

NEWBORN

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Screening

NBS bills seek nationwide coverage of newborn screening

Finally, a bill that will institutionalize newborn screening in the country has been filed in both the Congress and the Senate.

Senate Bill No. 1946 entitled "NBS Test Act - An Act Establishing the Newborn Screening Test, Integrating the same into existing Health Care Delivery System, Establishing Funds therefore, and for other purposes" was filed by Senator Noli "Kabayan" De Castro in May of 2001.

In May of this year, Senator Juan Flavio introduced Senate Bill No. 2564 entitled "NBS Act of 2003 - an Act Promulgating a Comprehensive Policy

and a National System for Ensuring Newborn Screening" in support to the Bill filed earlier by Senator de Castro.

Meanwhile, at the Lower House, House Bill No. 5919 entitled "Newborn Screening Act of the Philippines 2003 - an Act Institutionalizing Newborn Screening as Part of Routine Newborn Care in the Nationwide Health Care Delivery System of the Philippines" was filed by Congressman Antonio Yapha and co-authored by Congresswoman Filomena San Juan. Both House Representatives are medical doctors by profession.

Dr. Carmencita D. Padilla, one of the national conveners of NBS in 1996,

described the bill as pro-life, pro-child rights and non-controversial. She is very optimistic that the bill will gather more support from other legislators. Dr. Padilla hopes that the passage of the Bill will put newborn screening implementation in place and make it available and accessible to all newborns in the country.

All newborn screening advocates throughout the country are enjoined to help in lobbying for the immediate passage of the Bill. The early passage of the Bill will save 10,000 estimated newborns annually from possible mental retardation and death.

NTWG-NBS conducts workshop for regional coordinators



After almost four years since they first met in September 1999, newborn screening coordinators from the different DOH regional health offices gathered together for a workshop last April 28-30, 2003 at the Bayview Park Hotel.

The objectives of the activity were the following: (1) to update the coordinators on the current status of implementation of newborn screening in the country and; (2) to discuss critical issues related to the implementation of newborn screening and discuss the future directions of newborn screening at all levels.

Except for DOH Regional Office IX and ARMM, the rest of the DOH regional offices were represented.

When newborn screening (NBS) was started in 1996, two of the issues raised regarding its applicability in the community were the following: Who will pay for the NBS of indigent babies? How will babies be screened in far flung areas?

Every year, about 1.5 million babies are born in the Philippines. While 20 to 30 percent of these newborns are delivered in the hospital and attended to by physicians, the remaining 70 to 80 percent are born at home, assisted either by a midwife or a family member.

With majority of the population living below the poverty line, many public health workers were reluctant to promote NBS knowing that parents would have to pay for the tests. At present, only 3.0 percent of the country's annual births are screened.



Newborn Screening in the Community Setting

The Philippine NBS project and the Department of Health, thus, face a formidable challenge in making NBS accessible and available to all Filipino newborns. The Institute of Human Genetics of the Philippine National Institutes of Health, which implements NBS in the country, is doing a Herculean job of promoting and advocating NBS, especially in the community setting where many deliveries are done at home.

The Bayawan Experience

In February 2000, the Bayawan District Hospital, located at the southern part of Negros Oriental, offered its community a program that made NBS an accessible and affordable option for indigent patients.

Dr. Fidencio Aurelia, the chief of hospitals and the NBS coordinator of the said hospital, integrated NBS into a "micro-insurance" or community-based health care finance plan called the People Empowerment Saves One (PESO) program. The PESO for Health programa offers innovative health care management through mutual cooperation and active participation among members of the community, the local government unit

and the hospital.

Any family in the catchment area can avail of the program by paying P10 as household membership fee and contributing P1, P5 or P10 per household member monthly thereafter. Money collected monthly from members is augmented by Local Government Unit funds and various donors. The family is asked to make six month continuous contribution before they become eligible to avail of the health services offered by the program, such as provision of drugs or medicines, diagnostic services, newborn screening, and others.

The PESO program also emphasizes the role of Barangay Health Workers (BHWs) as frontliners in the delivery of health care. To motivate BHWs who are tasked with implementing NBS in the community, the worker who recruited the most number of parents who had their babies screened was awarded during the Annual BHW Convention which was held in 2001. LGU officials also provided crucial support in the implementation of the program.

Since its implementation, the hospital has been able to screen 224 babies, 89 of whom availed of the PESO

package.

The success of the Bayawan District Hospital in implementing NBS in its community is, thus, attributed to a combination of creativity, innovative thinking, dedication, and advocacy and a firm belief that, as articulated by Dr. Aurelia, "empowering people makes health accessible, affordable, and available."

