

newborn screening

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SPECIAL ISSUE

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Beyond Commitment:

This year's celebration of the Newborn Screening Awareness Week is made doubly special because of the 4th NBS Convention and because we are also celebrating the 10th year of NBS in the Philippines.

NBS has been in the country for nearly eight years when Republic Act No. 9288 or the Newborn Screening Act of 2004 took effect. With the inclusion of NBS services in the DOH licensing requirements for health facilities starting 2006, all hospitals and birthing facilities will, therefore, inevitably offer newborn screening.

We are continually inspired by many NBS advocates—organizations, local governments and individuals—whose exemplary and unwavering commitment to advocate newborn screening among their fellow Filipinos contribute to improving the health of our children.

In this special issue of the Newborn Screening newsletter, we've put together the experiences of some of the staunchest advocates of the program—reminiscing the early years of NBS in the country, the obstacles they faced in implementing NBS and how they overcame them, and some lessons for the rest to learn from.

We enjoin the rest to rise up and commit to the challenge of saving more babies from mental retardation!

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A Decade of Saving Lives



Turning Dreams to Reality

Carmencita D. Padilla, MD, MAHPS

Director, Newborn Screening Reference Center and Institute of Human Genetics
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Having returned in late 1990 from training in clinical genetics, I was expected to set up genetic services in the University. Dr D Daus-Lawas had retired and Dr T Briones unexpectedly passed away due to cancer, leaving a vacuum in Genetics in the University. In 1991, I presented my recommendations to UP College of Medicine Dean A Ramirez, who gave total support for plans in Genetics. However, Dean Ramirez sent me to DOH for discussion of my newborn screening (NBS) plans because of the public health implications. DOH Asst Sec A de Leon was very accommodating but he said that without local data (despite 1968 WHO recommendations) it would be difficult to consider because of competition with other public health programs.

I was Executive Officer of the Department of Pediatrics when Dr C Domingo was Chair. We shared our disappointments and frustrations that our fields (endocrinology and genetics) were NOT priority areas of funding agencies. In Nov 1995, Dr Domingo received an invitation to present a paper on NBS at a regional meeting and she could only present barriers to implementing the program. Likewise, I found it frustrating when I had to quote data on NBS successes in neighboring countries at meetings here and overseas. Dr Domingo and I decided to work on a small project to establish local incidences for the more common NBS conditions. Unfunded, we explored the possibility of support from other practitioners. In January 1996, we sent invitations to 75 hospitals in Metro Manila to join us - 28 responded; 24 eventually bonded as the Philippine NBS Study Group embarking on the Philippine NBS Project. This group presented pilot data to DOH in 1998. Unfortunately, DOH was not ready to take on NBS. Although setting up a national NBS program was not part of my original plan, we continued our NBS activities with the original 24 hospitals and eventually expanding to other hospitals in the country, while waiting for DOH to take over.

It is now history that the research project of 24 hospitals started in 1996, has been integrated into the Philippine health delivery system with passage of Republic Act 9288 (the Newborn Screening Act of 2004) and DOH participation.

As I look back on the last 10 years, let me share my personal thoughts about the program.

The power of the numbers. Individually, Dr Domingo and I could not produce the data needed for policy development. The data generated by hundreds of hospitals was more powerful and showed that thousands of babies could be saved.

Dedication can be more powerful than money. In the beginning, the research group had no study funds. This project was self sufficient in the beginning and continues to be so today. It does not compete with any public health program for funding support.

Persistence is integral. I was rejected at all levels. Unable to successfully refute some of the health policy arguments, I decided to obtain a Masters degree in health policy studies. I graduated in 2005.

Private-Public Partnership. It is easy to say 'it is not my problem'. I commend all of the practitioners who supported us in helping the DOH to develop NBS policy. I consider the NBS Program to be an excellent example of a private-public partnership. With the University of the Philippines taking the lead, and with the support of more than 20 professional health societies and thousands of health professionals, NBS has a chance to reach every newborn in the country.

Prayers can move mountains. Confronted with a long list of implementation obstacles beyond the control of DOH, I decided to prepare a draft bill to address the major issues. In April 2003, I presented a draft bill to Sen Flavio and Cong Yapha. The first reading was in Aug 2003, and I was advised to be patient and return the next year because bills take a long, long time to become laws. With many prayer warriors praying for its swift passage, the NBS law was signed by Pres Arroyo on April 7, 2004.

