THALASSEMIA SOCIETY PUNE CHAPTER & RUDHIR - THE DAY CARE

Impact Report 2023

THALASSEMIA IN A GLIMPSE

Thalassemia is an inherited blood disorder that causes abnormal form of hemoglobin. It is a genetic hereditary disorder which while being entirely preventable causes physical, financial, emotional, psychological, and social drain on not only the person affected but the entire family!

Thalassemia Minors

4.2 Crores

2.96% of our population

Thalassemia Majors

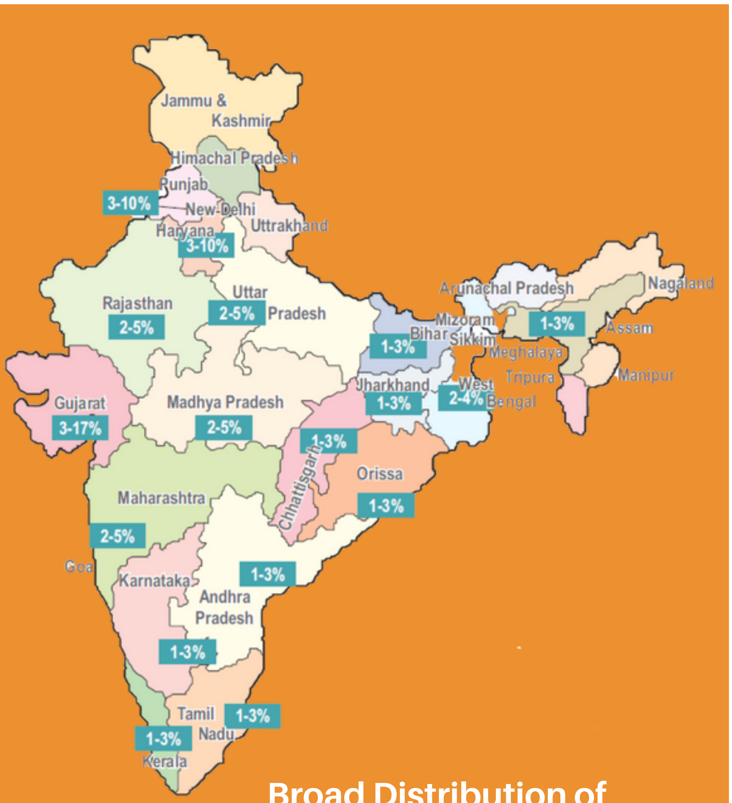
1,00,000+

+25,000 unregistered warriors

Estimated Number of births per year with Thalasemia Major

10,000

More births a year in India, than any other country



Broad Distribution of Beta-Thalassemia in different regions of the country.

▨ **β Thalassemia**

In India, every hour one child is born with Thalassemia, making India the Thalassemia Capital of the World

OUR AIM: TO CARE, CURE, CURB THALASSEMIA

We work towards patient welfare and aim to create mass awareness for the prevention of Thalassemia, striving to achieve ZERO Thalassemia births in Pune by the year 2030

The Thalassemia Society Pune Chapter (TSPC) was founded by warriors, parents and friends affected by Thalassemia Major. The foundation has 385 warriors registered, and provides hope, comfort and encouragement to those battling this disorder. The foundation maintains a strong relationship with the medical community that provides diagnosis, treatment, care and cure.

We at the Thalassemia Society are committed for Prevention and Awareness drives in and around Pune, with a goal to achieve ZERO Thalassemia births in Pune by the year 2030.

TSPC SNAPSHOT

32+

Years of Operation
Established in 1991

500+

Thalasemia Major
Warriors Helped

5000+

Individuals
Screened & Tested

Reflections From Dr. Nita Munshi, TSPC President & Mr. Jackie Shroff, TSPC Brand Ambassador

TSPC embodies an unwavering commitment and empathy in our mission to eradicate, prevent, and mitigate the impact of thalassemia.

However, TPSC is more than just an organization; we are warriors, caregivers, doctors, researchers, advocates, supporters and a community of passionate individuals who are coming together united by a common purpose.

Let the torch of philanthropy illuminate our path for years ahead, guiding us towards a future free from Thalassemia challenges."

Dr. Nita Munshi,
TSPC President

"I was introduced to Thalassemia by Dr. Nita Munshi in 2015, and I was shocked to learn, that if awareness is all that is needed, then why are people not speaking about it?

