California Newborn Screening Program Hemoglobin Trait Follow-up Services

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Cayenne Wellness Center Town Hall Meeting
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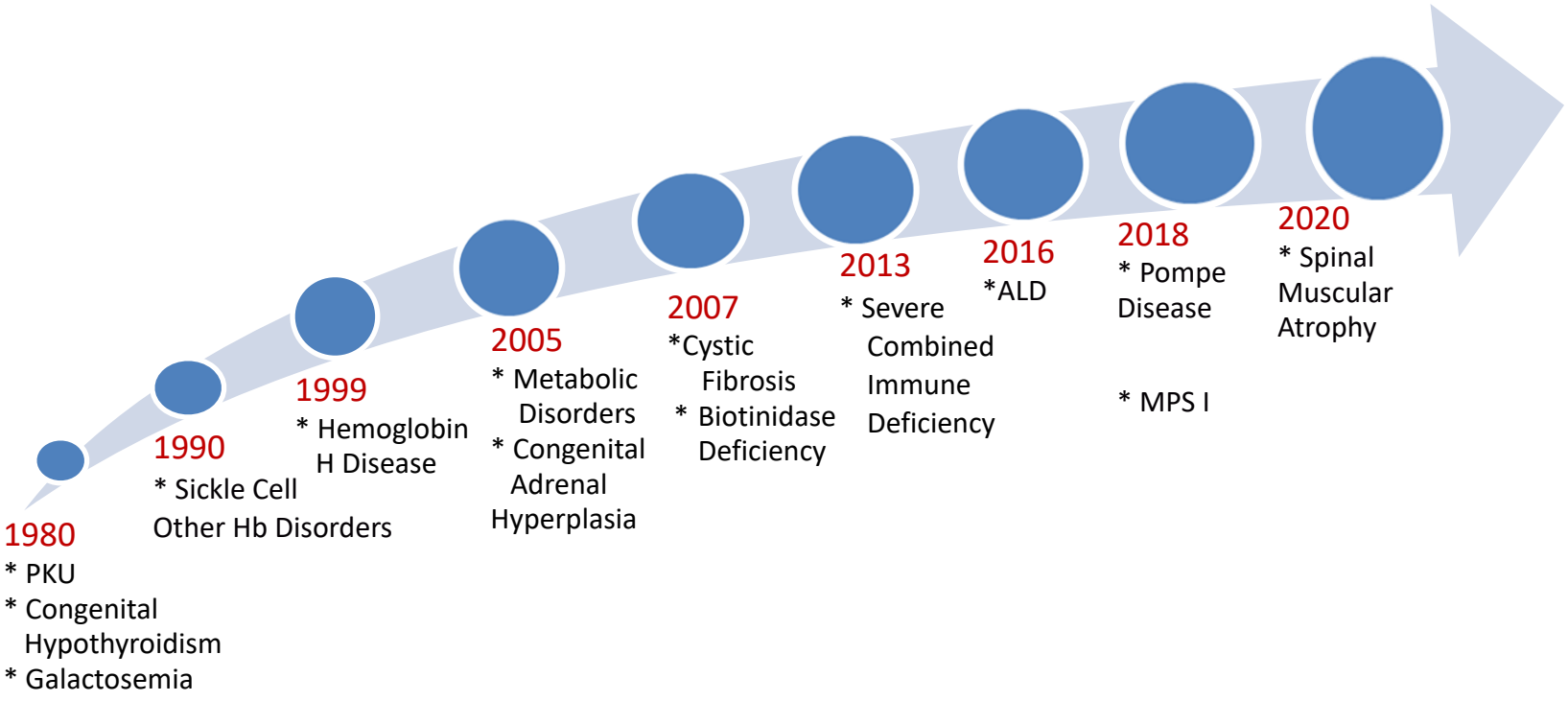
I do not have any relationships to disclose.

Newborn Screening (NBS)

