

ADHD, a Food-Induced Hypersensitivity Syndrome: in Quest of a Cause

**The effects of a restricted elimination diet (RED) on ADHD,
ODD and comorbid somatic complaints,
and a preliminary survey of the mechanisms of an RED**

Een wetenschappelijke proeve op het gebied van de
Medische Wetenschappen

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Parents' and children's accounts: RED research in real life

How a boisterous, bothersome boy calmed down and got friends

Teun had always been a lively boy. He couldn't sit still for a moment, was constantly chattering and seemed to be unlucky all the time: he often had bruises and scrapes. His teacher at nursery school once sighed: "I would not mind if Teun became a little less enthusiastic." When he grew older he became increasingly boisterous and impulsive, he talked a lot and very loudly, and he constantly touched and bothered other people. In the end children didn't want to play with him anymore and Teun was no longer invited to birthday parties. It was very sad. On top of that, his school results suffered from his behaviour. When Teun was six years old, his teacher suggested to have him tested for ADHD. Considering the nine month waiting list for an ADHD examination we decided to apply for the INCA study.

During the first weeks of the RED we already noticed a change at home. Teun behaved more calmly, was less impulsive, talked less and stopped touching or bothering others all the time. Results at school were positive as well: Teun managed to finish his work, wasn't constantly talking out of turn and was able to sit next to other children without bothering them. Given the positive results, Teun was eligible to enter the RED challenge period, during which foods were added to the diet. This period, lasting at least one year, was very tough but we couldn't have made a better decision for Teun. Halfway, my husband and I almost wanted to give up, exhausted from Teun's mood swings during the challenge period. But our son insisted on continuing the research, he did not want to lose his friends again. The RED research ended some time ago. We now know which foods are causal of ADHD, and we make sure he doesn't eat them. Right now he is almost nine years old and he is a great child – he still is a lively boy, but without ADHD.

Peace and quiet through medication: a blessing for school

In primary school we were already told that Monica showed worrisome behaviour. She constantly claimed the teacher's attention, couldn't sit still during group discussions and exhibited bossy behaviour towards other children; she even hit or threatened them sometimes. Those were the moments she had 'tickles in her body', as Monica explained her behaviour. She also complained about headaches



several times a week. In second grade rewards for good behaviour were introduced, and we all wondered whether Monica might need more challenging school tasks. In third grade at first her behaviour improved, but then got worse again by autumn holiday. A psychologist diagnosed Monica with ADHD, combined with an above average intelligence. Medication was advised and after consulting a paediatrician Monica started to take ritalin. Results were good, she was able to focus on her school tasks, and she behaved more calmly towards other children. It was a blessing for school!

We also had an appointment at ADHD Research Centre as well, as we weren't too eager to have Monica taking medication. We started the RED and took her off medication. Five weeks later, at the end of the RED, the headaches had diminished but her behaviour had not improved: she was not able to focus on her schoolwork, she had a lot of angry moods and she behaved badly towards other children.

Considering that Monica's behaviour did not react to food, we were advised to start medication again. Fortunately, she reacts well to that. We would like to have her participate in a special training course to improve her social skills and to support the effect of medication. Although the diet did not change her behaviour, we're happy she participated in RED research, as we wanted to know whether our child might be able to do without medication. We also know now that Monica has great perseverance; she stuck to the diet even on her own birthday and on two other children's parties! And she likes to eat mango now (but no rice crackers anymore...).

How a troublesome toddler turned into a cooperative adolescent

Bram's start of life wasn't easy. He was a whiny baby and seemed to have bellyaches all the time. His defecation was always too thin and definitely too often, the diapers could not be bought fast enough. Doctors called it toddler diarrhoea and tried to treat it, but whatever they did, the problems did not disappear. When he grew older he often complained of stomach-aches, he also drank a lot – he was always thirsty – and every night he was dripping with sweat. Apart from these physical complaints he couldn't sit still, not even a minute, and not only was he very active, he also developed tics, like squeezing his eyes, coughing, and pulling strange faces. He just couldn't stop doing it. He was compulsive as well: if it happened that he was not the first to go downstairs, he started screaming and shouting until everyone was upstairs again, letting him go first. At school he could

be aggressive, beating other kids for no reason, pinching them or pushing them off their chairs. In fact, he had been a 'troublesome child' ever since playgroup. Several examinations of intestines and blood did not reveal a cause of the physical problems, although he had been suffering from diarrhoea for more than four years. And his defiant behaviour, well, that might be resolved by parent training and maybe some medication, according to the physician.

