Messengers of Joy

The Song of the Bubble Bobble Dragon

A-Ying suffers Hereditary Epidermolysis Bullosa, which means that her skin constantly blister and break starting from birth. In more serious cases, amputation would be necessary. In order to nurture her daughter's physical and emotional health, Mrs. Liu works rigorously to learn how using the channels available to her in hospitals, schools, and handicapped organizations. Feeling that she had not saved A-Ying early enough,

Feeling that she had not saved A-Ying early enough, Mrs. Liu fervently searches everywhere for children with similar conditions in order to form a support network with which to save them.

Rushing through this world, the saints bring aid to those in need.

Others who face rare disorders no longer feel sorry for themselves after seeing this mother and her daughter: "With them at the forefront, we know how to follow."

Rain outside the window, disturbing my mood.

The cold wind blows, piercing my heart.

The night train's whistle blows, urging me to get aboard.

My mind is full of thoughts, but no one will listen.

My love for you will never change...

At the end of December in 1994, the Taiwanese song "You're My Entire Life" was broadcasted on the radio, filling the air with its heavy, melancholy melody. With the song playing in the background, a letter from Fengshan in Kaohsiung, southern Taiwan, was read aloud by radio show host Zhang Min:

For the past few years, I have been living like there is no tomorrow, severely depressed and there's no one to listen.

Heartless is the world—even the person closest to me doesn't even care.

Being a mother, I am always protective. Ever since my daughter was born, people have told us we should give up, but it would be so hard parting with her. It took so much effort to raise my daughter. Now that she's seven, our family will continue on with her.

My daughter is about to start elementary school, but not a single part of her body is intact. Taking a sip of milk or a breath of fresh air can be so trying for her. How long can I go on like this? People say this is the age of advanced science and technology, but there are still so many untreatable diseases. In essence, my daughter and I have been imprisoned for life. Looking at me on the outside, people say I'm a strong, optimistic mother. But only I truly know my inner pain. I never say a word, though, for fear of my daughter losing hope, of my husband losing hope. If hope is lost, then it's all over.

Today I am writing to you anonymously as someone who is in pain. I would like to tell everyone that we must have a caring heart, love our families and the people around us. Because who knows how many people in our society are struggling for their lives and survival...

The letter was signed Mrs. Liu. "You're My Entire Life" was the song she requested to be played on the radio.

Everyday at noon, the Kaohsiung Police Radio Station airs a short program called "One Song, One Story" in addition to the local traffic report. At the beginning, host Zhang Min gently read: "There is a song in everyone's heart. When we feel disappointed, this song encourages us. When we're sad, it comforts us. This song will remain in our hearts forever..." This rhythmic song accompanied by the moving events of Mrs. Liu's life in her letter struck thousands of listeners' hearts in southern Taiwan.

After the episode Mrs. Liu's letter was aired, the radio station received many call-ins from listeners. They asked what illness the child had and passionate doctors expressed their willingness to help with treatment. One after the other, many different people sent Mrs. Liu their own secret remedies.

Overcoming Grief and Lighting the Way for Others

Over the past few years, Mrs. Liu worried much about her daughter's illness and suffering, so mother and daughter rarely ven-

tured outdoors. She played the radio everyday hoping music could calm A-Ying's mood. By expressing her sincere concern and revealing the true story over the air, Zhang Min not only guaranteed Mrs. Liu would regularly tune in, the radio show host had also provided an outlet for Mrs. Liu to write her feelings down on paper and receive consolation. Every few months, Mrs. Liu wrote all her joy and grief into a letter, piecing it together using the little free time she had. Sometimes she wrote on a calm night, but occasionally she would run home agitated and upset, gasping for air as she wrote. After finishing a letter, she would request a song to accompany the letter as a DJ would.

In June of 1995, she requested the song "Under the Stage Pavilion" in her letter:

While the players are mocked by the audience,

There is no script in real life.

I am living like a noble on stage,

But like a beggar after stepping down.

I'm beautiful and admired on stage,

The greatest fear being to look in the mirror after the show.

The melancholy voice of the singer, rich but sad, accompanied Mrs. Liu's letter:

As a family with a severely handicapped member, we have undergone torment, fear and helplessness over these years and seen the ugliest side of humanity. But by walking along the edge of destruction, we have also learned how precious life is.

My daughter is always fighting for life. But people on the street keep their distance from her, pointing and saying, "Who wants to raise a child like that?!" These people have no grasp of life's meaning whatsoever.

My daughter and I once went to a corner shop. As soon as my daughter stepped into the store, the owner became angry immediately. "We might get infected, don't come in here!" he exclaimed. I was speechless at that moment, and hurriedly took my daughter out for fear she lose her dignity. Nevertheless, I still hear insults quite often...

The most important things in life are self-respect and self-esteem.

