



# **Newborn Screening Section CY2022 Annual Report**

**Submitted by collaborated team of:**

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## Introduction

Newborn screening (NBS) 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 2022, ninety-eight-point seven percent (98.3%) of the approximately 35,070 babies born in Arkansas were 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 Public Health Lab and Newborn Screening managers work diligently and continue to monitor monthly timeliness of data at three key points. Time is measured in hours and a goal of less than 168 hours (7 days) from birth to reporting of test results was set.

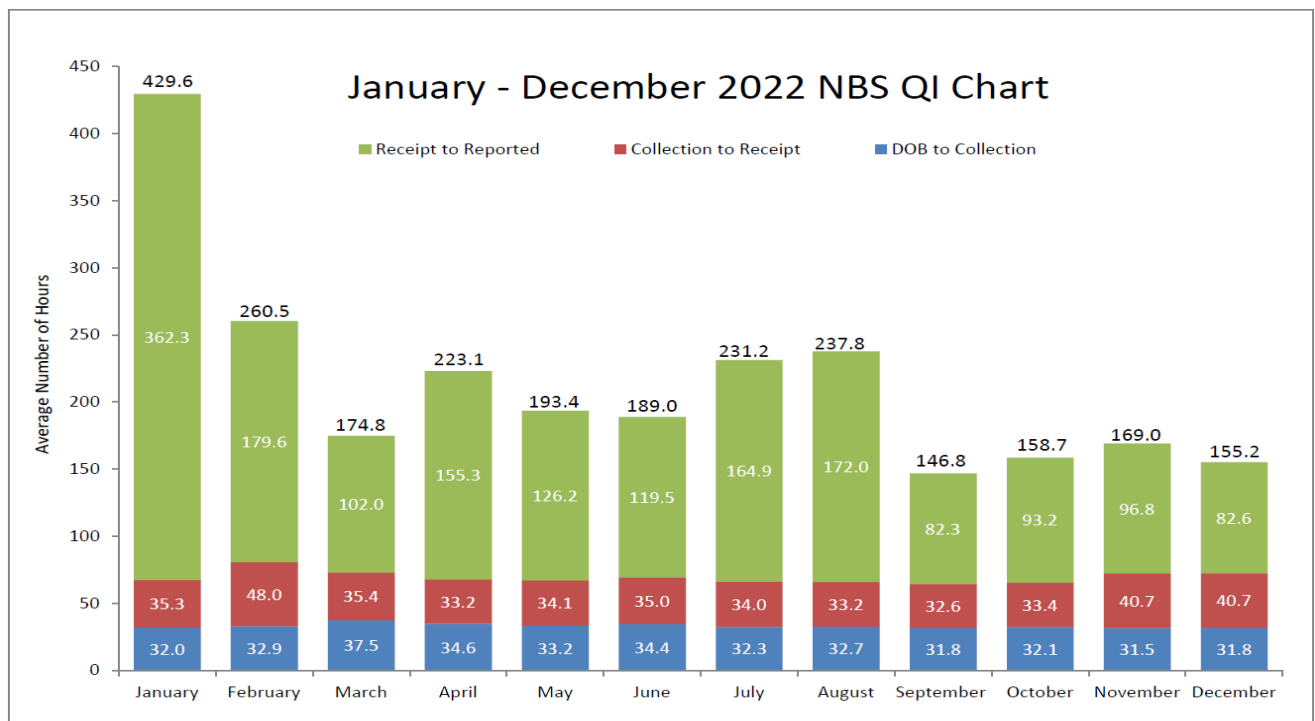
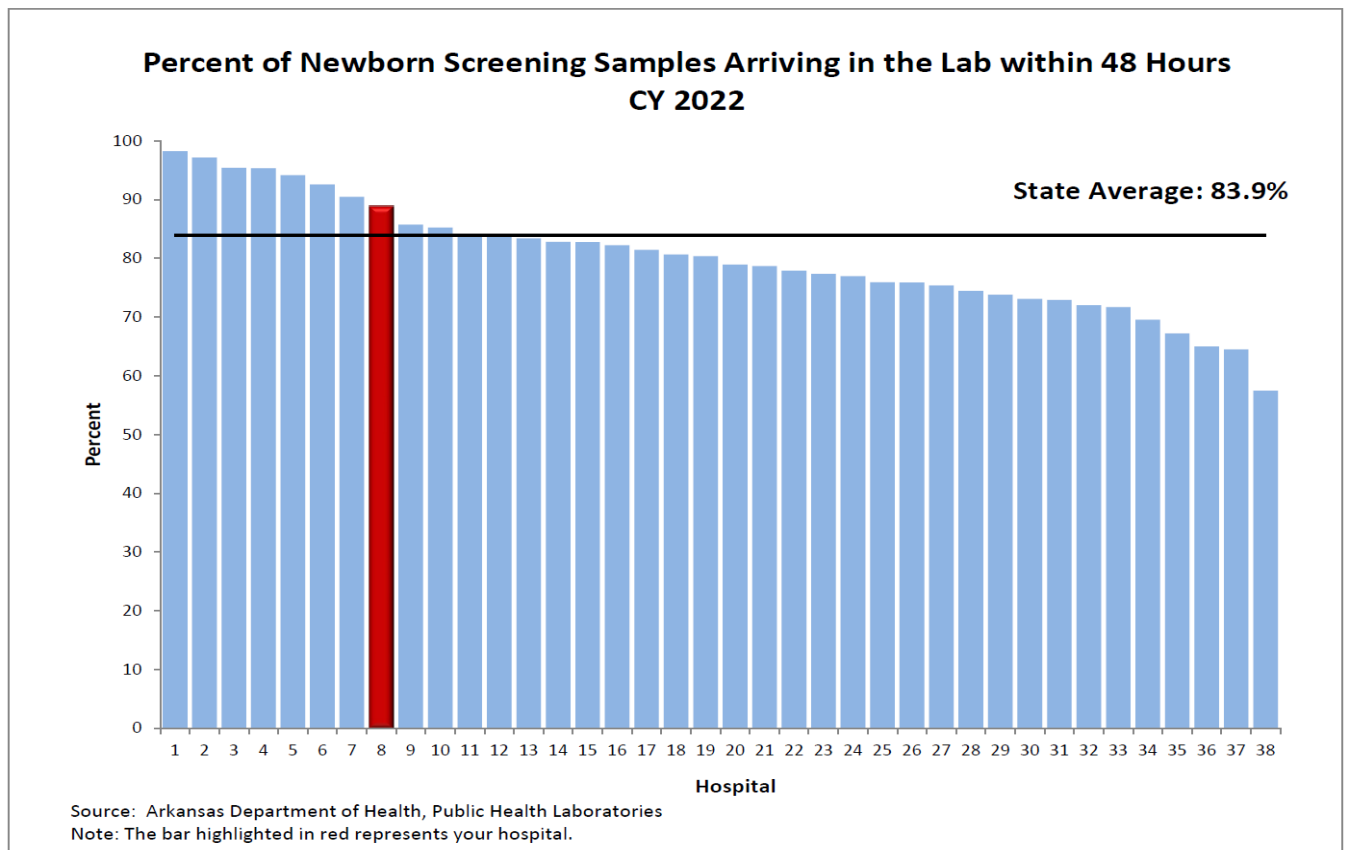