I did not intend to settle for the doctors answer. Our other children were doing just fine, so I considered it unlikely that our parenting capacities were causal of Bram's behaviour. But something had to be done, because not only our son, but also the siblings and everyone around suffered from his behaviour. Considering that he never had had normal defecation, I thought that food might be the cause of that problem. I contacted the food allergy foundation and happened to find information about the RED research on their site. We decided to give it a try. We started the RED when Bram was four years old and within three weeks we knew he strongly responded to food. His unmanageable, oppositional and aggressive behaviour disappeared, at home as well as at school. The teacher thought it was a miracle. Moreover, for the first time in his life he had normal defecation and his tics diminished, incredibly! His compulsory behaviour disappeared as well, he didn't feel the need to go downstairs first anymore. After four years of struggling and all kinds of examinations this *fantastic* result was achieved in no more than three weeks!

The following months were difficult. It's not easy for a child to continue a diet but with help of teachers, other parents and friends, Bram completed the RED challenge period with positive results. We found the foods he reacted to; products we were used to eat daily before we started the RED. Of course we stopped to eat these foods. Bram is 15 years old now, a son I'm proud of. He's a very social, cooperative and humorous adolescent with a lot of friends. He is doing quiet well at school and he wants to go to college. He is allowed to eat almost anything, but he still had better not eat some foods. Sometimes he eats them anyway, for example when he's with friends and can't resist the temptation. Then we all notice the effects. He becomes restless, the tics and compulsive behaviour return, he starts wiggling and coughing, and the intestinal problems return as well. Fortunately, we now know the cause of these problems, and they will disappear again, at least, if he sticks to his diet.



Friends and fun

Jeroen, a 7 year old boy suffering from ADHD started RED-research in 2007. He sent this letter at the end of the challenge period, resulting in the diet prescription to better not eat strawberries, liquorice or tomatoes.

"Hi Mrs Pelsser!

I am glad that you help us with my diet, and that you advise my mother about what I may and may not eat, and that you are working so hard for all this. I am very happy that I feel better now, and that I am calm. I really have much more fun at school, because now I have more friends. I found it hard if someone was eating treacle waffles at a party, but other than that the diet was not so bad. And I really think I am nicer now.

Thank you that you invented this diet for me.

With many regards Jeroen"

In 2011 Jeroen is 11 years old and he wrote another letter.

"I am still very happy and I am very calm now. I don't mind to stick to the diet. I have got many friends, at school and in the neighbourhood. I also do ice hockey and I have to listen very carefully to the instructions of the coach. I am very good at it, and it is no problem to listen and to keep quiet.

I am very happy that we did the RED. Everything is much more fun. I never want to have ADHD again.

Jeroen"

Rebellious behaviour disappeared like snow in summer

Sigrid was a cheerful although very lively toddler, but she got more rebellious as she aged; she became angry a lot, opposed rules, wouldn't listen and had a hard time dealing with changes or disappointments. She also had sleep problems and did not fall asleep until late in the evening, lying awake for hours. At home we were able to deal with her behaviour, although it was very demanding and aggravating. But at school Sigrid did not come up to the mark, she could not concentrate at all. Finally, a child psychiatrist diagnosed her with ADHD and medication was prescribed.

As Sigrid started to take medication, she changed. She looked washed-out and displayed robotic behaviour, unnatural to her real character. She seemed depressed and even said she wanted to die, even though she was only seven years old. In a newspaper we read about the RED research. It seemed like a good

idea to participate. Wouldn't it be great to prevent all the trouble by just not eating some foods? Maybe our daughter would no longer need medication.

