

# The ZB Foundation

SAVING BABIES HEEL BY HEEL

## Annual Report July 2020 – June 2021



# The ZB Foundation

The Zahra Beau Naqvi Foundation Welfare Trust (ZBF) is a registered non-profit Organization (NPO) and certified by Pakistan Center for Philanthropy (PCP). It aims to introduce, implement and propagate Newborn Screening program in Pakistan, considering it as a birthright of every baby born in Pakistan.

ZBF started the initiative of Newborn Screening (NBS) program with a mission to institutionalize NBS as a national protocol. Like other countries, ZBF has started the NBS program with Congenital Hypothyroidism as it is also the most abundant of the panel disorders found in Pakistan because of its prevalence, diagnostics and treatment availability.

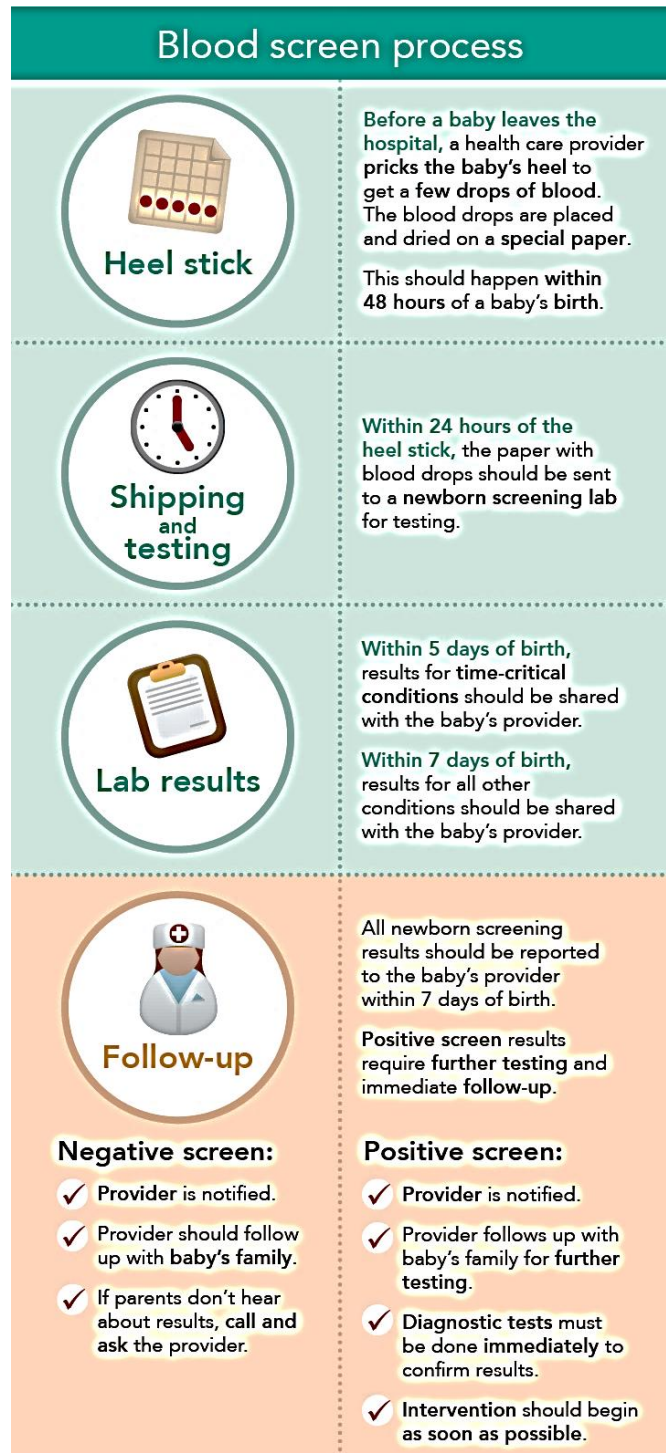


**PAKISTAN, A DEVELOPING COUNTRY WITH AN ESTIMATED POPULATION OF 207 MILLION INHABITANTS, 31.6% OF WHOM ARE UNDER 5 YEARS OF AGE, HAS AS YET NO NEWBORN SCREENING PROGRAM AT THE NATIONAL LEVEL. THE INFANT MORTALITY RATE IS 54 PER 1000 LIVEBIRTHS.**