Dear friends who are hurt or physically challenged: we must help and encourage one another no matter what others may say or what looks we may get. The most terrifying situation is when people don't respect themselves. I hope that society is willing to say a few words of encouragement. People who are hurt do not require sympathy and hand-outs, but equal dignity. Please give them a little extra leeway by allowing them exist...

After the letter was read, ripples were sent through the hearts in the radio audience. Many called in to the station expressing their support and how moved they were:

"More than twenty years ago, my child was only a month old with a skin disorder that could not be diagnosed," said Mrs. Hong of Daliao in Kaohsiung, who

shared the same pain and experiences. "Once we got onto a bus, people said things like, 'Hey, stay away! We're going to get infected!' A mother was hurt so much by these kinds of words..."

"After my friend was accidentally burned seven years ago, his whole world became closed off," Dou-dou of Tainan sobbed. "Everyone would point at him and hurt him a second time by doing so! Friends who are hurt need the power to move on. They're people too, and have the right to live..."

The tears of the audience filled the skies of southern Taiwan, and rained upon Mrs. Liu as she listened to the program every day. The songs drifted gently through the air as her letter was read, washing clean old wounds and illuminating the drearier parts of her mind. Mrs. Liu's description of the depression and panic in her life served as an excursion through her heart and mind for the audience. Through her encouragement, they learned what good fortune was, how to cherish it, and how to create it.

It seemed like the audience was tuning into a series being aired once in a while. With every episode, the story of Mrs. Liu and her daughter A-Ying gradually unfolded. The audience learned the daughter had Hereditary Epidermolysis Bullosa, and that other children called her a "Bubble Bobble Dragon". Blisters grew and broke all over her body, dotting her with scars. Her mother did her best providing care, and more to prevent cruel social isolation, which threatened to leave far deeper psychological scars.

Their efforts have moved many people in southern Taiwan. Sometimes along the way, people recognize "Bubble Bobble Dragon" A-Ying, and ask: "Are you the Liu family?!" Warmth pours forth from their smiles.

Nowadays, Mrs. Liu does not have copies of the original letters, but a set of recordings from the program which she treasures and plans to pass down as a family heirloom. While feeling the tapes with her fingers, she can't help but sigh, "There are scripts for Taiwanese opera, but there's nothing about my life to read."

Her life has been an extraordinary opera, difficult to sing, but certainly moving to the ear.

A "Broken and Smashed" Infant

Mrs. Liu's full maiden name is Lin Jin-gui, and her youngest daughter's name is Liu Pei-jing. Because Pei-jing was sick, her mother brought her to see a Taoist priest and received the more auspicious name of "A-Ying."

When A-Ying was born, her father Liu Rui-ding was the first to see her. A minute after she had been delivered, her palms and ankles looked as if they had been smashed with a hammer and scabs began forming all over. After five minutes, her body was covered with blisters that soon began to bleed. The father wept and did not want to tell his wife who still lay in the delivery room. In a short while, the twenty-nine-year-old mother learned of her daughter's condition because the doctor had called a taxi with the intention of transferring them to Kaohsiung Medical University.

A-Ying was headed for the intensive care ward crying and aching. Her father saw that blisters had even formed on her tongue, and many of the blisters on her body had begun to break one by one as she had been crying and writhing in pain. She was feeling sensations like experiencing deep cuts. Ten days later, the results of a

biopsy confirmed she had Epidermolysis Bullosa caused by an abnormality on one of her chromosomes. There was no available treatment. Besides her skin, every mucous membrane area of her body would form blisters, including the tongue, esophagus, intestinal tract, and anus. When blisters formed on her skin, they would have to be cut open and treated with ointment. After a few days, the wound might blister again. The epidermis will gradually begin to undergo fibrosis as the wounds repeatedly flared up, perhaps to the point where the amputation of extremities may become necessary, or even cause the esophageal passage to narrow and make it difficult to intake food.

The doctor told Mrs. Liu, "This kind of disorder may slowly lead to serious family problems. Be aware of this."

Looking at this "broken and smashed" infant, Mrs. Liu thought about how unaccepting her in-laws were, who repeatedly kept asking her to give up the child and leave it in the hospital for adoption. The tears she held for so long finally began to fall. She had lost her father when she was nine and then her mother at twelve. Although her three older brothers offered her places to stay, she worked and attended night school immediately after elementary school. Relying on oneself for survival was bitter and lonely.

Could she allow her newborn infant to become an orphan on the street?

"Your Child or Your Husband."

Mrs. Liu hurried between pediatrics and dermatology asking if there were any other patients in Taiwan with a similar condition, but none were to be found. She alone had to become skilled at dressing the wounds and keep her daughter healthy. There was no family history on the mother or father's side, however the doctor pointed out that both of them probably have a defective, recessive gene, making a one in four chance of their child acquiring this disorder. It was such a rare disorder that the medical interns did not know proper care. They picked A-Ying up with only one hand, and the area she was being held formed blisters, broke and bled immediately. Mrs. Liu felt as if she were bleeding on the inside from worry.