After the first four weeks of diet we didn't know what was happening to us. Sigrid became balanced and was able to deal with everyday events, without getting upset or defiant. All the above-mentioned complaints disappeared like snow in summer, she wasn't angry and rebellious anymore but became reasonable instead. She listened when she was told to do something without protesting right away. The sleep problems disappeared simultaneously with the behavioural problems. The teacher at school noticed a big difference: Sigrid's concentration was fine, she was able to do her work independently and she got better grades. Sigrid has followed her diet for three years now. She will start secondary school and tests have revealed that she will be able to go to a higher level than expected. We are convinced that this wouldn't have happened without the RED.

Constantly vigilant to prevent trouble

The most striking memories I have from Joris as a toddler are the everyday struggles. If he got his coat put on, he immediately would take it off again. The very same happened when he had to put on his shoes, or his socks, or when he had to get in the car; he made an issue of anything and life turned into a constant struggle. He easily got angry if something didn't work out the way he wanted, for example when a tower he had built would collapse. Joris often lost his temper, he was uncontrollable and he never listened. When we warned him *not* to do something, he interpreted it as an encouragement to do it right away. I was prepared for anything, since everything seemed to challenge him. He misbehaved in shops, running away, climbing on things and throwing with everything, so I had to keep him in the pram.

When Joris was two years old, we started homeopathy. We found that his concentration improved, but the therapy did not result in structural improvements. He grew older and his behaviour got worse. He never played with toys for a good while, but he constantly turned from one toy to another, in the mean time calling for a lot of attention. He also was selfish, the last piece of apple-pie was always supposed to be his, he didn't show any consideration for his brothers. It really isn't easy to be constantly vigilant, anticipating what might happen in order to prevent troubles and quarrels. Somehow things seemed to occur in his head and he was not able to suppress them.

When Joris was six years old, we learned about the INCA study. Joris was diagnosed with ADHD and ODD, and we decided to participate. After a 3-months waiting-period we could start the RED. It made a world of difference: our son, who never took 'no' for an answer, now accepted it and he listened to us, without arguing all the time. He calmed down and he became less angry and less rebellious. He could play with his brothers without fighting and we could drink our coffee without having to be alert and to intervene all the time. We really had to get used to this new situation, it was both bizarre and wonderful. Right now we're still sorting out to what products Joris reacts. He is doing very well, unless he eats something he should not eat. Then the 'old behaviour' returns. Those moments, when he behaves as he used to behave, we really wonder how we ever managed to cope with that behaviour.

Good marks at school

Simon followed the RED in 2008, when he was 10 years old. He suffered from ADHD and ODD. Right now he is aged 13 and he still adheres to his diet prescription, consisting of the advice to avoid potatoes, vanilla, peanut and cocoa. He wrote a letter.

"Hallo, I am Simon and I have been on a diet for several years now. Right now I feel fine, and I am doing well at school, but before I followed the diet I often felt terrible, especially when my medication had worn off, in the evening. Then I became restless, and I felt terrible and stupid, because I could not do my homework properly. Everything went wrong and I was full of grumbles. Then we started the diet, and at first I did not like it at all, and I did not want to stick to it, but then I felt better, and now I am used to it. Many different foods were tested, like sugar, and nuts and peanut and cheese and colourings and everything. Sometimes I felt worse, but most of the time I really was happy and I got good marks at school. Now I am allowed to eat almost anything because we now know which foods are causing my ADHD, and I am doing fine at school."

Medication definitely needed

Our son Michael is diagnosed with ADHD and he followed the RED. Unfortunately, it did not affect his behaviour, he remained hyperactive, unfocused and impulsive.

During the RED we took him off medication, but his teacher immediately raised the alarm: Michael did not finish his schoolwork anymore. We quickly started medication again, the diet was adjusted and once more we took him off medication, but again the problems returned. The diet just did not change our son's behaviour. We would have been happy if Michael were not to take his medication anymore, but now we know for sure that he really needs it, and the effects are quite well.

Although Michael's behaviour was not affected by the diet, we do not regret that we participated in this RED research. Michael stuck well to the diet, so he has shown that he really is able to go for something. We have supported him all the time, and that felt good; this experience has positively influenced our sense of family. We have also learned a lot about healthy food. Most of all, it is a good thing to know that for Michael there is nothing for it but to take medication.