The Tanjay Rural Health Unit Experience

The challenge of implementing NBS outside the hospital setting was initiated by a dynamic health team in Tanjay Rural Health Unit, Negros Oriental. The team was composed of a rural health physician, public health nurses, midwives, and BHWs. A very persuasive and energetic municipal health officer in the person of Dr. Elizabeth Sedillo spearheaded NBS advocacy among local government officials. As a result, a resolution was passed by the local government unit allocating funds for the implementation and integration of NBS in the regular health services of the municipality.

Within the team, different members fulfilled different roles. As the key implementers of NBS, the rural health

Stories of UNSAVED CHILDREN with CH depict need for newborn screening

Three children diagnosed to have Congenital Hypothyroidism (CH) were recently featured in one of the segments in the May 30, 2003 edition of *Magandang Gabi Bayan* (MGB) aired on ABS-CBN Channel 2. The parents of these children agreed to appear in television and in any multi-media material that will promote the significance of newborn screening in the public, particularly among expectant mothers.

Their stories depict the critical role of newborn screening in saving babies from mental retardation.

Mental and physical retardation caused by Congenital Hypothyroidism is preventable if treatment is initiated at least four weeks from birth. Debilitating effects resulting from delayed treatment are usually irreversible. What happened to JR, Jonathan and Arnel could have been prevented if CH was detected and treated early in life. These three children could have lived healthy lives if CH was detected and treated early.

Newborn screening can detect CH as early as 48 hours from birth.



Back row L-R: Patrick, a normal 13-year old teenager carrying JR, Jonathan, 13 years old with CH, and Arnel, 17 years old with CH. Front row L-R: Betina, 5 years old with CH, Joana Paula, 7 years old with CH, and Janelle, 6 years old with CH.

done about JR's mental retardation. They are hopeful that someday, JR could finally learn how to walk, talk and take care of himself without his mother or sister's assistance. JR is currently undergoing rehabilitation session at MACAU section of the Outpatient Department of PGH.



The Case of Redentor Cueto

Redentor Cueto is popularly known as JR. He is the 3rd child of Redentor and Teodora Cueto from Pagbilao, Quezon. JR is 13 years old and is approximately 3 feet tall. His current developmental stage is comparable to that of a month-old baby. At his age, JR cannot talk and cannot walk. His physical and mental disability is due to the lack of thyroid hormone in the body brought about by CH.

His parents noticed that there was something wrong with JR when he was 1 ½ years old but were uncertain on what to do and whom to approach about the condition of their child. JR's father is a part-time farmer and laborer. For the past 13 years, JR's mother was unable to help her family look for other means of living as her time was solely devoted to attending to the needs of JR. The family's impoverished condition was a hindering factor in seeking medical assistance to treat JR's illness.

A concerned family friend brought JR to PGH and was finally diagnosed to have CH when he was already 12 years old. Five months after he took the L-tyroxine, a hormone lacking in his body, the family noticed a great improvement in his physical and mental development. According to his sister, there was an increase of approximately five inches in JR's height, his fontanels finally closed and can now eat regularly. The family is aware that there is nothing that can

The Case of Arnel Orilla

Anita Orilla, Arnel's mother, is a part-time househelper of a foreign couple working in Metro Manila. Arnel is the first of four children of Anita. Arnel's delayed physical and mental conditions were observed during the first few years of his life. Anita noticed that while her nephews and nieces of the same age as Arnel developed normally, Arnel failed to catch up with their mental and physical development.

Anita shared that prior to his son's treatment, Arnel had dry skin, was irritable, constipated, inactive and unable to follow simple instructions. She usually complained of Arnel's irregular bowel movement and the typical advice she gets from health workers and friends was to include fruits and vegetable in his diet.

Through the help of her employer, Arnel was referred to PGH and was finally diagnosed to have CH at the age of 15 years old. Anita started to observe a big improvement in Arnel's physical and mental ability when he started taking his medication. At 17 years old, Arnel is currently a grade three pupil of a public school for special children.



How newborn screening saved the lives of these babies



The Case of Betina Gayoso

When Betina Gayoso was born at St. Lukes Medical Center, her attending physician advised her parents to have her screened. True enough, Betina was found to have a positive screening result in Congenital Hypothyroidism. It was indeed a shocking moment for her family, considering that Betina looked very normal at birth. After a series of laboratory tests, she was confirmed to have congenital

hypothyroidism and has started taking hormone replacement for life.

Betina turned five years old last February 1, 2003. Her parents are very glad that she is a normal, intelligent and beautiful child. She even excels in Arts. Betina was featured in a half-page newspaper advertisement promoting newborn screening.

