



NBSTRN NEWSLETTER



Have you seen the new NBSTRN website? Go to NBSTRN.org to check it out!

Have you seen a public training demonstration of the Virtual Repository of Dried Blood Spots? [Watch the video!](#)



New NBSTRN.org Website Features!

The Newborn Screening Translational Research Network launched a new website this October and not only did NBSTRN.org get a new look but the website is now the host of a variety of features

that are geared towards newborn screening researchers. A dedicated “Planning your Research” section includes helpful tools like the State Profiles page, which allows researchers to search each state profile to learn if the state has dried blood spots available as well as find out important IRB information. This section also provides investigator FAQ’s, and a “Request a Letter of Support” section where researchers can request a letter of support for their grant, or to their institutional review board.



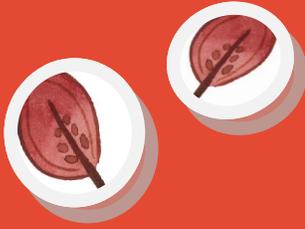
Request a letter of support from NBSTRN



In addition to the current Research Projects that the NBSTRN highlights on its website, the NBSTRN is also host to

three key research tools, the Virtual Repository of Dried Blood Spots, the Longitudinal Pediatric Data Resource and the Laboratory Performance Database. These three tools are hosted on our new unified registration page where investigators are allowed to sign up for one or more of the tools suited to their research needs. A researcher need only click the “Register For Tools” button and they will be prompted as to which tool they would like access to. To find out more about the NBSTRN.org research tools, go to the research tools landing page: <https://www.nbstrn.org/research-tools>





If you have topics for inclusion in future newsletters, please let us know by emailing

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Spotlight on a Newborn Screening Researcher

The Newborn Screening Project is pleased to announce that November's Spotlight Researcher is someone who has a strong focus in newborn screening for lysosomal storage disorders, Friedreich's ataxia, Wilson's disease and X-adrenoleukodystrophy. His primary interests lie in inborn errors of metabolism and their biochemical diagnosis. His special interests include fatty acid beta-oxidation disorders, organic acidemias, amino acidopathies, and glycogen storage disorders.

Are you still curious about the identity of this researcher? He has been a member of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) since 2011. He is also a member of the Advisory Committee on Heritable and Congenital Disorders for the state of Minnesota. He attended medical school at Ludwig-Maximilians-University in Munich, Germany and completed his residency at the Children's Hospital, at Albert-Ludwigs University. After completing his residency he went on to do his fellowship in Clinical Genetics at Duke University Medical Center. Since then he has been at the Mayo School of Graduate Medical Education as faculty.

Read more and find out who the Researcher of the Month is by visiting: <https://www.nbstrn.org/about/spotlight-researchers>

NBSTRN Team Goes to the ASHG Annual Meeting

The NBSTRN team went to the annual American Society of Human Genetics (ASHG) meeting from October 22nd-26th in Boston to showcase our resources, tools and upcoming webinars. The NBSTRN and the National Coordinating Center for the Regional Genetic Service Collaboratives (NCC) teamed up at Booth # 748 and it was a huge success! An NBSTRN team member was available throughout the meeting to demonstrate the Virtual Repository of Dried Blood Spots, answer questions on the new Longitudinal Pediatric Data Resource (LPDR) tool and showcase our improved website.

