CT-AAP WEBINAR: Strengthening Sickle Cell Trait Care in Connecticut: A New Statewide Initiative

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Debra Ellis, MSN, RN, NPD-BC, faculty for this educational event, has no relevant financial relationship(s) with ineligible companies to disclose.

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Strengthening Sickle Cell Trait Care in Connecticut: A New Statewide Initiative

November 2025

Agenda

Newborn Screening in Connecticut

Sickle Cell Trait vs. Hemoglobin C Trait

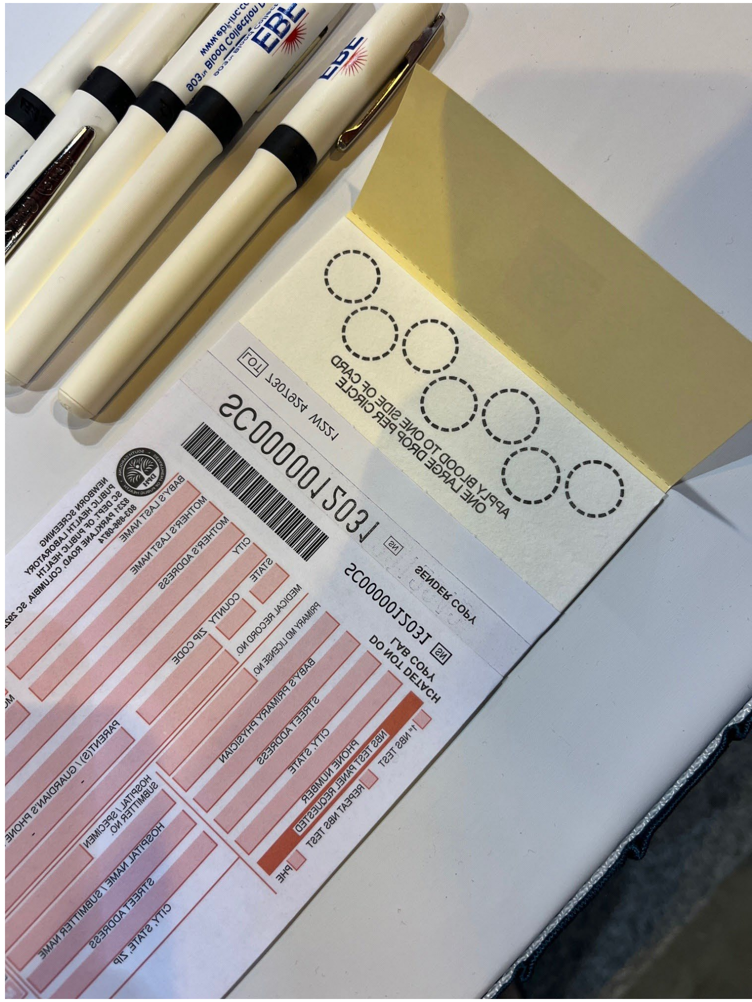
Why It’s Important

Old Workflow

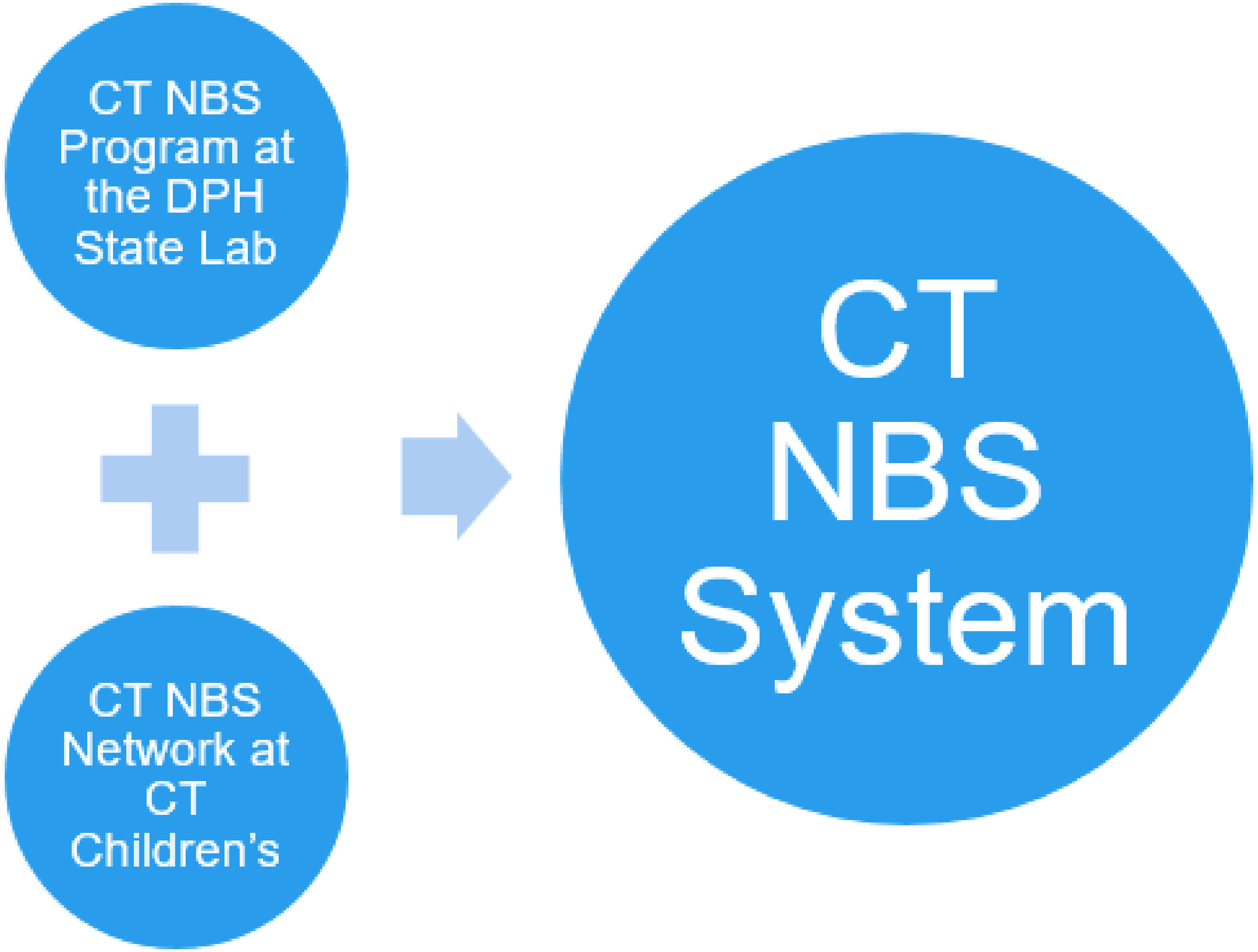
Challenges

New Workflow

cCMV Update



Connecticut Newborn Screening



CT NBS Program at the DPH State Lab

CT NBS Network at CT Children's

CT NBS System

Sickle Cell Trait vs. Hemoglobin C Trait

	Sickle Cell Trait	Hemoglobin C Trait
What it is	Carrier status: Inherits one normal (A) and one sickle (S) gene	Carrier status: Inherits one normal (A) and one C gene
Health effects	Usually no symptoms	No symptoms
Why it matters	Can pass the sickle gene to children Has important health, reproductive, and counseling implications	Can pass the C gene to children
If both parents carry a trait	Child could have sickle cell disease (HbSS) or HbSC disease	Child could have HbCC disease or HbSC disease

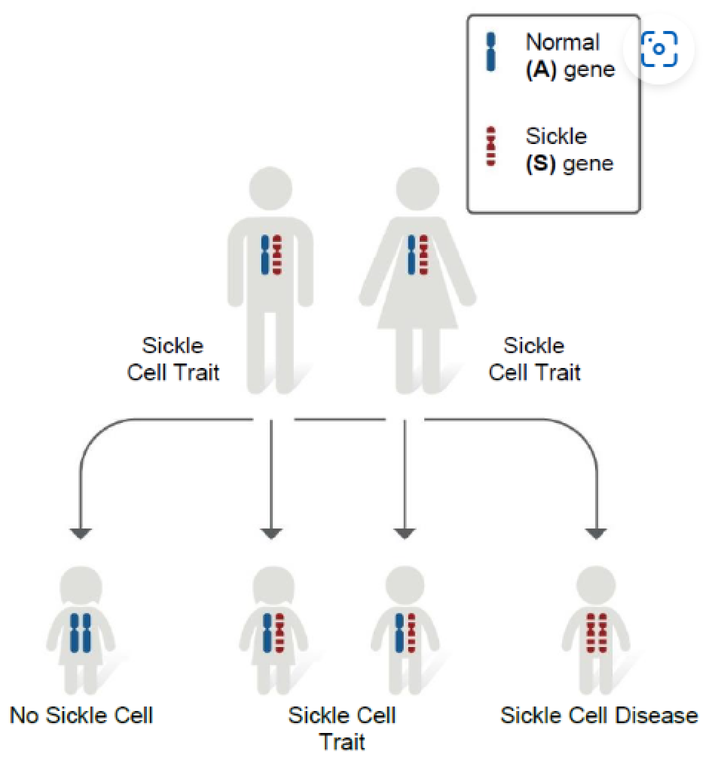


Image source: National Institute of Health, National Heart, Lung, and Blood Institute

Sickle Cell Trait (SCT) in Connecticut

≈ 1,000 babies in CT are identified each year as having SCT

> 80% of adults with SCT do not know their status

