



## A Letter from Mommy to Qing Qing Learning to Have a Simple Heart

Dear Qing Qing,

Mommy thanks God that I have you in my life just as I thank God for your father, brother and sister, Grandparents as well as all of our friends from church.

The love present in these relationships has enriched our lives and helped us to better appreciate God's love.

From you, Mommy has learned what it means to have a simple heart. You never felt you lacked anything in life. When you were able to move your little hands you would happily play with your toys. When you could open your eyes and watch your little TV set, you would be absorbed in watching your favorite programs over and over again. When someone paid attention to you and played with you, you responded happily and tried hard to express yourself. When you were able to go out, you observed this beautiful world with curiosity. You twisted your body and clapped your hands, determining to fully enjoy all that you were capable of doing. In illness, you shut your eyes tightly and bore the pain; only occasionally giving way to tears in order to release the sadness. Even when you experienced extreme discomfort, you were still mostly silent once in a while, you got annoyed and cried until your little face went completely red. However, the most important thing is that in every moment of your life God was with you. He

not only celebrated the beauty of life with you but also bore the pain of illness with you. He was there to comfort you as well as to cheer for you.

My dearest Qing Qing, you were a precious gift that Mommy initially opened with a hint of fear and trepidation; but I have truly savored this gift. It has been full of life's mysteries, making me stand in awe time and time again. Thank you Qing Qing, and much thanks to our Heavenly Father.

*Love, Mommy*



A drawing from Zeng Xin to her baby sister, Zeng Qing, titled “Our Family-Mommy, Daddy, and Xin Xin”. Xin Xin explained, “Each of us has a heart full of thoughts for Qing Qing.”









## A Letter from Mommy to Daddy You've Given Us Your all

Dearest Kevin,

I understand better than anyone how much you truly love Qing Qing. While fulfilling your obligations as a husband, a father, a priest, and a graduate student, you were still able to give everything possible to our family and to Qing Qing.

When Qing Qing was born, you were the first to look upon her adoringly, and touch her tenderly through the glass walls of her incubator. During our stay in the hospital, you listened attentively while the nurses taught us the techniques necessary for the care of our little girl. After Qing Qing had been diagnosed with Myotubular Myopathy (MTM), you scoured both local and foreign websites alike in order to find information about the disease. It wasn't long after Qing Qing came home from the hospital with us that you thought up the idea of modifying a car, fitting it with an oxygen unit, a suction unit, and a power wheelchair, so that you could take her along with you wherever you went. Whenever she was unable to sleep, even though you were busy working on your thesis, you would still keep her company through the night and into the wee hours of the morning. Each time our little girl had to be rushed to emergency, it was always you who held her tight, anxiously listening to the sound of the ambulance's siren on the way to the hospital.

You always had so many creative ideas to make Qing Qing laugh and wiggle

her body around merrily. I think that's why her eyes lit up whenever she looked at you. In the end, when Qing Qing's body only had enough energy to produce a feeble little heartbeat, you were the one who changed her for the last time, patted her head, sang her favorite tune, and told her that she was brave and that we all loved her very much.

Qing Qing was so blessed to have you as her father.

Furthermore, I know that during that time when you gave us your all, it was God who was behind you and gave you strength.

*Love, Nadine*





## Fragile Yet Strong: The 8 Lessons that Qing Qing Taught Me

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## A Letter from Daddy to Qing Qing The End Is Just Another Beginning

Dear Qing Qing,

The bell has tolled to signal the end of class. Yet, I do not want to leave the classroom.

I really wish you could stay, that you could continue to teach us with your silent presence, and help us to better understand the value of life, and the power of love.

Even as the impression you had made was still warm in our hearts, and we waited expectantly for the next amazing surprise you would offer, the lessons suddenly ended. This gave us pause. I raised my hand to ask you one last question, only to see that you had already, resolutely and gracefully, moved on. As I watched you leave, I could only wish that this class had never ended.

Is this the end? Does this mean that we have mastered the lessons? You've spent your short, difficult little life painstakingly teaching us and guiding us; I can only assume that you wouldn't want us to merely nostalgically think back on the good times that we had together, and passively accept our lot. I realize that you would have wanted us to continue on, to access those cherished memories: you teaching us how to live, how to feel alive, and how to see a glimmer of sunshine in every rainy day. None of us can claim mastery of these lessons, which you have so caringly offered us, until we have earnestly organized our notes, and used this information to create meaningful change in our own lives.

I want to thank you for everything that you have taught me over the course of these three years. Looking back on this huge classroom that we shared together, Mommy and Daddy were so lucky to have the best seats, right in the front row. We were able to observe your graceful character right from the very beginning. As the class went on, more and more people joined, and felt the deep resonance of your life force. These new students would sit beside us, behind us, and even far in the back row where we couldn't see them clearly, but we could still hear the sound of more and more of them coming in to take a seat and join the class. We smiled together, wept together, and even applauded together. I have never attended a class like this before, classmates of all different ages, occupations and social standings; they were all brought in by the power of your radiant tranquility.

You were such an enthusiastic teacher. You taught us so much in such a short time. How can I ever repay you?

Now you lay beneath the sakura tree, nurturing the earth with your presence. In Daddy's mind, the sakura is more than just a flower; I stand before it and ask myself, "How can I possibly complement the richness of your existence?" If a picture is able to capture the beauty of the transient blossoming and falling of the sakura flower, then by what means should we try to capture the essence of your three short years with us, in order to ensure that it will be imprinted in our hearts forever?

I decided not to waste my wonderful seat in this grand classroom, but instead use it as a place to organize the notes that I have collected over these years. I hope that one day, even although class is no longer in session, if an interested





student comes to read about your teachings, he or she will have the opportunity to see what I have seen, hear what I have heard, and feel what I have felt; In this way, this student will be contented, carry your story forward in their heart, and continue to learn from it.

My dearest Qing Qing, I truly wish that we may meet again one day, and on that day, this book will be my gift to you. In return, I only ask to see your smile, which I have yearned to see, and hear your little voice whisper the word Daddy into my ear, for that is something that I have never had the pleasure of experiencing.

---Your Loving Father

## Preface by the Editor

### Taiwan Foundation for Rare Disorders

The Chinese version of the book, published in 2008, was originated from a blog of a father who simply wished to share what he learned through the life of his brave little girl- Zeng Qing. Qing was born with a rare disease named Myotubular Myopathy, but demonstrated an excellent material for life education for all.

