



Newborn Screening Section CY2020 Annual Report

Submitted by collaborated team of:

- **Pat Purifoy, RN NBS Manager**
- **Jomeka Edwards, M.S.N.S. NBS Lab Manager**
- **Leslie Himstedt, BSMT (ASCP) Clinical/Biological Branch Chief**
- **Wanda Simon, Sr. Epidemiologist**

Introduction

Newborn screening for inborn conditions has been mandatory in Arkansas since Act 192 of 1967 stipulated screening of all newborns for phenylketonuria. Since that time, the number of conditions screened for has grown substantially. The program oversees follow-up on 30+ genetic disorders screened using the blood spot card in addition to two point of care tests, hearing screen and critical congenital heart disease, for a total of 34 core disorders. In 2020, ninety-eight-point three percent (98.3%) of the approximately 34,259 babies born in Arkansas each year are screened for genetic disorders.

Reports

Several reports are prepared throughout the year and shared with stakeholders.

Newborn Screening Quality Improvement (QI) Graph: Three key data points are monitored monthly: time of birth to time of collection, time of collection to time of receipt in the lab and time of receipt to time of reporting results. Data is provided to ADH Health Statistics representative for compilation. The combined goal for all three data points is less than 168 hours.

NBS QI project:

The Public Health Lab and Newborn Screening Managers work diligently and continue to monitor monthly timeliness of data at three points during the process: date of birth to specimen collection, collection to receipt in the lab and receipt to reporting of test results. Time is measured in hours and a goal of less than 168 hours (7 days) from birth to reporting of test results was set. ***The 2020 report indicated the average was 153.2 hours.*** This factor plays an important part by assisting the NBS Nurse educator in scheduling ZOOM or conference calls with the birthing hospitals that have the strongest need to meet the < 168 hours goal.

The program provides support to partner hospitals with virtual education opportunities and technical assistance to ensure effective collection to receipt in the lab for processing. We will continue to internally monitor monthly timeliness data at three points: date of birth to specimen collection, collection to receipt in the lab, and receipt to reporting results to ensure birth to reporting continues to meet the goal of < 168 hours (< 7 days).

Yearly Comparison Report:

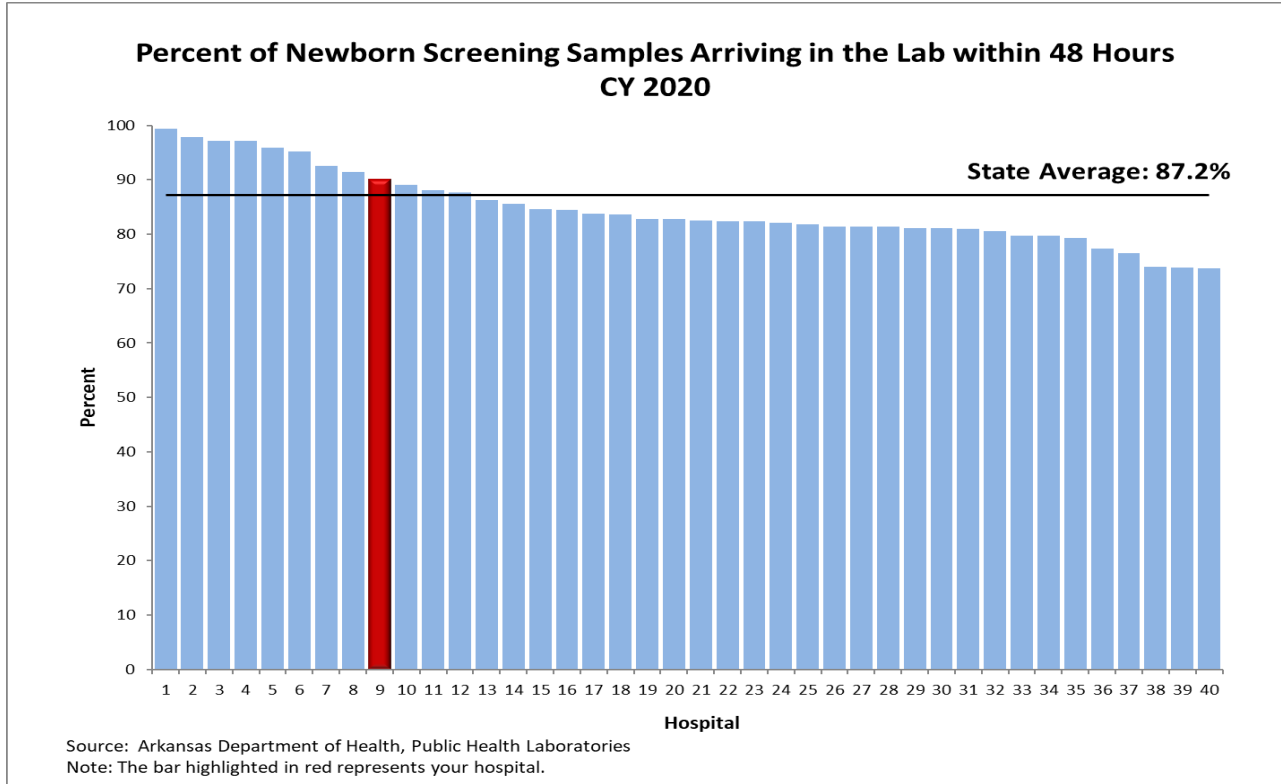


Figure 1

As illustrated in Figure 1: A yearly comparison graph in addition to the quarterly reports, represent all 40 facilities is distributed. This anonymized bar graph report shows placement among peers, with the specific hospital's bar in red, along with the average submission for the state.

Quarterly report: (January/April/July/October)