Why Parents Need to Know Their Baby’s SCT Status: Health Impact

- **Potential health risks**
  - Pain crises under extreme conditions
  - Heat stroke, muscle cramps, or weakness
  - Higher risk of complications such as:
    - Venous thromboembolism (VTE)
    - Chronic kidney disease
    - Hematuria and retinopathy
- **Emerging evidence**
  - Recent studies show SCT may not be entirely benign
    - Children with SCT had 44% -48% higher mortality, mainly from respiratory causes *(Tracking California, PHI; Public Health Reports)*
  - SCT can affect health across the lifespan, not just under stress.

Why Parents Need to Know Their Baby’s SCT Status: Family & Future Planning

- **Family Planning Implications**
    - Informs reproductive decisions
    - Supports genetic counseling and preimplantation testing
    - Helps families prepare for possible trait inheritance

- **Why Awareness Matters**
    - SCT is often seen as harmless, but research links it to long-term health affects.
    - Early knowledge empowers families and providers to monitor, prevent, and educate.

Megan Coco, APRN

Nurse Practioner

Connecticut Children's

Center for Cancer & Blood Disorders

Previous SCT Workflow in CT

NBS is suggestive of SCT

The Connecticut Department of Public Health NBS Program reports the result to the PCP office via phone call.

AND, faxes a letter to the PCP requesting:

1.) The family be notified of the result

2.) Hemoglobin electrophoresis be done at 6 months of age, and the results faxed to DPH

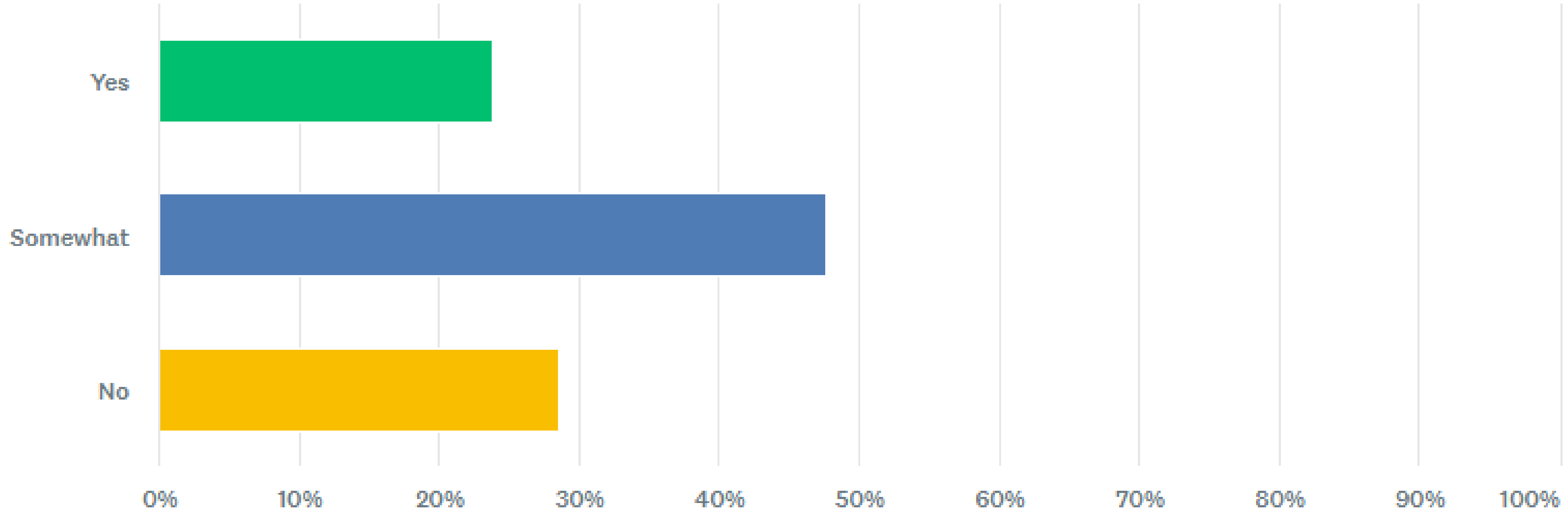
3.) Referral to a newborn screening genetic counselor for a no-cost telehealth appointment

