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DIET AND SUPPLEMENTATION FOR PERSONS WITH EDS (Transcript)

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Video https://youtu.be/5TqvY71f6g4

H. Collins Hi. Thank you all for coming. I know it's very late from a very long, tiring day. I would make mention, I know that the talks are going to be freely available, and some of my slides are fairly busy and some of you are pretty far back in the room, and I'm not sure how visible some of the smaller print is going to be on the slides. Just relax and listen to what's being said. If you can't see what's on the slides, you'll be available to make sense of it from the talk when it is available later on.

I've been tasked with clarifying some of the issues around diet and supplementation for persons with EDS. It's a really simple question. I should be done in about five minutes. It usually starts by somebody innocently asking their physician, "Should I change my diet? Should I take supplements?" In my experience, very few clinicians up until only recently, really had much to say about it. Partly because there's just not a lot in the literature. I've delved into it very, very deeply and, as I think Lara mentioned, great success of anything that I do for the patients that come to see me; if I can spend time educating them on how they can start from the ground up in paying attention to what they eat, supplementing what they need, it really gets them much further ahead to work on other areas that they can move forward with EDS.

A spoiler alert is you, contrary to popular belief, you are not what you eat. I didn't end this statement with an exclamation point because there is more to this statement and it's the gist of what I'm going to cover. We have to start somewhere. Let's start with the basics of foods and supplements. We need to think of our bodies as machines that require fuel as energy. We derive energy from our diet and we find ways to store or dispose of what we can't immediately use. From our diet, we also get the materials needed to build and maintain and repair our machines and keep them running efficiently and reliably. We need to think about nutrition at a molecular level to understand how it fits into human health, and in particular, in the health of persons with EDS. When it comes to foods and supplements, whatever we consume is made of molecules. So are we. We are constantly breaking apart big molecules into smaller parts and we reassemble the smaller parts into something we need. We recycle or reuse them, or we store or dispose of the smaller parts we don't immediately want.

That's what digestion and absorption, metabolism and elimination are. Again, food is just a mix of molecules. Molecules are neutrally charged arraignments of two or more ions held together by chemical bonds. They can be classified as inorganic or organic, and it's important to realize there's a difference with those terms "organic." It means something different when you're talking about molecules than when you're at the farmer's market. The terms macronutrient and micronutrient are important to understand. They don't refer to the size of the nutrient molecule. Instead, they're talking about the amount of the nutrient required for optimal health. If you notice on this slide we're talking about macronutrients that are needed in larger quantities. They are both inorganic and organic in that water doesn't have carbon, hydrogen, and oxygen in it. The organic molecules are proteins, carbohydrates, and lipids. Lipids include fats.

The micronutrients are needed in tiny quantities. That includes vitamins and minerals. And then there's a seventh thing, which is anything else. Anything that you eat, anything that you consume or put in your mouth is made of exactly those seven things. It has to be water, protein, carbohydrate, lipid, vitamin, mineral, and/or other things. This is a very busy slide and that's because water has a lot of roles in our body. It accounts for about 60-70% of your adult body weight. The water in the body is either free or bound with colloids or other substances. A very small amount of food hydrogen is excreted- after you eat something, you're going to take those hydrogen molecules out of the food and most of it is actually combined with oxygen to make water. A very small amount is actually excreted. Water serves purposes in terms of being a solvent. It's a medium for physical and chemical processes. It donates hydrogen or hydroxide ions to reactions. It has many physical processes that it is involved in.

I believe you may have heard this from other speakers, but this is a really important point to make. If I look around I see a lot of people with water bottles. Many of you have been told you must eight, eight-ounce glasses of water a day. That is a lie. That is a complete out-and-out lie. If you look at these resources, I've shown Snopes, which is more the public mass consumption dispeller of rumors. There are two articles that are peer-reviewed journals. The first review was a physician-researcher that wanted to do a review of all the literature to see where and when did it actually creep into the medical world to give people advice to drink eight, eight-ounce glasses of water a day. Ultimately, he could never find it. It wasn't printed in literature anywhere. There was no scientific basis behind it. Within that article, he points out some of the truths and myths about this belief that we need that much water.