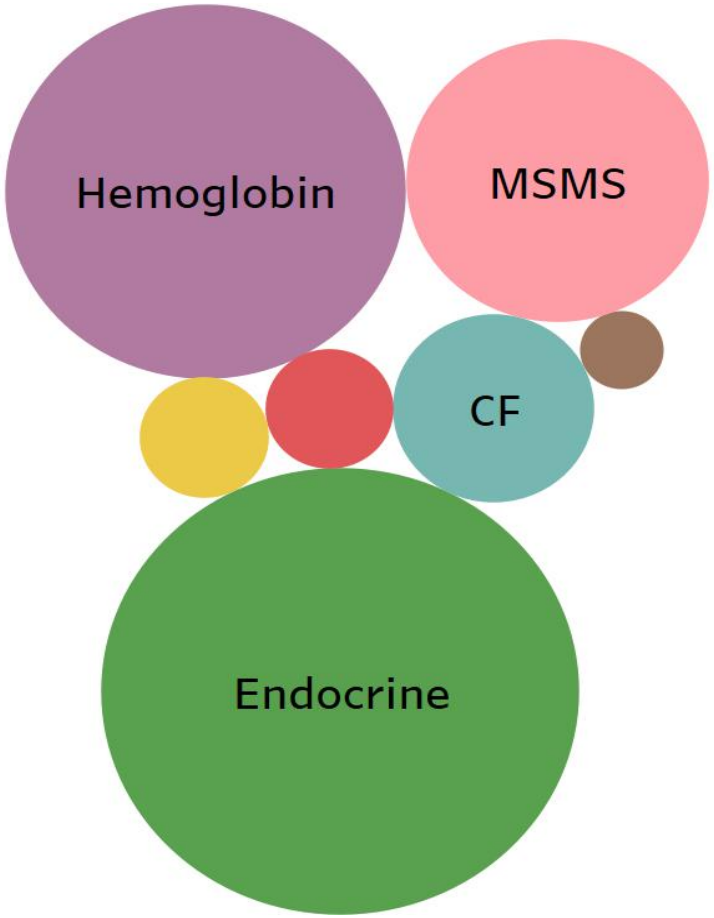
- Newborn Screening can identify babies with certain diseases so that treatment can be started right away. Early treatment can prevent disabilities, delayed growth and/or life- threatening illnesses.
- NBS in CA is mandated state public health program that started in 1980 and is governed by Barclays Official California Code of Regulations.
- Hemoglobin (Hb) screening started in 1990.

Newborn Screening Expansion in California



Incidence of Disorders Detected by NBS 2012-2016

Hemoglobin disorders are the second most common group detected by NBS in California.



Hemoglobinopathy Screening

- The hemoglobin testing methodology is automated high pressure liquid chromatography (HPLC).
- We identify around 200 newborns a year with Hb patterns that lead to further follow-up, including confirmatory testing and a referral to a California Children's Services Hb Center.
- Includes Sickle Cell and Thalassemias.

Hb Trait Follow-Up

- Our testing also identifies Hb carriers (almost 5,000/ year).
- Free telephone counseling and parent testing is available in English and Spanish. Staff use translation services for other language needs.
- Information about program services is provided to the provider listed on the NBS Test Request Form and the family.

Hemoglobin Trait Carrier Rate by Race/Ethnicity in California Newborns (2010-2014)

Race/Ethnicity	Sickle Cell Trait Carrier Rate	Hb C Trait Carrier Rate	Hb D Trait Carrier Rate
Black	1/14	1/47	1/3019
Native American	1/96	1/419	1/2094
Hispanic	1/192	1/1474	1/2169
Middle Eastern	1/268	1/3560	1/542
White	1/630	1/2962	1/2828
Asian Indian	1/637	1/24221	1/234
Filipino	1/855	1/3465	1/2772
East Asian	1/6072	1/12903	1/25806
Southeast Asia	1/1331	1/7763	1/2588
Pacific Islander	1/185	1/555	N/A
Other	1/210	1/1037	1/1004
Multiple	1/59	1/219	1/2429

Sickle Cell Trait Pamphlet

For Parents of Babies with Sickle Cell Trait or another Hemoglobin Trait

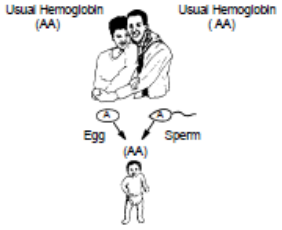
For parents of babies with a hemoglobin trait

You have just learned that your baby has a hemoglobin trait, either hemoglobin S (sickle) trait, hemoglobin C trait, or hemoglobin D trait. This means that your baby's red blood cells have a different kind of hemoglobin along with the usual kind. It is not a disease. It cannot cause your baby to become ill.

(1)

What is hemoglobin?

Hemoglobin is found in the red blood cells of all people. It gives blood its red color and carries oxygen to all parts of the body. There are many types of hemoglobin. They are passed down in the family from parent to child in the genes. Genes are the tiny bits of information found in the father's sperm and the mother's egg. Together this information forms a pattern for a new life. Most people have two genes for hemoglobin A. This means that they received one gene for hemoglobin A from each parent and make red blood cells with hemoglobin A only.



Babies get one gene for hemoglobin type from each parent. This baby has the usual hemoglobin.