Challenges

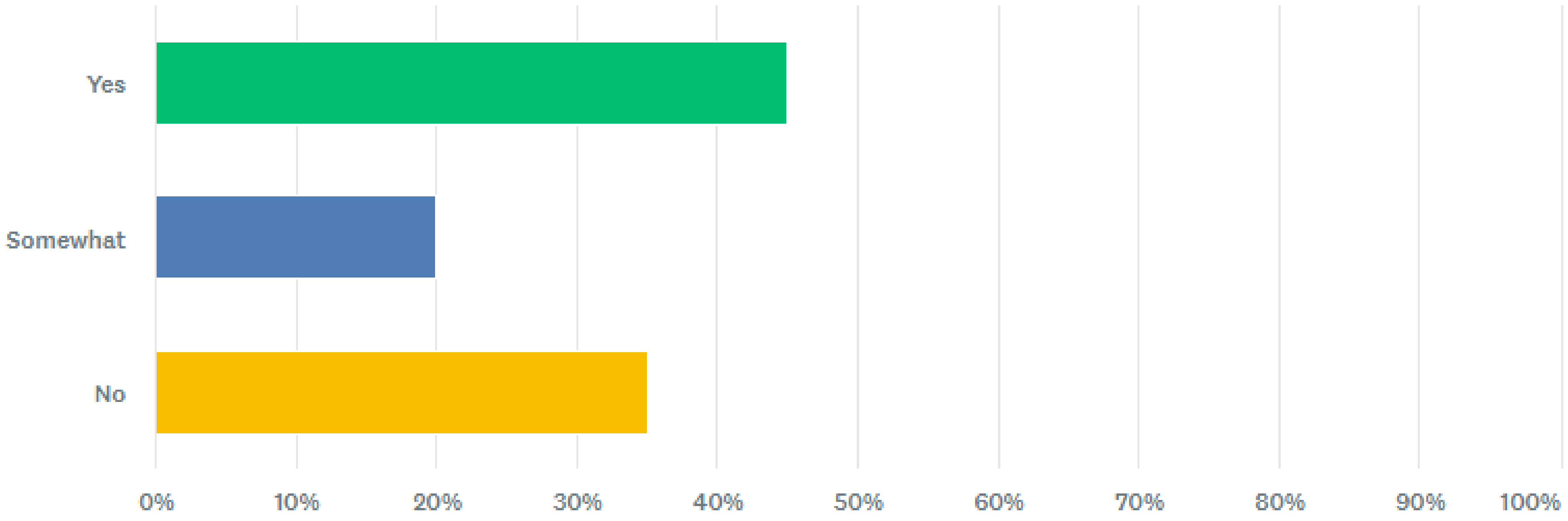
Of the 1039 sickle cell trait cases reported in 2024:

- 15 completed follow-up testing and submitted results to DPH NBS Program (1.4%)
- 2 scheduled an appointment with the genetic counselor

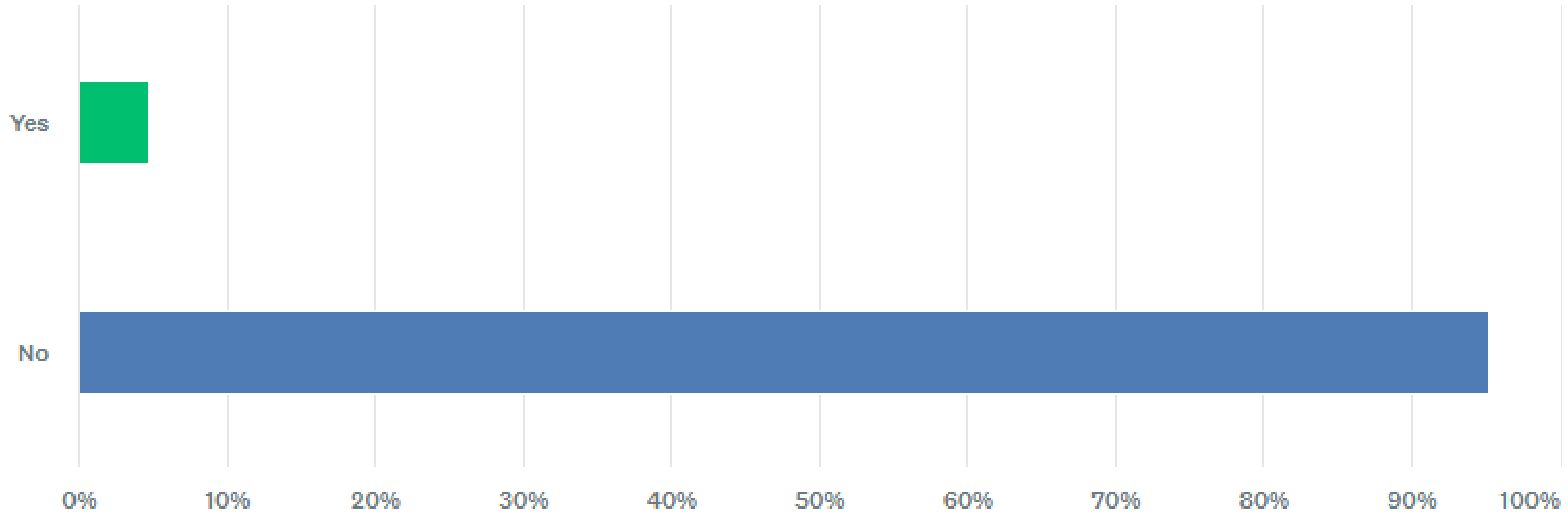
Do you feel like you understand what sickle cell trait is?



