

Dear Parent,

My child has PKU too, so firstly... **You are not alone.**

Secondly and most importantly to you, your child will be just as healthy as other children of a similar age...

Going back to my experience... My wife and I were thrilled at having our son Riley!

However, a few days later we were a little bemused as to why the Specialist Metabolic Nurse from the hospital unexpectedly dropped in on us.

As we now know, it was to tell us that Riley had a condition called Phenylketonuria.

**Like you, I hadn't heard of it before in my life!
Let alone how to say or even spell it!**



RILEY'S FIRST GAME!

PHENYLKETONURIA

HEALTHY!

Thankfully we now just use the term PKU.

I bet like us too, you don't know anyone with this condition, but we are fortunate to have very supportive professionals and parents across the UK as you will no doubt find in due course.

At first we had a lot of self posing questions, such as how did this happen to us? Why Riley? Maybe they got the results wrong? Maybe he will grow out of it? Is there a cure?

Ultimately your child will be fine!

The only difference is that you will have to learn that their daily routine will be slightly different from other children.

We used to refer to the term 'normal' or 'ordinary' children when speaking about others in comparison to Riley. However, the reality is that your child, is not ordinary, **they are EXTRAORDINARY** - why?

Because they are still your little son or daughter and you love them for all their differences - it makes them who they are and who they will become.



RILEY'S FIRST DAY AT SCHOOL!



THEY ARE
EXTRAORDINARY!!!



The unknown then, becomes the known now....

Riley's health

How will this impact him, both now and in the future? Riley is now 4, and is a very active, energetic and mischievous boy. If you lined Riley up alongside 10 other boys of similar age, I bet you wouldn't know who had PKU.

Riley's future welfare

Will he be bullied because he is different from the other kids? Again, similar to the above, his development is in line with other children. The only difference is in what he eats, but everyone across the world has different eating habits, so in this regard there are no issues. I explain his dietary requirements as vegan-like (most people understand this).

Uncertainty

What will it mean for me? A little more care and attention as to what your child eats, it is as simple as that. A good diet for life will ensure your child has a healthy upbringing. Remember, they won't miss out on certain things, as how can you miss something that you've never had?

What if I get his diet wrong?

Could I inadvertently harm my child? No, it is not what I call a toxic condition like a peanut allergy whereby there could be immediate symptoms. Constant monitoring of his blood levels, which you will do twice weekly, will help you keep on top of this.

So what happens next?



Meeting

From a personal point of view, we had a meeting the next day with a doctor, a dietitian and other members of the metabolic team. These are the people who know the ins and outs of PKU and deal with children like yours from birth right the way into adulthood.

Own research

As a new parent, I expect you will want to do your own research and find out every bit of information you can about PKU. You will invariably turn to the Internet and this is where you should be careful – make sure you visit reputable sites that will always provide credible information and sound advice. The following may be a good start:

Web www.nspku.org | www.vitafriendsPKU.co.uk/recipes
Facebook [Vitafriends PKU UK & IRE](#) | [PKU \(Phenylketonuria\) UK & IRE](#)
Twitter [@vitafriendsPKU](#) | [@MetabolicsBCH](#) | [@NSPKU](#)

Letting family know

This is where you will have to tell your close ones about the condition, and no doubt they will share some of the questions outlined above. But they too will embrace the condition and provide that support.

In time you will all be sharing recipes and new items available in supermarkets. In this regard, I found it really helpful to see what foods your child can eat in later years. This is where you will see an awful lot of household foods.

Again, I understand that this is a very overwhelming time for all concerned. Emotionally you will feel like you are on a roller coaster ride, but it will soon stop and you will see the road ahead is not as complicated as you see it now.

Congratulations on your newborn and welcome to the wider family of parents with PKU!

Lee Millard