From psychiatric day-care to public primary school

Our daughter Femke had serious behavioural problems, she suffered from extreme mood swings, compulsive behaviour and severe temper tantrums. She also often complained about headaches and bellyaches, but her behaviour was our most important concern. When she was six years old, our daughter was referred to psychiatric day-care. After an extensive period of examination, in the course of which, among others, MCDD was suggested, she finally was diagnosed with ADHD. We were told that she most likely would not be able to focus at school or even to learn at all without medication. Femke was advised to start medication and she was referred to a special education primary school.

We did not mind to send her to a special education school, but we did not like to start medication, so we asked for other options that might be helpful. The psychiatric institute's doctor told us about a diet that seemed to achieve spectacular results. We read all about it on the website, and we learned that RED research was a method to investigate the cause of ADHD and that this diet had high success rates. We considered this diet to be a more healthy approach than fighting symptoms through medication, therefore we decided to participate in the INCA study before starting medication.

When we started the RED we knew it wasn't going to be easy, so we decided that the whole family would follow the diet, not Femke only. First we were shocked when we received the RED instruction, however, within 2 weeks we were used to

it, we baked cookies ourselves and – to our surprise – the children did not protest. We didn't notice much of a result in the first weeks, whereupon my husband concluded that “we could not expect miracles from a diet, could we”. But the INCA-team was of a different opinion and they prescribed a more stringent diet. 2 Weeks later a miracle did happen: the temper tantrums, compulsive behaviour and mood swings disappeared, she became calm, happy and flexible and she could handle setbacks easily. For the first time in years we enjoyed ourselves during dinner, even though our dinner options were limited! Headaches and bellyaches disappeared as well, and her teacher was lyrical: Femke now finished schoolwork that used to take her one week in one day! She obviously felt good. She changed so drastically that even people who didn't know that we had started a therapy noticed the change.

One year later Femke had improved to such an extent that she switched to a public primary school, and she is doing really fine. Although she has some difficult moments, such as parties and birthdays, she is pleased with the diet that now is close to normal. During holidays, when it is difficult to stick to the diet, she may fall back in her old behaviour and she may become sad, angry and easily upset, fighting a lot. Fortunately that behaviour disappears quickly when we exclude the triggering foods, and Femke will be the first to stop eating them, stating: “I don't want to be angry and fighting anymore”. We're all really happy that the RED has solved a really difficult problem and has given us a happy child. We hope this method will become widely accessible.

How a diet made a beehive in an adolescent's head disappear

We already noticed that Dennis was hyperactive and unable to focus when he was attending nursery school, and this behaviour continued when Dennis started primary school in 1998. Although he found himself lying under his chair more often than sitting in it, and although he could hardly be described as an attentive pupil, he kept up remarkably well. Through the years his behavioural problems increased, his social behaviour did not develop as it should, and he even tended to walk away from school if he did not like the way things went. Other children did not really like him, because they constantly needed to say things like: “Dennis, stop it; Dennis, don't do that; no Dennis, we're not changing the rules; Dennis, don't touch that; Dennis, be quiet,” etcetera. Especially during school trips and other activities he did not know how to behave and seemed completely on the wrong track.

When he was nine years old it was not quite clear whether he should be diagnosed with ADHD or PDD-NOS. Eventually, PDD-NOS was chosen and it was advised to put Dennis on medication. In secondary school, a special education school for children with serious behavioural problems, we actually decided to start medication, risperdal. We definitely noticed distinct beneficial effects, but Dennis still needed a lot of structure and we always had to keep an eye on him, one never knew what would happen or what he would do when he was in company. His fantasy was boundless (what if..., imagine..., suppose we...), and he still talked all the time, mostly very quickly and unintelligibly. We were worried about his future, whether his maladjusted behaviour might lead him astray. Nevertheless, we also enjoyed Dennis and although there were some problems and conflicts in school (Dennis had been suspended for a couple of days), he graduated for his lower secondary education and started higher education.

Dennis remained an extremely restless adolescent, and our paediatrician advised to switch medication to Concerta. This change turned out well, Dennis indicated that his concentration improved substantially and he was able to play the piano for a longer period of time. Unfortunately, he still felt "a pressure in his head like a beehive hidden behind a wall", being his very words. When he happened to see a television program about the RED he knew for sure that he wanted to try that diet. He wanted the beehive to disappear. Although he was aged fifteen already, he was so highly motivated that he was allowed to participate and one and a half years ago we started the RED.