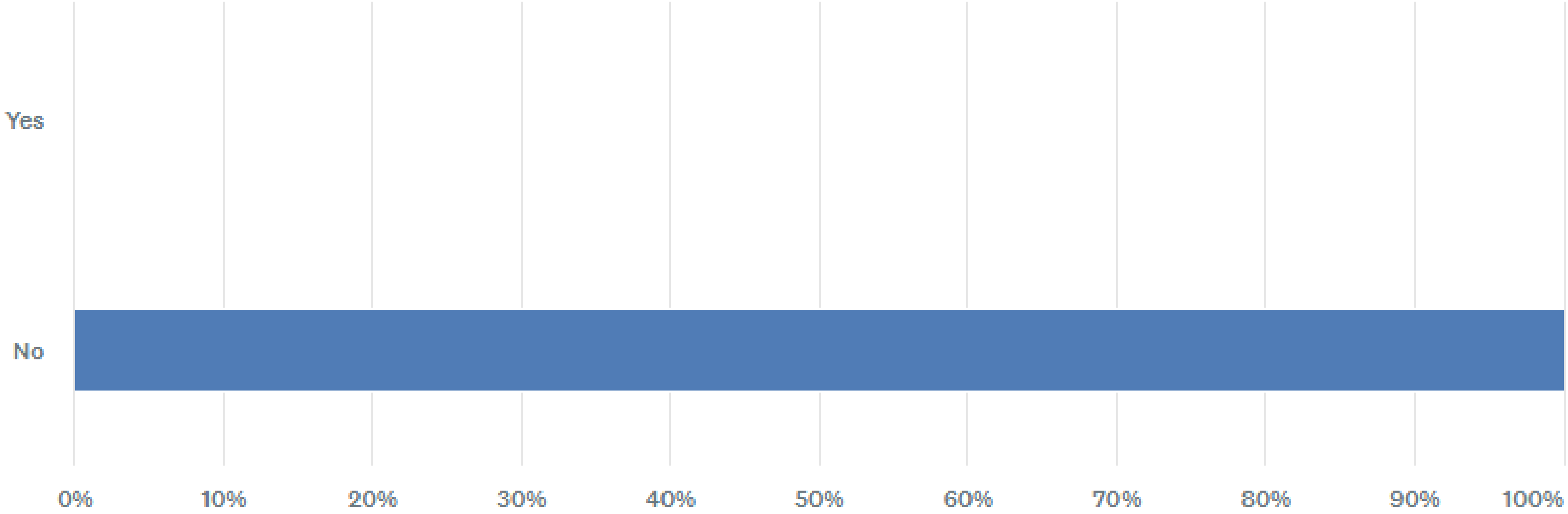
Do you know where to look for more information about sickle cell trait?



Have you received any educational materials about sickle cell trait from a healthcare provider?



Have you (the parent) ever had carrier screening to see if you also have sickle cell trait?



Goal: To improve the identification, communication, and follow-up care for newborns who screen positive for **sickle cell trait** and **hemoglobin C trait.**

