7/08 - 6/11	\$23,547
Ariel Berlinski	Gilead Sciences	7/08 - 6/09	\$27,987

CONSIDER BECOMING A CUMG REVIEWER

With the help of the investigators who agree to serve as reviewers, the CUMG intramural grant program is quite a success. Reviewers play a pivotal role in providing feedback to applicants who are “learning the ropes” and also help to ensure the award process remains fair and balanced in supporting the research community’s efforts for self-improvement and pursuit of extramural funding.

Each grant application requires two reviewers. Amy Stalls is assembling a list of faculty interested in serving as reviewers. If you would be interested in serving on the CUMG Review Committee please contact Amy (Phone: 364-3627).

Department of Pediatrics faculty members serving as reviewers should record this service on their Faculty Development Reports for annual evaluations. Researcher activities are reviewed by the Chair of Pediatrics and are taken into consideration for evaluations and raise consideration.

College of Medicine faculty members should list all CUMG review activities in their promotion and tenure packets. These types of volunteer services highlight a researcher's institutional commitment and willingness to encourage newer investigators.

ACHRI INVESTIGATOR MEETING

The next ACHRI Investigators' meeting will be held October 29 in the Brandon Auditorium at 11:30 a.m. Lunch will be provided to the first 50 attendees.

The [August meeting PowerPoint presentation](#) is available at the ACHRI web site.

FUNDING OPPORTUNITIES

The National Association of Children's Hospitals (NACH) prepares and distributes upcoming funding opportunities every two weeks. Funding opportunities recently distributed by the NACH are available on the ACHRI web site (http://achri.archildrens.org/resources/funding_opp.htm). This file is updated monthly. Bookmark the page! The listing of funding opportunities is located on the intranet; you must have access to MyACH vault files to open the file.

GRANT WRITING TIP: REMINDERS ON NIH ELECTRONIC APPLICATIONS

NIH has released a notice ([NOT-OD-08-095](#)) containing reminders on appropriate materials in grant applications.

In the Project Summary/Abstract and Project Narrative in the SF424(R&R) for electronic submissions (see SF424 instructions in Part I, 4.4, items 6 and 7), applicants should use text only. (This reminder also applies to the Project Summary and Relevance component in the PHS 398 paper application - PHS 398 instructions in Part I, 4.2.1.) The information provided in these components becomes part of the Summary Statement that documents the results of the review process. When a grant application is selected for award, the information become publicly available in the Computer Retrieval of Information on Scientific Projects database (CRISP; <http://report.nih.gov/crisp/index.aspx>). If figures or information not in standard text format are included in these components of application submissions, it is not transferred for the other uses and a blank section will appear. Therefore, it is important that applications consist of text only in these two components.

The notice also reminds applicants not to embed movies or other materials in the PDF attachments of the Research Plan or of other components of electronic submissions. These will not be available to NIH staff and/or reviewers after the transit of the application through the Grants.gov and NIH eRA processing systems. As noted in NIH Guide [NOT-OD-08-082](#) and accompanying [Best Practice Guidelines](#), the Scientific Review Officer should be contacted about such materials.

Submitting Electronic Applications to NIH?

ACHRI will hold a workshop providing an overview of downloading PureEdge Viewer and grant applications from Grants.gov. There will be a demonstration of completing and viewing application forms, using the SF424 Cover Component as an example, with PureEdge. Participants will work at a computer station to get hands-on experience with these tasks. There will also be a discussion of transferring completed applications to ACHRI for submission to NIH as well as an explanation of what happens during the submission process. The workshop is on August 25 from 2:00 to 3:30 in EC 59 (2nd floor, ACH East Campus Building). There is space only for 18 participants, so please email John Gregan if you would like to attend.