

## ***Florida Newborn Screening Results (FNSR) - online access system***

Location: Florida  
 Date Submitted: 4/2010  
 Category: **Emerging Practice**

TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED
N/A

### **BACKGROUND**

A sampling of newborn screening specimen cards taken by the Florida State Laboratory demonstrated that 90% of all specimen cards contained the name of a physician. However, hospital staff routinely noticed that the lab reports that were sent to the name of the physician listed on the specimen card were returned at an alarmingly high rate. It was estimated that half of the physicians listed on the specimen card were incorrect and the hospitals were unable to forward the results to the correct primary care physician providing care for the infant.

In 2004, a Florida statute was amended by the legislature to allow the Children's Medical Services to release newborn screening results directly to the child's primary care physician. Through the Florida Newborn Screening Results program (FNSR), physicians could now access the results of their patients without going through the hospital.

The idea to make newborn screening results available online to physicians was introduced in 2005 and it became available to all registered users in late 2008. The goal of this online component is to develop an online system that can be accessed 24 hours a day by the child's primary care physician to obtain newborn screening results.

### **PROGRAM OBJECTIVES**

Screening results are often received after the child leaves the hospital; therefore it is up to the primary care physician to collect any repeated specimens and follow-up on the results. The goal of FNSR is to get newborn screening results into the hands of the primary care physician by providing easy online access to these results. Some objectives include:

- Ensuring that each newborn is screened and proper follow-up is conducted
- Ensuring that newborns receive a repeat screening for unsatisfactory and borderline results

### **TARGET POPULATION SERVED**

Any physician licensed in Florida can register to become a user of the system. There are 1460 registered users as of March 2010. There are also plans to open FNSR to birthing facilities and to allow hospitals to search and print newborn screening results.

### **PROGRAM ACTIVITIES**

When the system became available online, it was announced to a select few physicians who registered. Their progress was monitored closely to ensure that the system was working properly. To prevent an overload and to monitor the system closely, users were added gradually. The number of users and the number of successful searches have been monitored on a weekly basis. In December 2009, it became mandatory that physicians must use the online system.

### **PROGRAM OUTCOMES/EVALUATION DATA**

Statistics show that 75-80% of physicians who currently request newborn screening results obtain the results using the online system. Future evaluations are needed to assess how physicians use this information to follow-up with their patients.

### **PROGRAM COST**

The online software took 8 weeks of developer time, which cost \$25,000. There are additional maintenance fees that are necessary for the upkeep of the computer server (~\$5,000).

## ASSETS & CHALLENGES

### Assets

In 2004, Florida Statute 383.14 was amended by the Legislature to allow Children's Medical Services to release newborn screening results directly to the child's primary care physician.

### Challenges

Challenges included obtaining the approval for the project by the Department of Health Information Technology Governance Committee; this process took several months.

### Overcoming Challenges

Patience and perseverance proved to be the biggest assets during the development and implementation stages of the FNSR project.

### Key words:

Newborn Screening, Health Technology, Infant Health, System Integration, Florida Newborn Screening, FSNR

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## LESSONS LEARNED

One does not need to purchase an expensive software application or an expensive annual maintenance agreement. However, it is essential to work with the in-house information technology staff's availability. Additionally, it was important that the use of the system is mandatory.

## FUTURE STEPS

Currently the system is maintained by the Florida Department of Health Information Technology services staff at no cost to the Newborn Screening Program.

## COLLABORATIONS

This work was completed with the help of the Florida Newborn Screening State Laboratory and the Department of Health Legal and Information Technology staff – software engineers, server team, security team.

## PEER REVIEW & REPLICATION

This program has not been replicated or peer reviewed as of 9/2010.

## RESOURCES PROVIDED

No resources were provided at the time of submission.