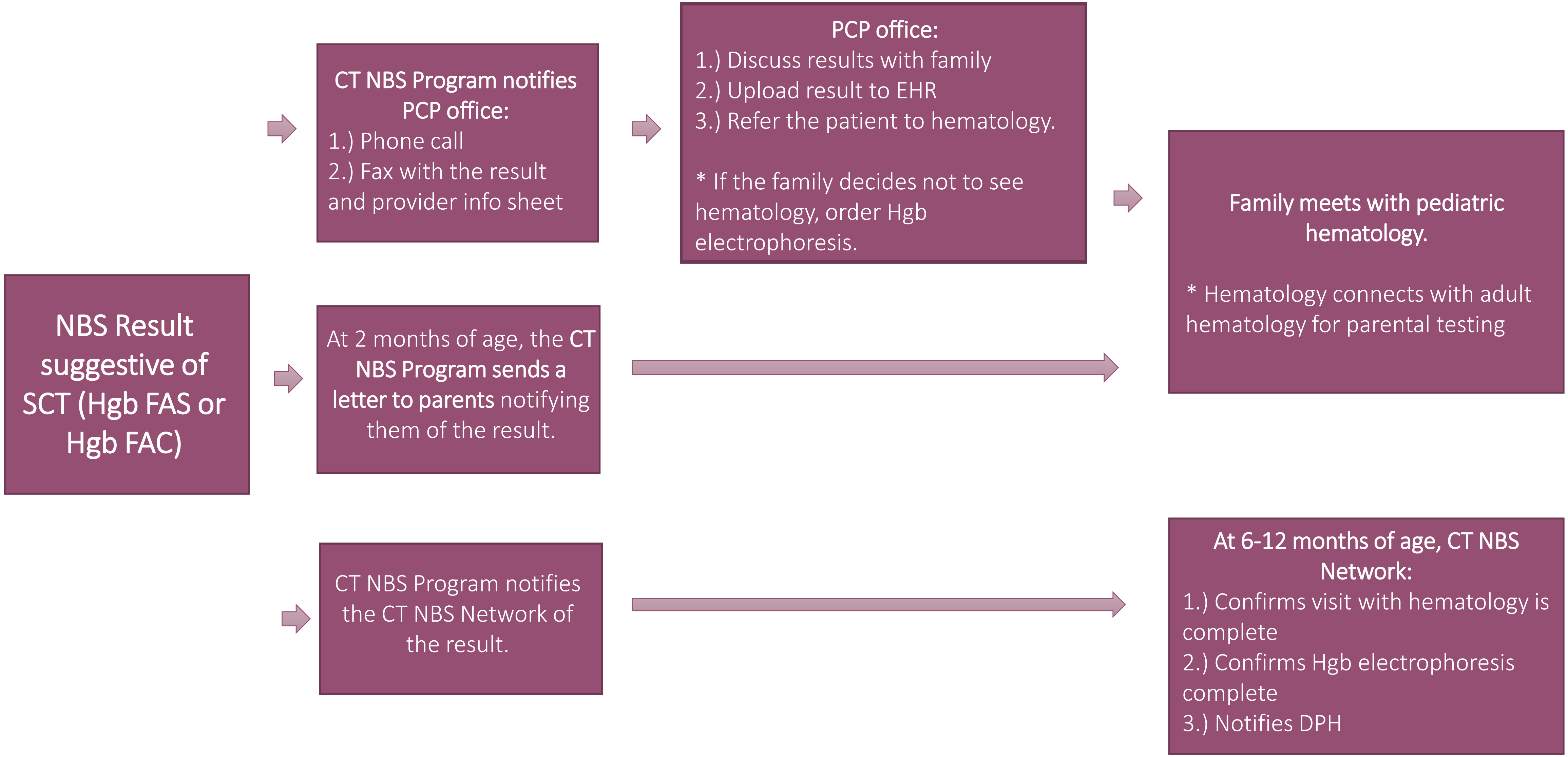
Input from Families

► Families would like to be notified by their PCP **AND** receive a letter in the mail that includes written information and next steps.

► Families would welcome the opportunity to see a pediatric hematologist.

► Families would like the option of in-person or telehealth visits.

New SCT Workflow



NBS Result suggestive of SCT (Hgb FAS or Hgb FAC)

CT NBS Program notifies PCP office:
1.) Phone call
2.) Fax with the result and provider info sheet

PCP office:
1.) Discuss results with family
2.) Upload result to EHR
3.) Refer the patient to hematology.

* If the family decides not to see hematology, order Hgb electrophoresis.

At 2 months of age, the **CT NBS Program sends a letter to parents** notifying them of the result.

Family meets with pediatric hematology.

* Hematology connects with adult hematology for parental testing

CT NBS Program notifies the CT NBS Network of the result.

At 6-12 months of age, CT NBS Network:
1.) Confirms visit with hematology is complete
2.) Confirms Hgb electrophoresis complete
3.) Notifies DPH

Provider Action List

1. **Discuss** the results with the family. Provide information about inheritance, the hematology referral, and confirmatory testing.

2. **Upload** the newborn screening result to the baby's electronic health record.

3. **Refer** the patient to pediatric hematology. If the family decides not to see a pediatric hematology, ensure that a hemoglobin electrophoresis is completed at 6 months of age to confirm trait status.

“If it’s not the disease, why do I need to see hematology?”

Knowing your baby’s trait status is important for the future:

1. It could affect your baby’s own children.

2. It may affect your future pregnancies. If both parents have sickle cell trait, there’s a chance of having a child with sickle cell disease. Knowing carrier status before pregnancy gives families the opportunity to meet with a prenatal genetic counselor to explore prenatal screening and testing options, such as pre-implantation genetic testing (PGT).

3. Since new studies show that children with the trait may have slightly higher health risks than previously thought, having this information allows doctors and you to be aware and proactive in protecting your child’s health.

Provider Factsheet

CONNECTICUT
Public Health

Connecticut Newborn Screening

Provider Factsheet: Sickle Cell Trait (Hgb FAS)

Information for Primary Care Providers

All babies born in the state of Connecticut are screened for hemoglobinopathies on their newborn screening (NBS) at birth. Each year over one thousand babies screen positive on their NBS for a hemoglobin trait in CT. This fact sheet is designed to empower pediatricians and primary care providers of newborns to discuss what this means for their patients' families.

Clinical Overview

An inherited condition known as sickle cell trait occurs when a person inherits the genes for normal hemoglobin (A) and abnormal sickle hemoglobin (S), leading to the genotype (AS). Sickle cell disease occurs when a person inherits two abnormal sickle genes (SS). Sickle cell disease (SCD) causes vaso-occlusive crises and other serious health complications.

While sickle cell trait (SCT) is not a disease and is unlikely to cause serious health complications, under certain circumstances, individuals with trait can experience complications. This can occur when the body is under severe stress or requires more oxygen.

It is rare for SCT to cause health problems and most individuals with SCT do not need treatment.

Despite the low risk of clinical manifestations for individuals with SCT, it is still important to discuss this result with patients and their families.

Provider Action List

1. Discuss results with the family at baby's next appointment. Provide information about inheritance and the plan for confirmatory testing.
2. Upload parent information sheet and newborn screening result to baby's electronic health record. Ensure a physical copy of the result is available to the family.
3. Refer family to pediatric hematology for assessment. Pediatric hematology will order hemoglobin electrophoresis at 6 months of age to confirm trait status. (Contact information for pediatric hematology to be added)

Sickle Cell Trait, Page 1 of 2, last updated June 2025

Connecticut Department of Public Health Newborn Screening Program • 860.920.6628
Connecticut Newborn Screening Network • 860.837.7870

CONNECTICUT
Public Health

Connecticut Newborn Screening

Provider Factsheet: Sickle Cell Trait (Hgb FAS)

Considerations for Inheritance

SCT can impact family members even though it is unlikely to cause health issues for this baby. Each pregnancy has a 1 in 4 (25%) chance of producing a child with SCD if both parents have SCT. Sickle cell disease is a disorder with the potential for serious health complications such as anemia, stroke, painful crises, splenomegaly, infection, and more.

Given that SCT and SCD are genetic disorders, genetic counseling should be provided. The **Connecticut Newborn Screening Network** provides free genetic counseling for newborns who screen positive for SCT. Their phone number is (860) 837-7870.

Scan here for more information about Sickle Cell Trait

Learn More About SCT – Just Scan the QR Code!

Scan the QR code to visit the CT NBS page on Sickle Cell Trait

Have questions? Call the Connecticut Newborn Screening Network at (860) 837-7871.

This fact sheet was written for information purposes only. It should not replace medical advice, diagnosis, or treatment.

Sickle Cell Trait, Page 2 of 2, last updated June 2025

Connecticut Department of Public Health Newborn Screening Program • 860.920.6628
Connecticut Newborn Screening Network • 860.837.7870

Family Letter

Connecticut Newborn Screening Program
Connecticut Department of Public Health
Katherine A Kelley State Public Health Laboratory
395 West St, Rocky Hill, CT 06067

Parent Name
Parent Address
Parent City, Zip

Congratulations on the birth of your baby!