Why let our children suffer from an entirely preventable disease? I urge everyone – my friends, my staff – to discuss their carrier testing and especially gynecologists to mandate the Hb electrophoresis tests for prospective parents

Let's make it a nationwide conversation! It's simple, and we must speak louder to prevent Thalassemia"

Mr. Jackie Shroff, Actor
TSPC Brand Ambassador

Our Dream

2030
Thalassemia Mukt Pune

2035
Thalassemia Mukt Maharashtra

2040
Thalassemia Mukt BHARAT

40,000

Thalassemia major warriors require blood transfusions in Maharashtra

₹270 CRORE

Annual cost to society for monitoring Thalassemia major warriors in India

600+

Thalassemia major warriors in Pune district

90%

Thalassemia-free survival rate of a matched sibling bone marrow transplantation patient

TSPC's Projects

The TSPC is dedicated to improving the welfare of Thalassemia-affected warriors by addressing key needs, actively conducting awareness and blood donation drives, and assisting economically challenged warriors in following effective treatment protocols

- **CARE: Patient Welfare**

Provide expertize of treatments involving different medical modalities to improve quality of life

- **CURE: Bone Marrow Transplant**

Provide access to medical expertize and financial resources for Bone Marrow Transplants

- **CURB: Screening & Prevention**

Create awareness to prevent Thalassemia births by conducting widespread screening

- **Medical & Government Advocacy**

Work closely with gynacalogy societies, health ministries & other government bodies

#1: CARE
PATIENT WELFARE

Challenges

Our warriors require routine medical interventions like **blood transfusions, iron overload medication, and frequent health monitoring**. Additionally, they face challenges in daily activities, **struggle with social interactions**, and lack parental focus on education.

Successes

TPSC offers a support network that addresses both medical needs and emotional well-being. This includes **end-to-end treatment costs, leukocyte filters at nominal costs, availability of safe-blood and ongoing mentorship** built on a foundation of positive hope and support.

Programs

TSPC enhances the well-being of Thalassemia warriors and families through various initiatives:

- **Subsidized Rate Leukocyte Reduction Filters:** TSPC consistently provides an **average of 90 filters** at a subsidized rate on a monthly basis.
- **End-to-End Comprehensive Care**: TSPC facilitated with the Mukul Madhav Foundation (MMF) to adopt the chelation cost of **38 warriors, amounting to ₹1.85 lakhs per month**.
- **Rudhir - The Lifeline, Comprehensive Day Care:** In collaboration with Sanjeevan Hospital, Avinash Cancer Clinic and Sudarshan Cancer Hospital and Research Foundation, TSPC offers **free-of-cost day care**, serving as a comprehensive one-stop service for warriors.
- **Education & Financial Empowerment:** TSPC is dedicated to fostering independence among Thalassemia major warriors through **education and employment opportunities.**
- **Blood Donation Drives:** TSPC secures safe blood supply for more than **600 Thalassemia Major warriors in Pune** through blood donation campaigns within corporate settings and universities. **100+ blood donation camps have been conducted in 3 years with a total of ~10,000+ donors**, also serving as an avenue for spreading awareness.
- **Annual Health Check-up:** TSPC conducts comprehensive health check-ups which include holistic blood tests, ultrasound and others. The costs are distributed with **25% covered by warriors, 50% by Ruby Hospital, and 25% by TSPC**. Moreover, Jupiter Hospital also does the **Dexa Scan and T2 MRI free of cost for all our Thalassemia warriors.**

JATIN SEJPAL

A Tale of Hope

Diagnosed at the tender age of 3, Jatin encountered a tumultuous path marked by not just the physical burden of Thalassemia but also the additional weight of the social stigma. His early years were marred by a lack of focus on education, as societal misconceptions often overshadowed his academic pursuits.

The common belief weighed heavily on young Jatin - that those with Thalassemia major were expected to live only until 20. This belief intensified the social stigma around his condition.

Today, at 47 years of age, he not only leads a happy & dignified life but also owns and operates a successful coffee shop at KEM Hospital.

More so, his inspirational journey is marked by selfless contributions, as he actively engages in organizing blood donation drives and extends genuine assistance to fellow warriors in navigating their physical and mental well-being. Jatin alone has organized above 150 blood donors in the last one year.

“Nobody knew much about thalassemia when I was born in 1980. It was a difficult childhood with continous medical interventions and social isolation.

Besides supporting my medical expenses, TSPC evolved into a social support group for me, that helped transition me from a patient to a motivator and a counselor.”

SIMRAN TEJWANI

The Gifted Life

Simran's journey commenced in November 1986, when she was diagnosed with Thalassemia Major, and at just a delicate age of 3 months, Simran started her blood transfusions, casting a lingering shadow of isolation over her childhood.

By age 7, the prospect of a BMT arose for Simran as a beacon of hope, offering the promise of a lifetime free from transfusions. However, despite the agonizing procedure, which even involved significant hair loss, her body rejected the donor's marrow, creating an exceptionally challenging scenario emotionally and physically for Simran and her family.

