

# Newborn Screening Program Report

Calendar Year 2017



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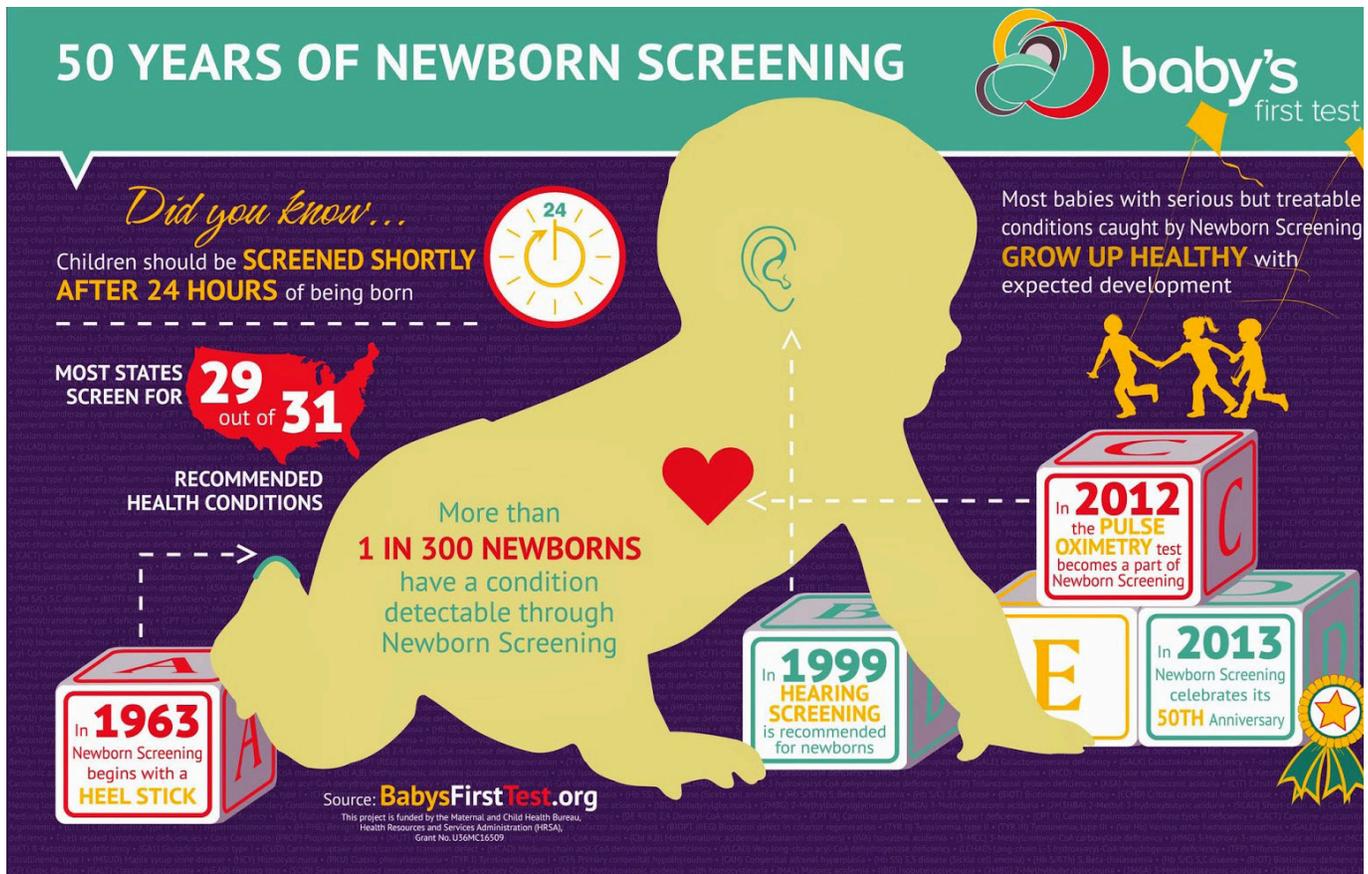
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# Newborn Screening Program

Newborn screening for inborn conditions has been mandatory in Arkansas (AR) 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 29 disorders using the blood spot card in addition to two point of care tests, hearing screen and critical congenital heart disease, for a total of 31 core disorders. Ninety-eight point five percent (98.5%) of the approximately 36,000 babies born in Arkansas in 2017 were screened for these genetic disorders.

