



Newborn Screening Section CY2024 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 has grown substantially. The program oversees follow-up on 30+ genetic conditions 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 35 core conditions.

The NBS Program is located within the Family Health Branch and under the Division for Health Advancement of the Arkansas Department of Health (ADH). The NBS Lab and Program's normal working hours are Monday – Friday from 8am – 4:30pm. The NBS Program nurses work alterative hours from 7am – 6pm on Monday – Friday. On Saturdays and holidays the NBS Lab and Program nurses provide coverage for emergent cases.

- How many are served by the NBS program?

In 2024, ninety-four-point seven percent (94.7%) of approximately 34,343 babies born in Arkansas were screened for genetic disorders.

- How is the NBS program funded?

The NBS program is funded by newborn screening fees, billed at \$131 per specimen.

- How are services provided?

The NBS program is responsible for providing follow up actions for abnormal, borderline, inconclusive or indeterminate screening results for inborn conditions. ADH NBS program collaborates with Arkansas Children's Hospital (ACH) medical consultants to develop and implement NBS condition protocols.

Reports

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

Newborn Screening Quality Improvement (QI) Graph: The Public Health Lab and the Newborn Screening Manager work diligently to monitor the monthly timeliness of data. The three key data points are: time of birth to time of collection, time of collection to time of receipt in the lab and time of receipt in the lab to time of reporting all 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. Data is provided to an ADH Health Statistics representative for compilation.