A-Ying remained in intensive care for nearly two months, receiving shots and taking medication every day. Hospital costs were too high, so mom and dad took their daughter home for a Chinese New Year reunion. The sores on this child's body were painful, causing her to cry day and night. It was very trying for everyone, and another concern was how long their financial situation could last. The couple rarely had visitors from then on—not even the telephone rang.

Mrs. Liu's in-laws looked at her with cold eyes, asking "Do you want this child, or your husband?"

She was speechless, and they angrily turned away.

Watching them at a distance, Mrs. Liu made a promise to herself as she wept: "I won't ask anything of anyone. I shall be proud of teaching her not to depend on anyone but herself, so that no one will look down on her!"

Gritting her teeth, Mrs. Liu quit her job and took on the task of raising her daughter full-time. Her husband Liu Rui-ding was a carpenter who worked day and night not only to get the money needed for A-Ying's medicine, but also to numb his mind and avoid his wife and child. He was being squeezed from the pressure arising between his wife and his parents and relatives, like the filling in an Oreo. He became so depressed that he would take out his frustration by throw-

ing furniture, punching the wall, even throwing his child. Luckily, he hadn't lost all reason, and only threw her onto the bedding. Even the words "I don't want to raise her anymore!" were once yelled out, despite his well-mannered appearance.

On one occasion, A-Ying cried for three days and three nights, mother and father were both on the brink of a complete nervous breakdown. The father exploded into a frenzy, destroying their television, air conditioner and electric cooking pot. All that remained was the electric hot water boiler, but that was smashed too after Mr. Liu lost her temper, with glass and mercury spilling all over the floor. A-Ying unexpectedly fell asleep from fright, and the clash of battle died into silence.

After several years, and to the surprise of Mrs. Liu, she learned Rui-ding had contemplated suicide on three occasions.

Accepting Fate

Actually Mrs. Liu understood her husband's predicament very well, having known him since childhood. They had grown up together, so one look was worth a thousand words. She knew he was willing to raise their daughter, but the road was long and hard. Courage could not be mustered so easily.

Mrs. Liu faced the cold, harsh words of her parents-in-law alone, then hid herself in a room treating her child's sores. It was difficult coaxing A-Ying to sleep because she was in so much pain, and even when she would not eat anything, Mrs. Liu still tried feeding her. This mother took care of everything in silence, for fear her husband would one day take their daughter away and commit suicide.

But did this mean she harbored no hatred? Why did the gods she prayed to answer that she must accept her fate? She once fell to an all-time low, and resorted to asking her close friend A-Ju if she would adopt A-Ying's older sister, which would allow Mrs. Liu to take A-Ying to Hualien on the east coast to do volunteer work at Tzu-Chi, an international Buddhist charity organization, for the rest of her life.

To this day she still remembers with the deepest clarity, times that scarred her to the point "no one would believe..." Mrs. Liu's voice seemed perplexed when she compared past and present, describing how her money had run out, relatives and friends had left, and how she had been forced to reside in a run-down apartment building.

Frustrations of the past included astronomical medical costs, six years of sleepless days and nights of feeding and comforting her daughter, and going everywhere to ask about possible treatments. Even more difficult was how Mrs. Liu bottled up all of her torment inside so her family could be protected and maintain its sense of entirety.

It was a long time until her husband's family heard "One Song, One Story" and was deeply touched. This turn of events began when they called Mrs. Liu after hearing the program to ask if she wrote the letters. Mrs. Liu was afraid to admit it at first, but Rui-ding knew from the several occasions he saw her writing the letters, that it must be her and admitted.

These hard times have passed since, and now the family of four is enjoying happier days. Mrs. Liu had given the recordings from the radio program last year for Rui-ding to listen to, and together they silently listened to storms of the past.

Heading Where Treatment Lie

A-Ying was a little princess whose mother held a class-C chef's license. Besides making delicious fish soup noodles for A-Ying, Mrs. Liu was also a skilled seamstress who sewed specially layered cloth shoes for her princess. This was because A-Ying's toes were deformed from meshing together, forcing her to walk on her soles. Needless to say, Mrs. Liu never gives up in the search for where treatment may lie.

When A-Ying was six, mother and daughter made their way to spend the nights in a temple for more than half a year rain or shine. A household revolution nearly took place, as this decision met opposition from relatives. Afraid not enough information was being gathered while spending nights at the temple, Mrs. Liu wrote several articles and letters which she submitted to magazines and radio stations. Not surprisingly, lots of information was gathered about especially peculiar treatments, most of which were met with heart-breaking disappointment after paying.

"I tried everything I heard for fear of missing something that could save her."

The father was equally determined. There was one occasion when he traveled to Jiuhua Mountain in Miao-li county several hours drive north from their home in Kaohsiung. From dusk till dawn, he knelt every three steps and kowtowed every nine steps starting at the foot of the mountain. From the temple at the top of the mountain, he retrieved a bottle of holy water for A-Ying and went to work immediately that same morning without any sleep.

