

Class Notes

Lesson Eight

Heaven

I am more confident now than I have ever been that the Kingdom of Heaven is close at hand. It wasn't until we had accompanied you on your short journey that we began to recognize the precarious nature of our own lives; the end is actually not that far off. With a clear understanding of the impermanence of life, one's priorities fall neatly into place.





Before the incident that caused the brain damage, Qing Qing was glowing and healthy, playing in her crib.



After suffering from extensive brain damage, you were basically unable to interact with the world around you. While the world bustled with activity around you, you seemed to fall deeper and deeper into silence. The number of people hoping to hear your profound message had increased several-fold, but no matter how much they pleaded for your teaching, they were still unable to rouse you from your silent state.

According to the results of the sensory evoked potentials test (SEP), both of your eyes were totally non-reactive to light, but your left ear was still able to register some sound. In other words, any sound that entered into your left ear would be transmitted to your brain and create a response. However, this did not mean that the brain was actually capable of interpreting those sounds. After all, your body was incapable of any voluntary movement. Therefore, even if you did hear our voices, you would still be unable to react. Of course, seeing you like that broke our hearts. Relatively speaking, you were much healthier before suffering the brain damage.

It was so sad to see you just lying there, unable to interact with us. We missed the cute facial expressions that you used to make. To add insult to injury, based on the results of the neural reflex tests, the doctors had confirmed that you were still sensitive to pain. I couldn't help but regard that as a horrible existence: Lying there in total darkness, unable to hear, and unable to control the functioning of your own body. To top it all off, you were still able to feel pain. At that point, it seemed to me that there were really only two possibilities: Either to hope for a miraculous recovery through the help of physiotherapy treatments, or to hope that you would be delivered to the Gates of Heaven as quickly and as painlessly as possible. I wished with all my heart that you would choose one of these options as soon as possible, and not linger in some no man's land somewhere between the two.

Either way, no matter how long this marathon stretched on, or how difficult it was to accept, the one thing that Mommy and I were sure of was that we would see it through all the way to the finish line.

Groped in the Dark to Understand Your Needs

According to the doctors, the first two months following the brain damage were a time in which we might see some significant improvement in your condition. However, once you hit the six-month mark, any chance





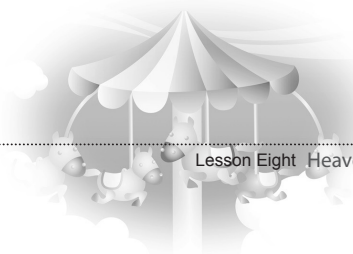
of further improvement would be highly unlikely. So, during those first few months, we tried our best to give you physiotherapy treatments, play your favorite *Teletubbies* DVD on the TV set, and have your sister sing your favorite songs for you. We hope that these things would somehow help to bring back the old you.

In fact, we did see some improvement during those first couple of months. Your arms and legs were not as rigid as they had been, and your face muscles began to relax. Moreover, whenever I called out your name, the heart monitor would show a significant increase in your heart rate. We were certain that you could hear us. Unfortunately, you were still unable to respond in any way. Even though we started to be able to tell when you were experiencing discomfort by the expression on your face or by the change in the heart monitor readout, it was still difficult for us to know the cause of your discomfort. We had to guess: Did your diaper need changing? Was your position on the bed uncomfortable? Were you hungry? Were you bloated? Was the ventilator pumping air into your stomach? Was there some tubing loose? Or, were you just feeling lonely? Where you in pain? Or, were you feeling ill? Actually, the list of potential causes was endless. In order to ascertain the cause of your discomfort we had to go through each of the possibilities and make adjustments accordingly, until we finally saw a sign telling us that we had stumbled upon the right one.

A Note From Mommy 2007.4.5

We don't want you to suffer for too long. Once your soul has ascended to Heaven, we hope that your physical body will still be able to make a contribution to those in need. Thanks to Dr. Lu's help, we have determined that the NTU Hospital Organ Donor Group will accept your corneal and epidermal tissue. Qing Qing, you really are amazing!

In reality, your improvement slowed substantially after those first couple of months had passed. Periodically, a tear would fall from the corner of your eye, or the corners of your mouth would seem to be curling up into a smile; but for the most part, we would just look at you, as if in a daze, remembering the way you had been before. Of course, we didn't let you know how much of a challenge it really was for us to see you like that; instead, we continued to offer encouragement, and support the best we could. Whenever Mommy would help you with your suctioning, she would talk to you in her soft little voice. This was one way to help strengthen your hearing again. It definitely seemed to us that you were able to hear and understand what was going on around you. Because whenever you heard the sound of your least favorite device, the cough-assist machine, your eyes would open very wide as if to say, "Oh no, not that again!"





Since you were unable to move, and the brain damage had been so extensive, your health was really nowhere near to what it had been. You could easily catch a cold, and the cold would very quickly turn into pneumonia, forcing you back for another stay in the hospital.

Because your health was so fragile, any time that you or your sister caught a cold, the alarm bells would go off in our house! We were concerned that one of you might pass the virus on to the other. As a precautionary measure, we would quarantine off two separate sections of the house: one for you, and one for Xin Xin. In order to further guard against the spread of the virus, Mommy and I would split up, each of us concentrating our attention on one of you; one of us would look after Xin Xin and one would care for you. Of course, the one who was in charge of your care would be faced with the prospect of several sleepless nights.

I recall one particular time, you had started to come down with a fever and so I was to be in charge of your care while Mommy stayed with Xin Xin. Unfortunately, a few days later Mommy also started to run a pretty high fever; so, in order to protect Xin Xin from getting sick, the two of them had to be separated. I ended up having to take care of all three of you, by myself! In the end, Xin Xin also fell ill, and your condition worsened to the point that you had to be taken to the hospital. By the time Mommy had recovered, I was just starting to get feverish myself. Again,

in order to prevent any further spread of the virus, I could not even go to the hospital to see you!

