



“Blessings” by Anna Parker

Not too many people out there know what it’s like to have PKU. People hear about it and feel sorry for me. People say “Oh how awful!” But I have a different point of view. I count my blessings.

I was diagnosed with PKU at ten days of age. The hospital I was born in called my parents and told them I would be mentally retarded, and sent them to Egleston for more information. My parents were devastated, as I’m sure some of you have been. They got to Egleston and learned that PKU was actually a treatable disorder, and that I would not have to suffer brain damage. What a relief! Now here came the hard part....they were told I would never eat meat, eggs, cheese, milk, ice cream, peanut butter, cupcakes, milkshakes, sandwiches, pasta, and I could go on and on.

Instead of taking on a “pity” attitude, my mom decided that I was going to grow up and lead a normal life just like anyone else. She learned everything she could about PKU and how to keep control over my diet. From as far back as I can remember, she was teaching me what I could and couldn’t have to eat. I told my preschool teachers that I couldn’t eat sandwiches because “they made me sick.” She started out just telling me yes and no foods. Then, as I got into elementary school, she began having me track my own phenylalanine intake. She worked so hard to be sure I could take care of my own diet.

My mother also wanted to make sure I was eating the same thing as the rest of the family, so she got pretty creative with dinners. There was no Cambrooke Foods at that time, and the only low protein items I ever got were some cookies and bread. The bread used to come in a metal can, similar to a coffee can, and it was pretty awful. It had a very distinct taste (which I can still remember vividly) and it was as hard as a rock! The cookies weren’t much better. My mom would make all sorts of casseroles and vegetables for me to eat. If the rest of the family was eating broccoli casserole, she would make me a mini-casserole using broccoli, cream of mushroom soup, and

cracker crumbs. If they had pizza, she'd make me a pizza by toasting a piece of lowpro bread topped with ketchup and sliced olives. I loved it. To this day, I think my mom's low protein cooking is better than anything in this world!

By the time I was reaching the end of my elementary school years, I was making my own formula (it was Maxamum XP), measuring my food, counting phes, and doing my own diet records. By middle school I was pricking my own finger for blood tests. It was my mom's mission to make this PKU thing work. She never allowed people to slip me food because they felt sorry for me. She never allowed me to "cheat." And she never let me feel sorry for myself. If I ever started to cry or whine about having PKU, she always managed to convince me that it was what made me special.

High school is a difficult time for anyone. But for a kid with PKU, it can be a turning point. Kids are brutal to one another, and a lot of teens with PKU feel so pressured to fit in, they eat "normal" foods when they are around their friends. I guess that I didn't have that urge as much as some do, because I had always been so disciplined that it just wasn't in my scope to cheat. I never even thought about it. Sure, I got embarrassed sometimes. I hated to drink my formula at school because everyone within a 100-foot radius noticed the smell. But I did it anyway. I got cruel comments from the other kids sometimes, such as "here, eat this chicken, I wanna see what happens," but I managed to stick with my group of friends and they were supportive and protective of me. I live in a small town, so everyone at my school knew me (probably because of PKU) and most of the fascination with it wore off after a year or so. I became very active in groups, including concert band, colorguard, student council, and various honors groups.

Having PKU has never held me back from doing anything I wanted to do. I went to college, lived in my own apartment, traveled on mission trips to Mexico and the Bahamas, and participated in the Glenn Draper Singers' World Tour to Singapore, Jakarta, Bali, and Paris in 2002. I'm sure that for some people that's not a big deal, but when you consider the fact that I spent almost a month in Asia without being able to eat rice or fish, that's an accomplishment. What did I eat? Lots and lots of fruit. Yes, I was hungry some of the time, but I managed pretty well.

Now I am 26 years old. I am a Kindergarten teacher in North Georgia and I am working

on my master's degree in elementary education. I am married to a wonderful, supportive man. He understands PKU and is one of my biggest supporters. He has even tried his hand at creating some low protein dinners for me!

Having PKU has not been easy. Actually, it's pretty tough! But I think that having PKU has made me who I am. Don't get me wrong- I am not defined by PKU. But I have selfdiscipline and a sense of determination that I might not have otherwise had. Having PKU has allowed me to meet wonderful people like genetics team at Emory. It has given me the opportunity to be a mentor to others like me, and to make priceless friendships with other people with PKU from all over the world. It has given me a sense of responsibility for myself and for the next generation of PKU kids.

I am blessed. I can see. I can walk. I can hear. I have a wonderful family. I have a job that I love. I have great friends (some of whom have PKU too). I can enjoy all of the things in life that are truly important. Having PKU reminds me of that. Food is just food. People aren't going to remember me for the food on my plate. They will remember me for who I am and the difference I made. And that's pretty cool.