The Case of Jannele Barameda

Jannele Barameda is six years old and salutatorian in her class. At her age, Jannele is tall compared with other children of her age. Jannele was diagnosed to have CH after her newborn screening yielded an elevated result. Like Betina, Jannele received treatment prior to the onset of signs and symptoms of CH.

Jannele's parents are very grateful that their baby was saved from mental retardation. Together with other parents of children suffering for the debilitating effects of CH, they committed to advocate the passage of the Newborn screening Bill currently filed in Senate and the House of Representatives.

Jannele and her mother appeared in the Magandang Gabi Bayan episode last May 30, 2003.



The case of Joana Paula

If not for newborn screening, Joana Paula could have died early in life. Joana Paula is one of the first babies saved

by newborn screening from early death due to Congenital Adrenal Hyperplasia (CAH).

Her story started when she was born at the Chinese General Hospital in 1996 and her newborn screening showed an elevated result in CAH. The initial sex assignment given to them by the resident physician was that of a male because her enlarged clitoris was mistaken as a penis. CAH, especially the salt losing type, needs urgent medical management because the baby may die anytime. Physical manifestation of the disorder includes ambiguous genitalia, severe dehydration, vomiting and hyperpigmentation of the skin.

When Joana was born, she was mistaken to be a daughter of a Negro because of her very dark skin. According to her mother Teresita, her daughter was so ugly. It was an unforgettable experience for her family, especially when the doctors revealed that the child is a female based on the chromosomal studies conducted. It was indeed a hysterical moment for all the members of the family.

Joana Paula is now seven years old and had already undergone reconstructive genital surgery. Joana learned to read at the age of three and is now an outstanding pupil of her class.

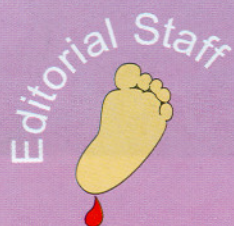


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The case of Jonathan Agudo

Jonathan is now a 13-year old boy. Unlike JR and Arnel, Jonathan was diagnosed to have CH when he was only two years old. Her mother Susan, a manicurist from Paranaque, noticed that Jonathan was delayed in development compared to her younger child. Susan was advised to go to PGH for medical attention.

Jonathan is currently in level two of a special public school in Paranaque. According to Anita, Jonathan can now write and is learning to read. Despite his mental ability, Anita is proud to say that her son can now help her in some of the household chores.



Riza Concordia N Suarez, *Editor*
Cynthia M Villamor, *Editor*
Aileen D. Baccay, *Layout Artist*
Peging Sur, Cha Jomento, *Writers*
Carmencita D Padilla, MD, *Adviser*
Eva Maria Cutiongco, MD, *Adviser*

The Philippine Newborn Screening Program
3/F Institute of Human Genetics
National Institutes of Health-Philippines
University of the Philippines
The Health Sciences Center
P.O. Box 297 (Manila Central Post Office) 1000 Manila
Fax: 526-9997 Email: newborn@humangenetics.com.ph

NBS tackled in Magandang Gabi Bayan

ABS-CBN Channel 2's *Magandang Gabi Bayan*, popularly known as MGB and hosted by Kabayan Noli De Castro tackled Newborn Screening in one of its segments in their May 21, 2003 episode. A special segment discussed the importance of saving babies from mental retardation and early death.

JR and Jonathan, who were not spared from the debilitating effects of Congenital Hypothyroidism or CH, were featured in that segment. Parents of both children shared their difficulties in raising special children like JR and Jonathan. They also expressed sadness upon knowing that their children's condition could have been averted if newborn screening was already available at that time.

Janelle, a seven-year old child with CH and six-year old Joana Paula with Congenital Adrenal Hyperplasia or CAH, were also featured in that episode. Both kids belong to the first group of babies saved by newborn screening during its early implementation and who are now living healthy lives like other normal kids.

The NBS Process was also discussed during the show. The staff of Chinese General Hospital, Philippine General Hospital and the Institute of Human Genetics, National Institutes of Health, UP Manila demonstrated how blood samples are collected and processed.

Through this feature, the public was informed about NBS. As a result,

many parents sought NBS services for their babies and numerous health institutions inquired on how they could offer NBS in their respective institutions. True enough, many babies were found to be positive with some of the disorders and are now currently being managed by their attending physicians.

The MGB segment on Newborn Screening will be available upon request. Please e-mail newborn@humangenetics.com.ph

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midwives were assigned to collect samples from babies in the community. The BHWs led and directed the promotion of NBS among parents and would be parents in their respective barangays. The public health nurses, in addition to advocating NBS, were tasked with systematically organizing the financial aspect of the project.