Intensive Training Program for Thoughts and Beliefs

All of the topics that you chose to teach us over the course of your short little lifespan were extremely challenging. However, if we take the principles of weight training as an analogy, a muscle must be pushed beyond its limits in order to become stronger; the same applies when training our thoughts and beliefs. Anytime we are able to persevere and to work our way through the difficult times, our faith will grow stronger. This was the sort of mindset that helped us overcome the challenges in our lives. For example, at the same time that your condition had taken a turn for the worse, and you required so much more of our attention, I was actually right in the middle of preparing for the final defense of my master's thesis. I was forced to burn the candle at both ends. As a result, when it came to taking over the night shift of your care schedule, I was the perfect man for the job. Besides, it was a great opportunity for me to have some alone time with you.

During my time working the night shift, I noticed that you would occasionally become a little bit more lucid, and start to blow bubbles! Even although your limbs were unresponsive, it seemed that your lips





were still able to move; with the help of the extra airflow provided by the ventilator, you were able to move saliva out through your lips to form white saliva bubbles around your mouth. Usually it only took about ten or twenty minutes before both of your cheeks were covered in bubbles. Each time I wiped your face clean you would just start again, piling bubbles up around your mouth. I figured that if this bubble blowing was left unchecked for a couple of hours, you might be able to create your own little bubble bath! It was so impressive to me that even in the face of such great suffering, and physical limitations, you were still able to find a way to entertain yourself!

Once again, I was reminded that during difficult times it is so important to be aware of what sorts of things you are focusing your attention on. Most of us are too focused on the negative. In the process, we lose sight of the important stuff, the things that we should be grateful for, and the things that we should remember. Therefore, it comes as no surprise that the Bible should offer the following advice, “Keep your heart with all vigilance, for from it flow the springs of life.” (Proverbs 4: 23)

Enshrouded in Beautiful Clouds

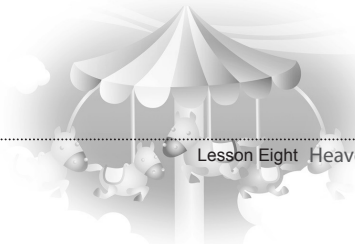
Even though our circumstances at that time were not very pleasant, it was wonderful to see that many of our family and friends were still

enthusiastically offering their support and assistance to our little family. As I reflected upon their profound kindness, I was able to completely transform my own outlook on life. As I brought each of these special helpers to mind, I began to think that perhaps I should have kept a special notebook to jot down each person's name along with the nature of their contribution, in order to ensure that I would never forget them as long as I lived. Instead, I posted the following article, titled “*Enshrouded in Beautiful Clouds*”, on the blog site:

This Wednesday, I finally handed in my graduate thesis. Of course, I might still have to make some minor corrections before I sit the oral exam; but it was still such a relief to finally hand it in.

This week was not an easy one! On Monday, Xin Xin fell ill and ended up with a fever of 40.5°C. Taking the usual precautions, we quarantined both Xin Xin and Qing Qing. Nadine looked after Xin Xin while I stayed with Qing Qing. By the time Friday rolled around, Xin Xin was starting to get a bit better; unfortunately, then Nadine started running a high fever. In order to avoid any further spread of the virus, Xin Xin stayed in the master bedroom, Nadine took the living room, and I stayed with Qing Qing in the kids' room.

Funnily enough, Qing Qing was the healthiest of us all at that time! It





was as if she was floating peacefully right in the eye of the storm.

In any battle, it is important to be persistent, and to be able to endure. The notion of endurance that is written about in the Bible is not the kind in which one grits their teeth and just plows forward in the face of adversity; instead, endurance refers to the ability to change one's outlook in order to find greater strength.

I have learned not to give up in the face of despair; not to give in to self-pity when I am feeling powerless, and never to waste energy complaining. Instead, we must confront our difficulties with a sincere heart, and calmly allow them to run their course. I have also learned anew how to appreciate the diligence, inspiration, and blessings that are all around me. There are always those wonderful companions, just waiting in the wings for that perfect moment to come forth and let us know that we are not alone. With these companions gathered all around me like soft, beautiful clouds, my attention is once again brought back to God, the source of my strength.

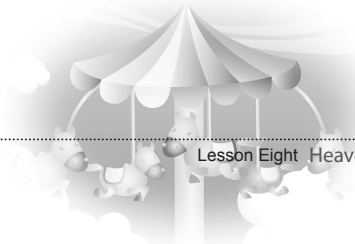
People too often focus their attention on the unimportant, negative aspects of life. They do not appreciate these all-important clouds that blanket us in love and support throughout our lives.

Well, in order to help focus my attention back onto the love and support of these helper clouds, I would like to take a few moments to thank some

very important people:

I would like to thank:

- *Wei Liang and Pei Shan for their help in preparing the interview transcripts*
- *Sheng Min for helping me gather information*
- *Master, A De, Yan Fang, Xiao Ya, Angela, Jia Wen, and You Xian for sending me messages*
- *Professor Yi Jia for her patience and reassurance*
- *Grandpa and Grandma for bringing us such nutritious, and delicious care packages; as well as for taking Xin Xin out to play*
- *Chong Hui for the homemade Wontons, lunch boxes, and Pork Ball Soup*
- *Ivan and Karen for the most delicious Ginseng Chicken Soup that we have ever tasted*
- *Qing Zong and Ya Ping for the essence of chicken, and the food supplements*
- *Shang Wen for the extra-moist cheesecake from Tian Mu*
- *Amysterious little angel for giving us healthy Subway sandwiches*
- *Hui Ying for the avocado milk and the delicious salads*
- *Shi Qi and Man Zu for sending over a steaming pot of Red Wine Beef Stew*





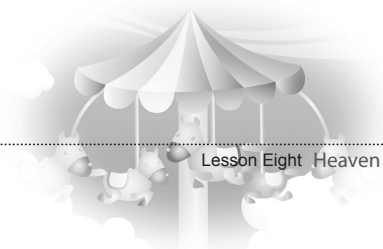
- *Nora, the stylist from William Beauty Salon, for coming over to the house to cut Qing Qing's hair, free of charge*
- *Xin Yi and Xiao Bi for giving Nadine traditional scraping therapy in order to get rid of her fever (this was really a big help since she was unable to take conventional medicine at that time.)*
- *Shun Bin for bringing over the afternoon tea, and staying on to reminisce about the old days with me*
- *Jasmine for keeping an eye on Qing Qing while Nadine and I went out for a little break*
- *Our friend Yi Xuan, one of the nurses from the neonatal intensive care unit, for coming over to the house to help with Qing Qing's care*
- *All of you who shared your wonderful messages with us on Wednesdays, it was very encouraging for me*
- *The people over at the Path Toward the Truth of God for their continual support; I still remember you guys*
- *All of you who prayed for, and with, us; we found reconciliation for all of our hardships within those prayers*
- *Huai Ren for sharing with us the story of how Qing Qing had brought about such change in his life*
- *All of our Internet friends for their support and concern Of course, there are many more people who I would like to thank, to all of you:*

Thank you, thank you so very much!