Figure 1

Figure 1 illustrates: The NBS QI 2022 report indicated the average number of hours that elapsed from birth to reporting of NBS results was 214.1 hours. The factors that contributed to the increase NBS QI 2022 hours was due to various lab equipment issues as well as numerous vendor kit assay failures. The lab experienced equipment issues involving MSMS (Tandem Mass Spectrometry (MSMS): Fatty, Organic, Amino Acids, X-ALD. PerkinElmer, the vendor for the Arkansas Public Health Lab worked to resolve these issues. Arkansas and PerkinElmer Genetics worked in partnership to complete testing of these disorders. During this time frame, the Arkansas NBS Lab and Follow-up managers developed a protocol/process with PerkinElmer Genetics to receive critical results in a timely manner.

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.

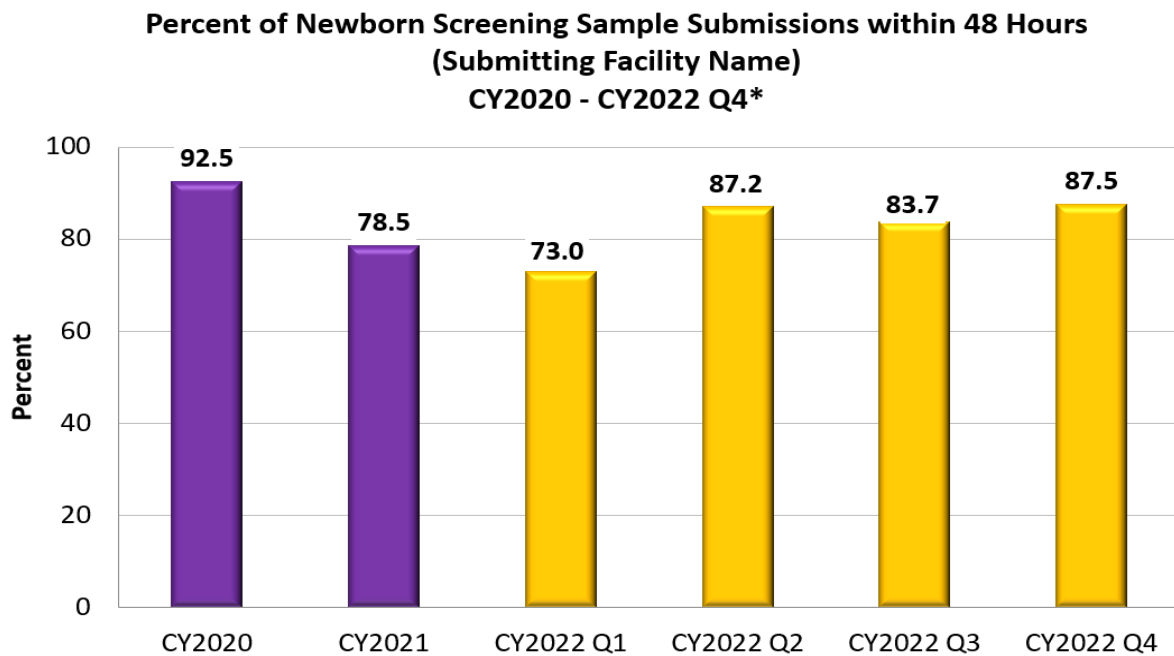
**Yearly 2022 Comparison Report:**



**Figure 2**

Figure 2 illustrates a yearly comparison graph in addition to the quarterly reports, representing all 38 facilities are 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.

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. These sessions are conducted via ZOOM which has the capability to involve responsible parties at the birthing facility along with ADH NBS Follow-up Manager and AR State Genetics Coordinator. **At the end of 2022, a yearly comparison report of all birthing facilities had an average of 83.9%.**



\* Total number of samples submitted by hospital in CY2022 Q4 = 32  
Source: Arkansas Department of Health, Public Health Laboratories

**Figure 3**

Figure 3 illustrates an example of the quarterly report sent to the hospital administrators, lab, and Nursery/Nursery Intensive Care (NICU) managers at each birthing facility and Arkansas Children’s Hospital (ACH).

