

# HUMANITARIAN BULLETIN #6

THALASSEMIA – JUNE 2023

## ROOTED IN TRUST

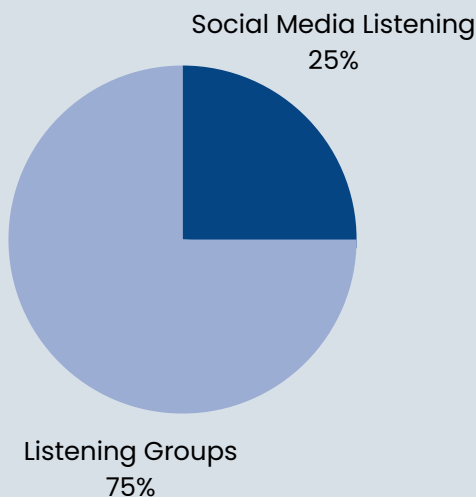
Rooted in Trust (RIT) is a USAID BHA-funded project run by Internews to support humanitarian, public health agencies and local media to strengthen information ecosystems and respond to the spread of rumors and misinformation about emerging health topics. This regular collection of community insights aims to provide humanitarian and public health agencies with ideas to integrate and align their risk communication activities with community perspectives and provide information according to the needs of the community. In Afghanistan, Internews is collaborating with local media partners and the Risk Communication and Community Engagement Sub-Working Group (RCCE SWG).

From April to May 2023, Internews conducted data collection on rumors, misinformation, and concerns related to thalassemia throughout Afghanistan. This information was gathered through social media listening, live radio programs and through listening groups held in six provinces: Kabul, Herat, Nangarhar, Khost, Kandahar and Balkh. This bulletin aims to provide humanitarian actors with analysis and updates regarding these rumors.

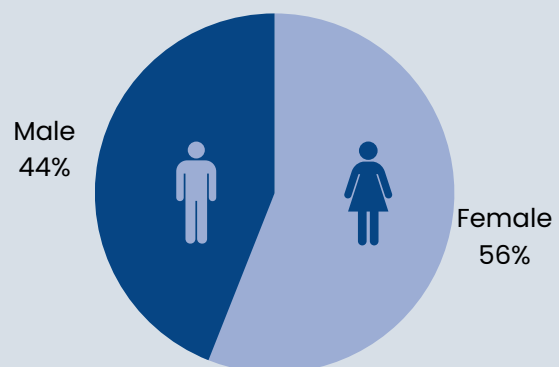
## AFGHANISTAN SITUATION OVERVIEW

- According to officials from the Ministry of Public and Health (MoPH), a total of 12,103 thalassemia patients have been referred to and registered with the Central Blood Bank in the past year. It is important to note that there is currently no comprehensive national thalassemia census, which suggests that the actual number of affected individuals might be even higher. [1] [2]
- The existing facilities are not adequate in meeting the needs of patients requiring treatment. Recognizing this pressing issue, Mohammad Nabi, a renowned Afghan cricket player, has expressed his intention to join forces with the MoPH to establish a dedicated cancer treatment center. This center would not only address the needs of cancer patients but also extend its services to provide care for individuals with thalassemia. [3]
- A report by The Killid Group published in May 2023 indicates a concerning rise in thalassemia cases in in Kandahar and Uruzgan provinces. In Kandahar, 800 children afflicted with thalassemia have required hospitalization, while an additional 70 children in Uruzgan have also been affected. [4]

## RUMORS BREAKDOWN BY SOURCE



## RUMORS BREAKDOWN BY GENDER



## Rumor #1

**“Thalassemia or anemia (red blood cells) is mostly hereditary and does not have any risk of death...”**



### Why is this important?

- A part of this rumor is true that thalassemia is hereditary which makes it more believable. However, if the communities believe that thalassemia does not pose any risks, particularly risk of death, there is a chance that the community may not give necessary attention to thalassemia patients. Also, if people believe that thalassemia does not pose any risk, they might neglect to seek appropriate healthcare and treatment, which can have serious consequences.
- The risk of passing on the genes which can cause thalassemia is higher in couples who are close relatives, which is commonplace in Afghanistan. [5]

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### Recommendations

According to Mohammad Nasser Sadeq, Director of Afghanistan Central Blood Bank, high cases of thalassemia in the country are attributed to insufficient public awareness about thalassemia, and parents with thalassemia genes not taking pre-marriage blood tests resulting in infected children birth. [12] Considering this, here are some recommendations for humanitarian organizations working in Afghanistan:

- In close collaboration with MoPH and local health NGOs, humanitarian actors should work on developing educational resources about thalassemia in local languages and disseminate them through awareness campaigns in communities with the help of media, religious leaders, and community frontrunners. These campaigns should tell people about the root causes, symptoms, associated risks, and available treatments for thalassemia.
- Humanitarian organizations can advocate for policy changes that would help to reduce the incidence of thalassemia in roots. This could include rules that are compatible with Afghan customs for requiring blood tests before marriage or programs to promote awareness about risk associated with marriages between relatives.

### Fact Checking

- ✓ Thalassemia is a hereditary blood disorder that can lead to anemia, iron overload, infections, bone deformities, enlarged spleen, slowed growth rates, and heart problems. [6]
- ✓ Thalassemia happens when your body produces either no or too little hemoglobin. Hemoglobin is a vital protein which is used by blood cells to carry oxygen around your body. [7] [8]
- ✓ Signs and symptoms of thalassemia vary depending on the type and severity of the disorder. In general, people with thalassemia may experience fatigue, weakness, pale yellowish skin, facial bone deformities, slow growth, abdominal swelling, and dark urine. [9]
- ✓ Thalassemia can be fatal in severe cases, particularly when there are multiple gene mutations. At least 10 children lost their lives to thalassemia during 2021 in the northern province of Balkh. [10] The numbers could be higher, lack of a national census limits statistics available.
- ✓ It is important to note that marriage between relatives is not a direct or exclusive cause of thalassemia in offspring, but it can increase the chances, because when two people who are closely blood-related have children, their children are more likely to inherit two copies of the same recessive gene, which can lead to some genetic disorders including sickle cell anemia and thalassemia. [11]

### USEFUL RESOURCES



Read more about thalassemia here:

- [Thalassemia International Federation](#)
- [What is Thalassemia? | CDC](#)
- [Meeting the health needs of people from Afghanistan \(thelancet.com\)](#)

## Rumor #2

**“Low-fat meat, fish, drinking more than 2 liters of water a day, egg yolk, sheep's liver, and any type of vegetable and fruit are useful [to treat thalassemia].”**



### Why is this important?

While consuming vegetables, fruits, and maintaining a healthy diet has numerous health benefits, it cannot directly cure, treat, or prevent thalassemia. Relying solely on this information can have negative impacts:

- It can mislead people to delay or avoid necessary treatment. Such actions can have serious consequences, as thalassemia is a serious condition, if left untreated can lead to fatal outcomes.
- It may also lead individuals to make uninformed choices about their dietary habits. For instance, they might consume excessive amounts of iron-rich foods, which can be harmful to individuals with thalassemia.

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### Fact Checking

There are various treatment options available to manage the symptoms and enhance life quality of thalassemia patients. The choice of treatment depends on the severity of thalassemia and individual's specific requirements.

- ✓ **Blood transfusion:** The most common treatment globally, including in Afghanistan. It involves providing the body with healthy red blood cells, alleviating anemia, and improving symptoms. Individuals with thalassemia may require regular blood transfusions, sometimes as frequently as every few weeks. [13] [14]
- ✓ **Iron chelation therapy:** This treatment helps eliminate excess iron from the body. Since regular blood transfusions can lead to iron build up in the body, this therapy becomes crucial in preventing potential damage to the heart, liver, and other organs.
- ✓ **Bone marrow transplant:** For some individuals with thalassemia, a bone marrow transplant can offer a potential cure. The procedure entails replacing a person's blood-forming stem cells with healthy stem cells obtained from a compatible donor. However, it should be noted that this option is available only to a limited number of individuals with thalassemia and it is not accessible in Afghanistan. [15]

### Recommendations

- Early diagnosis and treatment can help and improve the quality of life for people with thalassemia, but unfortunately, current healthcare facilities in Afghanistan are inadequate for treatment of thalassemia patients. [16] Humanitarian actor should fundraise in order to establish treatment centers for thalassemia all over Afghanistan.
- As Afghanistan is in the middle of a malnutrition and food insecurity crisis, WFP has already assisted 23 million people with food assistance in 2022, but they still have a shortfall of 1.46 billion USD over the next six months to help people in need. [17] Humanitarian actors should contribute to this appeal and help to provide food assistance through a variety of means, such as distributing food rations, providing cash, or supporting local food production.
- Besides raising awareness about all aspects of thalassemia, humanitarian, and media organizations with the help of medical experts, should promote healthy diets. This should ultimately debunk the myth that a healthy diet is the only treatment for serious medical conditions such as thalassemia. These campaigns should encourage people to seek medical care as soon as possible if they have thalassemia. This can be approached and achieved through campaigns on social media, radio, television, and publications.