You are receiving this letter to share important information from your baby's newborn screening.

Every baby born in Connecticut gets a newborn bloodspot screen (NBS). This is done by taking a few drops of blood from the heel of your baby's foot when they are 1 to 2 days old. The newborn screen checks for many conditions, including the hemoglobin in your baby's blood. Hemoglobin is the part of blood that carries oxygen throughout the body.

Your baby's newborn screen showed that they might have **sickle cell trait**, a type of **hemoglobin trait.**

What is Sickle Cell Trait?

Sickle cell trait means your baby carries a gene for sickle cell disease but **does not** have the disease itself.

- Sickle cell trait is another way to say someone is a **gene carrier** for sickle cell disease. People with sickle cell trait can live healthy lives.

Knowing your baby's trait status is important for the future:

- It could affect your baby's own children when they grow up.
- It may affect your future pregnancies as parents

What Happens Next:

1.) Talk to your baby's healthcare provider.

Your baby's healthcare provider has been notified of this result. Please bring this letter to your **baby's next doctor's visit** and talk about the results.

2.) Have follow-up testing to confirm the newborn screen result

The doctor will refer your baby to a **pediatric hematologist (a blood doctor** or **blood specialist**). Work with their doctor to get the appointment scheduled.

A pediatric hematologist is different from a regular pediatrician or doctor. They are experts in blood conditions (like sickle cell trait) in children. The visit with the hematologist and the follow-up testing should happen when your baby is between **6 months and 1 year old.**

- ☐ Visit this website for more information: https://portal.ct.gov/newborn-screening-program
- ☐ Bring this letter to your baby's next doctor's appointment.
- ☐ Schedule an appointment with a pediatric hematologist (a blood doctor). Your child's doctor will place the referral for the appointment.
- ☐ Visit the pediatric hematologist and complete diagnostic testing.

Scan here for more information about Sickle Cell Trait

We Are Here to Support You!

Your baby's health and well-being are our top priority.

While you wait for your appointment, you can find more information at:

👉 https://portal.ct.gov/newborn-screening-program

If you would like to talk to a **genetic counselor** about the results while you wait for your appointment with the pediatric hematologist, call the Connecticut Newborn Screening Network to set up a no-cost appointment. Ask for an appointment with the Newborn Screening Genetic Counselor by calling:

📞 (860) 837-7870

Contact Us Anytime:
Connecticut Newborn Screening Program
Phone: (860) 920-6628
Email: dph.nbstracking@ct.gov
Website: https://portal.ct.gov/newborn-screening-program

Outcomes

- ► More families will access follow-up resources (recommended labs, genetic counseling)
- ► More individuals will be aware of their trait status

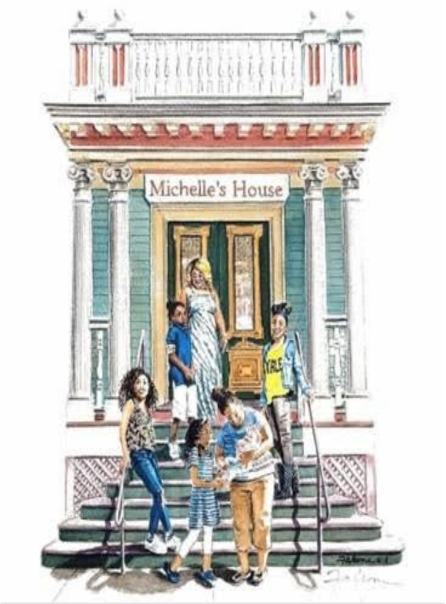
Sickle Cell Disease Association of America, Connecticut

Connecticut Newborn Screening Network

Webinar

November 19, 2025

Presented By:



Gary R. Smart, MPA, FACHE
Interim Executive Director
Sickle Cell Disease Association of America, CT
1389 Chapel St.
New Haven, CT, 06511

Sickle Cell Disease Association of America,
Connecticut

Our Organization

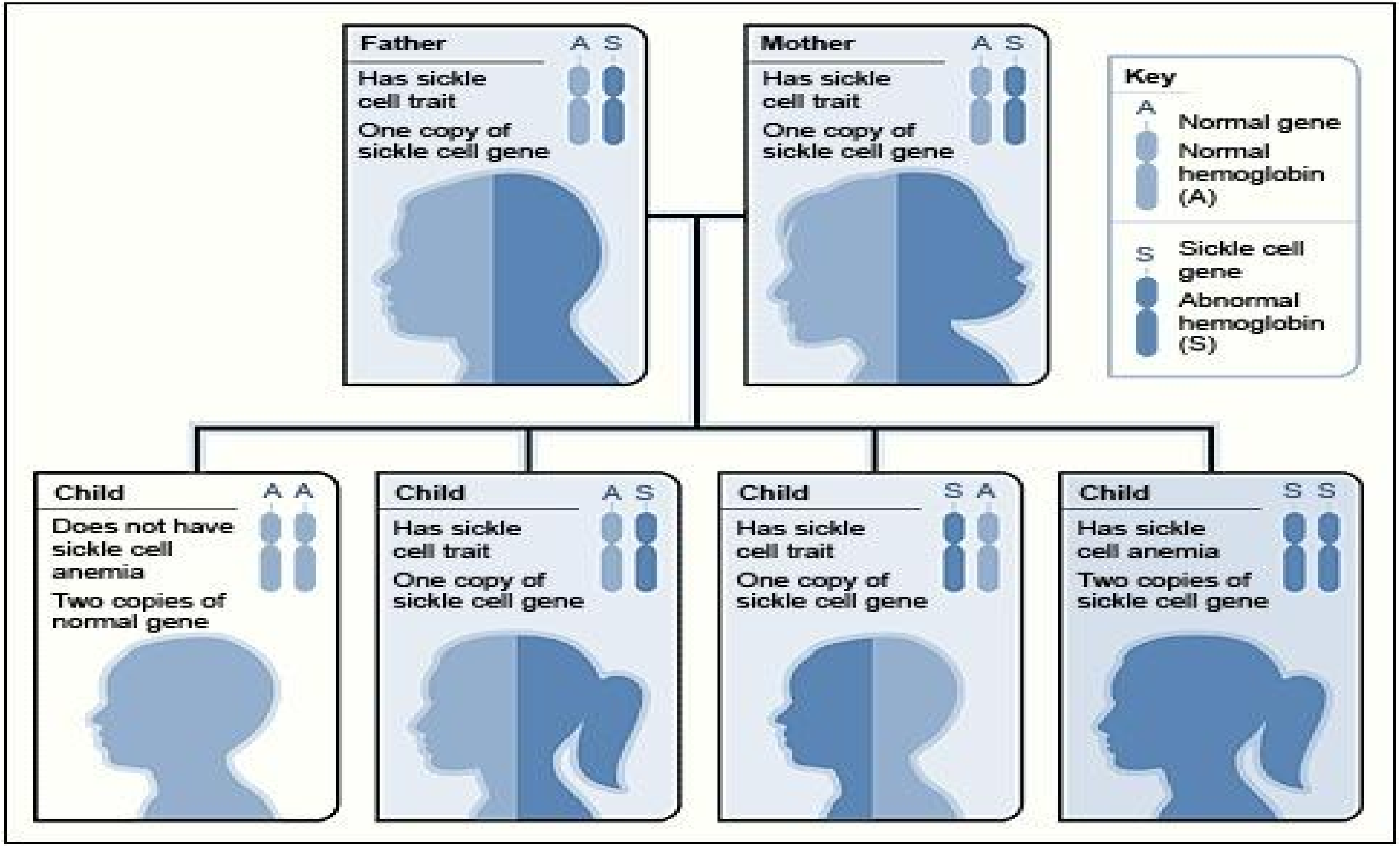
Statewide CBO: (Sickle Cell Disease Association of America: Connecticut Chapter)