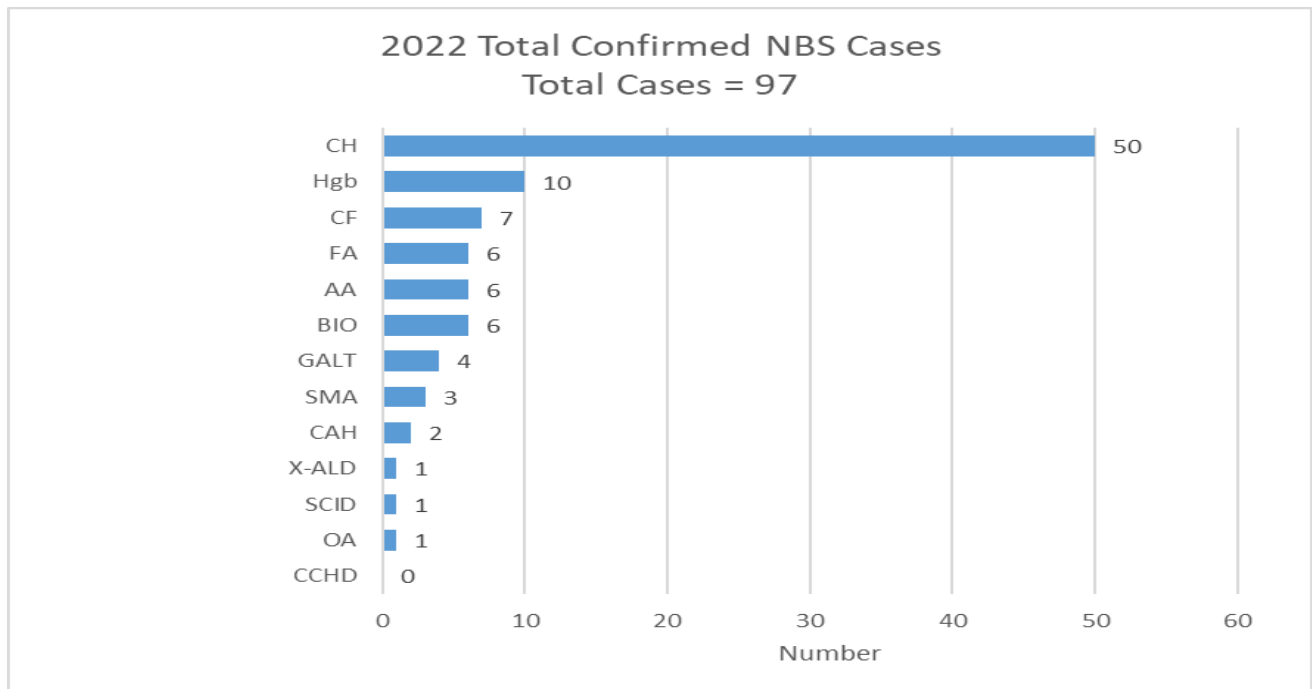


Figure 4

Figure 4 illustrates the breakdown of the 2022 total number of confirmed cases ranging from the most to the least cases. Congenital Hypothyroidism (50 cases) was the leading category with Organic Acid, Severe Combined Immune Deficiency (SCID), X-linked adrenoleukodystrophy (X-ALD), and Spinal Muscular Atrophy (SMA) being the least at 1 case for each category. There were **97** confirmed cases in 2022.

### 2022 Disorders/Categories

- Biotinidase Deficiency = **6**
- Congenital Adrenal Hyperplasia = **2**
- Congenital Hypothyroidism = **50**
- Cystic Fibrosis = **7**
- Galactosemia (classical) = **4**
- Hemoglobinopathies = **10** Sickle cell
- SCID = **1**
- SMA = **3** and 1 SMA carrier
- Fatty Acid Oxidation = **6** (4-MCAD & 2 VLCAD)
- Amino Acid = **6** (4 PKU & 2 CIT)
- Organic Acid = **1**(1 GA1) Disorders
- X-linked adrenoleukodystrophy (X-ALD) = **1**

Critical Congenital Heart Disease (CCHD) = **0**

*\*CCHD test is completed at the birthing facility via pulse oximetry and recorded in the birthing record (ERAVE). NBS Follow-up program monitors/reports the positive cases.*

