



Guided

Indonesian Youth Sofyan Sukmana's Overseas Medical Journey

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In 2004, TIMA (Tzu Chi International Medical Association) discovered Sofyan Sukmana in the Tzu Chi Free Clinic in Jakarta, Indonesia. Sofyan's face was distorted by a 15-centimeter-wide tumor, which protruded and nearly blinded his right eye, leaving his left eye blurred, and scarred his mother who was concerned with her child's wellbeing and blamed herself for the inability to find adequate medical treatment.

In April 2004, 15-year-old Sofyan traveled abroad for the first time, heading for Taiwan. The surgeons at Hualien Tzu Chi Hospital removed the bone tumor caused by Fibrous Dysplasia. In 2005 and 2008, Sofyan returned for additional treatment. In the fall of 2012 Sofyan, Then 23 years old, returned to Taiwan a fourth time as a mature, ambitious youth instead of a shy teenager. As much as he changed, Tzu Chi will forever be the "family" to help Sofyan achieve his dreams.

Sofyan Is Back!

After a five-hour flight, on October 15, 2013, 23 year old Sofyan Sukmana, accompanied by his mother, Rosnilah, and Indonesian Tzu Chi volunteers, Ms. Hsia-Li Lin and Ms. Li-Li Ji, set foot on the familiar ground of Taiwan. He was surrounded by old friends when they arrived at Hualien Tzu Chi Hospital. "A young man now!" Still wearing his cap, Sofyan quickly and affectionately hugged a familiar "auntie," Hui-Mei Yen, and smiled shyly when she remarked about his growth. Superintendent of Hualien Tzu Chi Hospital, Dr. Ruey-Ho Kao, gently patted Sofyan's shoulder and said, "Welcome back! Can you still understand Chinese?"

"A little bit," Sofyan replied. After his surgery in Taiwan, Sofyan continued learning Chinese when he returned to Indonesia, just to be able to communicate with his Tzu Chi family members in Taiwan. Later, Deputy Supt. Dr. Peir-Rong Chen, whom Sofyan had not seen for a while, took a brief moment to visit Sofyan and discuss his medical history and follow-up arrangements with Dr. Kao and Neurological Director of Oncology, Dr. Tsung-Lang Chiu.

Expressing Familial Love through Guitar

"I am so happy I can return to Hualien Tzu Chi Hospital for a check-up!" he said. Translator Ms. Lin remarked that along the



Director of Ophthalmology, Dr. Rong-Kung Tsai, examined and confirmed Sofyan's vision.



Sofyan undergoes a pre-operative evaluation with magnetic resonance imaging (MRI) to identify the tumor's proliferation area.

way, Sofyan kept expressing his gratitude and spoke of his familiarity with Hualien. "Wow! You've turned into a handsome fellow. Do you still remember me?" asked Head Nurse Jia-Lun Yu, who cared for Sofyan years ago when he was first admitted to the neurosurgery ward. Nurse Yu had to ask Sofyan if he smoked or had consumed any alcohol, Sofyan's gave a witty response, "No smoking and no drinking! Master Cheng Yen would not be pleased!" Though he is an Islamic follower, he has kept in mind Master Cheng Yen's teaching and has preserved the pure innocence of a child. Everyone was comforted by his response and smiled.

"Mom, I love you..." Sofyan sang softly while gently played his guitar as they were waiting for his exam at the ophthalmology department. The Indonesian song "Mother" was his way of showing gratitude to his mother, who accompanied him throughout the ordeal. Besides Indonesian songs, he sang Tzu Chi songs "Let Your Love Distribute" and "One Family". Sofyan's warm voice and soft melody filled the ears and hearts of patients and their family, like an afternoon musical feast Southeastern Asian style.

Ophthalmology Department Director Dr. Rong-Kung Tsai happily reunited with Sofyan. He, along with Dr. Jin-Liang Lin



Diligent college student, Sofyan, has a girlfriend. Sharing cell phone pictures of his girlfriend, Anna, made Sofyan shy and happy.

and Examiner Nai-Fung Liang, completed a detailed eye exam with Visual Evoked Potentials (EVP), fluorescein angiography (FAG), and Indirect Ophthalmoscopy. Soon after, Sofyan had to have a Magnetic Resonance Image (MRI). In the waiting room, a familiar "auntie," volunteer Megumi Yan said, "This is the red bean bread I just purchased. She knew in the next two days Sofyan would have to undergo a series of intensive and detailed exams and would be tired as a result. Therefore, she brought "the most delicious red bean bread in Hualien" for him, his mother, and translators Ms. Lin and Ms. Ji to enjoy.

The Blind yet Diligent Youth **Follows His Dreams**

On October 17, the day after attending physician Dr. Chiu carefully examined Sofyan's results, he, Nurse Practitioner Pao-Hui Tseng and intern Chi Huang made a medical round that afternoon. "Sofyan has a girlfriend?" Someone asked as Sofyan shared a photo of Anna, who is one year younger than him. Sofyan had met her via Facebook and they have been together for over a year. Sofyan's family had even invited Anna to their home many times.