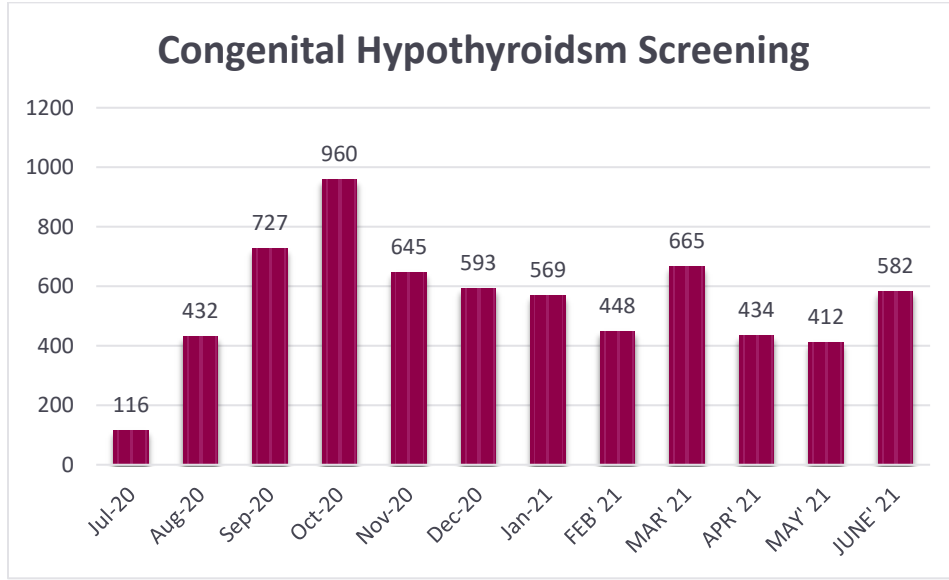
## Sustainable Development Goals

The proposed SDG target for child mortality aims to end (GOAL 3), by 2030, preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 deaths per 1,000 live births and under-5 mortality to at least as low as 25 deaths per 1,000 live births.

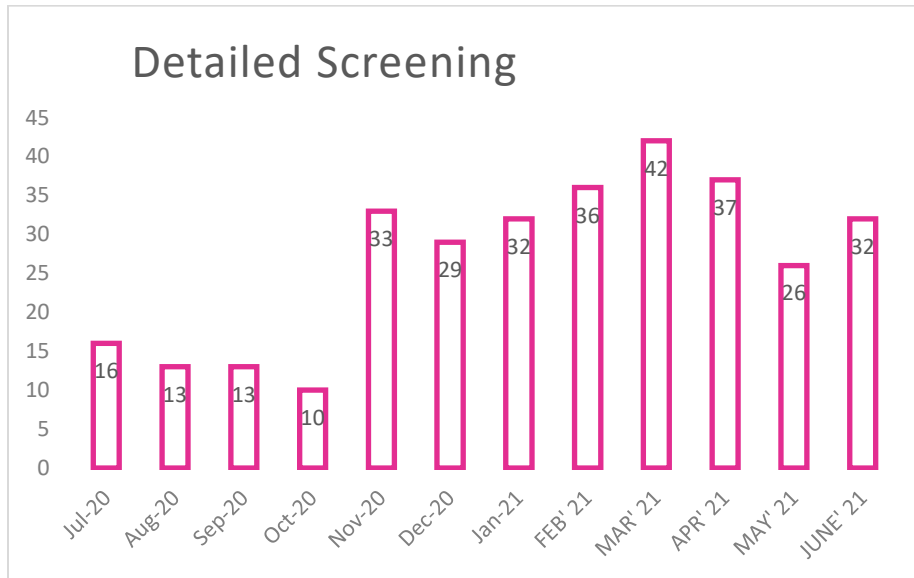
We cannot achieve the Sustainable Development Goals (SDGs) target of ending preventable deaths of newborns and children under 5 years of age by 2030 by ignoring one of the causes of childhood mortality. According to UNICEF Child Mortality Report of 2017, congenital disorders contribute 11% to the deaths in children who are aged under 5 years and Pakistan is one of the five countries which are accounted for half of all newborn deaths.



- 6584 babies were provided free of cost screening for Congenital Hypothyroidism



- 315 babies were facilitated for Detailed Screening



## Program Delivery and Progress

Despite the Pandemic, the Zahra Beau Naqvi Foundation Welfare Trust (ZBF), which is a non-profit organization, continues to introduce and implement Newborn Screening (NBS) Protocol at a national level. Till now ZBF has screened **33,209** newborns for Congenital Hypothyroidism. To further spread awareness about the importance of newborn screening and enhance its reach, ZBF mainly targets: parents, expecting mothers, newlyweds, policy makers, public health professionals, donors, and general public.

Furthermore, in its quest for increased coverage of newborn screening tests, ZBF has provided NBS with more than 45 hospitals till date. Despite of downsizing the organization due to limited resources, ZBF continue the NBS program for CHT to eradicate mental retardation and immature somatic growth caused by deficiency of thyroid hormones in the body. Currently, ZBF is providing free NBS to two largest tertiary care hospitals in Islamabad and Khyber Pakhtunkhwa. Below is the list of hospitals which have collaborated with the ZBF:

<i>Hospital Name</i>	Contact Person	Contact Details
<b><i>Pakistan Institute of Medical Sciences (PIMS), Islamabad</i></b>	<b>Tahira</b>	<b>03340528529</b>
<b><i>Lady Reading Hospital (LRH), Peshawar</i></b>	<b>Haleem Khan</b>	<b>03319130416</b>
<b><i>Mardan Medical complex (MMC), Mardan</i></b>	<b>Alamgir Khan</b>	<b>03449572563</b>
<b><i>Izzat Ali Shah Hospital (IASH), Wah Cantt</i></b>	<b>Tahira</b>	<b>03115184373</b>
<b><i>Sheikh Zaid Hospital, Raheem Yar Khar</i></b>	<b>Dr. Asma</b>	<b>03017790794</b>
<b><i>IHS Children &amp; Family Hospital, Islamabad</i></b>	<b>Adeel</b>	<b>03345250800</b>

