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1.INTRODUCTION

I shall best begin by telling my story and how I came to the idea of writing this book in the hope of giving others, who might be in the same situation, a chance of regaining some quality in their lives.

It was one of the most beautiful summers that I had ever experienced in the city of Vienna. This is where I grew up and go back to, to visit my friends and my father. I have lived there most of my life although my family originally comes from the UK and The Netherlands. It needs to be said that I am normally a very positive person, full of energy, who shrugs off minor ailments. So although some of this chapter might read like one long moan - that’s not how I am. But I have to spell it out in order for you to understand it-so here goes.

I had been feeling a little queasy, to say the least, for quite a while. Only a few weeks earlier, while still in the UK, I had a problem with one of my teeth, an infection, and was given an antibiotic - later in my voyage of discovery I was to learn that this antibiotic contains one of the very substances I should not have taken in combination with all my other health issues. The barrel was full already and this medication caused the barrel to overflow and sparked off a very severe reaction.

A year earlier I had started feeling increasingly tired and occasionally suffered from the “trots”, to put it politely. In addition I was increasingly plagued by cramps in my abdomen. And since this was not happening on a regular basis I played it all down, as one does. My psoriasis, which I have had ever since I can think, started to play up really badly. The previous year I was plagued by a bout of what may have been urticaria – it was nasty whatever it was – which went away again after a few months. No cream I smeared on the red patches seemed to help. The irritating circles just mysteriously disappeared from one week to the next. At the time I did not know what it was, and only during my research, during the writing of the book I have found out what it actually could have been. For several years my legs were swelling up in summer. My eyes were full of gunge in the morning, I blamed the contacts but still kept wearing them out of pure vanity. Before midday I could set the clock by regular sneezing fits after breakfast. I blamed some mystery plants which, according to this particular theory of mine, would have had to release pollen all year round. I also developed a tremor in my early twenties, and was often asked why I was so nervous that I was shaking – even when I felt perfectly calm. When I got annoyed about it I started shaking even more. It seemed like a lose-lose situation, especially when my head felt like it was going to bob off my shoulders when the shake would take over the rest of my body, especially in exam and stress situations. The list of symptoms and occasions is long, and I always had some self-diagnosable explanation for everything.

My speculation was that possibly I just needed some rest because I might have been too stressed, and the pains were because I might be getting my period, although it often didn’t start, and the trots because I might have eaten something that had gone because maybe I had been sold something that was well past its use-by date, or similar... Are you confused? I was!

I guess it was not so wrong with the whole “out of date” idea in a way, but that is as far as I got. Now I know that cured meats and mature cheeses, some of my favourite former foods contain high level of histamine, not because they have “gone bad” but due to the way they are matured. I am continuing to reintroduce them carefully and one by one, in order to test my personal threshold.

So, in Vienna in the midst of all that lovely warmth, while spending the evenings next to open French windows with friends, drinking red wine and eating lovely dishes, mostly with tomatoes in them, and happily working away on a project for a client by day, it all went pear-shaped. The cramps got worse, I got desperately tired. On top of that I felt sick, or rather bloated, in my abdomen. “Ah, it’s a bug!” I thought. Going to the doctor did not cross my mind. I felt I had no time for that anyway, as usual. I held out until about the fourth week, when I decided that it might be something more serious than just a bug after all and that maybe I should listen to my friends and go to the doctor.

Sitting in front of him, I told him of my dilemma-that I had to continue to work because I am freelance and must keep clients happy or else I fear I might not get a good reference, which is what is vital to my career. You’re only as good as your last job. I work as an Associate Producer and Fixer, mainly on television documentaries. It is a tough job that involves a lot of pressure, with long and stressful days, but is still very rewarding. You really need to be fit for this job otherwise you won’t last too long in the industry. I had not seen this particular medic for a long time because I had moved to the UK a couple of years earlier. But he had broadest knowledge of my medical history. In general I always went to doctors wherever I happened to be in the world, so my data is certainly spread around. I told him about the last years, that I had been to doctors several times because of various cramps in my lower abdomen, but they had never found anything and put it all down to stress or something similar. What they all agreed on was that absolutely “nothing was wrong with me”! I was truly confused by all of this, because by now I was convinced that there was something really weird going on. Had I turned into a classic hypochondriac?

The doctor listened patiently. First of all he gave me a good old Viennese-style, but still friendly, telling off. I should have been sitting in front of him four weeks ago when it started. Diarrhoea is nothing to be messed with. He suggested we do some tests. One of them would be for an enzyme called diamine oxidase. At my request he explained what it was and why he did the test, but it all went right in one ear and out the other. I was too exhausted to take anything in.

A couple of days later it turned from bad to worse. My body reacted badly to anything I ate or even drank. I was dehydrating really fast, and we were in the middle of the hot phase with my clients. I did actually tell my clients that there was a small problem, and promised to keep someone else in background as back-up in case I or my clients felt that I was unable to work on the project according to the expected standards or put myself in any danger. I muttered vaguely about a “grumbling appendix”.

I checked with the doctor, and he gave me advice on what I should do-basically to go home and look after myself. Finally I was presented with the facts. I had very low levels of the enzyme diamine oxidase. The result was that I suffered from Histamine Intolerance (HIT). I was to avoid tomatoes, aubergines, spinach, cured meats, mature cheeses, and most of all my beloved red wine. Information pack in hand, I went back to base, and shortly after, home to the UK. At last – my condition had a name!

The list of foods to avoid or reduce for a while was long – very long. At first glance I felt there was nothing left to eat. The list of “forbidden foods” was basically all those things that had been on my plate on a daily basis. I was gripped by panic. But it was a beginning of a new life, a wonderful life full of energy and, most importantly, without pain.

When I returned home the first thing I tried to do was to find a dietician who could help me to work out a plan. I felt like a fish out of water, I needed help. Getting an appointment took an endless amount of time, and meanwhile I resorted to German sources on the internet. I bought German literature on the subject. All that I could get from English language websites was fuzzy, scatty and often in medical terminology quite foreign to me. The dietician I finally was able to meet in a hospital was sweet, sympathetic and helpful, and even though I was admittedly her first patient with this condition she had never heard of before, she actually gave me some great advice on how to go about it all. She did what she could with the means she had, after I, the patient, explained to her what I had read up about this intolerance. By that time I had already started to explain to everybody else around me what this was, so i was pretty good at it by now.

The diet seemed to work – kind of. Four weeks further down the line things were quite a lot better. I started to go on a really “healthy” diet, tried to learn more about 5-a-day principles, and learn to cook. But something wasn’t quite right. I kept on really getting nasty bouts of wind and diarrhoea, sudden, painful, that sometimes even had me lying on the floor, as I had in the past, gasping for breath. I just couldn’t figure it out, even when I was really good and cut out the alcohol altogether – which I was not always very disciplined about.

On my next trip to Vienna I went to visit my father once more. We were watching TV, his wife had just made a low-histamine dinner for me, when an item about an HIT patient was broadcast on Austrian TV. She explained about the HIT condition and the two other intolerances she has on top of that, and how she selects her food in the supermarket. I decided track her down. Through her I was able to contact several HIT patient who are members of self-help group. All of them urged me to get some more tests done, since they did not know anyone who just had histamine intolerance alone. The stories of their particular search for the truth behind their symptoms were truly mind-blowing.

So I went back to the UK and contacted the GP. Of course, I had to explain what it was about all over again because I got to see a different GP from last time. But things were going so slowly through the system that by the time I went to Vienna again. I still had no answer. Not much time was wasted in deciding to go back to the Austrian medic. I must add to this point that when I went for these tests I was in full denial. The prospect of having to combine two diets with two very long lists of foods to avoid was gruelling, unthinkable and felt a bit like a “well you might just as well stop living then” kind of life sentence. I vividly remember saying “I am sure that I don’t have any of these, but I just want to check, and prove everyone wrong”, and putting on my brave smile.

I had tests done for gluten, lactose, fructose and a long list of allergies. All of them were negative-except for one. Guess what-I also happen to have dietary fructose malabsorption. Surprise, surprise. And guess what again... with the tweak I have been able to control the symptoms, although it was all terribly complicated at the beginning. So here’s everyone in Vienna, “Thank you! Thank you! Thank you!”