The team also defined strategies to answer the financial needs of their economically deprived populace. The "Hulugan System" allows parents to pay for the tests on installment terms. A more sustainable financial scheme is currently in the planning stage.

The health team of Tanjay Rural Unit believes that commitment is crucial to any endeavor—not only the commitment of health practitioners in implementing a health program that they believe will benefit the people, but also the commitment of parents to provide for the welfare of their children, and commitment from the local government to support the program. Such commitment has its roots in the strong, tireless advocacy of its members.

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Hospital Coordinators of participating DOH-Retained Hospitals were also among the participants of the activity. It was a reunion for many participants who attended the first gathering of regional newborn screening coordinators in 1999.

During the first day, the participants were able to attend the 2nd National Convention on Newborn Screening organized by the Newborn Screening Society of the Philippines, Inc.

The workshop served as a venue for the participants' sharing of accomplishments and problems in implementing newborn screening. Assistant Regional Director Dr. Paulyn Jean Rossel Ubial presented the experiences of DOH Region 6 in implementing newborn screening at the regional level. Dr. Perla Yray, DOH regional newborn screening coordinators of Region 7, shared their experiences in implementing NBS at the community level and in utilizing community-based health care financing

in a local government health hospital. Dr. Nitz Basilio, chair of the National Technical Working Group of NBS presented the DOH Strategic Plan for Newborn Screening for 2002-2005.

The last day of the activity was devoted to formulating the plans of each region and DOH Retained Hospitals for the next six months. Among the important matters that were discussed and agreed upon were the following; (1) preparation of a Manual of Operation for Newborn Screening that will be distributed later on to NBS implementers at all levels; (2) regular update on DOH NBS implementation through features in the NBS newsletter and; (3) a regular update on NBS coverage and cases which shall be provided to all regions to monitor the performance of each participating institution.

The group is set to meet in October of this year to review the performance of each region.

Los Baños Doctors Hospital bares newborn screening goals for 2003

In line with its mission to deliver quality health care and be the model hospital in Southern Tagalog, the Los Baños Doctors Hospital identified its short-term goals for 2003. These include the following:

- To maintain its 100 percent consistency in screening all newborns in the hospital
- To initiate and implement a newborn screening advocacy program to all midwives in Los Baños, Laguna
- To set up a linkage between the hospital and all midwives handling home deliveries so they can access the newborn screening program
- To start an information campaign and network where LBDH can be an active “drop off” center for newborn screening blood specimens in the whole of southern Tagalog

For the past years, the factors which were critical to the success of the LBDH Newborn Screening Program were the following:

- Good management support coming from the LBDH Board of Directors through its commitment to the goals of the program
- High level of awareness and support from both the professional and allied staff members of the hospital
- Direct supervision and support from then Medical

Director, Dr. Renato V. Torres, the chairperson of the Department of Obstetrics and Gynecology, Dr. Marilyn M. Garcia and the chairperson of the Department of Pediatrics, Dr. Rowena A. Pua.

- The enthusiasm and commitment of its overall coordinator, Dr. Rowena A. Pua, to sustain the growth of the newborn screening program through awareness and advocacy lectures to the different barangay health workers in Los Baños, Laguna.



Team effort secret to success of St. Patrick Hospital's newborn screening program

It was through the enthusiasm of the administrators and personnel of St. Patrick Hospital Medical Center (SPHMC) that the newborn screening program was implemented.

Pediatricians, obstetricians, nurses and medical technologists attended the orientation on NBS which included lectures, video presentations and update on data on neonates tested with various deficiencies that might affect their growth and development. Open fora and discussions paved the way for the strong desire of everyone to participate in the program.

After the orientation, SPHMC Medical Director Dr. Abelardo Perez immediately organized the Newborn Screening Committee which was coordinated by Dr. Belinda Kalaw, assisted by the chair of the Department of Pediatrics Dr. Josefina S. Villena and the chair of the

Department of Obstetrics and Gynecology Dr. Beulah G. Zaragoza.

Eleven months after the NBS was started in 2002, 99 percent of all babies born in the hospital were screened. The efforts and commitment of the Admitting and Laboratory Departments and the all-out support of all hospital staff contributed to the success of the program.

SPHMC aims to motivate and educate all patients on newborn screening. The hospital is committed to provide an environment that is open and flexible to meet patients' expectations and needs as well as to achieve quality service and excellence.

With this goal, SPHMC vows to continue to make screening available not only to the newborns of Batangas City but to all Filipino newborns.