As a pastor, Kevin Zeng, the author and Zeng Qing's father, believes no matter sick or healthy, Zeng Qing is a gift from God. Before Qing was born, he and his wife, Nadine, had already prepared a 100% love for her. Therefore, shortly after Zeng Qing's diagnosis was confirmed, Kevin created "Fragile Yet Strong" blog on March 1st, 2005. The purpose of the blog was to share every piece of medical information of the disease he translated from English into Chinese for other people in need. More importantly, it was to keep a record of what they have said or done with Zeng Qing since she was born in the hope that one day she could see how important and beloved she is to them herself, and she could tell her own story in her unique way.

Unexpectedly, the story touched thousands of hearts of Taiwan people, which attracted a large number of visits on the blog and caused extensive response among online community. Mass media including newspapers, magazines like readers digest, and even TV shows, both religious like Good TV and nonreligious ones, were competing to report her story. As the result, Zeng Qing's story was edited and then published by Common Wealth Magazine, one of the biggest







magazine companies in Taiwan.

For the foundation, Qing Qing's story, on one hand, is just one case of rare disease family of the many, but on the other hand, portrays all the worries, anxiety and problems that a rare disease family go through.

Ever since the Foundation was established in 1999, ten year has past. Looking back, we have put much effort on advocating patients' rights on both medical and social welfare provided by the government. With the advancement of laws and medicine, we are glad that many rare disease patients' lives have been improved greatly. Nevertheless, for the general public and each rare disease family, there are much more to do. Having a rare disease baby has always been a shock and brings extraordinary change to a family, both psychologically and socially.

In the Zeng's case, it's the love of God that helped the family go through the hard time and even transform what normally perceived as obstacles into a blessing. As Kevin Zeng quoted, "There is no fear in love. But perfect love drives out fear, because fear has to do with punishment. The one who fears is not made perfect in love." Whether believers or not, we believe that in love, families are able to conquer difficulties derived from diseases. This book defined the happiness, "as long as we are able to give, we are people of happiness." The imperfection is a necessity to remind us that love should flow between us, so that everyone of us is able to embrace and give love.

Therefore, we believe Qing Qing's story provided an excellent life education material for public education that how we see and interpret disease and death have greatly affected our attitude and ways to deal with it.

## About the Author

Kevin Zeng was born in 1974. He studied Geology, Sociology, Surveying Engineering in the top universities of Taiwan, and he has a master degree of religion study. He married Nadine in 1996 and they had three children Zeng Xin, Zeng Qing, and Zeng Yi. Kevin is a minister of Taiwan International Churches of Christ. He is also one of the ambassadors of Taiwan Foundation for Rare Disorders and was selected Taiwan's 100 Educators in 2006.

After the story of their family was spread out by mass media, Kevin was then often invited to give inspiring speech to different churches, schools, and cooperations. His blog which recorded the growth of Zeng Qing had already attracted more than 2 million viewers from all over the world. The name "Zeng Qing" was rated one of the 2007's top searched keywords by Yahoo search engine in Taiwan.

They are now living in Hsinchu county in Taiwan.





## About the Cover

In April 2007, Kevin proposed an entirely new way for people to offer support and encouragement to Zeng Qing. He suggested that whenever anyone felt the urge to give Qing Qing a hug, they should, instead, use their energy to give their own loved ones a big hug.

Kevin then invited everyone to upload pictures of themselves hugging their loved ones. These pictures would confirm that they had indeed acted on their initial urge to express concern for Qing Qing. Within only two weeks of initiating the photo-post activity, he had already received about 1900 photos from all over the world. He took those hug pictures and created a collage in the image of Qing Qing's face.

“There were those that could not comprehend why a beautiful little angel like you would be chosen to shoulder such a heavy burden. But who ever said that life was supposed to be perfect, and why are we so unwilling to accept the fate that we have been given? The fact that God has allowed imperfection, and suffering, to exist in this world is not because He enjoys seeing people suffer. Rather, He knows that without these forms of hardship there would be no need for the flow of love. Take for example the existence of a poor, broken-winged angel like yourself; if not for your presence in this world there would never have been the need for all the love that has been spread in your name. Even the collage that was created in your honor would not have ever come into existence, if not for the fact that you suffered from such a rare illness as MTM.”

--Kevin Zeng

Class Notes

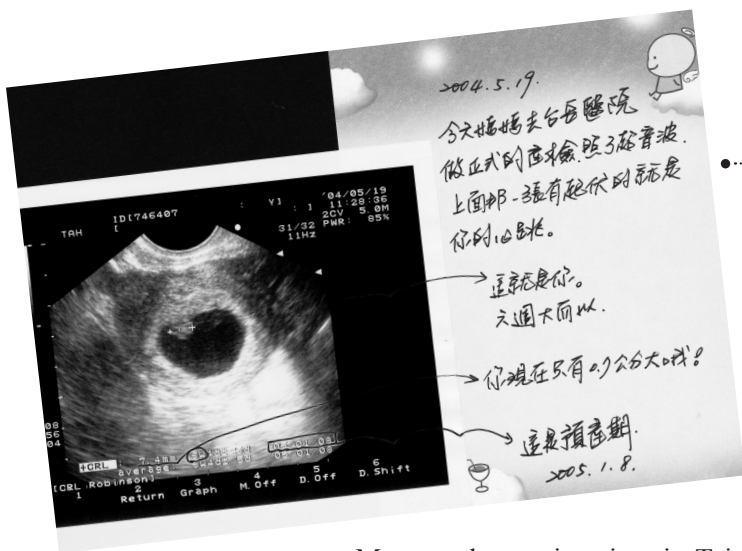
## Lesson One

# Preparation

Three out of every one hundred children are born with some form of congenital disorder. Instead of waiting in fear, and hoping that your child will be one of the lucky ninety-seven percent, it is much better to decide that whatever happens, as a parent, you will always give your child one hundred percent of your love.







You appeared as a small bright spot on the ultrasound monitor; it was enough to make us feel endless joy.

May can be a rainy time in Taipei. It is usually quite inconvenient to go out and run errands, but we couldn't wait any longer. We rushed to the nearby obstetrics clinic because we wanted to check for sure that you were coming.

You have a very cheery big sister Zeng Xin. The pronunciation of her name sounds very much like the Chinese for "True Heart." Just as her name states, she is a sweet and truly genuine little girl. She has never hidden her emotions; it is easy to know from quite some distance whether she is happy or upset. On this particular day, her mood was especially good, even inside the clinic she was bouncing about almost as if she knew of your arrival before we did.

The doctor held up the ice-cold ultrasound sensor and slid it back and forth across Mommy's tummy in order to find out where you were. And there you were! You appeared just as a small bright spot on the



ultrasound monitor, but it was enough to make us feel endless joy. We knew that it was still early and that there was still some time before we would be blessed with your presence. So on our way home we asked God to bless you and to help prepare us for your arrival.

