

October 13, 2008

APIPA
Appeals and Claims Dispute Department
3141 North Third Avenue
Phoenix AZ 85013

Re: PATIENT
Case ID

I'm writing to appeal your decision in denying our daughter, **PATIENT**, the **Zevex Enteralite Infinity** feeding pump. The reason for your denial stated that the Kangaroo Joey is an acceptable alternative to the Kangaroo PET and is comparable to the Zevex pump.

I feel that you have incorrect information about the difference's between the three feeding pumps. The Zevex Enteralite Infinity is greatly smaller the Kangaroo Joey and even significantly smaller than it's Zevex predecessor the Zevex Enteralite. The idea behind having a smaller pump and back pack; (we are requesting the Super Mini which is smaller than the Zevex mini) is to allow our **daughter/son** to achieve her maximum potential in her activities of daily living and her growth and development.

Attached with this letter is the literature that includes the actual weight and dimensions of the Kangaroo Joey, the Zevex Enteralite and the Zevex Enteralite Infinity. I have included the dimensions of the two back packs for the Zevex Enteralite Infinity.

Also included , is the brochure provided to us by Preferred for the Joey. The picture shows two people, a child about 7 years of age and probably about 40 - 50 lbs in weight, the other and adult male in a wheelchair. I have included the Kangaroo Joey user manual as it has specific details that are vital to our appeal. Please note, nowhere in the manual does it state that this pump is used for pediatric care below the age of 5 years.

Kangaroo Joey Section 1 page 1 - General Information. Ergonomics - Tabletop usage or IV pole mounting. Page 8 - General Setup - There are two recommended placement methods for the Kangaroo Joey - Attached to a vertical IV pole via the clamp peripheral device, included with the pump. Placed on any stable surface. Section VI- Re- Certification of Performance - Certifying the Accuracy of Pump Flow Rate - Suspend the pump set bag so that the top of the water column is 6 inches above the pump. **This is an important statement since Preferred believes that using the Zevex mini back pack with the Joey is acceptable alternative to the actual Joey backpack.**

I have included pictures of the Zevex back pack with the Joey set up. You will see, that it is not more than 6 inches above the water column, even at full capacity of 500mls. The height of the Joey unit is 4.1", the Zevex Mini Back pack is 9.5", the water column is a minimum of an inch from the top of the back pack. I have also provided pictures of the Joey in the Zevex back pack where the unit would not be pressing up against her back and feeding pump. Again, it is not stable and hangs very low. In order for **PATIENT** to efficiently use the Joey, as instructed/ intended by its manufacturer; she needs to be leashed to the IV pole by the 6 foot length of feeding tube, or carry a backpack made to fit a small adult, and not **her/him**.

Next - Section VII - Cleaning. You can see that cleaning the Joey is much different than the Zevex Enteralite Infinity. The Joey can not be immersed in water or other cleaning solutions.

Great care must be taken in cleaning the unit, carefully unscrewing parts and gently cleaning the different mechanisms of the machine.

Now to the Zevex Enteralite Infinity. Included is a Business Wire article about Zevex International and the introduction of the new Infinity in 2005. I starred areas that are key. Enteralite Infinity patients are **mobile** and can feed at any place or time. The new pump carry packs provide portability to users of any size, from infants to adults. I starred a point about how this pump does not need annual calibration of pump sensors, can be washed under running water, further reducing the cost of ownership of the pump. Also that it won an award because it offers patients increased portability, improved durability and an expanded feature set that increases the number of applications in which the pump can be effectively used.

From the Zevex Enteralite Infinity users guide. Product overview - It is able to operate in any orientation. It's size weight, accuracy, and portability **promote and support health improving physical activity**. Cleaning instructions from the users guide The Super Mini Back size dimensions weight and height when filled with 500mls of water. The specifications of the pump are, most importantly, specific to the pediatric population.