P.S. I encourage all of you to post your own letters of appreciation on your own blog sites; showing gratitude to those that have helped you is really a wonderful habit to get into.

All of these people who offer their love and support to us are similar to the spotter who offers assistance to the weightlifter; they offer a little bit of extra support in order to help us push ourselves to do just a little more. In the case of the weightlifter, this added support enables him or her to lift even heavier weights without bringing any harm to the muscles; this helps the muscles to grow stronger. The encouragement given by our companions is much like the encouragement given by the spotter; they tell us, “Come on, just one more! You can do it!” Looking back, I am surprised at how much extra weight I was actually able to support. Over the past three years, even though we have not had much time or energy to exercise our physical bodies, your teachings have ensured that we have thoroughly exercised our faith muscles. Just as the Bible states, “Though outwardly we are wasting away, yet inwardly we are being renewed day by day.” (2 Corinthians 4:16)

Some of our friends on the Internet have indeed taken my advice and posted their own letters of gratitude. Each one of them has confirmed





for themselves that such reflection can be very beneficial. This sort of practice not only draws our eyes upward to glance upon the pure, beautiful clouds that enshroud us, but also forces the corners of our mouth upward along with our spirits. When we focus our attention on those that have helped us, we can't help but feel warmth in our hearts and energy in our limbs.

Mommy Was Pregnant!

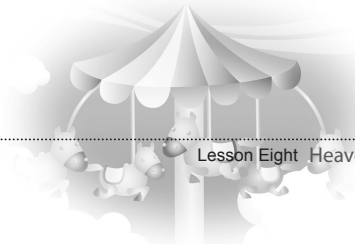
Some very clever Internet friends, who saw my “*Enshrouded in Beautiful Clouds*” post, very astutely came to the accurate conclusion that Mommy had become pregnant again. They were really quite sharp to have come up with this discovery; I am sure that you would have given them top marks!

As soon as the news of Mommy's pregnancy was out, people were quick to suggest the possibility of stem-cell therapy; perhaps it could save your life! In the beginning, we hadn't really given it much thought; however, after a little bit of research, we began to feel that perhaps it truly was a viable option, one that God had dropped right into our laps. If the human leukocyte antigens (HLA) in the new baby's blood were compatible with yours, a whole array of new options would begin to unfold for us.

The whole family happily awaits the arrival of your new little brother, Zeng Yi.



Unfortunately, stem-cell therapy research was still in its infancy; although it seemed to have great potential, there was only very limited clinical knowledge pertaining to it. In reality, the possibilities of using this kind of therapy were not quite as promising as the media had made them out to be. We were fortunate enough to have the CEO of the VIA Cord Blood Stem Foundation, Professor Zhang, give us a wonderful lesson regarding the basics of stem cells and genes. That basic understanding gave us an even deeper reverence for the marvel of God's creation. Sadly, the result of everyone's efforts had merely brought us to the unfortunate conclusion that your baby brother's HLA were not compatible with yours. Even though this was not the result that we had hoped for, we still felt grateful that God had ensured that people had been there to help us gain an accurate assessment of the situation. Thanks to these types of experiences, we were making steps toward getting a handle on the more profound life-lessons that you had given.





Zeng Xin: I love you
Qing Qing!



Around that same time, you went through another difficult period in which you had to spend more and more time in the hospital. On several occasions, the doctors were once again forced to initiate critical emergency interventions in order to keep you alive. Each time, the doctors were able to give us a clearer idea of how your illness would progress. It became clear to us that the end of your suffering was drawing near. That also meant that you were getting closer to your final destination, Heaven. We prayed to God that your passing would be peaceful, and not entail too much suffering. Since none of us knew exactly when you would leave us, we made sure to cherish every last moment with you.

Helped Xin Xin to Prepare

Although Mommy and I had prepared ourselves for the possibility of your passing, we were still concerned about how Xin Xin would take it. She wasn't even five years old at the time, but her love for you was very strong. We could see how much she loved you by the little things that she would do for you. For example, anytime she saw us placing you in the physiotherapy chair, she would come across and give you a little kiss in order to cheer you up. Another thing is that Xin Xin loved stickers; whenever anyone gave her some as a gift, she would choose the prettiest one and stick it to the headboard of your bed. When she played house, she would also make sure to prepare some imaginary food for you, and place it down beside you. Each time that you had to stay in the hospital for any length of time, Xin Xin would tell us how much she missed having you around.

It is true that young children often don't have much of an understanding

A Note From Mommy 2007.4.5

Qing Qing, looking back on the time that you and I have spent together over the past two years, apart from the times that you were forced to suffer through the pain of your illness, the rest of the time was really full of happiness. Of course, there was also the exhaustion. Thanks to your influence, Mommy learned to become more resolute, more content, and more able to enjoy the happiness of everyday life. I love you.





about death, but we felt it important to allow Xin Xin some preparation for your imminent journey to Heaven. Leading up to that point, the notion of Heaven had always been a topic that came up often in our conversations, and we all felt totally comfortable discussing it. In Xin Xin's mind, Heaven was a marvelous place that we would all be able to visit one day, but it wasn't the kind of place that you could just go to whenever you felt like it. The first time that we had discussed these sorts of things with her was when the doctors were planning to remove your endotracheal tube. At that time, I had posted the following letter, "*Helped Xin Xin to Prepare*", on your blog site:

Dear Qing Qing,

Over the past few days it has become clear that perhaps Xin Xin has started to become aware that something is up; she has been constantly reporting to us about how much she misses you. This morning, after she had given both Mommy and I one of her favorite Cars stickers, she marched over and stuck another one of them on your bedpost. It was as if she wanted to affirm, for everyone, your place as a member of our family.

