

Sybille Kraft Bellamy and Ivor Cummins talk about her son Max's condition - Angelman Syndrome - using keto diet protocol alone and sticking to it to massively improved the symptoms. Find out more [@ ihda.ie](https://www.ihda.ie) and [TheFatEmperor.com](https://www.thefatemperor.com)

Ivor Cummins: 00:00 Sybille Kraft Bellamy, great to meet you here in Denver.

Sybille Kraft Bellamy: 00:02 Nice to meet you. Thank you very much for having me.

Ivor: 00:06 Oh, not at all. Well, you have a very fascinating story which I was enthralled by around your son having Angelman Syndrome.

Sybille: 00:14 That's correct. Yes, Angelman syndrome.

Ivor: 00:17 Yeah. I thought that was extremely rare, but actually around one in 8000 is not quite so rare at all really.

Sybille: 00:23 No, it's not. And I think it's maybe even higher than that. But many children are not diagnosed properly, or some adults were not diagnosed properly. So they may have a form of **Autism** diagnosed instead. I think sometimes they even go to 1 in 8000 yes.

Ivor: 00:41 Right. Okay. And that was quite a profound disability. And of course, the reason I was particularly interested in the story is the dependency on a ketogenic diet to greatly improved the symptoms. Now, from talking to you, it appears that the ketogenic diet is a dramatic improvement of the symptoms - not just a minor help.

Sybille: 01:02 Yes, totally. The most effective aspect of the diet is to control the seizures. So we have really good control of the epilepsy, like over 90%. In our case, 100%. So Max is only on the diet, not taking any medication. But there is a lot of other aspects that the diet helps with in a condition like Angelman's syndrome.

Ivor: 01:26 Right. And perhaps if we go back a step to originally when you had Max, and you discovered - maybe just that story of how you discovered, you diagnosed the problem, whether it was diagnosed rapidly or maybe late, and how you actually worked your way towards diet as a solution? I believe, actually your mother's advice or someone in your life was involved?

Sybille: 01:47 Yes, totally. Yeah. Max had a health problem starting at birth. He was born preemie and he was on oxygen

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and his development was abnormally slow. He had oxygen for first six months of life. He had a lot of weight gain problem and pneumonia by aspiration, a lot of different kinds of respiratory distress were very, very important and life threatening in many times.

02:15 My mother was the first one telling me that a child like him would have to have a diet pretty strict in some ways - and be sure never give him any sugar because it was literally poison for a child that fragile. She was the first one really telling me not to give him sweet products and avoid as much as possible everything white - like potatoes, rice, things like this.

Ivor: 02:40 Right. That's kind of interesting, because, you know, we often say with obesity that our grandmothers and the old wisdom was kind of "avoid the starchy foods" for say, obesity. But your mother, she was quite adamant on this. Where did she get this idea herself? Is that just kind of a cultural, historical knowledge?

Sybille: 03:03 There is a mix of cultural. Because in France we do use... I mean, diet is still a very important part of your health. It's considered being like, even crucial to be healthy. But in my mother's case, she was still from this generation where diet was a real treatment – it was medication. During World War II, some of the family were deported. When they came back, the ones who survived, they had these major health problems like tuberculosis, typhus, and other really serious conditions. And the way they were treated in 1944, 1945 - antibiotics were not there - and they were treated with food, with diets. And my mom was always telling me that being very young at that time, she loved to help the doctors to prepare some meals for one of her uncles. And it's obvious he was fasting. He had a lot of broth and it always had to be with meats, bone marrow or raw eggs and cream. And she really remembers well what the doctor was saying at that point, what he needed to eat.

04:22 When I was a child I used to listen to her because she was telling me that the doctor in the morning was like coming in, smelling the breath, checking the urine. When I said check, I mean tasting the urine and smelling the breath. And I thought it was really interesting because he was in ketosis. So obviously she never learned the word "ketosis" - but that was the way he was treated. And when he died, he was 85 years old.

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Ivor: 04:48 Right. And they were actually looking for the smell of acetone on the breath...

Sybille: 04:53 Yup.

Ivor: 04:53 ... without fully understanding why acetone would indicate that the person's in a very good physiological state. Wow! And the urine as well, I'm not sure I know...

Sybille: 05:03 I've no idea...!

