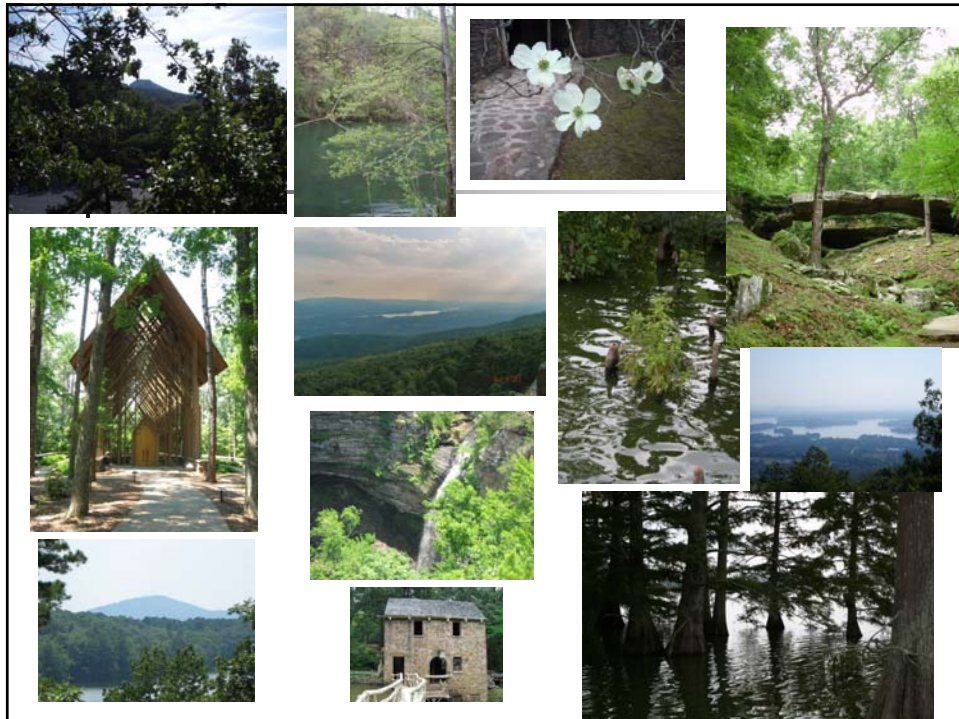


An Update of Medical Genetics in Arkansas

A Report to Heartlands Regional Genetics and
Newborn Screening Collaborative





B. Schaefer





UAMS
UNIVERSITY OF ARKANSAS
FOR MEDICAL SCIENCES

 **Pediatrics**
UNIVERSITY of ARKANSAS for MEDICAL SCIENCES



HIGHLIGHTS OF GENETICS IN ARKANSAS – 2009

UAMS, ACH and DOP have made a joint commitment to expand and develop medical genetics in Arkansas. This collaboration supports clinical and research efforts in medical genetic

Increase in Clinical Workforce


Jun 2008

- 1 pediatric geneticist
- 1 adult geneticist
- 3 genetic nurse specialists
- 6 genetic counselors
- 1 metabolic nutritionist
- 3 MFMs

Sept 2009

- 3 pediatric geneticists
- 1 adult geneticist
- 6 genetic nurse specialists
- 12 genetic counselors
- 1 metabolic nutritionist
- 3 MFMs






Pediatrics Genetics

Arkansas Children's Hospital

- 7 weekly general genetics clinics
- Specialty / inter-disciplinary clinics:
 - Dystrophinopathy
 - Autism
 - Endogenetics
 - Down syndrome



Metabolism

Arkansas Children's Hospital

- Metabolic clinic
- Metabolic continuity clinic
- Newborn Screening clinic



Birth Defects Surveillance

- State BD Registry
- CDC funded Center for Birth Defects Prevention Network



Adult Genetics

University of Arkansas for Medical Sciences

- Clinics
 - Adult genetics
 - Cancer genetics
 - Retinal genetics
- \$1.1 million gift for adult genetics
 - Research
 - Clinical support



Adult Down Syndrome Program

- Winthrop P. Rockefeller Chair in Clinical Genetics
 - \$ 3.4 million endowment
 - Adult Down Syndrome Program
 - Adult genetics clinic



