

Thalassemia in the Chinese Community

Thalassemia affects a diverse population, particularly those originating from South Asia, Southeast Asia, and the Mediterranean.

HOW MANY PEOPLE HAVE THALASSEMIA IN CALIFORNIA?

California Chinese, per 100,000 people:

- 2.1** have alpha thalassemia major.
- 46.1** have hemoglobin (Hb) H disease.
- 6.3** have Hb H/Constant Spring disease.
- 4.2** have Hb H with some type of mutation.
- 2.1** have beta thalassemia major.
- 2.1** have Hb E/beta thalassemia.

A total of about **60 per 100,000 births in California** have some form of thalassemia, which is about 1 in 1,700 births.¹

Once rare in California, thalassemia has become one of the most frequent disorders detected in the state newborn screening program.²

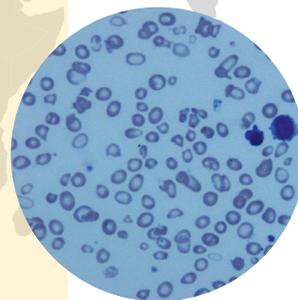
HOW MANY PEOPLE HAVE THALASSEMIA WORLDWIDE?³

Over 128 million pregnancies occur annually, and of those, **55,875** result in major-thalassemia births. Including the pregnancies affected with alpha thalassemia major, nearly 1 out of 500 couples is at risk. Many affected children die in early childhood.

- Over 55,000 affected infants are born annually with a form of thalassemia.
- At least 40,000 of these affected infants are born in South, East, and Southeast Asia.

HOW MANY PEOPLE HAVE THALASSEMIA IN CHINA?⁴

- The estimated number of thalassemia births in China will be over 20,000 per year.
- The estimated number of thalassemia carriers is around 47.48 million, making it one of the most common hereditary red blood cell diseases in China.
- Southern Chinese have a higher risk for carrying the trait or having a form of thalassemia than people in other regions of China—approximately 5 percent are carriers for alpha thalassemia and 4 percent for beta thalassemia or Hb E.
 - » 1 in 254 Chinese carry the trait for Hb E.
 - » Over 5 million people in China are carriers of the Hb E trait.



Thalassemia is a genetic blood disorder. This means that if both parents carry the thalassemia trait, their children are at risk for being born with thalassemia disease.

If both parents carry the genetic trait for thalassemia, there is a 1 in 4 chance with each pregnancy that the child will be born with the major form of the disease.

People with the thalassemia disease are dependent on blood transfusions every 2 to 4 weeks in order to survive.

Getting screened is QUICK and EASY!

- Contact your physician.
- Request:
 - A complete Blood Count (CBC)
 - Hemoglobin electrophoresis



UCSF Benioff Children's Hospital Oakland offers a prenatal diagnosis. Please visit our website at www.thalassemia.com or call 510-428-3885, ext. 5427

¹ Adapted from Feuchtbauer, L., et al. (2012). Birth prevalence of disorders detectable through newborn screening by race/ethnicity. *Genetics in Medicine* 14(11): 937-945. Data found on <http://thalassemia.com/PHRESH-1.aspx#gsc.tab=0>.
² Thalassemias. (n.d.). *Thalassemias*. Retrieved July 11, 2014, from http://www.ufrgs.br/immunvet/molecular_immunology/pathohomotissueblood_RBCthalassemia.html.
³ Darlison, M., and B. Modell (2008) Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization*, 86(6) 480-487.
⁴ Thalassemias. (n.d.). *Thalassemias*. Retrieved July 11, 2014, from http://www.ufrgs.br/immunvet/molecular_immunology/pathohomotissueblood_rbcthalassemia.html.
Li, CG, et al (2009). Thalassemia incidence and treatment in China with special reference to Shenzhen City and Guangdong Province. *Hemoglobin*, 33(5) 296-303.
Lorey, F. (2000) Asian immigration and public health in California: thalassemia in newborns in California. *Journal of Pediatric Hematology/Oncology*, 22(6) 564-566.