



Newborn Screening
Saves Babies
One Foot
at a Time

We are very excited to take this opportunity to introduce NBS Connect, an interactive clinician supported patient registry. NBS Connect will serve as an internet-based support network connecting parents, guardians, and individuals with heritable metabolic disorders to clinicians, industry and academia. Emory University and the HRSA funded, Southeast NBS & Genetics Collaborative (SERC) under the leadership of Dr. Rani Singh, is partnering with Save Babies Through Screening Foundation Inc to bring this project to fruition.

Over the last several months immense progress has been made on NBS Connect. The two main areas of focus have been informatics infrastructure development and partnership building in order to maintain financial sustainability. Kyle Brown of Innolyst Inc. has been diligently working on the technology components of the project. Due to his hard work NBS Connect now has health tracking tools allowing individuals to track weight changes, pertinent blood values, symptoms, and even treatments, which will enable longitudinal clinical data to be collected. In addition to these tools, the system will allow questions submitted by individuals to be automatically forwarded to an established network of experts for response. This function will also allow individuals to become more aware of the resources in their region including clinics, laboratories, patient assistance programs, and key clinicians such as metabolic dietitians.

Along with working on the technology infrastructure a large amount of energy and focus has been placed on reaching out to parent and support organizations. With Save Babies Through Screening Foundation serving as our host organization NBS Connect will be able to serve a large number of individuals; however the support and guidance of other parent organizations is also needed. Recently, National PKU Alliance was the first parent organization to become involved with NBS Connect and has made both a financial and programmatic commitment.

Currently, NBS Connect staff are planning for a consumer and industry focus group to be held in early 2010. This focus group will be an opportunity to bring together different parent and support organizations as well as representatives from industry to ensure that all groups are represented and their needs are heard. The hope is that this focus group will help to establish a united front through partnerships with several organizations while Save Babies Through Screening Foundation Inc. serves as a host of the overall project. In the meantime, progress will continue in developing the questionnaires for each disorder, beginning with PKU. We hope to go live with NBS Connect in Spring 2010. For more information about how to get involved, contact Sarah Travis RD, LD at sjtravi@emory.edu.