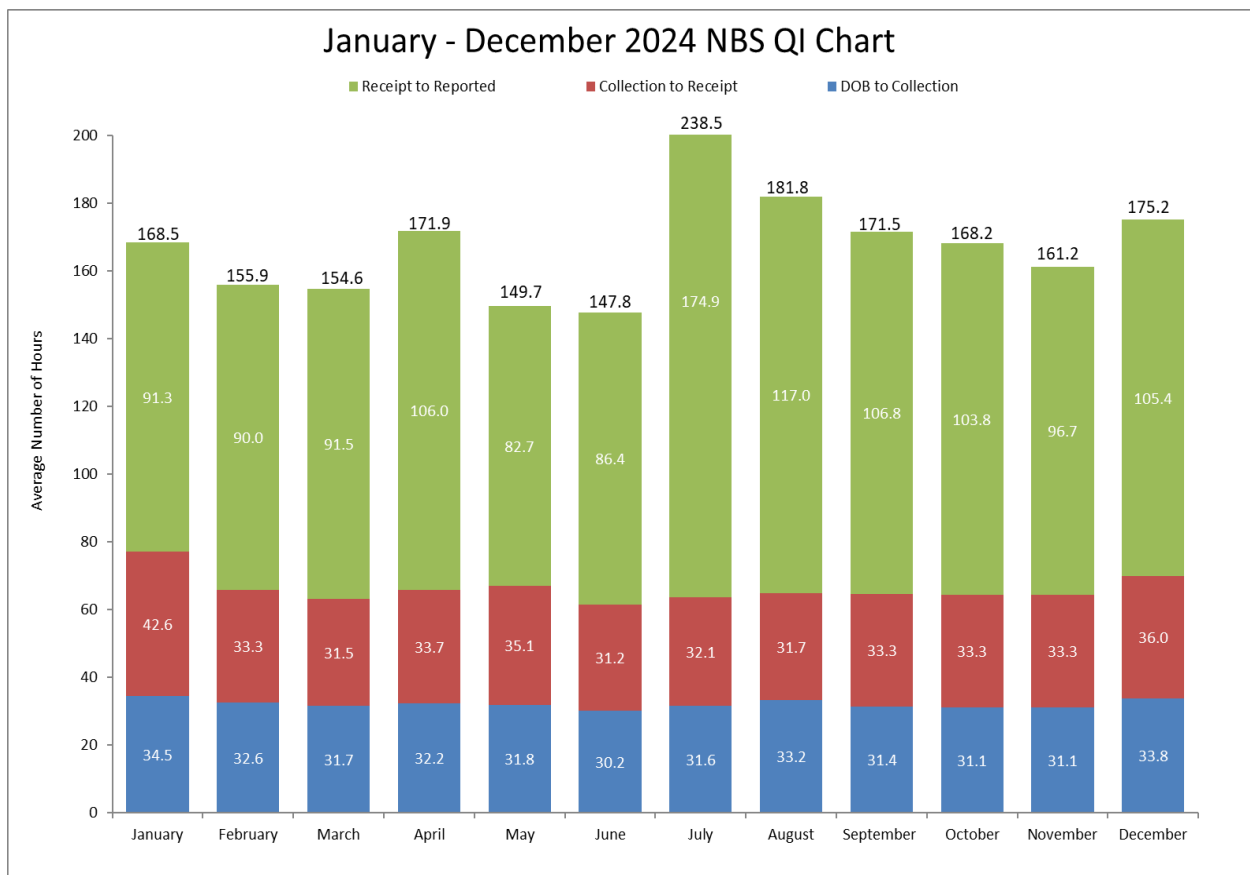
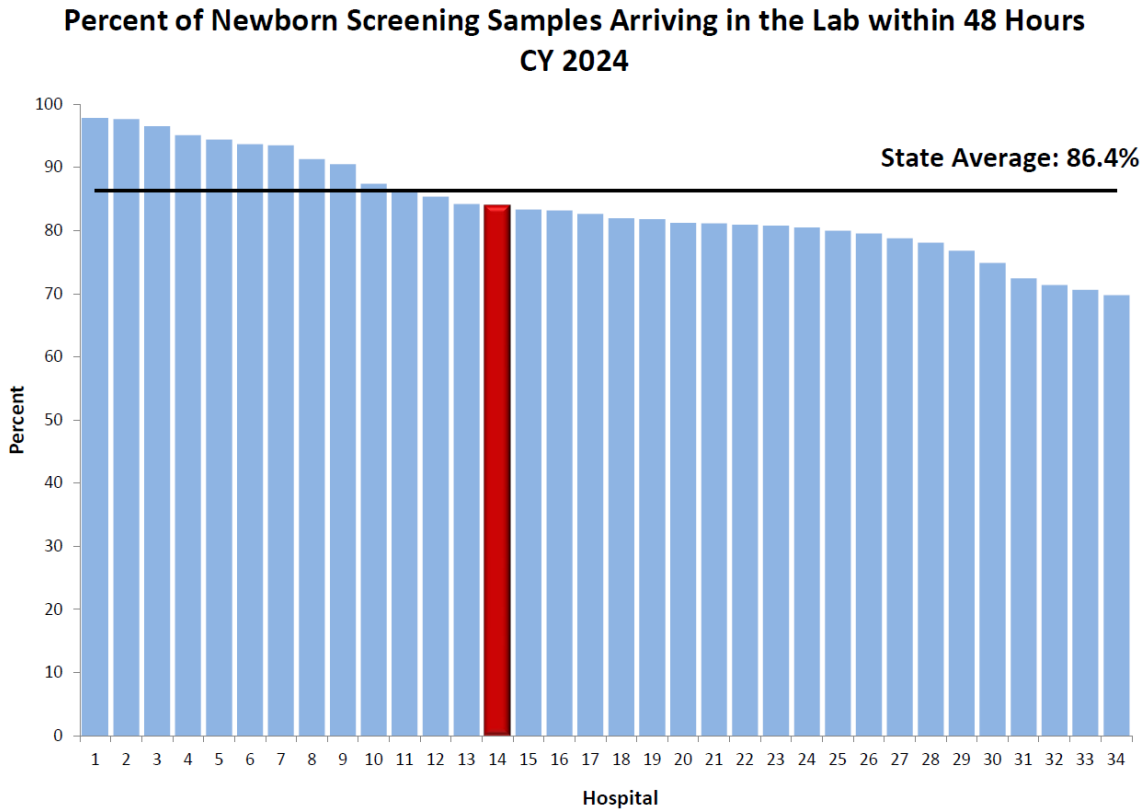


Figure 1

Figure 1 illustrates the NBS QI 2024 report, indicating the number of hours that elapsed from birth to reporting of results. The average time is calculated to be 172 hours which is just over our target goal of 168 hours. The NBS lab identified several factors that contributed to our increased reporting time for FY2024 including disruption in operations related to instrument failure and samples that were outsourced for testing causing time delays before final report. An additional factor was the implementation and validation of a new database with one hospital going live on electronic submission. Collaborative efforts with vendors and the implementation of protocols have expedited critical result reporting and improved coordination with birthing hospitals.