Ivor: 05:05 We won't go there! But I know in the early days of diabetes like centuries ago, maybe thousand years ago, they would taste the urine for the sugar because that was a clear sign of diabetes. I'm not sure if you can taste ketones. But in any case, we'll move on.

05:20 So this cultural knowledge, it sounds like they were doing a ketogenic diet to help with people's illnesses in the absence of medicines - before there really were medications that would work very well. And they didn't even know what they were doing, but bone broth, highly nutrient dense foods, meats, and I suppose eggs and fish - they kind of knew to stay away from empty carbohydrates and grains. Your mother then was able to tell you this with Max. Did you start that pretty much straight away? What kind of happened?

Sybille: 05:55 I did almost right away when he started eating regular food. He had very nutrient-dense food products. I give him like sardines very early and that was always mixed in with butter and avocado. So right away he had very like, what I call today is "brain food". Very young age for sure. And I was ready to give him syringes of oil.

Ivor: 06:23 Oh okay. Orally syringed oil just to... because he also, again Angelman syndrome, you know, there would be difficulty feeding, you know, quite significant challenges.

Speaker06:35 Yes. Which was his case. He was very young, he was choking very easily. And I had to kind of adapt because he didn't eat well with the spoon. He didn't want to eat as much as he should be eating. And at that point, some of the doctors wanted him to have a feeding tube, which I refused. And I just prepared his regular meal and put it in the bottle, because he was fine with the bottle, and I kept the top of the nipple. Everything in a bottle, he was taking it. So, his weight stabilized and went up and everything went better and better.

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Ivor: 07:13 Right. And you mentioned to me as well Sybille, that this is genetically identified - and he actually had a genetic or genotype, a very serious form of the disease, which should have fairly profound problems with fits and everything. But the phenotype then is your environment; how much you express the challenges and symptoms. So you very early on we're getting him to have a lack of serious symptoms that was out of step with his genotype - which said he should have very severe problems.

Sybille: 07:45 Yeah, totally. Like for the epilepsy, usually, it's the genetic deletion form that he has. It's very often the one which is pharmaco-resistant epilepsy from the young age and even added adulthood which we don't have with Max. He started having some seizure pretty late because I started feeding him very young the way we were talking about. So high fat. So he only had a couple of seizures in his life only - when he was sick with fever and dehydration.

Ivor: 08:16 And that of course disturbs the glucose balance and homeostasis.

Sybille: 08:20 Electrolytes, everything. Yeah. This is the key for children like him. If they stay well hydrated with extra electrolytes. Plus, the diets. He had flu a couple of times with high fever. He had Strep, he had major illnesses and no seizure. But it is definitely some work at that point. Mostly at the beginning. You have to understand and see what he needs and when he needs it. So, it's a lot of observation. But if you keep it like as soon as you detect fever, or as soon as you know that there is a virus or somebody else is sick, we go in on protocol, keto protocol.

09:03 He has to drink a lot. I prefer one liter of just water and electrolyte. I put a timer on and I just squeeze in his mouth. Every 10 minutes he's going to have 20 ml. It's just the way we go - then we avoid seizure. We, not only avoid seizure - he is usually the one who recover the fastest.

09:25 They had rotavirus a couple of weeks ago in my house. The two other boys were decimated - they were like crawling off the floor. It was really bad. And he's the one obviously, we gave him the priority. And he had like the standard of care - like top care. So he gets sick, like anybody else. But only one day, and the day after he was fine. He was just looking at everybody and was like, "What's your problem?"

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Ivor: 09:50 Excellent. So, you really from the very start, you were right onto an excellent ketogenic protocol so you never really had to suffer the major issues. You did mention though that I think in a hospital once a mistake was made and it caused a major issue.

Sybille: 10:04 Yeah. That was my mistake not telling them that he was on ketogenic diet. And we came because he was dehydrated. I wanted him to have an IV to rehydrate him a little faster. But I forgot to say that he was on a keto diet [very low sugar intake] so he had an IV with glucose. And it was like, I think less than two minutes, he had the worst seizure we never saw. And it was a heart seizure. It took us almost two weeks to really, really control his brain to shut down the seizure. It took a while.

