

Research News

Newsletter of
The University of Kansas Medical Center
Department of Pediatrics



Division Highlights: Project EAGLE

Each quarter the Research News highlights one division within the Department of Pediatrics to focus on their research projects and goals. This issue we have chosen Project EAGLE to be the highlighted division.

Project EAGLE joined with the Department of Pediatrics in 2002 after fourteen years of working independently in the community. The project was started in 1989 and is directed by Martha Staker who serves as both director and principal investigator. The project has about 3 million dollars per year in grant money to work with children in Wyandotte County, and currently has 10 funded grant projects. Project EAGLE has 40 full time staff members and serves approximately 300 children and families each year. Children and families are referred to the program through a number of means. Eligibility is based upon income, zip code and age (for some projects certain ages are solicited). The project does currently have a long waiting list, but some of the research currently underway may assist with decreasing the wait.

Project EAGLE is currently running 10 programs to help children and families from Wyandotte County, all of which are research projects. The newest project involves piloting a centralized intake program for families in need of early intervention services in Wyandotte County. This centralized scheduling will allow Project EAGLE to track patients, identify their needs, refer them to appropriate resources, and follow them up to be sure they receive the correct services and that their needs are met. Project EAGLE also has a large Head Start grant to provide Head Start and Early Head Start services for Wyandotte County. Early Head Start programs “work with families where there is a pregnant woman or child between the ages of birth and three years living in the home.” For this project family support advocates visit families at home to help them meet their developmental and educational needs.

In addition to the large Head Start grant, Project EAGLE also has several other ongoing research projects. They have a project to help families find a medical home, rather than frequently changing medical providers in the community. They also have a childcare or CDA grant to provide for the childcare needs to parents of low income.

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Martha Staker has several research goals for Project EAGLE. Her main priority at this point is to build a large new campus for Project EAGLE in downtown Kansas City Kansas. She already has approximately 3 million dollars committed to the new campus. Once the new facility is built, it will include green space for soccer fields and other recreational activities, as well as homes for Project EAGLE and possibly medical and developmental assessment and treatment offices for the patients they serve.

Congratulations Dr. Rapoff!!!

Dr. Mike Rapoff has been notified that he has received the **2003 Distinguished Scholar Award** from the Association of Rheumatology Health Professionals, a division of the American College of Rheumatology. This award is presented annually to "...an individual who demonstrates exceptional achievements in scholarly activities in the rheumatic diseases." The award will be presented on October 26, 2003 at the joint Annual Scientific Meeting of the Association of Rheumatology Health Professionals and the American College of Rheumatology in Orlando, Florida.

Research Tips: HIPAA

Ann M. McGrath, Ph.D.

Behavioral Sciences

As the new HIPAA guidelines have been implemented, many questions have arisen as to how these guidelines will affect our research. KUMC does have a website dedicated to HIPAA, which can be found at <http://www.kumc.edu/hipaa/>. Simply click on "research" and you can access more details about the information listed below.

As you know, HIPAA was designed to protect patient information and to make patients aware of how their information is being used. To be compliant with HIPAA, a HIPAA review will now take place on all applications submitted to the Human Subjects Committee (HSC). As part of the HSC review process, all applications will be reviewed to ensure they also meet HIPAA guidelines. What this means for researchers is that for new applications we now need to submit an extra copy of your proposal when you submit your HSC application. Also, a new template titled "HIPAA Requirements for Informed Consent" should be added to all HSC applications to ensure they are HIPAA compliant. This template can be found at <http://www.kumc.edu/hipaa/research/> under the "Research Documents" section. However, if you have a project that is currently underway, you will need to contact the HIPAA office to determine how to get your project HIPAA compliant.

Another issue that has come up as a result of the new HIPAA guidelines is subject recruitment. It is no longer acceptable for researchers to contact subjects through medical care clinics, unless the researcher is a part of the clinical care team. Rather, a member of the medical care team who has contact with the patient in a clinical role must make the initial contact and solicit participation. Then, if patients indicate they are interested in participating in the research project, the medical care team can release information to researchers who can contact the subjects for recruitment. It is still acceptable for patients to self-refer from flyers and adds in the community and in publications.

As there is also clinical research going on in our department that is completed as a part of clinical care, it is important to note changes in this area. If patient information is being collected with the intent of using the information for publications or for other research purposes, consent must be sought from patients. As the HIPAA website states "creation of a research repository requires HSC approval...and patient authorization." Therefore, if the project is ongoing, contact the HIPAA office for suggestions (588-0952). If the project is new, prepare and submit an application to the HSC with the new HIPAA template mentioned above.

For any additional HIPAA questions, contact Karen Blackwell, the Director of HIPAA Compliance, at 588-0942 or Rachel Dalthrop, the Assistant Director at 588-0940.