Going a little further, a few years later we have some kidney specialists who went so far as to say, "Well, if eight, eight-ounce glasses is not what we need, what do we need?" The reason I was mentioning about hydrogen being taken out of your food is that we all think of getting our fluids through what we drink, but even what we might consider a very dry food has hydrogen molecules in it, which can be combined with oxygen to make water. The kidney specialists actually pointed out, very few people will need to take more than just a small beverage in addition to what they eat, if they have a reasonably healthy diet, in order to meet their nutritional needs. That is, of course, talking about the general population. Taking into account that we're talking about people with Ehlers-Danlos, they may have certain other issues that lead them to have a higher requirement. Telling any patient that just arbitrarily without knowing anything more about them, "All humans need to drink eight, eight-ounce glasses of water a day" is absolutely a myth.

The organic macronutrients include proteins. This is a busy slide. What we see, the largest of the illustrations is just showing you that there's structure in proteins and it starts with tiny building blocks put together. They either get arraigned in a chain that then becomes more of a coil or a sheet and then you'll have multiple coils or sheets put together to end up with a very complicated final structure. There's an illustration on the lower left that is showing your two amino acids. When you combine them, a water molecule is removed to form a peptide bond. That peptide bond is what links these amino acids together in a long chain-like molecule to get started into the protein structure. The other picture that is the lower right of the three pictures, that is actually just a representation of a very complicated protein structure. It's what we call a lectin. Proteins can be categorized. They're amino acid building blocks. We have to realize that some of them we can actually make from smaller building blocks in our body, but others we have to get through the food that we eat, and they're considered essential amino acids.

They include phenylalanine, valine, threonine, tryptophan, methionine, leucine, isoleucine lysine, and histamine. The other amino acids include conditionally essential amino acids, which means that most humans don't have to eat them, but in certain disease states or certain stress conditions, they become essential. The last ones are considered dispensable because we can build them. Proteins have two roles in the body. They, on the one hand, could be taken and burnt as fuel. That's inefficient. It's not nearly as high-yield as carbohydrates or fats. More of what we use protein for is we take those amino acids that the proteins can be broken down into and then we reassemble them into the building blocks that we need in our body.

When we talk about proteins, I'm sure we have some people in the room who are vegetarian or vegan, and some who are not. This is a comic that was near and dear to my heart years ago: Gary Larson and The Far Side. If you can't see caption it says, "It's early vegetarians returning from the kill." I've given reference here to an article written by two authors about plant proteins and how it relates to our nutritional needs. What they pointed out in the article is very important. There are many myths, again, myths, circulating around about nutrition that vegetarians cannot get complete protein, complete amino acid with all the essential amino acids from their diet. It is not hard at all to get complete sources of amino acids from your vegetables. It is true that some combinations of vegetables are rivaling animal products for how complete they are. Some are even higher in concentrations than the essential amino acids. Take home message is, you can choose how you want to eat. You just need to be diligent at getting a good variety of protein sources, whether it be plant or animal.

How much protein any given person needs varies. Unlike some of the nutrients we look at on labels saying a recommended daily allowance – you have to take into account whether you are growing, whether you're grown, whether you're male, female, active, inactive, sedentary, and whatnot. It's usually expressed in terms of 2,000 calorie-per-day diet in a 70-kg man, is what you see on the labels in America for protein consumption. Take home message is that it varies and you may need guidance from somebody to help you figure out just how much protein would be ideal for a diet. That goes for anybody, including people with EDS.

Carbohydrates are next in the macronutrient category. They are classified as sugars, including monosaccharides and disaccharides. The monosaccharides are just one ring of either five or six carbons and they can be linked together to make the disaccharides. If you have chains of three or more of those, but less than nine, make oligosaccharides. If they're a sugar alcohol they're called a polyol and if they are more than nine monosaccharides linked together, they're called polysaccharides. The reason I'm naming all these for you is because we hear people mentioning the FODMAP diet. It's kind of Greek to some people what those letters stand for. It stands for fermentable oligosaccharides disaccharides monosaccharides and polyols. The idea is those are the smaller, shorter carbohydrates that are more easily broken up quickly in the gut. That's why that becomes relevant.