In 2017, Arkansas celebrated fifty years of newborn screening. The Baby's **First Test** poster identifies the growth of the NBS Program nationwide:



The Newborn Screening Program (NBS) is located in the Child and Adolescent Health Section of the Arkansas Department of Health. NBS Program staff consists of:

- NBS Program Manager
- Arkansas State Genetics Coordinator
- Nurse Educator
- Nurse Coordinators (3)
- Assistant Nurse Coordinator
- Administrative Assistants (2)
- Advanced Practice Registered Nurse Consultant
  - Position is shared half-time with Arkansas Children's Hospital General Pediatric Clinic. This partnership includes the Professor of Genetics and Pediatrics at the University of Arkansas for Medical Sciences (UAMS), as NBS Medical Director, in addition to consultants from UAMS staff on Newborn Screening cases.

## NBS Follow-Up Process

NBS staff work together and are responsible for the follow up of abnormal and borderline screening results. The nursing staff follows disorder-specific protocols that were approved by local pediatric subspecialists at Arkansas Children's Hospital. NBS nurses contact babies' physicians immediately about abnormal results and provide nationally-recommended guidelines for clinical and laboratory evaluation. The NBS program is tasked with assuring prompt evaluation for infants with abnormal or borderline screens.

NBS nurses make regular contact with the baby's Primary Care Physician (PCP) and/or family until the baby is diagnosed. The amount and frequency of contact depends upon the presumed disorder and clinical status. In 2017, 102 babies out of approximately 36,000 births were identified through newborn screening with a confirmed diagnosis. Once diagnosed, the case is followed for 5 years to assess health and developmental outcomes.

NBS nurses collaborate daily with the Arkansas Children's Hospital (ACH) NBS nurse to coordinate follow-up care for babies with abnormal newborn screening results and those requiring second tier testing. Second-tier testing

for CAH (Congenital Adrenal Hyperplasia) and Cystic Fibrosis (CF) is completed at the Arkansas Department of Health, Public Health Laboratory

