



Vol 10, Issue 4

Celiac Digest

A publication of the Southern Arizona Celiac Support Group (SACS)

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DISCLAIMER: This publication is intended as a general information resource for gluten-intolerant individuals. It is NOT intended for use in diagnosis, treatment, or any other medical application. Please consult your physician for professional medical advice and treatment.

Autism, other "Broken Brains", and Gluten Intolerance

By Carmen Emilia Palacio, R.D.

Autism is a devastating neurological and biological disorder that typically affects children between the ages of 18 months to five years of age.



Autism currently affects 1 in every 91 US children today. It is estimated there are over 1 million

people in the United States alone with autism. Autism affects each individual differently and at different levels of severity. Some people with autism are severely affected, cannot speak, require constant one-on-one care, and are never able to live independently. Others who have less severe symptoms, can communicate, and eventually acquire the necessary skills to live on their own. Autism affects people in five areas. These are communication (both nonverbal and verbal), social skills, behaviors (such as self-injurious behaviors), learning, and medical.

The rate of Autism has dramatically increased over the past 30+ years. At the end of 1970s, the rate was 1:10,000. In

1990, it affected 1:1000. Since it affects more boys than girls, the US rate is now 1:60 boys. These children today not only have Autism, many of them are medically sick as well. Some medical issues that have been found are gastrointestinal disorders, nutritional deficiencies, detoxification system impairment, heavy metal toxicity, and immune system dysregulation. Each of these medical problems require help from the medical profession to better manage the overall health of the children.

Autism is not the only "broken brain" that is affecting this generation of children, whom I have termed 'the new canaries in the mine'. ADHD now affects > 8% of children ages 8-15. Learning disabilities affect 5% - 10% of children and 1:10 US children are taking a stimulant (such as Ritalin). Fifty four (54) percent of the US children have a chronic illness. Asthma now affects > 10% of all US children.

More than 20% of US children have some type of psychiatric disorder as well. Various diets have been studied to determine if dietary modifications can improve the quality of life for children with



Autism. The history of research on dietary interventions dates back to 1976, when studies observed that certain foods produced behavioral problems in a child with Autism. Throughout the years studies began to focus on the use of a Gluten-Free / Casein-free (GFCF) diet. In 2002, studies found that children who followed a GFCF diet for 1 year had significantly better development than the group of children who followed a regular diet. Over the past four years dietary intervention studies have looked at urinary peptides, gut bacteria, vitamin supplementation and diet and seizures. Research done in 2009 showed significant reduction of urinary peptides after a GFCF diet was used for more than one year. Studies of the GFCF diet done in 2010 showed that the diet may positively affect developmental outcomes for some children diagnosed with autism. If a change is needed to the GFCF diet, the parent/family needs to be well prepared. The parent needs to learn about cross contamination problems, learn about other alternative nutrient rich foods to incorporate into the diet, be willing to trial the diet for an extended period of time, and be willing to teach others in the child's life that the diet trial needs to be done by all.

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Gluten proteins (wheat, rye, barley, and US oats) have become problematic for many people in America. Celiac Disease has increased 400% over the past 50 years. Non-celiac Gluten Intolerance is estimated to now be affecting 1:15 – 1:20 Americans. The gluten grains have changed dramatically over the years. A few



generations ago, wheat contained very low amounts of gluten and was harvested once a year. Today, wheat has been engineered to not only increase yield production, but also have more elasticity texture to it. This ‘new wheat’ is very high in gluten. Wheat gluten and other gluten grains (malted barley flour, for example) are added to wheat products, such as bread. We’re changing our environment faster than our bodies can adapt to it. Over the years, I have recommended that my clients “Slow the Flow”, as nutrition and health matters. I have educated towards a diet that is “real, whole, local, and fresh”, with a goal to reduce / remove foods that are also adulterated, processed, and contain, or are produced with, hormones, chemicals, and antibiotics. This process takes time to learn and is not easy. It does “go against the grain” of what has become the Standard American Diet. Dietary changes are big pieces of the puzzle to helping the

“broken brain”, but do not complete the puzzle. We begin to analyze other ways to “Slow the Flow” around them to work towards improving overall health.

For more information or questions regarding the studies referred to in this article or a list of the works cited, please contact me at carmen.palaciord@gmail.com.