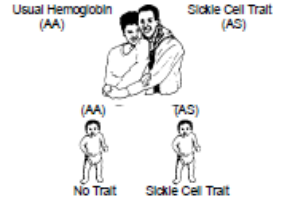
(2)

What is a hemoglobin trait?

A hemoglobin trait occurs when a baby receives a gene for hemoglobin A from one parent and a gene for a different hemoglobin type (S, C, or D) from the other parent. The baby makes red blood cells containing both hemoglobin A and the different hemoglobin. This is **not** a disease.

Hemoglobin S, C, and D are more often found in people whose families came from Africa, Mexico, Central America, and in some cases, India, the Middle East, and parts of Europe and Asia. However, **anyone can have red blood cells with hemoglobin S, C, or D.** In addition, there are other hemoglobin traits such as beta thalassemia trait and other less common traits.

(3)



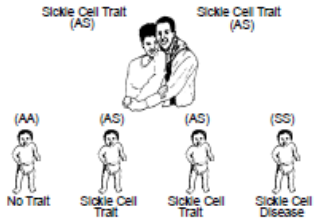
If one parent has usual hemoglobin and the other parent has sickle cell trait, they have a 50% chance with each pregnancy of having a baby with sickle cell trait.

If our baby is healthy, why should we be tested?

There are some combinations of hemoglobin types that can cause serious health problems. Blood tests can tell you your hemoglobin type. If one parent has only hemoglobin A and the other has a different hemoglobin type, future children will not have a hemoglobin disease. However, if both parents have a hemoglobin trait, a future child may have a hemoglobin disease, such as sickle cell disease.

What is sickle cell disease?

Sickle cell disease occurs when a person receives one gene for sickle (S) hemoglobin from one parent and a sickle (S), C, D, or beta thalassemia gene from the other parent. This disease can cause serious long term health problems.



If both parents have sickle cell trait, they have a 25% chance (1 in 4) with each pregnancy of having a baby with sickle cell disease.

(4)

Remember - your baby is healthy

Your baby has a hemoglobin trait. It is **not** a disease. It will never change into a disease.

For more information:

- talk with your doctor
- call the **Newborn Screening Sickle Cell Trait Counselor** toll-free: **1 (866) 954-2229**
- **Kaiser members:** call your nearest Kaiser Genetics Department (see letter for phone numbers)

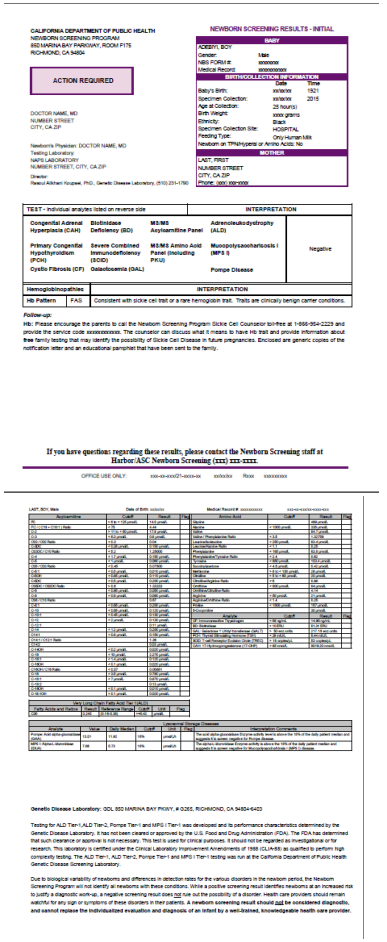
(5)

California Department of Public Health
Newborn Screening Program

NBS Provider Result Mailer

Follow-up:

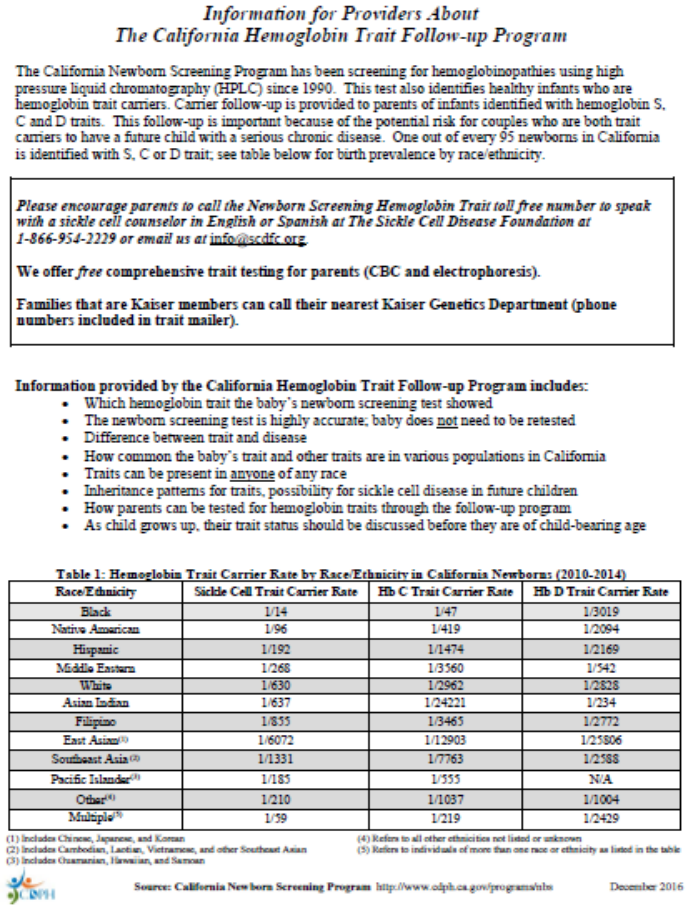
- Hb: Encourages the parents to call the Newborn Screening Program Sickle Cell Counselor toll-free at 1-866-954-2229 and provide the service code xxxxxxxxxxxx.
- The counselor will discuss what it means to have Hb trait and provide information about free family testing that may identify the possibility of Sickle Cell Disease in future pregnancies.
- Enclosed are generic copies of the notification letter and an educational pamphlet that have been sent to the family.



CDPH California Department of PublicHealth

Provider Fact Sheet

- Describes the services offered in the follow-up program
- Explains that that trait is found in all ethnicities
- Addresses the risk for a child with disease if both parents are carriers



Information for Providers About
The California Hemoglobin Trait Follow-up Program

The California Newborn Screening Program has been screening for hemoglobinopathies using high pressure liquid chromatography (HPLC) since 1990. This test also identifies healthy infants who are hemoglobin trait carriers. Carrier follow-up is provided to parents of infants identified with hemoglobin S, C and D traits. This follow-up is important because of the potential risk for couples who are both trait carriers to have a future child with a serious chronic disease. One out of every 95 newborns in California is identified with S, C or D trait; see table below for birth prevalence by race/ethnicity.

Please encourage parents to call the Newborn Screening Hemoglobin Trait toll free number to speak with a sickle cell counselor in English or Spanish at The Sickle Cell Disease Foundation at 1-866-954-2229 or email us at info@scdfc.org.

We offer *free* comprehensive trait testing for parents (CBC and electrophoresis).

Families that are Kaiser members can call their nearest Kaiser Genetics Department (phone numbers included in trait mailer).

Information provided by the California Hemoglobin Trait Follow-up Program includes:

- Which hemoglobin trait the baby's newborn screening test showed
- The newborn screening test is highly accurate; baby does not need to be retested
- Difference between trait and disease
- How common the baby's trait and other traits are in various populations in California
- Traits can be present in anyone of any race
- Inheritance patterns for traits, possibility for sickle cell disease in future children
- How parents can be tested for hemoglobin traits through the follow-up program
- As child grows up, their trait status should be discussed before they are of child-bearing age

Table 1: Hemoglobin Trait Carrier Rate by Race/Ethnicity in California Newborns (2010-2014)

Race/Ethnicity	Sickle Cell Trait Carrier Rate	Hb C Trait Carrier Rate	Hb D Trait Carrier Rate
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(1) Includes Chinese, Japanese, and Korean
(2) Includes Cambodian, Laotian, Vietnamese, and other Southeast Asian
(3) Includes Guamanian, Hawaiian, and Samoan
(4) Refers to all other ethnicities not listed or unknown
(5) Refers to individuals of more than one race or ethnicity as listed in the table

Source: California Newborn Screening Program http://www.cdph.ca.gov/programs/nbs December 2016

Hb Trait Letter to Family

- Sent three days after Physician letter
- Explains test results
- Explains trait is not disease
- Explains basic inheritance
- Explains risk for SCD in future if both parents are carriers
- Offers counseling and parent testing services

CALIFORNIA DEPARTMENT OF PUBLIC HEALTH
NEWBORN SCREENING PROGRAM
850 MARINA BAY PARKWAY, ROOM F175
RICHMOND, CA 94804

Service Number
xxxxxxxxxxx

MOM NAME
MOM STREET
MOM CITY

Congratulations on the birth of your baby!