It's important to learn about glycemic index and glycemic load. Those are two ways of categorizing a food or a meal and saying just how sugary is it? How much of that can be released quickly into the bloodstream? Something with a very high glycemic index dumps sugar into your bloodstream very quickly. Something that is a lower glycemic index is more likely to keep you at a very steady blood glucose level. One of the reasons this is relevant: I put up here a reference to an article in the journal *Nutrients*. I doubt that all of you can see this chart and it's not really necessary. The gist of it is, when you look at all the different carbohydrates, they vary greatly in whether they have a high glycemic load or a low glycemic load or index. If we look at the simpler sugars like monosaccharides and disaccharides, they're more likely to be dumped into your bloodstream, cause a rapid absorption, rapid release, and a release of insulin that spikes and then drops your blood sugars.

You tend to have this cycling up and down, where you get the sugar and then your sugar drops, and you need more because of what's going on in your bloodstream with the sugar. Additionally, this chart alludes to fructose metabolism. Fructose gets a lot of press about how it is just corn sugar and it's just fine. It's just the same as glucose, doesn't really matter. It really does go through a different metabolic pathway. Glucose is rapidly absorbed, whereas fructose can be metabolized without insulin secretion. It involves liver metabolism, where if your body is not going to use that sugar, it can decide very quickly to change that fructose into fat. To me, this is very relevant when we see that our food industry relies very heavily upon fructose as a long shelf life, cheap accessible sweetener. It really does have implications for fat storage in the liver and sugar metabolism.

The other side of the flowchart starts to talk about starches. Starches are not all created equal. We have the slowly digestible starches, versus the rapidly digestible starches, and then we have resistant starches. When you look at the slowly digestible starches, they are more of a low glycemic index. They're going to be slowly digested with sustained glucose release. They're not going to have that big insulin spike and you're going to have sort of a continued satisfaction of your hunger. It's one that if you're deciding to eat your carbohydrates, it's one of the good carbohydrates, because it overall gives you energy and doesn't have all these bad characteristics, whereas the rapid digestible starch leads to hypoglycemia, hungry feeling, and the same kinds of things as the simple sugars do. The resistant starches, they're just really not digested by you and your chemical processes. They're more handed over to the bacteria and the microbes that live in your gut, and they ferment them for you.

They become a little bit important when you're thinking of people who are – that's a good way to get energy. You're energizing those bacteria. Those bacteria have roles in metabolism as well and do favors for you. On the other hand, if they're evil bacteria that are in there, they're likely to contribute to abdominal pain and bloating because they're using that fermentation to make gas. The next category is lipids. Lipids are basically not dissolvable in water. The most important ones that we're going to talk about are fatty acids. Fatty acids are categorized as either essential or nonessential. There are some fatty acids you have to get in your diet. Your diet can't be completely fat-free. There's also a combined molecule that takes a glycerol backbone and gets three fatty acid, either one, two, or three fatty acids linked to it. We call those monoglycerides, diglycerides, or triglycerides. Triglycerides are kind of special. They are either fats, they're solid at room temperature, or they're oils, which are liquid at room temperature. The last category of lipids that are relevant are the sterol lipids.

That's what we derive our steroids from, including the steroids that are the precursor for our sex hormones and our androgens, as well as the cholesterol precursor. There are other classes of lipids, but they're less important. Some of the lipids include some of our micronutrients. They're called prenol lipids and they're the basis of vitamins A, E, and K. There are other classes like glycerophospholipids, sphingolipids, saccharolipids, and polyketides. There's just an endless variety among this lipid class. I'm going to make special mention of lysopines here. You've probably have seen lysopine listed as an ingredient and that is actually a lipid. It's actually a lipid mixture and it's something called glycerophospholipids. They're added by the food industry to smooth food textures and emulsify and dissolve things and keep them appetizing, basically. They can repel other materials, like Pam cooking spray would be a lysopine. Something you use on a noncooking surface.

