



RESEARCH update

January 2009

Two Hearts Beat as One



At ACH, Dayne (with surgeon Dr. Robert Jaquiss) had access to a Berlin Heart, which provided mechanical cardiac support until a heart was available for transplant.

In early 2008, Maria took her 7-month-old Dayne to his pediatrician in their northern Mississippi town. Her son was fussy and sleepy, and Dayne also appeared pale and had odd breathing. From the pediatrician's office, Dayne's parents took him to a hospital in Memphis. "He was dehydrated and had no pulse or blood pressure," Maria says, "Dayne's heart was working at five percent. It was rocking, not beating." After a 12-day stay, Dayne went home with his family.

Almost two weeks after returning home, Dayne's family took him back to the pediatrician who then had the family go immediately back to Memphis. The doctors determined Dayne would require a heart transplant. Within two days of returning to Memphis, Dayne was sent to the nearest heart transplant center, Arkansas Children's Hospital, aboard an ACH helicopter to Little Rock.

In Memphis, doctors also told Maria that at ACH it was possible to support Dayne's heart using a Berlin Heart, a device that assists the heart with pumping blood. Though approved for use in other countries, the Berlin Heart is currently being tested in the US. ACH is participating in a Food and Drug Administration (FDA)-regulated investigational trial of the Berlin Heart for pediatric use having implanted its first in 2005.

"Keeping a child alive until they can get a heart is the trick," says Dr. Robert D.B. Jaquiss, a cardiovascular surgeon at ACH. If a child needs a heart transplant but may not survive until a heart is available, the Berlin Heart is an alternative to extracorporeal membrane oxygenation (ECMO). ECMO requires the patient to be bedbound needing a ventilator and heavy sedation. Although ECMO is useful for short-term cardiac support, the risks of ECMO-related complications such as stroke or life-threatening infection rise sharply beyond two weeks; the typical waiting time to receive a heart for most children who require mechanical cardiac support is actually closer to six weeks. The Berlin Heart can be used for much longer periods and, in fact, has supported children for over a year. Furthermore, children supported with the Berlin Heart do not usually require a ventilator or any sedation at all—patients are even encouraged to walk and exercise under supervision to maximize their pre-transplant rehabilitation.

Within a week of Dayne arriving at ACH, Dr. Jaquiss and the cardiovascular surgery team attached a Berlin Heart to Dayne. "At ACH, these children have access to technology that other children don't," says Dr. Jaquiss. He indicates, "At ACH our average support time on the Berlin Heart has been six weeks, far longer than the two week time frame we could have anticipated with ECMO. We believe that most of these children would have died if the Berlin Heart had not been available."

The wait for organ availability can be unpredictable, but the morning after the Berlin Heart surgery, a heart was available for Dayne. Seeing him after the surgery, Maria said the device hung to Dayne's legs like an oversized medal. "It was wild," says Maria adding, "It was amazing to see how it worked."

So far Dr. Jaquiss and Dr. Michiaki Imamura have implanted 22 Berlin Hearts in children at ACH making it the largest pediatric Berlin Heart implant center in North America. Patients have come from around the world to have the surgery performed at ACH. As an early adopter of this technology, ACH serves as a resource for other Berlin Heart centers to get advice. "We've learned so they don't have to learn the way we did," comments Dr. Jaquiss. ACH's experience with the Berlin Heart provides insight into the benefits of its use and with improving patient management and outcomes. ACH shares all data with FDA as it determines the device's US commercial release.

Dayne's stay at ACH was 6 weeks. "They were awesome," Maria says reflecting on the ACH staff. Dr. Jaquiss affirms that it is a team effort, "We have a dedicated pediatric cardiology team that is with the families before, during, and after surgery. The team is exceptional."

Now one year old, Dayne makes regular visits to ACH following up on his transplant surgery. When Dayne is older and asks about his operations, Maria says, "I'll tell him that God saved his life, but without the Berlin Heart he wouldn't have made it."