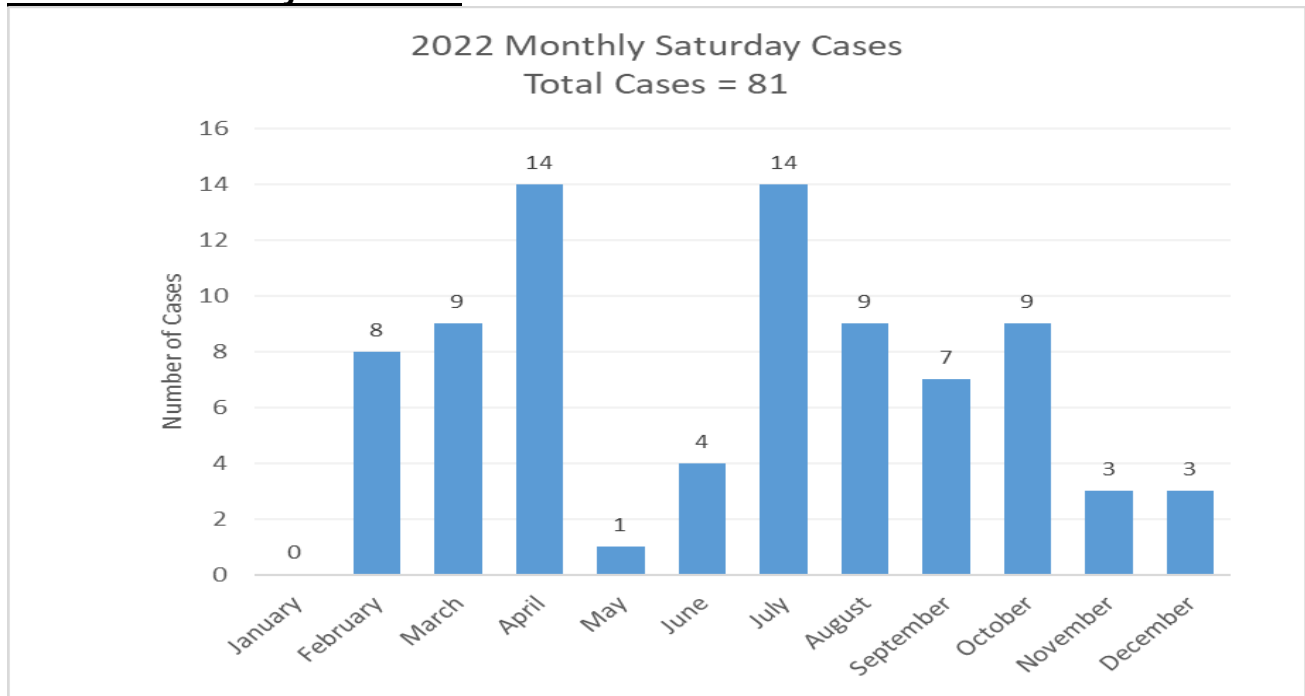
**Breakdown for number of tests performed:**

Total number of tests from Jan. 1, 2022 – Dec. 31, 2022, the total number of tests are nine (9) categories due to the addition of Spinal Muscular Atrophy (SMA) to the testing panel.

1. Total number of births by occurrence: **35,070**
2. Total number of samples received for CY2022: **38,676**
3. Total number of tests performed for CY2022: **348,084**
4. Total Number of births receiving at least one screen - with samples rejected: **34,358**
5. Total Number of births receiving at least one screen - without samples rejected: **34,270**
6. Data source year: **2022**
7. Number of presumptive positive, indeterminate, or inconclusive screens (on any screen – initial or repeat): **7,406**
8. Number confirmed cases: **97**
9. Number referred for treatment: **97**

***Note: 7,406 newborn screens involved extensive follow-up by the NBS nurses until cases were resolved.***

**NBS 2022 Saturday call cases:**



**Figure 5**

Figure 5 illustrates the number of 2022 critical cases reported on Saturday:

April and July 2022 represented the largest number of critical cases per month with 14 identified on Saturdays.

January = 0 cases  
February = 8 cases  
March = 9 cases  
April = 14 cases  
May = 1 cases  
June = 4 cases  
July = 14 cases  
August = 9 cases  
September = 7 cases  
October = 9 cases  
November = 3 cases  
December = 3 cases

**NBS Education: on-line courses 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.**
- 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.

Educational upcoming on-line courses:

- Introduction to Galactosemics (GALT)
- Introduction to Mucopolysaccharidosis Type 1 (MPS-1)
- Introduction to Pompe

**NBS ADH Pediatrician:**

Dr. Steven Schexnayder, Professor of Pediatrics, and Internal Medicine, Executive Vice Chair, Dept. of Pediatrics at UAMS College of Medicine Chief, Critical Care Medicine, at Arkansas Children's Hospital joined Arkansas Department of Health as the Medical Director of Child and Adolescent Health.

