

Good afternoon ladies,

I have a bit of an unusual request that I hope the Board might consider. I have an almost three year old little boy on my caseload who has very complex needs and I will give you a very brief medical history. He was born extremely premature at 23 weeks gestation and spent the first 18 months of his life in hospital. He presents with a number of chronic medical conditions related to extreme prematurity and prolonged mechanical ventilation (more than 100 days). He has chronic lung disease, infantile asthma, hearing loss, cerebral palsy (wheelchair bound), global developmental delays and short stature. Diagnostic testing when he was younger suggested severe to profound hearing loss in both ears and he has been fitted with hearing aids. He recently had his ABR repeated under sedation at Randall Children's Hospital as his auditory behaviors are very inconsistent and he will not always tolerate his hearing aids. He seems to hear better than would be expected with severe to profound hearing loss. The outcome of the ABR from Randall suggested Auditory Neuropathy Spectrum Disorder. In very simple terms, this means that this child may have true cochlear hearing loss but in addition, his brain is not making consistent sense of what is being said. Children with this disorder can exhibit varying behaviors and responses that can be inconsistent from day to day.

This child is unable to talk. He has some signs but not enough to develop a consistent language system. He receives services for Hearing, Speech, Occupational Therapy and Physical Therapy both through Willamette ESD and privately. His insurance is Oregon Health Plan and as such, will not cover some items that may be beneficial to him. His care providers believe that he could greatly benefit from technology to develop a communication system. It has been recommended that he may benefit from:

Apple iPadAir2 – 128 GB – for programs for communication – estimated cost - \$650.00  
Otter Box or other protective cover – estimated cost \$150.00  
Key guards to limit screen access - \$100.00  
Wheelchair arm stand - \$200.00

I am wondering if this is something that KEX might consider helping to fund. I'm not sure if I should be writing this to the entire board or if I need to wait until our July meeting. I would appreciate your thoughts ladies. Thank you. Glenda

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