

致霍太及嚴太:

真的很感謝你們對我們給予無條件的幫助，記得當初我們發現 BB 滿月時手腳活動能力下降，哭叫時身體並沒有任何掙扎，經健康院轉介兒科做了各樣如腦掃瞄等的測試，仍然沒有任何結果，直至 BB 約 3 個月時被確診患有一型 SMA。想起等待遺傳學報告期間，醫生已告知了我們最壞的情況，當時我每天起床後眼淚便不受控制地流出，而言心裡雖然也作了準備，但當得知報告結果時，還是接受不了，那種心情，相信只有親身經歷才會明白。

經過兩次於政府醫院的例行復診後，我知道他們在有限的資源下並未能對此病症提供於照護上具體的幫助，當時我感到相當徬徨，幸好有你們的明燈及幫助。當你們首次帶著數包尿片到訪我那位於路途遙遠的家，並抱著 BB 告訴我一些經驗及可能遇到的情況時，我真的感動了，你們還再突地拿來急救的 Ambu Bag 和抽痰機及安排樽裝氧氣以便我們能應付 BB 的突發狀況，無奈我們從未接觸有關物件，並不懂得使用。有幸得到你們為 BB 安排了物理治療師劉姑娘到家中，教授我們如何使用有關物件及技巧，劉姑娘很詳細地告訴我們若缺氧情況出現時的應付方法、Ambu Bag 及樽裝氧氣使用時應注意的地方，以免過大的力度及過高濃度的氧氣會損害肺部，以及示範如何拍痰和將抽痰的膠喉從鼻孔中插入氣管並進行抽痰，但由於時間有限，我們只能牢記有關方法而未能實習，我們在沒有專業人仕指導下，也不敢貿然將該喉管放進 BB 那細小鼻孔內。當你們得知情況後，便立刻再為我們安排劉姑娘到家裏作出指導，更給我們租借了血氧監測儀，經過數次練習後，我們終於可以正確地為 BB 抽痰及使用那些設備了。

最近，BB 吃奶時常常有嗆喉的情況，我們很擔心這情況會引致肺炎以致呼吸系統衰竭，遂向你們求助，熱心的你們立刻為 BB 預約了言語治療師以更進情況，希望問題可以於言語治療師到訪後會有改善。

再次衷心感謝你們，特別是嚴太為我們著力的聯絡及安排，真不能相信

素未謀面的你們竟帶來了無限的關懷及實際的支援。

媽媽謹啟
2011 年

English Translation

Mrs. Fok and Mrs. Yim,

I am very thankful to your unconditional help to us. I remember the time when we found our baby's ability to move decreased that he was unable to struggle while he was crying in his 1 month old. After several tests such as brain scan carried out by paediatrician with the referral of health centre, there was still no result until it was diagnosed with SMA in 3 months old. I recalled the waiting period of genetic report, the doctor had already told us the worst situation. At that time, every day when I woke up, my tears ran down out of control. Although I had preparation in mind, I still could

not bear it when I got the result. The feeling can only be understood by those who have the same experience.

After two times of routine body checks in public hospital, I know that the doctors cannot provide specific help on caring issues with inadequate resource. I was so puzzled at the moment. It was lucky to have your help and guide as our light. When you first time took long journey and brought several packs of diapers to visit our home, as well as telling us some experiences about the situation that might happen on our baby and hugged him, I was really touched. You also brought us specially an Ambu Bag for first aid as well as sputum suction machine and bottles of oxygen so that we could handle the emergency situation. However, as we had not seen these things before, we did not know how to use them. Luckily, you made arrangement for physiotherapist Miss Lau to come to our home, teaching us how to use them. Miss Lau told us in details about the available ways to deal with the situation when our baby is lack of oxygen. She also told us the attention points when using Ambu Bag and bottles of oxygen so as to get rid of the possibilities of too much pressure and concentration of oxygen which would harm the lung of baby, together with the demonstration of spit stroking and how to put the tube of sputum suction into trachea through nostril for carrying out the sputum suction. But due to the limit of time, we could only remember the ways and did not have time to practice them. In the absence of instruction by professional, we were afraid to put the tube into baby's tiny nostril. After you knew our situation, you immediately made another arrangement for Miss Lau to give instruction at our home and you even leased a blood oxygen monitor for us. Several practices afterward, we could carry out the sputum suction for baby and use the equipment properly.

Recently, our baby often got choked when sucking milk. We were worried that this would lead to chest infection and even respiratory failure, so we called you for help. You immediately made an appointment with enthusiasm for speech therapist to follow up the case. We hope that there is an improvement for the problem with the visit of speech therapist.

We would like to express our thankfulness to you again, especially Mrs. Yim for her help to make contact and arrangement for us so eagerly. It is really unbelievable that you never meet us before but bring us unlimited caring and practical support.

Best regards,
Mum
2011