



## Frequency of Albinism / Rates of Occurrence

### **North America, Europe, Africa and Tanzania\***

While numbers vary widely and no comprehensive studies have been conducted, it is reported that in North America and Europe, an estimate of 1 in every 17,000 to 20,000 people have albinism.<sup>1</sup>

In Africa it is estimated that 1 in every 5,000 to 15,000 people have albinism with selected populations having estimates as high as 1 in 1,000.<sup>2</sup> In Tanzania where UTSS is based, the prevalence of albinism is estimated to be 1 in 1,400 and 1 in 19 carry the gene.<sup>3</sup> This means that there are over 33,000 persons with albinism<sup>4</sup> in Tanzania, with a rate of more than 14 times that of North America & Europe.

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<sup>1</sup> The US' National Institute of Health in 2007 cited 1 in 20,000 as the frequency of oculocutaneous albinism worldwide, <http://ghr.nlm.nih.gov/condition/oculocutaneous-albinism>. See for example, Vision for Tomorrow, <http://www.visionfortomorrow.org/albinism/> NOAH, a national group serving persons with albinism in the USA report the frequency to be 1 in 17,000 in USA, see [http://albinism.org/publications/what\\_is\\_albinism.html](http://albinism.org/publications/what_is_albinism.html)

More recently, groups serving persons with albinism report it to be 1 in 17,000.

<sup>2</sup> See Preliminary Report of the United Nations High Commissioner for Human Rights, Persons with Albinism, 12 September 2013 ["UN Preliminary Report"] at para 14, available at [http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A\\_HRC\\_24\\_57\\_ENG.doc](http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_ENG.doc), citing Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, "Albinism in Africa as public health issue", *BMC Public Health*, vol. 6, No. 212 (August 2006). Available from [www.biomedcentral.com/1471-2458/6/212](http://www.biomedcentral.com/1471-2458/6/212).

<sup>3</sup> 1 in 1,400 data is from Luande J, Henschke CI, Mohammed N: **The Tanzanian human albino skin.** *Cancer* 1985, **55**(8):1823-1828. Note however that this study advises that this is "A study of individuals with albinism who were registered in the Tanzania Tumour Centre in Dar-es-Salaam estimated a prevalence of 1 in 1,400. this estimation is difficult to extrapolate to the entire population, given the data's limitation only to those individuals enrolled in the registry." *Regarding this paper, American Geneticist Dr. Murray Brilliant says:* "I don't think it has been done in a rigorous fashion and so I would take this as an estimate. There are no other (independent) studies where the incidence has been reported. My estimates were for carrier frequency and were consistent with a 1 in 1,400 occurrence. (**NOTE:** Dr. Brilliant's DNA testing revealed that 1 in 19 Tanzanians carry the gene for albinism.).

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<sup>4</sup> This is based on a national population of 47.78 million (World Bank data 2012).

\*We presume the "albinism" that was measured in all cases include mostly oculocutaneous albinism which is the most visible form of albinism affecting all of the hair, skin and eyes.