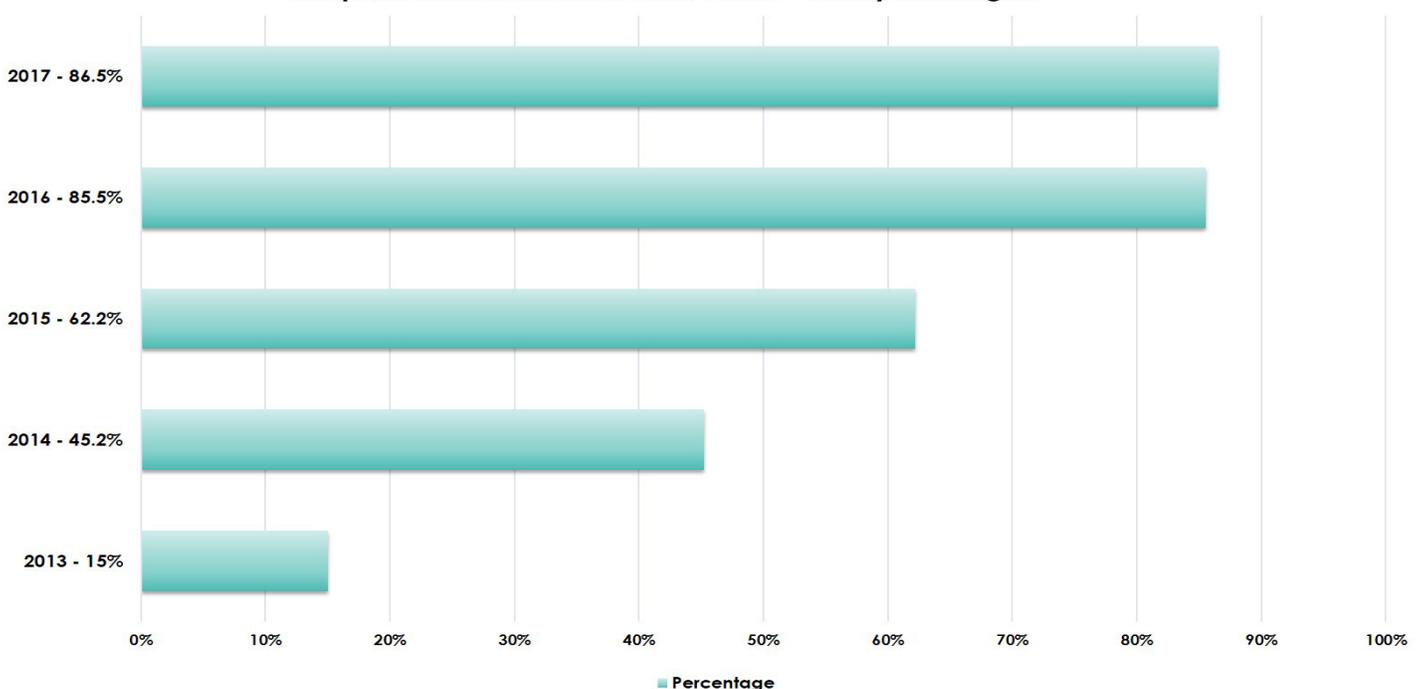


**PerkinElmer (electronic medical record for NBS):** PerkinElmer participates in monthly conference calls with the Lab

Manager and NBS Manager. This action has assured follow up on projects and additions to protocols. The vendor was on site in March and October to provide an in-service for new NBS nurses, review the program and to discuss future plans for growth.

**Birthing Facility NBS Quarterly Reports:** Quarterly distribution of sample delivery progress charts are sent to each birthing facility as are yearly trend charts showing placement of the facility in relation to other hospitals in Arkansas. This report is sent to three key personnel at the birthing facilities: Facility Administrator, Lab Manager and Nursery/NICU Managers. If there are any questions or clarification requested by the facility they are guided to contact the Lab or NBS managers. We continue to monitor timeliness in delivery of specimens to the lab. In 2017, 86.5% of all specimens submitted were received within 48 hours of collection.

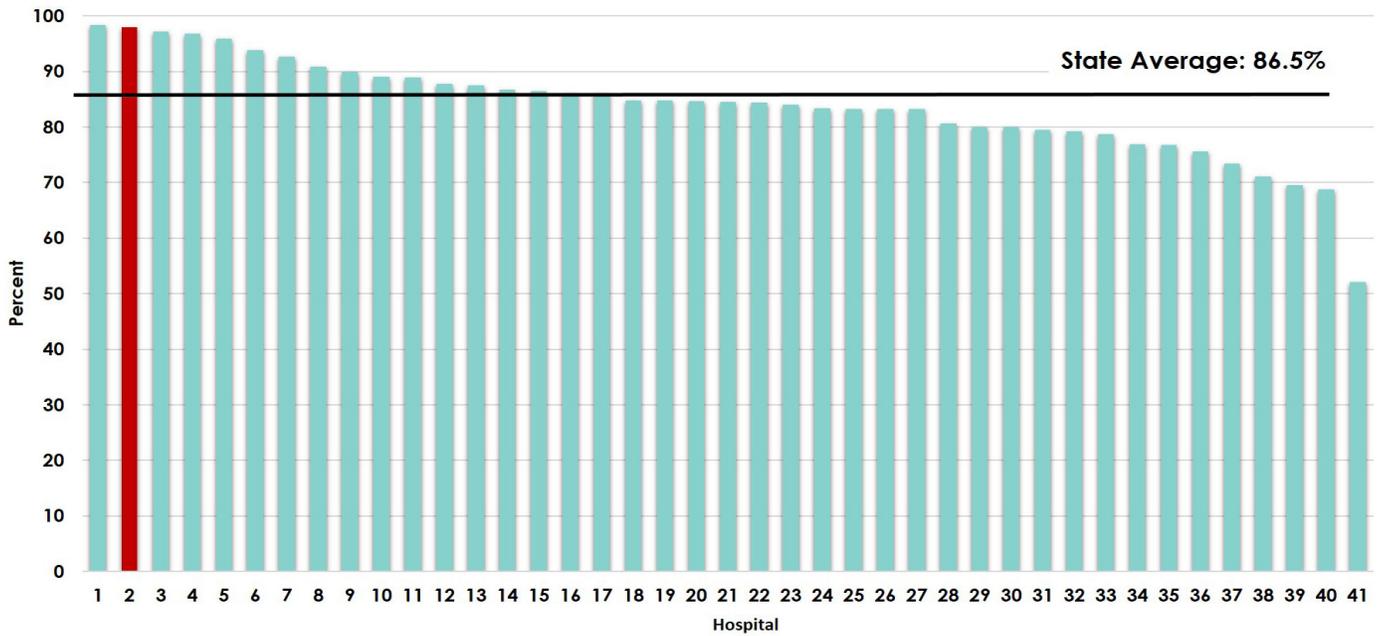
**Hospital Timeliness from 2013-2017 - Yearly Averages**