They're kind of a hot topic in nutrition because they were appealing for all these characteristics, but just like margarine has been thrown under the bus, lysopines are coming into question as well. You've all heard about trans fats. This picture shows you a top molecule that is actually a saturated fatty acid. It has no double bonds anywhere in it. It's just single bonds on its carbon chain. It would be a solid at room temperature. The middle molecule has one double bond in it, which makes it an unsaturated monosaturated fatty acid. It's going to be a liquid at room temperature. That particular molecule is actually a trans-fatty acid. If you notice, it's a nice straight molecule. The one beneath it is actually a cis-fatty acid. Trans-fatty acids, it has to do with the fact that the hydrogen atoms on either side of the double bond, are arraigned on opposite sides from one another. If you notice in the picture, that allows the molecule to stay straight. Cis-fatty acids occur in nature. Trans really don't occur in nature. Trans are a manmade phenomenon by food engineers. The cis molecules are bent. Why is that relevant? When they're floating around in your bloodstream, when they're mixing with one another, they stay kind of fluffy and don't pack in. The ones that are straight, they combine together or pack together, and they can make things like plaques. That's why they're bad. It's their shape that makes them bad.

Why would we want to make trans-fatty acids? Apparently, in nature, those bonds are unstable and they break easily. Well, that's okay. They make terrible-smelling molecules, so it's basically when these nice unsaturated oils spoil and they become rancid, it's because those bonds break. When we were wanting to use them in the food industry, we didn't like that they went rancid, so we wanted to stabilize them.

The interesting thing about nature is that nature combats that by having antioxidants within the plant food so that it's less likely to go rancid when it's in the actual olive or whatever you're getting your oil out of. It's an example of us extracting something for our convenience, that really defeated nature's purpose, and then manipulating it so it's more convenient for us.

Vitamins are species-specific. Something that is a vitamin for us is not necessarily a vitamin for another species. They were nicknamed vital amines back in about 1912 because the first one that was isolated was an amine. The researchers that were looking into it figured they'd all be amines. They were later proven not to be, and somebody just lopped the E off the end and called it a vitamin. They are organic molecules and they occur in something called vitamers. You'll see vitamin D2 and D3 or you'll see retinal, retinol, and keratinoids, which are the vitamin A family. They have many, many different functions. They can act like hormones. They can regulate growth. They can be an antioxidant. They are required cofactors for some reactions in the body and they can be carriers that shuttle chemicals or electrons back and forth.

A key issue that I would stress about vitamins: regulation varies greatly from region to region or country to country. They are considered not a drug, so it's not up to the government to regulate them. When you're going to go buy a vitamin, you're at the mercy of the industry for self-regulating themselves for the quality of what you're getting. Minerals are also regulated like vitamins, even though they come from nature. You wouldn't think there's much variability, the issue would be, is the concentration of what you're getting in your supplement what it promises to be. That kind of regulation. Minerals are elements. They're all found on the periodic table and they exist in nature, typically not in an organic molecule, in the rocks, and in the soil. They become incorporated into organic molecules for use of living things.

The busy-looking molecule on the right side is actually a chlorophyll molecule, which has a really similar structure to a hemoglobin molecule. It's got magnesium in the middle, rather than how we have iron in the middle of ours. On the periodic table, you can see all the purple elements. They are the ones that are more common in larger quantities in our bodies, including hydrogen carbon, nitrogen, and oxygen for all the organic molecules. And then there's the large quantity ones like sodium, magnesium, potassium, calcium and phosphorus, and then smaller ones that we consider trace, and then the green ones are considered ultra-trace. All of those that are listed on the periodic table are considered important and necessary in human physiology.

That last category is a big gray zone because it could be anything. The molecules I have up here, the one on the top left is caffeine. The one in the middle is blue dye #1. The one on the upper right is BHT, a preservative. Then we have curcumin and quercetin on the bottom right. They can be anything. They can be hybrids of other molecules like glycoprotein is a hybrid of glucose and protein. Glycolipids are a combination of carbohydrate and fat. Lipoproteins are a combination of fat and protein, and so on. They can be food additives, fillers. They can be good for you. They can be bad for you. They're in your food and your supplements. Is there such thing as a superfood? No. It's a marketing claim. Some foods are touted as superfoods because they're more nutritionally dense than other foods, and some more easily digested than others that might have a similar nutritional content. You can quote me, kale is not going to solve everything, neither is hemp, or chia, or blueberries, or acai, or beets, or anything else that somebody wants to call a superfood. The Europeans are way ahead of us because they actually regulate the use of the term. It's used very freely here in America.