Yearly 2024 Comparison Report:

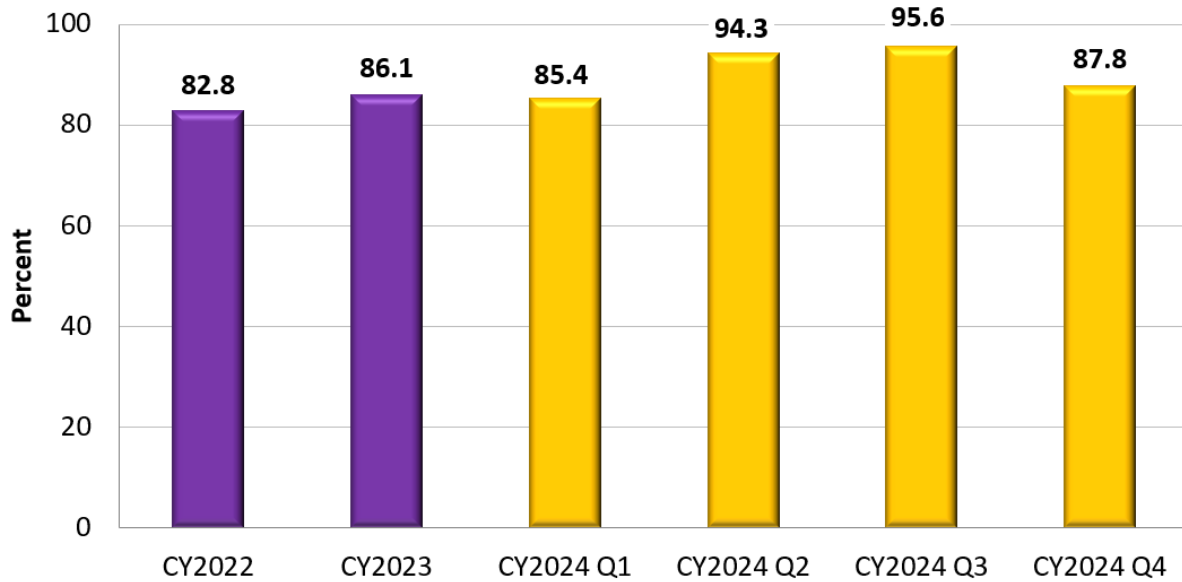


Source: Arkansas Department of Health, Public Health Laboratories
Note: The bar highlighted in red represents your hospital.

Figure 2

Figure 2 illustrates a yearly comparison graph, sent in addition to the quarterly report example shown in Figure 3, representing 33 birthing hospitals plus Arkansas Children’s Hospital. 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.

**Percent of Newborn Screening Sample Submissions within 48 Hours
{name of submitting hospital}
CY2022 - CY2024 Q4***



* Total number of samples submitted by hospital in CY2024 Q4 = 41
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 Intensive Care (NICU) managers at each birthing hospital and Arkansas Children’s Hospital (ACH).

Each birthing hospital 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 birthing hospital 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. The ADH NBS Program Nurse Manager offers to all facilities or persons educational or troubleshooting sessions via ZOOM to assist in resolving issues. **At the end of 2024, the yearly comparison report of all birthing facilities and Arkansas Children’s Hospital had an average of 86.4% which exceeds the 80% goal.**

The NBS Lab and Program Nurse Manager began internally monitoring timeliness and NBS QI projects monthly in 2017. This action seems to assist birthing hospitals and submitters with early solutions before receiving the quarterly reports. The NBS lab and Program Nurse Manager continue this practice currently.