**Medical Professional and Educational events presented and/or attended:**

Title:	<a href="#">Heartland NBS Marshallese Video</a>
Author(s)/Organization(s):	<a href="#">Heartland Regional Genetics Network</a>
Meeting/Conference Name:	
Year Presented:	<a href="#">3/28/22</a>
Media Type:	<a href="#">Video available on ADH website</a>
Target Audience:	<a href="#">Medical professional, stakeholders &amp; parents</a>
To obtain copies (URL or email):	<a href="https://healthy.arkansas.gov/programs-services/topics/newborn-screening">Healthy.arkansas.gov/programs-services/topics/newborn screening</a>
Keyword	<a href="#">NBS for Marshallese</a>
Status	<a href="#">current</a>
Action	<a href="#">To provide NBS education opportunity for a proximally 15,000 Marshallese in AR</a>

Title:	<a href="#">“Disproportional Transient C3 elevation on Marshallese NBS: What do this mean?”</a>
Author(s)/Organization(s):	<a href="#">Dr. Laura Hays, PhD/APRN (UAMS/ACH NBS consultant)</a>
Meeting/Conference Name:	<a href="#">Heartland Quarterly meeting</a>
Year Presented:	<a href="#">05/06/22</a>
Media Type:	<a href="#">ZOOM live</a>
Target Audience:	<a href="#">NBS medical professionals</a>
To obtain copies (URL or email):	
Keyword	<a href="#">C3 (Elevated Acylcarnitine) Organic Acid-NBS test panel disorder</a>
Status	
Action	<a href="#">To increase awareness &amp; educate about C3 on Marshallese population.</a>



Title:	Medical survey on Sickle Cell trait & disease
Author(s)/Organization(s):	Dr. Rakhi Nail, MD, MHS @ John Hopkins School of Medicine
Meeting/Conference Name:	ZOOM
Year Presented:	06/14/22
Media Type:	Live Survey-50 questions-taken & discussed results @ later date
Target Audience:	NBS medical professionals (Pat Purifoy, RN NBS Manager, Ruby Moore RN, AR State Genetic/NBS nurse Coordinator
To obtain copies (URL or email):	
Keyword	Sickle cell
Status	
Action	Compare all states protocol/process, & review of educational tools

Title:	ZOOM meeting: Sickle Cell protocol, process, share AR educational tools & discussed family involvement.
Author(s)/Organization(s):	Dr. Shannon Phillips, University of South Carolina 7 grad. DNP student Najibah Galandanci from Nigeria
Meeting/Conference Name:	Completing graduate research studies in Sickle Cell
Year Presented:	06/06/22
Media Type:	ZOOM-live
Target Audience:	NBS Nurses that are involved in Sickle cell
To obtain copies (URL or email):	
Keyword	Sickle cell
Status	
Action	Provide sickle cell experience/brainstorming ideas utilized

Title:	ASTHO video made (Association of State & Territorial Officers)
Author(s)/Organization(s):	ASTHO
Meeting/Conference Name:	I was asked to participate in a taping session (video) which included 20 nurses throughout ADH featuring Sherian Kwanisai, RNP/MPH, Director Center of Local Public Health. Questions with discussion were asked to the nurses in the audience for an response.
Year Presented:	06/15/22
Media Type:	video
Target Audience:	Public Health professionals
To obtain copies (URL or email):	
Keyword	Nursing duties in public health
Status	
Action	

Title:	AR Family Practice Scientific Assembly
Author(s)/Organization(s):	Kim Scott, Infant Hearing Program (IHP) Section Chief Pat Purifoy, RN Newborn Screening (NBS) Manager
Meeting/Conference Name:	Conference
Year Presented:	08/03/22-08/06/22
Media Type:	In person (exhibit booth)
Target Audience:	AR family practice doctors
To obtain copies (URL or email):	
Keyword	IHP & NBS
Status	
Action	Provided IHP & NBS programmatic data, examples of education tools available to medical professional

Title:	APHL Newborn Screening Symposium LIVE/VIRTUAL
Author(s)/Organization(s):	Board of conference: APHL
Meeting/Conference Name:	APHL Newborn Screening Symposium LIVE/VIRTUAL
Year Presented:	10/16/22 – 10/20/22
Media Type:	LIVE-Tacoma, Washington or Virtual
Target Audience:	Medical professional in NBS & Genetics
To obtain copies (URL or email):	
Keyword	NBS or Genetics
Status	
Action	Jennifer Simmons, BSN/RN & Andrea Kingsley, RN/MBA attended symposium virtual