Now, in 2011, Dennis is still on the diet and he is off Concerta. He talks more calmly and clearly and most of all he does not sail close to the wind anymore. He is happy with the diet and indicates that the beehive has disappeared, except for the moments he eats foods he should not eat. We really had to unlearn to vigilantly watch him every moment in order to correct him if things went wrong, as we were used to. When he is among others we don't need to interfere anymore to keep things pleasant. There has been taken a weight off our shoulders. Meanwhile we have finished the RED challenge period and we know to what foods he reacts. Dennis is very aware of the effects of food and he is determined to stick to his diet. We're really proud of our son! He does not feel sorry for himself about not being able to eat certain things, on the contrary, he would rather feel sorry if he didn't stick to his diet, because then all his behavioural problems would return. We completely agree with him: the diet isn't a restriction, but an enrichment of his life.

Homework

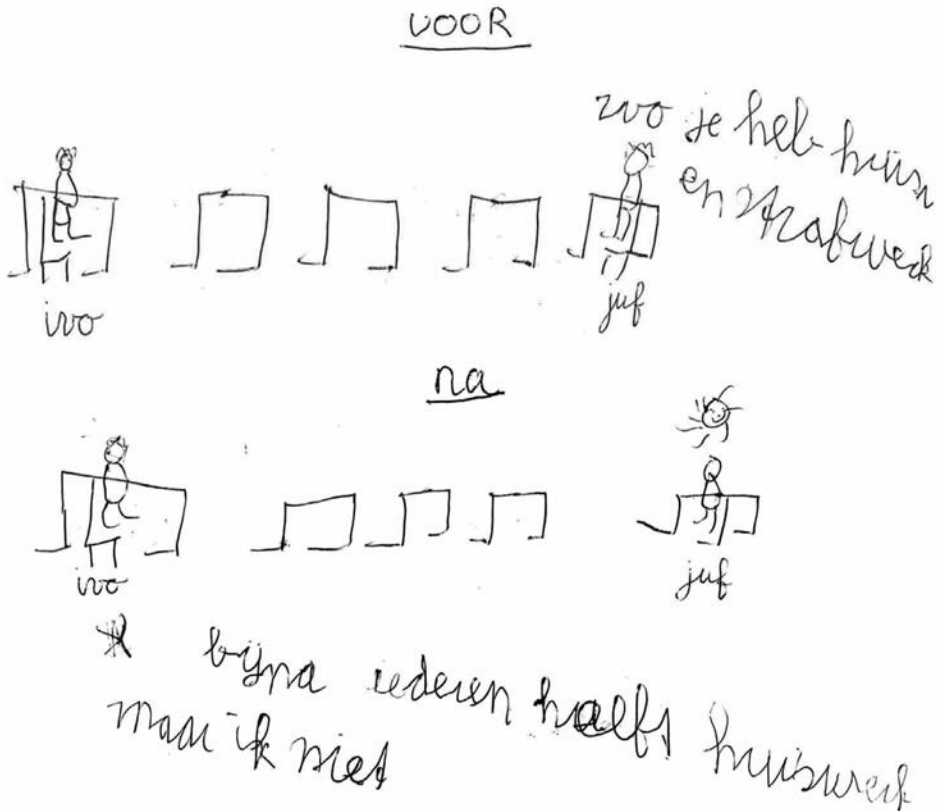
Ivo, an 8 year old boy diagnosed ADHD started RED-research in 2011. He made these drawings at the end of the 5-week RED. During the challenge period, which has only just started off, he reacted adversely to cheese.

Before the RED

At school: the teacher says: "Ivo, you've got homework and you'll have to write lines."