We had originally been hesitant to take Xin Xin to visit you in the hospital; we didn't want her last impression of her baby sister to be one with tubes poking into her body. However, we finally decided that

allowing her to see you like that might help us to better determine the most suitable fashion for her to say her goodbyes to you.

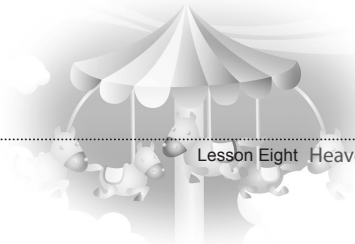
Amazingly, Xin Xin recognized you immediately, and shouted out, “It’s Qing Qing!” Without paying any attention to the tubes, she excitedly rushed over to say hello to you. In her mind, you hadn’t changed a bit. It was almost as if she just assumed that all young children had to go through a period in which they were hooked up to a nasogastric tube.

Xin Xin sang to you and showed you all the different games on my cell phone; she interacted with you just as she had always done in the past. She was so happy that I am sure she did not realize how different the situation really was this time.

We left the hospital and just strolled around for a bit. Suddenly, Xin Xin said, “I’m very sad.” When Mommy asked her why, she replied, “I miss Qing Qing. She has been in the hospital too long.” Mommy said, “I miss her too. If you miss her, you can sing that song of hers.” Xin Xin’s eyes began to well up with tears. We do all miss you so much!

The problem we still needed to face was how to explain the situation to Xin Xin. We knew that she too needed time to prepare. She loved you so much and was so used to your company that it was going to be difficult for her to let go.

Someone once shared with me the following analogy about parting





with loved ones: Imagine that a person's soul is like a letter, and their physical body is like the envelope in which the letter is contained. Once the letter has been sent and received, the envelope is no longer important. At that point, the envelope can be discarded because it is the content of the letter that is the important part. In other words, the body is just the vessel in which our soul is contained. I really like this analogy because it seems to describe your own situation perfectly; just as the words of a letter do not produce sound, your words are also silent, but also like the letter, your message may still be received very clearly. Furthermore, your message, similar to the words of a letter, exists in a physical form that can be passed from one generation to the next. Although this seems to be a very clear explanation of the situation, it might be a little bit too abstract for Xin Xin. We thought that perhaps we should try a different way to try to explain things to her.

We decided to take Xin Xin out for a fun-filled evening. First, we all went out and had a great meal together; and then, we took Xin Xin to an amusement center. We bought a bunch of tokens, and told her that she could play any game that her little heart desired! She played Hamster Bash, Super Shooter, Bowling, Fishing, Bumper Cars, Combat Games, Shooting Games, and on, and on... She was ecstatic! She even traded some of her tickets in for prizes. Once she had worn herself out at that



place, we went across the street and bought her a huge bag of candy. That was the first time that we had ever bought her such a big bag of candy. She was thrilled! As we walked along the street she was twirling and dancing around with glee. We figured that was as good a time as any to try to start talking to her about your situation. The conversation went something like this:

Daddy: You had a great time tonight, didn't you?

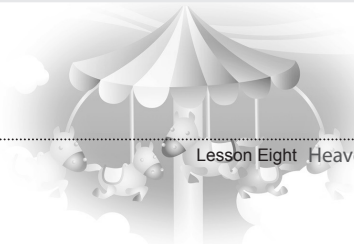
Xin Xin: Yes!

Daddy: Isn't it great that you were able to play so many different games, and then buy such a big bag of candy?

Xin Xin: Yes!

Daddy: There is a place that has more games than you could ever imagine, and so much candy that you could never eat it all! It even has all of your favorite toys. Do you know where it is?

Xin Xin: I know...is it a department store?





Daddy: Hmm... Well, the problem is that a department store cannot stay open all the time. The place that I'm talking about is always open, and you can play as long as you want without having to stop. Can you think of where it is?

Xin Xin: Well, I don't know. I can't think of where it is. Where is it?

Daddy: The place is called Heaven.

Xin Xin: Oh! Heaven?

Daddy: That is where Qing Qing will go after her illness comes to an end. She gets to go there and play all she wants. Amazing, eh?

Xin Xin: Wow! That is amazing.

Daddy: Qing Qing will go straight to Heaven; she won't have time to come to see us first. So, if you ever start to miss her, you will find that she is in Heaven having a great time while she waits for us.

Xin Xin: Oh.

Daddy: Do you think Qing Qing will enjoy that?

Xin Xin: Of course! She will see all of those toys, and be so happy.

Daddy: So, if you are a good girl, one day we will all be able to go and see her. How does that sound?

Xin Xin: Ok!

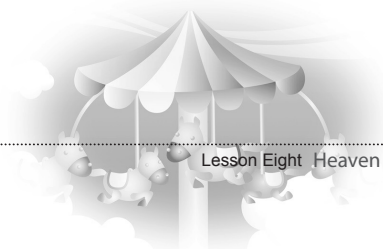
Mommy and I both feel that God sent you to us to help us prepare for the time that we, too, must pass. When the time comes, we will both be so happy to know that we are going to see you again.

We pray for you, and hope that you are as happy as you would be if you were on a fun outing.

Love, Mommy and Daddy

During those last few weeks, we just wanted to make you as comfortable as possible. We whispered in your ear, constantly reminding you that God loved you dearly, and so did we. To tell you a million times was not enough, we wanted to tell you a million and one times just to be sure.

We just prayed that you would be able to pass away peacefully. Unfortunately, the possibility of your death being due to respiratory failure was quite likely; that really would not be a nice way to go. Although the prospect of you having to struggle with respiratory failure weighed heavily on our minds, we knew that there was nothing we could do for you. The best we could do was to offer you our love, and our





Qing Qing wanted to go to a place that doesn't have any suffering; a place that only has merriment, a place called Heaven.

prayers. The rest would be left up to God.