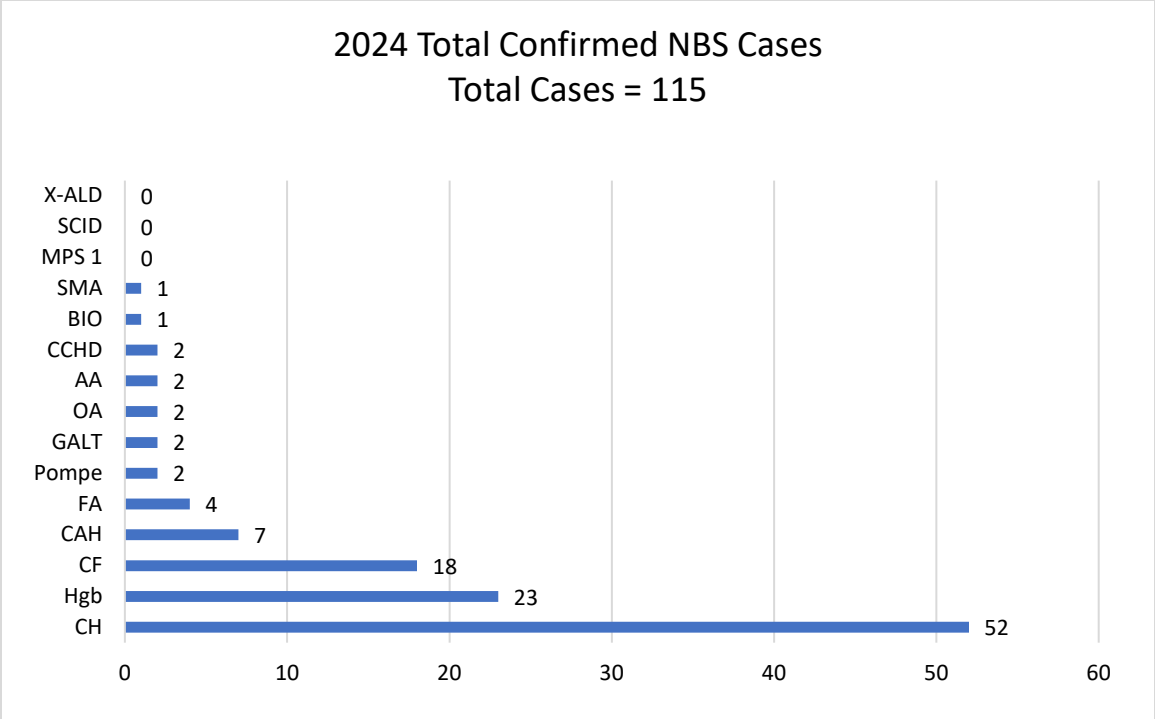


Figure 4

Figure 4 illustrates the breakdown of the 2024 total number of confirmed cases per screened condition.

Guide for abbreviations:

- X- linked Adrenoleukodystrophy (X-ALD)
- Severe Combined Immunodeficiency (SCID)
- Mucopolysaccharidosis Type 1(MPS-1)
- Spinal Muscular Atrophy (SMA)
- Biotinidase Deficiency (BIO)
- Amino Acids (AA)
- Organic Acid (OA)
- Galactosemia (GALT)
- POMPE
- Critical Congenital Heart Disease (CCHD)
- Fatty Acids (FA)
- Congenital Adrenal Hyperplasia (CAH)
- Cystic Fibrosis (CF)
- Hemoglobinopathies (Hgb)
- Congenital Hypothyroidism (CH)

Note: Confirmed cases increased from 63 total cases in 2023 to 115 in 2024.

Breakdown for number of tests performed:

Total number of tests from Jan. 1, 2024 – Dec. 31, 2024.

1. Total number of births by occurrence: **34,343**
2. Total number of samples received for CY2024: **39,518**
3. Total number of tests performed for CY2024: **382,754**
4. Total Number of births receiving at least one screen - with samples rejected:
32,596
5. Total Number of births receiving at least one screen - without samples rejected:
32,510
6. Data source year: **2024**
7. Number of presumptive positive, indeterminate, or inconclusive screens (on any screen – initial or repeat): **8,057**
8. Number confirmed cases: **115**
9. Number referred for treatment: **115**

Note:

- *There were 866 less births in Arkansas in 2023 than in 2022. In 2024 our birth rate only increased by 79 births.*
- *FY 2024, The NBS Program completed 8,302 extensive case investigations until all cases were resolved or confirmed with diagnosis. This was a significant increase of 2,300 more investigations than the program covered from the previous year.*