A week later, we went to a larger hospital for a more thorough prenatal check-up. This was the hospital where your big sister was born. The doctors there are good and they all know us fairly well. Mommy and Daddy thought that this would be the ideal environment for your birth. This time around, Mommy was able to see all 0.7cm of you, and even hear your little heart beat through one of the instruments in the examination room. The doctor predicted January 8th, 2005 as your arrival date.

Mommy and I offered each other encouragement saying, “January is a good time to have a baby. The weather is cooler, so carrying around

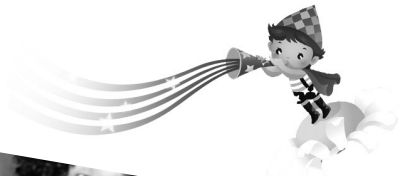
### *A Note From Mommy* 2004.5.14

Today, Daddy, Xin Xin, and I paid a visit to the obstetrics clinic. The doctor confirmed that I am, indeed, pregnant! We were very excited to hear the news, but not totally convinced it was true until the doctor found you with the ultrasound machine.

all that extra weight won't be so exhausting." We also reminded one another, "The second time around will be easier." After all, natural childbirth can be a real battle against pain. Along with the joy and excitement of looking forward to bringing a new life into the world, Mommy still remembered the pain of her first childbirth, so it wasn't easy for her not to feel a little nervous.

## **The Idyllic Bliss of Having a Large Family**

Mommy and I both love kids. Some people can't stand kids running and jumping around, but we feel that the lively image of a big family with many little faces huddled around the dining room table, all eating together, really warms the heart. I also really enjoy the idea of the entire family piling into a big station wagon and going out for an adventure, with me at the helm in charge of ensuring that all you little munchkins laugh and have fun. I have always believed that is how our life will look ten years down the road. We don't need to eat the best cuisine or drive the best car to be happy. We may not be able to afford all the material comforts that we desire, but that's ok because we can still come up with some creative solutions to make things fun; it's more fun that way anyway. Moreover, kids shouldn't just have everything handed to them on a silver platter, it is important to learn to appreciate the contributions



Zeng Xin as a flower girl at a friend's wedding. She insisted on wearing the afro-wig so Mommy and I accompanied her in this photo.



of others. This type of situation can really help children to develop and grow into good people. Mommy and Daddy often feel that although having more children will mean more work, it also means that there will be a greater sense of companionship and even more happy memories to share with each other. These glorious memories may actually be seen as the best form of nourishment.

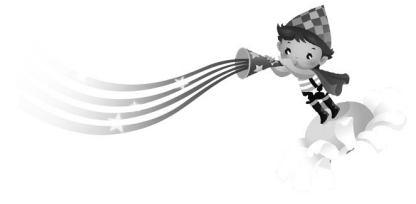
I have always been the idealist, while Mommy has taken on the role of the more practical partner. Of course, Mommy is the one that has to really take care of you. She has to do a lot more of the diaper-changing work than I do! I look after all the fun stuff. I get to eat with you, play with you, and when appropriate, even share the occasional heart-to-heart with you. In other words, I get to take care of all the good stuff! In fact, the most difficult job is that of the woman who stands behind and supports a



Daddy, Zeng Xin, and  
Mommy (pregnant with  
Zeng Qing)

successful man. One day when all of these dreams of a big family come to fruition, we can all agree that the one person who should be allowed the loudest cry of joy should be the one who has contributed the most to this family, Mommy. Of course, I, in my role as head of the family, will offer words of praise and encouragement. Not any great truths about the nature of the universe or anything, but just a ‘very good, very good’ here and there to maintain harmony and preserve a Father’s not-so-important face.

We have been told that raising a child could cost a fortune because of the high cost of education nowadays. However, some of my good friends were brought up in families that didn’t even have the financial resources to pay for their children’s schooling. Some of them were unable to continue their education, while others had to find part-time jobs to help pay for their studies. But in the end, through diligent hard



work, they all eventually found their own path and achieved success. These kinds of hard-working people have a great outlook on life, the sort of attitude that money can't buy. I feel that if we were to give you everything you wanted on a silver platter, then we would be taking away your opportunity to grow and to learn about life.

Over the past several years, the birth rate here in Taiwan has continued to drop. Many people are scared to have children. For some, it is the concern over economic issues, for others it is the unsatisfactoriness of the current social environment. There are even some who feel that having children would infringe upon their freedom. Many people even mentioned to me that they just don't know how to prepare for the arrival of a new little person in their life.

Of course, financial stability is an important factor. But many people who are financially stable forget that the love and energy that we give to our children is much more important than the amount of money that we spend on them. After all, it takes a life to create a life. Qing Qing, your birth brought big changes to our life. Our finances definitely felt the strain, but you also helped us to realize that what's really important is spirit — the spirit to help us understand how to allow the inherent radiance of a life to fully blossom.

## Preparing 100% of Our Love

While at the hospital with you, Mommy and I saw many heartbroken parents. Few parents are able to prepare themselves for the fact that their child might be born with some unexpected congenital disease. We hadn't considered it either. Who could have known that you would be born with a rare congenital disease? There is no history of this in our family, not even a premature birth. None of us could ever have imagined that this rare disease, which only occurs in one of every ten thousand births, would be yours to suffer.

“Please, just let my baby be healthy”, this was the sort of despair that could be seen on the faces of many of the parents waiting at the side of their baby's sick bed. Later, we learned that three babies in one hundred are born with some form of congenital problem. That number is not low. It is actually quite shocking. Whether it is accurate or not, I don't know; but I do know that each of us has our own imperfections, for some it is a health issue, for others it may be personality related. Instead of waiting in fear, and hoping that your child will be one of the lucky ninety-seven percent born without a congenital disorder, it is much better to decide that whatever happens, as a parent, you will always give your child one hundred percent of your love.



Qing Qing, you have led us down a new and completely different path. Actually, all new babies bring changes to the family, because you are not just a piece of luggage that Mommy and I have brought along on our journey, but a precious little travel companion with whom we will compose the story of our lives. Of course, each new baby will not be exactly what Mommy and Daddy expected. Therefore, aside from financial preparations, parents must also clearly recognize that each little baby has its own spirit. Mommy and Daddy must also prepare that precious love that will provide the best environment for your soul.

After thinking about it for some time, I have begun to realize that there is no need to worry about the problem of finances. If the dinosaurs in *Jurassic Park* were able to survive because Nature finds a way, then it must be true that God looks after all of His living beings who he cares so much about.