Newborn screening started as a dream shared by 2 persons and pediatricians and obstetricians from 24 hospitals. It is now a legacy for the next generation. Let us continue to dream to reach all of our goals, no matter how difficult.#



We would like to thank the following: The Bansi, Cueto, Del Castillo, Doctor, Fabul, Haveria, Lindog, Panaligan and Villaceran families who were part of the photoshoot and whose pictures of their lovely children appear in this newsletter. Aman, Dionalyn, Joanna Paula, Daniella, Florence, Maria Rollainne, Nakia James, and Ana Marie--kids saved by newborn screening--and of course, JR who, despite his handicap, has the best smile! You inspired us all!

To Mr. John Tronco (of John Tronco Photo and Video) and photographers Jeri Secretaria, Nickron Reyes, Laurenta Songsong and Abraham Laurente, Jr.

To Museong Pambata ng Maynila, with special mention to its president, Nina Yuson, and her staff, for giving us free run of the place for a couple of hours as we did the shoot. And to Aklatang Pambata for "bringing" the library to UP Lagoon so we can have our storytelling time outdoors! And to Ms. Peñing Sur, whose commitment to the program we hope to emulate.



How discomfort gave birth to NBS

CARMELITA FAGELA-DOMINGO, MD, MSc

University of the Philippines College of Medicine

Since the early 70's until the arrival of our younger colleagues in Pediatric Endocrinology, I was the sole member of the faculty of the UP College of Medicine who taught the subject. In this capacity I had to talk about endocrine disorders in infants and children which of course included congenital hypothyroidism (CH) and congenital adrenal hyperplasia (CAH), two of the more frequently encountered disorders. My embarrassment knew no bounds whenever a student raised his hand to ask about the prevalence of these conditions among Filipinos and whether they are worth discussing in class. Invariably my answer was "I'm sorry I do not know". In the years that followed, my embarrassment and discomfort on hearing similar questions from third year medical students compelled me to write a research proposal on the prevalence of congenital hypothyroidism. Essentially it was an attempt to provide answers through newborn screening.

Added to my discomfort at not being able to provide answers to students' questions was my frustration in the out patient clinics on seeing 10 to 15 year old patients who were not only extremely short but also very severely globally retarded. I consider this the most pathetic experience in my life as a pediatrician and doing nothing about it filled me with guilt.

At this point I began to dream of better times when students could have the right answers to their questions. I thought the next step to writing a proposal was to get out and work on it. I attempted to apply for funding, seeking the help of at least three large local funding agencies at three different times but the proposal was rejected. It looked like we had bigger and more urgent problems like the appalling national prevalence of tuberculosis. I had to shelve the proposal for a while.

Dr. Carmencita D. Padilla graduated from medical school in the early 80's, finished her pediatric residency at the Philippine General Hospital and went on to Australia for her fellowship in Genetics. Before long

she was back. Shortly after she joined the faculty she began to attend international conferences where newborn screening was often a major topic. On her return from these meetings she would tell us how deeply embarrassed she was when other countries would present their data while she had nothing to show.

I guess my embarrassment in having to face students with no answers to their questions and Dr. Padilla's embarrassment in having no data to present to the international community became the driving force that made us convene interested people to set up a newborn screening project which eventually became a program.

Getting pediatricians, obstetricians, general practitioners, nurses and midwives to help set it up was no small task. Getting the Department of Health to support the idea and to participate was a prime accomplishment. Getting the senators to sponsor and pass the bill on newborn screening was an effort largely put up by Dr. Padilla with the support of most of us. Watching and assisting in the delivery of the Philippine Newborn Screening Program, and watching it grow has been a pleasure. Knowing that behind the scenes were hundreds of meetings, hundreds of people working together and loads of effort to get it going and, having arrived at this point, makes us wonder how it has happened. The present state of the program may not be ideal and the current number of babies screened may not have reached our expectations, but the dream is real and the embarrassment has begun to fade.#

JAIME Z. GALVEZ-TAN, MD, MPH

Former Executive Director (2003-2005),
National Institutes of Health
University of the Philippines Manila

When I came in as the Executive Director of the National Institutes of Health, the newborn screening technology has already been defined, it was already mature. It was ready to become a policy and a technology that would be enjoyed by the masses at the community level.

It was a great occasion to be the NIH director during that time because my advocacy has always been research utilization. In a sense, my role was to provide the enabling environment, the nurturing situation that would move newborn screening forward. And I was happy to note that it was during those three years when we were able to mobilize resources inside the University, and we were able to have that policy to make newborn screening initially available to the community.