NBS 2024 Saturday, holidays or after hours call cases (total cases = 121)

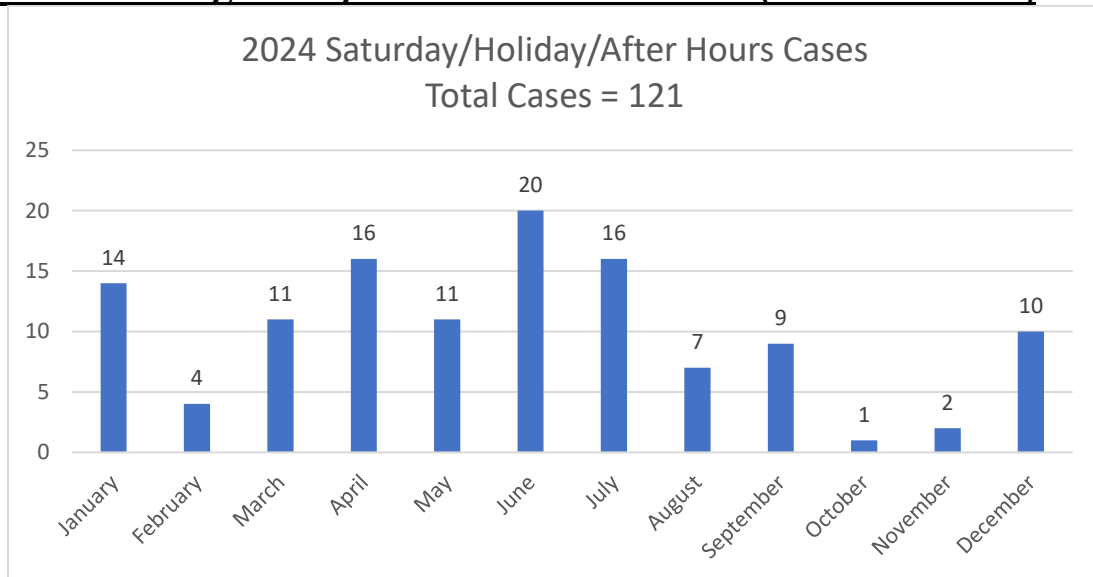


Figure 5

Figure 5 illustrates the number of 2024 critical cases reported on Saturday, holidays or after hours.

- January = 14 cases
- February = 4 cases
- March = 11 cases
- April = 16 cases
- May = 11 cases
- June = 20 cases
- July = 16 cases
- August = 7 cases
- September = 9 cases
- October = 1 cases
- November = 2 cases
- December = 10 cases

Medical Professional and Educational events presented and/or attended:

Title:	NBS Program learning exchange site visit
Author(s)/Organization(s):	Association of Public Health Laboratories (APHL) / NewSTEPs
Meeting/Conference Name:	Program Learning Exchange Site Visit (FLEX) at New York State Health Dept, Wadsworth Center
Year Presented:	August 27-29, 2024
Media Type:	In-person Albany, New York. Attended by Nurse Program Manager
Target Audience:	NBS program nurses that follow up on abnormal and borderline cases.
To obtain copies (URL or email):	
Keyword	Newborn screening and follow up processes
Status	
Action	Compare all states protocol/process, & review of educational tools. Peer to peer connection of program staff to address areas of opportunity and challenge. Promote site visits for program growth.

Title:	Cystic Fibrosis (CF) Screening Collaborative Team- State and National
Author(s)/Organization(s):	NewSTEPs AR Cystic Fibrosis (Ashley Johnson, RN CF Lead Nurse) Lauren Willis, CF Lead from AR Childrens CF Center
Meeting/Conference Name:	Cystic Fibrosis Algorithm Screening Collaborative
Year Presented:	2024 monthly for state and every other month for national
Media Type:	ZOOM
Target Audience:	All states that test for CF
To obtain copies (URL or email):	
Keyword	CF data, CF process map, CF algorithm
Status	
Action	Arkansas NBS program nurses, NBS lab staff, and CF Center ACH team lead, Lauren Willis, ACH CF NBS consultant physician, Dr Ariel Berlinski collaborated for State level to build a process map for timely follow up on positive CF screenings and confirmed cases. Our team also collaborated with the national CF team every other month to share working processes.