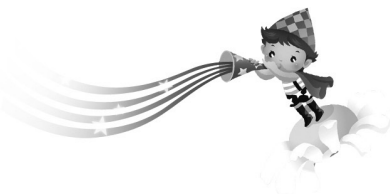
All of these issues were running through our minds while we watched that little bright spot on the ultrasound monitor gradually grow and grow. We wondered to ourselves, “God has chosen us to be your parents, but what is it that we can give to you?” People say that parents always raise the first child by the book, but that the second child more or less raises herself or himself. Although we had already gained lots of experience raising your big sister, and it would seem that we wouldn’t need to think



too much when raising our second child, we feel that you and your sister are really two different children and therefore you will both be able to teach us very different lessons. As we expected, you two were not only different, but very very different.

## **The Zeng Sisters: True Heart and True Love**

Whether you were going to be a boy or a girl, we were going to love you just the same. When you were still inside Mommy's belly, at about twenty-four weeks, we found out that we were having a girl; we were so happy! One reason is that it would allow us to save some money on baby clothes and baby-room decorations. Your big sister's old things would be perfect for you. I know that this doesn't seem fair because the new baby sister gets all the hand-me-downs instead of her own new things, but we still needed to be practical. We needed to have enough money to keep you in diapers. Growing up in the church you would always have friends to care for you and give you toys, clothes, and even a crib. We often shared things that we did not use anymore with others and they shared their things with us. The happiness that comes from this kind of sharing is really better than that which can come from buying a bunch of new stuff. Not only that, exchanging toys with the other families helps to save money and it allows everyone to enjoy the feeling of having a something new.



Zeng Xin ready to be the big sister! She would no longer allow anyone to call her little sister because now, thanks to you, she would be elevated to the status of big sister.

Now that we knew you were going to be a little girl, we began to call you by your new name, Zeng Qing. We had chosen this name even before your sister was born. In our family, we always try to choose names that carry a special meaning. Our family name is Zeng, which sounds quite similar to another Chinese word, Zhen, which means true or truly. Therefore, our friends would often suggest baby names such as: Zeng Li Hai (sounds like “Truly Formidable”) or Zeng You Qu (sounds like “Truly Fascinating”). Mommy and I felt that these types of names didn’t really warrant much attention and could easily be crossed off the list. We wanted to choose a name with only two characters in it so that it would be simple yet powerful. Again, our friends came up with suggestions such as: Zeng Guo (sounds similar to the Chinese name of the Japanese coffee shop chain Kohikan), Zeng Long (sounds like dumpling steamer), and Zeng

Jiao (sounds like steamed dumplings). But again we didn't feel that we could use any of these either. Our friends really were helpful; by listening to their suggestions, we at least knew which names not to choose! We didn't want to burden you with a name that would allow your classmates to tease you. If they did tease you, it would be all our fault. Letting others have a bit of a laugh is one thing, but it just wouldn't be worth it if this were to hurt your self-confidence or affect our precious father-daughter relationship.

In the end, I proudly told Mommy that you two should be named Zeng Xin and Zeng Qing (similar in sound to the Chinese "True Heart" and "True Love") because these two names were perfect for our family. Of course, your big sister took the first name and you the second. Both names fit perfectly with the spirit of our family, true heart and true love.

The following few times that we visited the hospital for the pre-natal check-up, we were able to hear your little heartbeat and the doctor assured us that all was well. The doctor usually asks if the family wants to do a genetic screening test. But after helping us with your sister's birth, the doctor knew quite clearly what our beliefs were, so she didn't bother to ask this time around. Mommy and I both felt that no matter what the circumstances, we would have our baby and we would love and nurture our child as best we could. Frankly, even if the doctor did



ask us if we would like to do a genetic screening test this time around, we still would have given her the same answer. “No”. Even if we would have done the test, the disease that you were born with would not have shown up anyway and the results would have indicated that you were completely healthy. The disease that you have is so rare that most genetic screening tests are unable to detect it.

As you grew inside Mommy’s tummy, she began to sense that you were different from your sister. When your sister was about thirty weeks, I would often get up close to Mommy’s tummy and play with her. She was always dancing around in there. I used to joke that Mommy had an alien growing inside her tummy and then I would shout and tap the little hands and feet that were bumping up against the belly. On the other hand, you were very different. Mommy rarely felt you moving and I seldom had the chance to play with you as I had with your big sister.

### *A Note From Mommy* 2004.12.10

During the latter part of my pregnancy, I have started to notice that you don’t kick, or move, much at all; you are very quiet. I am often concerned as to whether or not you are all right in there, but thanks to the ultrasound machine we are able to hear your heartbeat whenever we visit the obstetrics clinic. Aside from the odd kick here and there, that is the only reassurance we have.

We just thought that since your sister was so animated all the time, maybe your personality was different from hers, maybe you were a very peaceful, good tempered little girl, like the kind that would grow up to wear her hair long and play the piano. Because we felt that way, we didn't really pay too much attention to the fact that you weren't moving around in the womb. Moreover, the doctor assured us that every child was different and that the fetal movement would vary between children.

It didn't seem that it was anything to worry about. We were just content to look forward to your arrival. Even your big sister was ready for your arrival. She would no longer allow anyone to call her "little sister" because now, thanks to you, she would be elevated to the status of big sister.

Class Notes

## Lesson Two

# Acceptance

The bad news: our hope for your speedy recovery  
had been shattered. The good news:  
we finally knew what you were up against and we  
would no longer just be swinging blindly  
in the dark.





For several Christmas Eves running, my church would move out of doors in order to enjoy the spirit of Christmas together with the citizens of Taipei. When I say that we moved the church out of doors, I really mean to say that we just assembled outside. In fact, we didn't have an actual church building of our own yet. Based on the number of attendees we would just rent different types of locales to function as an assembly hall. Even so, we still wanted to give everyone the opportunity to experience the feeling of a non-commercialized Christmas. After all, the real meaning of Christmas is not about getting presents from Santa, but about celebrating the birth of Christ and allowing God's love to thrive inside of each of us.



Christmas 2004, we decided to celebrate together with the sea of people at the packed Mitsukoshi plaza in front of the Taipei train station. We constructed a temporary church; it had a stage and everything. The participants on stage sung hymns, while the audience followed along waving beautiful candle lit glasses to the sound of the music. Every hour

Christmas Eve 2004, we decided to celebrate together with the sea of people at the packed Mitsukoshi plaza in front of Taipei train station. We constructed a temporary church outside. Everyone sang Silent Night together; it was a glorious scene. Although it was a chilly evening, the atmosphere was still intoxicating.



on the hour, we would all come together, with the candles in hand, to sing Silent Night. It truly was a glorious sight. I remember that evening was quite chilly, but the atmosphere was intoxicating.

