



## Newsletter from Mark A. Petchey – December 2024

Mark is living his own low-income apartment with 24/7 care provider. He visited his GP doctor in July for his annual checkup. She approved of his good condition in general, especially for weight loss by 10lb(!) from 205 to 195. I was not aware this was such a big deal but she had been concerned with his slow but surely gaining weight for over years and was preparing for seeing health problems – blood pressure, blood sugar, salt, sleep apnea, etc. That was really a big deal. She encouraged to continue this discipline to keep his weight down or at least not going upwards. Her request is avoiding all clinical health issues because once it's caught, it is hard to get rid of it. Minor problems are occasional small rash, bruise, skin irritation and fungus but it is amazing that he is basically in good shape.

Once, Mark's physical medicine doctor, David Vidaurri, MD told me. Since Mark is sustaining the level of disability, that means he is improving!! As he is now covered by the team's care and not by me, I deeply appreciate them. Mark's care provider agencies changed in 2023 and the new team and the business owner, Gregoire of Optimum Care SLS II are deeply committed and very kind hearted.

One big change for his life came in April. His nearly 15 years' long-serving therapist, Letha Marchetti finally retired. That was really a big worry to us because she has been the key person for pushing Mark to be better since 2009. She communicated with him, established a strong rapport, taught patiently and encouraged him to do the exercise sometimes seemingly harder for him. She provided interesting articles regarding related medical matters. She pushed me to contact those resources for any chance to get him into new technology. She brought something possibly helpful. And it often actually helped. She was able to see his future to come. She was visionary. She had been the orator for Mark's well-being.

Despite this devastating situation, she brought us a new therapist. He started coming in March together with her until he succeeded in April. Glenn is soft spoken but showing his enthusiasm to get into Mark. He checked out his Junior College Adapted PE class to learn how he does at that end. He taught his care team several daily homework practice. His interactions with caregivers are well received.

Many other things happened as usual but one more memorable change was what he got a big gift from the State of California. Thank you to North Bay Regional Center. He finally got a standing mobile-wheelchair. He can now stand without transferring to the standing frame. Not only that, it goes horizontally so that can ease his back or legs. And there were other related changes. The state of California proposed a new program named Self-Determination-Program (SDP). This is totally a new way of servicing within the system. Instead of the government providing services from their contracted arena, the client, himself can initiate his way of living and choose his own services. This is a revolution.



He can attend Junior College, for example, instead of a disability day school. He can choose his own learning and entertainment program with his tutor. When I learned about this new program, I immediately started preparing this transition in June 2023. There, I met another miracle worker, Yadir Morales – an independent facilitator to design the program. Without her, I could never get out from this big complexity and administrative bureaucracy. I hoped it would start the new SDP by January or at least by March but all the complications to secure every step to clear took until October 2024. I hope I will be able to update you how this new program has been working next year.

This year is just so heavily packed with administrative tasks for his mom, too. But changes seem to energize Mark and his environments. At least, he is aware of this liberation.

Recently, when Glenn, the therapist, was leading Mark for conducting his mobile-wheelchair at the parking lot. He repeatedly asked Mark to change directions. I, then, interrupted, saying 'Mark! Remember old DOS command "cd\\"? Remember the old computer??'. Mark's face had an immediate reaction and was laughing quite indiscreetly. Mark is prevailing.

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The wheelchair can also go horizontal. The new therapist, Glenn is showing his exercise technique to Kafoune.



Shot in SRJC Adapted PE with his driver, Brian actually his childhood friend. Kafoune has been the leader of the care team nearly 5 years since she came to Mark's life.



Hideko's dance friend, Judy from Iowa came to see Mark with her service dog, George.