Definitely before I came in, the IHG has already been a very outstanding institute in UP Manila and its accomplishments were unparalleled. It's still, up to now, the most vibrant among the institutes in the National Institutes of Health. When I say that, my criteria for a real research is that the people themselves, the communities, families, the ordinary Filipinos, particularly the poor, are benefiting from the new technologies. And this is true when we say newborn screening is now available to the farthest barangay. And secondly, the biggest achievement of the IHG when it comes to newborn screening as a technology is that it has been able to move NBS to the policy level. I think these are the two great achievements of IHG and NBS, and it is a model in fact.

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Florence, Nakia James, Aman, Daniella, Ana Marie, Dionalyn, Maria Rollaine and Joanna Paula (back)--children saved by newborn screening





MA. THERESA G. VERA, MD, MSc
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When the Newborn Screening Act was enacted in 2004, a Technical Working Group was created to formulate its Implementing Rules and Regulations. I was one of the six members of the TWG. Brainstorming, writing, revising, editing, exchanging emails and text messages had been our daily activities for almost a month or so. Afterwards, the TWG had to go through the public consultations that had been very tough for us. In all of those undertakings, I saw how pain-staking Dr. Carmencita Padilla was. A true champion of Newborn Screening Program!

Advocating Newborn Screening Program to stakeholders, hospital owners in particular had been a challenge for me. Despite of the law requiring hospitals to provide Newborn Screening services, they continuously resist putting it into action and finds way to go around their obligation. During dialogues and consultations, I usually encounter strong negative reactions of hospital owners and administrators. Discussing the provisions of the law, naming the advantages of the program, citing strategies and good practices on how best they can provide the service were among my constant rejoinder to them.

What I had been a part of is just the beginning of the Newborn Screening Program. It has still a long way to go. Each and every one of us has a role to play. Joining hands we can make it a success.#

*Daniella and Aman,
both 8 years old*



The Key to Our Success in Newborn Screening...Thinking BIG!

PAULYN JEAN B. ROSELL-UBIAL, MD, MPH
Current Regional Director, CHD Davao Region,
Former Assistant Regional Director, CHD Western Visayas

When we were challenged by Dr. Carmencita Padilla of the National Institutes of Health (NIH) to fasttrack newborn screening implementation in the Region back in December 2001...we were devoid of bright ideas on how to go about this pioneering task. At that time I was only five months in the DOH office in Iloilo City as Assistant Regional Director, still finding my way around the region having been assigned at the DOH Central Office in Manila for most of my eleven years in public service. The regional accomplishment in 2000 was about 2000 screens and assessing the 2001 monthly trends showed the 2001 year end accomplishment is no different.

In January 2002, the Center for Family Health and NIH promised to return to conduct together with the CHD staff an orientation on Newborn Screening for selected health facilities and local government health partners in the region. The CHD technical working group which I headed at that time was asked to present the Regional Situation. At that time we decided to set ambitious targets so that if we fail at least we have accomplished more than if we have set low targets. We targeted an increase of 100% in screens per year for the first 2 years then 70-80% in the next 2 years, thus attaining nearly 25,000 screens by end of 2005 or 20% of all newborns in Western Visayas screened.

JAIME Z. GALVEZ-TAN, MD, MPH
Former Executive Director (2003-2005), NIH UP Manila
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10 years of NBS and 2nd year of the law. Let us learn lessons from these: 10 years of newborn screening. By the sixth year, there was already an acknowledgement that NBS was already a mature technology and it was time for it to become a policy. And therefore on the 8th year, it was made into a policy although on its 7th year it was already being pre-tested at the community level particularly in Iloilo.

For me, it means we need to look at newborn screening as a model of a very scientific breakthrough in the Philippine setting: knowing what the common congenital disorders that can be screened early enough right after the first 48 hours of life, and the data to save lives and prevent disabilities. This is truly a magnificent development where we can learn lessons from

We went about our affairs in the region with our goal clearly in mind....but with no clear cut strategy. After the orientation in January 2002, we hired a contractual nurse to handle the day-to-day affairs of the program. We included advocacy activities and regular meetings with the hospital coordinators in our work plan for the year and every year thereafter funded by varied sources of health funds like the OAA, UNICEF, ECD Project, DSWD, etc. We integrated newborn screening orientation and updates in all regional health activities on child health such as IMCI trainings, OP orientation, nutrition conferences, surveillance unu activities and even UNFP A & Family Planning initiatives.

