



**SINDH AJRAK WELFARE TRUST**  
**PROJECT - THALASSEMIA HEROES - GIVE MONTHLY, GIVE LIFE**

**WORKING PLAN FOR THE PROJECT**

**THALASSEMIA HEROES - GIVE MONTHLY, GIVE LIFE**

**BE A THALASSEMIA HERO & JOIN US IN SAVING FUTURES**



## SINDH AJRAK WELFARE TRUST

### PROJECT - THALASSEMIA HEROES - GIVE MONTHLY, GIVE LIFE

#### Introduction & Justification

Thalassemia is a genetic blood disorder in which the bone marrow fails to produce enough healthy red blood cells, forcing patients to depend on lifelong, regular blood transfusions. With an estimated **100,000 children suffering from thalassemia major** in Pakistan and approximately **5,000 to 9,000 new cases being born annually**, the country bears one of the world's heaviest burdens of this preventable disease. In **2024 alone, more than 8,400 children with known or newly diagnosed thalassemia** were treated in emergency rooms, often arriving in critical condition due to late diagnosis and lack of routine care. In **Sindh**, the situation is particularly dire, with an estimated **25,000 children suffering** and no dedicated thalassemia centre in the province.

The root causes are well-documented: a high percentage of consanguineous marriages (cousin marriages) and a dangerous lack of public awareness. The carrier frequency of  $\beta$ -thalassemia in Pakistan is estimated at **5-8%**, which is markedly higher than the global average, translating to **nearly 9.8 million carriers nationwide**. In some regions of Sindh, carrier rates have been observed to be as high as **28%**.

The financial burden is crushing. The average monthly cost for comprehensive care is approximately **PKR 30,000** per patient, including transfusions and iron chelation therapy. Iron chelation medicines alone can cost between **PKR 40,000 to PKR 50,000 per month**, which is unaffordable for the common family. Consequently, **90% of thalassemic children belong to low-income group families** who are unable to bear the rising costs of treatment. Welfare institutions represent their only hope for survival.

#### Project Objective

To save the lives of thalassemia patients in Sindh by providing **uninterrupted, free, and high-quality medical care** through a comprehensive support system that includes:

- Safe, timely blood transfusions
- Iron chelation therapy to prevent organ damage
- Financial assistance for advanced monitoring and diagnostics
- Awareness campaigns to prevent new cases
- Support for curative treatments (bone marrow transplants)



## SINDH AJRAK WELFARE TRUST

### PROJECT - THALASSEMIA HEROES - GIVE MONTHLY, GIVE LIFE

#### Key Project Components & Activities

##### Provision of Lifesaving Medical Treatment

- **Blood Transfusions:** Each child requires approximately **2 bottles of blood per month**. Sindh alone requires an estimated **22,000 to 25,000 bottles of blood monthly**. We will ensure a steady supply of screened blood for registered patients.
- **Iron Chelation Therapy:** Regular transfusions cause iron overload in the body, which can lead to life-threatening organ damage. The project will provide free iron chelation medicines to all registered patients.
- **Advanced Monitoring & Diagnostics:** Regular hemoglobin tests, ferritin levels, liver function tests, cardiac assessments, and viral screening will be covered to prevent complications.

##### Premarital Genetic Screening & Prevention Campaign

- **Community Awareness Seminars:** Organize seminars in rural and urban areas of Sindh to educate the public about thalassemia, its genetics, and the risks of consanguineous marriages.
- **Premarital Screening Program:** Following the passage of legislation mandating premarital thalassemia screening for couples in Islamabad and the inclusion of blood tests in the nikahnama in Sindh, we will establish screening camps offering **free or subsidized carrier testing** for couples planning to marry. Genetic counseling will be provided to carrier couples to help them make informed decisions.
- **School & College Outreach:** Organize lectures and awareness sessions in educational institutions across Sindh to reach young people before they marry.