"Sofyan," said Dr. Chiu, "You are amazing. I've tried Facebook for years and have yet to have an internet friend." Everybody laughed at the comment. With everyone's encouragement, Sofyan played the song which won Anna's heart, "You Are God's Gift to Me," and the lyrics moved translators Ms. Lin and Ms. Ji to tears.

Sofyan's mother shared with everyone that Sofyan, her eldest son, has always been an obedient child. Although his lefteye vision was only .01, Sofyan did not give up studying. Currently a sophomore in college, he aspires to become a psychologist. Even with poor vision, he would travel 4 hours from school and back, spending less than 70NT for transportation and meals, as a way to reduce his mother's financial burden. Sofyan informed his mother that since he is familiar with special computers for the blind, he will tutor others who are blind. And in doing so, he can help others while also share his mother's burden.

The warm welcome by the medical team made Sofyan felt at home. His biggest wish, though, was to see Master Cheng Yen. Along with Superintendent Dr. Kao, Deputy Superintendent Dr. Chen, Executive Secretary Hsing-Chu Chen, and Head Nurse Yu, Sofyan, his mother, and Ms. Lin and Ms. Ji as translators, returned



Frequent visiting volunteer, Hui-Mei Yen, is a familiar figure to Sofyan and his mother. Her timely gift of comfort as well as snacks and fruits has made the mother and son feel surrounded by love.

to their greatly missed spiritual home-Jing Si Abode.

"Sofyan is all grown up! You must study hard!" Master Cheng Yen encouraged. Upon hearing that he did not give up his study despite having poor vision, Master complemented his effort and prayed for his surgery.

Carefully Planned Surgery **Preserves the Bright Future**

After the results were released, the Hualien Tzu Chi Hospital medical team held a conference organized by Deputy Superintendent Dr. Chen and Neurosurgury Director Dr. Chiu, and Dr. Zei-Lun Huang of Ophthalmology. Dr. Huang noticed that Sofyan still had some visual sensation in his left eye, although his vision acuity fell below 0.01 (can only count fingers when placed 40cm away from eyes). Considering the chance of vision restoration for that eye was slim, Dr. Huang decided to let him retain vision to allow Sofyan to maintain daily activities like crossing roads. Dr. Chiu indicated that besides vision problems, they need to tackle the tumor. Despite the fact that fibrous dysplasia is a benign type of bone tumor, it commonly occurs in children and young adults. The dysplasia arises from multiple abnormal vesicle degeneration, and the tumor growth would only decline



Director, Dr. Tsung-Lang Chiu (right) and Dr. Kuan-Bin Chen (second from the right) used "Frameless stereotactic surgery" to locate the tumor and assess the condition with 3-D positioning on screen. This allowed the surgery to proceed smoothly. Dr. Zei-Lun Huang (left) entered the operation room early to apprehend the conditions. The cooperation of the interdisciplinary team made Sofyan's surgery a success.



Creating a weekend afternoon tea party in the lobby, Sofyan played and sang "One Family" for all the volunteers, patients, and families.

once puberty hits. A comparison between the 2008 biopsy and the current one indicated that although Sofyan's vision did not change significantly, the tumor on the right side of his face was growing.

Upon careful examination, they discovered that the tumor under Sofyan's right eye socket had occupied a vast region, including the skull, nasal cavity, frontal sinus, and lateral orbital area etc., while the tumor at the base of the skull spread inward, exerting pressure on frontal and temporal lobes, which may affect brain function. Also, the tumor pressured into the right eye, resulting not only the eye protrude, there was recurrence of corneal infection, swelling,

and ulceration. Dr. Chiu hypothesized the future tumor compression of the left optic and oculomotor nerves is likely and may affect the remaining vision, thus decided to remove the tumor. Once the tumor is removed, the right eyeball may be reinstated and once again protected by the eyelid.

Compassionate Medical Team Relay

On October 22, 8am, Sofyan entered the operation room. Director of Anesthesiology, Dr. Tsung-Ying Chen, Dr. Yi Lee, Dr. Pei-Jiuan Tsai, and their colleagues administered anesthesia with

careful monitoring of vital signs while ensuring the correct anesthetic dosage. At 9:18am, Dr. Chiu made the first incision. Deputy Superintendent ENT Dr. Chen had explained that the operation would be divided into three stages: First, Dr. Chiu and neurosurgeon Dr. Kuan-Bin Chen will remove Sofyan's tumor at the base of his skull; then ENT physicians Dr. Chia-Fone Lee and Dr. Yi-Tseng Bai will remove the tumors at the nasal and frontal sinus cavities; and finally, ophthalmologist Dr. Tzu-Lun Huang will remove the orbital tumors.

To ensure the tumors were removed. Dr. Chiu and Dr. Kuan-Bin Chen used "frameless stereotactic surgery", which immediately locates realtime the tumor on-screen to assist with surgery. However, because the tumor was surrounded by tiny blood vessels, hemorrhaging occurred just as the doctors expected. Upon transfusion, Dr. Lee discarded the original plan to remove the tumor through nasal cavity, and decided to remove the tumor through his right cheek. The numerous collaborations between Hualien Tzu Chi Hospital's neurosurgery, otolaryngology, and ophthalmology teams led to success in removing the tumors. Though it was not ophthalmology's "turn" yet, Dr. Zei-Lun Huang observed the surgery to apprehend Sofvan's current conditions, in hope to perfect the surgery with minimal time. The final suture was completed by ENT Dr.

