BackChat.....

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PKU and me

My name is Elizabeth Hooley and I am 13 years old. I have phenylketonuria (PKU) so cannot eat meat, fish, cheese, eggs, poultry, most dairy products, or anything else high in protein. Also, I cannot have any light, diet, or sugar-free drinks or food. I am allowed all fruits—but only one small banana a day. I can have most vegetables but ones like potatoes and sprouts I have to weigh into portions called exchanges. At the present time I have six and a half exchanges a day. I get most of my food, without charge, on a National Health Service prescription. This includes special milk, bread, pasta, biscuits, and chocolate bars. I also have to have a special orange drink called Maxamum, which gives me the nutrients I miss from foods that I am not allowed to have.

About every two months I go to my general practitioner's clinic where I have a blood test which is sent to a laboratory where it is tested for phenylalanine. The result is sent via my doctor to my dietician, who figures out the number of exchanges I am permitted. Twice a year I see my paediatrician and dietician. We discuss my general health and whether I have any problems. My height, weight, and blood pressure are taken and we discuss my progress.

I live with my grandparents and 17 year old sister Isobel. We both attend the local secondary school. I am doing

well and getting good grades. My favourite lessons are technology and maths. I play the clarinet and have reached grade 2. I am also learning to play the steel pans and this year I joined in the school's float at the local carnival. I also do drama and, until a little while ago, ice skating.

I have been on several holidays, both with my family, and with my school or independent holiday group. I take my own food and have no difficulty finding something I can eat and enjoy. Most places where I have stayed have been very helpful when I explain my problem.

I am no longer picked on by other children for my condition but, when I was younger, there was a time when I

wasn't invited to my friends' birthday parties. This was because their mothers didn't fully understand my condition and didn't want to invite me and end up giving me the wrong thing. Eventually my mother went into school and gave a half hour talk on my condition and its effects.

One thing I must always look out for is changes in products, especially drinks. This is because manufacturers are always changing the ingredients, adding some or taking them away. This means they can end up on what I call the "red list".

I have met other children with PKU when I visit my paediatrician. I find it exciting meeting others with my problems even though most are a lot younger than me. My doctor and I have not yet discussed my future but, so far as I know, I will have my condition for ever.

As you see, PKU has not stopped me having a normal life. Although at times it is a bit inconvenient—taking my food wherever I go—I can still enjoy normal activities and my food, within the limitations of my diet.

Elizabeth Hooley

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We impose a great deal on some of our patients in the course of trying to promote their best interests. It may be comforting to learn that one of those supposedly carrying the burden of a complex diet sees it as no burden at all. There is a sting in the tail, though, when Elizabeth Hooley writes that her paediatrician hasn't yet discussed her future. When he or she does, the evidence from what she writes is that this well balanced young lady will take whatever information is given in her stride.