Can diet and supplementation cure Ehlers-Danlos? Well, there have been no studies that prove that any particular diet modification or supplementation directly addresses any of the underlying defects. That's not to say that diet and supplement can't help you, but the point is, it's not going to change the disorder. No studies have identified a specific compound or compounds that universally everybody with one or more of the types of EDS needs to avoid. There have been no identified medical foods that are specifically regulated by the Food and Drug Administration or the European Food Safety Authority that are specifically labeled for dietary management of EDS, whether it be nutritional formulas or just for oral nutrition, or specific metabolic disorders, or even rehydration.

One question I get asked a lot is, "Well, should I take collagen? Should I eat collagen? Should I cook collagen?" Connective tissue is made of cells and a matrix. The matrix is where all the action is going on with gel-like fluid that has lots of different molecules in it, and one of the molecules is collagen. The jobs of those fibers – they promote the flexibility of tissue, or they can fill space. They can allow for stretch and recoil, like elastic fibers. Microfibrils are needed for building and support and the other fibers get built onto them. The key here is that EDS is a disorder that, in some of the forms of EDS, the collagen is faulty. In other forms, we have not found a biomarker and we just realized that we have faulty gene products that regulate or interact with collagen. Collagen is assembled from a whole set of amino acids, so if you're going to eat it, it comes in this big long chain of amino acids. The minute you eat it, it gets digested and broken down into individual amino acids.

If you already have a problem correctly utilizing these amino acids with your genetic recipe for your connective tissue, it's not going to work. It might give you an advantage that you at least have the building blocks to give it your best shot, but, typically when people are saying that they feel better because they're taking a collagen supplement, it's more because they probably aren't getting those building blocks, the glycine, proline, lysine, vitamin C, or even because they're drinking enough with their collagen supplement to hydrate themselves. I wouldn't waste your money on collagen supplements. I'd spend it on other things if you can.

"If I have Ehlers-Danlos and diet and supplement can't cure it, why would I bother changing my diet or taking supplements?" Well, the existing literature is very clear, even though it doesn't tell us specifically about diet. It tells us, when you have EDS it comes with other things. This was a very important paper, and Rodney was one of the authors on it. It talks about autonomic dysfunction occurring very frequently in EDS patients, and mentions some of the key symptoms, especially with POTS. The same article ties together a connection between POTS, or dysautonomia, and gastrointestinal symptoms. We're acknowledging that this disorder comes with secondary or comorbid conditions that are very relevant and can cause significant symptomatology. There's further mention of the symptoms that people have with the GI distress. Another article is, I think, Clair was an author on this one, I don't see Howard – high prevalence of food allergies in patients with EDS. We see food allergies. It seems to correlate with gastrointestinal dysfunction. We also are suggesting a mechanism of collagen or connective tissue abnormality that's allowing this gut surface to promote immune dysregulation, where we're having allergic responses falling between IgE and TH2 type responses, and they're mediated with interleukin. It causes these symptoms with classic mast cell degranulation.

We are aware that EDS has these things: this dysautonomia, GI distress, mast cell activation. There was a recent article, July 2016 out of, I believe, Duke, I believe. We are well aware, and this has been studied, there is a higher incidence of rheumatologic issues, including structural problems as well as inflammatory or autoimmune problems in persons with EDS than there is in the general population. I'm not sure if this article has been talked about, but I've been saying this for years, so I was really pleased to see that this came out and validated what I was already saying. Next, we see a mention. Just a couple years ago of a new disease cluster: mast cell activation syndrome, postural orthostatic tachycardia syndrome, and Ehlers-Danlos as a triad. We're starting to see this mention of really recognizing how these things run together. And then we have an article about a potential mechanism that might explain, in these families that have hypermobility, these multiple symptoms consistent with this triad of disorders, where we're mentioning triplications in a particular gene that could be a potential mechanism in these people. It ties us all together.

What I'm getting at is, if I have EDS and diet and supplementation can't cure it, why would I bother changing? Well, because you can eat and you can supplement for all the things that go wrong or many of the things that go wrong in it. The secondary or comorbid issues can be significantly aggravated by some of the bad dietary habits, or some of our Western-adopted dietary habits relating to our proportions and types of carbohydrates and lipids and proteins, our lack of vitamins or our lack of variety in our diet. What I'm sharing with you is, there is – I have a typed paper that I hand patients that when they come and see me in consultation because I got tired of verbalizing it. I finally wrote it down one day. That got put out there on the internet a while ago, and I didn't want to come to this talk and just review that list of guidelines that I give. I wanted to be able to have a talk that would stand on its own, that you could refer to, that explains how it was I got to these recommendations. The best way I could think of organizing it was treating each different kind of nutrient and how it fits in, why we give the recommendations we do about it.