Unfortunately, I was unable to really enjoy the moment because I was in charge of the event. Aside from arriving early to ensure that the program and facilities were all in order, I also had to run back and forth between the stage and the audience viewing area in order to ensure that everything was going smoothly. I also needed to ensure that the media crews covering the event, as well as the special guests in attendance, were well taken care of. On top of all this, I was also keeping an eye on Mommy because earlier that day she had started to feel labor pains, indicating that you might arrive early! Daddy just prayed to God, who we all know is in charge of time, that everything would go as smoothly





as possible.

## Sweet “Little Money Saver”

The intermittent labor pains were the signals that you and Mommy used to co-ordinate the time of your birth. They also allowed Mommy’s body to be ready for your arrival. That night, amongst the noise and excitement of that outdoor venue, you must have slept well, since the labor pains were not all that frequent. As you got older, growing up in the church, you were used to the sound of a large group of people and it never really bothered you. Your big sister, who always gets excited around crowds, was no problem that evening either. She spent the entire evening just happily enjoying the program, not giving us the slightest bit of trouble.

After the evening’s events had finished, it seemed like you had woken up, because you began to let Mommy know, through the labor pains, that you were on your way.

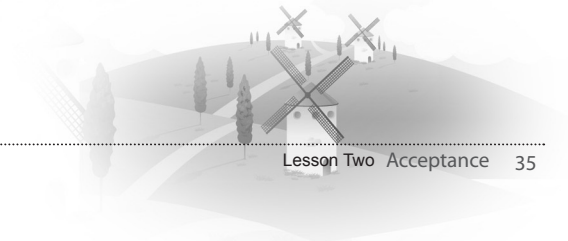
I asked one of the friends from church to help wrap up the event, while I rushed your big sister home to stay with Grandma and Grandpa. We packed a simple overnight bag, and I drove Mommy to the hospital. On the way to the hospital, Mommy and I discussed how the timing was unbelievably perfect, and we thanked you for being so thoughtful as

to allow us to first finish the evening’s festivities before heading to the hospital. I told Mommy that we should give you the nickname “Truly Dutiful One”. Mommy laughed, and agreed that you really would be a dutiful, precious little Christmas baby.

When we arrived at the hospital, the nurse helped Mommy to lie down on the bed in the labor room, and then proceeded to hook up the fetal heart and uterine contraction monitor. The sound of your little heartbeat through the amplifier sounded so crisp and clear. Mommy was in a bit of discomfort, but since it was her second childbirth, she was in good spirits and fairly relaxed. In between the labor pains, Mommy was even able to chat and joke with the nurses. I stopped worrying now, and went to arrange for a hospital room for Mommy and you. The nurse informed us that since it was already past midnight we would save one day’s ward fee. Once again, I joked with Mommy that your nickname should be “Little Money Saver”, we both laughed together while we contently awaited your arrival.

## **The Joyous Atmosphere Suddenly Turned Cold**

When your big sister was born, I was by Mommy’s side the whole time, offering encouragement and video taping the entire event. Of course, this time I also changed into the surgical cap and gown, being





ready to witness this exhilaratingly moving event for a second time. However, as the birth drew nearer, the sight of Mommy sweating and trembling in pain made me pretty nervous; but this nervousness was nothing compared to shock that the following words brought us.

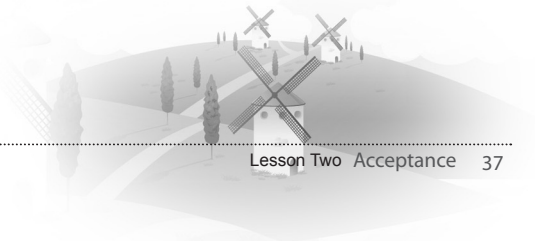
“How can it be the bottom?” exclaimed the nurse while she felt for the baby. She felt your bottom instead of your head. Coming out bottom first was dangerous. The doctor might have decided to do a Caesarean section if you had not entered the birth canal yet. Voices shouted, “Where is the doctor?” “Get on the phone and ask her to come over right away!” “Hasn’t the doctor arrived yet?”

There was no time to think. I could only wonder whether or not there was really a serious problem with the birth. All at once, the joyful atmosphere just iced over and the whole delivery room began to feel cold, freezing our minds and just leaving a tiny space in which to envision both Mommy and you safe and sound. The time too seemed to be frozen solid, passing painfully slowly. The doctor was to arrive immediately, but it felt like an eternity.

The doctor was very confident, acting swiftly. It seemed that maybe Mommy and I were overly concerned over this small hiccup. The doctor comforted us a moment, and then told me that I would not be able to be in the delivery room this time. Then the doctor and the nurses pushed

Mommy into the delivery room. I was alone in the labor room, still pretty shaken up, with the surgical cap and gown, and the reverberating sound of Mommy’s cries. I tried to force myself to calm down, hoping that everything would be all right, but I couldn’t restrain myself from trying to listen in at the delivery room door in order to get some sort of reassurance that all was well. I stood in the corridor looking up and down at all the delivery room doors, unable to be sure which of the rooms belonged to Mommy and you. I returned to the labor room and continued to pace back and forth.

I knew that at a time like this, the best thing to do was pray. Although it was already past midnight, I knew that our good family friend Steve, who always had such strong faith, would still be awake. Steve was the head pastor of our church at the time, and he always looked after me. I called and asked him to pray for you. After hanging up the phone, I got down on my knees and prayed to God. At the time many different passages from the Bible came floating into my mind: “The Lord is at hand; do not be anxious about anything, but in everything by prayer and supplication with thanksgiving let your requests be made known to God. And the peace of God, which surpasses all understanding, will guard your hearts and your minds in Christ Jesus” (Philippians 4:5b-7), “For I know the plans I have for you, declares the Lord, plans for welfare





and not for evil, to give you a future and a hope” (Jeremiah 29:11), and “What no eye has seen, nor ear heard, nor the heart of man imagined, what God has prepared for those who love him.” (1 Corinthians 2:9) These passages, as they have in the past, comforted me and helped me to realize that no matter what happens, everything is in God’s hands.

What else could happen? I asked God to make all of this go away, and hoped that it was just a false alarm. But what if something serious were to actually happen? I knew that if something was going to happen, I just hoped God would still reveal His glorious decree to us.

While I was praying, a noise started to come from the otherwise peaceful corridor area. It sounded like someone talking on the telephone. It sounded like the nurse reporting to someone about the circumstances of the birth. From off in the distance, I could only roughly make out that Mommy was fine but that you were experiencing difficulties. It was something about you not being able to cry. Later I would find out that they were talking about some index of childbirth and that they were in disagreement about how it related to your birth.

