

Beginning The GF/CF Diet

(BBB Autism; PDF article #1)

With thanks to www.gfcfdiet.com

Deciding to begin a Gluten-Free (GF), Casein-Free (CF) and Yeast-Free (YF) can be very intimidating. As challenging as this diet is, many parents go on to further restrict such substances as dyes, sugar, preservatives, and fats from their children's diets. Taking things one step at a time can help make it less of a burden for you and your child.

One of the first things you may want to do is have your child tested for urinary levels of the gluten and casein peptides that may be present. There are several places to have this done, a couple of which are listed below. Testing is not a requirement to begin the diet, but it can help to provide encouragement and impetus to start and stick with the diet if you know your child has unusual levels of peptides.

TESTING SOURCES

Most, if not all, of these tests must be ordered for your child by a medical doctor.

AAL Reference Laboratories, Inc. 1715 E. Wiltshire #715 Santa Ana, CA 92705 800-522-2611 714-972-9979 Urine testing for Urinary Peptides/IAG levels

Alletess Medical
216 Pleasant Street
Rockland, MA 02370
800-225-5404
Blood test for antigliadin and anti-casein antibodies.

Karl Reichelt, M.D., Ph.D.
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Dept. of Pediatric Research
Rikshospitalet-The National Hospital Pilestredet, 32
N 0027 Oslo, Norway
phone:47-22-86-91-10 and 47-22-86-91-11
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Urine test for urinary peptides



Dr. J. Robert Cade 2800 Archer Rd. Surge Area-University of Florida Building #683 Gainsville, FL 32611 904-392-8952, speak with Malcolm Privette 24 hour urine collection required, no fees

William Shaw Ph.D.
The Great Plains Laboratory
9335 W 75 St
Overland Park,KS 66204
Phone:913 341-8949
fax 913 341-6207
e-mail williamsha@aol.com
Urine test for organic acids, possible indicators of yeast overgrowth (among many other things)

Great Smokies Diagnostic Laboratory
63 Zillicoa Street
Asheville, NC 28801
800-522-4762
Comprehensive digestive stool analysis, possible indicators of yeast overgrowth (among many other things)

Once you have testing out of the way, it helps to begin reading as much information as you can about WHY the diet works, WHAT gluten and casein are, WHERE to buy the foods, and HOW to do the cooking and shopping to avoid gluten and casein. These topics are all covered in the other

introductory posts from the GFCFKids List. Read them thoroughly and you should have a solid start to planning and implementing the diet.

FREQUENTLY ASKED QUESTIONS

Q: How exactly does one implement a special diet when a child's food choices are already limited to those foods you wish to eliminate?

A: Patience, patience, patience. There are at least two schools of thought on how to start this diet. The abrupt introduction--just do it and wait out the food strike your child will likely begin. Or you could do it gradually—one meal or one food at a time. That is, for a week, just make dinner glutenfree and casein-free. Then once you've got that figured out, add in breakfast. Then after that's done, add in lunch and snacks. Some kids need the abrupt approach--they may figure out that suddenly dinner tastes different so they will wait until lunch or breakfast to eat. Some kids cannot survive with ambiguity; others need gentler handling.



Whichever way you do it, I would suggest adding more foods to your child's diet that are acceptable BEFORE you start the diet. Start introducing rice and potatoes if your child only eats noodles. Add

fruits and vegetables to every meal so that your child may eventually try the new foods. The reason I suggest this is that the gluten-free and casein-free substitutes don't really taste like the "real things" they know and love. Rather than having them starve during a hunger strike, you will have backups in case they reject the gluten-free and casein-free substitutes.

Another suggestion is to stock up on enough prepared gluten-free and casein-free foods for a three or four week trial. They will cost more than making your own foods from scratch, but it will be easier. Do a three or four week trial with strict adherence to the diet. It's a little like AA: the task is less daunting if you think about doing this diet one day or one week at a time. Do the elimination and then let your child go on a gluten- and casein-feast for a weekend and see what happens to their behavior/mood/toilet learning. If things degrade, then you know the diet was helpful. Obviously don't pick a time for the challenge when you're moving, changing schools, doctors, teachers, adding a new baby, or you won't know if any behavior degradation is due to the other upheavals or the diet. Some people would argue that you need MORE time than a 3 or 4-week trial in order for your system to clear out the bad stuff. It may indeed take a year to clear out excess opioids, but if the diet is clean, then you could see a change sooner than that.

Q: What about looking for milk products in foods?

