

Robin Bodnar

Andrew Bodnar

On the morning of December 17, 2009, Andrew Bodnar woke up a "normal" 14 year old boy. On the 18th, he woke up vomiting, and in extreme pain. On the 19th, He woke up in the ICU of CCMC attached to a respirator, several other tubes, and two IV poles with several medications on each. During the early hours of the 19<sup>th</sup>, Andrew underwent emergency surgery to remove 90% of his small intestine. On the 20<sup>th</sup> he had more small intestine removed, his appendix removed and a central venous catheter placed. During his 48 night hospital stay he had a few more minor procedures and started the process of living a new normal. He never ate a meal while hospitalized. Even today most of what he eats is for social purposes only. This is why he needs a specialized formula.

When he was released on February 3, 2010 we came home to a whole new world. We have become accustomed to our "new normal". Each evening, it takes about 45 minutes to take his medications, set up his enteral feeds, and hook up to his nightly IV feeds. Our morning routine takes 30 min to complete.

Andrew goes to school with a backpack just like most other teens, except Andrew's backpack does not contain books. It contains a medical pump, 1 and ½ liter of Elecare formula, an ice pack, and other misc. medical supplies

He is hooked up to get his Elecare by g-tube for 22 hours a day, 7 days a week. He goes to school, robotics club, Boy Scout meetings, and events, helps out with our local Cub Scouts, and is active in our church's youth group. He hopes to climb Mount Washington this coming summer. He has to do all this while attached to his backpack or lifeline as we see it.

Andrew has all of the normal stresses of a 16 year old boy except he has a few extras to deal with. He worries about his pumps alarming at inappropriate times, his formula bag springing a leak, or worse yet, bursting. He worries about getting his tubes caught on stuff because he didn't secure them well. He worries about waking up with, or getting a fever during the day. He worries about getting a cold that will likely land him in "Club Med." He worries about getting laughed at, stared at or the worst thing of all, being pitied.

His father and I have some fears also. On top of the constant worries about his health, and the normal fears every parent has, we worry about his future. What is going to happen to him when he ages out of pediatrics, and our health insurance?

Andrew was not, and is not sick and he cannot be cured. He will live with this condition for the rest of his life. Our hope is that they will be able to wean him off of his IV's and remove his CVL. It is doubtful that he will ever have his g-tube removed. Currently he needs about a full can of Elecare a day. At current prices that comes to \$238.00 a week, or just over \$12,000.00 a year. If they remove his IV those amounts will likely double.

Our biggest fear is that when he graduates college and starts his life he will have the added expenses of his formula. With the added expense it is unlikely that he will ever contribute to society, and more likely that he will be a lifetime Welfare recipient, and a burden on society.

Please don't let this happen. This could be your son, your daughter, your grandson, or your granddaughter,

This is my son, Andrew Bodnar, who I would like you to all meet.