The Diagnosis

By Kevin Ehrichs

This heartbeat that I could hear in my head, had been happening to me since I was a child. When I say heartbeat, I’m talking about a pounding in my head so loud that focusing on something is unbearable. As I grew older, it progressively became worse. I was sitting in my Algebra 2 class, and it became so loud that I couldn’t even hear the teacher teach her lesson. Up until that point, I didn’t think it was that big of a deal but not wanting my grades to suffer, I decided to go see my pediatrician. The first thing that my pediatrician Eve, did was test my blood count. Already having almost no blood in my body they took even more, drawing my blood through that long, thick needle. Returning with shocking results, my doctor said, “any normal person should be in a coma, or even dead.” Why I didn’t




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pass out, still remains a complete mystery.

I remember as if it were yesterday—laying in bed, waiting for Santa to arrive and bring me my presents; I could literally hear him stepping across the rooftop. It was a loud step though, almost as if he were carrying something heavy. Exciting myself even more, I was completely unaware of my Iron Deficiency. At this point, the “footsteps” would come along every once in a while and when it wasn’t Christmas, I could never quite figure out who they belonged to.

As I graduated elementary school and moved onto middle school, I started to develop these, excruciating migraines. Assuming that it was just another side effect of puberty, I dealt with them and they went away eventually, only to come back in a few days. After middle school, the headaches finally ceased. But I started to notice that these “footsteps” in my head were getting even louder, and more common. Still thinking

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nothing of it, I pressed on striving to be the best I could be. Working on my near perfect GPA and expanding my extracurricular opportunities, little did I know I had been losing blood since those nights when Santa would walk across the roof. Approaching my senior year, the footsteps turned into a pounding. This pounding in my head got to the point where it became difficult to concentrate in class. It also became constant, from the time I woke up, to the time I went to bed. I remember my only break was when I was sleeping. I finally decided to speak up about it, because more than anything, it was annoying me.

The day I spoke up about it was the day I was hospitalized. That over night stay in the hospital was the longest night, because it would be the deciding factor of what I was to do with the rest of my life. Seeing that I had little to no blood in my body but still

being able to stay conscious, all the doctors' first guesses were leukemia. I spent that whole night with 3 bags of blood hooked straight up to my IV, praying to anyone that would listen for me not to have leukemia. Eventually the nurses arrived back into my room with negative test results. The oddest part of the situation, was that I showed almost no emotion to these results. I was just thankful, with complete calmness.

Those next few months were the most painful, and tedious of my life. Every week for a month, I had to go the UMC Oncology Center and sit in a chair for 3 or 4 hours while iron was pumped into me through an IV. All the doctors knew, was that I could not absorb iron though my digestive system. Having no iron in my body, there was no way for me to produce red blood cells. After a series of long and painful tests, I was finally diagnosed with Celiac Disease. Scientifically

known as Celiac Sprue, I am now allergic to gluten, a protein found in wheat, barley and some oats. Whenever I consume even trace amounts of gluten, my intestines attack themselves and as a result restricts me from absorbing iron.

Always trying to look on the bright side of life, I have come to the realization that this new lifelong diet will be a way to help me stay healthy. Celiac Sprue, becoming more prevalent in people, is passing through genetics and also not knowingly showing up. This happened to me. One of the culprits of this "spreading" is Genetically Modified Organisms (GMO's). Wheat has always contained gluten, but now that we are genetically modifying the genome of wheat, it is containing too much gluten. My theory? This vast amount is too high of an increase for people to adapt to, thus causing this "allergic reaction."