College of Nursing

- APN faculty
 - Education
 - Clinical service



Perinatal Medicine

- Maternal-Fetal Medicine prenatal diagnostic clinics
- High risk pregnancy management
- Selected fetal interventions
- ANGELS (Antenatal and Neonatal Guidelines, Education, and Learning System)
 - Designed to provide
 - best practices in diagnosing and treating high-risk pregnancies,
 - providing continuing medical education for Arkansas obstetricians and family practice physicians,
 - and facilitating referrals of pregnant women with severe medical complications to UAMS for specialized care



Arkansas VA Hospital

- Vacated position open for a GC

Outreach

- First Lowell clinic – October 2009
- Anticipate 3 additional sites



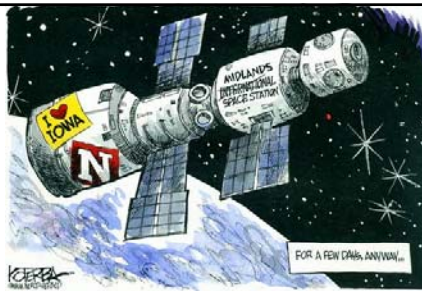
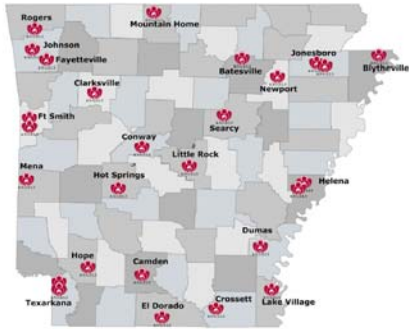
Outreach

- Wichita
 - 1 genetic counselor
 - UAMS physician support (telemed)



Outreach

- Telemedicine to 27 sites
 - Adding 7 more this year





Genetics Laboratory

- Human Genetics lab (UNMC)
 - Contracted for services
- Metabolic (ACH)
 - uAA, sAA
 - uOA
 - Acyl-carnitine
 - Trimethylammonuria
- Molecular (ACH)
 - CF
- Cytogenetics (Myeloma Center)



Department of Health

- State genetics coordinator
- Re-organization of Arkansas Genetics Health Committee
 - NBS
 - Pediatrics
 - Adult
 - (?) Perinatal



Newborn Screening

- Medical Director, Laboratory Director, Lab Supervisor, nurses (7)
- NBS hearing coordinator
- 1 year into advanced NBS
- \$ 5.1 million Medicaid contract for NBS infrastructure



NBS-ANGELS

- 10 project deliverables:
 - Guidelines/protocols monitored, assessed and modified
 - Consultation for appropriate health-care providers
 - Perform second tier screening components
 - Development, education, refinement and dissemination of the Newborn Screening Follow-up guidelines/protocols.
 - Develop database and reporting system
 - Examine Medicaid claims data; cost analysis
 - Coordinate access to services
 - Perform an evaluation to compare outcomes
 - Develop the infrastructure and software to aid in identification and treatment and track case management of true-positive
 - Augment provision of metabolic formulas and foods

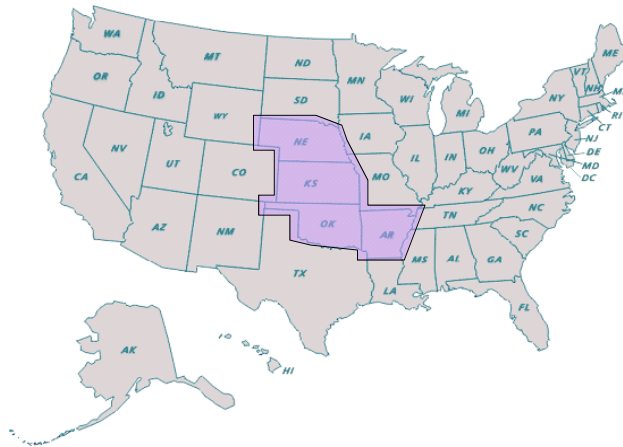


Education

- Medical School 2nd year course
 - New textbook
- New GEM rotation in pediatrics
- Increased genetics in Pediatric resident core curriculum



Mid-America Genetics Education Consortium A tangible result of regional collaboratives





What's Next?

- Recruitment
 - 1 pediatric geneticist, 2 adult geneticists, 1 VA genetic counselor, 1 adult genetic counselor, lab director(s), 2 GCs (Wichita)
- GPGSN / Heartlands
 - Great way to find a job



What's Next?

- Consolidate Telemedicine networks
- Newborn Screening infrastructure
- New specialty clinics
 - Neurosensory genetics, craniofacial / orofacial clefts
 - Transition
- Laboratory Development