A: Here are the suggestions for using Kosher markings to avoid dairy in products you buy from the grocery store: The Kosher mark has two parts. The first part tells who did the inspection....thus showing markings with a U, K, or others. This marking is usually printed inside of a circle. The second part is located just outside of the "circle containing the inspector" designating the status of the product:

"D" dairy - Product contains dairy or has been processed on equipment that processes dairy

"D.E.".....dairy equipment - possibly dairy-contaminated

"Parve"parve - neither dairy or meat per Jewish law

"Pareve"....parve - neither dairy or meat per Jewish law

"MEAT".....meat - meat that is free of dairy

"P" Passover - not pareve



a marking with a U inside of a circle is considered parve/pareve. The "parve/pareve" text after the inspector marking is optional. Kosher inspections are voluntary. The company agrees to answer all questions and allow open supervision of the plants. If an ingredient is not made on site, it is traced

to its source for kosher status.

The FDA allows casein (a milk protein) to be used in foods that can legally be labeled "non-dairy." But in recent years, even trace amounts of dairy makes a product not "parve" by kosher inspectors.

A directory of OU (parve/pareve) products can be obtained by calling (212) 563-4000 for \$10. I use these markings for checking commercial frostings, syrup, mayonnaise, and most things I guess! :) (by Janice Cupples, <u>ij-cupples@email.msn.com</u>)***

***Please note that it has been said that many companies are not following proper kosher procedures. A kosher expert in my city said that the only way to be certain you are receiving casein-free merchandise is if the word "parve" or "pareve" is actually printed out on the label. He suggests buying parve merchandise at a kosher butcher or Jewish grocery store, as all of their products will be fully parve if they are so marked. Your best bet is to call the company if you are not sure if a product might contain trace amounts of casein and ASK. (L.E.)

Q: How do I know if my child might be a candidate for the GFCF diet?

A:I thought I'd also pass along what Beth Crowell says in her book about who should look into this diet. (page 18-20)

Is Your Child a Candidate for Dietary Intervention?

We have assembled a list of questions for you to ask yourself. This is by no means a complete list. Every child is different. Each has a totally different environment, genetic makeup, etc.. However, a pattern has begun to emerge around all autistic kids we've personally encountered, as well as parents that we have spoken to. Our list of common denominator questions keeps growing.

Go through these questions. If you answer "yes" to a significant proportion, then chances are good that your child could benefit from the diet therapy.

Does the child--

---have a "blotchy" complexion over his entire/part of body?



- ---seem to be "healthier" and perform better in the summertime?
- ---have sessions of "shakiness" (NOT of a seizural nature) in the hands, etc. when hungry or immediately after eating?
- ---need to eat something sweet before he will eat anything else?
- ---lick salt off chips, crackers, pretzels, etc.?
- ---consume large quantities of liquids over the course of the day?
- ---have an irregular stool pattern?
- A) Soft and pasty, foul smelling?
- B) Frequent bouts of constipation/diarrhea?
- C) Large, bulky stools that float?
- D) Light colored stools?
- E) Grainy or gritty stools?
- F) "Foamy" or "Frothy" stools?
- G) Combination of the above?
- ---have a history of illness in infancy and/or early childhood that occur in "cycles?" For example, vomiting, diarrhea or upper respiratory infections, colds, etc. every 3, 6, 8 weeks?
- ---have a constantly running nose?
- ---urinate more at night (quantitatively) than for the same length of time during the day?
- ---suffer from numerous ear and/or sinus infections?
- ---have a history of prematurity, postmaturity, hyper-bilirubinemia, or other neonatal traumas?
- ---have psoriasis or eczema, or other "unexplained" rashes?
- ---appear to have cycles of dramatic behavioral changes (good or bad) that recede after 3-4 days?
- ---seem to have "headaches?" i.e., like to have his head rubbed or pressed hard against an object or person, burrowed or be held upside down?
- ---have excessive flatulence?



- ---jump or bounce for an extended period of time?
- ---have certain times of the day when he is more "hyper" than others? i.e., before or after meals?
- ---have a preference for chicken, fish, or pork over beef or lamb?
- ---prefer extremely bland or excessively spicy foods?
- ---have a history of reflux? (burping up acids, vomitus)
- ---have small raised "bumps" similar to "goose bumps" or little white bumps that remain unchanged all over his/her body?
- ---have a "furrow" between his brow?
- ---have a "colicky" infancy?
- ---have a strong smelling urine or breath?
- ---have a thick "inner tube" of fat build-up around his neck?
- ---have a history of being extremely "difficult" to burp as an infant?
- ---does the child have an excessive wax build-up in his ears?