"If she had been sent away, we would have searched for her in orphanages," said her father.

Today, thirteen-year-old A-Ying acts like her father's nanny. "Dad, you were drinking again?" Dad gets home late once in a

while. A-Ying rubs her father's head, saying "Come on, be good and go brush your teeth. Then it's off to bed." Then he obediently brushes his teeth before going to sleep.

The year they spent nights at the temple, Mrs. Liu and A-Ying rode over the Love River in Kaohsiung on their motorcycle every evening. Mrs. Liu was often feeling despair to the point where she nearly jumped into the river instead of returning home. However, she knew that A-Ying's had a strong will to live, so she dared not do such a thing.

Sometimes mother and daughter had to fly back and forth from northern and southern Taiwan in order to do charity work. Mrs. Liu thought to herself, "If there were a plane accident, the compensation money would make the lives of my husband and A-Ying's older sister much easier. They wouldn't have to always worry about how hard A-Ying's future will be either."

Then A-Ying unexpectedly said, "Mom, did you ask Zi-xin the fortuneteller if it was OK for us to leave the house today? It wouldn't be good if we died today."

The more threats encountered in life, the more life is cherished. Mrs. Liu's heart felt as if it had been struck. "Have I been thinking wrongly?!" she thought.

"I'm really pretty, actually!"

Mrs. Liu forgot that it was her who had taught A-Ying to cherish life. Despite spending three to four hours having her sores treated and bandaged, wearing special casts on her hands all night long, even undergoing reconstructive surgery on her arms and legs (grafting skin from her scalp for her fingers, or skin from her waist for her toes), A-Ying has a big heart, is very outgoing and has a very special

personality!

When she was almost three, A-Ying accompanied her mother to the supermarket to buy milk formula. Another young child saw her and yelled, "I see an alien!" Having learned these words from a popular television program at the time, A-Ying's skin color changed from the mixed emotions she was feeling. As Mrs. Liu looked at her daughter, A-Ying said quietly: "I want to go home." Both of them turned around and took the long road home without speaking another word. Pressed against one another, they could feel each others' hearts racing as they sped home on their motorcycle.

Mrs. Liu was concerned, but did not want to make any judgments about what had happened. "A-Ying must face all sorts of people in her lifetime. Perhaps she might hear even more hurtful words in the future," she said.

After getting home from the supermarket, Mrs. Liu put A-Ying inside the bedroom and started cleaning. With one eye watching as she cleaned, Mrs. Liu saw A-Ying staring at herself in the mirror. A-Ying played with her hair, adjusted her clothes a bit, stared in the mirror a while longer and then said to herself, "I'm really pretty actually!"

Throwing aside her broom, Mrs. Liu ran over crying and hugged A-Ying. "That's right, you are really pretty!"

Their difficult journey had only just begun.

When A-Ying was two, Jin-gui had finally come to accept the fact of her daughter's illness. She stopped only searching for sources of treatment and began placing importance on educating her daughter how to handle her emotions. She wanted A-Ying to bravely face the world and herself. She bought several fairy tales, including "The Ugly Duckling" and "Cinderella." But as her daughter

grew older, the mother realized fairy tales would not continue to hold. She said, "My hope of finding treatment is dashed, and one day her dreams (of becoming beautiful) will be shattered as well."

Therefore Mrs. Liu took her daughter on the road to charity work. A-Ying's eyes and ears could be opened up to the world, and at the same time Mrs. Liu had found a way to make herself feel useful. Mother and daughter volunteered at the R.O.C. Chinese Burn Association, the Eden Social Welfare Foundation, as well as other organizations. They helped the elderly and the blind by doing household chores and cooking delicious meals for everyone.

One time, a blind person who frequently came offered his cane to A-Ying, wanting her to try walking around with her eyes shut. A-Ying used her hands to feel the ground and squatted down for a long time, not daring to take a step. Mrs. Liu took the chance to tell A-Ying that many people were sick. Some had trouble with their lungs hidden on the inside, while others might be blind. A-Ying had a skin disorder, but could still help many who weren't even able to walk up or down a flight of stairs.

Life's Lessons

The most beautiful part of life is in possessing a complete soul. In the living room, two calligraphy scrolls represent their family values:

Cherishing food and clothing is not being miserly, but grateful for good fortune.

Seek a good name and prosperity, not relying on others but oneself.

Though not rich, the bookshelves were piled with books aimed at fostering the spirit. I pulled out one by random, and it was *No One's Perfect* written by Japanese handicapped author Hirotada Ototake. On the opening page was written an inscription of encouragement from A-Ying's mother:

To A-Ying and Wan-yu (A-Ying's older sister)—
Heaven has bestowed you each with a unique body for a special purpose. Happily and bravely accept it!

Mom

These words are rightly said by Mrs. Liu because she adheres to them most faithfully. When A-Ying was only three, Mrs. Liu began doing volunteer work at A-Ying's future school which allowed everyone to get to know her daughter in advance. Elementary school was A-Ying's first step into society, and although the education office suggested A-Ying receive home schooling, her mother still insisted that her daughter go through the education system like everyone else does.

