

NOV. 21-2013

To whom it may concern

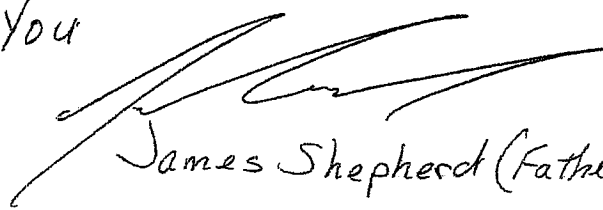
I have 2 daughters ages 17 and 19 that have an unknown disease. I have taken them to many Doctors, Such as John Hopkins Hospital - Mayo Clinic, ST Louis - ETC. No doctor know what they have. The doctors say they have a unknown mitochondrial disease, which affects their muscle in the entire body. They both developed this when they were two, the youngest one has always been in a wheel chair and has had a trach since age 3. they are both deaf and blind. I have dealt with this for 16 years, still no answer as to what is the name-cause or treatment for what is wrong with them. This has gotten worse the last 6 mo. they both have a trach, Both on ventilaters 24 hrs a day. they are both bed fast. the youngest one can not move any part of her body, has to wear diapers because she has no control of bowels or urine. She has to have someone with her at all times. If she needs to be suctioned - she can not make any noise or move around. She can use her mouth like a whisper. You have to watch her mouth, she will whisper cough when she needs to be suctioned. This has to be done right away or her oxygen level will drop very fast to a dangerous low level. then you will have to bag her and suction at same time. the older one is now on oxygen and has a trach or she does the same. they are both on oxygen 24 hrs a day they take many medicines, they both have G Tubes so the medicine can go directly to their stomach

Robert G. (Bob) Bethell Joint Committee
on Home and Community Based services and KanCare Oversight
November 25, 2014
Attachment 26

They can not eat, they get nutrition from
pedasure put into the g. tube - 24 hrs a day
The older one still has control of her bowels, but
she can not stand, sit, use her arms and hands.
She has to be lifted to a potty chair by her bed
their minds are good. they can tell us when they
are in pain and need more medicine - day and night
They have lots of pain. they have both had surgery
on their back for scoliosis (twice) which did not
help much. They have had biopsy so Doctors can
do research. I worked at Lear Jet for 18 years.
I was on F.L.M.A. leave but you can only have
so many weeks a year and I have used it all.
I had to quit my job. they were in the hospital
so many times. they can still open their mouth to
tell us what they need. they are very hard to understand.
They are losing mouth + throat muscle. also. they both
did sign language but their eyes have gotten so
bad they can not see us sign and they can not
move their hands or fingers so they can not sign
to us. They have lots of medical equipment they are
hooked up to so they are not in the same room. The
Doctors say they can not do anything to help them
they are losing control of their body. I can not
care for them all by myself. I need help by
nurse that know the medical care for them
It would be impossible for me to take total
care of these girls without the help of nurses
and Kan Care

I give my permission for this to be read to the Legislative Committee

Thank you


James Shepherd (Father)