

DIET IN GALACTOSAEMIA SINCE 1993

My daughter was my first child born in January 1993.

After a very long hard labour she was born on a Sunday evening at 6.10pm in the Rotunda Hospital in Dublin.

At that time, the mother stayed in the hospital for at least five days on a first birth. She was born a nice weight at 7lb 20z and appeared to be a fine healthy baby girl. While I was in the hospital I was breast feeding her which was going quite well. While my mother was visiting me one day my daughter vomited up a bright illuminous substance which I brought to the attention of a nurse who told me the baby was fine and it was normal but I always remember telling my mom that I thought something was wrong with the baby. The following Thursday she received her heel prick test and we went home with the baby. She cried all night and was not feeding well and as new parents we hadn't a clue what was wrong and put it down to where her heel prick test had been done being sore. Very early the next morning the Rotunda called us to bring our daughter back immediately. She was still crying and I actually fed her to try to calm her down and I had no idea I was doing more harm than good!

After a hellish few hours in the Rotunda and the baby being taken to the intensive care section we were sat down and told our daughter had Galactosaemia. We struggled so hard to remember the name "Galactosaemia"- We had never heard of a metabolic condition and we just could not remember the name Galactosaemia. Our lovely baby was seriously ill and they told us it was touch and go if she would make it. She got excellent care from the team in the Rotunda and the experts in Temple Street Metabolic Unit. She spent a few weeks in the Rotunda before being well enough to move to Temple Street and we were transferred there to start the long learning process of how to deal with Galactosaemia.

This is where the Dieticians came in. At the time the Metabolic Unit was a prefab at the back of the hospital and one dietician! She started on Infasoy milk and we had lots of meetings with the Dietician as well as the team to tell us how to feed our little daughter from now on. We started off with just the basic information of Infasoy and how to get this formula which at that time in 1993 was only available from the chemists—it could not be bought in the supermarket as they just did not stock "unusual " formulas for babies! Moving on to solids... we were given a printed list of the jars of baby food and dry food you could buy – the list was tiny..... so baby solids were easy enough to buy – usually only one type you could buy and a few jars – so make your own was a better option.

The list of allowed foods was one page for babys and easy enough to follow as no choice was really available in 1993.

After a few years a new booklet was brought out by the UK Galactosaemia Support Group but was mostly for UK grocery shops but the only foods from this list you could get in Ireland were from M&S which I found invaluable. Great for treats and snacks. An Irish Support Group was organised and one of the first things we did was fundraise for a food book for families for foods that could be bought in Irish grocery stores which the dieticians put a lot hard work into getting all the ingredients from all the food producers. This was always great for trying new foods but you always had to remember to check the ingredients as manufacturers could change their recipes without notice. Lactose was not always included in the ingredients even though it was present – things have changed for the better now.

When our little girl started school I knew the time would come when she would get invited to parties. Family parties were ok as family knew what she could have and we always went with her to make sure she didn't eat anything she was not allowed and we brought the treats with us that she could have. When she got invited to school pals parties it was always awkward. I would have to call the parent on the invitation who I wouldn't know and try to explain what she had and they never understood – they always called it an allergy as they would never have heard of Galactosaemia. I would tell them that I would bring goodies with me and I would ask to stay with her just in case she ate something she was not supposed to-not always easy when you don't know the people. We would never stay long! I did say no to a lot of invitations. After a few years, parents were quite good and knew her and I would send over goodies with her to the party. She was also very good at saying she could not eat the stuff at the party -she was very good at just eating her own supply! As she got older it was easier from a diet point of view as she knew she was not allowed to eat anything at parties unless I had said it was ok. This was normal for her.

For her own birthday cake – this was always hard. Luckily for me, I have a brother who is a pastry chef and he made her cakes... but finding one off the shelf was next to impossible and I am no good as making cakes so that was out!

Eating out again usually consisted of her having chips for dinner as this was the only thing on the menu she could safely have. If we asked to find out the ingredients in a particular dish we were usually looked at funny as it was not the done thing back then!! Happily it is a completely different story now and most restaurants are happy to help now. The only time we may have difficulty still is if we are in a foreign country where we cannot trust the menu completely – so we would always go for self-catering and make sure we give her something to eat before we go out and then she can have her trusted “chips” as a snack and she is happy.

When we travel abroad we get a letter from the Metabolic Unit outlining her condition and the need to bring certain essentials with us i.e. her butter and other items like medicine etc that we cannot be sure to get in that country. There are a lot of support groups in Europe so if you need help with food in these countries it is always good to contact them in advance and they could have similar booklets to help in that country.

Our daughter is now 23 years old and diet is the least of her problems – foods are so well labelled now that shopping for the Galactosaemic child is relatively easy and for new parents its just giving yourself time to get used to the whole new way of cooking etc. The dieticians in the unit are always there to help out if you are unsure of a food.

I am happy to say that huge changes have taken place since 1993 and it is a hell of a lot easier now than then to shop for the Galactosaemic child in your life.

Angela O'Connor, November 2015