Mrs. Liu became very nervous before A-Ying went to school, worrying that A-Ying's body and mind could not undergo this kind of ordeal. So the mother asked that the school to be prepared for A-Ying. Mrs. Liu made a copy of the article she wrote discussing her experiences and prepared a doctor's written diagnosis of A-Ying's condition. On the other hand, the school arranged special programs to familiarize teachers, students, and other parents to special children. On the first day of school as A-Ying stepped into the classroom there was the expected stirring and talk, but after everything had been explained, A-Ying quickly overcame this test and made

friends with the other children.

Mrs. Liu takes A-Ying to school everyday, just in case another student accidentally steps on A-Ying's foot. If that happens, Mrs. Liu would take A-Ying aside, opens up the first-aid kit, cuts the blisters and treats them. It's so painful that A-Ying cries. But she wipes the tears away and runs off to play in the classroom.

In accompanying her daughter to elementary school, Mrs. Liu felt as if she were attending a community college, learning a lesson in life together with her daughter.

Growing up with My Child

March of 1996 was the end of A-Ying's first winter vacation, and Mrs. Liu requested the song "A Footprint With Every Footstep" on the radio:

Every footstep leaves a footprint, the dew drips into your heart...

Walking on the path of life requires we all work hard...

The world is full of misfortune, so you

must become more determined as the road gets tougher...

The sorrow in Mrs. Liu's letters began to dissipate. The lines now brimmed over with content, the words of which were shared with old and new acquaintances over the air:

Everyday when I step into her school, I sense this inner joy like a child does, innocent and energetic. This is the magnificent gift my daughter A-Ying has given me.

The teachers always leave a small space for me in the

classroom and school counselor's office.

The school counselor's office is a place that revitalizes me. The many books on the shelves have helped me grow. I hope to use my time the best I can and grow up with my child.

On the long road of life I have littered my diary with bits and scraps of what occurs. I hope very much to keep a record of my daughter's childhood, because these are the most wonderful days of my life...

It was this year that Mrs. Liu was named one of the "Ten Most Loving Mothers" in Taiwan. But the sense of achievement which sprouted from raising her daughter and keeping her healthy was an even greater honor. Mrs. Liu instilled confidence and joy in her daughter by encouraging her to make art. A-Ying could not run or jump very fast, but with her long, thin fingers, she loved to play the piano and loved to draw more, all despite having no fingernails.

"When I began learning the piano," wrote A-Ying, "my fingers would blister as soon as I began playing. I kept playing even though I was crying. And Mom was worried, so she asked me if I wanted to quit, but I insisted to keep on learning." In her composition book, the entry titled "Learning the Piano" reflects how much she resembles her mother in how full of determination she is.

Doctors said if A-Ying did not exercise her fingers, they would slowly begin to curl and degenerate, which would leave amputation the only recourse. Mrs. Liu was not about to let that happen, so she always massaged A-Ying's fingers and encouraged her to play the piano as a way of keeping them fit. Playing until blisters formed, A-Ying had to have them cut open by her mother to drain the blood, wipe them with antiseptic and bandage them, after which A-Ying continued to play. She had a talent for the instrument, and often played during charity fundraiser concerts. The rich melody of life spread throughout the audience, and both the ill and healthy gave a warm round of applause.

A-Ying had also won many painting awards. Her dream is to become an art teacher after she grows up. She loves painting, especially nature scenes. Her brush and infinitely energetic spirit produce a wide spectrum of bright colors, at times fine and delicate, at other times free and wild.

"Every blade of grass has its share of dew," was what Mrs. Liu loved to say most. A-Ying, her precious little flower, grew from the irrigation of a mother's love.

A Beautiful Scene of Life

There is an unforgettable picture of the shore that has sunk deep into my mind.

In early 2001 on a warm afternoon, Mrs. Liu and A-Ying took me on a tour of Cheng Ching Lake on the eastern side of Kaohsiung. The three of us rode on a small motorcycle, with my hands stretching past A-Ying's thin, fragile waist and holding onto Mrs. Liu's. A-Ying said she was not being squashed in the middle and wouldn't be hurt if touched. She had gentle, smooth hair, and the newly grown skin on her face appeared wrinkled like that of a newborn. Her eyes, which had to be treated with different ointments by her mother in the morning as well as at night, shone as brightly as two stars in the sky. Her petite body was as beautiful and delicate as crystal, just as others had said.

Mother and daughter stood on the shore of the lake for a

moment, looking at their reflection in the water, talking about how to use a brush to paint the beauty of ripples in water. Their gestures and voices traveled through the air, which were reflected off the lake's surface creating a beautiful scene of life.

