How do I join ScreenPlus?

After your baby is born at a ScreenPlus pilot hospital, a study member may visit you to discuss the study. You can also visit our website, www.ScreenPlusNY.org, for more information.

If we missed you during your stay, we will still call, email, or message you through the hospital's patient portal to see if you are interested in joining!

After you've learned about the study, you can decide if you'd like to have your baby screened for the additional ScreenPlus disorders. You can enroll anytime in the study by scanning the code below or by going to: https://redcap.link/screenpluspass

Do I have to participate in ScreenPlus?

No. **This is your choice.** Your baby will still have the routine newborn screening tests even if you choose not to have the additional testing.

Congratulations on your new arrival, and we wish you the best!

For Questions and Comments, Contact Us!

ScreenPlus | 929.525.6428

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The study is supported by the National Institutes of Health and is being done in conjunction with the New York State Department of Health. Please visit our website to find a list of industry and advocacy sponsors who provide additional support to expand our reach.

Scan the QR code to learn more or enroll!

ScreenPlus

Pilot Newborn Screening Program

What is ScreenPlus?

About Newborn Screening

Shortly after birth, all New York (NY) babies have a routine newborn screening test that checks for more than 50 treatable disorders that can affect their health, because early diagnosis allows early intervention and treatment. *More information can be found at:* www.wadsworth.org/programs/newborn.

Research Study Examining Additional Newborn Screening for Rare Disorders

ScreenPlus is a study that offers parents of babies born at select NY pilot hospitals the option to screen for 14 additional, rare disorders that are not currently on NY's routine newborn screening panel. These conditions were chosen because they are potentially serious, but early detection may improve outcome. The 14 disorders are: ASMD, CLN2, CTX, Fabry disease, Gaucher disease, GM1 gangliosidosis, LAL-D, MLD, MPS II, MPS IIIB, MPS IVA, MPS VI, MPS VII and Niemann Pick C. *For more information about these disorders, please visit:* www.einsteinmed.edu/research/screenplus/conditions-tested/.

Follow Up Care and Family Support

In the rare case that your baby receives a positive result, a ScreenPlus doctor will contact you to set up a time to evaluate your baby and discuss next steps for their care. Your pediatrician will also be notified.

What will happen if my baby participates in ScreenPlus?

- The NY Newborn Screening Laboratory will test your baby's sample for the additional disorders. **No extra blood will be taken from your baby.** These additional tests will be done on the blood that was already taken from your baby's heel for routine newborn screening.
- Most babies will have a normal result and you will not hear from us. By the time your baby is one month old, their ScreenPlus results will be included in their routine Newborn Screening Report which can be accessed by your pediatrician. If the result is positive, you will be contacted directly by a ScreenPlus doctor who specializes in genetic disorders.
- If your baby has one of the disorders on the ScreenPlus panel, it is helpful to know as early as possible. All ScreenPlus disorders have an FDA approved treatment or ongoing clinical trials.
- There is always a chance of false positives in newborn screening. One of the goals of ScreenPlus is to reduce false positives, so we use a multi-tiered testing approach. This means that if the first screening result is abnormal, the sample will be tested with different method(s) to be as accurate as possible.

English/Version 3.0/Weiler Site

How is my baby's data protected?

- ScreenPlus keeps some of your personal details in a password protected database that is stored behind the firewalls at Albert Einstein College of Medicine. We hold this information for about three months before removing them. More details on how we protect your information can be found the HIPAA authorization section of the consent form.
- For more information about how your baby's blood spot is protected, please visit the website listed in the "About Newborn Screening Section".

Why should I participate?

- ScreenPlus may help identify rare diseases early, before symptoms begin.
- Early diagnosis can help your baby get treatment if they need it.
- This research may help future babies get diagnosed and receive treatment as early as possible.
- There is no cost to participate.

> *If there is one thing I have learned in our rare disease journey, **it is that knowing earlier** about the health status of your child **is so much better***

– Pam Crowley Andrews
Parent of Belle and Abby,
Children living with Niemann Pick Type C1 (NPC)
Co-Founder and Executive Director, Firefly Fund