

## **Family Council**

“Family: A Hub to Cheer You Up” Family Education Videos – Fearless of Rare Disease  
WU Yui-kwan and Her Mother

### **How I found out about the disease and what I felt**

Kwan’s mother : When Kwan was 3 months old  
she had a fever and was admitted to Tuen Mun Hospital  
She was eventually diagnosed with muscular diseases  
collectively known as muscular dystrophy  
Hers are of a relatively rare type  
She lacks a certain substance in her muscles  
(The average life expectancy is) 10 years at most  
I don’t feel particularly upset  
since I’ve been too busy coping with lots of medical equipment  
say, a ventilator  
I’ve to clean her breathing stoma after getting home every day  
so I don’t have the luxury of thinking too much

### **Aspiration for broadening our horizons together**

Kwan’s mother : Kwan had a little brother  
with the same medical conditions  
I must take some of the blame  
because while his attending doctor recommended  
a breathing stoma for him when he was 5  
I let the matter sit  
until he was 7  
Then he suddenly had a fever  
and died of lung failure  
Kwan was 8 at the time  
Deep down I thought  
Kwan only had 2 years left to live  
Should I continue to make her attend school  
or should I take her to see other things?  
That’s how I aspired and began to go on annual trips to Japan with her  
visiting a different place each year

### **From animation and comics fan to game creator**

Kwan : I love Japanese animation and comics  
They (Japan) have released a great many games  
but I can’t enjoy those games (that require agile and speedy responses)  
My main goal was to create a game that I can play  
Case investigation and the heroine’s growth  
were pivotal to the game’s design

My game falls into the psychological and criminal investigation type  
making professional knowledge the biggest challenge to me  
I needed to search for a lot of information online  
because any error or omission in such professional knowledge  
would result in a big plot hole  
That's why I made an extra effort in this area

## **You are my pride**

Kwan's mother : What makes me proud is that, since 3 months old  
she was said by doctors to have only 10 years to live  
She's the only one left with this medical condition in Hong Kong  
the only one who lacks a certain substance in muscles  
So, each additional day she lives  
is a miracle to me  
Over the 15 bonus years  
she's been able to do what she likes  
The further she goes down her desired path  
The better she just has to stay well  
It's that simple  
I've no expectation for anything else

## **Message for those going through similar ordeals**

Kwan : I think, first and foremost  
you must find out what tickles your heart  
Whether it's viable or not to proceed  
you should try first  
If you don't give it a go  
you'll never know the final outcome

Kwan's mother : When she was in primary school  
I met some parents who were going through similar ordeals  
They started to take me doing volunteer work  
and I saw what autism, mental disability  
and Mucopolysaccharidosis were  
I started to realise that in fact, my life didn't look utterly bad  
Accepting our children for who they are is the most important step  
because only when there's acceptance  
will we be able to think over the way forward