Xin Xin has always been a smart little cookie; a couple of days before you passed, she told me that she was sad because she knew that your illness was very serious, and that you would not be getting better. By that time, Mommy was already very pregnant with your little brother, Zeng Yi. The due date was rapidly approaching. We figured if there was any emergency, we could all ride in the ambulance together to the hospital and then you could be taken to the ICU, and Mommy to the delivery room.



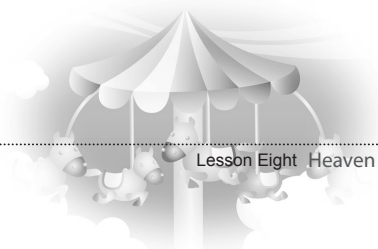
By Your Side Until the Very End

You passed away in your sleep on the morning of December 12th, 2007. Before you passed, your breathing did not become especially labored,

nor did your blood oxygen saturation level plummet drastically. Instead, your heartbeat just gradually slowed down until the very last moment when it stopped for good. We did make a few attempts to suction you, and ventilate you with the Bag-Valve Mask; however, it was clear that we would not get a response. God had answered our prayers. You did indeed leave this world as peacefully and comfortably as one could hope, surrounded by your loved ones.

Once we realized that it was all over, we held you in our arms and wept. It was still going to be difficult to let you go. But we remembered that we still needed to get you to the hospital because the doctors would need to make the necessary arrangements regarding the donation of your corneal, and epidermal tissues. We called the ambulance, and accompanied your body to the NTU hospital.

Xin Xin, who always sleeps very soundly, suddenly awoke and asked where we were going. We told her that you were going to Heaven, and that we wanted to see you off. Xin Xin responded sleepily, and then curled up and fell back to sleep. In just a matter of moments, she was up again; she told us that she wanted to say goodbye to you as well. At first, we were hesitant because we didn't know if she would be able to bear to see you go; however after giving it some thought, we decided that death was a natural part of life and she should be allowed be part of this





A Note From Mommy 2007.4.7

- In order to help Xin Xin understand what Heaven is like, Daddy took her out to have a delicious meal, play all the games her little heart desired at the entertainment center, and then bought her a huge bag of candy. Of course, she was very pleased. Daddy told her that you were going to go to Heaven soon, and that Heaven would be just as much fun as all of those places that they had just visited that evening.
- He told her that Heaven is so wonderful that everyone wants to go there one day. Be brave Qing Qing. We will all meet up again in Heaven.

important event.

Once we arrived at the hospital, the doctors confirmed that you were gone, and allowed us some time alone with the body. You were no longer connected to all those tubes, and machines; your face looked so peaceful. The color had already begun to leave your cheeks, and your skin had a pale luster to it, like smooth, white jade. You were as beautiful as an angel, radiant with a pure heart.

The whole family stood at your side, singing your favorite songs and offering prayers for you. Xin Xin grabbed onto your little hand, and then fell peacefully to sleep in my arms. Although I wasn't able to be in the room with Mommy and you when you came into this world, at least on the day that you left it, our whole family was there at your side. In comparison to the terrifying circumstances that marred your birth, your death was not the horrifying mystery that one might imagine it to be. You

were on your way to a better place.

It didn't take long before the media received word of your passing. That morning, several stations broadcast the story as soon as they had received it. That evening, some of them even put together a memorial video as a way to say goodbye to you. Everyone found it difficult to let go; your blog was bombarded with posts expressing everyone's sadness. There are some people who pass away and never have anyone remember them, but there are also those who have touched the hearts of many, and when they pass, many tears are shed, and many people think about them. In the three short years that you were alive, you were able to live a much more meaningful life than most. You had made a profound impact on a lot of lives.

That evening, we were finally able to get a good night's sleep for the first time in three years; there would be no more unexpected emergencies in the middle of the night. Although we did miss you, what we really felt was relief that you, too, would finally be able to get a good night's sleep. Our feelings sort of swung back and forth. One minute your cute little face would come to mind and we would start to feel an ache in our hearts; the next minute we would think about how everything must have been perfect for you in Heaven, and we would start to feel happy again.

Some people say that it is common to grieve the loss of a loved one for





about a year after their death. There are also those who say that it takes longer. In fact, I feel that since everyone is different, they will all grieve for different lengths of time. Besides, we feel that there is no need to try to standardize these things; when we feel sad and miss you, we cry; we know that this sadness will pass and eventually give way to a deep sense of appreciation. Remembering you will help us to appreciate the rich life that you had, and give thanks for the fact that you were able to return home to Heaven. Sometimes we look back on the suffering that filled the last nine months of your life, and realize that it was one of the main reasons we are now able to look forward to the promise of Heaven.

Zeng Yi's Arrival

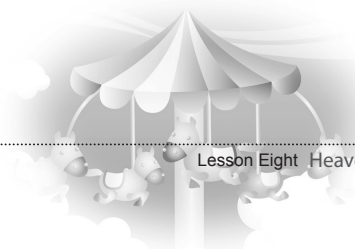
God's plan always exceeds our expectations! The day after your departure, once we all had had enough sleep, Mommy started experiencing labor pains, and your baby brother, Zeng Yi, made his trouble-free arrival. Zeng Yi was born a very healthy little baby. We had guessed that he was going to be healthy by all of the activity that took place while he was inside Mommy's belly. He seemed to be cut from the same cloth as your sister Xin Xin. As opposed to your peaceful, laid-back nature, they were both very lively, and outgoing. When Zeng Yi was born, his cry could be heard loud and clear; Mommy and I could only look at each

The day after your passing, Zeng Yi was born. What a dramatic time that was!



other and smile. That was a time in our lives that seemed to be full of drama! It was clear to us that all of this was part of God's greater plan: You being born on Christmas Eve, and your little brother coming into the world the day after your passing.

Some of the people who were still clinging on to your memory, suggested that perhaps Zeng Yi was a reincarnation of you! This was simply not possible since Mommy was already pregnant with Zeng Yi several months before you passed away. Besides, it was very clear to us that your brother and you were very different individuals, with separate paths to follow. One thing that you did have in common was that you were both our special little treasures. When the day comes that Zeng Yi is old enough, we will definitely tell him about you and your miraculous story. His birth really came at a good time for us; being able to hold him, and put all of our energy into loving him, helped to ease the pain of losing you.





