# DR JOHN JENKINS JUNE 7 2004

**Well Doctor Jenkins, we will begin asking you about the condition known as hyponatraemia and just what is your understanding or just of the condition and how it actually occurs.**

Well Trevor, hyponatraemia is a condition where there is an imbalance of salts in the body. The body has a lot of different salts but sodium is one of the most important ones and hyponatraemia simply means not enough sodium in the body. Now that can happen either because there isn't enough sodium or if there is too much water then that dilutes the sodium or it could be a combination of both of those.

**So where do we see it and how does the condition normally arise?**

It happens in lots of different conditions. We would see it in our new born babies for example. It's a normal process that they have to cope with sometimes after they are born if they have an illness, and we would also see it in people who have had an operation because hormone levels change in the body and we can also see it in children who have conditions like gastro-enteritis where they're vomiting or losing sodium from their gut in that type of problem.

**So in Northern Ireland how many cases would we expect to see over the course of a year?**

It's something which we would see on a daily basis in paediatric practice, but it has to be said the most of those are not severe and most children respond very well normally just to extra oral fluids until the condition settles and they get better.

**So how is it identified or is there awareness now in the wards in Northern Ireland or of it and how is it identified that a child is suffering from it?**

Well we know that in any situation where a child is vomiting or has abnormal losses in that sense it's a possibility so we would do a blood test. A simple blood test will always tell us what the sodium level is in the blood and we can then take action, if necessary, to monitor that, to correct that if it's abnormal.

**So there has been some discussion of it in legal journals which we have already reflected on and whereas some of the deaths that have occurred in Northern Ireland over the last few years in one hand have been described as idiosyncratic or physiological while other say they're not that at all. What is your view in all that in that debate?**

Well I think first of all I have to say its complicated. There's no simple black and white in this and that's been reflected within the paediatric community where its still very much an open subject. Even within the past month articles have been published arguing one way arguing the other way about this condition, but I do think that its important to recognize that different children, indeed different adults, will respond to a particular set of circumstances in different ways, and I have seen situations where children have had very severe abnormalities of hyponatraemia but who in fact have not suffered any complications as a result of that and have got better, whereas we know that some children unfortunately seem to respond in similar circumstances by developing severe complications which can even lead to death.

**So where do you come down the side of the debate are you coming down on the physiological side?**

What I'm saying really is that different children can respond so even if appropriate fluids are given its still possible for some children to have a, I suppose you could say an abnormal response - I wouldn't personally use the word idiosyncratic but I know what that term is being used to describe, that some children will respond and develop complications where others would not. Now that's not to say that there may be circumstances where if an abnormal regime is prescribed or a problem arises then all children might develop complications in those circumstances.

**Yes that's exactly the point if an appropriate clinical regime is implemented here whether its too much fluid or too much of the wrong fluid or whatever the fact is that a child could be is going to be more susceptible its nothing to do with this physiological or idiosyncratic make up.**

Well this is something which we are increasingly recognizing and again I would have to say that it's very much in the past few years that this has come to the attention of doctors. We can look back and see evidence of this in the past but in most of our own personal experience we haven't had this. I have practiced paediatrics for over twenty years and have used the same type of fluid regimes that we have been using until recently without seeing any child run into problems with this condition, but we now recognize it can happen and we've taken steps to try to avoid it happening wherever possible.

**What's your view on solution 18, which has been at the centre of some of these discussions?**

Solution 18 was designed very specifically for children because it provides a certain amount of salt, it provides their water that they need if they're becoming dehydrated, and it also provides glucose which children also need to avoid having a low blood sugar when they're not able to eat or drink anything else; so its ideally suited for some children in those circumstances. But the problem is I think in retrospect we recognize it was being used as a panacea and being used more widely than is perhaps appropriate, and so the recent guidance that has been produced has shown us that we need to be more specific about the circumstances where it is a safe solution and indeed those circumstances where it is not a safe solution.

**So just where to do you think isn't a safe solution?**

Particularly in any situation where the body has lost salt then the amount of salt in solution 18 is not adequate to replace those losses.

**And we would have known that for some time since solution 18 was around?**

Well solution 18 was never designed for those circumstances. Now if the loss of salt is very minor, if a child is say less than 5% dehydrated, then in fact the body can cope as long as its given enough fluid with almost any type of fluid. The important thing is the amount of fluid is really more important in that situation than the type of fluid - if too much fluid is given then problems arise.