Ivor: 10:41 Wow! That must have been very upsetting indeed. But it shows that you must stick to the protocol pretty religiously and you can't veer off it at all. You spoke as well about trials that were done, small scale trials. And I think you said 90% effective was the diet in a range of children, but also the 10% where it was not effective, you suspected that the protocol was maybe not being fully followed. So maybe a little on that trial.

Sybille: 11:13 It's possible that it was not well prescribed. It's possible that it was not well followed, and it's possible the child had specific microbiota at that point which didn't help the diet to be as effective. Our children take so much medications the time they're born. So much antibiotics, steroids. This has for sure major impact on the microbiota. So I believe for some of them, the diet doesn't work as well because there is a shift in their microbiota that we do not allow them to follow the regular ketogenic diet. More data, more sample and analysis should be done to see exactly what's going on with our microbiota to see how we can address the diet. They may have like inflammation or allergy with some vegetables, some fruits, some dairies, some eggs, but this should be done.

Ivor: 12:11 Yeah, I think the lion's share of work and again, there's no conspiracy per se - but the lion's share of effort in these diseases is towards finding a pharmaceutical or similar cure. And there's very little funding generally for diet-based things. It's just the way the system works. So, I think you had some frustration coming up against this challenge. You obviously have had massive success with the diet. You've many friends who have children with Angelman's syndrome, they are

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having similar success - without drugs. And most of these kids like Max and your colleagues, they're pretty much not using drugs, just diet.

Sybille: 12:48 Just diet, yeah.

Ivor: 12:49 Just diet. So you've got all this huge relief of the symptoms, and would like to share it with the world. But what was your experience when you dealt with the professionals and the medical system a few years ago - in Boston, I think?

Sybille: 13:03 They're all for the diet [on the surface]. They believe it is the first line of treatment and it should be the first line of treatment for many of our kids. But unfortunately, it's not [pursued]. Why? Well there is a lack of communication. Still at that day if you go on the major website of the Angelman Syndrome Foundation, if your child gets diagnosed, you don't know anything much about the [diagnosis], I mean even the syndrome, you go on this website, you're not going to find... it's going to be very hard to find the diet. You really have to look for it.

13:39 So my point is when you arrive on the website, you're not going to have this like blinking information saying that the diet should be started as the same way you're going to start PT or other therapy, it should be started very early. And also, that people should be informed about it. But most of the time, they're not. If they are today, it's because of social networking.

Ivor: 14:05 Yeah, that [SM] is changing everything. It's quite interesting that this, and I agree with you, it should be front and center in the Angelman societies that, okay, testimonials, some of the science explaining it and showing how this is a crucial intervention. And maybe you need some drugs as well if you don't respond incredibly to the diet, but to let people know front and center and then the drugs are secondary. But it's horse and cart the wrong way around currently.

14:31 It's similar actually in parallels with low carb and keto diet in general. Like the British Dietetic Association are very strong to come out and say, "Well, we acknowledge low carb diets in 2011." You know, on the record, they used to fight them. But now in 2019, if you go on their website for diabetes - it's buried. The low carb is just buried. It's there for the record - but it's buried.

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Sybille: 14:59 Yup. Same thing.

Ivor: 15:00 It's the same kind of thing. So, you found with these professionals that they are more focused on developing a "cure". And I think you told me that they really all believe in America that they can find a cure and therefore, they're just less interested in the diet because they're going for the "magic bullet."

Sybille: 15:18 Yeah. Yeah, totally. Which is, I mean, after that, I think everybody believe, every parents have the right and the choice to believe in any form of treatment or to do any kind of therapy. I don't think it's the problem. The problem is to not do the diet first. Because this is working in 2019, we know it works very well for a long time now. So - it should be done immediately. And after that research or cure or whatever on the side, that's fine. But many parents don't do the diet because they believe the cure is so close, that they don't need to do it. And that's what is absolutely abnormal.

Ivor: 16:36 Yeah, that is frustrating because their faith is... it's interesting that they have such faith, because the reality is with drug development for genetic diseases, is that it has been extremely disappointing in the last 20 or 30 years. There have been advances for sure, but compared to the great hope of genetics 20, 30 years ago on the genome, it's actually been hugely disappointing. So I think a rare disease, complex and genetic like this, it could be decades before there's a substantial move forward. And right now there's the diet that appears - in everyone who does it properly - to offer enormous relief to the people with Angelmans.