The rest is history. By end of 2002 we have screened more than 4,000, at the end of 2003 about 8,000 and by 2004 nearly 12,000 at this time Western Visayas was the region with the highest screens outside Metro Manila and we were screening about 8% of the newborns, the highest screening proportion of any region! From 12 participating health facilities in 2001, we were up to over 50 health facilities with the most number of RHUs participating in any part of the country. So when the Western Visayas University Hospital vied for being established as the next Newborn Screening Center in the country, it was a sure thing! In October 2005, we made history when we launched the second newborn screening center in the country right in Iloilo City to serve referral screens from Visayas and Mindanao.#

and which can be an inspiration to all the technologies. Let us also be patient when we try to develop a technology that it's just not left in the lab, it's not just left in the four walls of the Institution, but rather, goes beyond that. It's a national hallmark as a legislation, and as a national program policy by the Department of Health which is now being enjoyed by Philhealth and other policy making bodies in health care—and of course being enjoyed by communities and local governments.

Let us learn from this very inspirational research and may there be more of this in the future. And may there be more people behind this technology who are led by Dr. Padilla who commit themselves to do more magnificent things for Philippine health!#

COL. ESTELITA T. GALUTIRA (RET)

President, Mother and Child Nurses Association of the Philippines (MCNAP), Inc.
Member, Board of Nursing, Professional Regulation Commission

The first time I got involved in newborn screening was when Mrs. Erlinda Ahorro, the MCNAP president in 2001, and myself, then the VP for Plans and Programs, were invited by NIH to represent our organization in the round table discussion for health organizations and societies entitled "Successful Newborn Screening Through Advocacy." Being part of an organization that caters to the needs of the newborn, we committed ourselves to the program. We told Dr. Padilla, we'd be staunch advocates of newborn screening. It also happened that I just recently retired from the service so, when Dr. Padilla asked for my help to advocate NBS in the military hospitals, I took on the job.

I was the one who spoke in behalf of NIH to the military hospitals about newborn screening. I started with AFP Medical Center (formerly V. Luna Medical Center)—which was then sending samples through Rizal Medical Center. So when I came to them, the Department Head of Pediatrics said, "*Naku, Ma'am, anghel ka! Kasi naghahanap kami ng paraan kung paano makakaderecho sa NIH!*" Then I went to Manila Naval Hospital, Cavite Naval Hospital and Fort Bonifacio Hospital. Sad to say, some of them are having problems then getting fund allocations for newborn screening since the first priority for the military is spending for the health and hospitalization of the men in uniform. The AFP Hospital has no problem. The Cavite Naval Hospital's NBS program's already taken off. When I went to Manila Naval Hospital this April, I reminded the Vice

Commander of the hospital to be active in implementing NBS since it's already a law. I told them, in the meantime, they can help in advocating newborn screening to the parents when they come for pre-natal visits, motivate them to save early for the service. They look forward to the time Philhealth includes NBS in its benefit package.

What really strengthened me was when I was enjoined to attend the Newborn Screening Speakers' Bureau Training in April 2002. We had fun during our sessions, specially the practicum where we simulated motivating parents. After I gave a feedback to Mrs. Ahorro, MCNAP decided to adopt NBS as one of its core programs and, to highlight it, it was the theme of our 21st convention in 2002: "MCNAP: Strengthening Its Advocacy Role in Newborn Screening." From there, everywhere I go, giving orientations and talks to members, other health practitioners and hospital staff, parents, local and barangay officials, or enlisted personnel, I talk about newborn screening. One of the most important strategies we've come up with to advocate newborn screening is to have NBS as the first seminar to be given for all new members, alongside mental feeding, every time we organize a new MCNAP chapter in the provinces and when we do our outreach activities. That's why MCNAP has a long list of NBS orientations and seminars in its accomplishment reports from 2003 to present.

