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# Photographic Exhibition of Down Syndrome

# A Blissful Smile

Written by Szu-Chi Huang

Round faces, flat noses, honest looks and genuine smiles, each unique and adorable faces on the photograph exhibited the happy moments of children with Down syndrome and their families. The photo exhibition tour "A Blissful Smile", which had just ended on June 15 2012, was exhibited in the admission/discharge center of Hualien Tzu Chi Hospital since April 2. Every shot, taken medical students after long acquaintances with these children with Down syndromes, captured their most significant moment. The protagonists of these shot, despite their ages, appeared friendly and genuine, and every audience who view the photos could not help but smile as well.

"Medical clinical work is not simply a study of diagnosis from textbooks, as interacting with patients and accompanying them demands genuine exchange from the heart!" Chia-Lin Liao, a 5th-year medical student of Tzu Chi University, represented a dozen students when he spoke the motivation behind the exhibition. Down syndrome is one of the most common chromosomal disorders. According to statistics, the incidence of Down syndrome in Taiwan is 1/800, and approximately 30,000 Down syndrome patients are present in Taiwan. As they always exhibit child-like

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innocence, Children with Down syndrome are also known as Down's babies. For the public to accurately understand Down syndrome and to accept Down's babies, on April 2, Hualien Tzu Chi Hospital Pediatric Dept., Tzu Chi University College of Medicine and Down Syndrome Foundation R.O.C." collaborated a "A Blissful Smile - Down's babies Photographic Exhibition", which was displayed at the corridor in front of the admission/discharge center, and later toured Cafe Jade and Tzu Chi University until June 15. This exhibition, initiated by the medical students of Tzu Chi University, included 24 photographic works and 3 paintings, all done by the 5th-year to 7th-year medical students of Tzu Chi University. One of the painting, drawn by fountain pen, was from the instructor, Dr. Shao-Yin Chu, depicting the joyous moment between Down's babies and their families.

# Integration of Resources to Accommodate "Double-Aging"

The inspiration for the photographic exhibition came from the national tour forum "Carefree Senior Couples" last year held by Down Syndrome





The medical team conducted a series of examination for the Down's babies. No one dared to move during blood draw. Photo/ Wen-Shuo Yeh

Foundation. Medical technology advancement toppled with low birth rate had led the world into an aging social structure. People over the age of 60 are commonly regarded as senior, but for Down's babies, the threshold is lowered to 45 years of age, which prompts a phenomenon where senior parents are taking care of their senior children. To accommodate the social issue of "double aging", Down Syndrome Foundation launched the national tour forum "Carefree Senior Couples". With the active endeavor of Dr. Shao-Yin Chu, the only forum in Eastern Taiwan was held in Hualien Tzu Chi Hospital, the participants, in addition of the medical teams of the hospital, included approximately 30 Down's babies and their parents, and the guest speakers included scholars and professionals from National Taiwan University Hospital, Mackay Memorial Hospital Taitung Branch and Tzu Chi University.

"Bobi...bobi...bobi...oh..." The forum began with the contemporary dance performance "Bobi" from Down's babies. The hospitality and excellent rhythm of Down's babies are evident on Yen-Hao, currently a 2nd-year high schooler. Seek perfection is another quality of the Down's babies. Hsiao-Han's father introduced his daughter, now a high school graduate, as her





Head to head, shoulder to shoulder, every child is forever precious to their mothers. Photo/ Szu-Chi Huang

mother's best helper at home, particularly with folding laundry, each piece of clothing are neatly folded just like in stores. The only issue he had with Hsiao-Han is that all the buttons must be buttoned-up, since you have to undo all the buttons one by one when wearing.

All 10 Down's babies present are capable of handling daily living tasks, which, in the eyes of parents and medical teams, are particularly inspiring and motivating. The activity incorporated medical forum to advocate proper understanding and health examination for Down's babies. By utilizing gaming with examination, a series of approximately 20 items health care assessment, including blood, urine, physical, nutritional, psychological adaptation and counseling, for Down syndrome patients 15 years old and higher.

Down syndrome is one of the most common chromosomal disorders, with an incidence of 1/800 or 1/1000. Ordinary human cells have 23 pairs of chromosome, and Down syndrome patients suffer from Trisomy 21, which leads to symptoms such as slow growth and mental disabilities. Another troublesome symptom is early aging. Mei-Chih Lin, the CEO of Down Syndrome Foundation R.O.C., had recently discovered white spots and white





The Down's baby, captured by the medical student, is earnestly engaged in rehabilitation. Photo/ Yi-Hao Hsiao

hairs on her son, who was only a 9th grader. Down's patients often experience accelerated aging and degeneration as they grow; their parents, also facing issues of aging, would not be able to offer the same care as before. This phenomenon of double aging illustrated the demand for multiple care services. Therefore, as Mei-Chih Lin pointed out, it is crucial to integrate medicine, family and social resources to establish "Carefree Senior Couples" health forum, so that everyone can receive proper health care information; by increasing the awareness of Down syndrome through forums, Lin hopes to accelerate the advancement of the entire social environment, so the Down's babies and their parents would no longer be bothered by the issue of double aging.