The NBS program received such positive response from the birthing facilities since the quarterly report process began. The program will continue to provide a quarterly distribution of sample delivery progress charts to each birthing facility and yearly trend charts showing placement of the facility in relation to other hospitals in Arkansas.

Birthing facilities receive a de-identified graph at the end of the calendar year indicating their submission time compared to others.

**Percent of Newborn Screening Samples Arriving in the Lab within 48 Hours  
CY 2017**



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



## NBS Education:

The NBS program works to provide various types of annual education opportunities for birthing facility staff, Licensed Lay Midwives, and providers to increase awareness of the NBS protocols and processes. These opportunities are typically offered as onsite in-services, annual conferences, and online courses. Participants are eligible to earn continuing nursing education (CNE) contact hours. Additionally, NBS staff actively participate in available professional opportunities offered to NBS programs nationally.

The ADH NBS Nurse Educator completed site visits to birthing facility nurseries to provide education, resources, technical assistance, and hospital-specific data until June 2017, at which time that position was vacated. In the interim a committee comprised of the NBS Medical Director, Child and Adolescent Health Medical Director, NBS Manager, and Lab Manager was created to re-evaluate the job responsibilities of the Nurse Educator and to identify where the greatest improvement could be made in the job duties.

The following plan will be implemented:

- Discontinue annual site visits to every birthing facility and focus on hospitals whose

timeliness is less than 80%. Site visits will be conducted if a birthing facility requests a site visit or if the Lab Manager/NBS Manager assess a need for a visit.

- Conference call will be scheduled with birthing facility staff and NBS Nurse Educator to better utilize time and decrease/eliminate the need to travel to the birthing facility. This will allow the NBS Nurse Educator the opportunity to include ADH Lab or NBS Managers if warranted.
- Continue providing birthing facility quality quarterly reports and letter from the ADH Director.
- Continue monthly internal timeliness monitoring by Lab Manager and report to NBS Nurse Educator and NBS Manager.
- Develop CNE activities on-line TrainingFinder Real-time Affiliate Integrated Network (TRAIN) to focus on NBS disorders.