We also joined the lobbying for NBS bill at the congress and senate—and MCNAP is one of



the signatories of the Bill in support of newborn screening. I think the general sentiment then was they (the senate and congress) were in support of the program—but where to get the funds? I remember, during the senate hearing, when one of the senators asked Dr. Padilla, "is there any funds to be charged from the government?" I think she said, "No, Your Honor. This will be an individual responsibility of the parents." Then senator immediately said, "*Madali 'yan! Kasi kung magpapasa ka ng bill na walang funds manggagaling sa gobyerno, mabilis 'yan. Pero kung may funds na hihingin sa government, very nil ang chances.*" *Kaya kami nagpalakpakan!*

I'm proud to say that, in MCNAP, the program has a very active partner. And we are thankful for our other partners—our sponsors—who enabled, and continue to enable, us to reach out to our members, the mothers, health workers, the barangays and our enlisted personnel to tell them about the importance of having their babies undergo newborn screening.#

JUN EUGENIO

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I remember having an eerie feeling as Malen led me to her "office" for the orientation almost ten years ago. It must have been the place, quiet and dimly lit at that time or her uncanny presence, a scene straight from a suspense movie. I guess it was both. Her office turned out to be the laboratory itself and as I discovered later, will also serve as the reception area, data room, stock room and lounge and which we will be sharing with 2 other med-techs and 2 nurses. Patient samples came in by the trickles, about 30-50 the most in a day. Sometimes there weren't any and time was spent performing backlogs and paperwork.

Having to work with an all-female staff required a lot of understanding and perpetual patience. Fickle-minded as they are sweet, I was left to contend with their natural

unpredictability for the next five years or so. Obviously, I survived. Yet these very same creatures taught me a lot about the program, including the "*art of pricking*".

My first attempt at blood extraction wasn't something to be proud of though. Having to fill-up three large circles with blood was an ordeal. I finally accomplished the feat after the 3rd try and while I felt relieved, I couldn't look directly at the poor baby's mother. With little more practice I have become an "expert", no thanks to constant sighs and dagger-looks from the parents.

I remember we used to have a fluorometer that takes an eternity to read a one-plate sample and which bogs down more often than not. A far cry from the high-tech ones we're using today, they're now reduced to museum pieces

in the dark corners of the stock room. The filter card was improved (it now has 4 circles!), and the database was upgraded to accommodate the growing number of samples. From a small room, the lab has transferred to larger one and has occupied some of the other rooms. We've grown so big that I felt we have taken half of the building.

Some of the original staff has moved on, mostly abroad. Malen got married and had a daughter. And after 4 AO's, 4 head nurses, and being a godparent 4 times to staffs kids, some things never changed at NBS. I miss the fun, the friendships, and the ghost stories of flickering lights and falling vases, and fire alarms coming off at night. I miss my buddy Eric. This guy's so crazy it made me more convinced of the need to screen our babies.

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ASTER LYNN "PEGING" SUR, RN, RND

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Indeed, time ran so fast. Joana Paula Doctor, the first baby saved by NBS from CAH is now 10 years old. If not for NBS, she could have been part of the infant mortality statistics in 1996. In my recent meeting with Joanna, I had this overwhelming feeling. Looking at her living a normal life like anybody else, I could say to myself it is really worth it.

The past decade of NBS implementation was full of significance, meaning and lessons for all its active advocates. Convincing parents to have their baby's screened and persuading legislators to pass the NBS bill was the easiest part of the implementation. The most difficult task that we had to hurdle was how to persuade the health sector to act as one in achieving the goal of making NBS accessible to all babies born in this county. Dr Carmelita Domingo, a pediatric endocrinologist whom I considered the grandmother of NBS, took many years and many DOH secretaries to take the first step. But, she did not stop from convincing them until, finally, NBS was adopted by DOH. Not all in the health sector were convinced of the importance of NBS to their patients. Some were even detractors of NBS. Those in the public service were very reluctant because of the cost of screening. The most common reply that an NBS advocate would hear was "our indigent patients cannot afford NBS—it is useless to offer something that they can't

afford. NBS will not work in government hospitals". Hearing these comments did not discourage us from mobilizing the widest section of the health sector to the NBS cause, instead, it led us to be more persuasive and creative in our promotional and advocacy work. The increased awareness of the public about the significance of NBS had contributed a lot in making health professionals realize their role in NBS. Some expectant mothers preferred to deliver in hospitals with NBS—pushing health professionals to persuade their hospital administrators to include NBS in their hospital services.