When it comes to carbohydrates, I've just put for a reminder the flow chart that talks about the different kinds of carbohydrates and how some are good and some are bad. Some can lead to the glucose fluctuations and some have a nice steady level. The other illustration is actually a set of amino acids and the modifications that they undergo for phenylalanine to become adrenaline. In my mind, bells immediately go off when I hear that. Phenylalanine is where [they] derive aspartame from. If you're taking lots of phenylalanine, how does that – I don't know. I know it's something that I'm going to want to read more about. If it feeds into adrenaline metabolism, and people have dysautonomia. I have to wonder. I tell people to drink isotonic fluids, rehydrate, support your intravascular volume, avoid excessive amounts of hypotonic fluids.

Protein, again, that's where I'm getting at these amino acid precursors and where they fit in with things like dysautonomia. With the lipids, we want to limit the bad fats, which end up causing insulin resistance and POTS actually occurs with respect to vitamins. Vitamin B12 deficiency can significantly aggravate an underlying dysautonomia. Minerals: I want to see people liberalizing their salts. This has been talked about before. Magnesium is actually an alpha-adrenergic blocker. If people are dysautonomic and tachycardic, if they're short on magnesium, their adrenaline can run wild. If they are repleted, it may tone down the adrenaline function, especially with respect to heart rate. Eat to minimize gastrointestinal dysfunction. The big message here, you'll see mentioned over, and over, and over again: you want to work to improve your bacterial population because they do the work for you. They will help you with metabolism in a healthy way, your carbohydrates, your lipids, your vitamins, your minerals, everything. It's a key to what I espouse with changes for gastrointestinal related issues. I've given you a list of all the ways that are in the literature, shown to help to support or normalize your bacterial population.

Eating to minimize immune dysfunction is highly individualized. It takes having food intolerances, allergies, eosinophilic reactions, mast cell disorders – have to be on the radar and have to be taken care of. People may need to use a food journal to recognize how their immune system is reaction to specific things they've eaten. They should really strongly consider just getting rid of notoriously inflammatory foods because it's just – I see results with people when they're proactive and they just avoid them. I've not had a person come back to me and not tell me that they're doing better. Supplementation is commonly required. I prefer that people get their minerals from foods rich in those minerals, and the same thing with their vitamins. If you do have a deficiency or you have clinical evidence of a deficiency, even if your labs are normal, but you have all the signs of it. You really need to go after repleting them. The five common ones that I see are magnesium, vitamin B6, vitamin D, vitamin B12, and vitamin C. Deficiencies in those areas exacerbate some of those other comorbidities that we talked about.

They can be challenging to address because your very interface that you're trying to absorb through can be the problem. You may need shots, IVs, topicals, something to actually get that into you. It may not be a matter of what you swallow because you can't absorb it. In the interest of time – this is a massively tangled web. Dysautonomia can aggravate GI problems and immune dysregulation, and they each can aggravate one another. Because all of those things are so complex, and every person is unique with other factors, we have to consider a multidisciplinary approach. It sometimes takes professionals speaking to one another, and it may be more than one clinician can handle. That probably is the experience of many of the people in this room. It's like playing Jenga. You try to adjust one thing and something else goes wrong, or you try to work with one clinician and you end up getting sent to another, and you just feel like it's too tangled.

I'm going to switch gears a little bit. This is Little Joe. Little Joe was a canary who had a job and he died in 1875 at the age of 3 after he served his time helping his friend in the coal mine, letting him know as an early warning system, that things are bad in the coal mine. This is the way I think of us. I find it analogous to the coal mine. I think that, whereas you've got carbon monoxide in this coal mine, that somebody is more vulnerable to than the general population, for whatever reason, I could hypothesize or go into a lot of detail, but, for whatever reason, those of us with Ehlers-Danlos seem to be a lot more vulnerable to all the things that are bad, potentially dangerous, about our Western diet, our modern food industry and the whole era of better living through chemistry.