Sybille: 17:12 Totally.

Ivor: 17:13 And it's not getting out there. Hopefully this will help get it out there more.

17:17 Something occurs to me now Sybille that, I've been obviously pushing the low carb diet and keto diet perhaps for diabetes and for heart disease, people who have profound heart disease, and there's a lot of resistance. But we've got diabetes, heart disease, we have epilepsy now - for a low carb keto diet, Angelmans. I met a guy in San Diego rare disease, glycogen storage disease. His life was transformed when he went to keto diet - from being able to be out of breath walking 10 feet, to actually jogging a kilometer or two slowly on a keto diet. His life was transformed. I could go on and on.

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17:59 People think the keto diet is primarily for drug resistant epilepsy. And the orthodoxy kind of acknowledge that quietly. But we could list more and more conditions, profound conditions where it can be transformational, and many depressive disorders as well is becoming increasingly apparent. So the keto diet needs to really get out there more and be embraced by physicians, even if they just try it out.

Sybille: 18:27 Clearly.

Ivor: 18:27 Yeah.

Sybille: 18:27 And mostly in pediatric.

Ivor: 18:29 Mostly in pediatric.

Sybille: 18:30 I mean, they are young bodies who are forming to become an adult. So medication are not helping all the other aspects that Angelman syndrome can have, like sleeping disorder, osteoporosis, muscle problem, gastrointestinal reflux. I mean, the list is so long. A kid like Max, he was sick all the time when he was a child. He had all these very weak muscles, he had a lot of pneumonia. He always had this very shallow breathing. No real muscle to function properly. No energy; his muscle didn't receive the proper energies he needed to be as effective that they should be.

19:20 So today, Max is a very strong 17 years old boy. No respiratory problem anymore. No scoliosis. No osteoporosis. No acid reflux. No constipation. All these aspect in Angelman syndrome. In fact, constipation is one of the main triggers for epilepsy for some children. So it's very severe and on the side, it's painful, uncomfortable. And it goes with sleeping disorder. It's going to have an impact on their mood on so many aspects. And all of that with Max is absolutely being normal.

Ivor: 19:59 Wow! So pretty much all of the severe symptoms of Angelman's are largely controlled with this ketogenic diet.

Sybille: 20:06 Yes.

Ivor: 20:06 And when you step outside it as we know, does immediate crisis, immediate problems. The nature of the diet then, maybe just describe for the viewer very briefly the nature of the diet and what's in it roughly.



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Sybille: 20:19 Okay. Well, the main diet was developed for Angelman syndrome at the beginning which works very well and very easy is LGIT.

Ivor: 20:27 That's low glycemic index treatment.

Sybille: 20:33 Yes. So it's one of the most liberal diets in all the ketogenic diets. We're entitled to have between 40 to 60 grams of carbs, but the glycemic index has to be under 50. In our case, we did this for many years on the side of extra help with MCT Oil, so medium chain triglycerides and extra coconut oil. And getting older, his puberty started to come in and he started having... muscle-wise and body-wise need of more energy, so we switch to a more regular ketogenic diet. A 3:1 ratio. He's getting close to a Modified Atkins or Modified Ketogenic diet. He's a boy who loves meats, and he has a lot of protein in his diet.

Ivor: 21:23 Yeah, well meats are very nutrient-dense as well so anyone with any condition - and even person with no condition particularly - nutrient-density is so important. So it's great that he likes those nutrient-dense foods. And you avoid, of course no vegetable oils, anything like that, but Omega 3 and cod liver oil.

Sybille: 21:39 Yeah, he had that every day. Yeah. He do have some extra seeds or nut oil - walnut, pistachio. Mostly where I live right now, walnut oil is done locally.

Ivor: 21:51 But again, that's not a vegetable oil made in the industrial process. That's crushed real, like olive oil, real food oil.

Sybille: 21:58 Exactly. Yeah, it's pretty thick product and you can see it's very intense.

Ivor: 22:02 So, a real-foods nutrient-dense, ketogenic diet - and just very careful to stick to it and not step outside.

22:09 I have another topic now, not another topic, but just a related thing. You mentioned a couple of days ago that in France, perhaps in contrast to America, the official bodies, maybe hospitals, maybe government are actually open to supporting that interest.