Within only six months I learned to cook all kinds of different meals which would not even have crossed my mind before. I have learned the experiment, pick different meals and adapt them. My HIT symptoms have gradually subsided in the last years, except for a few days before my period is due, or when my symptoms in the bowel area are triggered by a dietary error due to my additional fructose malabsorption. If I am lucky then the diamine oxidase levels will be normal again sometime in the future. But who knows when or if. For all I know I will just have to live with it.

Over time I realised that there are only a very few medical professionals who are even aware of the existence of this intolerance. The situation may not be perfect in continental Europe, but I can confirm that at least it has reached public awareness in the German language area to some degree. At least every second person I talk to there has grasped the general concept, and I have even met people on my travels that have been diagnosed. Some pharmacies will immediately pull up their information on their computer and give you advice on what you should or should not be able to take.

Bering the daughter of two former war correspondents and myself having taken the route of working in the world of television documentaries, I dropped myself quiet deliberately into a flurry of research to try and find out what the deal is. The deal looks distinctly rotten for those who are affected by the condition. No matter where they are in the world, most HITers are struggling with their diet, do not know what medication to take or not to take, have no idea if their reaction is because of HIT or something else. Many are diagnosed and left on their own devices once their pockets have been emptied. My question is, how can this be in what we call the modern age? Aren’t we supposed to be a little more advanced than this?

Concerning the number of people currently affected, there are several estimates swirling around. Personally I don’t care about an exact number or statistic of people who are out their struggling with this rather elusive intolerance. It doesn’t matter anymore if it is thousands or millions. We are not a number but individuals, each of us with a life, family and friend.

The main objective is that help becomes available for those who have this condition, for whatever reason. I do understand that since the diet really is the key, and there is not much to sell here, there is little interest in research. I also understand that the media still needs some more proof of its genuineness and significance, and that, at the time of writing this book, this may still be considered to be something we might call a “niche subject”=less interesting because of limited reader, listener or viewer numbers. I fully comprehend that at least some in the pharmaceutical industry have little interest in purchasing any further research because some of their products will certainly be branded unsuitable for a lot of their consumers once research is confirmed, hence less profit. I also understand that there may not be much participation from a lot of food manufactures, since the prospect of having to admit that certain meals consist of chemical brews and are actually not suitable for a percentage of the population, and in the case of someone with HIT can even be a cause of death from anaphylactic shock, is certainly not what they are aiming for.

BUT:

It is absolutely priority that this subject is being properly discussed out in the open, and there is a proper system in place in hospitals, at GP’s practices, dieticians offices, dentists, the lot, for those who have this condition. Those who have HIT should be equipped with a pass similar to those for diabetics, and should not be turned away at hospitals and told “sleep it off”, just because hospitals may not know what to do with them. This is one more of the rather bizarre and forgettable experiences I have had in the last two years-and apparently from what I hear I am not the only one who has experienced problems at a hospital... I was able to deal with it in the end, but I was reeling with anger after having to cope with a nasty infection. Not exactly the best for an HITer’s histamine count either, which automatically goes up when a person is stressed. If hospital staff had the relevant education, training and the information then this would not happen in the first place.

The following chapters are based on peer-reviewed and published research conducted by scientists and researchers all over the world. References can be found in the back of this book. Whatever conclusion you may come to after reading these chapters, if you think you might be a candidate for histamine intolerance then I strongly advise you to consult with a GP or nutritionist about a diet. It would be even better if you could get yourself referred to a professional who has a grounded knowledge of allergies and intolerances. Do make sure that any people offering medical advice outside the NHS or any other state-sponsored system are registered practitioners. In the UK, for example, that would be with General Medical Council (GMC), where you can check whether the doctor you plan to visit actually has a license to practice (further information on the GMC website [www.gmc-uk.org](http://www.gmc-uk.org)). Self-proclaimed experts or so-called world-experts, especially on the internet, are not to be regarded with extreme caution, and should be checked thoroughly in advance before you put your life in their hands.

If you do decide to go on this diet then I have included some recipes in the second part of the book. These are recipes that I have either worked out and tested myself or have been supplied by friends. They are food for ideas and need to chosen accordingly to the person’s degree of intolerance in combination with any other conditions. This means that not all recipes will be suitable for everyone. All in all, do not be afraid of trying out new versions, adapting old recipes you may once have liked. There is a lot you can do.

So here we go: Experiment! Experiment! Experiment!

2. HISTAMINE INTOLERANCE – IN A NUTSHELL

Knowledge is a power. Some of you may find this chapter really hard going, but I urge you to persist. Others will devour the knowledge, learning at last what is behind it all. The other reason for putting all this information here is that you can take it and rub it under the noses of those who just don’t believe that HIT exists. Friends and family, doctors and dieticians, may need a bit of convincing. It also contains information you can refer back to if something is not clear in a later chapter, or in something else you are reading on the subject. But don’t worry. Plough through this and it gets easier, more down to earth and more personal. I promise.

***What is histamine?***

In chemical terms, histamine is one of a group of biogenic amines. Histamine is produced as a result of the breaking down of histidine, its predecessor, with the help of microorganisms such as bacteria and yeasts. It’s s fellow that has its finger in all pies. Histamine is present in many parts of human tissues. There it is stored in those tissues together with other substances mostly in grain-shaped deposits (granula) in storage units (mast cells). Additionally there are other elements of blood (basophil granulocytes) which will store histamine amongst other substances. In healthy humans these storage places will release histamine when necessary in order to fulfil their tasks. Let’s talk about the positives first: it helps us as neurotransmitter sending messages throughout the body, contributes to the regulation of body temperatures and to our memory. It also helps us with the wound-healing process, takes part in defending us against substances that are foreign to our body, stimulates gastric acid secretion and bowel movements, transmits chemical signals in the brain, has an effect on the smooth muscle tissue of lungs and the uterus, and it provides us with the widening of our blood vessels. It even plays an important part in the sleep-wake cycle. All in all it is quite an all-rounder and a very essential piece of our kit.

***What is Histamine Intolerance?***

Histamine Intolerance (HIT), also known as Histamine Intolerance Syndrome (HIS), and sometimes referred to as enteral histaminosis, is a condition that is caused by the lack or reduced activity of an enzyme called diamine oxidase (DAO). A lot of DAO is produced in the intestinal mucosa, the membrane that lines your guts, and is generally responsible for metabolising (breaking down or processing) histamine and other biogenic amines that enter our bodies in the form of foods and drinks. Among those foods which have been classified as having higher levels of histamine are tomatoes, spinach, aubergines, avocado, pickles, cured meats, mature cheeses. Yeas has been accused of being a histamine production catalyst during the processing of foodstuffs, especially when hygienic standards are not up to scratch, even though the actual yeas itself, nowadays, should not contain histamine anymore. There are also other foods, such as fruits containing citric acid and strawberries, which are believed to release the histamine already stored in mast cells. Certain additives in food and drinks, such as glutamate, food colourings and sulphites, for example, are believed to have the same effect. The subject of food and histamine will be looked at more closely in the following chapters. There is also another enzyme by the name of histamine-N-methyltransferase, to be found in the human tissue, which are currently takes a bit of a back seat in discussions, although it should not be ignored! Patients, who are taking medication which blocks this enzyme should consult their doctor about possibility changing to another more suitable medication.

***What is diamine oxidase?***

Let’s first of all get to grips with one of those names for DAO. In medical and scientific circles diamine oxidase (DAO) is also known by the synonym “histaminases”. In the article by the German medical journal “Ärzteblatt” in 2006 the term “histaminases” was defined as the “former description” of diamine oxidase. This is just a note to keep you from wondering what this is all about if you come across it. Don’t let it throw you.

DAO is responsible for metabolising – thus breaking down – histamine, and also other biogenic amines – the close relatives of hista- mine, so to speak. (These other biogenic amines also play an important role in the way our body functions. Some act as neurotransmitters or tissue hormones, some are found when something decomposes. A selection of these biogenic amines is tyramine, dopamine, noradrenaline, tryptamine and cadaverine. Putrescine and tyramine, for example, is also found in red wine. Cadaverine is a bacterial product which we can smell when animal tissue is decomposing).

