

Family and Friends of Mark Petchey

Prior to last summer, our friends' twin kids graduated from high school. I recall they were born when Mark had the accident. That made me realize the timeline of our lives – Mark's and mine as well as family and friends. We have traveled a long time yet life goes on timelessly.

At the beginning of this year, there was a plan to have a new standing frame, a new wheelchair and a new speech device. How did they go? He surely got 3 including the one – the standing frame is supposed to be on its way. We resurrected the broken one for nearly one year but it finally gave up. Things take time around here on any single subject. Meanwhile we are battling to obtain a new shower chair commode which recently went out of order.

The wheelchair was delivered in March but went back to the shop for some fitting and reasons for another few months. Finally after the thorough changes and adjustments along with endless detailed discussions by medical team, it came to Mark. It is a new challenge to learn the equipment for caregivers. They are not the same – my primary concern was and is on how to avoid hitting my knees and lower legs from the sticking out breaks on the back of the wheelchair. So far, I have bruises and scratches below my knees daily. Meanwhile the one of the great features is the back seat which is contoured to remind his body to stay in central position. Together with the head rest, it should always keep him in the center. Yes, it should. But Mark always challenges the theory. Mark surely likes this one better than the previous one. He is motivated to pedal around the hallway between his room and kitchen. He can check out the dinner! Unless he backs out and hit me or the wall of this house with the sticking out back breaks, everything seems to be under control those days. This is the main gear for him. Without it, he can't get out to school or to walk.

The speech device actually arrived first among 3 in early January but it is supposed to be mounted on the wheelchair so that it took a while to get acquainted. And after being installed, it went on dropping and deforming the originally setup position of the frame attached to the wheelchair. This kind of fundamental issues are always causing troubles. The device is supposed to be in front of Mark. In order to use, the screen should be on the right location in front of him. The button should be in front of his right hand. The device should be fully charged as well as the speaker – there are a separate attachment and needs charging. The charger should be connected to the electrical outlet, of course. All those comes to my job. Those are matters kids are able to taken care on their iPhones but if the device relies to others, what is a big difference??? After his bed time, this is what I have to check around nightly. Then, if I forget it, messages are to school.

Then, Mark's frequent usage is another issue. An ideal young man who wanted to help for this already left us. It took too long for employment procedures for a program to cover his fees though it was not a big fund to reward and he also has to live. I am still working out to find out someone who can come to communicate with Mark using this device – the person who comes and communicates with him. I have

recently visited other speech pathologist office in Santa Rosa for help but they started everything from the start. It is not something I would like to do again. All I wanted was to find someone to help with the current device.

There is a challenge ongoing. Challenge to Mark and challenge to my patience. I am nearly busted because of never ending projects. I became very grumpy difficult monstrous mom.

Meanwhile this is a team effort – the device provider/speech pathologists, Mark's therapist - Letha, his school supervisors and computer room staff, school personal assistants and home caregivers all trying to make it happen. Putting more energy towards this time consuming project is making Mark feeling connected to the community.

And while we are bustling and hustling all those device, Mark himself improves his capacity. That was unexpected and really exciting. Please read Mark's therapist, Letha's comments about Mark in 2017. Let me also mention about her – after her publication on ortism invovelemt method and therapy, she is now this specialty lecturer all over the places. She regularly provides her services at Mark's school – Becoming Independent for Ortism Department on the same day she comes to Mark's work out.



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Letha's message - Here is a summary of the year. It has been a big year of new things for Mark.

Mark's new wheel chair has proved to be a challenge and opportunity for new abilities. Mark is now able to move his body fully back on the seat, without help. It's a big, little thing and so important to his comfort during the day. The new wheelchair provides better trunk support and Mark finally has foot support that really works. This means Mark can look at his surroundings while someone pushes his chair, instead of using all his strength to lift his legs as he curls forward into a semi circle. You can guess, Mark likes his new chair.



The really big news is a state of the art communication device operated by a single button. Mark is learning to control it, though it is very tiring for him, he avidly works with it and his team. We are still working out the kinks and Mark is developing an understanding of how it functions.



In occupational therapy, in addition to training of new personnel and following through with Mark's use of various equipment at Becoming Independent, Mark is retracing development. Injuries like this leave people with missing or damaged foundations of development and movement. For example, Mark has been unable to lie on his tummy. Just a few months ago, in OT, for the first time, he was able to tolerate a flat tummy position. Mark has made this neuro developmental gain and it is solid now. This means that all the time sitting (with his spine bent) can be counteracted by lying on his tummy. He also tolerates some time with his head turned to his right side while on his tummy. Very importantly, Mark can get in and out of these positions himself.

One of Mark's greatest assets continues to be his sense of humor. He jokes with his team and finds pleasure in all aspects of life.

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