##### Establishment of a Dedicated Thalassemia Centre in Sindh

- **Proposed Location:** Karachi (to serve patients from Sindh and Baluchistan)
- **Facilities:**
  - Daycare for routine blood transfusions (capacity: 100+ patients daily)
  - Inpatient ward (20 beds)
  - High Dependency Unit (HDU) for acute management
  - Diagnostic lab for hemoglobin electrophoresis and PCR-based mutation analysis
  - Pharmacy stocking iron chelators and supportive medicines



## SINDH AJRAK WELFARE TRUST

### PROJECT - THALASSEMIA HEROES - GIVE MONTHLY, GIVE LIFE

- **Partnership with Government:** Leverage the Sindh government's existing 50% support to thalassemia centres and expand to underserved districts like Dadu, Jamshoro, Tharparkar, and Mithi.

#### Bone Marrow Transplant (BMT) Support

- **Partial Sponsorship:** BMT offers a permanent cure for eligible patients (younger patients with matched related donors achieve success rates of **80-95%**). The cost ranges from **PKR 2.5 million to 7 million**.
- **Referral & Financial Assistance:** Collaborate with existing transplant centers (e.g., PATHWEL Rawalpindi, National Institute of Blood Disease) to facilitate transplants for eligible patients and provide partial financial sponsorship.
- **Advocacy:** Advocate for the establishment of a BMT facility in a government hospital in Sindh, as currently no such facility exists in the province.

#### Financial Assistance to Low-Income Families

- **Monthly Stipend:** Provide a monthly financial stipend to cover transportation costs for families traveling long distances to transfusion centres.
- **Zakat & Donor Fund Management:** Establish a transparent Zakat-based fund to cover treatment costs for patients from low-income backgrounds.

#### Expected Outcomes & Impact

- **Reduced Mortality:** Provide uninterrupted treatment to **2,000+ thalassemia patients** in Sindh within 12 months, directly reducing deaths from iron overload and transfusion complications.
- **Prevention:** Screen **10,000+ couples** through premarital screening camps, enabling informed decisions and preventing an estimated **200+ new thalassemia births annually**.
- **Curative Treatment:** Sponsor **10-15 bone marrow transplants**, offering permanent cure to eligible patients and freeing them from lifelong transfusions.
- **Awareness:** Reach **500,000+ individuals** through seminars, school lectures, and media campaigns, shifting social norms around consanguineous marriages.
- **Policy Change:** Advocate effectively for mandatory premarital screening in Sindh, following the model successfully implemented in Islamabad.



## SINDH AJRAK WELFARE TRUST

### PROJECT - THALASSEMIA HEROES - GIVE MONTHLY, GIVE LIFE

#### Monitoring & Evaluation

- **Patient Registry:** Maintain a digital database of all registered patients with their medical history, transfusion schedules, and chelation adherence.
- **Monthly Reports:** Generate metrics on number of transfusions conducted, chelation compliance rates, and new patient registrations.
- **Quarterly Audits:** Financial audits by an external chartered accountant; programmatic audits to assess impact on patient survival and quality of life.
- **Feedback Mechanism:** Establish a patient and family feedback system to continuously improve service delivery.

#### Call to Action & Sponsorship Opportunities

- **Monthly Sponsorship of a Child:** PKR 30,000 (\$100) sponsors one month of comprehensive care for a single patient.
- **Sponsor a BMT:** PKR 3.5 million (\$12,000) sponsors a bone marrow transplant for one eligible child.
- **Sponsor a Screening Camp:** PKR 500,000 (\$1,800) sponsors a premarital screening camp testing 500 couples.
- **Zakat & Sadaqah:** Donations in the form of Zakat, Sadaqah, and general donations are welcomed. Pakistan Bait-ul-Mal has provided PKR 637.7 million in aid to thalassemia patients over five years — but private welfare institutions remain the only regular source of care.

#### Closing Statement

Thalassemia is a silent epidemic that continues to steal the futures of thousands of children in Pakistan, children who are born into families already struggling to survive. But this is a preventable tragedy, and with your support, Sindh Ajrak Welfare Trust can turn the tide. Every blood donation, every rupee donated, and every marriage screen performed is a step toward a Pakistan free from thalassemia.

**Be a thalassemia hero. Join us in saving futures.**

For donations, partnership inquiries, or patient registration, please contact **Sindh Ajrak Welfare Trust**.