Sickle Cell Awareness Month closed with a roundtable devoted to improving the care and access to care for individuals living with sickle cell disease across the state. The event was co-hosted by the Arkansas Minority Health Commission, UAMS Partners for Inclusive Communities, Sickle Cell Support Services, and the Arkansas Legislative Task Force on Sickle Cell.

The roundtable was held September 30th at Philander Smith College in Little Rock. Of the approximately 31 attendees several groups and organizations were represented including St. Jude Children’s Research Hospital, Arkansas Department of Health, UAMS’ Living Well with Sickle Cell Program, UAMS- College of Nursing, Arkansas Foundation for Medical Care, Title V Children with Special Health Care Needs Program, Mutual Sickle Cell Support Group, Inc., Arkansas Children’s Hospital, Qual Choice and UAMS-Delta AHEC.

The roundtable opened with a video conference presentation from Shawn M. Bediako, Ph.D., director of the Laboratory for the Social & Psychological Study of Sickle Cell Disease in Baltimore, Md.

He is also assistant professor in the department of psychology at the University of Maryland, Baltimore County, where he contributes to behavioral medicine and community/applied social psychology programs. Bediako provided an overview of the clinical, social, and economic impact of sickle cell disease in Arkansas. He also highlighted the disparities between the funding that is given to sickle cell research and that which is given to other diseases. Although there are approximately 38 percent more individuals in the United States living with sickle cell disease than cystic fibrosis, cystic fibrosis receives 70 percent ($128 million) more NIH funding than sickle cell ($90 million), Bediako stated.

The participants were then divided into four groups to discuss the key question: “How can we improve the quality of life for sickle cell patients in Arkansas?” Each group focused on a different topic, including education and awareness, support services, health care, and social and emotional barriers.

After breaking for lunch, the participants reconvened to report about their small group discussions. Overall, they proposed 24 different strategies that can be used to address sickle cell issues across the state, from general public awareness campaigns to statewide education programs for health care providers to workforce development services for sickle cell patients.

Throughout the event, attendees discussed the critical lack of data that

Roundtable Continued on page 2

Dr. Shawn Bediako of the University of Maryland shares with the audience the state of sickle cell disease in the United States.
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is available about the actual rates of disease in Arkansas. It was noted that the only information available about the prevalence of sickle cell disease is the Arkansas Department of Health’s newborn screening program, which does not include anyone born before 1988 and cannot account for patients who move in and out of the state.

Germaine Johnson of Sickle Cell Support Services also brought attention to the need for well-coordinated care and effective communication between sickle cell patients and providers. He said that not only should there be a clearinghouse but Arkansas should use the hub/spoke model approach and that all locations should deliver the same message.

To conclude the discussion, Representative David Rainey (sponsored the bill that established the Arkansas Legislative Task force on Sickle Cell Disease) shared his personal experience with his son’s sickle cell disease as he transitioned to the need for adult care. “Our doctor was very knowledgeable and even as he got older, we kept going back, but he needed to transition to adult care.”

Arkansas does not currently have a comprehensive health care system for adults living with sickle cell disease.

He also highlighted the significant work that has been done to address this issue in recent years. He praised Robin Lockhart of Partners for Inclusive Communities, who he had first contacted while she was doing work to pass legislation for autism. She shared the model that she had used and recommended people for the Arkansas Legislative Task Force on Sickle Disease, which released its final recommendations to the legislature in September.

Idonia Trotter, executive director of AMHC and member of the Arkansas Legislative Task force on Sickle Cell Disease, closed the roundtable by encouraging everyone to take action. Let’s continue to educate and create greater awareness until every adult impacted with sickle cell disease has increased access and utilization of healthcare services in Arkansas,” said Trotter.

After the meeting, each participant had an opportunity to complete an online survey to rank all of the proposed ideas and make suggestions for further action. AMHC, Sickle Cell Support Services, and UAMS Partners for Inclusive Communities will use this information to build on the passion and commitment of those who are dedicated to improving the lives of sickle cell patients across the state and more importantly to make life better for sickle cell consumers.