The highest DAO activity was found in parts of the intestines, in the kidneys and in the placenta.

You have to see DAO as being like a regiment of little security guards most of whom are ready and waiting to intercept an advancing mass of histamines and/or their relatives. When too big a crowd of histamines arrive, then the DAO guards might be overwhelmed, either because they have been outnumbered, or because they are wrestling with histamine’s brothers and sisters, or they might have been sedated by the outsider, often by slipping them a dose of a specific medication. The histamines are then free to rampage through your digestive and the rest of your system and can at some point reach a toxic level. Parallels with an uncontrolled crowd entering a football stadium come to mind.

***What is Histamin-N-Methyltransferase (aka HNMT or HMT)?***

Histamine-N-Methyltranferase is an endogenous enzyme (produced within the body) and is responsible for breaking down histamine inside cells. HNMT is able to deal with it up to a certain extent. If the patient however takes medications that inhibit the enzyme or has the genetic disorder HNMT, which compromises the degradation of histamine, in addition to a DAO-impairment, then it will be extremely difficult for the HNMT enzyme to work properly. This can generate a domino effect. Experts still have much to do in this area of research in order to be able to reach specific conclusions. This book primarily deals with the subject DAO, unless HNMT is specifically referred to.

One last point on this subject: It is worth mentioning here that as part of the diagnostic investigation experts do suggest the testing for histamine and methylhistamine through the use of 12-hour or 24-hour urine collection. Before HNMT leaves our body via our urine it is converted into measurable methylhistamine.

***What can trigger histamine intolerance?***

Now, DAOs are very sensitive little things and do need some tender loving care because otherwise they will not function correctly. There are several reasons why this enzyme can be negatively affected:

* There has been an intestinal infection and the production of the enzyme is disturbed, or the cells in the small intestine do not have a sufficient amount of DAO present in them.
* DAO production is affected because of another intolerance that affects the digestive system (see other intolerances). Not exclusively, but quite often this is when the patient’s symptoms include diarrhoea.
* DAO is blocked or suppressed and its function is impaired. For example, let’s say, if a patient with HIT is given a specific medication, such as a certain antibiotics that suppress DAO, the result could be that symptoms get more severe because histamine is then able to build up in the system to an uncomfortable level. Other blockers are hidden in specific foods and additives.
* Other foods, food additives or medications may have a histamine-releasing effect. Just one example is morphine, used in anaesthetics, also for surgery. A person who is unable to degrade the released histamine and who then adds more through food will certainly feel the effect and can be at risk in hospital.
* Other biogenic amines, such as tyramine, putrescine, spermine and cadaverine, also need the DAO enzyme in order to be broken down. Putrescine is broken down by DAO before the histamine gets its turn. This can also cause a temporary DAO shortage. There’s just not enough to go around.
* Alcohol is an arch-enemy of our DAO friends. It releases histamine that is already stored in the body cells, then uses one of its by-products called acetaldehyde to suppress the DAO enzyme. This also enhances the effect of other biogenic amines, histamine’s close relatives, who happen to pass through at the same time.
* In some very rare cases, it appears, people have been born with DAO deficiency.
* In the case of an additional genuine allergy the body itself starts to release extra histamine. If foods with a high amount of histamine are eaten at this stage, then it is possible for the amount of histamine in the body to reach critical levels.

Histamine Intolerance can turn up temporarily and in many cases it can disappear again completely – for example when someone has had a stomach bug that was successfully treated, or when another food intolerance which has caused diarrhoea has been discovered and been brought under control.

There are several mechanisms normally at work in our bodies that stop an excessive amount of histamine from entering the bloodstream. But if these mechanisms fail because of reasons above then the person concerned can be facing some very unpleasant consequences. The severity depends on the individual threshold.

***Food poisoning and HIT***

The best-known example of histamine “overdose” is food poisoning from fish, also known as scromboid – or ciquatera fish poisoning, when high histamine levels develop due to bacterially contaminated or inappropriate storage and are often at least a partial contributor to severe illness, especially after consuming warm water fish such as tuna. This can affect anyone, however. When two people have exactly the same meal, a person with a low histamine threshold can be severally ill while a healthy person may only feel slightly off-colour. An uptake of >200mg of histamine has been classified as toxic and is part of the disease pattern of histamine intoxication (scromboid intoxication). Several rules and regulations have been established by the European Union in order to prevent fish products with high histamine levels from landing on our plates. One of these regulations limits the amount of histamine that fish is allowed to contain when it reaches the consumer.

***Pre-prepared foods and HIT***

HIT patients need to be aware of the danger lurking for them in pre-prepared food. A whole industry nowadays is based on the processing of food, from frozen meals to canned or packaged soup. These widely available products come in all shapes and sizes and have often become a great asset for our society. We all, in some way, have become dependent on the industry, whether economically or just to save time. But this 20th Century development also has its drawbacks and these have only become visible recently. Some of us are simply not able to digest some of the chemicals used as preservatives and taste-enhancers. Even without these, some “normal” ingredients can trip us up if the labelling is unclear. This can turn the mere consumption of a ready-meal into a journey into hell for those who react more severally. It does not mean there is anything inherently wrong with the product – it is just wrong for us! The laws of chemistry determine that a certain build-up of chemicals will at some point spark a reaction, also in our bodies, especially when our diets are very simple and we keep eating the same food regularly. This could explain why we suddenly react especially badly to precisely those food and products we like most. The convenience game turns against us.

Pre-prepared foods have thus become identified as one of the highest ranking culprits with regard to HIT because some of them have extremely high histamine content. More of the reasons why will be explained as you read on. The only positive way out is for the food industry to realise the economic potential of food intolerance and depends on its willingness to cooperate with us, the consumers. They have proved that they can do it, with “free-from” ranges for some conditions. We HIT folk are a big and growing market segment. Together, we can be strong! As a great friend and supporter of mine said, ”Our bodies should not have to cater for the food industry, but the food industry for our bodies!”

***Wine and HIT***

Another example for “overdosing” is red wine. Red wine generally contains high levels of histamine, which is why some people suffer from symptoms when they have had only one glass. Additionally there is the issue of several wines containing the biogenic amine putrescine, which is broken down before histamine by DAO. One of the most well known and very obvious reactions is flushing in the cheeks or red patches on the chest. This is not to be confused with wine allergy, where symptoms appear much faster as a reaction to one or more of the components in the wine. Then we have sulphite, traditionally used in wine production, which can also lead to unpleasant side effects for some. In general a bad reaction to wine, though, does not necessarily have to mean an automatic histamine intolerance since the affected person may actually have an intolerance, or even an allergy, to another component in this particular beverage. This means red wine may be a strong indicator of histamine intolerance, but is not a means of self-diagnostic.

***Why do some of us get HIT?***

Histamine intolerance appears to be a condition that is acquired over time. Some experts are, however, exploring the theory that there is a sub-group of HIT suffers who are genetically predisposed to being affected by HIT. Scientist examining this are trying to find out whether there is a common genetic denominator in this sub-group which is also affected by other adverse reactions to food, such as celiac disease, Morbus Crohn and other similar digestive disorders. It will be down to scientists to get to the bottom of what the basic causes are for a person acquiring it. The current generally accepted hypothesis, though, s that this may be a life-style related issue. Basically our bodies are not given the time to adapt to a fast-changing world. Seeing as how our digestive systems have not changed much since the Stone Age, it is remarkable how resilient they are to what we throw at them.