After the RED:

At school: Almost every child has got homework, but I haven't.



thuis:

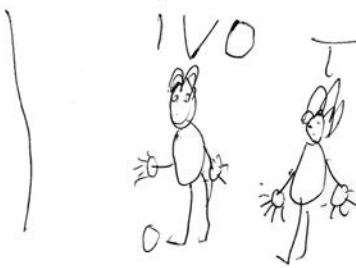
VOOR

veel ruzie met Tim

thuis:

na

En nu hebben we ^{veel} ruzie met veel ruzie



Before the RED

At home: I am always fighting with my brother

After the RED:

At home: my brother and I hardly ever fight

More support needed during RED challenge period

Thom especially had behavioural problems at school and at football. He just couldn't focus, whether it was on his schoolwork or on the ball. Eventually, he even was forbidden to participate in football matches, because he was rather a nuisance in the field than anything else. Of course, that is a woeful experience for a boy who loves to play football. We had him tested and he was diagnosed ADHD. We also were informed about the RED research, so we put forward our son for this investigation. To put it briefly, the improvements in Thom's behaviour were gigantic, at school and at football. He was allowed to play games again, which really was wonderful. He even scored a goal! We were very happy, and so was his teacher, he did well at school.

We started the RED challenge period, but this really was a disappointment. Every time we introduced a new food I spent the next ten days anguishing about how it would turn out, because I desperately wished him, and us, a less strict diet. I also found it aggravating that we always had to take his diet into account, we just couldn't have a day out or go out for dinner, because we always had to bring something along for him to eat and drink. Furthermore, the longer we participated, the more difficulties I experienced in judging his behaviour. I knew this challenge period would take about 15 months and would eventually come to an end, but I did not know *when* it would end or to what foods Thom would react, and this uncertainty unbalanced and unsettled me. In truth, more guidance, a coach, someone to lean on, someone who might visit us and might offer practical assistance would have been very welcome. The monthly consultations at ADHD Research Centre unquestionably were encouraging, but it was not enough to help us see this period through. One month ago we have stopped, and we're not sure how we will proceed. It really is great not to have to think about his food anymore and to be able to eat whatever and wherever we want, but Thom's behaviour definitely has worsened. Right now it is our summer holiday, so we will manage. In September, when he has to go to school again, we must decide whether we will start medication or give the RED challenge period another try. If we opt for the RED, then I honestly wish we would get some more help.

Medication if a diet doesn't work

Jeffrey, our 10 years old son, started the RED four months ago, with remarkable effects. We're definitely not opposed to medication: after he was diagnosed with ADHD in 2007 Jeffrey got medication, for three years, with varying success. He first was on Concerta, which worked quite well in the beginning, but eventually the effects diminished. We switched to Strattera but Jeffrey did not react favourably to this medication, so we continued with Medikinet. This worked out fine, although in the evening when the effect of medication had worn off, the restlessness in his head returned. That's why we started the RED research. During the RED we took him off medication and we honestly couldn't believe what happened: our son became calm and concentrated, sat still at dinner table but most of all, he was cheerful, laughing and enjoying life. This was our Jeffrey.

In the RED challenge period we figured out what products were causing Jeffrey's behaviour. We started with beef, slowly increasing the amount. Within a few days he started bouncing through the room and the ADHD behaviour completely returned. We couldn't really believe this, we were doubting ourselves. We stopped the beef challenge and one week later his peaceful behaviour returned. It was unbelievable, but true!

We think it is remarkable how well Jeffrey continues the diet. It's not easy, so he says, but it's worth it. He pointed out that the motor in his body has been switched off now and he is feeling much better. The every evening's restlessness in his head has disappeared, and he is keen on keeping it that way. Not only Jeffrey, but also his environment (his family, his teacher and the children at school) profits from the behavioural changes, it seems a win-win situation. We would like to advise other parents to try this diet first. In case it does not help, medication will always be an option.

Temper tantrums

Floor, 8 years old, was diagnosed ADHD and ODD. She entered the INCA study in 2009. She responded favourably to the RED, and the ADHD and ODD behaviour returned when eating too much wheat, corn or fish. She sent a postcard and a drawing at the end of the challenge period. Now she is 10 years old, she still adheres to the diet prescription based on the results of the challenge period and she is doing fine.



Text postcard:

Dear Mrs Pelsser, I made a drawing for you. Thanks to your diet I hardly ever have a temper anymore. That makes me very happy.



Text drawing:

Before the RED: grrrr, I am angry and I've got a headache

After the RED: I am not angry anymore, I don't have a headache anymore