### USEFUL RESOURCES



Read more about thalassemia treatment and Afghanistan malnutrition crisis here:

- [WFP Afghanistan: Situation Report | February 2023](#)
- [Transfusion-dependent beta thalassemia in Afghanistan | \(tandfonline.com\)](#)

**“Sometimes it is also said that when a woman is married at a young age, when the child is born, then the child is not properly taken care of or not given the right food, then the child suffers from thalassemia.”**



### Why is this important?

- Communities should know whether improper childcare and improper child diet cause thalassemia or not, and also understand the consequences of a poor diet in children.
- Additionally, they should know what child marriage is, and what are its impacts on the health of mother and their offspring.

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### Recommendations

It is important to understand the dynamics of child marriage and address its impacts on girls and their offspring. Many people in Afghanistan are unaware of the negative consequences of child marriage. Here are what humanitarian actors can do:

- Humanitarian organizations should work with MoPH and media organizations to develop educational packages in order to raise awareness about serious consequences of child marriage.
- They should also help MoPH, local NGOs, media organizations, religious leader, frontrunners, and women activists to collaboratively promote the educational resources through inclusive outreach programs on social and traditional media.
- Afghanistan has laws that prohibit child marriage, but these laws are often not enforced. Humanitarian organizations can work with the government and communities to support these laws and ensure that they are monitored and enforced.
- Education and economic opportunities can help to empower girls and make them less likely to be married off early. Humanitarian actors should support and advocate for girls to access to educational opportunities through schools and religious studies centres.
- Child marriage is often seen as a cultural norm in Afghanistan. Humanitarian organizations can work with communities to alter these attitudes by raising awareness about the harmful impacts of child marriage and promoting alternative ways of thinking about girls' futures.

### Fact Checking

- ✓ Improper childcare or improper child diet either by an underage or an adult mother do not cause thalassemia in children. But it is important to understand that poor diet in children can cause other serious consequences such as malnutrition.
- ✓ According to UNICEF, any marriage or union before the age of 18 is child marriage, but in Afghanistan, the lawful age for marriage is 18 for male and 16 for female. [18] [19] Child marriage is common in Afghanistan, according to live stats by Girls Not Brides organization website, as of 13 June 2023, 28% of Afghan girls are married before the age of 18 and 4% are married before the age of 15. [20]
- ✓ Underage pregnancy significantly increases the chances of premature birth, low birth weight, and an elevated risk of infant mortality. [21] Afghanistan has one of the highest infant mortality rates in the world. In 2017, maternal mortality rate in was 638 per 100,000 live births, and the infant mortality rate was 56 per 1,000 live births in 2018. Besides inadequate access to health care for women and mothers, child marriage is one of the factors that contribute to high maternal mortality rates in Afghanistan. [22]
- ✓ It is also important to understand that if you have thalassemia, you can still have a safe pregnancy. But there is a chance that the baby born is normal, thalassemic or carrier of the disease. If both the parents are a carrier of thalassemia, then there are 25% chances that child born will have thalassemia. Prior to conceiving a child, it's important to consult your healthcare provider to discuss your intentions.
- ✓ Thalassemia is a hereditary condition, meaning it can be passed down to your baby. [23] [24] [25]

### USEFUL RESOURCES



Find more about child marriage and child pregnancy in Afghanistan:

- [Girls increasingly at risk of child marriage in Afghanistan \(unicef.org\)](https://www.unicef.org/afghanistan/stories/girls-increasingly-at-risk-of-child-marriage-in-afghanistan)
- [Afghanistan - Girls Not Brides](https://www.girlsnotbrides.org/)

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We would love your feedback on this product! Contact us also to join our mailing list, collaborate and share data. Please contact Mir Rohullah Sadat, Project Manager Rooted in Trust Afghanistan, Internews - [\*\*msadat@internews.org\*\*](mailto:msadat@internews.org)