***HIT mimics allergy and vice versa***

The main problem with trying to define HIT as a cause of discomfort is that, first and foremost, it mimics the symptoms of an allergy. It does this so well that most doctors initially think the symptoms are caused by an allergy. They can be taken in just as easily as someone can be taken in by the double of a well-known person in the street. The symptom caused by an allergic reaction might be asthma; the symptom caused by histamine intolerance might be... have a guess... asthma. Histamine intolerance is very frequently confused with allergies. Excluding the possibility of allergy as a responsible culprit is extremely important, and should be one of first things you should check out. HIT is also frequently “diagnosed” as IBS, which can be another way of saying “I know you’ve got something, but I don’t know what it is, so deal with it.” This response by people who have no knowledge of this condition is understandable because histamine plays the major role in allergies. If you have an allergy, such as hay-fever, then you take antihistamine tablets, don’t you? The words “allergy” and “histamine” are linked in most peoples’ minds, and for a good reason too.

This brings in the subject of the role of allergologists in the discipline of recognising the difference between the two. Future allergologists (who study the medical side of allergies) are well-versed in recognising signs and identifying the cause of histamine-related reactions. An integration of HIT into their field of expertise can only bring them more recognition by patients as well as an upgrade in reputation. Some allergologists have already realised this and are at the forefront of this new development. Much is being discussed about them on the web, which almost certainly puts them in a very good position, at least in the public eye.

One of the organisations that has now integrated food intolerances and HIT into their program is the charity Allergy UK, which has a dedicated team of experts, including gastroenterologists and nutritionists, now working on this very issue. Their services include a dedicated website, a separate forum section for food intolerances, an on-line helpline as well as a telephone helpline. A highly encouraging development to say the least.

***The difference between HIT and allergy***

But allergies and HIT are completely different, and they can both show up in different ways. In the case of allergies, histamine is released by the body as part of an excessive immune system response to a normally harmless substance like pollen or peanuts. Cross-reactivity in people who are allergic to certain pollens or other substances also plays a role. On the other hand, in the case of HIT the immune system is not involved at all. It is more the fact that our old friend DAO and/or HNMT are not doing their job properly, for whatever reason. Another major difference is that symptoms can be felt almost instantaneously in a type I allergy and in severe cases can result in an anaphylactic shock even when the person is only exposed to a trace of the culprit substance – remember the horror stories about traces of peanut, resulting in the “may contain nuts” labels on packaging, or mention of the fact that something has been produced in a factory where nuts might just have been some time in history... In the EU producers of industrially processed food therefore have had to print the mandatory warning label “may contain traces of nuts” on their packaging since November 2005. The EU regulation of 25th October 2011 on the provision of food information to consumer puts manufacturers under the obligation to declare a total of 14 types of the most common trigger of allergies. The EU regulation additionally makes it mandatory for food business operators – which includes restaurants, canteens, cafes, hotels, guest houses, market and other stalls and buffet cars on trains just to name a few – to declare those 14 allergens and types of food that can cause intolerance from 13th December 2014 on non-pre-packaged foods.

With HIT it is also possible to experience an anaphylactic shock, but it takes much longer to build up this stage. The symptoms of HIT take much longer to appear, sometimes as long as 24 hours depending on how fast it all passes through our bodies. This also depend on the type of food that has been ingested, how much histamine is in it, how much of the enzyme DAO is available and its level of activity, or in how far it has been suppressed by different factors such as certain medications. This makes it all the harder to identify the “culprit”.

***Symptoms of HIT***

The symptoms of HIT might be one or a combination of the following:

***Digestive disorder:***

Diarrhoea, stomach ache, cramps, feeling nauseous, full, bloated

Diarrhoea alternating with normal motions (often diagnosed as Irritable Bowel Syndrome – IBS)

Additional HIT as a result of an intestinal infection or chronic gastrointestinal diseases such as Morbus Crohn or Colitis Ulcerosa

Chronic constipation

Flatulence and feeling of fullness, often quite extreme and irrespective of food intake, sometimes already beginning in the morning

***Symptoms affecting head and face:***

Headaches, similar to migraine, where drugs are often ineffective

Redness and feeling hot around the face and neck

Runny or blocked nose and weepy or red eyes, often during and after meals, although there has been no diagnosis of any allergies

Fits of dizziness, often feeling as though the head is stuffed with cotton wool.

Sleeping disorders, extreme tiredness, often during or after meals, which results in compulsive sleeping disorder and requires several hours of sleep, often without a feeling recovery (feeling “knocked out”)

Sudden psychological changes (e.g. aggressiveness, inattentiveness, lack of concentration), often during or after intake of meal

Panic attacks

***Skin problems:***

Skin rashes, eczema, urticaria, partly already existing for a long time, coming and going although there seems to be no identifiable cause

Acne rosacea (chronic facial redness, sometimes with scales and additionalpimples)

Wheals

Itchiness

***Chest area:***

Asthma

Cardiac arrhythmia, such as a fast beating or irregularity heart beat

***Women:***

Dysmenorrhoea (severe period pains)

HIT symptoms go away during pregnancy and return after birth of child

***Other symptoms:***

Feeling chilly, shivering, indisposition

Low blood pressure (rarely high blood pressure)

Breaking out in a sweat.

In a survey by Austrian Portal for Food Intolerance (nmi-Portal) with 141 affected people the following description of symptoms was established: Headache (38%), flush – redness of skin in the face and neck area (36%), abdominal pain (31%), diarrhoea (26%), runny nose or swelling of the nasal mucosa (19%), bloating and nausea (17%), and rapid heartbeat (12%). Less often, but still in 5% of the cases rashes, itchy skin, tiredness, dizziness and circulation problems were reported.

The worst case scenario can be that a patient suffers an **anaphylactic shock**. In many cases a combination of several symptoms can be seen.

Medical units will face the challenge in future of recognising the indications of HIT, and this will be especially relevant to those experts in field of gastroenterology, allergy and dermatology, but also all other medical fields.

***HIT and other heath issues***

The other problem is that HIT might be one of a combination of health issues from which a person suffers, such as other intolerances, allergies or chemical sensitivities, which is why it is very important to work with professionals to work out the whole picture. HIT often, but not exclusively, appears in combination with :

An allergy to one or several substances

Coeliac disease

Lactose intolerance

Fructose malabsorption or fructose intolerance (rare)

Sorbite intolerance

Casein intolerance

Glutamate intolerance

Quite often HIT has been identified as a secondary condition, caused by another health issue such as the conditions above.

**HIT can be confused with other conditions such as mastocytosis and Irritable Bowel Syndrome (IBS)**

**Mastocytosis – or what happens when the system produces too much for its own good**

Mastocytosis is believed to be a rare condition, which can be overlooked easily because its symptoms are similar to those or other conditions. It can also be mistaken for HIT due to the similarities to symptoms caused by high histamine levels. In very general terms mastocytosis is cause by a proliferation of mast cells. To put it simply: People who suffer from mastocytosis have mild to severe symptoms because they produce more mast cells – storage facilities for substances which are involved in the immune system, to put it crudely – than is good for them. Mast cells release up to 60 sub- stances as part of their defence function for the immune system. Histamine is only one of them, which is very reason why people with mastocytosis have to stick to a diet that is as low in histamine as possible.

Mastocytosis can only be detected via the means of biopsy, not with a blood test. The diagnosis must adhere to the standards of the WHO guidelines and include histological, immunehistochemical and molecular examinetions.

Mastocytosis is differentiated into two completely separate conditions, whereas those are again divided into subcategories:

* Mastocytosis affecting the skin (cutaneous mastocytosis): is a solely dermatological condition. Urticaria pigmentosa is incidentially the most common form of cutaneous mastocytosis. “Cutaneous” means “relating to, or affecting the skin”.

OR

* Systemic mastocytosis: is a haematological condition. Haematological means “relating to the blood”.

If HIT is considered as a possible cause, then it is important to check foe mastocytosis, if there are signs that point towards it. A mastocytosis specialist will need to figure out whether there is any reason for suspicion.

More information concerning the above, paediatric- and adult mastocytosis as well as genetic, anaesthetics and more can be found on the website of the UK Mastocytosis Support Group.

**Irritable Bowel Syndrome (IBS) or Food Intolerance (FI)?**

IBS is often given as a diagnosis when all tests and examinations fail to lead to any other diagnostic result. In some circumstances there is no detailed investigation and the patient is told that the cause of the irritable bowel is psychological, and psychological treatment with anti-depressants may also be suggested. Because there have been some cases in which patients were lumbered with the diagnosis of IBS for years and only much later, after much suffering along the way, arrived at specific, successful treatment following a diagnosis of Food Intolerance, we shall take a quick look into this subject matter.

