California Newborn Screening Program
Hemoglobin Trait Follow-up Services

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Cayenne Wellness Center Town Hall Meeting
May 19, 2020
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

1980
- PKU
- Congenital Hypothyroidism
- Galactosemia

1990
- Sickle Cell
- Other Hb Disorders

1999
- Hemoglobin H Disease

2000
- Metabolic Disorders
- Congenital Adrenal Hyperplasia

2005
- Cystic Fibrosis
- Biotinidase Deficiency

2007
- Severe Combined Immune Deficiency

2013
- ALD

2016
- Pompe Disease
- MPS I

2018
- Spinal Muscular Atrophy

2020
- ALD

California Department of Public Health
Newborn Screening Program
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.
<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Sickle Cell Trait Carrier Rate</th>
<th>Hb C Trait Carrier Rate</th>
<th>Hb D Trait Carrier Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>1/14</td>
<td>1/47</td>
<td>1/3019</td>
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<tr>
<td>Native American</td>
<td>1/96</td>
<td>1/419</td>
<td>1/2094</td>
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<td>Hispanic</td>
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<td>1/1474</td>
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<td>Middle Eastern</td>
<td>1/268</td>
<td>1/3560</td>
<td>1/542</td>
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<tr>
<td>White</td>
<td>1/630</td>
<td>1/2962</td>
<td>1/2828</td>
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<td>Asian Indian</td>
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<td>Filipino</td>
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<td>1/2772</td>
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<td>East Asian</td>
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<td>1/12903</td>
<td>1/25806</td>
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<td>Southeast Asia</td>
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<td>1/7763</td>
<td>1/2588</td>
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<tr>
<td>Pacific Islander</td>
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<td>1/555</td>
<td>N/A</td>
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<tr>
<td>Other</td>
<td>1/210</td>
<td>1/1037</td>
<td>1/1004</td>
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<tr>
<td>Multiple</td>
<td>1/59</td>
<td>1/219</td>
<td>1/2429</td>
</tr>
</tbody>
</table>
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), 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.

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.

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 come 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 units such as beta-thalassemia trait and other less common traits.

If your 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 baby’s 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, or D, or beta-thalassemia gene from the other parent. This disease can cause serious long-term health problems.

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: 1-800-554-2712
- Kaiser member: call your Kaiser Permanente Doctor (see letter for phone numbers)
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 xxxxxxxxxxxxx.
- 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.
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
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
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

<table>
<thead>
<tr>
<th>Service</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hb trait inquiry only</td>
<td>283</td>
</tr>
<tr>
<td>Hb trait inquiry only - Spanish</td>
<td>50</td>
</tr>
<tr>
<td>Trait/Carrier follow-up intake done</td>
<td>400</td>
</tr>
<tr>
<td>Trait/Carrier follow-up intake done - Spanish</td>
<td>56</td>
</tr>
<tr>
<td>Counseled by phone</td>
<td>373</td>
</tr>
<tr>
<td>Non-English phone counseling done</td>
<td>46</td>
</tr>
</tbody>
</table>
## Parent Testing Numbers 2019

<table>
<thead>
<tr>
<th>Service</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lab kit sent</td>
<td>267</td>
</tr>
<tr>
<td>Lab kit sent - Spanish</td>
<td>32</td>
</tr>
<tr>
<td>Test results counseling done</td>
<td>72</td>
</tr>
<tr>
<td>Test results counseling done - Spanish</td>
<td>18</td>
</tr>
</tbody>
</table>
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