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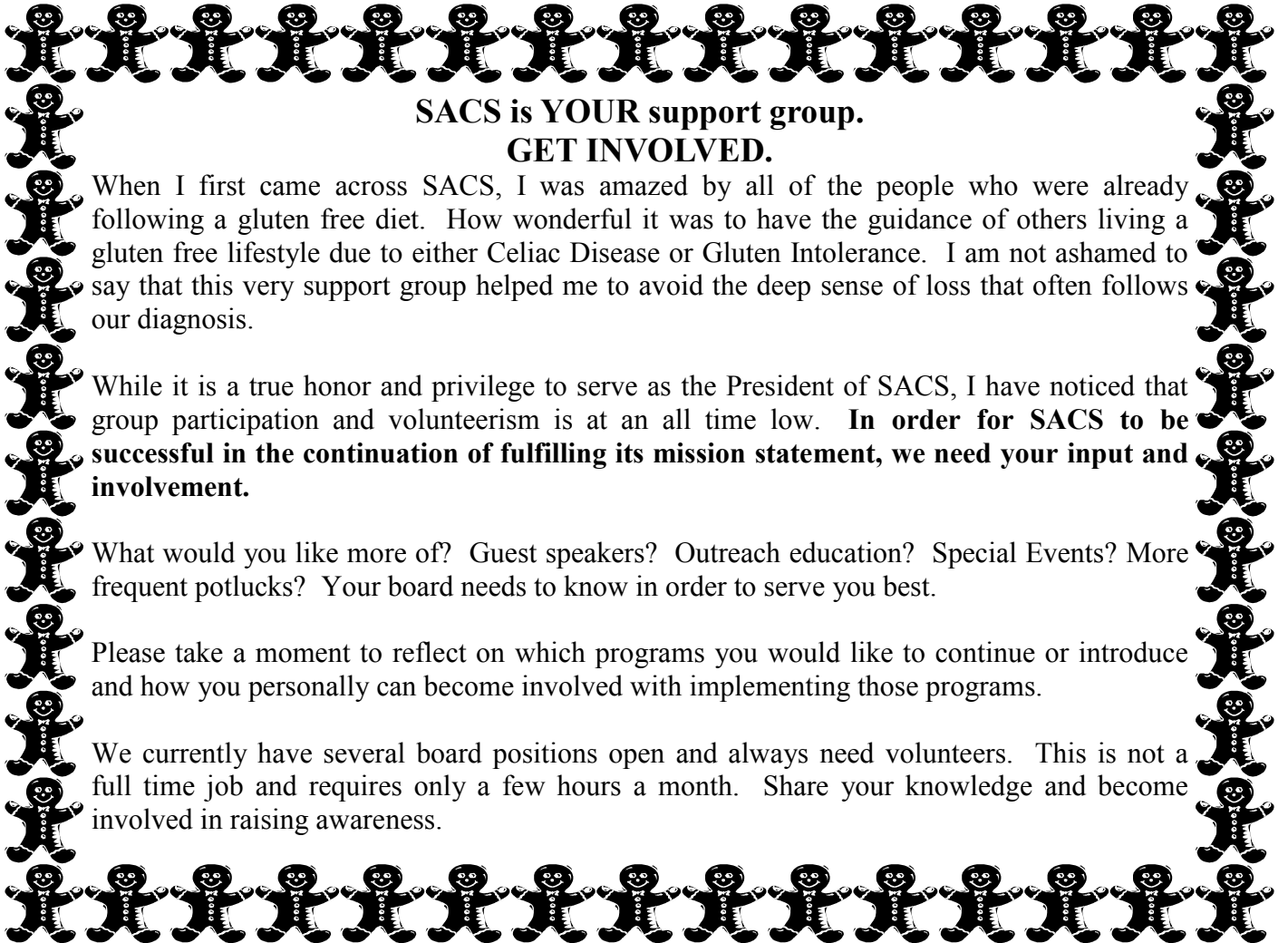


Joining our SACS Community is Kathy Addis, the newly elected Membership Chair. She was diagnosed with celiac 11 years ago. She has just started blogging under the name Your Gluten Free Kitchen.com and enjoys developing recipes that everyone will enjoy. She is also going to be taking over the GF Cooking Classes which will start again in the near future. Come say Hi to her at the next General Meeting where she will be at the front table greeting all of you!

Susan Fulton, co-owner of Gourmet Girls Gluten Free Bakery/Bistro in Tucson has recently joined the SACS Board as a member-at-large. We welcome the local business perspective she brings to the group, along with her extensive knowledge and expertise with GF food preparation for those following the Celiac diet. Susan herself is gluten intolerant, and is passionately dedicated to preparing delicious and safe foods for her clientele. She would love to have her all gluten free business



become a center for networking and community outreach projects developed by the group and is excited to be part of the growth of SACS. Susan looks forward to meeting all of the SACS members and working with their various dietary requirements to provide a dining experience they will be able to enjoy. Gluten free Eggs Benedict for Sunday brunch, anyone? Or French bread bruschetta? Sounds like a tasty addition to our board!



SACS is YOUR support group. GET INVOLVED.

When I first came across SACS, I was amazed by all of the people who were already following a gluten free diet. How wonderful it was to have the guidance of others living a gluten free lifestyle due to either Celiac Disease or Gluten Intolerance. I am not ashamed to say that this very support group helped me to avoid the deep sense of loss that often follows our diagnosis.