Title:	2024 Association of Public Health Laboratories (APHL) Newborn Screening Symposium
Author(s)/Organization(s):	APHL/NewSTEPS
Meeting/Conference Name:	October 20-24, 2024 Omaha, Nebraska
Year Presented:	2024
Media Type:	Conference: LIVE attendance by the following staff. Asst. Lab Manager, Keacha Payne Clinical Bio Branch Chief, Leslie Himstedt NBS Program Manager, Jennifer Simmons Genetics Coordinator, Keri Lafferty AC Liaison Nurse, Mallory Henderson NBS Consultant, Dr. Laura Hays
Target Audience:	Medical professionals with expertise and focus in NBS (physicians, genetic counselors, nurses, laboratory)
To obtain copies (URL or email):	
Keyword	NBS, genetic testing, lab, follow-up process
Status	Annual Symposium
Action	Empowered to confidently perform follow-up activities and will be able to describe the newborn screening system, communicate NBS results to providers and families, explain the numerous conditions on NBS panels, and participate in data analytics and new condition implementation activities. Information will be shared with staff members and management on lab and follow-up topics pertinent to the processes.

Title:	Family-Centered Genetic Education Services for Hemoglobinopathies in Rural Arkansas
Author(s)/Organization(s):	Dr. Laura Hays, PhD/APRN (UAMS/ACH NBS consultant)
Meeting/Conference Name:	ISONG (International Society of Nurses in Genetics) 2024 ISONG World Congress Meeting Dr Hays is President-Elect
Year Presented:	November 2024
Media Type:	In-person
Target Audience:	Physicians, nurses, counselors, social work/case management in genetic related fields
To obtain copies (URL or email):	
Keyword	Hemoglobinopathy, Genetics, ISONG World Conference,
Status	
Action	<p>Addressed issues of patient access and provider resources by engaging with telehealth resources for family counseling and follow-up appointments.</p> <p>Discussed educational modules that the newborn screening team had under development and the recently identified gaps in care for infants with hemoglobin traits being addressed by expanded follow-up opportunities for families of these infants in Arkansas.</p> <p>*According to an Arkansas Newborn Screening Long Term Follow-up Database analysis, distance to specialty care in rural areas is a barrier to essential care - leading to delayed care, increased sickle cell disease-related emergency department visits and hospitalizations (<i>Genetics in Medicine OPEN</i>, Hays et al., 2024).</p>

Newborn Screening Workgroup (NBS WG):

The NBS WG schedules quarterly (Virtual/ZOOM) meetings on the 4th Tuesday of the first month of the quarter.

Chairperson

- Dominique DuBois, RN, CPM, APRN

Co-Chairperson

- Jennifer Simmons, BSN, RN

Purpose:

- Provides an opportunity for the NBS lab, NBS program, ACH NBS staff, and our 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 2nd Thursday of the first month of the quarter.

Chairperson

- Dr. Laura Hays, PhD/APRN.

Co-Chairperson

- Ruby Moore, RN Genetics Coordinator – retired July 1, 2024. Position vacant for remainder of 2024.

Purpose:

- Implementation and monitoring of the Arkansas State Genetics Plan, five-year (2022 – 2026) plan of genetics services in Arkansas.

Newborn Screening Program 2024 update including Plans for 2025:

NBS ADH Pediatrician:

Dr. Sarah Labuda joined the Arkansas Department of Health in February 2024 as Medical Director of Immunizations and Child Health Programs. She is also a Board Certified Pediatric Infectious Diseases Specialist and sees inpatient infectious diseases consults as an adjunct Assistant Professor of Pediatrics with UAMS College of Medicine at Arkansas Children's Hospital.

Newly Added Conditions for Arkansas Newborn Screening

In April of 2023, ACT 490/HB1102 was voted into law by the State of Arkansas Legislative body. In compliance with ACT 490 the testing for core medical conditions

newly added to the Recommended Uniform Screening Panel (RUSP) shall begin within thirty-six (36) months upon introduction to the RUSP. On July 1, 2024, Infantile Krabbe was added to the RUSP.