Established in 1985: Bridgeport, CT (Sickle Cell Disease Association of America, Southern CT)

Mission: We embrace prevention strategies to enhance the quality of life and well-being of the community affected by sickle cell disease (SCD), trait and related conditions. We provide individuals and families with critical education and access to support services. This work is accomplished through partnerships and advocacy.

Sickle Cell Disease Association of America,
Connecticut

SCD Trait & Its Impact



Philadelphia Story

The Value of Communication

Sickle Cell Disease Association of America,
Connecticut

SCD Facts/Statistics

SCD can cause pain and other health complications

- Life expectancy is 20 years shorter than the average person
- Approximately 100,000 U.S citizens are living with SCD
- 1 in 13 African American babies is born with SCT
- 1 in 365 African American babies is born with SCD
- We have identified over 800 individuals in CT living with SCD, however it is estimated that close to 2000 more are unidentified/unknown.
- There are approximately 75,000 carrying the Sickle Cell Trait in CT
- Annually, 600 babies are born with the trait throughout the state

Social Statistics

SCD predominantly affects communities of color

- SCD can also be found in Latino and Middle Eastern communities as well
- Children with SCD more likely to repeat grades than the general public
- Gene Therapy (Casgevy & Lyfgenia) provide hope, however they are considered **potentially curative or transformative** rather than a definite cure
- Gene Therapy is not accessible to everyone, a patient can spend upwards of 16 months in the hospital, if they qualify
- Clinical trials and treatment can be prohibitively expensive ($1- 3 million per case)

Sickle Cell Disease Association of America,
Connecticut

2026 Goals & Objects

- **Coalition Development:** to have all health providers use SCDAA, CT as central point of reference for those in need of resources and more importantly reduce unintentional harm to future generations through trait testing and educational campaigns. This will also include a central database to better serve SCD Warriors.
- **Generational Health:** As many talk about Generational Wealth, we keep our focus on Generational Health as a cornerstone of our fight to Break the Sickle Cell Cycle and improve the quality of life for all of the Sickle Cell Warriors in the state.
- **Case Management:** We will be developing a program model of support that provides wrap around care for our Warriors prior to and after treatment at health care service sites for issues related to social determinants of health.
- **Educational Support:** Partnerships with academic institutions of higher education and superintendents of school systems across the state to ensure tutorial opportunities are available. This support would also include advocating for student inclusion in 504 plans and/IEP, if appropriate.
- **Increase Trait Testing Statewide:** This would require using the model of clinical partnership established in New Haven as a procedural template for use at additional health care service sites i.e. hospitals and FQHCs.

Sickle Cell Disease Association of America,
Connecticut

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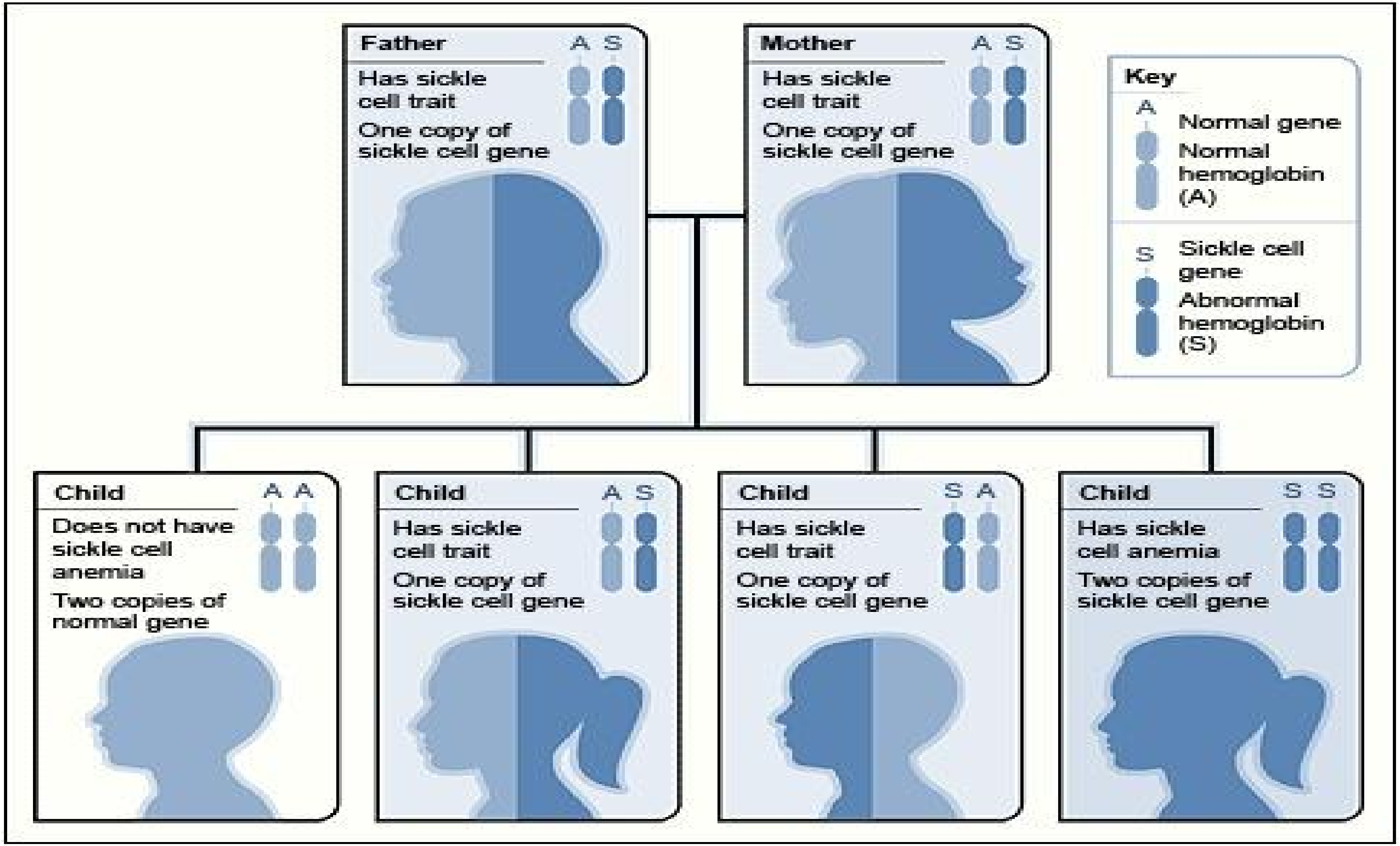