Here is some important information for you. In California all babies have their blood tested soon after birth. One of the tests done on the baby's blood is for hemoglobin type. Hemoglobin is found in the red blood cells of all people. It gives blood its red color and carries oxygen to all parts of the body. The test showed that your baby is a carrier of sickle cell trait or another hemoglobin trait. A trait IS NOT A DISEASE, and will not cause your baby to become ill.

Traits are passed down in the family from parent to child. Since your child has this trait at least one of the parents is a carrier of a hemoglobin trait. If BOTH parents have a trait their next child may have a serious health problem. A special blood test can tell if both parents have a trait.

- Information and free testing are available by calling the Newborn Screening Sickle Cell Trait Counselor toll-free at 1-866-954-2229. All of the services are confidential. When you call, please give the Sickle Cell Trait Counselor the service number listed at the top of this letter.
- This information has also been sent to your baby's doctor. Please take this letter with you to the baby's next appointment and discuss it with your doctor.

¡Felicitaciones por el nacimiento de su bebé!

Aquí esta una información importante para usted. En California, a todos los bebés se les hace una prueba de sangre al poco tiempo de nacer. Una de las pruebas que se hacen es la del rasgo de hemoglobina. La hemoglobina se encuentra en los glóbulos rojos de todas las personas. Le da a la sangre su color rojo y lleva oxígeno a todas las partes del cuerpo. La prueba mostró que su bebé es un portador del rasgo de células falciformes u otro rasgo de hemoglobina. Un rasgo NO ES UNA ENFERMEDAD, y no hará que su bebé se enferme.

Los rasgos se pasan en la familia de padres a hijos. Como su hijo tiene un rasgo, por lo menos uno de los padres es un portador del rasgo de hemoglobina. Si AMBOS padres tienen un rasgo, su próximo hijo puede tener problemas serios de salud. Una prueba de sangre especial les puede decir si ambos padres tienen un rasgo.

- Información y exámenes son disponibles gratis llamando al consejero de rasgos de hemoglobina sin cobrar al 1-866-954-2229. Todos los servicios son confidenciales. Cuando llame, dé el número de servicio que aparece en la parte superior de esta carta.
- Esta información también se le ha enviado al médico de su bebé. Por favor lleve esta carta a la siguiente cita médica de su bebe y hable con su doctor sobre el contenido

xxxxxxxxx xxx-xx-xxxx/xx-20xx-xx mm/dd/yy

Hb Trait Counseling

- Free telephone counseling and parent testing is available for the parents of infants identified with sickle cell trait, hemoglobin C trait and hemoglobin D trait.
- The counseling is provided by our contractor: Sickle Cell Disease Foundation.
- Genetic counseling, as needed, for interesting cases

Counseling Session Information Includes

- Which hemoglobin trait the baby's newborn screening test showed.
- Difference between trait and disease.
- How common the baby's trait and other traits are in various populations in California.
- Inheritance patterns for traits, possibility for sickle cell disease in future children.
- How parents can be tested for hemoglobin traits through the follow-up program.
- As child grows up, their trait status should be discussed before they are of child-bearing age.

Hb Trait Counseling

- Average counseling session lasts approx. 45 minutes.
- Paperwork and consents are sent to parents and are returned with signature.
- Lab authorization paperwork is sent to parents.
- Parents take paperwork to a designated local Quest draw.
- Quest performs blood draw, bills the CA NBS Program.
- Results available within 2-4 weeks in the Quest portal.
- Results counseling provided and copies of lab results sent to parents.

Hb Trait Program

- Currently, only an uptake rate of 8% and we are working on increasing the number
- Numbers of Hispanic/Latinx calls increasing and they tend to have less information about Sickle Cell.
- We have recently begun outreach to families when the parent letter comes back to the program with an incorrect address.

Counseling Numbers 2019

Hb trait inquiry only	283
Hb trait inquiry only - Spanish	50
Trait/Carrier follow-up intake done	400
Trait/Carrier follow-up intake done - Spanish	56
Counseled by phone	373
Non-English phone counseling done	46

Parent Testing Numbers 2019

Lab kit sent	**267**
Lab kit sent - Spanish	**32**
Test results counseling done	**72**
Test results counseling done - Spanish	**18**

COVID-19 Response

- Free parent testing continues to be available.
- Advising families to follow the stay at home guidelines.
- Continuous communication with families on next steps concerning parent testing once the stay at home ordinance is lifted.

Acknowledgements

- Newborn Screening Staff
- Sickle Cell Disease Foundation Staff
- Quest Diagnostics Staff
- Genetic Disease Laboratory Staff

Questions?

For questions regarding our Trait program, please email us at:
HbTrait@cdph.ca.gov

Thank you