Plans for additional conditions to be screened for compliance with RUSP and thirty-six month rule are as follows:

- MPS II (goal August 2025)
- GAMT (goal- January 2026)
- Krabbe (goal July 2027)

Updated Electronic Medical Record for NBS Program

STARLIMS Electronic Medical Record for the NBS Program was implemented January 2, 2025. January 2025, Arkansas Childrens Hospital went live with electronic submission of the newborn screen.

7/1/24, grant received to benefit the Arkansas Newborn Screening Program. Updates below on the grant metrics and development for 2024/2025:

July 1, 2024, The NBS Program received a Health Resources and Services Administration (HRSA) NBS Co-Propel grant to further increase public awareness, educate healthcare providers, and engage families by developing a comprehensive NBS educational outreach program for families, providers, and the public. This \$1.4 million collaborative grant was awarded to Dr. Laura Hays, a NBS Clinical Consultant and Associate Professor with the UAMS College of Nursing.

Providers. Through a contract with the UAMS Institute for Digital Health and Innovation (IDHI), the NBS Program has developed and implemented interactive educational modules for healthcare providers to introduce the Arkansas NBS Program structure, law, and rules and regulations, including the conditions screened for and what to expect with follow-up for a positive NBS from a procedural perspective. These modules are housed on LearnOnDemand, a dedicated website hosted by IDHI which allows us to place additional content on the site for state-wide exposure. Continuing education (CE) is available at no cost to the providers and includes credit for medical residents, advanced practice registered nurses (APRN) and APRN students, nurses and nursing students, physician assistants, and physician assistants studies students.

We developed educational CE modules in the same manner for women's health providers around "Anticipatory Guidance for Newborn Screening" to provide guidance for them on how to educate families about NBS during prenatal visits. As of this report, the modules have CE credit designations by the American Medical Association Physician's Recognition Award, the American Nurses Credentialing Center, and the American Academy of Physicians Assistants.

Another area of the provider website will allow providers to gain training and support in how to have difficult conversations with families when they must deliver bad news. We partnered with the directors of Pastoral Care at Arkansas Children's Hospital and at

UAMS to deliver a panel discussion which included Pastoral Care from both institutions and two physicians who work in palliative care and neonatology, respectively.

Families. To help educate families and raise awareness of NBS in the prenatal period, we also developed a family and patient-focused interactive module that includes NBS information that parents need to know before giving birth. We had the final module script translated into the Spanish and Marshallese languages. Each module was modified to attain cultural appropriateness.

Like the dedicated website for providers on IDHI LearnOnDemand, we have a second dedicated website for individuals, families, and the greater public through IDHI PatientsLearn. This patient and family-focused website hosts the three modules for expectant families, as well as links to HRSA's NBS educational information, the CDC's NBS guidance, and the American College of Genetics and Genomics (ACMG)'s NBS Action Sheets. We aim to make this website an easy resource for Arkansas families seeking information about NBS or genetics. We are developing 4 x 6 inch cards with QR codes for families to easily link to this website that can be available at prenatal care visits and other opportunities that will reach families (health fairs, etc.).

The provider and family website are scheduled to be available on July 1, 2025.

This educational project was 100% funded with federal funds from a federal program of \$1.4 million supported by Cooperative Agreement #UC1MC53085-01 from the Health Resources Services Administration (HRSA). Its contents are solely the responsibility of the project team and do not necessarily represent the official views of HRSA.

Public awareness. The AR CNECT Program was the UAMS featured news story and press release on 9/5/2024. This gave our program many other public-facing opportunities. The story was “picked up” by the following state and local community news stations and papers:

- The Arkansas Times (Facebook & X);
- Talk Business & Politics; newsbreak.com;
- The Jonesboro Sun; the Magnolia Reporter;
- MSN.com; and Arkansas – express.com.

The story was also linked and featured on the UAMS College of Nursing's Facebook page. The local ABC affiliate KATV interviewed Dr. Hays, our PI/PD, and aired the story on 9/9/2024 at 3:00, 6:00, and 10:00 pm, and on KATV.com and their YouTube channel. In addition, the news article was featured in the Healthcare Journal of Arkansas on 9/15/2024.

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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