Is there anyone in the extended family that---

- ---has a history of alcoholism or heavy drinking?
- ---has a history of depression?
- ---has a mild learning disability? i.e., dyslexia, speech impairment, hearing impairment, etc.?
- ---has ADD or ADHD?
- ---has diagnosed allergies?
- ---has diagnosed kidney disorders?



- ---has diagnosed liver disorders?
- ---has a dairy intolerance?
- ---has irritable bowel syndrome, spastic colon, colitis, hiatal hernia, nervous stomach, celiac sprue, or Crohn's disease?
- ---has severe mood swings?
- ---has unresponsive high cholesterol?

During the pregnancy, was the mother---

- ---on any medication?
- ---ill? (flu, food poisoning, etc., especially in the 4th or 5th month)
- ---able to eat properly? (nutritionally with a minimal amount of processed foods)

Does the mother have---

---a propensity toward ovarian cysts or other reproductive system disorders?

Once again, the foundation of our theory is based on a sequence of known chemical reactions that occur within the human body. It considers specific pathways of "nutrient" utilization and apparent inherent breakdowns in the pathways present within autistic individuals. All of these questions are derived from our observations and theory. This is, again, a very BRIEF set of questions....we will not list the other hundred here! (Beth and Andy Crowell, "Dietary Intervention as a Therapy in the Treatment of Autism and Related Developmental Disorders," page 18-20)

I highly suggest you add this book to your library of books dealing with the dietary aspect of autism. It is available through the DDR. ***

Jenny W
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Mother of Olivia, 5, autism
Homeschooler, NACD, 1 year, **Please note that ear infections during early childhood frequently can indicate a sensitivity to milk.



Q: I know that gluten can be hidden in many things. What should I look out for?

A: Wheat is processed into quite a few food items with non-wheat names. Wheat is used in almost all processed foods. The main reason that processed food is comparatively cheaper is that wheat by-products are used to thicken and imitate flavor. I found out to my sadness that barley is also gluten. :(The wax used to coat raw fruits and vegetables has wheat in it. Candies can be coated with wheat flour to keep them from sticking. One gluten free candy was making coeliacs sick. Turns out the cutting board was dusted with wheat flour.

I started reading labels again! I look for:

- *modified food starch
- *hydrolyzed vegetable protein
- *malt

There are other names to watch out for, but I hardly ran across them so I never did learn them. A good gluten intolerance book will list all the aliases. If the ingredient is just 'malt' assume it came from barley. Maltodextrin is from corn. Starch or modified food starch is from wheat or another gluten - most of the time. Starch from corn is cornstarch. (That's why packaged, mixed chocolate milk hurts me, it has wheat starch in it!)

Read everything. The packaged noodle and rice mixes have the food starch. Before my kids started having to avoid obvious wheat, they were affected by the by-products. One bite of food with starch in it would hurt their stomach. Cream sauces from canned soups were out of the question. (by magsschwa@aol.com, Margaret)

Q: Where can I shop?

A: Some parents suggest shopping online (see the post entitled GFCF Websites and Resources), others shop at local health food stores. Many products can be purchased at local grocery stores, so it is helpful to have a listing of GF/CF products to help with shopping. Look for their health foods section, and don't be afraid to ask if they can special order products for you-many stores are willing to help with special dietary needs. Don't forget that most meats (nonbreaded), fresh well-washed veggies and fresh well-washed fruits are gluten and casein free.

Many parents also have found that Chinese, Indian and Japanese groceries are good places to find many of the unusual flours and other products necessary for GFCF cooking. When shopping at these specialized stores, however you need to exercise EXTREME CAUTION to avoid cross-contamination. It may be best to consider buying all of your supplies from reputable gluten-free companies for the first few months of the diet so you can be absolutely sure that your child is not receiving any gluten. After that, if you are sure the diet is helping, you can begin introducing exotic or bulk flours. Then, if a



problem develops, you can more easily track down the cause. If you can track down a local celiac support group, it can be very helpful for finding local sources of GF products.

Q: How do I go about beginning the diet? I don't know where to start!

A: Do not go cold turkey as you will have an ugly opiod withdrawal reaction as any addict would. What seems to work best is:

Week 1 remove all casein

Week 2 remove all wheat

Week 3 remove all oats

week 4 remove all barley etc

and if necessary for yeast, remove sugar at week 5.

My health food stores here have started to produce fresh baked lines of goods, everything from breads and rolls to cookies and cakes and brownies etc. Approach your health food store bakery managers and plead your case! You might be surprised how willing they are to produce things for you. I bought mine copies of the "Special Diets for Special Kids" and The Crowell's "Dietary Interventions", so it was all easy for him.

(by Holly Bortfeld, maximom@mindspring.com)

From the gfcf mail list

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