Congratulations to Dr. Amy Scurlock!

Dr. Amy Scurlock has received an NIH Mentored Clinical Scientist Research Career Development Award (K08) from the National Institute of Allergy and Infectious Diseases (NIAID) for her project "Immunoregulatory Networks in Chlamydia Genital Tract Infection". The K08 award will provide Dr. Scurlock with support and "protected time" for an intensive, supervised research career development experience. The project period is five years with a total award amount of \$661,500.

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.

- James SJ, Melnyk S, Fuchs G, Reid T, Jernigan S, Pavliv O, Hubanks A, Gaylor DW. Efficacy of methylcobalamin and folinic acid treatment on glutathione redox status in children with autism. *Am J Clin Nutr.* 2009 Jan;89(1):425-30.
- Aitken ME, McCarthy ML, Slomine BS, Ding R, Durbin DR, Jaffe KM, Paidas CN, Dorsch AM, Christensen JR, Mackenzie EJ; CHAT Study Group. Family burden after traumatic brain injury in children. *Pediatrics.* 2009 Jan;123(1):199-206.

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. To see all recent publications by ACHRI researchers and their collaborators, please visit the [publications web page](#).

Arkansas Center for Birth Defects Research and Prevention Collaborates with the North Pole

For the past four years, the Arkansas Center for Birth Defects Research and Prevention has sponsored a UAMS Head Start classroom for Christmas. In December, the Center arranged for the 20 pre-K children to meet a special guest—Mrs. Claus. She came from the North Pole to read "The Night Before Christmas" and to deliver gifts from her husband, Santa Claus, to the children. Mrs. Claus also took a photograph with each child. Santa's helpers with the Center report the children were thrilled with Mrs. Claus' stopover. ACHRI applauds the spirit of the Center noting that they are already on Santa's "Nice List" for next Christmas. A special thank you goes to Mrs. Claus (who looks an awfully lot like Joyce Norton) as well.



ACHRI Address Change

With the dedication of Children's Way (formerly Marshall Street), ACHRI has a new street address: 13 Children's Way. Use this address on grant applications submitted through ACHRI. Refer to the [sample SF 424](#) with ACHRI information at our Web site to view the change for NIH submissions.

Business Mileage Rate for 2009

The IRS has announced that the business mileage rate for 2009 will be \$0.55. This is a decrease from the 2008 rate of \$0.585. For travel occurring after 12/31/08, the new rate should be used when requesting mileage reimbursement.

Recent Grant Awards and Submissions

Awards				
PI	Agency	Project Title	Project Period	Total Funding for All Years
Jill James	DHHS sub Massachusetts General Hospital	UA# Autism Interv. Research Network AIR-P Network Admin Project	9/1/08-8/31/09	\$80,000.00
Amy Scurlock	NIH	Immunology Networks in Chlamydia Genital Tract Infection	12/25/08-11/30/13	\$661,500.00
Submissions				
PI	Agency	Project Title	Project Period	Total Funding
George Fuchs	Autism Speaks	A Study of Sleep Disturbance and Gastrointestinal Disease in Children with Autism	1/1/09-12/31/12	\$255,000.00
Dennis Kuo	HRSA	Family-to-Family Health Information Center	6/1/09-5/31/12	\$29,917.00
Judy Weber	Allen Foundation Inc.	Health Food and Fitness News Projects	7/1/09-6/30/10	\$55,150.00

New Industry-Sponsored Projects

Clinical Trials	Agency	Project Period	Total Cost
James	Merck	12/08 - 11/09	65,683.20
Romero	3M	12/08 - 11/09	74,630.00
Garcia	Duke University	12/08 - 11/09	45,000.00

Drop that Pencil!