Over the years, Simran learnt to navigate around her condition. However, it was only until a pivotal moment where she found strength and resilience to embrace a life of her dreams - Participating in advocacy sessions and conferences with Dr. Munshi, representing TSPC, she found solidarity and learnt of other Thalassemia Major warriors excelling academically and forming profound social bonds. The power of community transformed Simran's perspective on Thalassemia, empowering her to lead a more fulfilling life.

TSPC played a crucial role by providing her a positive outlook on life, developing life-long bonds, offering her access to medical expertise, emotional counseling, and subsidising crucial medical interventions, allowing her the disposable income to pursue her dreams and indulge in her passion for travel.

Now, at 37, she is a happily married, financially independent woman, steering a thriving corporate gifting business. Simran's story is not just one of resilience but a testament to the strength that emerges from community and self-belief.

#2 CURE: BONE MARROW TRANSPLANT

Challenges

While bone marrow transplant (BMT), is one of the most effective treatments for Thalassemia major, significant challenges are faced in **finding a compatible donor & bearing the costs of the transplant.**

Successes

TPSC has collaborated with **specialized medical facilities and has offered financial assistance for BMT procedures**, alleviating the financial burden on warriors and their families.

Programs

TPSC is working tirelessly to create a brighter future for Thalassemia warriors and their families, making bone marrow donation an executable reality from a distant dream.

- **Jupiter Hospital** is a dedicated advocate for the TPSC, and has committed to conduct 2 BMT entirely free of cost, in addition to facilitating 5 BMTs at a 50% reduced rate. The remaining 50% of the cost will be generously covered by ChildCare.

- **9 Free of Cost HLA (Human Leucocyte Antigen) camps,** have been conducted in the past 3 years, and 500+ samples have been collected to match patients and donors for BMT.

- **Bajaj Finserv** has pledged to fully fund 10 BMT's for Thalassemia major warriors who have found a 100% sibling match.

> *Aryan, 6, was born with Thalassemia major and had a BMT via an unrelated donor in 2022. Earlier, he was quiet, reserved little boy. He didn't like to try anything new, was very shy around new people. Since his transplant, things have changed so much. He is chatty, loves outdoor sports and his self-confidence has increased. The BMT granted Aryan a chance at life brimming with hope, and the boundless possibilities of a future he once could only dream of.*

#3 CURB: SCREENING & PREVENTION

Challenges

Lack of awareness about Thalassemia, the importance of carrier testing, the **prohibitive costs for screening** are a few challenges faced

Successes

TSPC has encouraged **gynaecologists for genetic testing, conducted widespread screening, and subsidized costs of testing**, as helpful initiatives to reduce Thalassemia major births

Programs

TSPC provides all-encompassing **health screening camps at a nominal cost of Rs 500 per person, accommodating 225-250 participants per camp**. The screening includes CBC, HBA2, Sugar, and Reflex molecular testing. Key insights from our activities are as follows:

- TSPC's widespread testing has revealed a **carrier status of 2.2%** compared to a 3.4% national average
- Over the past 5 years, **TSPC has successfully screened more than 5,000 individuals** at renowned corporations such as Infosys, SRPF, FIAT, Mahindra & Mahindra, Tata Consultancy Services and the Symbiosis Institute of Management to name a few
- With the help of MMF, in the last 6 months itself, we have tested around **2,000 students at various city colleges in Pune , Ratnagiri and Panchgini**

> *Amid the excitement of Priya's pregnancy, Ramesh discovered his thalassemia carrier status during a screening at Infosys. Shockingly, Priya was also a carrier. Swift genetic counseling informed their decisions, ensuring the birth of a healthy child. This highlights the vital role of early screening in preventing Thalassemia major births.*

#4 PATIENT & GOVERNMENT ADVOCACY

CONFERENCES

TSPC's engagement with the medical community is dynamic and robust, epitomized by our bi-annual National Conferences that bring together medical professionals. We actively **engage with gynecological societies, recognizing that testing during pregnancy is a crucial** and practical step to curb Thalassemia entirely.

Additionally, we regularly host Continuing Medical Education (CME) sessions, inviting doctors from across Maharashtra. Over the years, we have successfully organized **a major international conference in 2005 and a national conference in 2022**, attracting a combined total of over 850 delegates.

Notably, Dr. Munshi, actively participates in numerous conferences, contributing to the exchange of knowledge and advancements in Thalassemia management.