The pilot implementation of NBS at the RHU and District Hospital level in Negros Oriental disproved the myth that indigent clients cannot afford to have their babies screened. One unforgettable experience I had with a sugar cane farmer made me realize that, indeed, we health professionals do not have the right to decide for our indigent parents. The farmer's post-partum daughter had already signed the NBS dissent form for her grandchild but I decided to reinforce the explanation done earlier by a member of the NBS team. That time I showed them pictures of unsaved and saved babies, and after a thorough explanation to the family, the grandmother ran after me to ask if she can still have her grandchild screened after 5 days. According to her, she cannot

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PGH was one of the 24 participating hospitals thus the Newborn screening started. The main objective was to increase the compliance level in NBS by doing an advocacy campaign specifically to PGH healthcare practitioners through orientation, education and training. In February 2002, the NIH trained 26 nurses from different areas in PGH on newborn screening. The "PGH Newborn Screening Nurses Core Group" was organized. In September 2002, and a system wherein NBS nurse was assigned in the nursery to answer referrals for newborn screening was started.

Out of 26 nurses, it went down to 20 nurses because some of them went abroad. So another set of enhancement training was offered by the Division of Nursing Education and Training (DNET) in September and December 2005 where a total of 56 nurses were again trained. At present, there are now 60 trained NBS nurses from

different clinical areas. Last October 7, 2005, the group received a special award from the Department of Health and the National Institute of Health as a core group for the system developed that contributed to the increase in the compliance rate at the Philippine General Hospital. The creation of the PGH NBS Nurses' Core Group strengthens the role of a nurse as health educator as an intervention to a very low compliance in newborn screening particularly in PGH. It has been found out in other countries like Thailand and Hongkong that health education plays a vital role in increasing their compliance in newborn screening. Recognizing the importance of giving an intervention through health education, compliance to newborn screening means fulfilling the mission of ensuring all Filipino children will have access to and avail of total quality care for their optimal growth and development of their full potential.#



Joanna Paula, 10 y.o.

afford to have a family member who is retarded that will eventually become economically unproductive and a burden to the whole family, thus, she would find all means to have her grandchild screened. That experience opened my eyes when I do advocacy and promotional work: the poorer your client is the more you have to convince them to screen their baby because the economic burden of taking care of a mentally retarded child is certainly incomparable to the actual NBS cost.

My involvement in Newborn Screening was a family affair. When I started to join the quest for the nationwide implementation of newborn screening in 1999, my daughter Liana was only 3 years old. At her early age, she already knew that her Nanay, Dra Menchit, and Dr Domingo were working very hard to lay down the requisites to fulfill the dream that someday all babies born in the country will have the opportunity to be saved from possible mental retardation and early death. I used to drag her along and became my assistant during my lectures and training held anywhere in the country. She would sometimes remind me of some important points that I missed to emphasize. She patiently waited for us as we hold our long meetings and as we were lobbying for the urgent passage of the NBS Bill which used to last very late in the evening. Probably, when my daughter reaches her adolescence, she would proudly say "I was part of the Newborn Screening Family." If I have my daughter who supported me, Ma'am Menchit had her Patrick and her late Mommy Loreta who were visible in all NBS major activities. Mommy Loreta did not only support us physically and morally but she also mobilized all her religious groups and friends to pray for us during public hearings at the senate and congress. No wonder the NBS bill was passed in less than a year. Dr Padilla and I used

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Provincial NBS Coordinator, Province of Negros Occidental

Newborn Screening Program in the Province of Negros Occidental started three years ago at Don Salvador Benedicto Memorial District Hospital in La Carlota City. It was the first implementor among the district hospitals of the Province. NBS was institutionalized in the hospital thru a hospital policy including NBS in the routine orders of all newborns delivered in the hospital. Advocacy campaign regarding benefits and importance of NBS was made to all mothers at OPD, among health workers in the community, members of the Interlocal Health Zone and people in the community.

The NBS fee was then a big constraint. So to answer such problem, NBS fee was included in the delivery package thru Provincial tax ordinance, while giving NBS fee a priority in the payment of hospital bills. Pregnant mothers were encouraged to save on their deliveries. The excess amount of P50.00 (charged beyond the P550.00 NBS fee) paid by other patients were used to subsidize the

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Once upon a time in 1999, in the City of Golden Friendship, a small group of dedicated pediatricians embarked on a journey to spearhead the NBS project in Region 10. Then in 2003, Region 10 was chosen as the recipient of the advocacy program under the Canadian International Development Agency (CIDA). This program involved two training hospitals: Ma. Reyna Hospital representing the private sector and Northern Mindanao Medical Center (NMMC) for the government sector. The program gradually evolved to include CDO Medical Center, Cagayan Capitol General Hospital, Polymedic General Hospital and Madonna and Child Hospital.