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Sybille: 22:27 Yes, yes. I just created an association named "Connections Cetogenes". It's an association who will be able to give information and support for patients or parents or the medical community to start a diet in the proper way, in a safe way, effective way. In France we have many centers which have already a ketogenic department. In our association, we have an epileptologist, neurologists, we have research people in brain, in spine. We have research people in microbiota.

23:05 We just thought it like two months ago and we just started to send our explanation to hospital and people represent major Associations in France from autism and other medical conditions. I was just amazed by how quickly they answered back and how positive they were. This month, we're invited to a major nutrition hospital, they want us to present the diet. Major, like symposium in Paris about nutrition, they invite us to present the diet. And people at the government level are extremely interested by what we're doing. Even a nutritionist went to a hospital close by to where she lived and explained what we would like to do, to have like a service where people can come in, have consultation with medical practitioner and a kitchen where they can have workshop. And we were pretty like kind of getting ready to have a negative answer, or at least to have to push more. But the conversation ending was, "How much do you want and when can you start?"

Ivor: 24:22 Wow!

Sybille: 24:22 Which was like, "Oh my God!"

Ivor: 24:24 That is fantastic and that is such a rare thing to occur. Ketogenic diet, you're much more likely to see newspaper articles like we saw last week, "keto crotch" and all these scaremongering articles than to be actually embraced for deploying keto to help people. So that's amazing. I guess "Vive la France!" I might say there. Cliché I know!

Sybille: 24:47 I think French like fats! They are not scared of fats. It's something so part of their diet, that... again, culturally, people agree that we eat too much sugar. That's a fact. Everybody agrees with that and everybody agrees that sugar doesn't bring anything. This is like, mainstream knowledge. People know that to eat a cake that it's not... I mean, nutrition, it doesn't bring you anything. It's not what you need to be healthy and just go to work. It's not what you need.

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Ivor: 25:17 Yeah, and France culturally as well a lot of high fat foods, in Gascony and you know, the Foie Gras, the duck, the terrines, the patés - the gastronomy in France is incredible. And most of it - actually if you look through the Bible of Gastronomy, I was told by Professor **Fineman** once - every second page is a low carb recipe – only they don't actually call it low carb or keto – it is. I'm going there on holidays by the way to Villefranche, in the middle of the summer with my five kids and I can't wait. I love France! I'll put that on the record.

25:49 So this is incredible though. This is being embraced by government officials and hospitals and dieticians, a keto diet to actually help people.

Sybille: 26:00 Yeah.

Ivor: 26:00 And in contrast in 2013 I think in Boston, you gave a talk on that but very little has happened in America for you over the years, relatively.

Sybille: 26:10 Relatively yeah, not that much. I went to the Congress. I met a couple of Congressmen and Senatora, and I explained what I thought would be a priority, like when a child is being diagnosed under the age of three. In United States, you have a program named “early intervention”. So every child is entitled to receive in their home some form of physical therapies, speech therapies, whatever they need. And my goal at that point was to put nutrition immediately in at the same time, that they have consultation with a dietitian. Because if a child is being diagnosed, he/she is entitled to receive early intervention, that means if there is a disease or syndrome that the child is going to need extra help from not being healthy to be healthy again. Like in some case, just to get over the syndrome, I mean to have a better quality of life.

27:08 And I presented to them and they were not interested. They were just like “pleasantly polite”, and listened - but it didn't go anywhere farther than that.

Ivor: 27:19 No interest, yes. So **then France** it sounds like may be where you can spearhead this venture to get this available for all of these kids. And not just with Angelman's but with all the other conditions that could benefit, even beyond epilepsy and glycogen storage disease. There are probably many more rare conditions where the stability - the blood glucose stability, the benefits of the ketones neurologically, you know, where there could be mitigation of many other diseases. Once

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the orthodoxy embraces this, that it's a powerful tool rather than some kind of fad diet.

27:57 I think that's probably a positive note to finish on, that going forward. Your leadership is fantastic Sybille. Fascinating story, extraordinary leadership you're showing, and we'll try and get the message out there in as much as we can.

Sybille: 28:12 Thank you very much.

Ivor: 28:13 Thank you, Sybille.

Sybille: 28:13: It was a pleasure. Thank you.