When collecting study data use a pen, not a pencil, to complete source documents and case report forms. Pencil marks fade over time and could also be erased or changed, but writing in non-erasable pen creates a permanent record that can't be changed without documenting the change. When you make a mistake with your pen, simply cross it out with a single line; correct the entry; then initial and date the change. Signatures should always be original, in pen, and signed/dated/timed by the person who is signing— you should never use pencil, crayon, or signature stamps. For more information on study procedures feel free to contact Margie Brackeen in the human subject protections area of ACHRI at 364-3586 or brackeenmargie@uams.edu.

Dissecting Research Misconduct (a 3-part series)

The Office of Research Integrity defines Misconduct as: "...fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or in reporting research results..."

As a general working definition, ORI considers Fabrication to be making up data or results and recording or reporting them.

Whether what you are doing is as "small" as filling in a missing piece of data (such as a blood pressure you "forgot" to write down) or going so far as to create subjects in your study who do not exist, this is considered fabrication by the ORI. Fabrication (when discovered) can lead to severe penalties from loss of grant funds, retraction of publications, exclusion from federally funded research, and depending on the severity of the offense, jail time.

Check out the ORI Case Studies at <http://ori.dhhs.gov/misconduct/cases/> for more details.

Look in the February edition of this publication for our third part of this series on falsification.

2009 Summer Science Program - Mentors Needed

The UAMS Department of Pediatrics and ACHRI are again co-sponsoring the Summer Science Program. The program is intended to give college students experience in working in medical research and a view of medicine in general. The program lasts ten weeks during the summer. To learn more about the program and to download the mentor or student application, please visit the program web page at <http://achri.archildrens.org/Education/SummerScienceProgram.htm>.

Applications are due no later than March 2, 2009. Please forward completed applications to Jenny Kubacak, Summer Science Program Coordinator, at ACHRI Slot 842.

Wanted: Researcher Profiles!

Last month there were almost 900 page visits to ACHRI's "Our Researchers" index page. These views were from many of the over 1,800 unique visitors to ACHRI's Web site. Would you like to add your researcher profile to our Web site? If so, send [John Gregan](#) the following information: your title, a paragraph about your research interests and accomplishments, a list of your current research funding, appropriate contact information, and a list of five key publications. Include a current digital photograph if you have one available. You can view the profiles we've developed here: <http://achri.archildrens.org/researchers/faculty.htm>.

If you already have a profile at our web site, contact John if you need to revise it in regards to accomplishments, publications, and funding.

Yale Agrees to Pay \$7.6 Million to Resolve Allegations

In December, the Associated Press reported that federal authorities announced that Yale University has agreed to pay \$7.6 million to resolve allegations that it broke the law in managing federally funded research grants. At issue was alleged violations of the basic principle that recipients of federal grants are only allowed to charge to each grant account the costs that relate to the specific objectives of the grant project. The complete article is available at http://news.yahoo.com/s/ap/20081223/ap_on_re_us/yale_settlement_2.

Grant Writing Tip: Commitments from Outside Collaborators

Conducting most research plans includes the participation of others, and many times this means persons from other institutes. To ensure internal completion and approval of your application, be sure to obtain the necessary documentation from other institutes concerning the inclusion of these collaborators in your application.

Your collaborator should contact his or her office of sponsored research to notify them of the collaboration and to establish what requirements the institute may have concerning this issue. Your collaborator will have to meet the conditions set by his or her institute to receive its approval for the proposed association.

From your collaborator, ACHRI will require either a completed PHS 398 form approved by the collaborator's institute or a letter from the institute regarding the collaboration. The letter should confirm the commitment of the participating institute and refer to the proposed project. If the collaborator will be contributing a measurable effort to the proposed project, the letter should have an attached budget and statement of work regardless whether the effort is paid or is in-kind. An authorized institutional representative from the collaborator's institute must sign the letter.

Addressing and documenting an outside collaborator's commitment early will facilitate budgeting and administrative authorization. If any questions arise concerning what you may need to document collaboration for ACHRI, contact [Lee Smith](#) (364-3581).