

Dear Carmen:

你好，之前都有回復給你，也不知是什麼原因，你一直沒有回復，後來 martin 有聯繫我說未收到信件。或許是網路的緣故，那邊是否會遮罩國內的郵箱或者是視為垃圾郵件？如果有收到信，麻煩告知我一下，謝謝。

早前去了香港，非常感謝你們從百忙之中抽空陪我們見了三位小朋友，真的給了我很大的信心。可愛的喬喬，聰明的阿聰，堅強勇敢的 Howard 的。。他們都是最棒的孩子，一型的孩子可以護理的那麼好，真的非常不容易。這和家長的努力也是分不開的。更堅定了我要堅持下去的信心。我相信只要孩子活著就會有希望。我要學習的東西還有很多很多，或許小 mia 的出現就是為了讓我肩負這個使命的吧。這種罕見的幸福並非是每個家庭都會經歷的。我想生命的意義不在於結果，而在於不斷追尋意義的過程。其實比起孩子們的辛苦，我們這些根本不算什麼。看到他們有一些些進步，在別人眼裡或許不算什麼。但是在我們的眼裡，看到了他們的努力，就會不斷堅定自己的信念。其實現在在 icu 待的時間多了。看到了很多的生離死別，往往只是一瞬間的事情，所以讓我更懂得珍惜目前所擁有的一切。好好的對待小 mia,讓她天天快快樂樂的。有一天或許在我的努力之下，她也會像阿聰一樣說話，期待這個奇跡。

另外香港之行之後，我一直想為在國內的 sma 患者做些事情。在國內，包括在上海，由於這種病的特殊性（無法治療），醫生都採取的是消極治療。今年 10 月份有一個一型的孩子，12 個月齡，由於呼吸衰竭，醫生沒有採取任何措施，他不幸的離世了。由於那個時候我還不認識他的媽媽。所以不能把我學到的護理經驗轉告她，真的很遺憾，那個小天使就這麼離開了。國內對於一型孩子的護理基本是空白，我很想在這方面做一些努力，在自己的摸索之後，結合自己看到的學到的經驗，結合國內的現狀把日常護理經驗點滴寫下來，一方面為小 mia 的成長做一個記錄，另一方面想把這些經驗寫下來幫助更多家長，讓他們面臨這樣的孩子，不要失去信心，希望有更多的一型孩子可以在沒有發生呼吸困難的情況前，維持一個好的狀態。避免使用呼吸機，減少痛苦。

另外，國內的情況，我們是有建立一個 QQ 群，專門是為 sma 患者和家屬提供資訊交流的群。目前是剛起步階段，希望可以慢慢的形成氣候。讓更多的家長樹立起信心，一起克服難關。martin 也有籌備網站的事情。我們希望可以團抱起來，讓更多的患者以及大眾瞭解和關注 sma 這個病。

天氣冷了，游小姐你也要注意身體。還有 mary,還有司機先生，感謝大家對我們的照顧。大家都要保重。另外替我向霍太以及其他家長問候。我會以他們為榜樣，一直堅持下去的。非常謝謝。有機會明年再去看你們。

對了，游小姐，我不知道你們那邊有沒有孩子用中藥之類的調理身體。我個人覺得黃芪是一種很好的藥材。可以補氣增強抵抗力。我每天都有給小 mia 用煮出來的湯水煮粥。效果還不錯。大家可以試一下。老少皆宜~

另外還有一個很好的中醫推拿方法，捏脊，這個也是小 mia 每天會做的日常保健。如果問過那邊醫師可行的話。可以推薦大家試試。祝大家健康平安~

mia 媽媽

2010-12-02

English Translation

Dear Carmen,

Hi, I have replied to you but I don't know why I haven't got your reply. Later Martin contacted me and told me that you didn't receive my mail. I guess it was due to the network problem. Are mails from mainland blocked and treated as junk mails? If you receive this mail, please let me know. Thank you.

Previously we came to Hong Kong. Thanks so much for sparing time to accompany us to meet the three kids. You really gave me confidence. Lovely Kiu Kiu, Smart Chung Chung and brave Howard are the greatest kids. It is not easy to take such good care of children with SMA type I. This cannot be separated from parents' effort. What I saw had strengthened my confidence to carry on. I believe as long as our kids are living, there is always hope. There are so many things I have to learn. Perhaps little Mia's existence is to give me such a mission. This rare blessing does not come to every family. I think the meaning of life does not depend on the result, but the process of keep finding the meaning. When compare to the suffering of the kids, what we experience is nothing. In others' eyes, their little bit of improvement is nothing. But in our eyes, we see their effort. And this confirms our belief. As the time staying in ICU becomes longer, seeing breakups and deaths happened in split second made me know better how to cherish what I have at the moment. I want to treat little Mia well and make her happy every day. Perhaps with my effort, one day she can talk like Chung. I am looking forward to this miracle.

After the trip to Hong Kong, I really want to do something for SMA patients in mainland China. In China, including Shanghai, doctors usually adopt passive treatment because of the incurability of the illness. In October this year, there was a one-year-old child who was diagnosed with SMA type I. His doctor did not do anything to his respiratory insufficiency and passed away. As I haven't known his mother at that time, it was a pity that I was not able to share my caring experience with her and this little angel left the world. In China, they know nothing about taking care of children with SMA type I. I hope I can do something on this area. I noted down my learnt experience with my exploration, as well as the current state of China, taking notes about daily caretaking. On the one hand this is a record of Mia's growth; on the other hand, these experiences can be shared to other parents to help them. So when they take care of their children, they would not lose confidence. And more type I children can maintain in a good condition before developing any breathing difficulties and avoid to use any mechanical ventilation which causes a lot of pain.

Apart from that, we created a QQ group as a communication platform for SMA patients and families to share information. It is only in a starting state. I hope it can encourage more parents and give them confidence to overcome obstacles together. Martin is preparing the website, we hope to unite to help more patients and the public to understand and be concerned with SMA.

It is getting cold. Carmen, may you please take care of yourself. I am also thankful to Mrs. Yim

and the driver for the caring to us. You all take care. Please also give my best regards to Mrs. Fok and other parents. I will treat them as my role models and keep going. Thank you. I hope to see you all again next year.

By the way, Carmen, do you know any kids there take Chinese herbal medicine to keep healthy? I think huang qi (Leguminosae) is a very good herb to nourish one's vitality and strengthen one's resistance against illness. I use it to make soup and use the soup to cook congee for Mia every day. I think the effect is quite good. I recommend this to others to try. It is suitable for even the elderly and young ones.

I also found a very good way of Chinese massage --pinching the back. I do this for Mia every day as daily exercise. If doctors think it is possible, I recommend others to try.

Wish you all healthy and peaceful.

Mia's mum
2nd December, 2010