On the other side of the lake stood the Holiday Towers Mrs. Liu worked at as a janitor. After cleaning twenty-two flights of stairs in the morning, she rode home on her motorcycle to make lunch for A-Ying and change her bandages. In the afternoon she picked up a rake and started in the Holiday Towers gardens. After A-Ying grew up, she would no longer need her mother's protection and support all the time. So Mrs. Liu began to save money and buy more insurance, in preparation of the unknown future that lay ahead.

"I really want to publish a compilation of A-Ying's paintings and write captions introducing each of her works," said Mrs. Liu. "But I don't know the trick, plus I'm not holding a small pen, but a big one!" she said jokingly in reference to her mop. "There's no ink in it either, and I just scrape it along the ground." Mrs. Liu liked making jokes about herself, but one could see how outgoing she was from the movement in her eyebrows above the dust mask she wore. One could also see how confident and without regret she was by the rough gardening gloves she wore. Her delicate figure looked like a beautiful sculpture while tending to the gardens, attracting long views from passersby.

The wind on the lake's shore began to pick up and Mrs. Liu held A-Ying closer. Mother and daughter cared deeply for one another in this world, living colorful lives with earnest and strength.

There Can Be No Perfection Without Imperfection

In April of 1998, Mrs. Liu requested the song "When the

Applause Rises."

Standing alone on stage,
I hear the applause rise.
My heart fills with such a sigh of relief.
The many failures, the long waits
Taught me how to be patient.
I hear the applause rise, and I better understand...

Writing a letter to radio show host Zhang Min was more like writing to the audience, and it seemed both joy and sadness were in Mrs. Liu's heart:

March 30 started out like every day. I brought A-Ying to school. When I was ready to set off for work, A-Ying's teacher appeared in front of me, and said: "Congratulations, Mrs. Liu. Pei-jing [A-Ying] has been selected as the Most Outstanding Role-Model for Impaired Persons in Kaohsiung County. On April 12th, she will receive her award from the Department of Education, Taiwan provincial government, and both of you will be accompanied by another teacher from our school."

For a moment, all I could do was express my thanks. Then I turned around and felt hot all over. I lost control and ran crying all the way back home. I cried my sadness all away.

This award came as a result of suffering.

Actually, I don't need an award, but peace. There is a reason for my reaction upon hearing that A-Ying had won

this award. For ten years, I have taken care of her with all my heart and energy. I entered a circle of disadvantaged friends and have experienced first-hand the world of the handicapped.

There can be no perfection without imperfection, no joy without pain. Those who are handicapped, are actually fairies of this Earth, they are messengers of joy...

Searching for Other Messengers

Mothers possess the more strength than others in this world, and Mrs. Liu's love was not just limited to A-Ying. For several years, she has been searching and caring for children with similar conditions. Sometimes in the afternoon, she would walk straight into the dermatology ward of the hospital and hunt for these children like a hound.

Some of these children's parents hid in the dark, licking their child's wounds. Others were just as hard-working as Mrs. Liu, learning how to care for their own flesh and blood by themselves. Mrs. Liu was very aware of how ignorant or unaware doctors and nurses were of rare disorders. They administered improper treatment to A-Ying, and caused her toes to stick and mesh together. It was already too late for her fingers, too, so they had to be operated on time and time again. If Mrs. Liu had lacked knowledge of proper treatment on the formation of blisters in A-Ying's esophagus, it could lead to malnutrition.

"If there is another kid like A-Ying out there, how could I let him or her suffer?"

Mrs. Liu left her home telephone number in several hospitals for medical staff to contact her in case they must treat a patient with Hereditary Epidermolysis Bullosa. Whether she came across a patient by complete coincidence in the hospital, or a child had been abandoned in a far-off Hualien orphanage on Taiwan's mountainous east coast, Mrs. Liu has always rushed to their aid and provided her expertise.

But it can be very frustrating some times. "I'm totally willing to help and people can be so cold," Mrs. Liu said. "I'm willing to help anytime. As soon as they call I take action." She has encountered patients unwilling to come into the open, calling her a crazy. She even ran into a mother who had lost it completely and was waiting for her child to die.

When Huang Bo-chen was born, he was diagnosed with Ichthyosis, and the doctor said he could only live for three months. Mrs. Huang was waiting for Death to come. Her child's eyes and ears had not developed completely, possessing no eyelids to blink with, and the skin was so tight around his mouth that it couldn't close. Mrs. Huang learned about Mrs. Liu through social workers at the hospital, but did not want to meet her. Mrs. Huang felt this sick child "wasn't worth it." However, Mrs. Liu called her incessantly, and offered both encouragement and counsel on treatment.

"What are you telling me all this for? He's going to die anyway," Mrs. Huang said angrily.

"He's not wounded. It's not infectious. He won't die," replied Mrs. Liu.

"Why isn't he dead yet!? I don't want him to live."

"Life has its laws. Take him home so he can be well cared for."

"It's too much trouble, who would want to raise such a child?"

"I do."

"Your child can't be in as serious condition. I don't even dare to touch him."