A baby unable to cry at the time of birth, what did that mean? Did that mean you were born mute? I had no idea. All I could do was to continue my prayers. I am unable to remember many of the details of that confusing time, but I do remember that I realized that regardless of

## *A Note From Mommy* 2004.12.25

In the delivery room, after I had given one last, big push, and could feel that you had finally arrived, as I was just about to lay back and take a well deserved rest, I realized that something wasn't quite right: The room was too quiet! The doctors and nurses were trying to get you to cry but you did not make a sound! I became very concerned. As I was wheeled out of the delivery room, and caught a glimpse of Daddy waiting in the hallway, I anxiously told him what had happened ...

my many faults and limitations, God still loves me unconditionally. I repeatedly prayed to God that if you, Qing Qing, were to really be born mute, then would He please allow you to be the happiest mute girl ever to be born. I also asked God to enable Mommy and I to be able to know how to make you happy.

As it turned out, you really were born mute. If you are able to speak one day, I do hope that you will tell me whether you have felt happy over the course of your short little life.

## **Our First Meeting**

One hour later, I looked through your little incubator window to see you for the first time. "Hello, Qing Qing!" I had never really imagined that this was how we would meet for the first time. I saw through the incubator that your skin was a kind of purplish-black color; this was



very different from the reddish-white color of your sister's skin when she was born.

The nurse told me that your skin was purplish-black because you had trouble breathing at the time of delivery, and therefore you were suffering from hypoxia. You were hooked up to a heart monitor and a machine to monitor your blood oxygen saturation levels. You just looked as if you were in a very deep sleep. Your little legs were spread out and unable to move. The nurse explained that babies that are delivered bottom first, due to the great force by which they are pulled out, usually spend several days lying on their backs with limbs open like this. It is called the frank breech position. I couldn't understand why you weren't able to cry when you were delivered, and why you didn't have the slightest bit of strength in your body; you couldn't even suckle, just lying there paralyzed in your little incubator. I watched you, hoping that on your second day, you would come alive with an incredible new life force, and we could put all of this terrifying stuff behind us.

When I returned to Mommy's bedside, we started to discuss this sudden turn of events that had become such a frightful event on this Christmas Eve. We wondered if you had been hurt because, due to the breeched birth, you were unable to get enough oxygen while you were in the birth canal. But the doctor had pulled you out within only a few

I couldn't understand why you weren't able to cry when you were delivered, and why you didn't have the slightest bit of strength in your body; you couldn't even suckle, just lying there paralyzed in your little incubator. Your skin was a kind of purplish-black color; this was very different from the reddish-white color of your big sister's skin when she was born.



seconds, so it couldn't have been that. If the hypoxia was not the cause of your inability to produce sound, then what was the reason? And, why was your entire body so flaccid?

We were silent for a moment.

We really didn't have any answers. I held Mommy's hand and we prayed together. I still hoped that this was all just a bad dream and that tomorrow everything would return to normal.

## **Steadfast in Faith**

The next day was Sunday. Grandma and Grandpa brought your big sister to the hospital to meet you, only to find out that you were being cared for on the intensive care unit (ICU). Because of prior commitments, I had to go to the auditorium at the Min Sheng community center and preach a sermon to our congregation. I still remember the







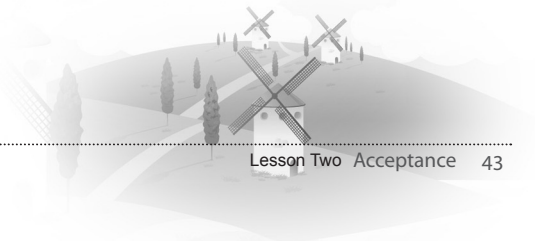
topic of the sermon for that day, In the Presence of God. That sermon was not only for the congregation, but it also helped me to solidify my faith. If it wasn't for those two hours spent reestablishing my faith, I don't know what frame of mind I would have been in when I returned to see you at the hospital.

I recall that God gave me strength, as He had done many times before, and I was able to deliver the sermon as I always had done in the past. The scripture of that week, along with words of the brothers and sisters in the congregation, made it a very moving sermon. I waited until the end of the sermon to tell them about your situation. I asked them to believe that even if you were indeed born mute, you would still be blessed because we are all in the presence of God. Furthermore, you are not just our child, but moreover, you are God's child as well. Everyone was crying, but I managed to hold it back until the very end, when we sung together "Glory, glory, hallelujah", and then the floodgates opened.

That was the first time I cried for you. There were many more times after that, but it wasn't only out of sadness or pity that I cried, rather it was that I was filled with empathy, inspiration, and strength. It was you who gradually taught us that tears might arise from many different kinds of emotions. These tears do not bring about despair, they actually enable us to carry on and face the world.

After church was over, I quickly returned to the hospital, hoping that the nurse would have some good news. When I entered the ICU, it was obvious that your situation had not improved. The nurse told me that you were still unable to breathe on your own, and that they had inserted a tube through your nose in order to feed you. The nurse said that they would continue testing, in order to determine the cause behind your lack of physical strength. If you became able to swallow on your own, then the nurses would remove the tube. You never really did develop the ability to be fully independent of that tube.

Over the course of the next week, the doctors ran many tests, such as brain echography, chest x-rays, echocardiograms, and blood tests. None of these were able to turn up any obvious problems. During this time, Mommy and I took the public bus everyday to go and see you, gave you massages and talked to you. Our friends at the church suggested us to take taxi to and from the hospital and offered to pay for us. However, we still preferred the bus. It wasn't only that the hospital was right on the bus route, but more importantly, the short walk to and from the bus stop allowed us time to hold hands, share, and pray. This offered an opportunity for us to forget about the situation at hand, to think, and to give thanks. It just wouldn't be the same if we were to take a taxi.





## **The Scary Experience of the Hospital Transfer**

Since the doctors at the hospital were unable to find anything wrong with you, we decided to have you transferred to the National Taiwan University (NTU) Hospital after the discussion with our doctor. But the hospital transfer was awful! The ambulance driver reeked of smoke and drove recklessly. When we arrived at the NTU hospital, the accompanying doctor had difficulty finding the neonatal ICU since he was not familiar with the big hospital. And even worse, you had to go without oxygen for a spell because the accompanying doctor had chosen not to use the portable oxygen unit. As Mommy and I watched your blood oxygen saturation levels drop, we were as anxious as ants on a hot pan, but there was nothing we could do except hold you tight and follow this careless young doctor as he rushed around asking everywhere for directions. By the time we reached the neonatal ICU, your blood oxygen saturation level had dropped to about seventy percent! Mommy and I were badly shaken up, unable to think about whom was to blame for all of this. Our only concern was that you were all right.