The first order of the day was so simple: offering orientation seminars to hospital administrators and personnel, pediatricians, obstetricians, and to midwives who were tapped as the frontliners in recruiting parents to have their babies screened. Not an opportunity was missed just to be able to spread the good news about newborn screening. From as far as Ozamis City in the west and Caraga Region in the east, to as far as Don Carlos in Bukidnon in the south, representatives were sent during some of the seminars and workshops. Sometimes even the nursing schools in the city were oriented. Joan Pajo (our NBS-CIDA Nurse Coordinator) was always there to spread the good news. Pure sweat and dedication was the real theme of the

indigent patients. As a government hospital of which collection and payments has always been a problem, we were able to establish an efficient and effective collection and payment of NBS fees by providing a Trust Account for NBS for each individual hospital. The strategies and system of implementation of NBS at Don Salvador Benedicto Memorial District Hospital were adopted by other district hospitals of the province as in Cadiz District Hospital, my current station, and other hospitals.

The support and political will of our local officials, especially the Governor, the dedication and commitment of hospital staff and the active community participation were the key to the successful implementation of NBS program. We, in the Province of Negros Occidental, strongly believe that we can save more and more babies from mental retardation and death. #

people behind the task. Thanks to Dr. Emily Reyes for her untiring efforts of coordinating all NBS activities with all DOH-Retained Hospitals and LGUs and to Dra. Patsy Gaid for spearheading the project at CCGH.

And who could forget the one-woman show of Ma'am Peking Sur who always made sure that nothing is missed during seminar/workshops or may even acted as proxy to some of the speakers who at times did not make it. But Ma'am Peking's dedication extends beyond this. Anytime of the day when problems crept up or jumped on us (like no results, lost specimens, repeat sampling, confirmatory testing, payment/fees), all you have to do was text Peking and in less than an hour you'll get your response.

All these efforts paid off when Cagayan de Oro Medical Center, after a few years of low NBS coverage, was cited as one of the country's Outstanding Newborn Screening Facilities for 100% screening in 2003. It even began offering NBS services to outborns.

This success only means that obstacles can be overcome because what is truly important at the end of the day is that each baby should be given the best chance in life.

The saga continues...#

TAN KING KING, M.D.

Chairman, Chinese General Hospital and Medical Center

Chinese General Hospital and Medical Center began its participation in the Newborn Screening Project in 1996. Despite being relatively new and unpopular to parents, CGHMC was able to screen 30% of the total population of newborns in its initial year. This was made possible through the joint effort and dedication of our consultants, both Pediatricians and Obstetricians, together with residents on training and nurses.

Over the succeeding years, the percentage of newborns screened has steadily increased. In fact on our 10th year it reached as high as 98.89%. We are constantly resolving the issues of parents' lack of awareness and the additional expense. With the institutionalization of Republic Act No. 9288 or the Newborn Screening Act of 2004 and through the effort of the Newborn Screening Society of the Philippines, our government has finally made the dream of Newborn Screening Program a reality. This act ensures that every newborn baby in the Philippines is offered the opportunity to undergo newborn screening and thus, be spared from heritable conditions that can lead to mental retardation and/or death if undetected and untreated. Furthermore, with Proclamation No. 540, the President of the Philippines has declared the first week of October of each year as National Newborn Screening. With the implementation of the RA 9288, more parents are now aware of the importance of having their babies screened. At present, it is the goal of CGHMC to attain a 100% population screened. #

Ana Marie, 9 y.o.



CHARITY M. JOMENTO

Medical Technologist, Newborn Screening Center-National Institutes of Health
University of the Philippines Manila

When I joined Newborn Screening ten years ago, I was an OFW fresh from Saudi Arabia. Salary wise, I was tempted to return to Saudi Arabia since I was earning much more over there compared to what I will be earning here. But the patriotic streak in me got the upper hand. When I applied for the job I was half-wishing I won't be hired so that I have good reason to go back to a foreign land. But on the day I was hired I was beside myself with joy because deep down in my heart I realized I really wanted to stay and be useful in my own little way here in my homeland. I then remembered that while I was in Saudi Arabia I whispered a prayer to God that He would make me useful in my own country. It was wonderfully answered when NSC-NIH hired me.

The first home of Newborn Screening was a small room at Pedia Office in PGH with only two staff. As time went by, the office expanded as more work is trickling in. It became bigger and bigger with matching new and state of the art equipment. With the new equipment comes addition of personnel. More and more staff was hired. There were various trainings both local and international to update the staff with the latest trend in technology. From just a humble beginning we were moved to a roomier place and is presently housed at the UP NIH.