> "I know the difficulties. I will teach you how to raise him. I live too far away, otherwise I'd go and raise him for you."

> Mrs. Liu persisted, and after unremitting consolation and encouragement, Mrs. Huang began to escape despair. Once thinking the disadvantaged were meant to be so by nature's mandate, Mrs. Huang now understands how much hope this group has for attention and concern from society. This is what gives them the strength to face society.

Six months later, Mrs. Huang and her son went home, and Mrs. Liu brought A-Ying to visit them in Taichung. Upon seeing A-Ying and how serious her condition was, but at the same time noticing how well she was raised, Mrs. Huang felt encouraged and said with determination "I can do it too!"

Little Huang Bo-chen's ears had become clogged, so Mrs. Liu employed a home remedy slowly pouring oil into his ears to open them. Mrs. Liu then showed Mrs. Huang how to wash his ears, and nowadays two-year-old Bo-chen is able to hear. He has also been undergoing reconstructive surgery for his hands and eyes. His innocence received the attention of his mother, who looked in his eyes and was moved. She was sharing something beautiful with this flawless soul.

The memory of Mrs. Liu's selflessness and her own dark times were deeply embedded within Mrs. Huang's heart, which swelled with undying gratitude.

Life's Luster

On a few occasions, Mrs. Huang called Mrs. Liu while she wasn't home, so she ventured to ask A-Ying, "Do you ever hate your mother?"

Mrs. Huang's doubt and fear manifests the torment all parents of handicapped children go through. Parents of severely handicapped children often struggle with the choice whether to save the child and raise it. Would this child be able to survive in society with equal opportunity and dignity? Would they hate their parents for letting them live and suffer? Parents struggle with the imbalances of right and wrong their entire lifetimes.

A patient with thalassemia major relied on blood transfusions to live for a long time. When twenty, his mother asked him, "If you had a choice, would you live this life again or just not be born?"

"Who would want to go through this suffering?" he answered. These simple words were still insufficient to fully express the help-lessness and cruelty of life he felt.

Fortunately, life is not a single-sided coin. If illness is made from dark threads, there is still a silver lining that may reveal itself and be extraordinarily beautiful to those who behold it. Responding to this question asked by Mrs. Huang, A-Ying answered, "Hate her? No, I love my mother, and she loves me. We're a very happy family."

"...And your father?"

"My Dad loves me very much too. Mrs. Huang, take good care of Bo-chen."

At this moment Mrs. Huang began to weep uncontrollably.

A-Ying and her mother were the same. They were both enthusiastic and willing to help others, sell things or perform for charity. Mrs. Liu said, "When A-Ying grows up and makes money, we can make a big donation to establish a charity organization and help even more people."

This was a dream Mrs. Liu had had for many years: seeing everyone walking together under the sun free of darkness.

Later on, however, she found out while there were many patients who would ask about social welfare, very few were willing to join this charity they hoped to establish. This was because if they were labeled as people with hereditary disorders, they would have difficulty finding a spouse and raising a family, as well as searching for employment. Although Mrs. Liu loved helping people and wanted to support more of them, she did not have enough resources. She mailed letters to the President's Office and the Legislative Yuan several times, pleading the government to establish a national center for the mentally and physically impaired. Unfortunately, she was only one person and received no official response. When her spirits were low, she hoped her daughter would grow up faster.

A Road of Thorn and Thistle

On a bright summer weekend in 2000, Mrs. Liu arrived in Taipei. She attended a workshop on an initiative to create a "Taiwan Organization for Disadvantaged Patients." In the afternoon she was going to meet another mother named Zheng Se-meng.

Se-meng looked very tired holding her two-year-old son who had Hereditary Epidermolysis Bullosa. She and Mrs. Liu began talking about how their children felt so itchy, but scratching only made things worse. The mothers had to stay awake and make sure this didn't happen. These two mothers had been down the same road of thorn and thistle. Mrs. Liu was an invaluable source of experience for Se-meng—what scissors were best for cutting the blisters, where the best doctors could be found, how to apply for handicapped status, schools and nutrition, even whether Se-meng's baby would have to serve in the military.

There are no warning signs with recessive hereditary disorders.

With any form of treatment non-existent, Se-meng, the young mother, had also traveled down the path of self-pity and suffering.

"My child was only out for a few hours and returned home a messy pulp. One wound stays messy all summer from the Dragon Boat Festival until the Mid-Autumn Festival. New blisters grow out of the old ones, they never stop," said Se-meng.

She wanted to take her baby's place, take away his pain. Unfortunately this was her child's burden to bear. Sometimes when seeing all the scars and blisters on her child's body, Se-meng would suddenly feel unable to carry on.

"This is something only a parent could feel, I suppose," said Se-meng. "It's like being in a fire, burning and unable to find the exit. Then you can't help but cry." She tried holding back her feelings, but they still revealed themselves from the reaches of her soul in the form of sobbing: "You can't get anything done when you're swayed by emotions. There's no time to think an extra minute. You can only be brave and face every wound, clean it, treat it, and bandage it. As a mother, I'm willing to do this with every last drop of sweat and tears in my body."

