Newborn Screening

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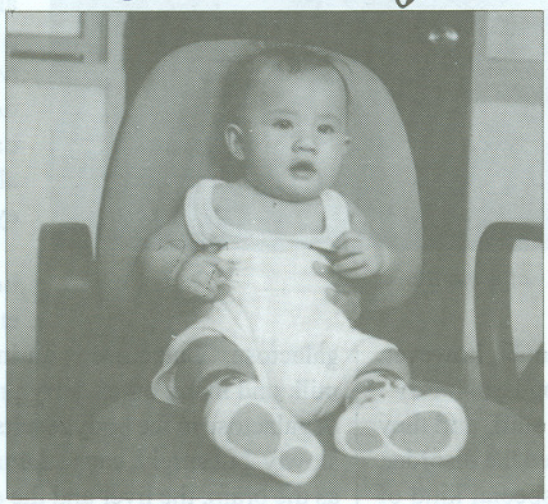
Journey to Hope

Baby V. appeared healthy when she was born on September 7, 1997, at the Rizal Medical Center in Pasig City. Nobody suspected that she has Congenital Hypothyroidism. A few weeks after discharge from the hospital, Mrs. V. noticed gradual but steady deterioration in Baby V.'s health. She was losing weight, her skin was becoming dark, coarse and wrinkled, her tongue was getting bigger and protruded from her mouth, and her umbilicus did not dry and fall off as with other babies. Moreover, she was frequently sick with coughs and colds, constipated, and fussy. Mrs. V. brought her to the doctor several times for treatment of her illnesses, but the true cause of her health problems remained unidentified. At 3 months, it was evident that Baby V.'s development lagged considerably in comparison with babies of similar age. Mrs. V. felt confused and helpless. One day in January 1998, a policeman who also happened to be a family friend brought to their house a letter from the Philippine Newborn Screening Project. It was incidentally handed to the policeman by a mailman who failed to locate the address. Wasting no time, Mrs. V. brought her daughter to the Newborn Screening Laboratory the following day and thus, began their journey to hope.



Baby V. at 7 months.

At the Newborn Screening Laboratory, the Nurse Coordinator casually asked the haggard-looking woman who she was as she walked into the office. The name rang a bell loud clear in her mind, and she gasped, "Matagal na po kayo naming hinahanap!". It turned out that they have been searching for her for 4 months! Baby V. was immediately referred to an endocrinologist, a doctor who specializes in hormones, and further tests confirmed that she, indeed, had Congenital Hypothyroidism. Hormone replacement therapy was prescribed. Presently, Baby V. is a robust, charming and truly healthy baby, a far cry from the sick baby who came to the laboratory months ago.

Congenital Hypothyroidism, which affects approximately 1 in every 4,834 newborns, is due to an absent or poorly functioning thyroid gland. The thyroid gland produces thyroid hormones which are crucial to the body's proper growth and development.

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PNSP Goes National!

On April 28, 1998, the Philippine Newborn Screening Project held an Orientation Seminar during the Philippine Pediatrics Society Convention at the PICC. Around 26 hospitals expressed interest in joining. As of June 1998, 7 hospitals from key areas outside of Metro Manila have formally commenced with the project. These are the following: Angeles University Foundation Medical Center, Angeles City; Dela Salle University Medical Center, Dasmarinas, Cavite; Perpetual Succour Hospital, Cebu City; Davao Doctors' Hospital, Davao City; Ma. Reyna Hospital, Cagayan de Oro City; Northern Mindanao Medical Center, Cagayan de Oro City; Mindanao Sanitarium and Hospital, Iligan City. More hospitals are preparing to join within the next few months.

STUDY UPDATE
June 1998

Total Number of Patients Screened		**62,841**
Total Number of Patients with Elevated Results		**206** (1:305)
CAH	46	
CH	96	
PKU	47	
GAL	9	
HCY	6	
MULT	2	
Total Number of Patients with Confirmed Results		**23** (1:2,732)
CAH	5	
CH	13	
PKU	1	
GAL	4	
(*Classical Galactosemia*	1	1:62,841)
(*Galactokinase Deficiency*	1	1:62,841)
(*Duarte Gene Variant*	2	1:31,421)

A Surprising Twist

Like Baby V., Baby J. was normal and lively at birth. He was born through normal delivery on September 25, 1997, at the Chinese General Hospital in Blumentritt, Manila. He was a lovely, responsive and affectionate baby. Naturally, his parents and 4-year-old sister doted on him. Nothing betrayed that he has galactosemia, a rare metabolic disorder that affects approximately 1 in 15,710 Filipino babies. Mr. and Mrs. J. were astonished to receive a letter from the Philippine Newborn Screening Project saying that their baby needs to be reexamined because of an increased result in one of the tests. "This must be a mistake," they thought incredulously, "Our baby could not possibly be sick." Unwilling to leave anything in doubt, however, they promptly brought Baby J. to the Newborn Screening Laboratory.

Baby J. at 6 months.

Baby J. easily charmed the Newborn Screening staff, and they were similarly baffled when more specific tests confirmed the disorder. It is even more interesting to note that Baby J. has a special kind of galactosemia, one which is due to the absence of an enzyme known as galactokinase. Diet modification was initiated at once to prevent the occurrence and further development of harmful effects. Moreover, surgery was done to correct a 4 mm cataract which had already developed in both eyes.

In Galactosemia, the body lacks a specific enzyme needed to process galactose. Galactose is an important component of milk and many other dairy products. Accumulation of galactose in the body results from this disorder, and slowly, but surely, cause damage to vital organs such as the brain, the liver and the eyes.

Sans Newborn Screening

Newborn Screening is not an auxiliary procedure. It is not an amenity for the advantaged. It is not even a special test for special kids. It is a basic, preventive procedure that should be performed for all babies to protect them from the mischance of metabolic disorders. Newborn Screening is a vital component of comprehensive neonatal care. Here are five indisputable reasons why Newborn Screening calls to every babe.

1.) Babies with metabolic disorders usually appear normal at birth. *Without Newborn Screening, these disorders will be discovered late or will never be discovered at all.*
2.) Manifestations of metabolic disorders are vague. *Without Newborn Screening, an accurate diagnosis may elude physicians until it is too late.*
3.) The effects of metabolic disorders are progressive and irreversible. *Without Newborn Screening, preventive measures cannot be initiated to check the insidious course of these diseases.*
4.) Developmental effects of metabolic disorders are seriously debilitating. *Without Newborn Screening, a child encumbered with a metabolic disorder has little chances of experiencing normal life.*
5.) Metabolic disorders are not infectious or contagious; they can affect babies even of the most careful of parents. *Without Newborn Screening, there can be no telling.*

For all the benefits of Newborn Screening, one need only pay P350.00*. Sadly, however, many still cannot afford even this minimal cost. 50% of the 3,000 newborns screened monthly are charity patients, needing P375,000.00 worth of sponsorships. We need the help of individuals or companies who would share our vision of making Newborn Screening available to as many Filipino babies as possible. Call tel. nos. 526-1725 or 526-1710, and ask about how to Sponsor-A-Child.

* *Newborn Screening fee for babies born in non-participating hospitals is P500.00*

editorial box

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