Although you recovered quickly after being hooked up to oxygen again, all of these ups and downs since your birth had really made us realize that there is a great difference between a doctor who is conscientious and one who isn't. This experience also caused us to be

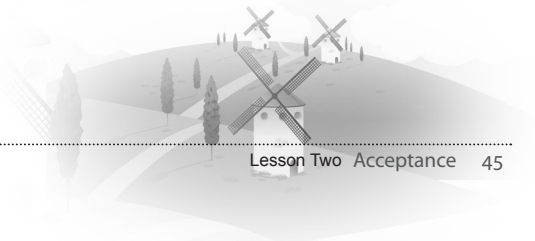
more careful when making choices about medical treatment.

Fortunately, after that incident, we were lucky enough to meet many excellent doctors and nurses at the NTU Hospital. We still remember to this day, those doctors and nurses and the conscientious care that they gave you.

## **Endless Tests**

The following three months were like one huge test. Since you had transferred hospitals, the doctors at the NTU hospital had to redo all of the tests that you had already undergone at the previous hospital. You not only received injection after injection, and constantly had to give blood. The veins in your little limbs were so delicate and difficult to find that every time they put in a new IV they had to try many times to just find a vein that was suitable. After so many injections, your blood circulation would worsen, the syringe would slip out, and the IV would need to be reinserted. It was tough on all of us since we could not bear to see your little body being covered with more and more needle holes.

In the beginning, we only had a vague understanding about the medical treatment that you were receiving. Your body was covered with so many tubes and wires; at times, one of the machines would suddenly make a beeping noise when we were trying to figure out the lines and the





readings on the monitors, putting us even more on edge. Although we realized that all of this equipment was necessary, the sight of our little baby hooked up to an IV and surrounded by machines was very difficult for us. Fortunately, the nurses took the time to explain these machines to us and to inform us of which tests you would be having on a given day. If necessary, the doctor would come and spend time with us, discussing the situation, until we no longer had any more questions. We were very moved by the fact that some of the nurses were able to tell which positions you liked best, what some of your habits were, and even what kind of personality you had. Although you still were not able to leave the hospital, seeing the nurses whispering to you quietly and offering you encouragement like that really helped to set our minds at ease.

Once the process of tracking down the cause of your disease had begun, the doctors proceeded with some basic tests, such as blood tests, X-rays, and chest echography. The doctors felt that since the cause of the problem wasn't clear from these tests, then perhaps it could be a neurological problem. They took you to have an MRI to see if there was any deficiency in your neurological functions. Talk of possible neurological problems, caused Mommy and I great concern. We just hoped that your cognitive abilities had not been affected. When the results came back negative, we both breathed a sigh of relief.

The doctors then began to suspect that you might have some genetic disease, possibly Spinal Muscular Atrophy (SMA) or Prader-Willi Syndrome (PWS). After having electro encephalography (EEG), electromyography (EMG) and blood tests, both SMA and PWS were ruled out. After a painstaking investigation, the only possible suspect left was the mitochondria. Although nothing had been confirmed yet, Mommy and I still wanted to be prepared. Every time we returned home from the hospital, we would get onto the Internet and read up about all these terms that we had never heard before. We began to realize there are many rare diseases that exist in this world, and that the functioning of the human body truly is marvelous. I started to imagine what kinds of limitations we might encounter and what kind of future we could struggle to have if you really had one of these diseases. Mommy and I would run through this same drill every time the doctor mentioned a new disease. Looking back, the training that this experience gave us was an excellent preparation for the future.



This is you hooked up to the IV drip and the other medical treatment equipment. It was very tough for us to see you like that.



The mitochondrion act as the cells' battery. If you had some problem with your mitochondrion then that would explain why you were always so low on power. However, before the mitochondrial test results came back, in order to be sure, the doctor suggested that you undergo a muscle biopsy. In other words, they needed to take a piece of tissue from your thigh and run some tests on it. If these tests were to come back negative, even these top-notch doctors might be at a loss as to how to proceed.

The needle holes on your tiny body were not healing very well, but we now had to consider the option of a muscle biopsy operation. It was a heart-wrenching decision to make. Frankly, it would have been easier if the doctors were to cut off a piece from Daddy or Mommy's body instead. However, the fact that your muscles did not have any strength was a clear indication that there was a serious problem in need of resolution. Finding the cause of the problem would be the only way to ensure that we could deal with your illness appropriately. Under these circumstances, we had no choice but to sign the consent forms. In our hearts, as any parent would, we still held on to a tiny thread of hope that there wasn't going to be any problem, you would be able to undergo some therapy and then you would gradually get stronger. As we waited, the results of the mitochondrial tests came back. They were negative! Our hopes had once again been given another chance.

## Learning to Care for You

The doctor told us that we needed to begin learning how to take care of you by ourselves. Once your condition had stabilized, whether or not the doctors were able to find the cause of your illness, we would have to be prepared to take you home and look after you by ourselves.

Throughout the course of these tests, it seemed that you had some improvement through rehabilitation. There were even times when you were able to swallow a few drops of water by yourself or breathe without the help of the oxygen unit. While we were waiting for the results from the muscle biopsy experiments, we began learning the techniques necessary to take care of you. This included rehabilitation therapy, suctioning techniques, as well as nasal tube feeding and replacement. I used a video camera to record the nurses' instructions so that we would be able to refer to them later if necessary. Finally, Mommy and I had to memorize all the different procedures, and perform them in front of the nurses before we were allowed to take you home. We even had to attend the hospital's emergency training class for families. Although we passed all of these exams and took many notes, we still wondered how would it be possible to take this knowledge acquired over such a short period of time and actually put it into practice at home. If an emergency actually occurred, what would we do? Would we be able to react or





would we just stand there in front of you, in a daze? The nurses always enthusiastically asked if we had any questions? But frankly, we didn't really even know what sort of problems might arise. It would be much like having to fly a commercial jet, full of passengers, after only having practiced once before on a flight simulator.

As your condition rapidly continued to stabilize, you were moved from the neonatal ICU to the intermediate care unit. It was ironic that being moved to the intermediate care unit meant your condition had improved! Over the course of three years, we have spent time on all of the different intensive care units of the fourth, fifth, and seventh floors of the NTU Hospital. This building, which was originally like a maze to us, has unexpectedly become our second home. We have become familiar with many of the nurses and doctors who cared for you, and even became friends with them, not to mention getting to know more about

### *A Note From Mommy* 2005.1.19

I still remember the first time that I saw you being suctioned by the nurse; you were crying, and struggling in pain. Although I realize that regular suctioning is necessary to help prevent potentially life-threatening complications such as choking, or fever, it is still extremely difficult for me to see you suffer through it. To cause suffering in order to prevent even worse suffering, this is the dilemma that I must come to terms with in the near future.