ASTER LYNN "PEGING" SUR, RN, RND

Nurse in Clinical Genetics, Institute of Human genetics, UP Manila

(From page 6)

to say that God had intervened during the most difficult times of the NBS journey.

The passage of the NBS law was not the end of the journey, rather the beginning of another stage of NBS implementation in the country. Sustaining and protecting the gains for the last decade is the most challenging part to all NBS advocates and supporters. Problems will still emerge but this time, we have the NBS law to give us the mandate. The NBS family is growing and becoming stronger everyday.

The success of NBS can never be attributed to only few people, everyone played crucial roles in laying down the foundation of what we have today. Our DOH active advocates also had their struggle to institutionalized NBS in DOH and I am glad they are also growing in numbers. The staff of IHG experienced sleepless nights to make the operations systematic and efficient so we can be of more service to our clients. Jessie,

As a Medical Technologist, our work is most often not in the limelight. Working behind the scene, every filter paper we receive everyday were examined with outmost care, urgency and attention. High standard of quality must be strictly observed because one filter card is equivalent to one life that might be saved from impending mental retardation and subsequent death. Each filter card represents a life of great potential and if not meticulously handled would spell a life of barrenness instead of a life of fruitfulness.

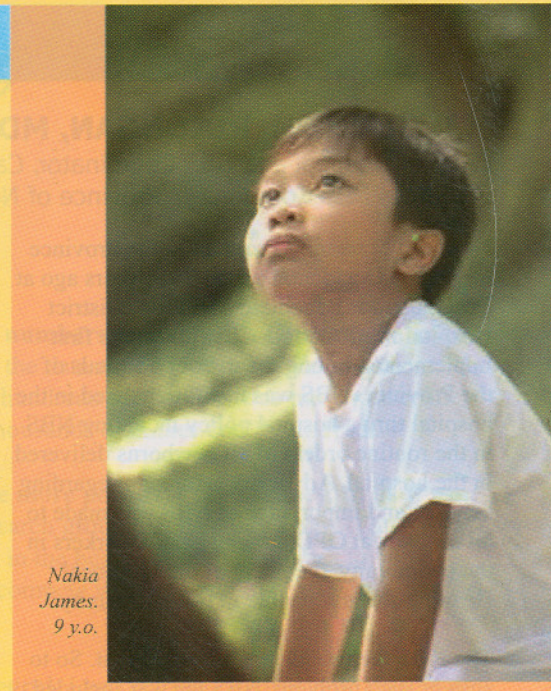
There were hard and tough times but everything was all part and parcel of the growing process towards progress and development not only for the Newborn Screening but also as a person. My experience in NBS has enriched my life and widened my horizon much more that I have ever dreamed or anticipated. Being in the Newborn Screening has enlarged by perspective that made me value life at a deeper level.

No regrets. Working in our homeland brings more fulfillment and greater sense of satisfaction because, somehow in my own little way, God had made me useful in helping save babies from mental retardation and death. My only regret is that Newborn Screening did not start much earlier. More mental retardation could have been arrested. More lives could have been saved.#

Malen and Rene, three of our IHG staff, may not be so visible during NBS activities but they were on-call 24 hours a day. Our artistic promotional and advocacy materials were attributed to two good and creative artists Zando and Albert, who most of the time do the work for free.

My passion in NBS is probably because I do not look at it as a technical work rather of it a noble cause. It is actually a heed to a spiritual call to advocate for all newborns who cannot speak and fight for their rights for a brighter future. #

**For more information on
Newborn Screening, visit
www.nsrc-nih.org.ph**



Nakia
James,
9 y.o.

JUN EUGENIO PerkinElmer

(From page 5)

And Dr. Padilla, I have seen her transform from a doctor to a mother to an endorser and the best salesperson I ever knew. And to top it all, she's even into "spirit questing". To say that newborn screening started from scratch is an understatement. Yet we managed to pull-through, a testimony to the hard work and dedication of the all people who have been a part of it. And yes, Malen is still with the program.#

Special Issue

October 2006

The Newborn Screening Reference Center (NSRC) has taken over the management and publication of this newsletter from the Institute of Human Genetics (IHG), National Institutes of Health (NIH) and the Philippine Newborn Screening Program (PNSP). This is in line with NSRC's role in providing resource and information in the area of newborn screening to benefit the public health community, consumers and government officials of the country.

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