Unwilling to Leave the Classroom

It had been a few days since you had passed, and people were already asking us about organizing a memorial service for you. The thing was, we felt that your life was so special that any kind of ceremony we tried to organize just wouldn't do it justice. The important point was to take what you had taught us, and plant it firmly in our memory. So, we decided to hold a celebration of thanksgiving at the Minsheng Community Recreation Center the following Sunday. We would take the opportunity to share all of your teachings with those who attended. On the day of the celebration, we all became students again. The 600-seat auditorium at the Recreation Center was jam-packed with people; there were friends from church, Internet friends, and media personnel.

Qing Qing, you have already dismissed the class, but none of your

pupils are of the mind-set to have the lessons end. Everyone was still anxious to receive your silent teachings. That Sunday, we all came together and revisited every single one of the great variety of lessons that you had given to us. It was a wonderful experience; we laughed and cried together. We missed you very much, but we also knew that it is not an angel's outward appearance that matters, but the content of her message that really counts. On that glorious day, many of those in attendance received your message, comprehended the deeper meaning of your story, and finally graduated from your class.

Even though the class was over, the classroom was still packed with people.

500 People Signed Organ Donor Cards

Even though the class was over, new blogs were still popping up all



Your brother's birth really came at a good time for us; being able to hold him, and put all of our energy into loving him, helped to ease the pain of losing you.



We held a celebration of thanksgiving in order to share all of your wonderful teachings with others.



over the Web; people were still using your story to touch others' hearts. There were university students who wrote papers about your story in order to offer encouragement to their classmates. There were even teachers who were using your story in the classroom in order to teach their students the importance of being able to cherish all that they had. Mothers also told their children about your unimaginable courage in the face of adversity, in hopes that they, too, would be able to be strong when faced with challenges. Your students had continued to





500 of your students assembled together to register for organ donor cards; they hoped to be as courageous as you had been when it came to making donations to help others.

share your teachings with anyone that would listen; what more could they do?

Approximately one month after your passing, 500 of your students assembled together to register for

organ donor cards. They hoped that when their time came, they too could give up their body as willingly as you did. Actually, the fact that there are so many families who are frantic to the point of not being able to wait for an organ donor, is not a sign that there is a shortage of organs, but rather, proof that people don't understand what really matters in life. In other words, people place more importance on their own decaying body parts than on the life of another individual. This little activity of ours seemed



to be just enough to set the ball rolling. The CEO of one of the Organ Donor Associations here in Taiwan informed us that the week following our activity, their website was flooded with applications for organ donor cards. They were very pleased to be so busy!

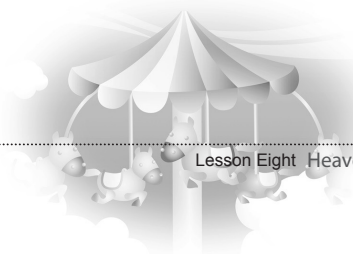
In the end, we decided to have your body cremated, placed in a decomposable container, and buried under a sakura tree in Yung Ai (Chant for Love) Garden cemetery; within a few months after the interment, the remains would be totally decomposed. We decided not to hold a traditional funeral ceremony because we had wanted your death to be treated as a part of our family's natural life cycle. The most important aspect was to allow your remains to return to the earth. The place you were buried is beautiful and very spacious. I enjoy going there to remember you or even to talk to you a little bit. In fact, going to that place also helps to remind me of the impermanent nature of our physical body; whether it is the tissue that you donated to the hospital, or the nutrients that your body is supplying to that cherry blossom tree, they are all symbols of the contributions you have made. In that way, there is no need for us to mourn the passing of your physical body. Whenever I see the sakura blossom, or the crisp, clear sky above, it brings to mind the splendor of your 1000 days on this earth, and of your current, carefree existence in Heaven.

Zeng Qing's remains were buried at the foot of the beautiful number 27 sakura tree in Yung Ai Garden cemetery; her body finally returned to the earth.



Vision of Heaven

I am more confident now than I have ever been that the Kingdom of Heaven is close at hand. Of course, we have always believed in the existence of Heaven, but perhaps because we are still young and healthy, we had sort of subconsciously imagined that Heaven was something away in the distance. It wasn't until we had accompanied you on your short journey that we began to recognize the precarious nature of our own lives; the end is actually not that far off. With that in mind, one's outlook on life becomes totally transformed. It is like being on holiday and suddenly realizing that you only have one day left before the vacation is over. Obviously, at that point you would have a completely different attitude toward the planning of the last day. Suddenly, your priorities become clear in your mind: What sorts of things are of primary importance? Which ones are only of secondary importance? What sorts of things are not worth fretting over at all?





Because of the existence of Heaven, we don't fear the unknown realm that follows death.

Because of the existence of Heaven, we are not constrained by attachment to impermanent phenomena such as the physical body, fame, reputation, and so on.

Because of the existence of Heaven, we realize that the hardship suffered in this life has all been worth it.

Because of the existence of Heaven, we realize that there are more important things to share with one's children than just material objects.

Because of the existence of Heaven, we realize that compared to the eternal, this life is fleeting; instead of wasting time worrying and complaining, we should use our time to do what is important.

Because of the existence of Heaven, we know that those who love unconditionally, and give without thought for recompense, will never lose hope.

Because of the existence of Heaven, we know that we will keep the faith if we have fought a good fight.

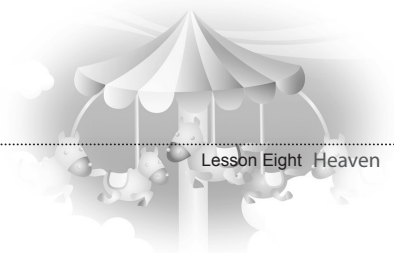
Because of the existence of Heaven, we recognize our faith in God not as a stipulation, but as a cause; a cause that enables us to courageously march onward without fear.

