

July 21 to June 2022 | Annual Report

PEHLA TEST ZAROORI TEST



The ZB Foundation

SAVING BABIES HEEL BY HEEL

Newborn Screening

Baby's First Step towards a Prosperous Life

What we do?

On The ZB Foundation (ZBF) is Pakistan's first organization that has introduced the Newborn Screening (NBS) program in Pakistan. NBS test offers timely detection and diagnosis of certain disorders that are not apparent at birth and prevent long-term threatening health conditions and mortality in newborns.

ZBF is registered under Trust Act, 1882 as a non-profit organization and it is certified with Pakistan Center for Philanthropy (PCP).

Problem and Solution

Pakistan is among the top 5 countries which contributes to half of the newborns death globally and 11% of them are caused by Congenital Diseases. NBS program is an established public health intervention for the identification of such disorders since last 50 years but it has still not been institutionalized in Pakistan.

Establishing and introducing Newborn Screening (NBS) program in Pakistan is crucial to mitigate mortality and morbidity rate in neonates and children.

NBS is child's birthright and ZBF is striving to assist Pakistan in achieving United Nations Sustainable Development Goals (UN SDGs) 3 i.e., to end child mortality by 2030.

Impact

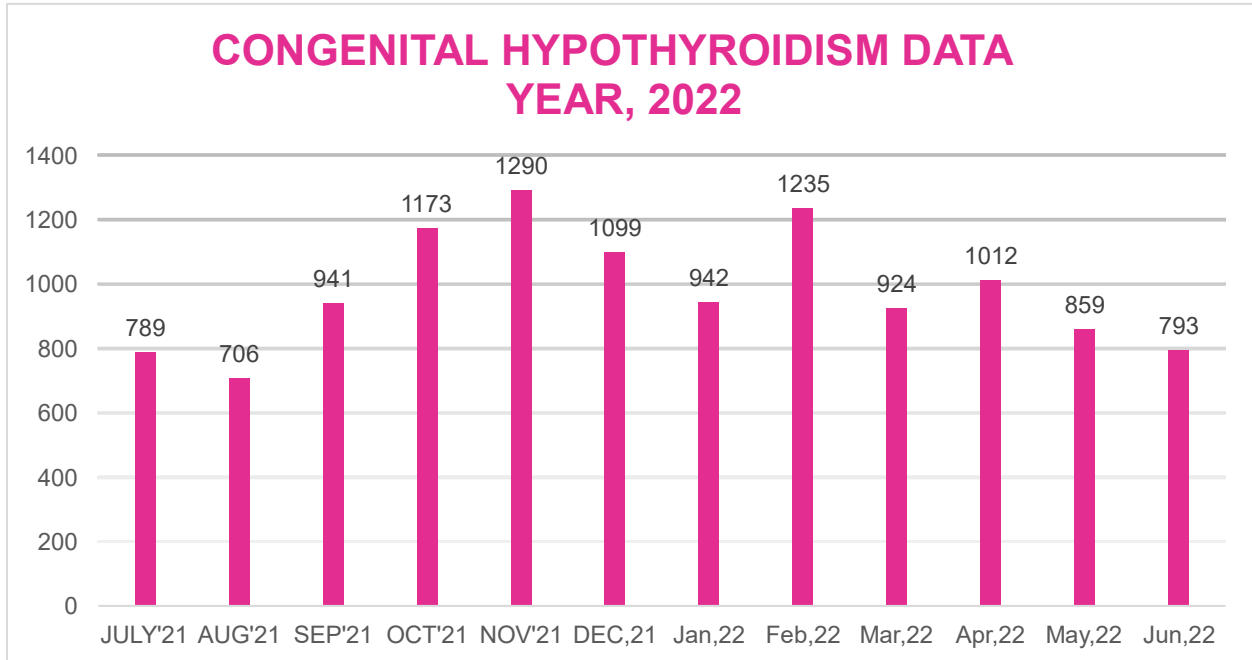
Till date, more than 43,000 babies have been screened, free of cost, for Congenital Hypothyroidism and more than 5000 high risk babies have been screened for Metabolic Disorders from different hospitals across the length and breadth of Pakistan.

So far, 33 positive cases of Congenital Hypothyroidism have been identified from different regions of Pakistan. Late treatment and diagnosis could have otherwise led to permanent, physical and intellectual disability in newborns.

