

## **Joey's Homemade Formula Story**

Homemade Formula? Why in the World would you want to go to so much trouble when you can just pop open a can? That is the response I have gotten from a number of people, most notably doctors and nutritionists. My reasons for feeding my g-tube fed child a diet of primarily homemade formula are numerous. The most important reason in my mind, is that it has given me a more active role in my child's diet and nutrition.

My son Joey, is a 6 year old with a genetic liver disease. He also has a number of GI issues that complicate his life including severe reflux, slow stomach emptying, and malabsorption of fats and vitamins. Eating has been difficult from birth and Joey was soon classified as "failure to thrive." At 7 months he received an NG tube for supplemental feedings and a more permanent G-tube at 9 months. We were prescribed Pregestamil formula and placed on a "feeding schedule." As time went on, Pregestamil was replaced with Peptamen Jr. canned formula. Joey has had continual occupational therapy over the years to promote his oral skills and improve his relationship with food. Unfortunately, it became obvious to us after a few years that it was unlikely that Joey would grow out of his reflux as we had hoped. He does eat some foods orally, much to the credit of our dedicated Occupational Therapists. The majority of his nutrition, however, continues to be supplied by his G-Tube.

The routine we had established for Joey's nutrition was very mechanical and also became rather depressing for us. We continued to pump formula into our son as prescribed, yet, we felt that his health and emotional well being could be better served. Despite the great amounts of formula he was receiving, he continued to grow and gain weight very slowly. Additionally, we felt that he was not always included in the family aspect of food preparation and mealtime. When we did have him join us at the table, the food he was served was most often not even touched. This "wasting" of food was particularly difficult for me to see and it amplified my sense of depression. Like most moms, I envisioned baking cookies for my child or making them special meals. I felt a little cheated out of that aspect of my relationship with my son.

Apparently I was not alone. Our occupational therapist started a G-Tube support group for parents looking to improve their children's lives. The initial focus of this group was to investigate the idea of homemade formula as an option for our children's nutrition. We read about and met some other parents who had had success with homemade blended formulas. I was convinced it could be beneficial for our son and decided to take the plunge.

The first step was to discuss the idea of homemade formula with Joey's doctors and his occupational therapist. At the time, Joey was 3 years old and his health status was fairly stable. Many of his doctors had a hard time understanding why I would want to work so hard when canned formula was so easy. Others were concerned that he would get adequate nutrition and calories. A few encouraged me and did believe that there were benefits in a more varied diet of fresh food that could not be obtained from a can. We

made appointments with a nutritionist familiar with Joey's particular dietary needs and together we developed a plan to slowly start incorporating fresh foods into Joeys blended diet. Once this plan was in place, we then asked the doctors to review it and give their blessings.

With a plan in hand, we slowly started adding new foods to Joey's diet. We approached each new addition carefully and only added one new food at a time. For example, we started by adding some baby foods, peaches came first. In a blender, we added some peaches to his canned food to make a smoothie that easily went through his G-tube. We continued to add peaches for 3 days until we were sure that his system could tolerate the change. We then tried a vegetable (baby food carrots) and again tried that food for 3 days. Luckily Joey was very tolerant of the changes and he did not appear to have any problems adapting to the changes. Within a short amount of time we began replacing the baby foods with fresh fruits and vegetables. Within a few months we had a recipe that included some canned food as the base of the diet, fresh fruit, fresh vegetables, whole grains, baby food meats, milk, yogurt, and an oil for additional fat.

As time went on, and we continued to investigate nutritional options for Joey, our formula evolved and became less and less dependent upon canned pre-made formula. We also eventually switched to a dairy free diet which seemed to help with Joey's slow emptying. We stopped using baby foods all together and now blend fresh cooked chicken, lamb, turkey, and fish (This has required us to invest in an industrial blender). Many of his meats and whole grains are prepared in a slow-cooker with onions, garlic, herbs, and spices. We also include table foods in his formula. Many times what he doesn't finish at the table is blended up and used in his G-tube. He receives a wide variety of foods that would be extremely difficult to get a typical 6 year old to eat - (brussel sprouts, salmon, avocado, flax seed, broccoli, etc.).

The results and pay-off that we have experienced have been phenomenal. The biggest improvements were almost immediate. Joey's weight gain and growth which had always been markedly slow, dramatically improved. His height and weight had never registered on the growth charts. Within about 6 months of altering Joey's diet, he finally reached the 5<sup>th</sup> percentile. At his present age of 6 1/2 , Joey is solidly at the 25<sup>th</sup> percentile for both height and weight.

Another immediate improvement that we witnessed was a new interest in oral foods. There was a direct correlation between the switch to homemade blended foods and Joey's willingness to try new food tastes and textures. He also seemed to take more interest and enjoyment in food preparation and eating with the family. We involve him in the preparation of the homemade formula and it is empowering for him to get to make some of the choices of what goes into the blender and eventually his stomach. He can decide if he wants peaches or pears, carrots or green beans, etc. He also enjoys blending up food that is left on his plate. He has the satisfaction of feeling that he finished his meal like everyone else.

The emotional benefits for the rest of the family are also evident. The sense of frustration that I once felt about "left-over food" is gone. I also have a new sense of control and pride in knowing that I am providing my son with the very best nutrition possible. I feel that the time I spend making his blended formula is an investment in his health and his future.

I would like to note that through our journey, I have learned that flexibility is the key to successfully incorporating homemade formula into our lives. There have been bumps along the road where Joey has been extremely ill or his reflux worsens. During these times, canned formula is easier to digest and we often come to rely upon it for a great deal of his nutrition. There are also times when our lives are extremely hectic and I will rely on canned formula as the basis for Joey's nutrition and simply add fresh foods to the canned formula. It is also a convenient supplement to have on hand at school and it is extremely easy to pack for travel or vacation. Once I decided to start working toward homemade formula, I realized that it didn't have to completely replace canned formula. The percentage of homemade formula that Joey receives on a daily basis varies depending upon his health and circumstances.

Today Joey is a happy, out-going 6 ½ year old. He is now in 1<sup>st</sup> grade and adapting well to the public school setting. He brings his snack and lunch to school like all the other kids. After eating with his classmates he goes to the nurse's office for a supplemental bolus feeding of homemade blended formula as well as some canned formula that I pack for him daily. Both Joey and I have come to see his feeding tube as a blessing. When he is ill or his reflux is acting up, he will sometimes ask to skip his oral meal and simply receive a bolus feeding. I have the piece of mind that no matter what he eats orally, he will still receive excellent nutrition through his tube fed meals.

Tina Valente, Joey's Mom