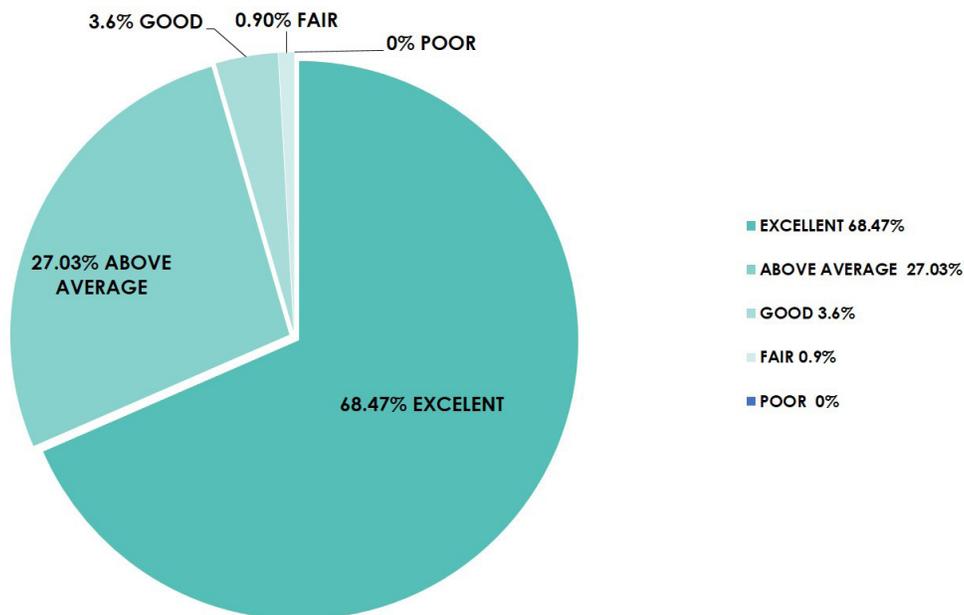
**AR Licensed Lay Midwives:** ADH Women's Health Section identified a need to clarify the NBS process and specimen collection for Licensed Lay Midwives. A NBS toolkit along with a letter of clarification was mailed out in March 2017 to all Licensed Lay Midwives.



## List of 2017 Educational Opportunities:

**On-line Course #1053880:** "AR NBS Protecting Babies Through a Simple Test". This CNE is worth 1.5 CNE contact hours. As of December 2017, 240 nurses have completed the on-line course. A total of 95.5% of participants rated course #1053880 above average or excellent. TRAIN collects stats of all courses offered through TRAIN. Evaluation results are listed in the graph below:

**240 TRAIN PARTICIPANTS for 2017**



**Live Course # 1069701:** The 2017 NBS Conference provided 6.75 CNE contact hours to eligible participants. The 2017 conference focused on specific newborn screening disorders: Congenital Adrenal Hyperplasia (CAH), Severe Combined Immunodeficiency (SCID), Cystic Fibrosis (CF) and Congenital Hypothyroidism (CH). Additional presentations were delivered on Patient Education on Infant Care, the Perinatal Collaborative Forum, Electronic Record of Arkansas Vital Events (ERAVE) and a 50 year history of the journey of the newborn screening program in Arkansas. There were two different panels of expertise offered this year. The first panel consisted of physicians (endocrinologists/geneticists) which provided an overview of NBS and Infant Hearing Program (IHP) along with discussion on newborn screening disorders and discussion of the impact of Zika virus in newborns. The physician panel included Dr. Brad Schaefer, Dr. Amy Scurlock, Dr. Naga Yenduri, Dr. Emir Tas, and Dr. Alan Mease. The second panel was a parents' panel sharing real life stories of how

early detection leads to positive outcomes for Arkansas babies.

Ninety-six (96) participants, representing 25 birthing hospitals and eight pediatric healthcare clinics in Arkansas, attended the 2017 conference. Attendees received information from the IHP and NBS programs on Quality Improvement projects, policy/procedure updates and educational tools to assist with providing updates to new nurses and current staff.

The evaluations from the 2017 NBS Conference were favorable. Sixty-five percent (65%) of the evaluations requested to have more on-line availability for continuing education instead of state conferences. As a result of those comments, TRAIN courses will be developed to review NBS processes and specific genetic disorders.

- Staff at birthing facilities, stated nurses were required to use annual time to attend the annual conference and would not receive reimbursement for expenses.

- NBS Medical Director, NBS Program and Lab Managers, NBS Follow-up nurses, and Child and Adolescent Health Section Chief discussed a state NBS Conference vs. on-line education. In conclusion it was decided to provide the CNEs on-line then re-evaluate a conference in the future. NBS Nurse Educator will be the lead in developing the on-line education. She will be mentored by the NBS Manager & ADH TRAIN Manager.
- These courses will focus on NBS disorders and be provided through TRAIN. The course will be available to all Arkansas nurses requiring pediatric practice-focused CNEs.

On-line training will be FREE to participants and provide CNE activities for renewal of nursing licenses. Participants will be required to establish an TRAIN account, [www.train.org](http://www.train.org).

**Educational Brochures:** NBS brochures are available for download on the ADH website. Additionally, the NBS program distributes brochures directly to healthcare providers upon request.