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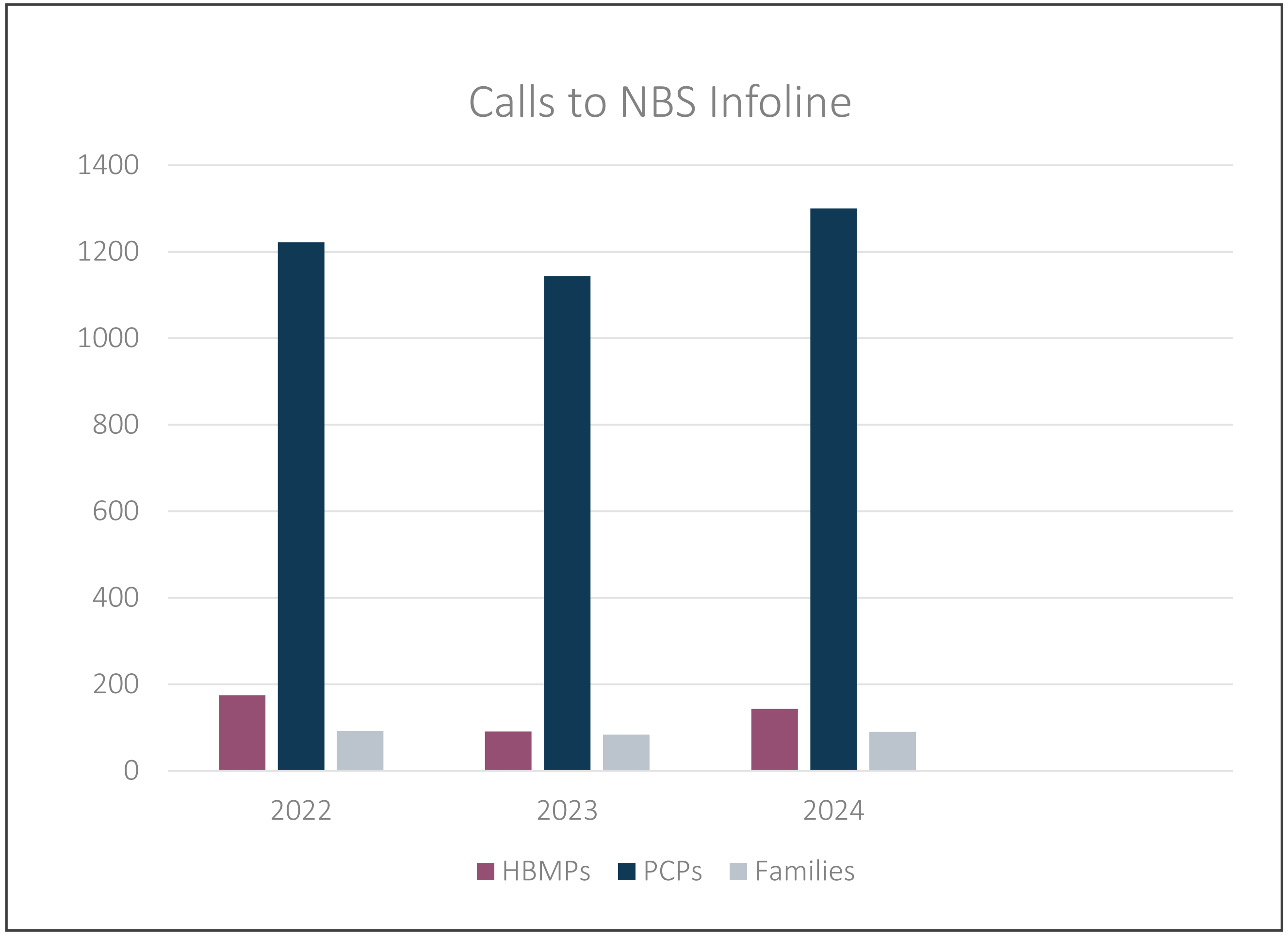
NBS Infoline

(860) 837-7870



Thank You!

Q & A

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Please complete this evaluation to claim your CME credit. A certificate will be emailed to you after the evaluation closes on **December 20th, 2025**. We appreciate your feedback, as this information is important for creating valuable CME experiences for you in the future.

EVALUATION QR

CT-AAP WEBINAR

Strengthening Sickle Cell Trait Care in Connecticut: A New Statewide Initiative

Thank you for joining us!

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