Heaven becomes the hope that can transcend all else. A belief in the

existence of Heaven is not just a way to console ourselves in times of sadness. It is a belief that gives us great strength and transform our lives. In your passing, we were able to feel that strength and experience that transformational power; that is how we came to comprehend the stability and reliability of that belief. This sort of belief functions in a similar way to a rock-climbing coach; the coach first hammers in the pitons to delineate the route, and then secures a safety rope for the climbers. Although the ascent might look dangerous, with the coach's support the climb can actually be safe and very smooth. If we are willing to give it a try, we can even attempt different climbing styles and work our way right up to the summit. A belief in the Kingdom of Heaven can offer that same kind of support as we climb the mountain of life.

In only three short years, you took all of us on such a splendid, worthwhile journey. The climax of the journey, Heaven, also acted as an all-encompassing summary of the many lessons that you had given us along the way. You helped us to understand that everything we had learned in your class eventually pointed to this glorious ending. This understanding has helped us to realize that no matter how much hardship we must struggle to overcome in our lives, the results that we attain are definitely worth the effort.

Dear Qing Qing, thank you for coming to this world to share your





message with us. One sakura tree is beautiful enough. But imagine if our world were covered in massive forests of sakura trees, whenever the wind blew, there would be a sea of sakura blossoms floating through the air. What a magnificent sight it would be!



Reflections on Qing Qing's Lessons

Farewell to Our Little Angel

Birth and Death — the Uncertainty and the
Certainty of Life

Qing Qing's story is not only a touching account of a little angel and her family, but it is also full of loving, compassionate lessons for all to learn from. The first time I saw the Zeng family was at the awards ceremony for the Father's Day photography competition held by the Taiwan Foundation for Rare Disorders. It was on that day that I learned of the story behind the prize-winning photo of Mr. Zeng, shocked, hair a mess and eyelids swollen, holding Qing Qing in his arms. Their story is full of hardship, but also full of love. It was wonderful to see the Zeng Family standing, and singing all together that day: Mommy and Daddy holding Qing Qing while Xin Xin stood at their side. I am no newcomer to the struggle against rare disorders, but seeing Qing Qing and her family that day filled me with a sense of hope and solace that I had never felt before. I truly wish that any family that has to deal with a rare disorder will be able to use the power of love to overcome their hardships, and never allow such difficulties to cause dissent within the family. In attendance that day, there were two brothers who also suffered from a rare disorder, and even had the same surname as Qing Qing.

Ironically, in stark contrast to the love enjoyed by Qing Qing's family, these two boys were actually forced to make an open plea for their father to return home and reunite with the family.

In this book dedicated to his daughter Qing Qing, Mr. Zeng has not only sincerely expressed his love and affection toward his wife and daughters, but also given a clear account of the wisdom he has gained over the course of his three years caring for Qing Qing. Mr. Zeng's love for his family has always been both rational and sincere. This has allowed him to establish clear priorities in his life so that he has been able to love more fearlessly, but also more instinctively. To me, this sort of love may be likened to a set of concentric circles fashioned around a central pillar of faith: The stronger and more solid the central pillar, the more powerful and far-reaching the power of love.

Following one of Qing Qing's dress rehearsals, when faced with the impermanence of life, the youthful Mr. Zeng was able to make a very profound reflection on human mortality. He asked himself, "In what way should life be lived?" In response, he optimistically replied, "[I hope that] my weary old soul would be able to hang on to its beliefs up to the very end when I would have the chance to meet up with Qing Qing again." Realizing the reality of death, Mr. Zeng was able to embrace a life, and love, free of regret. He had found his own happiness datum line within the chaos of his own imperfect existence. He realized that simple but true blessings are those that help to enable profound love, and establish warm, meaningful relationships.





Tirelessly struggling alongside Qing-Qing in the tug of war between life and death, Mr. Zeng spared no effort in his quest to gather information about his daughter's rare disorder. In the face of these mounting challenges, he came to the realization that both time and energy are indeed finite. As a result, he began to jot down the following notion, "Although I would be glad to sacrifice everything just to help you..."; however, as he was writing, he came to the realization that there have always been people throughout the world, just like him, who have felt the desire to devote their lives to help those that they care about. This realization helped Mr. Zeng to come to the following conclusion: Any person who was willing to see life's challenges as learning opportunities would never be alone.

It is true that even though we make great efforts to help our loved ones, there still comes a day when we must say goodbye to them. That parting is not something that we can prepare for. However, what really matters is that we are able to equilibrate our happiness datum line even in the face of life's imperfections. The hardships endured by our little angel Qing Qing have inspired thousands of families to enjoy the happiness of a loving embrace. We even have a wonderful collage, in the image of Qing Qing, made up of those families' hug photos to stand as clear proof of the powerful flow of love in our world. Through the eyes of our little angel, we have come to see the deep meaning of love, and the precious truths of life.

After reading this book, I feel truly indebted to Mr. and Mrs. Zeng

for their willingness, in the face of great despair, to make the effort to share their experiences with us, and to offer us some insight into Qing Qing's short but unique life. Their story helps readers understand how to employ the power of love in order to arrive at the gates of Heaven. Life and death; certainty and uncertainty; hardships and imperfections, these are all integral parts of the human condition. In reality, the drive to face these phenomena head-on is itself the key that opens the gates of Heaven. And, beyond those gates is where we will be reunited with our little angel!

By Serena Wu
Managing Director,
Taiwan Foundation for Rare Disorders



Appendix 1: What is Myotubular Myopathy?

We heard about the illness called Myotubular Myopathy (MTM) for the first time in our lives on February 28, 2005. It was on that same day that our younger daughter, Zeng Qing, began down a new path in her life.

As we searched for more information about the disease on the Internet, we gradually came to learn that this truly is a very, very rare disorder. I was unable to find a single support group related to the illness here in Taiwan. After coming into contact with the Taiwan Foundation for Rare Disorders, we finally learned that in addition to Qing Qing, there were also four male and two female sufferers of MTM in Taiwan; all of them were very young as well.