Current Pediatric Grants

Please let me know (at amcgrath@kumc.edu) if you have any additions or corrections for the next volume of Research News.

Ahluwalia, J. (PI), & Ahluwalia, H. (Co-PI) **08/01 - 06/05**
"Helping African-American Light Smokers Quit"
NIH/ NCI - Total direct costs: \$1,604,016

Casey, J. (PI), Delrosario, G. (Co-PI) **08/02 – 08/03**
"Kabi international growth study"
Pharmacia & Upjohn

Casey, J. (PI), Delrosario, G. (Co-PI) **08/02 - 08/03**
"Genentech national cooperative growth study (NCGS)"
Genentech

Greiner, A. & Ahluwalia, H. (Co-PI) **06/03 - 05/04**
"Assessing Obesity In Rural Kansas Primary Care Practices"
Sunflower Foundation - Total direct costs: \$137,958

Hyman, P.E. (PI), Danda, C., Cocjin, J., Comninellis, T. **03/03-02/04**
"Improving treatment for functional fecal retention"
KUMC Research Institute – Direct Costs \$25,000

Johnson, C. (PI), Richman, D. **07/00 – 06/05**
"Leadership education in neurodevelopmental disabilities."
Maternal and Child Health Bureau - Total Costs \$2,675,000

Lowry, J. (PI), Shaw, P. (Co-PI) **2001-2003**
"Lead and its effects of clytochrome P450"
Hall Family Foundation - Direct Costs \$75,000

Perry, G. (PI) **2002 - 2003**
"Epidemiologic study of cystic fibrosis: A multicenter, longitudinal follow-up study of patients with cystic fibrosis for monitoring pulmonary function, pulmonary exacerbations and the safety of long-term treatment with pulmozyme (dornase alfa)"
Genetec

Poston, C. (PI), Ahluwalia, H. (Co-PI) **06/03 - 05/08**
"An Analysis of Environmental Risk Factors for Obesity"
NIH/ NIDDK - Total direct costs: \$2,489,343

Human Subjects Committee Deadlines

Deadline**	Meeting
June 27	July 8
July 14	July 22
August 4	August 12
August 18	August 26
August 29	September 9
September 15	September 23
October 6	October 14

all deadlines are at **noon**

For more information, go to
<http://www2.kumc.edu/researchadmin/hs-meetdates.htm> or call 913-588-1240

Raghuveer, G. (PI) Mattioli, L (Co-PI) 07/02 - 09/03
“Effect of statin therapy on vascular function in children”
American Society of Echocardiography - Direct Costs \$75,000

Rapoff, M. (PI) 10/02 - 09/03
“Headstrong: A novel minimal contact behavioral intervention for recurrent pediatric headache”
AstraZeneca Pharmaceutical Company - Direct Costs \$50,000

Sahgal, Namita MD (PI) 04/02- 03/07
“Fetal Regulation of Placental Biology”
NICHD : KO8 HD 42171

Voziyian, P. (PI), Scheinman, J. 08/02 -07/03
“A new rx of hyperoxaluria”
NIH - STTR Grant - Direct Costs \$100,000

April-June, 2003 Pediatric Publications

If you have additions or corrections for the next volume, please let me know (amcgrath@kumc.edu).

Barnard, M.

Helping Your Depressed Child. (2003).
New Harbinger Publications, Inc.

Caldwell KL, Maxwell BC, Makhmudov AA, Pino S, Braverman LE, Jones RL, & **Hollowell JG.**
"Use of Inductively Coupled Plasma Mass Spectrometry to Measure Urinary Iodine in NHANES 2000:
Comparison with Previous Method"
Clinical Chemistry, 49, 1019-1021, 2003.

Chopra CW, O'Boynick PL, **Ahluwalia HK**, Witt PD.
Need for public and medical awareness of pediatric craniofacial trauma in Sierra Leone.
Plastic and Reconstructive Surgery 2003;111(1):515-518

Nelson, E.L., Barnard, M., Cain, S.
Treating childhood depression over videoconferencing.
Telemedicine Journal and e-Health: (2003), 9(1), 49-55.

Page-Goertz, S.

Weight gain concerns in the breastfed infant: Essential strategies for assisting families.
Advance for Nurse Practitioners, (2003), March, 42-48.

April – June, 2003 Presentations at National Meetings

If you have additions or corrections for the next volume, please let me know (amcgrath@kumc.edu).

Sahgal N, Kent LN, Soares MJ.
Fetal regulation of trophoblast cell invasion into the maternal uterine mesometrial vascular compartment.
Platform presentation, Pediatric Academic Societies Annual Meeting, Seattle, Washington . May 3-6, 2003.