Program Delivery and Progress

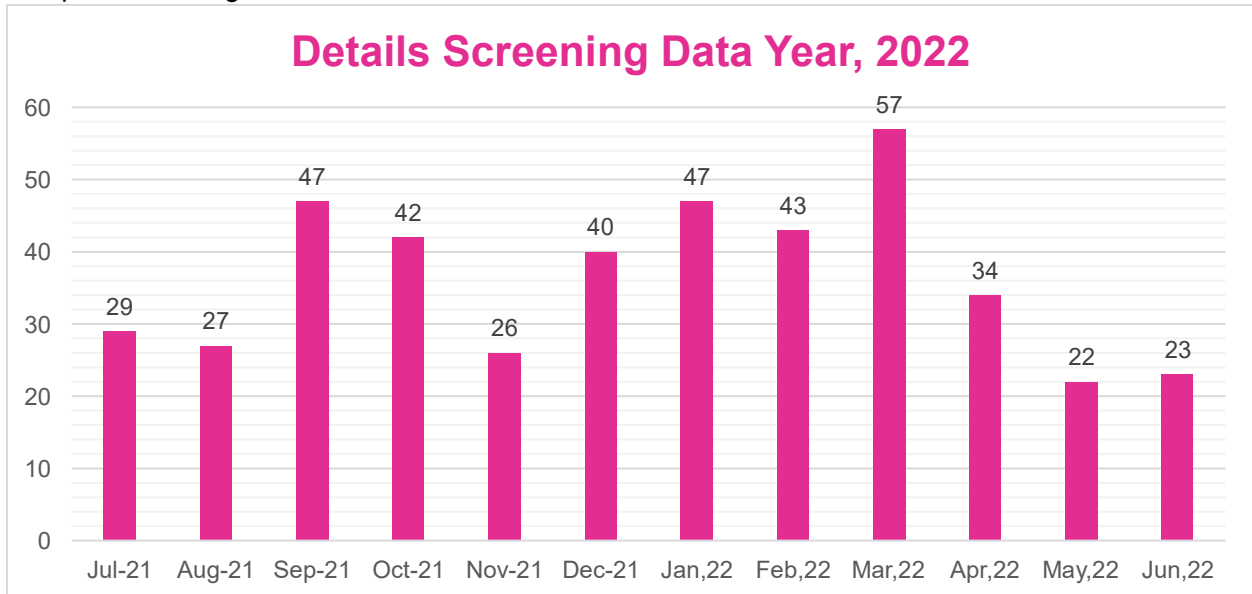
Congenital Hypothyroidism (July, 2021 to June, 2022)

In 2021, we screened **11769** babies. Out of these **13** Babies were identified Positive for Congenital Hypothyroidism.



Details Screening (July, 2021 to June, 2022)

In 2021, we sent **436** samples to Medlabs Jorden, out of these **164** samples were Positive and 272 samples were Negative.



Activities and Milestones (July 21 - June 22)

- Economic Affairs Division (EAD), Government of Pakistan, has approved our Application & MOU has been signed with them. In the context of Legal & Regulatory Compliance this is a significant achievement. This MOU establishes NPO Credibility & enhances Donors Trust/Confidence in matters concerning Transparency & Good Governance.
- Our co-founder Akber Naqvi participated in UTMB (Ultra Trail Mont Blanc). UTMB is an ultramarathon that is held on the last weekend of August in the picturesque town of Chamonix, France. It has been going for the last 19 years except last year. The race involves a runner covering 172km and climbing 10,000 meters. As always he took the opportunity to Highlight & Promote ZBF Cause at that Platform involving Participants & Sponsors from many countries.
- The ZB Foundation drew stakeholder's attention towards an "Increasing Need" for Upscaling the "Awareness Campaign" to highlight NBS Importance at the Grass-Root Level. Although we have screened more than 43,000 Babies so far but in isolation these numbers do not create the "Needed Impact" for the venerable sections of our society. As such, our experience over the years has shown that in the implementation of successful NBS Programs one faces various challenges. Despite the high prevalence of CH in Pakistan, there is no National Level Program for detection of Newborn Screening. In some countries public service organizations provide funding support including informational material, laboratory equipment, and facilities. However, in Pakistan very minimal support is available. Although services of NBS have been offered at very few private hospitals but these are not affordable for public. Besides, acceptance of new born screening procedures is very low. On a large scale, parents and health practitioners are not aware about the importance and effectiveness of NBS and therefore, considerable amount of effort is required for penetration of NBS program at the Supply Side i.e., Public Hospitals and Demand Side i.e., Parents of newborns.
- **Inauguration Ceremony at Pakistan Institute of Medical Science (PIMS) - Islamabad—** 01/12/2021 —Zahra Beau Naqvi Foundation Welfare Trust welcomed Dr. Nosheen Hamid as a Chief Guest to inaugurate the ceremony of the Newborn Screening Services at PIMS. The ceremony was held at the Children OPD PIMS hospital on Wednesday, 1st December 2021 from 11 PM till 12 PM.