Title:	NBS & IHP Programs—Heel/Heart/Hearing: “The Triple Threat”
Author(s)/Organization(s):	Pat Purifoy, RN NBS Manager Kim Scott, MSHS/CHES Child Health Section Chief
Meeting/Conference Name:	2022 ADH LHU Administrator & Regional Manager’s meeting
Year Presented:	10/20/22 – 10/21/22
Media Type:	LIVE
Target Audience:	ADH LHU Administrator, Regional Manager & LHU staff
To obtain copies (URL or email):	
Keyword	NBS & IHP
Status	
Action	Provided updated review & education about IHP & NBS

Title:	Social Media Campaign for Safe Sleep
Author(s)/Organization(s):	Andrea Kingsley, RN/MBA NBS Nurse Coordinator/Chairperson of Safe Sleep (MCH Block Grant)
Meeting/Conference Name:	Presentation by Andrea Kingsley, RN/MBA @ the Maternal/Child Specialist meeting
Year Presented:	10/21/22
Media Type:	ZOOM-live
Target Audience:	Stakeholders on the MCH Block Grant/Safe Sleep
To obtain copies (URL or email):	
Keyword	Safe Sleep
Status	
Action	Governor Proclamation Safe Sleep 5 Phases of Project management: <ul style="list-style-type: none"> <li>• conception/initiation</li> <li>• definition/ planning</li> <li>• implementation/execution</li> <li>• control/management</li> <li>• closeout/documentation</li> </ul>

Title:	UAMS Head Start/Early Head Start Health Service & Education Advisory Committee
Author(s)/Organization(s):	UAMS Early Head Start
Meeting/Conference Name:	The following NBS nurses were asked to service on the Advisory Board: Tanja Brown, LPN II-Asst. NBS Nurse Coord. /Outreach Pat Purifoy, RN NBS Manager
Year Presented:	10/25/22-started
Media Type:	Quarterly meeting
Target Audience:	Program professionals involved in Head start programs (Medical, Dental, Nutrition, Disabilities, Mental health & Education)
To obtain copies (URL or email):	
Keyword	Head Start
Status	Medical, Dental, Nutrition, Disabilities, Mental health & Education
Action	Provide resources for families

**Educational Material:**

In March 2022, Heartland Genetic Collaborative's Marshallese Newborn Screening Video was developed for educational purposes. The goal is to provide parents, medical professionals, and all stakeholders with outreach material in Marshallese 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>

**Newborn Screening Workgroup (NBS WG):**

The NBS WG schedules quarterly (Virtual/ZOOM) meeting on the 4<sup>th</sup> Tuesday every quarter. The meeting dates were: 01/25/22, 04/26/22, 07/26/22 and 10/25/22.

Chairperson

- Barbara Holcombe, BSN/RN, ADH/ACH NBS Liaison Nurse.

Co-Chairperson

- Mary Francis Dooley, BSN/RN, RNC-NIC, UAMS College of Nursing/ACH NICU

Purpose:

- Provides an opportunity for the AR Dept. of Health/NBS lab, Follow-up program and AR Children's Hospital NBS staff and medical consultants to discuss, update, educate and share information that affects outcomes of the newborn screening process.

**AR Genetic Health Committee (AGHC):**

The AGHC meet quarterly (Virtual/Zoom) on the 2<sup>nd</sup> Thursday every quarter. The meeting dates were: 01/13/22, 04/14/22, 07/14/22 and 10/13/22.

Chairperson

- Dr. Brad Schaefer, AR NBS Medical Director. At the July meeting, Dr. Schaefer nominated Dr. Laura Hays, PhD/APRN to transition as the new Chairperson. Dr. Hays was voted in unanimously.

Co-Chairperson

- Ruby Moore, RN/AR State Genetic and NBS Nurse Coordinator.

Purpose:

- Develop/update the Arkansas State Genetics Plan. The Arkansas State Genetics Plan is a five-year plan for implementation and monitoring of genetics services in Arkansas. In January 2022, the AGHC five-year final strategic plan was drafted, reviewed, and approved to implement.

**Newborn Screening Plans for 2023:**

The plans to increase the blood testing panel in 2023 include adding the following disorders: 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.

- 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

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