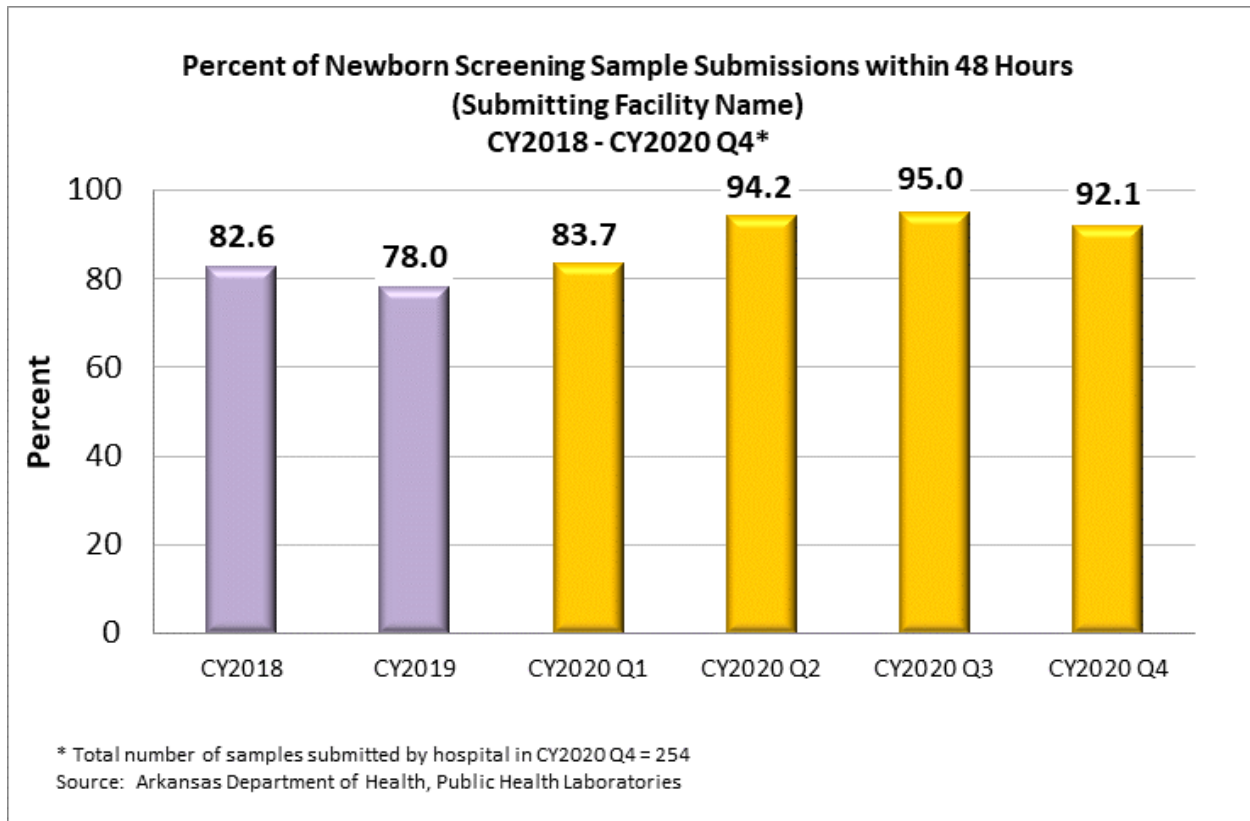


Figure 2

Figure 2 illustrates an example of the quarterly report sent to the hospital administrators, lab and Nursery/NICU managers at each birthing facility and Arkansas Children’s Hospital (ACH).

Each birthing facility receives a quarterly Hospital Timeliness Report to identify the number of specimens collected and received by the NBS lab within 48 hours of collection. Any facility that does not meet the goal of 80% of specimens reaching the lab with 48 hours is contacted to discuss potential issues related to timely specimen submission. ***At the end of 2020, a yearly comparison report of all birthing facilities had an average of 87.2%.***

The data for the birthing facilities and Arkansas Children’s Hospital are also monitored monthly. Data is compiled by the NBS lab manager and submitted to the AR State Genetic Nurse Coordinator/Hospital educator for use in outreach to the facility when needed. Any facility that does not meet the goal of 80% of the specimens reaching the lab within 48 hours is contacted to discuss any issues related to timely specimen submission.

Newborn Screening 2020 confirmed cases

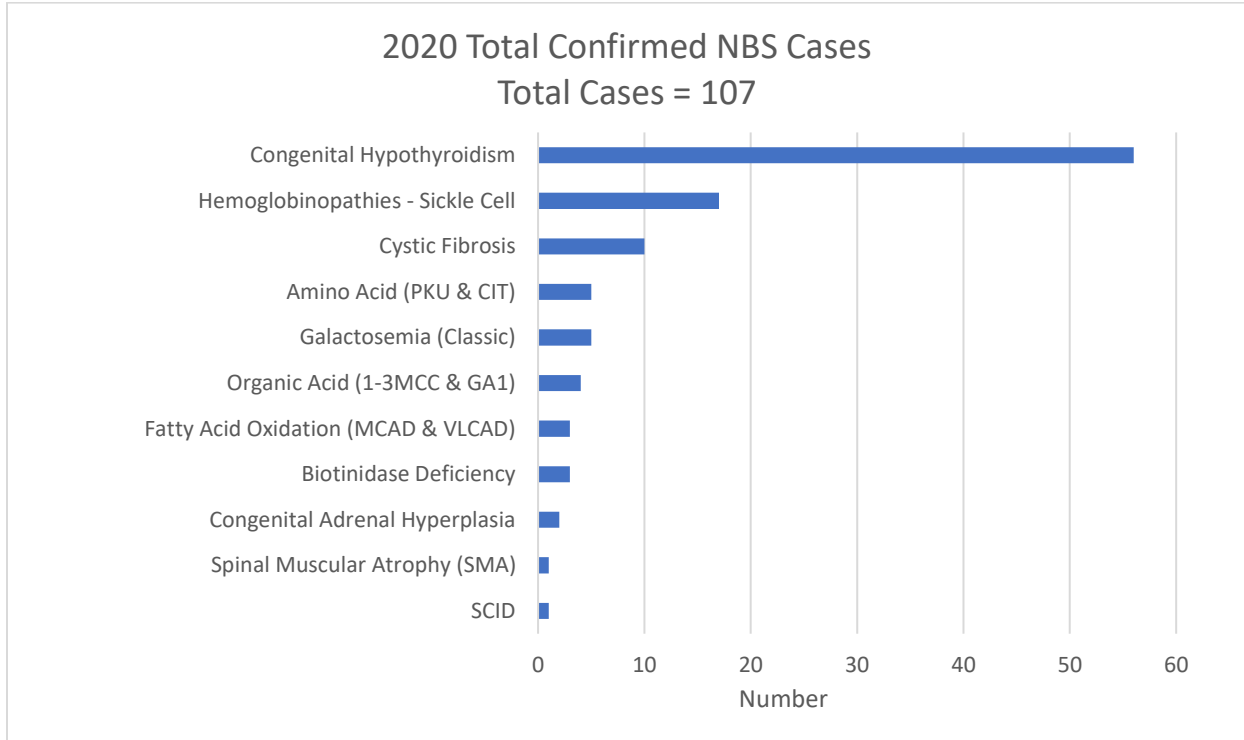


Figure 3

In Figure 3 illustrates the breakdown of the 2020 (107) total number of confirmed cases ranging from the most to the least cases. Congenital Hypothyroidism (56 cases) was the leading category with Severe Combined Immune Deficiency (SCID) and Spinal Muscular Atrophy (SMA) being the least at 1 case for each category.