**You have very specific knowledge of this because of some of the cases that have been around now over the last few years and you yourself got involved in a**

**working group can you just give me some background on that and how you get involved in that.**

Yes, it was recognized that after two children had died in Northern Ireland in conditions with hyponatraemia that we needed to look at this and the Department of Health, Dr Campbell our Chief Medical Officer, set up the working group which met first in September 2001 and, recognizing the urgency of producing guidelines, we worked very hard over a period of a number of months and those guidelines were then issued, I think it was March 2002, under cover of a letter from Dr Campbell sent out to all of the paediatric units and everyone else who would be involved in caring for children and giving them IV fluids, in order to highlight the dangers and also to give guidance about how best this can be avoided.

**Who where those two children just for the record?**

The two children were Lucy Crawford and Raychel Ferguson.

**So June 2001 Dr Campbell called together the working group and what exactly did you do then?**

Well I think it was September 2001 that we met. The working group first of all met and then had a correspondence mainly by email so that we could do this as quickly as possible to try to agree what guidelines could be produced. Now we would distinguish between guidelines and a protocol, where a protocol is more like a recipe - you give a little bit of this and a little bit of that. A guideline can't be as specific as that and because of the complexity of this condition its not possible to give a very clear and absolute recipe for every circumstance that could arise in clinical practice, so the guideline that we produced highlights the dangers of this condition and gives instructions if you like to those caring for children of the type of things that they would have to look for. For example monitoring the sodium level, checking the weight of the child, finding out how much the child is losing if they're vomiting or having diarrhoea, and then prescribing an appropriate fluid to deal with that situation.

**Setting out on that course did you examination the details of the cases you were particularly looking at?**

That wasn't specifically part of the working group's remit. I mean as you've said I have some knowledge of those cases from having looked at the individual circumstances but what we did do was we looked back at the literature within the medical journals and we discovered there were references to this condition, although not as many as we might have expected and, indeed, very few in the mainstream paediatric literature. It's only been more recently that in fact others seem to have wakened up to this danger as well and it is a very topical issue even at the moment.

**Well what is your information and how we came to be aware of the two cases who put up the flag?**

Well I suppose from my point of view I became aware of them because the Trusts concerned asked me to look at the details and in relation to the Coroner's Inquests asked me if I was prepared to give evidence as to my understanding of how these circumstances arose in those two cases.

**But in was there because the Royal dealt with the two cases was it the Royal you think that brought it to the attention of the medical community here that they**

**were seeing children coming through that seemed to be suffering from or had suffered from hyponatraemia?**

Well certainly informal contact was made and that was in June 2001 where a colleague working in the Intensive Care Unit in the Children's Hospital in Belfast made contact with a number of paediatricians, saying that they had seen a second child who again unfortunately died of this condition, and that they felt that the current fluid regimes while they had been in place for many years (and were indeed used throughout the UK) really needed to be looked at again, and that was where the process started, before the formality of the working group.

**So who was that in the Royal did that?**

Well the contact that I'm aware of was from Dr Bob Taylor.

**So Dr Taylor having spotted these coming through in the Intensive Care Unit alerted the medical community here that there had been two cases Lucy Crawford and Rachel Ferguson within fourteen months of each other.**

That's my understanding; it's certainly how I became aware of it and how the process started to try to bring something good out of these two tragedies, if we can do a little in that respect.

**An awful lot experts then got involved and you sat on the working group a lot of paediatrics there and people obviously a great amount of importance was attached to it at that stage by the Chief Medical Officer.**

Yes, the fact that we met so quickly and that we worked so hard I suppose in producing something, and, indeed, my experience of working groups is that they usually take at least a year to produce anything whereas I think it was probably around six months that we had something out on the website and widely circulated.

**And what was the remit given by the Chief Medical Officer at that stage?**

I don't have a memory of exactly what the remit was, but I know that in my understanding it was to produce guidelines to try to prevent the condition of hyponatraemia occurring where it was possible to do so.

**I mean that just gives us an idea of the significance that was attached and the importance of getting you guys in and looking at this that it was important actually to do deal with it and important to get some guidelines out as quickly as possible was that because of the concerning case of other children out there maybe the condition was being misdiagnosed or is that a possibility?**

There certainly have been other cases - as I've said some children don't respond with severe complications, and we would all have seen children who developed hyponatraemia but who got better without problems arising. I think the Chief Medical Officer recognized the significance of this condition, that the circumstances differed between the two cases, but that that was still no reason for us not to look at the underlying principles and to try to do something to protect children and to increase the safety.