WORKSHOPS

Twice a year, TSPC facilitates essential patient gatherings, serving as pivotal forums to heighten awareness among both warriors and parents. Moreover, these gatherings aim to **educate participants on diagnostic modalities, empowering individuals and their families in the effective management of Thalassemia.**

GOVERNMENT ADVOCACY

TSPC actively engage in advocacy initiatives with the state and national Health Ministries. Recently, all affiliated societies across India have collaboratively signed a letter requesting a meeting with the Health Ministry, for 3 key points:

- Designation of **chelation as duty-free**
- Implementation of **mass-scale prevention programs for pregnant women**
- Inclusion of **HbA2 testing alongside the existing mandate for sickle cell screening**

A SIGN OF HOPE

Latur district in Maharashtra has mandated couples to test for Thalassemia before issuing a marriage certificate, to prevent the growing numbers of Thalassemia cases in the region

The Gujarat state government is underway to pass a bill for the same mandate

OUR GOALS

RAISING

₹13.62 Crore

Annual Cost of 2.7 Crore x 5 Years

54% CARE

37% CURE

10% CURB

PROJECTS

CARE	**ASHA**	Provide chelation medicines and leukocytes filters to manage the iron overload for Thalassemia warriors	**₹1.29 Crore** (annual cost) • No. of Beneficiaries = 100 • Monthly Cost Per Beneficiary = ₹10,750/-
	SHIKSHA	Empower Thalassemia warriors, with a fundamental right of education, a step to making them independent.	**₹7.5 Lakhs** (annual cost) • No. of Beneficiaries = 25 • Annual Cost Per Beneficiary = ₹30,000/-
	HEALTH CHECK-UPS	Monitor the impact on various organs due to the complications arising from Thalassemia	**₹10 Lakhs** (annual cost) • No. of Beneficiaries = 100 • Annual Cost Per Beneficiary = ₹10,000/-
CURE	**BMT**	Provide BMT pre-transplant preparation, donor matching, transpalant procedure and recovery support	**₹1 Crore** (annual cost) • No. of Beneficiary = 10++ • Cost Per Beneficiary = ₹10 lakhs
CURB	**PREVENTION CAMPS**	Organize widescale screening camps to indentify Thalassemia traits for early intervention, pre-marital and genetic counselling	**₹26 Lakhs** (annual cost) • No. of individuals = 5,200 • Cost Per Beneficiary = ₹500/-

OUR 5 YEAR PLAN

500+

Warriors Supported

Supporting Thalassemia warriors through subsibidized cost of iron chelation, leukocyte filters, annual health check-ups, education and empowerment

50+

Warriors Cured

Providing cure through financial resources, access to best-in-class hospitals, facilities and health care expertise for Bone Marrow Transplant

20,000+

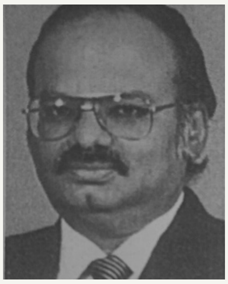
Individuals Screened

Empowering individuals with the knowledge on their Thalassemia status to make informed decisions, eventually resulting in Thalassemia eradication

OUR TEAM

Mrs. Majethia
Patron

Dr. Nita Munshi
President



Ramesh Arora
Vice President

Suren Sitlani
Secretary

Kailash Tile
Jt. Secretary

Shrichand Tejwami
CFO

Ashok Thadani
Treasurer

Nilesh Shah
Jt. Treasurer

Nayana Doshi
Executive Member

Shilpa Arora
Executive Member

Dr. Sweta Lunkad
Medical Advisor

Dr. Liza Bulsara
Medical Advisor

Simran Tejwani
Executive Member

Jatin Sejpal
Counsellor

Preeti
Design Consultant

Krupa Shah
Project Head

GRANDFATHER
Original Storytellers

Team Grandfather
Media Consultants

17+ Passionate Professionals with A Purpose

Within our team, diversity is not just a composition of varied professional backgrounds, it's a tapestry woven with personal threads of connection to Thalassemia. Each team member brings a unique life story, bound by a shared passion to eradicate this disease from the fabric of India. Our collaboration is fueled not only by professional commitment but also by a profound personal dedication to make a transformative impact on the lives affected by Thalassemia.

We could not do what we do without our volunteers and donors. Together, we are making a difference – and you can too help us make a Thalassemia Mukt Bharat.

For Donations

SCAN & PAY

UPI ID: thalsoc@ucobank

UPI ID: thalsoc@ucobank

Account Name:
Thalassemia Society Pune Chapter

Account Number:
17920110016800

Bank Name: UCO Bank, Pune 411001

IFSC Code:
UCBA0001792

TSPC is an NGO with 80G/12A/CSR Certificates

CSR Registration Number: CSR00049821

80G Registration Number: 211/2015-16/5964

12A Registration Number: 427/204/2015-16/5323

Contact Us

🌐 http://thalassemiapune.co.in

☎ +91-844-671-6162

✉ thalassemiapune14@gmail.com

on Facebook: @Tspc12

on Instagram: @Thalassemiapune14