I don't want to reinvent the wheel. This guy was one of Time's 100 Most Influential People in one of recent years. He's a best-selling author and I really was astounded to see that I had not read his books. I really had not known much about him. I did read the essay, but when I compare what I came up with during the course of treating patients, it's really very similar, the whole eat foods, mainly plants, not too much – f you don't want to order those two books, which I think are very, very relevant and I probably will now be planning to encourage my patients to refer to those two as a credible source. It is not just this man's opinion of how we should be eating. It is heavily referenced. There are many pages in the back of the book of peer-reviewed journal articles that explain how his essay and his book about how the modern food industry has affected the way that we eat. They're backed up with evidence and scientific mention.

I find it a lot more appealing than some of the social media blog-level treatises on why raw food is better than paleo, is better than Mediterranean. This is more just a commonsense approach. For those of you who don't want to buy the book, this is the lengthy essay that appeared in the New York Times several years ago. I think it really summarizes – it's kind of higher-level reading – but it summarizes some of his issues. I was particularly struck by him talking about nutritionism and talking that it's an ideology rather than a science because it has unexamined assumptions. The assumption is basically that nutrients are the key to understanding food. He spends his time dispelling that idea that we need to get away from thinking of nutrients and thinking more of food, not food-like substances.

I'm going to switch gears one last time and talk about something I'm not sure that anybody has covered. We talk about genetics and the genome and our own individual genome. It's what a genome – my genome makes me unique from you and your genome. The epigenome is actually something that you should become familiar with. It's a growing body of knowledge. It has to do with chemical compounds and proteins that mark up and affect your DNA without changing the sequence or the structure. What it's doing is telling your cells how to express the DNA, rather than what's in the DNA. It involves methylation and histone modification. The important thing to know is these marks within you when methylation happens or the histone modification happens, those changes stay and they're passed from cell to cell when the cells duplicate. They can actually be passed from one generation to the next.

The key to the epigenomic inheritance issue is that, typically, we were taught that any kind of marking of our DNA that had expressions change throughout our lifetime, that would be reset when we reproduce. In reality, we are learning that under certain circumstances, these chemical tags on the DNA actually get passed from one generation to the next. Bear with me, this is a study about reproductive inheritance and it was talking about maternal epigenetic inheritance. It showed that grandmothers, when they were pregnant and smoked—and this was done on humans, they didn't make rats smoke—they delivered their child and then that child's child showed up as asthmatic, regardless of whether the second generation smoked. They passed on, through their second generation to a third generation, these epigenetic changes. We're familiar with things that happen *in utero* and we think that, okay, what Mom did while she was pregnant with me, that might have affected me. There's dad's too.

This study is particularly relevant and how I'm wrapping this all up. The king of Sweden wanted very detailed records about harvests and there were such detailed records that scientists were able to go back and look at, was there a period of feast or a period of famine? Did they have plenty? They showed that if the grandfathers had a period of plenty and they ate plenty, their grandchildren had much shorter lifespans and died of problems like diabetes and obesity if they ate too much or if they overate compared to the calorie-restriction and the limitations without free reign on diet that happened when they had very poor harvests. The grandsons of those poor harvests had longer lifespans. This was examining these epigenetic mechanisms, capturing nutritional information about the environment and passing them to subsequent generations.

When I said you are not what you eat, it's that, more accurately, you are unique. You are complex. It involves not only what you eat but what your food eats. If you eat grass-fed beef versus grain-fed beef, versus hormonally altered things—what your ancestors ate, what your gut biome can help you digest, what you can absorb, and what your metabolism can do with it, which is influenced by genetics, epigenetics, congenital factors. Nature and nurture with diet lifestyle and environment. It's all what you can effectively utilize, minus whatever waste and toxins you eliminate. You are not what you eat. That's it.

I wanted to come in under the wire because I'm known to talk a lot. I guess the point of that being said is, my hope for this organization in the coming years, I would like to see more and more and more effort put into early diagnosis, pediatric clinician involvement because what I see when I prepared for this talk is that it's hard enough to figure out what I have to eat right now. I have EDS. I live this too. When I think of I have four kids. They're going to have kids. It's too late. Whatever I did before I had them is now potentially passed onto them. It really matters. I'm becoming more and more passionate about it. Sorry to go over on that one.

Transcription by Christina Cole