## Activities

- Research Paper prepared by our Lab Team has been published in PMA Journal. Its link is [www.jpma.org.pk/article-details/10377](http://www.jpma.org.pk/article-details/10377)
- Successful meeting with the Government of Punjab regarding the creation of a centralized lab in Punjab. The focus is to provide free of cost NBS for Congenital Hypothyroidism to Babies born in different Tertiary Care Hospitals of Punjab.
- Presented the Detailed Road Map and Implementation plan of Newborn Screening to Government of Punjab.
- Received the Non Objection Certificate for
- Renewal of MOU with Pakistan Institute of Medical Sciences (PIMS).
- PCP Certification-Renewal: ZBF declared “Qualified” in their by PCP and obtained 73% score against minimum requirements of 60%. Our Certification has been “Renewed” & we received the Certificate”& “Final Report.”
- The Co-Founder ZB Foundation Akbar Naqvi ran in Dubai's Al Qudra desert for 42 hours in memory of his daughter Zahra Beau Naqvi to support the foundation.

## Digital Awareness Campaign

For this purpose, social media campaigns including, short success stories videos, animated videos and documentaries will be developed. Social media advertisement campaigns will be launched to introduce these videos and other NBS related information utilizing ZB platform.

- a. Social media and other digital platforms will target the large population including general public, policy makers, and health care professionals in educating about the importance of NBS and also the negative consequences of avoiding it.
- b. Highlighting the experiences and reviews of individuals who have availed the NBS services will motivate and encourage parents to get their newborn tested.
- c. YouTube channel and animated videos for awareness:  
<https://www.youtube.com/channel/UCdPMtBStWM81rFYZfDJYhnw>

The awareness raising campaign material including brochures, flyers, standees, videos etc. were developed in Urdu language for enhanced understanding of the NBS information and messages.

After the successful implementation of referral model at PIMS hospital, The ZB Foundation will be implementing the same model in other partner hospitals for massive impact.

## Role of Various Department at Hospitals for NBS Awareness Raising and Referrals

### Antenatal (Gynecologist & Obstetrician)

- NBS awareness among pregnant women
- Share the awareness material with the expecting mothers
- Educate mothers regarding the importance of NBS

### Neonatal (Pediatrician)

- Encourage the parents to bring newborn for NBS test

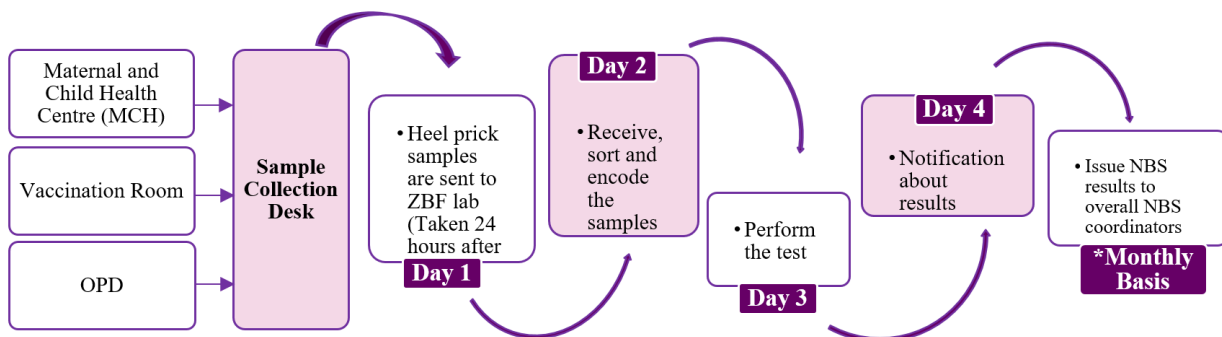
### Vaccinators

- Refer newborn to the NBS sample collection desk after first vaccine

### OPD

- Ask newborn parents about the NBS test and refer to NBS sample collection desk in case their child has missed it

## Operational Plan of Newborn Screening Test



## Future Goals and Targets



Networking – getting all pediatricians on one platform



Promotion and Advocacy



Increase awareness among health practitioners and the public



Sample Collection Training



Organize NBS Support Group



Develop National Protocol



## Financial Summary

### CHARITABLE WORK & SERVICES PROVIDED DURING LAST FINANCIAL YEAR (June 2021)

	Number of Beneficiaries	Amount Spent
Free newborn screening for Congenital Hypothyroidism (TSH)	6584	
Free newborn Full Metabolic screening from Medlabs Jordan	319	10,568,039
<b>TOTAL</b>	<b>6903</b>	<b>10,568,039</b>