Yan-Shen Chen.

While the medical team was meticulously removing Sofyan's tumors in the operation room, Tzu Chi volunteers accompanied Sofyan's apprehensive mother, Rosnilah, in the waiting room. Ms. Lin and Ms. Ji comforted and prayed with Rosnilah in Indonesian. Rosnilah expressed gratefulness towards the effort of Hualien Tzu Chi Hospital's medical team, as their treatment plan included not only the tumor removal, but the follow-up as well. She had hoped, prior to coming to Taiwan, to replace Sofyan's right eye with an artificial eye. Considering that an artificial eye does not look as natural and, despite the damaged optic nerve, the muscle and oculomotor nerves were still intact and allowed the right eye to move corresponding to the left eye, the medical team decided to keep the right eye for the sake of Sofvan's future social activities. After listening to the detailed explanations and considerations for her son. Rosnilah felt more at ease.

""Sofyan!" On the morning of the 23rd, Dr. Kao came to the Surgical Intensive Care Unit to visit Sofyan. Though intubation prevented him from speaking, Sofyan repositioned himself to respond to Dr. Kao's greeting. Under the nurses' demonstration, Rosnilah gently massaged Sofvan's arms and comforted him in Indonesian. Through eye contact, their love for one another was expressed.

On the morning of the 24th, upon Dr. Chiu's evaluation, Sofyan, who recovered excellently, was transferred from SICU to general ward. Seeing the nurse bring Sofyan out of the SICU, Rosnilah and the translators were relieved. Dr. Chiu pointed out that because the surgery proceeded successfully, Sofyan's right oculomotor nerve, facial nerves, and major blood arteries were preserved, and the recovery was beyond satiisfactory. The post-op would be primarily on the healing of the wounds and preventing infection in spaces once occupied by the tumors.

Songs Translate into Feelings Illuminated by Love

Nearly 20 days after the operation coupled with subsequent follow-up visits, on the morning of November 12, Sofyan was discharged with the blessings of the medical team of Hualien Tzu Chi Hospital and every volunteer. Everyone was pleased to see Soryan's recovery, particularly the restoration of his once disfigured feature to that of a normal perso. Compared to the previous two surgeries, Associate Director



After eight years of treatment, Sofyan has gained a beautiful smile and found an important goal in life. At the farewell party, Hualien Tzu Chi Hospital medical team and volunteers happily celebrated Sofyan's 23rd birthday.

Dr. Chen indicated, the postoperative recovery was even better than anticipated because Sofvan is now an adult. The risk of osteitis myelodysplastic growth is two out of hundred-thousands, to occur at the base of the skull so deep into the brain that oppressed the optic nerves and affected the patient's vision, such as in the case of Sofyan, is very rare. Through interdisciplinary collaboration, they allowed Sofyan to have a normal life physically and physiologically.

"I pray this will be the last surgery." Behind what appears to be a mundane wish, Sofyan has an unrelenting passion for life. Given the impact of the tumor, Sofyan was unable to complete his previous desire of becoming a physician; however, he hopes to quickly complete his study in Psychology. Even though he may not be able to be a physician, he can also use different methods to assist those in need. As such, Sofyan learned how to play guitar and use music to share his feelings with those wounded souls, accompanying them to face their plights.

Dr. Kao explained that, from Sofyan, one could see his passion for life. Director of Ophthalmology Dr. Huang exclaimed that the completion of this successful orbital reset operation took under eight hours to complete and yet did not affect the remaining acuity in the left eye, all due to the collaboration within an interdisciplinary team. Seeing



Sofyan ready to return back to Indonesia, in addition to cheering for him, the physicians also reminded him to follow-up regularly with any changes in his vision.

Prior to leaving Taiwan, Sofyan performed an Indonesian song he wrote called "Sinaran", meaning "Light", and a Chinese song, "One Family." Despite his affected vision, the accompaniment of Sofyan's family, the medical team, and the volunteers felt like warm sunlight, which guided his aspirations in life. Received blood transfusion during the operation, Sofyan is now of "mixed blood" between Taiwan and Indonesia, a family member to both nationns. With his guitar, Sofyan shall use his unrelenting passion for life and music to formulate stories to touch and heal more people.

Sinaran Light

Tercipta untuk ku You were created for me

Hadir mu di alam Having you in this world

Penye juk nafas yang panaskan dunia You've warmed up the world for me to breathe freely

> Hinga ku melawan segala amarah When I faced multiple obstacles

Yakin ku hati ini untuk mu seorang I know you'll always be in my heart

Suara memu kau sinaran bagi ku Your voice is like guiding light

Gengam lah tangan ku jagam kau lepas kan Your hands hold me tightly and never let go

Gengem lah selalu jagan kau lepas kan Tightly hold me until forever.