Dr. Nausheen Hamid acknowledged the contributions of The ZB Foundation being the pioneers to introduce, implement and advocate for the Newborn Screening Protocol as a nation-wide campaign across Pakistan. She also shared that the legislation of Screening for Heritable Disorders at national level is vital to enhance, improve, and expand the ability of government's healthcare system to provide screening, counseling, and health care services to newborns and children who have, or are at risk for, heritable disorders. In her closing remarks, she specifically highlighted that she will be playing an active role to establish Newborn Screening program at National level so that no baby gets deprived of the birth right.

The ZB Foundation is a non-profit organization that has been leading the mission to make newborn screening for Congenital Hypothyroidism the birth right of every newborn since its establishment. Not only that ZBF has been at the forefront, leading the awareness campaigns on-ground as well as utilizing digital platforms to aware the maximum number of families as possible.

The non-profit organization has been providing free of cost Newborn Screening services at PIMS from past 3 years. The major challenge was to raise awareness among parents to bring the babies for the test and create the strong system within the hospital to promote the test. Dr. Nosheen played a crucial role in bringing all the stake holders from PIMS together to raise the awareness on Newborn Screening for Congenital Hypothyroidism.

Clinical Director and COO The ZB Foundation, Dr. Ali Raza shared that the Advocacy and Awareness in various departments at PIMS hospital Islamabad has encouraged the parents to bring their babies for the test and it resulted in 640% increase in sample size at PIMS hospital, Islamabad in just one month.

Mr. Ali Javed Naqvi, Chairman, The ZB Foundation Presented the shield to Dr. Nausheen in recognition to her outstanding contribution for advocating the need for Newborn Screening. The shield was also presented to Hospital Director, Dr. Ejaz Qadir on the behalf Children Hospital PIMS in recognition to its extraordinary contribution in institutionalizing Newborn Screening Program in collaboration with The ZB Foundation.

The other honorable guests who were the part of this ceremony include:

1. Dr. Ejaz Qadir, Hospital Director PIMS Hospital
 2. Dr. Amjad Chaudhry, Joint Executive Director Children Hospital PIMS Hospital
 3. Dr. Shereen Gul, Head of Neonatology PIMS Hospital Islamabad
- **Advocacy and awareness session on Newborn Screening at Shifa International Hospital, Islamabad** – ZBF team highlighted the need for Newborn Screening and how it can prevent child morbidity and mortality. The team delivered the presentation to share the journey of ZBF till date and current status of NBS in Pakistan. They have also presented the methodologies used for expanded Newborn Screening Panel and their efficiency.
 - **CSR Award** - The ZB foundation was awarded with CSR award for its contribution in institutionalizing Newborn Screening program in Pakistan by National Forum for Environment & Health (commonly known as NFEH).
 - **Rare Disease Day** - Team World This Morning-PTV World invited us on World Rare Disease Day. Rare Disease Day is the globally coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease Clinical Director and COO The ZB Foundation, Dr. Ali Raza emphasized the need for the Newborn Screening test in Pakistan and highlighted The ZB Foundation's contribution till date in providing free of cost screening test to babies born in different districts of Pakistan.
 - **Advocacy and awareness session on Newborn Screening at Madina Teaching Hospital Faislabad** - Awareness seminar on Newborn Screening organized by the Department of Pediatrics, UMDC/Madinah Teaching Hospital and The ZB Foundation. The seminar and panel discussion was largely attended by the faculty members of Pakistan Pediatric association, faculty members UMDC, the medical students and paramedical staff members. We are also great full to Prof. Dr. Muhammad Khaleeq-ur-Rahman, Rector Madina Teaching Hospital for endorsing the Newborn Screening services by The ZB Foundation and for honouring us with the shield.

Future Goals

- Promotion and Advocacy of Newborn Screening through social media
- Increase awareness among health practitioners and the public
- Active partnership for Metabolic Screening
- Arrange fundraising event

Financial Summary

CHARITABLE WORK & SERVICES PROVIDED DURING LAST FINANCIAL YEAR (June 2022)

	Number of Beneficiaries (2021)	Number of Beneficiaries (2022)	Amount Spent (2022)
<i>Free newborn screening for Congenital Hypothyroidism (TSH)</i>	6584	11759	15,008,777
<i>Free newborn Full Metabolic screening from Medlabs Jordan</i>	319	436	
<i>TOTAL</i>	6903	12195	15,008,777

Gallery



CSR Award



CSR Award



Awareness Session at MTH



Awareness Session at MTH



Awareness Session at MTH



Awareness Session at MTH



CSR Award



CSR Award



Awareness Session at MTH



Awareness Session at MTH



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HAVING BABY?
NEWBORN SCREENING IS YOUR CHILD'S
BIRTH RIGHT



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