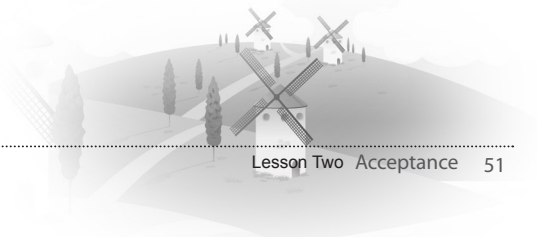


Daddy, on the intensive care unit, holding you for the first time.

all of that equipment that used to make us so nervous. Gradually we have even begun to understand some of the medical terminology; it really is amazing how people are able to adapt.

## **The Super Family That Would Come to Take Care of You**

The ICU at the NTU hospital was open for visiting three times a day, each time for half an hour. During the three months that you were receiving tests, we would visit you every day for two of those three visiting periods. Since some of our friends from the church either worked at the hospital or were students at the medical school there, they would often stop in to see you as well. In order to prevent the spread of germs on the ICU, only two visitors were permitted at a time, and therefore there was always a line of visitors in the hallway chatting and waiting for their two minutes to go inside and see you.





At that time, we hadn't yet set up a blog for you, so we used the church's prayer website to post updates about your condition. Many of our friends from church would go to the website to get the latest information about you and to offer a prayer for you. The count of the number of prayers offered for you on the site continued to skyrocket.

It seems that you were really born into a super-family. Aside from family and close relatives, hundreds of people from our extended family at the church also came to share the love with us. There were always visitors coming and going by your bed. Once, a nurse at the ICU even curiously asked us how it was possible that you had so many uncles and aunts. We realized that in order to prevent the spread of germs on the ICU, it would be better if there were less people visiting. However, we still felt that perhaps it was because of all this love and best wishes, not to mention the sunny and positive atmosphere it created, that you were able to really fight off any disease. Nevertheless, since we did not want to disturb anyone on the unit, we asked everyone to hold back on their visits and instead continue to pray for you. There would be many opportunities to visit you after we took you home.

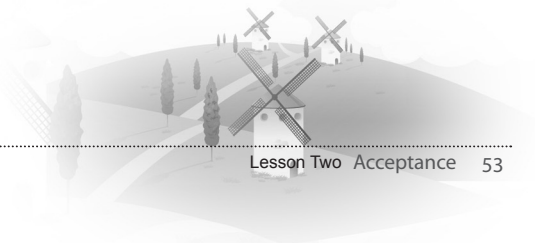
## **The Cause of the Disease was Found**

The muscle biopsy results confirmed that you did not have a mitoch-

ondrial disorder, but that you did indeed have a rare disease called Myotubular Myopathy (MTM). After some further genetic testing, we found out that while MTM was the more commonly diagnosed disease of this type, you actually had the more rarely seen Centronuclear Myopathy (CNM). You had a genetic problem that caused your body to be unable to produce an important kind of protein, and this in turn caused incomplete development of muscular function. Unfortunately, we still didn't know the cause of this kind of genetic deficiency.

Nevertheless, we now knew the bad news was that our hopes for your speedy recovery had been shattered, but the good news was that we finally knew what you were up against and we would no longer just be swinging blindly in the dark.

The day we received the phone call telling us the results of the muscle biopsy, we frantically got on the Internet and searched for any information related to MTM. We soon realized that information in Chinese related to this topic was almost not existent. Furthermore, aside from a support group website which was no longer being maintained, the only information in English pertaining to MTM was to be found in a few obscure medical journals and some medical indexes. Even the doctor told us that this was about the extent of the information that she was aware of as well. Qing Qing, you were really testing us this time. I





hurriedly called upon one of the members of our church, Zhi Dong, who was doing a PhD in genetic studies at the time, to help answer some of my questions about the topic, and to help us find any related research. I hoped to piece together some understanding about this disease that you were going to have to face.

The only clues I had at that time were the following:

- This type of disease was extremely rare
- Currently there was no cure for it
- Initially the life expectancy estimates were about one year, but advancements in respiratory therapy had led to more and more babies living past this mark
- Due to the mode of inheritance, it is very rare for girls to have this disease, and if they do their symptoms will be less severe (this may be the reason that you were able to breathe on your own)
- Some children, through the help of a wheelchair and respiratory apparatus, are even able to live past the age of ten. These children's cognitive abilities are not affected, many of them even perform quite well in school.

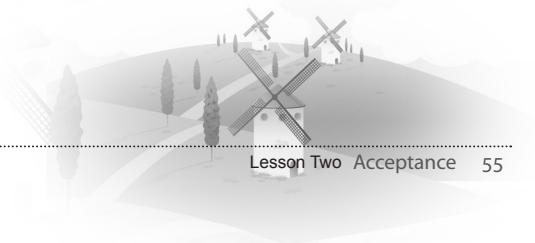
Based on this little bit of information, Mommy and I suspected that even if you could survive the first year, it would still turn out to be

a long battle with this disease. However, relatively speaking, your symptoms were fairly mild compared to some children. With the right care and treatment, you might even be able to experience further development. Even though you were unable to produce sound, with the rapid development of new technologies, we truly believed that one day, with some assistance, you would be able to interact with others. As I thought about it, I started to realize that there were many possibilities. As expected, God had truly given us a special Christmas gift. By relying on our faith we would be able see the abundance that actually existed in this little gift.

Mommy and I both agreed that we wanted to take care of you as best we could, and to diligently strive to help you live a full and happy life. As we continued to think things over, we realized that our faith in God enabled us to have hope, but we wondered about you. How would we ensure that you realized the value of your uniqueness? What could we do to help you understand that even with all the deficiencies that this disease created, you would not be loved any less than anyone else?

You have always presented us with difficult challenges, teaching us that seeing life's splendor is not always so easy.

On March 1st, 2005, we decided to create a weblog for you. We called it 'Fragile Yet Strong'. Daddy translated all the English language





medical information regarding your disease into Chinese, and put it up on the blog. We hoped that in the future, any Chinese speaker searching for information of this type would have an easier time of it. More importantly, we wanted to have a record of everything we had said and done with you since you were born, so that you could see how much we loved you and how important you were to us. One day, you might even be able to use your own unique methods to express your story to others.

Once the doctors had confirmed the diagnosis, and we had learned the appropriate techniques to take care of you ourselves, you were finally able to come home with us.