**Educational Toolkits:** Toolkits were provided to birthing facilities, Licensed Lay Midwives, and ADH Local Health Units. The NBS Manager and Lab Manager provided educational updates to Patient Care Managers and Maternal and Child Health (MCH) Specialists during their quarterly meetings as requested.

The NBS staff completes professional development by participation in conferences offered by host organizations such as Association of Public Health Laboratories (APHL) and Newborn Screening Technical Assistance and Evaluation Program (NewSteps). These organizations are proactive in providing education opportunities with limited cost to participants.

The following educational opportunities were offered and attended:



**APHL (Association of Public Health Laboratories) conference:** "Gene Sequencing in Public Health" was held in February

2017. The NBS and Lab Managers attended this conference which focused on discussing future

plans in gene sequencing along with current NBS follow-up protocol.

**2017 APHL Newborn Screening and Genetic Testing Symposium:** In September 2017, the ADH NBS Manager and Lab Manager, ACH NBS Nurse Liaison and Program Director attended the symposium. This international symposium is provided every 18 months. The learning outcomes of the symposium describing state and international experiences with candidate conditions and clinical outcomes in newborn screening included: evaluating quality assurance and quality control measures for newborn screening laboratories, the effectiveness of current newborn screening and genetics follow-up programs.



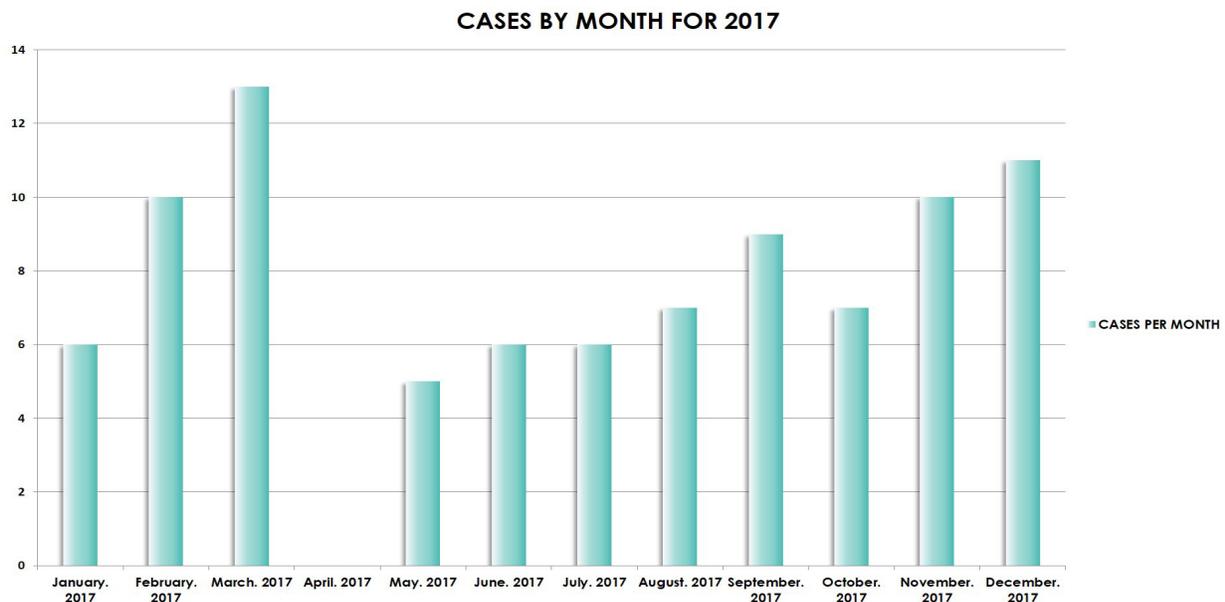
## 2017 Statistics:

The 2017 data shows 40,488 newborn screens were conducted. The difference in the number of screens versus the number of births (35,788) is due to repeat submissions of unsatisfactory specimens and compliance with Neonatal Intensive Care Unit (NICU) recommendations. Within the 40,488 newborn screens completed, 5,451 abnormal and borderline results were reported by the ADH NBS Lab with 102 cases indentified with a confirmed diagnosis through newborn screening. The graph below indicates a breakdown of the 102 confirmed cases. CH cases were the greatest number of confirmed cases in 2017.