APIPA and Preferred have made a corporate/contractual based decision that all children needing a feeding pump, are to be provided with the Kangaroo Joey. I have learned from several sources, that the PET Pumps are being replaced with the Joey. It does not appear that anyone is reviewing the needs of each member on a case by case basis, but making a blanket assumption that no matter what the medical condition, whether the patient is ambulatory, what the patients weight and size is, that the Joey is acceptable. I feel that this assumption on the part of APIPA is wrong and, furthermore, I believe it to be in violation of patient rights.

Is PATIENT receiving her nutrition? Yes. But at what cost to her overall well-being and treatment plan? The Joey, if not stable, consistently rings with flow error alarms, and develops air pockets in the line, which then go into her tummy. It causes unnecessary discomfort and pain.

APIPA states on the first page of their DD handbook "**Quality is what we stand for at APIPA. We are committed to giving you the best care possible. We want you to get the services that you need for a happy and healthy life.**" I feel that this is an instance of perceived cost (although I am not sure why Preferred keeps telling me its is \$800.00/month for supplies when I can find them online for less than \$250.00 through Med Ex) contradicting a very obvious mission statement.

APIPA is not in mind of my **daughters** best care. They are not promoting her growth and development to its fullest potential. She can not gain improvement on her gross motor, cognitive, social personal skills by being forced to be tethered to IV pole and sitting in a chair for her long feeds to receive her nutrition to survive. APIPA is not allowing PATIENT to develop her maximum potential for normalcy in her day to day life . I am working very hard to provide her with a day to day life that is as close to normal as possible. She will be in therapies a far greater length of time to improve on her developmental delays, thus costing the state even more money, because she is being hindered by her feeds.

You are asking a child with low muscle tone, mitochondrial disorder who already has low energy to carry something almost 19% of her body weight. You are asking that a mobile child, be confined to a chair and tethered to an IV pole during her feeds. She can not benefit in improving her muscle strength by being confined to a chair to receive her nutrition to grow. She can not benefit by having more damage done to her small failure to thrive stature

by asking her to carry something MUCH too heavy for her, and by being hindered to improve on her delayed skills.

I am providing letters from her therapist and her new GI doctor, discussing the risks of PATIENT trying to use and carry the Kangaroo Joey, which she can not. Also I have provided several articles discussing the risks of "HEALTHY School Age children" and back pack weights. The ideal is for no child to carry a back pack more than 10% of their body weight and no more than 4" below their waistline to prevent serious back injuries and other skeletal issues.

PATIENT is today an inpatient at Phoenix Children's Hospital. She is being fed now continuously and will be discharged on continuous feeds. Meaning she will now be confined to a chair the entire time she is awake or having her parents chase her around the house while she is tethered to a IV pole. Both of these are impossible scenarios. I can not chase a two and half year old child around hours on end carrying her backpack or pushing an IV pole around while trying to run a household and take care of my other children. This also means that I would never be able to leave the house as I would have to be available to push her IV pole, or carry the back pack so she can receive her nutrition. Plus PATIENT falls constantly and if I am not precise distant to her and her line, she could greatly injure herself by yanking out her g-tube, causing a trip to the ER, possible surgery and so on. This does not give PATIENT a better quality of life while trying so desperately to grow, work on her gross motor, cognitive, and social skills. This decision does not give her a meaningful treatment plan.

I ask you to seriously consider all of the facts and how they affect **PATIENT** quality of life as you review this case. **And that you MUST consider this case on it's own merits, on a case by case basis, and not as a corporate decision.** This is a medically fragile, special needs child whose doctor is saying she needs this pump to improve her quality of life and give her the most optimal chance at succeeding and improving on her developmental delays. We are not asking for the pump because it's cute and small. We have a small, underweight, failure to thrive child with numerous medical issues, who is mobile and trying to learn how to walk. This case is more than just about providing her nutrition, it's about making her therapies successful, AND improving her overall quality of life.

Thank you,