Myotubular Myopathy, otherwise known as Centronuclear Myopathy, is a rare hereditary disease. It is a congenital muscle disorder that manifests itself as a defect in the cell structure of muscles of the voluntary musculoskeletal system. The disease causes extremely low muscle tone and is usually apparent at birth. Sufferers of this disease often also have respiratory problems and are usually partially or totally dependent upon a ventilator for survival. A normal musculoskeletal cell contains several nuclei, and these nuclei are located at the periphery of the cell. In contrast, in muscle biopsy specimens of MTM patients these nuclei are

often observed to be more centrally located.

MTM may exist in any of four different forms: X-linked (sex-linked), autosomal recessive, autosomal dominant, and non-congenital. Zeng Qing was diagnosed as having the non-congenital type. These different forms of MTM reflect different hereditary patterns and different clinical symptoms.

X-linked MTM is almost exclusively observed in males. It is the most severe form and sufferers of this form of MTM will rely most heavily upon mechanical ventilation. According to a US report published in 1999, with access to proper medical treatment approximately 74% of patients would survive the first year of life, but 80% of those survivors would still be either partially or completely ventilator dependent. Another source indicates that about one half of all sufferers of this disease do not live longer than two years. Curvature of the spine is one complication that may accompany this type of MTM.

Autosomal recessive and autosomal dominant forms of MTM usually present much later in life. The severity of the autosomal recessive form lies somewhere between X-linked and autosomal dominant forms of MTM. The autosomal recessive form affects boys and girls in equal proportion. Unfortunately, the condition does tend to worsen over time. The third form, autosomal dominant, is the mildest form of MTM. In this type as well, the sufferer's condition may deteriorate over time.





Myotubular Myopathy is a disease that arises due to a genetic defect that has either been passed along hereditarily or comes into existence as the result of a genetic mutation. Due to the fact that this is a genetic disorder, there is no known cure at the present time. Yet, with the proper care, sufferers may still be able to grow up and lead a somewhat independent life. There are some countries in which there are success stories. Since brain tissue does not consist of muscle cells, the intellectual abilities of MTM sufferers are not affected by the condition. In addition, as a result of the MTM sufferers' inhibited mobility, they may tend to focus more attention on scholastic pursuits rather than sports and the like, and therefore quite often will excel in academics. Obviously, if a tracheotomy is carried out, the sufferer will more than likely lag behind in the area of linguistic development. With respect to communication, it is advisable to teach young MTM sufferers to communicate with sign language even before they are old enough to talk. Language therapy techniques are also helpful in strengthening facial and throat muscles.

Appendix 2- Support Groups and Research Organizations

I. Taiwan International Churches of Christ

<http://www.taiwanchurch.tw/>

This is the church in which the author, Kevin Zeng, serves as an evangelist. Taiwan International Churches of Christ is an organization made up of Christian followers who are passionate about life and the Truth, as well as being devoted to spreading the Word of the Gospel. With the Bible as foundation, this organization adheres to the principles of Faith, Fun, Family and Friendships, in order to grow, learn, and face life's challenges together.

II. Taiwan Foundation for Rare Disorders (TFRD)

<http://www.tfrd.org.tw/>

As the name suggests, rare disorders are those illnesses that are extremely rare but at the same time may exist in any number of forms. Very few people ever actually contract these illnesses, but those that do, require many different kinds of treatments, or support. According to current medical understanding, the majority of these disorders are caused by genetic defects. These defects may be inherited or may arise through genetic mutation. In some cases the causes are, to date, still unknown.



At present, the TFRD offers assistance to sufferers of approximately 204 different kinds of rare disorders. In Taiwan alone, there are close to 5,000 individuals suffering from rare disorders. Ms. Serena Wu and Dr. Min-Chieh Tseng, both of whom have had a family member suffer from a rare disorder, established the TFRD in 1999. Starting from very early on, the TFRD advocated the passing of bills ensuring equal rights, as well as financial assistance for sufferers of rare-diseases. More recently, the TFRD has set up new offices in both central and southern Taiwan in order to offer local support and services. The TFRD has tried to establish a holistic aid-network that includes physical, psychological, and spiritual forms of support. With the help of all members of society, the TFRD hopes to establish a nationwide support network in order to offer as much assistance as possible to Taiwan's numerous sufferers of rare disorders.

Please feel free to contact the TFRD. Any contribution would be greatly appreciated, and truly bring a new ray of hope into the lives of those who suffer from rare disorders.

Tel: +886-2-2521-0717

Remit money Chunghwa Post

Taiwan Foundation fro Rare Disorders

19343551

III. Support Groups for Sufferers of Rare Disorders

- **Myotubular_Myopathy**

http://health.groups.yahoo.com/group/Myotubular_Myopathy/

This is a support group that was established on Yahoo!Group by an individual who was also diagnosed with MTM. There is a lot of interaction and exchange that takes place between the members of this site. In order to join the group you need to have a Yahoo account.

- **The Information Point for Centronuclear and Myotubular Myopathy**

<http://centronuclear.org.uk/>

Set up in 2001 by a group of rare-disease sufferers and their families, the site abounds with useful information.

IV. Research Laboratories

- **Children’s Hospital Boston;** laboratory under the charge of Dr. Alan Beggs.

http://www.childrenshospital.org/cfapps/research/data_admin/Site1694/mainpageS1694P0.html

- More information about **Dr. Alan Beggs:**

http://www.childrenshospital.org/cfapps/research/data_admin/Site122/mainpageS122P0.html





- **Myotubular Trust**

<http://www.myotubulartrust.com/page4.htm>

Most of the research sponsored by the Myotubular Trust has been under the charge of Professor Francesco Muntoni of Pediatrics and Child Health at Imperial College in London.

V. Foundations

- **Joshua Frase Foundation (JFF)**

<http://www.joshuafrase.org/>

This is a US-based foundation that sponsors MTM-related research.

- **Myotubular Trust**

<http://www.myotubulartrust.com/>

This is a UK-based foundation that sponsors MTM-related research.

VI. Websites of MTM Sufferers

- **Andre**

<http://centronuclear.org.uk/>

- **Kaylee**

<http://www.caringbridge.org/cb/viewHome.do>

This is a girl who suffers from the autosomal dominant form of MTM.

Fragile Yet Strong

The 8 Lessons that Qing Qing Taught Me

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