The ADH Lab began Saturday hours October of 2014 to prevent delays in testing follow up exceeding 48 hours. A total of 90 critical cases were identified during the 52 Saturdays in 2017.

March 2017 presented the largest number (13) of critical cases identified on Saturdays. There were no critical cases identified on Saturday in April. The graph below indicates the number of critical cases reported on Saturday in 2017:



**NewSteps:** This program provides case definition worksheets, classification tables, a list of time critical disorders and definitions for medical intervention and diagnosis by disorder. The Arkansas State Genetics Coordinator developed a system ensuring confirmed diagnosis cases are entered in a timely manner.

## Outreach:

**UAMS Genetics Counselor students:** NBS Manager and Lab Manager provide a review of protocol to students twice yearly. This opportunity increases the knowledge base of the genetic counseling students in laboratory and follow-up program processes. The students spend time in the laboratory to discuss specimen receipt, processing, testing and reporting. An in-service provided by the NBS nurses takes students through the follow-up processes involved when an abnormal or borderline test result is received.

**Heartland:** Dr. Lori Dean, UAMS Genetic Counselor Professor, along with Dr. Brad Schaefer, NBS Medical Director, decided to focus on improving the genetic counselor program for the Heartland NBS workgroup. One major issue in this program was identified as the inability to retain students to practice in Arkansas after graduation. There are few educational facilities that provide the quality of education that UAMS provides and the majority of the genetic counseling students leave Arkansas after graduation. Heartland plans to identify a strategic plan to retain genetic counselors after graduation.

**Local Neonatologists:** Early in 2017, Dr. Brad Schaefer, Medical Director of NBS held a meeting/conference call to provide clarification of NBS preterm, sick, and new birth weight protocols. An educational tool was made available under the guidance of the Clinical and Laboratory Standards Institute.

**Registered Nurse Practitioner students:** IHP Manager and NBS Manager presented a program overview to the Fall and Spring UAMS Registered Nurse Practitioner (RNP) students. The Dean of the RNP Nursing Department at UAMS requested a presentation to discuss the follow-up program for NBS test results.

**Arkansas Genetic Health Committee (AGHC):** The Arkansas Genetics Health Committee (AGHC) serves the function of an independent advisory committee to the Arkansas Department of Health, UAMS, State of Arkansas Legislature and other organizations involved in providing genetic services within the state. Committee activities promote, expand, or

coordinate genetic services with the goal of prevention or amelioration of genetic conditions. The committee strives to coordinate genetic services statewide by facilitating communication, coordinating with other regional programs, and overseeing educational opportunities for professionals and laymen including families and patients with genetic conditions.

The committee was instrumental in the success of Phenylketonuria (PKU) Bill 1715 being passed to provide adult PKU food to be paid for by patients' insurance. In 2018, AGHC plans to focus on supporting the Genetic Counseling Program by providing in-services to students as requested. Dr. Brad Schaefer, NBS Medical Director, chairs the committee which met twice in 2017. Dr Thomas A. Burrow, UAMS/ACH endocrinologist staff and faculty member, and Representative Mary Bentley, registered nurse and the Arkansas House of Representatives committee member, were introduced as the newest members

**NBS Workgroup:** The workgroup meets quarterly to provide educational activities, reports of submission data, and current strategies in newborn screening. This workgroup is comprised of ADH NBS program and Lab staff, ACH specialty physicians, QI representatives, and other stakeholders with an interest in newborn screening.



## Quality Improvement (QI) projects:

**ADH Local Health Units:** As a result of a 2016 Performance Improvement Project, a NBS toolkit was created and provided to all MCH Specialists and all local health units. The NBS Manager and Lab Manager provided two sessions including updates of NBS processes at the Patient Care Managers and MCH Specialist meetings. The NBS toolkits were reviewed and staff were asked to ensure NBS toolkits were located in local health units. A question and answer session was provided to allow an opportunity to discuss avenues of improvement. The Lab Manager continues to provide quarterly timeliness and unsatisfactory reports to the MCH Specialist overseeing QI activities in the local health units. The NBS Manager and NBS Nurse Educator continue work with local health unit nurses to insure QI goals are met.