IBS is seen as a widespread gastrointestinal illness in which the clinical symptoms, which are very similar to those of FI, play the major role:

* Irregular bowel motions
* Diarrhoea
* Constipation, or a mixture of these
* Abdominal pains
* Flatulence

When IBS is suspected, then a differential diagnosis is of the utmost importance. An anamnesis (otherwise known as the case history), determining whether the pattern and the degree of the symptoms matches those of IBS, is decisive. This differential diagnosis should encompass, among other factors, determining whether the patient has a FI. The list of symptoms that present similarly to IBS are the following:

* Infection of the bowel
* Celiac disease
* Bowel cancer
* Incontinence
* Chronic inflammation of the gut (Morbus Crohn)
* Food intolerance
* Overactive thyroid
* Bacterial incompatibility DD
* Microscopic colitis
* Medication
* Neuroendocrine tumour

Organic diseases must be ruled out in advance in all cases.

In recent years it has been shown that in cases of many IBS patients, the trigger has been a severe infection. This is known as post-infectious IBS. In his lecture Professor Konturek also referred to the case history of a Canadian town, Walkerton, with 4000 inhabitants. This quiet town was flooded in May 2000 and as a result the drinking water was polluted with Escherichia Coli and Campylobacter. Over 2000 people in the town suffered a severe intestinal infection. Two years later it was observed that 35% of those affected had developed an irritated bowel. You can find more about this piece of research here: The Walkerton Healthy Study.

The prevalence in the general population in the UK is estimated to be between 10% and 20%. In the USA, about 1 in 6 patients are reported to suffer from IBS symptoms.

It is believed that in Germany around 15% of patients have IBS, of which most are in the 45-65 year age group. Then there is the difference between those patients who have a light, medium or severe form of IBS, and of all these 1% go to see a specialist who understands something of the subject – a remarkable 80% of them receive no therapy at all.

There are no uniform dietary recommendations for IBS – any more than there are for FI. Every one of us has a different combination of problems. Besides eventual medication and probiotic therapy, as well as possible psychological support, a patient with a diagnosis of IBS needs dietary advice that is tailored precisely to their individual requirements. Just as in the case of people with FI, it will be unavoidable for anyone with IBS to also keep a food diary in order to achieve a satisfactory result. The doctor, the dietician and the patient have to work together.

If you suspect that you are suffering from IBS or FI or a food allergy, then please get your general practitioner to refer you to a suitable specialist. If you have been diagnosed with IBS but suspect that you have FI instead, without having had tests for this, then make sure to look up a medical specialist.

***HIT testing issues***

Because of limited awareness and lack of education among doctors, despite research results pilings up to point where they cannot be ignored, tests for DAO activity, developed in Austria and more widely on offer in a number of European countries, are very difficult to obtain. The validity of this particular test is however much argued about and can only be regarded as a momentary snap-shot. Much research is being done concerning genetic testing for the DAO and HNMT status. Whether these currently excruciatingly expensive genetic tests will turn out to be helpful to get a successful diagnosis remains to be seen, because as far as we know up to now, histamine intolerance is normally an acquired condition and rarely has a genetic cause. We can certainly expect more discussion on the topic.

That leaves the sufferer currently with only one option. This is to test for HIT by using a temporary elimination diet. This needs the help of a practitioner who might be open-minded on the subject of intolerances or at least a referral to a dietician. A competent dietician, currently also very scarce in connection with HIT, will work out a balanced diet plan in order to establish which foods are causing trouble. The professionals have to work together with the patient in order to establish how long this temporary elimination diet will have to be maintained, depending on the seriousness of the condition and the number of other health issues, involved. Normally an elimination diet does not last longer than 3-4 weeks.

At the time of writing this book it is extremely difficult to get access to this kind of diagnosis in the UK. If you are unable to get a diagnosis please notify your MP and ask them why you are unable to get the service you are requesting.

***The speculation over numbers***

It is difficult, of not even impossible, to say what percentage of the population suffers from HIT. The lowest estimate given is 1%, the highest 5% in the Western population – though some sources believe it is even higher. It is also difficult to determine at this stage what degrees of HIT affect how many people. If we take the most conservative estimate of 1%, on the basis of a French study quoted by Professor Reinhart Jarisch, the head of an institute for allergy and food intolerance who has been studying the subject over a long period of time, this would mean that approximately 600.000 people in the UK, for instance, are affected by HIT to a greater or lesser degree, depending on their individual threshold. That is a great many people considering that only a very few know about it. An estimated 80 percent of those affected are reckoned to be female and they are predominantly aged around 40.

***Discussion topics***

This gives rise to a whole bunch of questions: Why do so many medics not know anything about it? Is it because there is little funding for research on the subject, or because there is no backing for research from a powerful major company that might see a prospective financial gain – because there is no “magic bullet”? Have medical professionals got stuck in the rut of scepticism with regard to food intolerances as was prevalent a decade ago? Why have they not moved forward to use fresh scientific knowledge to establish the validity of these adverse reactions to food? Have they not kept track of the scientific evidence that has been produced since then?

How much money is going down the drain at the different health services in each country because people are being treated for the symptoms but not the cause? These health services have huge budgets to provide care for their consumers, us, the patients. Most patients who feel well will certainly not to go to the doctor without a very good reason. How much suffering is being caused to patients by this lack of knowledge, or downright ignorance? How many patients are thus being prescribed the wrong medication which, in many cases, makes their condition worse, not better? How can it be that a condition that can be controlled by a change of eating habits and, in theory, does not require any extra medication, has been overlooked and under-diagnosed?

A big re-think and more patient-friendly approach is desperately needed, unless many of those in the medical profession don’t want to redeem their honour and their celebrity. We patient are not stupid. We need people who listen to us, not people who tick boxes in order to meet targets. We need doctors who will work with us, not patronise us. Many gods in white have a nasty smudge on that pristine coat and do not look quite so divine and all-knowing to their patients any longer. Along the way they harm the reputation of those colleagues who are doing some fantastic work. So many patients are flocking in desperation to all kinds of alternative medicine, some of which may be good for a partial solution and some of which may result in you being given advice that could be extremely harmful...

3. HOW DO I FIND OUT IF I HAVE HIT?

***Questions to ask yourself***

Should you be able to answer two or more of the eight questions below with a yes, then it is a clinical indication that you may be suffering from histamine intolerance. It would then be advisable to take this knowledge to the medical expert you believe is most suitable to help you to obtain a further diagnosis.

1. Do you frequently have headaches or migraines?
2. Are you intolerant (do you get any obvious symptoms) to red wine and other alcoholic beverages?
3. Do you have any bad reactions to mature cheeses, cured meats, tomatoes, ketchup or chocolate?
4. Have you had any stomach or intestinal troubles, especially with soft faeces or diarrhoea over a longer period of time?
5. Have you frequently suffered from low blood pressure?
6. Have you had any heart problems such as a high pulse rate (tachycardia) or heart rhythm disturbances (cardiac arrhythmia)?
7. For women: Do you have severe pain on the first day of your period (dysmenorrhoea)?
8. Do you experience sea sickness or motion sickness?

***Where do I find an expert – or finding your way around the labyrinth?***

This is unfortunately still a bit of a challenge. Clinical establishments in many places still know little or nothing about HIT. This leaves people affected by HIT to fend for themselves. They remain extremely vulnerable.

There are labs scattered all over the globe that offer tests via the internet. Some, for example, offer to send a test kit to your home, to take to the GP, and then send the sample to a pathology lab close to your home. There is no talk of anamnesis on some of the sites. The cost is sometimes prohibitive and you need to look closely at what form of transport is chosen as well as whether the blood sample is still valid by the time it reaches the lab, depending on packaging, length of transport as well as temperature fluctuations, and whether that particular lab has had much experience with this test in the first place. Some of the companies might be very professional and know what they are doing, but just snooping around the net and selecting anyone at random could easily be compared to putting your money in a slot-machine at the Casino. You may be lucky, but the risk is high, and it is your health that is at stake.