Disorders/Categories

Biotinidase Deficiency = **3**

Congenital Adrenal Hyperplasia = **2**

Congenital Hypothyroidism = **56**

Cystic Fibrosis = **10**

Galactosemia (classical) = **5**

Hemoglobinopathies = **17** Sickle cell

SCID = **1**

Fatty Acid Oxidation = **3** (2-MCAD & 1 VLCAD), Amino Acid = **5** (4 PKU & 1 CIT) & Organic Acid = **4** (3 1-3MCC & 1 GA1) Disorders

SMA---added March 23, 2020 = **1**

Breakdown for number of tests performed:

Total number of tests from Jan. 1, 2020 - March 23, 2020 involved eight (8) categories. In March 2020, the total number of tests increased to nine (9) categories due to the addition of Spinal Muscular Atrophy (SMA) to the testing panel.

1. Total number of births by occurrence: **34,259**
2. Total number of samples received for CY2020: **39,058**
3. Total number of tests performed for CY2020: **370,145**
4. Total Number of births receiving at least one screen - with samples rejected: **33,683**
5. Total Number of births receiving at least one screen - without samples rejected: **33,597**
6. Data source year: **2020**
7. Number of presumptive positive, indeterminate, or inconclusive screens (on any screen – initial or repeat): **10,021**
8. Number confirmed cases: **107**
9. Number referred for treatment: **107**

Note: 10,021 cases were the total number of cases which involved extensive follow-up by the NBS nurses until cases were resolved.

NBS Lab and Follow-Up affected by COVID-19-: Challenges and Strategies:

COVID-19 created several challenges for NBS Lab personnel and Follow-up Nurses.

NBS Lab:

- Staffing cut by 50%
 - Three staff members were sent home for 12-16 weeks based on CDC high-risk guidelines.
 - One staff member re-assigned to assist in another lab.
- Remaining staff ensured all processing and testing duties were covered.
-

NBS Follow-Up:

- While some staff were reassigned to COVID-19 duties, the remaining staff members absorbed additional NBS duties. Increased caseloads resulted in extended workdays.
- Staffing challenges were also due to personnel becoming ill from COVID-19, exposure to the virus, or living with a person(s) who were deemed high risk.
- Staff who were isolated, but not ill, worked from home.
- Equipment and access to programs were needed to meet the challenges:
 - Laptops purchased prior to COVID-19 and were used while working remotely.
 - Communication was enabled through utilizing Virtual Private Network (VPN).
 - Agency cell phones were utilized.
 - ZOOM meeting weekly with staff or as needed.

- NBS nurses were prepared to work remotely using the NBS protocol guide which includes contact information for PCP, birthing facilities, and Licensed Lay Midwives.

The Lab and Follow-Up managers operated together to ensure NBS cases were processed, and protocol was followed.

NBS 2020 Saturday call cases:

October 2014 the ADH Lab began Saturday hours to prevent delays in testing follow-up exceeding 48 hours from collection. A total of **88** critical cases were identified during the Saturday call in 2020.

May 2020 presented the largest number of critical cases (12) identified on Saturdays. Figure 4 illustrates the number of critical cases reported on Saturday in 2020:

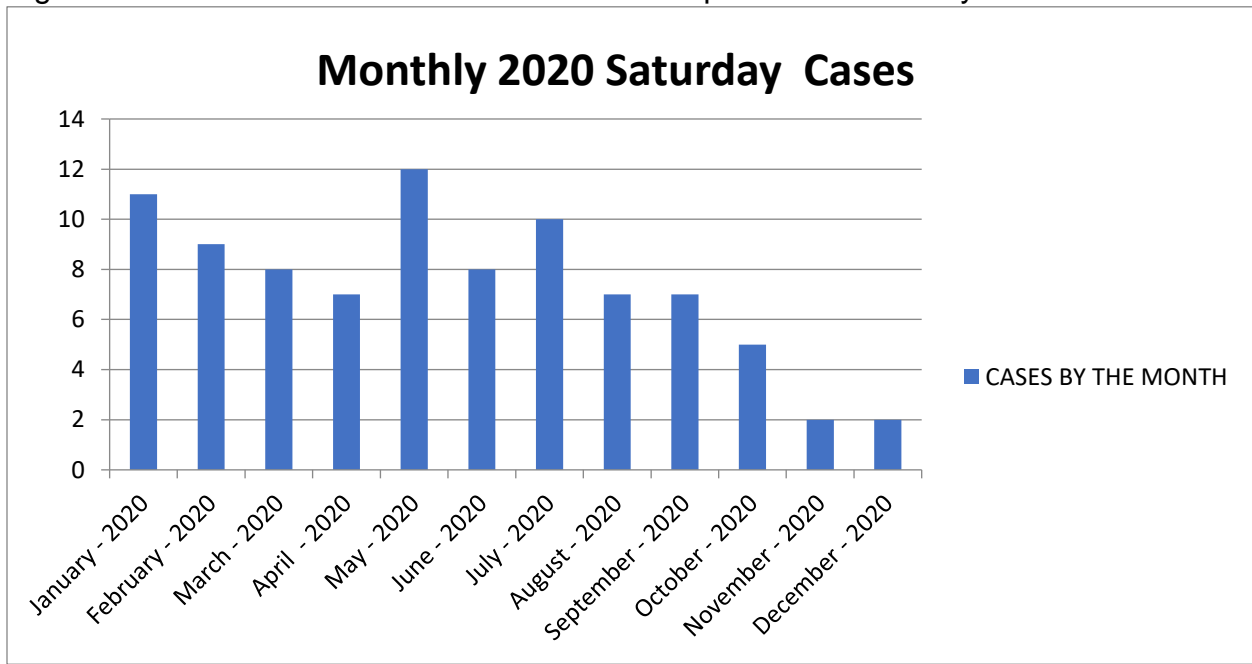


Figure 4

January = 11 cases
 February = 9 cases
 March = 8 cases
 April = 7 cases
 May = 12 cases
 June = 8 cases
 July 10 cases
 August = 7 cases
 September = 7 cases
 October = 5 cases
 November = 2 cases
 December = 2 cases

NBS Education: on-line courses/list Course available on TRAIN:

- AR NBS-protecting Babies Through a Simple Test: Course #1053880 (1.5 contact hrs.)
- Medical Aspects of NBS: Course #1075665 (2.0 contact hrs.)
- Introduction to CAH: Course# 1076702 (2.0 contact hrs.)
- CCHD Screening in Arkansas: Course #1087269 (2.0 contact hrs.)
- ERAVE Enduring for Hospital Users: Course #1086116 (2.0 contact hrs.)-**NOTE this course is taken after the learner has trained on site with the hospital trainer).**
- ERAVE Enduring for Hospital Users (**LIVE**)Course # **1087154** (2.0 contact hours)-**NOTE this course is taken after the learner has attended a LIVE training (ZOOM or face to face) with Traci Massery, ADH ERAVE trainer.**

Educational upcoming on-line courses in the future:

- Introduction to SMA (Spinal Muscular Atrophy) Enduring Course # 1091128 = 2.0 contact hrs.
- Introduction to X-ALD (X-Linked Adrenoleukodystrophy Disease) Enduring Course #1094925=2.0 contact hours

Education events attended:

- January 13th through 17th, 2020

Keri Lafferty, BSN/RN-NBS Nurse Coordinator was selected to attend “*Screening Tandem Mass Spectrometry Workshop for Follow-Up Staff*”. This was sponsored by NewSTEPS and Association of Public Health Laboratories and was the last LIVE educational course provided.

Education activities provided:

- March 26, 2020 (rescheduled to August 20, 2020):

Dr. Katie Seely-ADH/Public Health Laboratory Director, Leslie Himstedt-BSMT ADH/Lab Manager and Pat Purifoy, RN-ADH/NBS Follow-Up Manager presented a one hour continuing educational presentation at Grand Rounds (Virtual): “*AR NBS Process: Birth to Results*”. This presentation provided program specific information and data about the process of the NBS laboratory and Follow-up programs.