# **Beautiful to the Mindful Eye**

Although many people would give strange looks to Down's babies, Dr. Shao-Yin Chu, currently the only physician who specializes in medical genetics, pediatric metabolism and pediatric endocrinology, accompanied many Down's babies for the past 12 years. Down's babies are present from





The medical students realize their knowledge from textbooks through long companionship and interactions, and therefore they could truly understand the uniqueness of these children and empathize with their feelings. Photo/ Chia-Lin Liao

heaven, Dr. Chu claims, allowing us think outside the box. Due to the extra chromosome, Down's babies often suffer from congenital heart disease, intestinal abnormalities and developmental delay. Despite these difficulties, they also have unique qualities such as friendliness, good sense of rhythm and insistent to do good. Down's babies can excel with individualized education, Chinese musical conductor Yizhou Hu and artist Kuan-Ting Lin, the son of National Taitung Living Art Center Director Yung-Fa Lin, are two perfect examples. Yizhou Hu's, who always followed his father to work at a orchestra, was discovered to be a musical prodigy at the age of 6, and is now a renowned conductor in the West. Kuan-Ting Lin, similarly, followed his father to paint and sketch when young, and can now utilize his unique imagination and strokes to produce painting and calligraphy of his own.

As the only specialist in medical genetics, pediatric metabolism and pediatric endocrinology, Dr. Shao-Yin Chu often brought her students to attend related international symposiums, and this forum was no exception, since it was a rare occasion for so many Down's patients and their parents to gather together. Since her students are quite proficient in photography, Dr.





Dr. Shao-Yin Chu(Right), currently the only physician who specializes in medical genetics, pediatric metabolism and pediatric endocrinology, wishes the illed children and their parents in Eastern Taiwan, who are relatively disadvantaged, could attain more resources.

Chu came up with an idea to ask her students to photograph these Down's babies as a form of participation. Since the opportunity to see so many Down's babies at once is difficult to come by, she wished the students could spend this special day to capture the loveliness of these beautiful souls, and to observe and understand them.

Education was defined as the indoctrination of ideas from teachers to students, but majority of learning demands personal experience, Dr. Chu indicated. Since these medical students had been equipped with fundamentals, she preferred the students engage the patients directly through photography, to comprehend and empathize the patients' cognition through their angles. Because the students had to accompany the patients for an entire day, they can only capture the uniqueness through intricate and intimate observation of their behaviors and actions. For example, the textbook described the Down's patients as friendly and sociable, which can be both an advantage or a disadvantage. But, as Master Cheng Yen said, these Down's babies are pure and innocent, so many of these medical students would learn this genuine innocence from them. Several students even visited the homes





Caring for these Down's babies for over a decade, Dr. Shao-Yin Chu used a meticulous painting to illustrate the genuine appearance of the Down's babies and the wonderland in their eyes.

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of these Down's babies after the event, or accompany them to music lessons, in order to capture more variety of images.

Because of direct participation, the medication students acquired more profound experiences, and hence decided to compile 23 selected images with 3 paintings and held the "A Blissful Smile - Down's babies Photographic Exhibition". The 5th year and 7th year medical students of Tzu Chi University practically arranged and ran the entire event, as dozen of them utilized the break time besides internship to prepare. On the opening day, Supt. Ruey-Ho Kao of Hualizen Tzu Chi Hospital, Prin. Pen-Jung Wang of Tzu Chi University, Vice CEO Ying Huang of Down Syndrome Foundation R.O.C., Tzu Chi University medical students and the parents of Down's patients were present for the inauguration.

# **Photograph the Decisive Moment**

"Without any complicated techniques, but a simple mind, to share with everyone what we saw and felt from these angels through our lenses."

Yi-Hao Hsiao, 7th-year medical student of Tzu Chi University, is one of the photographers. He gave a tour for his instructors the meaning behind each photo. From the right is Director Yung-Fa Lin of **National Taitung Living** Art Center, Prin. Wang Pen-Jung of Tzu Chi University, Supt. Ruey-Ho Kao of Hualizen Tzu Chi Hospital, and Photographer Yi-Hao

Hsiao.

In general, medical students begin clinical training in their 5th year, the pressure from facing life directly on top of schoolwork practically occupied the majority of their time. For these students, though, the humanistic medical education they have received at Tzu Chi required them not to simply abide by textbooks, but to empathize with every patient! Yi-Hao Hsiao, a 7th year intern, was invited by Dr. Chu to this photography exhibition because he is a photography enthusiast, and he was interning at the pediatric department at the time. While photographing the Down's babies and their parents, the major difference he noticed in contrast to landscape and item photography is "interaction". To capture the natural and emotional moments, the photographers have to be acquainted with their subjects; medicine is the same, doctors can only help their patients to a speedy recovery when they are familiarized with their patients and families. Tou-Yuan Tsai, a 5th year medical student who had just began clinical work, said that "whenever I am tired and irritated, I like to visit the Down's babies, they are a tremendous motivation in my pursuit to become a doctor."

Including Director Yung-Fa Lin and his son from Taitung, many of the parents whose children were in the photos came to attend the opening ceremony of the exhibition. Yung-Fa Lin said that his son Kuan-Ting, after 20 years, had grown from what was thought to be a burden into a sweet responsibility and the source of happiness. Now 25 years old, Kuan-

Ting have found his destinty, and still treat this world with an innocent and kind heart. "My son is like the incarnation of God who came to transform us. When I face a bottleneck when painting, I often seek him for help. A sentence or a guidance from him would direct me to a new world, a world much more interesting." Lin said.

Observing the sincere interactions among the medical students, the Down's babies and their parents, Supt. Kao and Prin. Wang witnessed the medical humanities they advocated thriving in the hearts of these doctors-to-be.

Supt. Kao claimed that he could see the vibrance and sincerity of the Down's babies, as well as their admirable parents, from the exhibited photographs. He envied these medical students to have the opportunity to experience such an invaluable event as a student, as these experiences would definitely transform into a strong sense of mission once they mature into doctors. Prin. Wang, a specialist in pediatrics, observed the medical students as they attend to the Down's babies and share their joy, and wished these heartwarming interactions could expand from the wards to the entire hospital, or to expand beyond the confines of hospital to create blissful cities and countries.