In the UK it is possible for a GP to send the blood sample to a lab that provides services to doctors. This will cost the patient approximately GBP 50,- at the very most as of 2013 (also see the section about different points of view on diagnosis a little further on in the book). This cost is currently not covered by the NHS.

In 2009 the NHS Customer service Centre at the Department of Health declared that “Neither Departmental officials nor the NHS professionals whom we contacted were aware of this test”, and further stated that “It is not one that is offered in mainstream NHS Clinical Pathology Accredited laboratories run by appropriately qualified immunologists that provide NHS specialised laboratory diagnostic services for allergy”. And further, “It is conceivable that the test might be offered by some private laboratories in the UK, or by laboratories in Europe. As it is not an established NHS-provided test, neither officials nor NHS clinicians are aware of any information validating the quality or validity of the test, or any evidence that it yields result that are clinically meaningful”. At the time this was quite a disappointing answer to say at least.

By the end of 2012 there seems to have been a change of policy and a sudden acceptance of Histamine Intolerance as a health issue. In reply to simple question whether they could tell me where it would be possible to get diagnosis for histamine intolerance, I got the following reply from the Ministerial Correspondence and Public Enquiries office at the department of health:”Thank you for your correspondence of 14 November to the Department of Health about getting a diagnosis in the UK I would suggest that, in the first instance, you consult GP to discuss your concerns. Your GP can conduct an examination and arrange for any necessary tests...”.

Well, well, well. Is it true? Can I believe my eyes? No confusing answer about allergies? This may not mean much to many, but for me this is a small step in the right direction, which is the recognition of histamine intolerance as a health issue by the authorities. A recognition that means that those who are so seriously affected by it may in future have a shorter path to diagnosis and pain-relief than so many of us have had up to now. Years of useless visits by patients to their GPs and other specialists when the problem could be recognised much earlier, and the excessive use of medication to control pain and suffering, could be avoided. And this can help cut down on costs for the health budget too, if the patients get the right diagnosis with the right treatment.

Going private will of course cost more than just the lab fee since the overheads for the practice and consultation have to be calculated in, but the point that is being made here is that although getting tested for HIT will cost money, it does and should not cost a fortune.

It has been pointed out that in the new field of diagnostics of ad- verse reactions to food it is often quite difficult to get the cost reimbursed in Germany as well as in Austria. Some private insurance schemes have, however, started to incorporate these items into their insurance schemes. This only goes to show how far the rest of us still have to go, if even Germans and Austrians who are far more advanced in this field are struggling to get these tests on their medical insurance. But it makes sense. Private insurances have a strong interest in getting fast, accurate diagnoses, since then they are likely to have to pay out less for their patients in the long term. They seem to have caught on to the idea.

On the positive side, a most recent development in Austria has been the establishment of the 1st Austrian Out-patient Clinic for lactose-, Fructose-, Histamine Intolerance and Food In tolerances, which opened its door to the public at Vienna’s Hietzing hospital on 1st September 2009. Their services and tests are covered by the national health insurance funds and they are working closely with the Austrian Ministry of Health in order to inform the general public about food intolerances by distributing informational leaflets.

***What is currently seen to be a proper diagnosis?***

A proper diagnosis is made by a thorough establishment of the medical history and background (anamnesis) in combination with testing for diamine oxidase levels and activity. These tests are definitely being offered to a much greater extent by practitioners in Austria, Germany and other European countries. This same degree of awareness obviously seems rather slow in reaching the English language area as of yet, but hopefully it can only be a matter of time.

At the moment there is no clinical testing method that can stand alone to give you a diagnosis. They can only help to substantiate the diagnosis of histamine intolerance if there is need for this. Here are some examples:

***Clinical tests for histamine intolerance:***

* A test for low diamine oxidase activity in your blood. There are two different methods, either a “radio extraction assay” or an “enzyme immunoassay” for DAO activity. Depending on the person’s threshold and whether the patient has recently eaten food that is low or rich in histamine the test results can vary. Patients have been advised to be on a “normal” diet (whatever they normally eat) before having the blood sample taken. Other factors, such as pregnancy, intake of certain medications or alcohol can falsify the results. The results of such tests always need to be seen in context with the anamnesis, elimination diet and differential diagnosis. Some experts have criticised the test as unreliable. Since the problem seems to be primarily located in the intestinal area, they are questioning in how far the DAO-activity in the blood is related to the DAO-activity in the intestine. They have suggested that a final diagnosis would only be possible with the help of a tissue biopsy.
* A test for low levels of diamine oxidase concentrations in your blood. This test too has advantages and disadvantages. One may be able to see how much of it is in the blood, but it does not tell you anything about the actual activity of the enzyme itself.
* A test for methylhistamine. 24-hour urine collection where components in the urine can be measured. If the DAO does not do its job well, then the other enzyme HNMT has to help out. HNMT gets turned into methylhistamine, which in turn can be measured in the urine, via lab tests. This can possibly help to substantiate a diagnosis.
* A test for high levels of histamine in your blood. Lab tests for histamine need to be done preferably on site since histamine levels can rise due to decarboxylation in the blood. Some principle as with food deterioration. A test for histamine levels is usually conducted at the same time as a DAO-activity test.
* Furthermore one or several of the following tests have been suggested by experts, in order to collect more data: Endoscopy with extraction of biopsy material in connection with histamine, DAO and HNMT; a genetic test for DAO or HNMT, whereas the genetic tests are only thought to be useful in some cases, because in most instance – at least in connection with DAO – the main cause is an acquired HIT.
* A strong and lengthy reaction to the positive control of an allergy prick-test can be an indicator, but is far from a proof of histamine intolerance. Another method is a single prick test where a substance called “histamine dihydrochlorid” is placed on the lower arm, and if a wheal larger than 3 millimetres develops after 50 minutes then the result counts as positive. Again, this is just another indicator, and not valid as a stand-alone diagnosis. A full allergy test is highly advisable to be done by an allergologists since some patients may otherwise be misdiagnosed as histamine intolerant.
* Excluding the possibility of mastocytosis as a cause. Mastocytosis is a condition caused by a presence of too many mast cells in a person’s body, and thought to be very rare. Blood tests for tryptase can establish whether the mast cells are very active. If they are continuously active this is an indication for mastocytosis, which expresses itself similarly to allergies and histamine intolerance. Mastocytosis patients have to be on a low-histamine diet for life.

***Different points of view concerning the subject of diagnosis***

**Histamine Intolerance**

With regards to the diagnosis of histamine intolerance there are slightly different approaches that have been suggested. This is a comparison, which should only serve as an overview of information gathered from some very detailed articles from the German language area.

**Example 1:**

The authors of the article “Histamine Intolerance in clinical Practice” first published in German in the magazine “Ärzteblatt” in 2006 suggest the following:

* A detailed anamnesis of symptoms caused by high-histamine foods of medications which have an influence on the histamine metabolism.
* Detection of other accompanying gastrointerstinal conditions and allergies.
* Exclusion of food allergy via a skin prick test.
* Exclusion of occult mastocytosis with the means of serum tryptase assay.

A diagnosis can be made if the following points have been fulfilled:

* At least two typical symptoms must be present.
* Improvement shows on histamine free (sic) diet and antihistamines. DAO activity is low and/or the histamine level is raised.
* Additionally the clinical relevance should be checked with the means of a provocation test, if possible.
* Keeping a food diary and dietary advice have proven to be helpful.

The gold standard for diagnosis is a double-blind, placebo-controlled provocation test after the patient has been on a histamine-reduced diet.

**Example 2:**

In the publication “Aktuelle Dermatologie” (engl.:”Current Dermatology”) the autor, Reinhart Jarish, of the article “Histamine Intoleranz” published in 2012, talks about the following approach:

The diagnosis is based on three parameters. The author mentions that a GPS also needs at least three satellites.

* Anamnesis – Suspected HIT due to known food with higher histamine levels, red wine, matured cheese, salami, tomato; Symptoms which are linked to HIT such as headache, diarrhoea, bronchial asthma etc.; hypotension; the patient mentions red wine intolerance.
* If HIT is suspected then histamine levels in the blood plasma are determined.
* DAO-activity in the blood serum is also determined.