**When you look at the Lucy Crawford and Rachel Ferguson's cases as you did back then I mean did you see a problem there with how their bodies reacted**

**individually to the solution 18 or was it the case in both cases that both had been given to much fluid and too much of the wrong fluid and that's what ultimately caused the end of the line?**

Well it's always possible when you look back at things to, I suppose, see how things could have been done differently, and from my analysis of the situation relating to Lucy Crawford I agree with what the Coroner's verdict was - that a mistake was made, the wrong fluid was given in the wrong volume, and that I think is, from my point of view, the importance is not just to find where perhaps blame can be attributed, but to try to find how the system failed, and to try to put in place some changes that will enable the system not to fail for a child in the future. With regard to Raychel's death she had vomiting, there's no doubt severe vomiting, following her operation; but in fact many children have vomiting of that severity and don't come to the same problems that she came to, and as far as I could determine the fluid management that had been used in her care was the standard one that many other units were using. Now in retrospect we can see that there is a better way to manage that situation, and our guidelines will help people to deal with it in a better way in the future.

**And that's the importance out of all of this but when you look back at the Lucy Crawford case and look it really no guidelines could have prevented Lucy Crawford's death if the wrong amount of fluid was given to her nothing that you could have done would prevent that is that the case if mistakes are made as they are going to happen in hospitals.**

Well I suppose I look at it from a slightly different angle and that is that mistakes will always be made. No one is perfect and other industries like the airline industry have recognized this and so what they have done is put in place systems that find mistakes before they cause damage. We don't have those systems in medicine at the moment and a system which required a prescription to be written down, communicated properly and checked would have prevented Lucy's death.

**Other thing though if you look at how that when you look at how that working group got together it is only due to the informal nature of the way that Bob Taylor brought it to the attention of the medical community unit that it was raised at all, is that a problem as well in terms of communication of what people are seeing throughout the medical community here in Northern Ireland?**

Well there certainly has been a problem in that we have not had a system whereby issues that arise in one particular area, in one Trust or in one group of patients, are necessarily recognized by others, and this is something which Northern Ireland would be too small to deal with alone, so an organization has been developed across the UK called the National Patients Safety Agency. It's really only relatively recently and is only now getting off the ground, but I very much hope that Northern Ireland will be part of that, because that is how we could pick these things up, by looking at the whole of the UK - finding out a case here and perhaps a case in Scotland, wherever - recognizing them more quickly and being able to take effective action.

**The problem with that is that its on the National Patients Safety Organisation is only in England and Wales its not in Scotland and Northern Ireland.**

At the moment, but my understanding is that our Department in Northern Ireland are looking very actively at us joining with them - however that's going to work out I'm not aware, but certainly it would be my desire, I believe it very important that we are part of that work in whatever way that can be arranged as soon as possible.

**What do you think are the great lessons out of all of this and there has been great focus and the death of Lucy Crawford and Rachel Ferguson what going back to the sort of work that you were doing in September 2001 what do you think are the great lessons that need to be learnt from the deaths of those two children and what your working group is looking at?**

Well communication is at the heart of so many problems, where a doctor makes a judgement as to regards the treatment for a child and passes that information on, but perhaps doesn't write it down, or someone mishears what they say; and I think that communication and the record keeping which gives a written record of what a doctor prescribes or the treatment that a doctor wants a child to have, that to me is at the core of this, that is the thing that can best protect our children.

**And do you think that society out there the public interest in general on these sorts of issues do you think that they should be satisfied and have faith in the authorities here that not only can they identify exactly what is going wrong but that they properly investigate it in that it does come to the attention of the right authorities and something is done about it?**

Well I think that's what we need to make sure. It may be that in looking back we could see ways in which this could have been recognized more quickly, although I have to say that the two cases out of the thousands of children who are treated in this way and while there were common factors in the two cases i.e. the hyponatraemia there were also different situations -

one child had an operation, one didn't; one was older, one was younger; so there were differences as well. The important thing is for us to develop a system which actually enables us to see the similarities in cases that arise and then to take it forward from there.

**It was how can I put it, it was so important that Bob Taylor took those two cases to the Chief Medical Officer back in June 2001**

Well I'm not sure that he took it to the Chief Medical Officer - I mean I'm not fully aware of the circumstances that led to her being formally informed of this, but by whatever method certainly it came to the attention of the paediatric community and was taken forward from there.