In July 2017, the NBS Manager and the Safe Sleep Coordinator provided a program report and update at the ADH Northwest Region Clinic Coordinators' meeting. There were 31 Clinic Coordinators present at the meeting. The presentations provided information on safe sleep, NBS report of NW Region local health units, NBS process for collecting specimens, and the role of the local health nurse in educating clients about "safe sleep" and newborn screening.

**NBS QI project:** NBS continues to monitor timeliness data on a monthly basis 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. In 2017, NBS saw a high of 167.2 hours in January, likely due to two holidays and inclement weather in which the lab was closed, and a low of 141.5 hours in October. The 2017 report indicated the average was 149 hrs = 6 days. The QI findings play an important role in assisting the NBS Nurse Educator when scheduling annual visits or conference calls with the birthing hospitals that have the strongest need to meet the <168 hours goal. The NBS program will continue monitoring monthly timeliness data at each point to ensure birth to reporting continues to meet the goal of less than 168 hours.

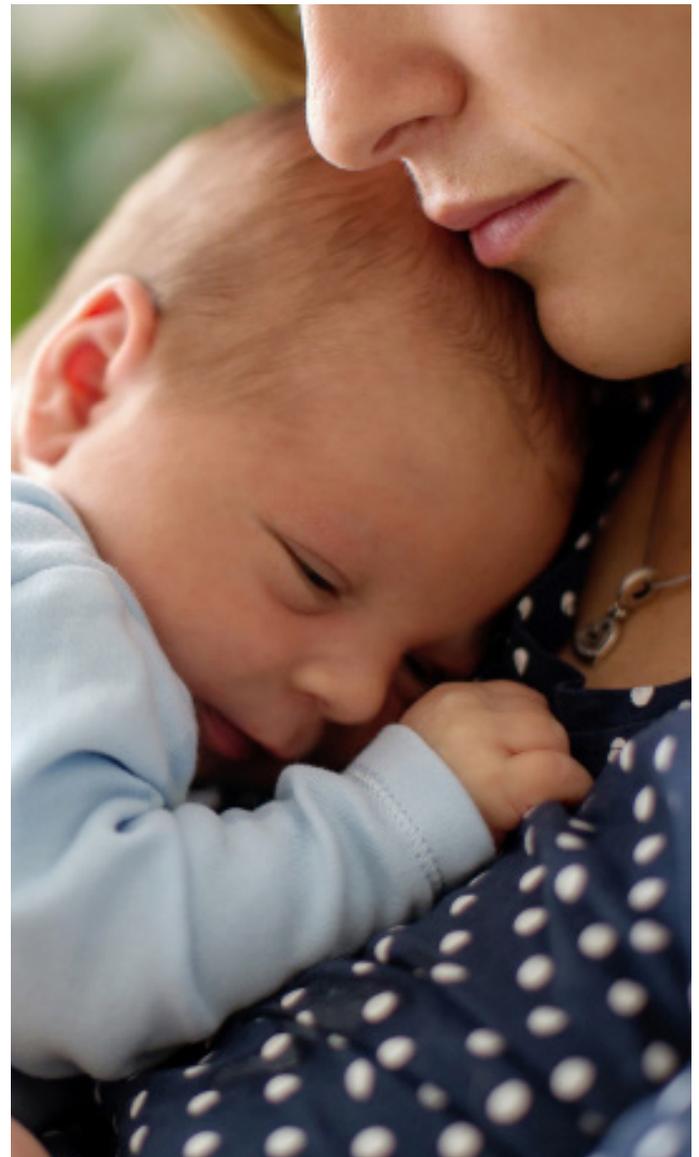
**"Survey Monkey" project:** Dr. Emir Tas and Dr. Brad Schaefer requested a questionnaire to go out to all AR Pediatricians. The survey focused on identifying the level of awareness/education of CH in relation to newborn screening.

### Conclusion:

The 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.

NBS is constantly evolving to better serve Arkansas families.





# Newborn Screening Program Report

## Calendar Year 2017

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