In this particular article the author distances himself from the usage of a provocation test as a method for diagnosis as gold standard. The reason he gives is that the provocation test has been attempted repeatedly, occasionally resulting in an anaphylactic shock, and it has therefore been scrapped. He reports that even healthy people, where the dosage chosen may have been too high, were experiencing symptoms.

His institute has therefore decided to conduct a “negative provocation test”, which takes around 14 days. Here a histamine-free (sic) diet is prescribed. Afterwards they will do the DAO and the histamine test again, and they enquire how the patient feels.

He believes that HIT is present when the histamine level is (usually) down by half and if the DAO rises. He also mentions that it sometimes becomes very difficult to make a diagnosis, because some patients have already read about the subject on the internet and have started an elimination diet before a diagnosis could be made.

**Example 3:**

In 2012 a guideline called “Vorgehen bei Verdacht auf Unverträglichkeit gegenüber oral aufgenommenem Histamin” (Procedure for cases of suspected intolerance to orally introduced histamine”) was published in cooperation of three allergology institutes. They suggest a slightly different approach.

* The medical record (anamnesis) must be recorded.
* A case-specific differential diagnosis (making sure that there are no other diseases or conditions around) needs to be conducted and anything foundneeds to be treated.
* The differential diagnosis must also include skin disease, inflammatory bowel disease, carbohydrate utilization malfunctions, Celiac Disease, and allergies.
* A symptom diary and a diet diary can help to identify suspicious amounts of biogenic amines.
* A determination of DAO and histamine levels in plasma/serum is not recommended by this guideline in view of the data currently available.
* If the suspicion of HIT can be confirmed, then a dietary change will be done in three steps while considering factors such as stress, menstruation, medications taken, etc. An abstention phase&test phase of the duration of up to 6-8 weeks followed by an individual recommendation for the long-term dietary plan.
* If there should be no improvement, further diagnostics should be conducted depending on the leading symptom.
* If there should be an improvement, then a titrated provocation with histamine dihydrochloride could be made under medical supervision (because of the potentially strong reaction, which would need to be immediately controlled). In simple terms this would means an administration of the substances in increasing dosage during a certain timeframe.
* A professionally competent nutrition consultation can prevent patients from following a diet that will consequently restrict their quality of life.
* General, restrictive and long term low-histamine forms of diet, which will restrict the patient’s quality of life, are to be avoided,
* For the authors of this guideline it is conceivable to treat patients with suspected HIT with H1/H2 receptor blockers for a certain period of time in order to check whether complaints change in intensity or not.

**Example 4**

The last example is the answer given in an interview by Prof.Dr.med Martin Raithel of the University of Erlangen to the following question: “How do you go about diagnosing HIT? Do you need several indicators?”

This answer also included a chart as follows:

Chart: Histamine Intolerance diagnostics

* **Anamnesis, physical examination**
* **Mediator diagnostic blood test (single determination)**

Plasma histamine, ECP and tryptase in serum, cytokines if necessary

* **Functional mediator diagnostics with at least 2 days of normal food and 2-14 days of hypo-allergenic, low histamine potato-rice diet:**

Determination of combinations in normal diet and after potato-rice diet each to be compared (therapy effect)

Plasma histamine, plasma-DAO

ECP and tryptase in serum, cytokines if necessary

Histamine and methyihistamine in 12 hour urine

* **Endoscopy with biopsy sampling (nitrogen):**

Histological assessment (mast cell density), DAO immune-histochemistry if necessary

Determination of histamine levels in tissue, further mediators if necessary

Determination of isolated enzyme activity of DAO, HNMT

Determination of biologically available total histamine degradation capacity

* **Oral provocation testing with 50-150 mg histamine or placebo**

On-call/emergency service (if necessary intensive-care monitoring)

Symptom score, cardiac monitoring, peak-flow measurement etc.

Mediator diagnostic for plasma histamine, if necessary DAO and other parameters.

The complete exclusive interview with answer to 10 questions can be found in Genny’s Blog on the Histamine Intolerance Awareness website, at

[www.histamineintolerance.org.uk](http://www.histamineintolerance.org.uk)

These are only a few several documents – which have been released by authorities in the last few years – in order to show you the slightly different perspectives on how to get to a diagnosis that is most suitable for a positive outcome for the patient. Depending on the scientific research, we will hopefully see a standardized method at some point in the future.

***The elimination diet as another option***

If you are unable to get the blood test for some reason, then the only other option is first to exclude or establish whether there are any other illness, allergies or intolerances and then start the process of a temporary low-histamine elimination diet. This needs to be done under medical supervision. Whatever you do, do not go it alone. Self-diagnostic is not possible and potentially dangerous unless you have a medical degree and are specialised in intolerances and allergies. Doing a provocation tests for histamine intolerance on your own is out of the question. You can, as alternative, take antihistamines (H1 or H2 blockers) for a couple of days, and see if any symptoms disappear. If this is the case you should consult your doctor. Anyone who might tell you otherwise may not have much interest in your well-being but is just spinning you a yarn and is after your money (see “Useless tests – the Commercialisation of Health” further on in this book).

You will need to find out, in cooperation with your physician, whether you are basically healthy so that any other factors can be brought into equation. It is also necessary to do any relevant allergy tests just to include – or exclude – this factor as well. HIT is often seen as a secondary condition in combination with other conditions that affect the digestive system such as those described in chapter two, Morbus Crohn and other digestive disorders. Patients with IBS (Irritable Bowel Syndrome) are also likely to be candidates for HIT. In many of these cases the object of the exercise is to stop the vicious circle. Some lucky people may even see the histamine intolerance disappear at some point, and will then be aware of it should it return for some reason.

***How they will determine your medical history, if they don’t have it already***

The medical expert will need to have access to as much of your medical history as possible, including former diagnostic reports, the medication that you have taken and are taking at the moment, a list of nutritional supplements and vitamins you may taking, and a list of foods that you are sure you react to badly (food diary) as well as those to which you react well.

***How they should be able to establish the likelihood of HIT***

In the first stage they will need to ask you about how often you perceive any or several of the following symptoms:

Stomach cramps

Stomach pain

Wind or flatulence

Diarrhoea

Rashes or Eczema

Itching

Flu-like symptoms, runny eyes/nose or sneezing

Headaches

Rheumatic pain

Dizziness

Nausea or vomiting

Extreme tiredness

It is possible that several of the symptoms will apply. This is certainly not unusual. Once the symptoms have been identified you will be asked about the frequency of each one of them.

Possible answers are:

Occasionally (around once a month or less)

More often (up to around twice a week)

Very often (twice a week or more)

In the next stage it will be necessary to find out if you react badly to certain foods that are known to be the biggest culprits.

They are:

Champaign, red wine, alcoholic drinks

Tomatoes, matured cheese, pizza, chocolate

Acidic foods (citrus, fruits, vinegar, pickles)

Fruit juices with pineapple, strawberries or banana

Aubergines, spinach,

Nuts

Ready meals

Salami or other raw sausage

Shellfish

Glutamate (additive)

Normally you should also have an HIT test done at this point, which, as we have said, can be determined with the help of a blood sample. If you do the test you must absolutely NOT be on a histamine- low diet as otherwise you will get a negative result although you might have the intolerance. The logic behind it is that if you ingest a very low amount of histamine then your diamine oxidase level should, in theory, rise because it is not being used as quickly. Therefore more DAO will be seen to be around.

***The importance working out a diet***

On the basis of these results a professional nutritionist can and should at least be able to work out a dietary plan and give advice on how to keep your diet in balance. If there is no balance in the diet, then other health issue may crop up – which is not exactly helpful and will make your life even more complicated than it already is.