Angela Mull, B.S.N., with Arkansas Children’s Hospital educates everyone on the process of caring for a patient with sickle cell.

Germaine Johnson points out focus areas in health care for sickle cell disease.

Representative David Rainey, giving his closing remarks, shares his personal experience with sickle cell disease.

Senator Hank Wilkins
FAITH-BASED COMMUNITIES MUST BE EMPATHETIC SAYS SANDERS

In an effort to provide faith-based organizations with the tools necessary to educate their congregants about HIV/AIDS, a small group of church leaders were invited to the Little Rock Hilton, October 5th for HIV Prevention: The Role and Impact of the Church.

History has shown that the church strongly influences knowledge, attitude, belief and behavior about health. Therefore, AMHC has taken steps to reach out to faith-based communities in Arkansas.

Pastor Edwin Sanders of Nashville, Tenn., provided participants with a unique perspective regarding the intersection of HIV/AIDS education and awareness and the call or response of faith-based organizations.

Sanders is the Senior Servant and founder of Metropolitan Interdenominational Church that has outreach ministries in the areas of substance abuse; advocacy of children, sexual violence and harm reduction.

Metropolitan also has a ministry dedicated to providing services to persons infected with and affected by HIV/AIDS through its First Response Center founded in 1992.

At the pastoral luncheon, Pastor Sanders began by expressing that we as a “country” have to first deal with social and socio-economic issues before effectively addressing HIV/AIDS such as under-education, lack of healthcare and race relations.

He stated that in order to do the work, one must have an empathetic spirit, meaning that an individual must understand the thoughts, feelings and experiences of another. “Look at it as if it is you,” he said. Sanders stated that the church can have a great impact on health education and awareness; including HIV/AIDS prevention.

Pastor Sanders spoke of “social justice” preaching. “You have to look critically at what you see and respond to it,” said Sanders. “Elevate your assessment not just on a plane or on the surface. Faith-based organizations have to see the problem from an elevated perspective,” he said.

In closing, Sanders encouraged pastors, “We have a real opportunity to bring people into the church that otherwise would not come by addressing the needs of the community…we have to learn and grow in relationship to each other.”

Reverend Edwin C. Sanders, II

How Health Care Reform Affects You and Your Family’s Health Insurance

Even though the Patient Protection and Affordable Care Act was passed nearly eight months ago, many of us are still wondering how we will be affected by the new laws. As you can see from the charts (see below), there are still many minorities in Arkansas who do not have health insurance. Many of the biggest changes to guarantee health insurance will not happen until 2014. For many who are suffering or struggling to pay their families’ medical bills, it seems like a long time to wait for reliable health care. Fortunately, there are some changes that may already benefit you and your family.

Children

*If your children need insurance, check out ARKids First*
- According to Arkansas Advocates for Children and Families, of the 65,000 children in the state without insurance, 43,000 are eligible for ARKids first.
- There are two types of ARKids Insurance—A and B.
  - A: For a family of four, you are eligible if your income is less than $1,837.50/month ($22,050.00/year).
  - B: For a family of four, you are eligible if your income is less than $3,675.00/month ($44,100.00/year).
- Call 888-474-8275 (English) or 800-482-8988 (Spanish) or check out the ARKids First website (http://www.arkidsfirst.com/) for more information.

*If you have insurance, your children cannot be excluded from your coverage because of their health*
- On September 23, insurance companies will not be allowed to refuse to cover children because they have a pre-existing condition, like asthma, sickle cell anemia, or any other disease.
- This applies to any plan that is sponsored by your employer, even those that were already in effect before the new laws.

Adults

*Do you need insurance? You may be able to join Arkansas’ new Pre-Existing Condition Insurance Plan.*
- If you have not had insurance for the past six months because you have a pre-existing condition (like hypertension, diabetes, or another disease), you can apply for the new high risk pool. It’s not free; monthly premiums range from $156 to $624 per month (depending on your age and smoking status), with a $1,000 deductible.
• Only 2,500 spots are available. Applicants will be accepted on a first-come, first-serve basis, so if you are interested, you should apply as soon as possible.