Why? Why was there such suffering?

Se-meng could only look up to heaven.

She remained unanswered. But she found a source of power through religion.

Its power had no boundaries and provided her the will to treat her child's sores with love. "This is exactly like how everyone has their own cup and drink. God bestows a cup to everyone and they cannot drink from each other's cups. They can only drink from their own. You only know what it tastes like if you've drunk from it."

This positive state of mind Se-meng has towards her fate is not

> attained in a single day. It had been a long and painful road for mother and son, and Se-meng still had her share of depression.

> How long does it take to cast off these chains which bind us in life?

As One

God looks down upon us from far above.

Yet there are also saints living amongst us.

Se-meng learned of Mrs. Liu and A-Ying on television, seeing how they both bore a crown of thorns on their heads. Se-meng said, "Since then, we've stopped feeling sorry for ourselves. There are others worse off than we are but still live on. This is a tremendous amount of encouragement. Being able to see what they do ahead of us lets us know what to do when it's our turn."

Se-meng added that women have potential. Much strength, endurance and will should be combined in providing care for a loved one.

Since Mrs. Liu took up the needle to sew this network that could provide aid to those in need, others would not feel they were too burdened or lacking in support. Se-meng and Mrs. Liu became allies in this war against illness, one in Taipei in the north, and one in Kaohsiung in the south. They often exchanged news about other patients' conditions and went to different social welfare conventions separately, compiling all the data afterwards.

When Mrs. Liu feels depressed, Se-meng cheers her up. "Jingui, if there's anything you need just let me know. Getting the association started isn't easy. But it will take twenty or thirty years for our kids to grow up; our generation has to do something first."

Creating a network with which patients, hospitals and disorder

associations could effectively communicate with was Mrs. Liu's greatest hope. "The medical field can offer no treatment, so we have nowhere to go but search for patients with the same condition. In this way we can take care of each other and find our own forms of treatment," she said. Encouraging genetic screening tests was also a big wish of hers. "To be honest, would you be willing to give birth to this kind of child? What would you do if you did? I daren't to have another child."

But parents who have already given birth to such a child will give all the love and care in their power.

The Next Life

Seeing her daughter's blood flowing on the outside, her mother's tears flow on the inside. Mrs. Liu holds back the storm clouds so as to give the light and warmth her daughter needs to grow healthy and vibrant. A-Ying's grandparents now spoil their granddaughter every chance they have and pray for her good health every day.

During summer vacation in 2000, twelve-year-old A-Ying requested a familiar song to be played on the radio:

My family is so lovely Clean, beautiful and nice Brothers and sisters happily playing Mom and dad are so benign...

Following the song "My Sweet Family," A-Ying who had been listening to the program since she was in her mother's womb, wrote a letter introducing her family of four. She started with her handsome father, and said she hoped he wouldn't sneak off to drink

when she was having an operation. Then there was her big sister, who could make scrambled eggs and mesmerize her by playing the piano. The person who took up most of her letter was her mother:

Not even doctors knew what to do about my condition, but my Mom has made breakthroughs. With no sleep or rest, she has sacrificed everything for me. I am so grateful!

Mom was afraid I couldn't attend school, so she volunteered to work at school first. Then I got in without a hitch. Many people knew that I had a rare disorder, so everyone took good care of me and protected me. They have made my life a very happy one.

I hope in my next life we can still be mother and daughter, so we made a pact. In the next life I'll be the mother and she'll be the daughter so I can take care of her...

All the precious recordings still carry the smell of Chinese herbal medicine, which were from special remedies brewed by Mrs. Liu for A-Ying. The fragrant bitter and sweet smell remains, and it is also the scent of their living room in Fengshan which brought happiness to the visitors.

I remember on that evening, A-Ying and her sister were in their small house looking for information on the internet together, their heads pressed against each other. Husband and wife were sitting leisurely side by side. "If patients don't want to get involved, it's like I'm performing solo on stage with no one paying attention," Mrs. Liu said.

"You still have me as a confidant," said Liu Rui-ding rubbing her hair.

Husband and wife laughed together. In their eyes, one could see they had been through the same trials.

How many years of scars were there? How much love and tolerance?

That evening, I listened to the soft sound of their tapes in the evening, and recalled all the laughs and cries of Mrs. Liu. The winds of early spring had come, blowing away many of this family's woes. I was wondering if I was qualified to feel sorry for them. I have seen this family on several occasions holding hands tightly. It is just like in A-Ying's letter: the four of them are symbiotic stars. They live very happily.

Life is rough, full of many twists and turns...but this is what creates the beauty of a prism.

The rough grains of sand that squeezed into their lives have been shaped into beautiful pearls, taking a tragedy and elevating it to the status of a heart-moving performance full of joy.

This joy radiates forth in all directions like the sun on the open sea...