I myself have had two tests for my diamine oxidase levels (in Austria). The first result was extremely low. After that I went on a low histamine diet, and returned again for the second test four months later, out of curiosity. The result showed some improvement. Not what I would have liked it to be, of course. Still, the question remained whether the results were really as conclusive as they looked. The fact that I had been on a low histamine diet means that naturally more diamine oxidase was available; it hadn’t been used up so fast because I hadn’t supplied the histamine. I also had tests done for celiac disease, lactose and fructose as well as a general allergy test. This established that I also have fructose malabsorption (also known as dietary fructose intolerance).

Most important, though, is that I have been able to track down what the causes of my problems are. I now feel confident that I am in control of the situation and can improve my quality of life.

**A WORD OF CAUTION!** Some patients may be so desperate that they choose the path of self-diagnosis. This is understandable, since the trust in one’s own doctor might take a dive if there are no results and the patient is struggling more and more with general aspects of life, such as work and socialising. But self-diagnosis is a dangerous path to take, especially when there is no background knowledge. The internet may provide some answers and hints, but since every person has an individual medical history the advice offered there is likely to be too general and inaccurate unless given by organisations that are committed to the subject of intolerances. Although some of these organisations are very good and have their own forums, it will not be possible to get a detailed diagnosis through them. What these websites are very good for is to get extra information after the diagnosis, although this is also limited. The interpretation of the test result, all of them, will need to be done by a well-informed professional!

***Useless tests- the commercialisation of health***

Another big pitfall is companies that may raise your hopes by selling tests that are in no way helpful, except maybe for their bank balance. An article in the UK’s renowned independent consumer magazine Which? Magazine illustrates how companies and socalled experts, some even self-proclaimed world experts, are risking the health of patients by promising them test results what will lead to better health through the avoidance of certain foods they claim to have tested for correctly.

***IgG Testing***

Some labs offer IgG tests for allergies and intolerances. “They use a sample of blood and test it against a range of foods to detect levels of an IgG (immunoglobulin G) antibody. They claim that raised levels of IgG antibodies within your blood indicate food intolerance. Which?’s verdict states that “Although IgG testing is a validated scientific test, our three experts believe that, in line with our findings and other published research, its use in diagnosing food intolerances is difficult to prove scientifically. IgG antibodies are commonly found in healthy people and do not prove intolerance, only that food itself has been eaten. The experts were also concerned that the diets recommended by these tests exclude up to 39 foods – which could lead to nutritional problems”.

As it currently stands there are those who say IgG testing works, and those who say it doesn’t work at all. What is for sure is that this test does not have any relevance concerning the diagnosis of histamine intolerance and other enzyme-related conditions. People who are not aware of this will be at risk of helping put on the wrong diet. It would be a bit more truthful if the companies involved would honestly state what their tests are not for. They tend to otherwise give the impression that they test for everything and more.

In a guideline called “Keine Empfehlung für IgG- und IgG4 bestimmungen gegen Nahrungsmittel” (engl.: Testing of IgG and IgG4 for foods is not recommended), valid until 2014, the Allergy Society from German, Austria and Switzerland as well as Physician’s Society of German Allergists have taken the following position: “...Due to current scientific understanding IgG(4) antibodies to foods should not be misinterpreted as an indicator for disease causing mechanisms but rather as a sign of a normal (physiological) human immune response after repeated exposure to food components. Therefore, the allergen specific measurement of IgG or IgG4 antibodies to foods is useless and is definitely not recommended for the work-up and diagnosis of various types of food hypersensitivity. This is also true for chronic diseases and health complaints, falsely believed to be caused by an underlying food hypersensitivity, which has not yet been diagnosed...” This guideline supports the Task Force Report of the European Academy of Allergy and clinical Immunology (EAACI), published in 2008. In May 2010 the American Academy of Allergy, Asthma & Immunology (AAAAI) also issued a statement of support for the EAACI Position Paper.

***Vega Testing***

Vega testing is another of those tests that cannot be applied to testing for intolerances, although it claims to diagnose food intolerances, and sometimes is also advertised as allergy testing – make your mind up, guys – by a method called “electrodermal testing”. The person being tested has to hold a metal probe that is connected to a computer, or sometimes to a very strange-looking machine that could be right out of the sixties. Another probe, looking like a kind of pen with a metal point is placed on pressure points next to the nail-bed of one of the fingers. This will create an electric circuit. One by one the tester will put an “essence” of a food substance into the machine and see how high the current reads. If the current is low, they will specify it as a food that needs to be avoided. Researchers from Which? Magazine were told to avoid foods with which they had no problems at all, including wheat (!). Which?’s verdict rightly stated that “Dietician Catherine Collins was particularly concerned that the private practitioner advised Dee (one of the researchers) to exclude all grains from her diet. “This significantly reduces the intake of fibres, selenium and B-Vitamins, and would make it difficult to get a balanced diet”, she said. ”Neither test for either researcher gave matching results for food intolerances. The authors of the article agree that this method cannot be recommended and Dr.Adrian Morris, allergy specialist at the Royal Brompton hospital said: “Clinical studies have repeatedly shown Vega testing to be ineffective in diagnosing allergies and intolerances”.

***Hair Analysis***

Some companies will try to sell you the story that they can find intolerances through analysing your hair. According to Which? Magazine one of them claims to test intolerances through, “the vibrational energy pattern of your hair which represents the energy state of your body”. Another company claims “genetically examine the DNA at the hair roots, to investigate food intolerances.” Let’s just take the example of histamine intolerance. Could some of these experts, please explain to me how they can test for the amount of or activity of the enzyme diamine oxidase? Don’t try unless you have the scientific evidence. It is probably unnecessary to state that the researchers of the article found they were given results that bore no resemblance to their real situation. One of them was told to avoid cow’s milk although she has no lactose or cow’s milk protein intolerance.

***Kinesiology***

Last in the row of tests that are absolutely useless, especially for intolerances, is kinesiology. The tests involve lying down and either touching or being close to vials containing food extracts. The practitioner applies pressure on your legs and arms to test resistance. The lower the resistance the more food is believed to interfere with the body. The authors again found a complete lack of consistency. Results for both researchers show that this technique has no use as a diagnostic tool. They felt that the recommendations given by practitioners were worrying. One of the researchers had been told that she “would go into shock if she ate peanuts” although she had neither allergies not intolerances.

***Conclusions:***

What this article shows is that we need to be very careful with our choice of experts. It can be downright dangerous for people with intolerances and allergies to go down the wrong route because they have been misguided. It prolongs their suffering and may even kill them. Just think of the example of a person who has a peanut allergy but is not told in time because it happened not to show up in the hair, in the muscle tension, or in the energy levels!

From my own experience I can confirm that Kinesiology and the Vega Test were not useful at all. On the contrary, the Vega test proposed a diet containing a lot fruit, and given the fact that I also have fructose malabsorption this would have made me even worse. Good thing I got a proper medical diagnosis on time. Needless to say that the neither of the above tests detected either histamine intolerance or fructose malabsorption. I also know a case of a person close to me, who was sent to a kinesiologist by their GP and was given a potion by the kinesiologist after being tested the same way as described above. After taking the potion he started to feel very unwell and decided to go to bed. Most disturbingly, he told me that when he woke up a short while later he was having serious trouble breathing. After this very frightening episode he decided to try other avenues. I rest my case.

***Beware of rip-offs!***

If you should by any chance “meet” someone on the internet who claims that a certain drug or therapy is “new on the market” and seems especially helpful, then think twice. Watch out for people in forums or websites who recommend a “doctor” who might not even be one. In the UK you can check with the GMC register on the net. In the UK doctors have to be registered by law, otherwise they are not allowed to practice. The more people who let the GMC register know when they have been deceived, the more likely that the culprits will not be able to get away with it. Concerning products mentioned on the net, there are often hired marketing employees behind them, sometimes even disguised as patients, hiding behind one or several false names, in order to praise a certain product, which then creates the impression of high demand that doesn’t actually exist. Some of the lazy marketers use the tactic of dropping the same message into as many places as possible related to the subject. You can catch them out easily by just as lazily copying and pasting the message into Google search and having look at how many results there are. Some people may go as far as visiting a “doctor’s office” where they are then coaxed into doing a rather expensive “long-term therapy”. Don’t let yourself in for something like that. Go to a proper doctor and get them to refer you to a specialist.