AWARENESS PROGRAMME ON THALASSEMIA

To observe NATIONAL YOUTH DAY-YUVA DIVAS-2025

Date: 20th January 2025 **Time:** 11:30 am-1.30 pm

Venue: Gallery Room, Vivekananda Baan, Raidghi College

Organized by: Raidighi College NSS Unit-1 in collaboration with Amra Rakta Yoddha Group

Chief Patron: Dr Sasabindu Jana- Principal, Raidighi College

Resource Person: Shri Malay Kumar Hati, MT, Lab Raidighi Rural Hospital & Member of

Amra Rakta Yoddha Group, Raidighi

Student Participant no: 87

Teachers:04 Non-teaching:01

Programme Officer (PO-1): Dr Arvinda Shaw

Introduction:

Thalassemia is a genetically inherited blood disorder that affects the body's ability to produce hemoglobin, a vital component of red blood cells. Hemoglobin carries oxygen from the lungs to the rest of the body, and in people with thalassemia, this process is disrupted, leading to severe anemia and other serious health issues. Despite being preventable, thalassemia continues to affect millions of individuals worldwide, particularly in regions such as South Asia, the Middle East, the Mediterranean, and parts of Africa.More than 10,000 newborns are born with Thalassemia in India every year because there is not enough awareness among the general population. On January 20, 2025, Raidighi College NSS Unit-1 organised an awareness programme on Thalasemia to disseminate knowledge about it among the students and volunteers.

Objectives of the Programme:

- 1. **Increase Public Awareness:** Educate people, students and volunteers about what thalassemia is and how it affects the human body.
- 2. **Promote Carrier Screening:** Encourage early screening, especially for couples planning to start a family.
- 3. **Reduce Stigma:** Dispel myths and social stigmas surrounding genetic disorders.
- 4. **Promote Blood Donation:** Encourage regular voluntary blood donation to support those undergoing treatment.
- 5. **Support Affected Families:** Connect individuals with medical, psychological, and community support systems.
- 6. **Advocate for Policy Change:** Urge governments to implement nationwide screening and prevention programs.

Understanding Thalassemia:

What is Thalassemia?

Thalassemia is a group of inherited blood disorders characterized by reduced or absent production of one of the globin chains that make up hemoglobin. The two most common forms are:

- Alpha Thalassemia: Caused by defects in the alpha globin gene.
- **Beta Thalassemia:** Caused by defects in the beta globin gene.

Beta Thalassemia is more prevalent and further classified into:

- Thalassemia Minor (Trait/Carrier): A person carries one defective gene but usually shows no symptoms.
- Thalassemia Major (Cooley's Anemia): A person inherits two defective genes, leading to severe anemia that requires lifelong treatment.

Causes and Risk Factors:

Thalassemia is inherited in an autosomal recessive manner. A child must inherit the faulty gene from both parents to develop thalassemia major. If both parents are carriers, there is a:

- 25% chance the child will be affected (thalassemia major),
- 50% chance the child will be a carrier (thalassemia minor),
- 25% chance the child will be completely unaffected.

The risk is higher in populations where consanguineous marriages (marriage within the family) are common.

Symptoms of Thalassemia Major:

Symptoms usually appear within the first two years of life and include:

- Severe anemia
- Fatigue and weakness
- Pale or yellowish skin
- Facial bone deformities
- Slow growth and development
- Enlarged spleen and liver
- Frequent infections

If left untreated, thalassemia major can be life-threatening.

Diagnosis and Screening:

Early diagnosis plays a vital role in managing and preventing thalassemia. Key diagnostic and screening methods include:

- **Hemoglobin Electrophoresis:** Identifies abnormal hemoglobin variants.
- Complete Blood Count (CBC): Checks for anemia and red blood cell size.
- **Genetic Testing:** Confirms the presence of mutations in globin genes.
- **Prenatal Diagnosis:** Includes chorionic villus sampling (CVS) and amniocentesis to detect thalassemia in the fetus.

• **Premarital and Preconception Screening:** Helps couples understand their carrier status and reproductive options.

Treatment and Management:

There is currently no universal cure for thalassemia, except for bone marrow or stem cell transplantation in some cases. Management focuses on improving quality of life and includes:

1. Regular Blood Transfusions:

Patients with thalassemia major often require blood transfusions every 2–5 weeks to maintain healthy hemoglobin levels.

2. Iron Chelation Therapy:

Frequent transfusions cause iron overload, which can damage organs. Iron chelators (e.g., deferoxamine, deferasirox) help remove excess iron from the body.

3. Folic Acid Supplements:

Support red blood cell production.

4. Bone Marrow/Stem Cell Transplant:

A potential cure, especially if performed early, but it carries risks and requires a matched donor.

5. Psychosocial Support:

Counseling and emotional support are essential for both patients and families to cope with chronic illness.

Prevention is the Key:

Preventing thalassemia starts with awareness and education:

- **Public Education Campaigns:** Use schools, universities, social media, and community centers to spread knowledge about thalassemia.
- **Genetic Counseling:** Essential for at-risk couples to understand their reproductive choices, including prenatal diagnosis and in-vitro fertilization with pre-implantation genetic diagnosis.
- **Mandatory Screening Policies:** Some countries have implemented national screening programs for high-risk populations, significantly reducing new cases of thalassemia major.

Role of the Community:

Voluntary Blood Donation Drives:

People with thalassemia major rely on regular blood transfusions. Community blood donation drives can help ensure a steady and safe blood supply.

Creating Support Networks:

Support groups provide patients and families with a sense of belonging and shared experiences. They offer emotional, financial, and logistical help.

Education and Awareness Events:

Workshops, seminars, health fairs, and media campaigns can help normalize discussion around genetic conditions and promote inclusivity.

Thus Raidighi College NSS Unit-1 made a small effort by organising an awareness program on YUVA DIWAS-2025, where more than 87 students, volunteers and teachers participated. This event was attended by the Principal of Raidighi College who gave the inaugural speech, Dr Arunima Biswas, HoD, Dept. of Microbiology, who in her short speech stressed on the need for such awareness programmes and appreciated the efforts made by the NSS unit.

Guest Resource person-Shri Malay Kumar Hati, member of Amra Rakta Yoddha Group and associated with M.T Lab, Raidighi Rural Hospital, gave a detailed presentation to our participants and discussed ways for prevention like Pre-marital screening, Carrier screening, and Prenatal screening. All these facilities are provided free of cost at Government Hospitals. Dr Hamid Iqbal, HoD, Dept. of Political Science, Mr Sital Sing, Faculty Dept. of Education, Mr Hamidur R. Molla, HoD, Dept. of Physical Education, Raidighi College were other participants who actively participated in this program.

Efforts made by NSS Program Officer Dr Arvinda Shaw was appreciated by one and all.

Conclusion:

Thalassemia is a preventable yet widespread genetic disorder. Through education, early screening, compassionate care, and active community participation, we can significantly reduce the burden of this disease. The fight against thalassemia is not only medical but also social—it requires informed individuals, strong healthcare systems, and collective responsibility. Raidighi College NSS Unit 1 through such an initiative is trying to generate awareness for a thalassemia-free future for the coming generations.

Acknowledgement: Raidighi College and NSS Unit-1 extend heartfelt gratitude to **Mr Malay Kr. Hati** for accepting our invitation to act as a resource person and spreading awareness on such an important issue among students and volunteers.







Dr Sasabindu Jana-Principal



Non-teaching staff- Mr Kamal Krishna Khanra



Participants- NSS Volunteers

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