





## How do I join ScreenPlus?

 After your baby is born at a ScreenPlus pilot hospital, a study member will visit you to discuss the study. You can also visit our website, [www.ScreenPlusNY.org](http://www.ScreenPlusNY.org), for more information.

 If we missed you during your stay, we may still call you 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.

 Your decision will be recorded by the ScreenPlus researcher, and you're good to go!

## 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!

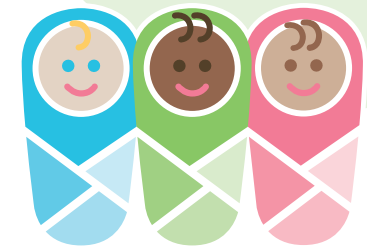
ScreenPlus | 718.741.2496  
[screenplus@montefiore.org](mailto:screenplus@montefiore.org)  
[www.ScreenPlusNY.org](http://www.ScreenPlusNY.org)

Suhas Nafday, M.D.  
*Site Principal Investigator*  
Jack D. Weiler Hospital/  
Montefiore Medical Center

Melissa Wasserstein, M.D.  
*ScreenPlus Principal Investigator*  
The Children's Hospital  
at Montefiore  
The University Hospital for Albert  
Einstein College of Medicine

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 visit the website.**



# 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.

## Research Study Examining Additional Newborn Screening for Rare Disorders

ScreenPlus is a research study that offers parents of babies born at select NY pilot hospitals the option to screen for 14 additional disorders that are not currently on NY's routine newborn screening panel. ScreenPlus requires your permission and will help us understand how well newborn screening works for these additional conditions.

## 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 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*