- April 17th, 2020 (rescheduled to August 7, 2020):

Pat Purifoy, RN NBS Manager presented: “*NBS-Good News for AR Babies*” at the Famous Family Bistro Virtual Conference for DHS. This presentation provided resources, networking, and program information specifically for parents or stakeholders. There was one educational contact hour awarded for presentation.

AR Licensed Lay Midwives (LLM):

The LLM requested the NBS program to schedule a face-to-face meeting to clarify the NBS process in Arkansas, discuss how the bordering states provided NBS follow up care, payment issues and verbalized a need of a resource guide. The meeting audience was made up of LLM, and Midwife students. The presenters were the NBS Follow up manager, Lab Manager, Infant Hearing manager and Women’s Health Program Nurse

facilitator. The meeting was scheduled for March 13th, 2020, at Fayetteville Library in Fayetteville, AR. Due to COVID-19-19, Governor Asa Hutchinson cancelled all face-to-face meeting and encouraged ZOOM/Virtual meeting. The NBS program offered to schedule a ZOOM meeting, but LLM preferred to have a meeting face-to-face.

In place of the face-to-face meeting, the NBS Team of nurses collaborated with the Women's Health Program Nurse Facilitator to develop a FAQ (frequent ask questions) resource guide to include all requested questions. The FAQ resource guide was implemented and distributed electronically or mail to all LLM. Currently, all new LLM receive a NBS Tool Kit which the FAQ resource guide is included.

Educational Material: Banner/50 years of NBS/Triple Threat Flyer

In 2020, NBS developed a NBS Banner and a Flyer for educational purposes. The goal is to provide parents, medical professionals, and all stakeholders with outreach material about the Arkansas Newborn Screening Program. This material is available on the ADH/NBS website, or by request and will be utilized in promotion setting like conferences, seminars, meetings, and health fairs.

<https://www.healthy.arkansas.gov/programs-services/topics/newborn-screening>

- NBS Banner: "Newborn Screening: Saves or Improves the Lives of Over 12,000 Babies a Year"
- Fact Sheet: "50 years of Saving Lives with Newborn Screening"
- Flyer: "Triple Threat of Newborn Screening"
- Note: After English version of Fact Sheet and Flyer is approved the Spanish version will follow protocol for content approval

APHL & NewSTEPs conferences were changed from live to virtual meeting due to COVID-19-19.

The APHL 2020 NBS & Genetic Testing Symposium was held in Des Moines, Iowa Events Center. The conference was changed to virtual educational sessions and was scheduled from Oct 18th through November 12th divided up into different days of the week and usually starting at 11am. During this time frame, NBS nurses were involved with COVID-19 contact tracing/investigating and working follow-up cases which prevented time to attend the virtual learning opportunities.

The NewSTEPs Short Term Follow-Up meeting was scheduled to be held in Seattle, Washington on May 12th, and 13th, 2020 but due to COVID-19 the meeting was cancelled.

AR Genetic Health Committee (AGHC):

Due to COVID-19, Dr. Brad Schaefer (NBS Medical Director) scheduled ZOOM meetings. The goal of this committee was to update the Arkansas State Genetics Plan (2021-2025).

Newborn Screening Plans for 2021:

In March 2020, Spinal Muscular Atrophy (SMA) disorder was added to the blood testing panel giving us a total 30 disorders along with Critical Congenital Heart Disease (CCHD) and hearing screening which is completed at the birthing facility. The plans to increase the blood testing panel within 2021 – 2022 by adding X-linked Adrenoleukodystrophy (X-ALD), Glycogen Storage Disease Type II (Pompe), and Mucopolysaccharidosis Type 1 (MPS-1).

The Arkansas NBS program prides itself in being consistent to meet the established mission and vision goals.

- **Mission:** To protect and improve the health and well-being of all infants, children, and youth in Arkansas.
- **Vision:** Infants, children and youth in Arkansas are healthy and reach full developmental and academic potential.

The Arkansas NBS program is constantly working to better serve Arkansas families and health professionals.

Arkansas Department of Health Newborn Screening Program

4815 W. Markham, Slot 17

Little Rock, AR 72205

Local: 501-280-4780

Toll Free: 1-866-769-9043

www.healthy.arkansas.gov