• If you are interested, call (800) 285-6477 or go to the Arkansas Insurance Department’s website (http://www.insurance.arkansas.gov/administration/HighRiskPool.html) for more information.

*Are you under 26? Check out your parents’ insurance plan.*

• 42% of Arkansans between the ages of 19 and 26 are uninsured. If you are under 26 and need insurance, you may be able to stay on your parent’s insurance, even if you are married, file taxes independently, and are not in school.

• Check with your parents’ insurance company to find out when you can enroll.

*Have you recently enrolled in a new plan? Take advantage of the free preventive health services.*

• Starting September 23, all new health insurance plans must pay for preventive health care. They cannot charge you anything for services like cholesterol, diabetes, and breast cancer screenings, and alcohol, tobacco, and healthy diet counseling.

• Unfortunately, these requirements do not apply to existing private health insurance plans, but some insurance plans have decided to offer these preventive health services. Contact your insurance company to ask if you are eligible for free screenings and counseling.

• See the U.S. Preventive Services Task Force website (http://www.uspreventiveservicestaskforce.org/uspstf/uspsabrecs.htm) for the complete list of services that are required by the new law.

*Don’t worry if you are diagnosed with a new disease—you are protected if you get sick.*

• It is now illegal for insurance companies to stop your coverage if you get sick or put a cap on the amount that they will pay for your care.

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**Percent of the Population without Health Insurance and Living in Poverty by Race: 2009**


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Check out “How Health Reform Helps Communities of Color in Arkansas.” This is one of 25 state summaries released by Families USA. The eight-page summary includes sections regarding access to coverage, assistance for minority-owned small businesses, funding for community health centers, workforce diversity, data collection and support of community health workers.
Public Health Fair

BLYTHEVILLE, ARKANSAS

SATURDAY, OCT. 23, 2010
10:00AM - 3:00PM
Public Health Fair

WHERE?
THE BOYS AND GIRLS CLUB
801 ELM STREET
BLYTHEVILLE, AR 72315
870.762.1788

FREE HEALTH SCREENINGS!
Blood pressure, glucose, cholesterol...and more

HEALTH INFORMATION PROVIDED BY MINORITY HEALTH VENDORS

FOR MORE INFORMATION, CALL
501.686.2720
1123 S. University, Ste. 312
Little Rock, Arkansas
arminorityhealth.com

Lunch provided by the Arkansas Minority Health Commission
Putting Your Tobacco Settlement Dollars to Work!

Idonia L. Trotter, JD, MPS, Executive Director
PLEASE JOIN THE SENATE SUBCOMMITTEE ON MINORITY HEALTH

SENATOR JACK CRUMBLY, CHAIR
SENATOR PERCY MALONE • SENATOR GILBERT BAKER • SENATOR TRACY STEELE • SENATOR RANDY LAVERTY

Legislative MEETING

BLYTHEVILLE, ARKANSAS

FRIDAY, OCT. 22, 2010

6:00PM - 8:00PM

THE BOYS AND GIRLS CLUB
801 ELM STREET
BLYTHEVILLE, AR 72315
870.762.1788

FOR MORE INFORMATION, CONTACT JUANITA WITHAM OR KIM BAXTER
501.682.1937

Bureau of Legislative Research
State Capitol Building
Little Rock, AR

Dinner Courtesy of the Arkansas Minority Health Commission

ATTENDEES WILL BE PROVIDED:

• A synopsis of public health concerns expressed by citizens living in counties where life expectancy at birth based on death data shows that minorities die 10 years earlier than non-minority citizens.
• Demographic snapshot of minority Arkansans (including Health Screening data) living in counties where minorities are expected to die 10 years earlier.
• Legislation passed in the 2009 Session that will impact public health.

ATTENDEES ARE ASKED TO PROVIDE THEIR VIEWS ON:

• Next Steps
• Services Needed
• Use of Existing Services
• Gaps in Service
Black AIDS Institute Testing Tour in Arkansas
November 11, 12 and 13
For more information call Patricia Minor at 501-686-2720

Now available!
Request your copy today!