While it is a true honor and privilege to serve as the President of SACS, I have noticed that group participation and volunteerism is at an all time low. **In order for SACS to be successful in the continuation of fulfilling its mission statement, we need your input and involvement.**

What would you like more of? Guest speakers? Outreach education? Special Events? More frequent potlucks? Your board needs to know in order to serve you best.

Please take a moment to reflect on which programs you would like to continue or introduce and how you personally can become involved with implementing those programs.

We currently have several board positions open and always need volunteers. This is not a full time job and requires only a few hours a month. Share your knowledge and become involved in raising awareness.

What's Happening at the UA?

By Hana Feeney, MS, RD

There is a lot going on at the University of Arizona to promote healthy gluten-free lifestyles. The changes afoot will increase awareness of celiac disease, increase the number of gluten-free foods on campus and make it easier for us with celiac to identify gluten-free foods at the UA.

A New Student Group

UA Gluten Free, a student group I advise was formed this year, and is led by, Jenna Oertle. Jenna's older sister has celiac disease and although Jenna has not been diagnosed with celiac, she chooses to eat gluten-free. Jenna saw the challenges that her sister faced on the UA campus and was motivated to create a student group to provide a support system for those eating gluten-free. Jenna's mission for the group is "to facilitate friendly relations and interactions between students and UA Dining Services, to increase access to gluten-free foods on campus and to provide a forum for students to share their experiences during their gluten-free journey!" "Like" UA Gluten Free on Facebook and email Jenna at glutenfreecampus@hotmail.com

Nutrition Services for Students with Celiac Disease

I am a Registered Dietitian with celiac and I work at the UA Campus Health Service, in addition to my private practice off-campus. Students have access to two excellent dietitians, Gale Welter, MS, RD, and me, at Campus Health for very affordable nutrition counseling. We have loads of free information on our website, including a gluten-free

diet guide for those who are newly diagnosed, a gluten-free brand name list and a sign and symptoms checklist for those who suspect that they may have celiac. You can access all of these handouts and more at: http://www.health.arizona.edu/hpps_nutrition_handouts.htm Gale and I are available by appointment: 520-621-5700.

Identification of Gluten-Free Foods

The UA Dining Services department is working diligently at overhauling their nutrition analysis programming so that they are able to provide accurate nutrition facts, including allergen information. They will be able to provide detailed information online regarding gluten, dairy, soy, peanuts, wheat, eggs, tree nuts, fish, and shellfish in all the food on campus. Currently there is a Healthy Choices guide that identifies gluten-free foods and students are able to speak directly with Jianne Johnson, the Retail Dining Service Manager, who also eats gluten-free, regarding gluten-free options on campus.

Regarding cross-contamination, Jianne says, "At the Student Union, we take multiple precautions in preventing the cross-contamination of our gluten-free products. In addition to changing gloves and preparing the gluten-free food choices in separate stations, the Student Union has also purchased multiple pieces of equipment, such as toasters, small grills and food service shelving that is only dedicated to gluten-free foods offered in those environments. Furthermore, while we provide food handling training of allergy sensitive items on a unit basis, the Student Union is partnering with multiple organizations in and

outside of campus to develop an all-encompassing educational training program so that our employees are well versed not only in how to handle allergy specific foods, but also to educate them on the complexities of why it is so important to handle these foods properly to avoid cross-contamination. With all of these goals in mind, the Student Union plans to expand their gluten-free offerings in many of their establishments as we continue to make the commitment to provide a safe environment for gluten free eating on campus."

Lots of Tasty Foods

Eating gluten-free on the UA campus is relatively easy. Gluten free breads and pasta, naturally gluten free grains, such as quinoa and brown rice, and a baked potato bar are just a few of the gluten free options. Cross-contamination in the kitchen is taken seriously, so you can be sure that a food identified as gluten free in the Healthy Choices Guide, has not been contaminated with gluten.

For More Information

Please contact me with any questions or comments that you have regarding celiac, nutrition, and food, on or off campus. Hana Feeney, 520-429-3418, nutritionist_hana@msn.com

SACS in the Community

By Patricia Hirsch

Gourmet Girls GF Bakery/ Bistro is Open!

You will love this new all-GF bakery/bistro which serves breakfast and lunch Tuesday through Sunday, between 7 am and 3 pm. **Mary Gibson** and **Susan Fulton** have perfected the 100% GF eating out experience. It is our good fortune that Susan is one of SACS' newest board members. You'll want to visit them in person at 5845 N. Oracle Road in Tucson (on the west side of the road, between Orange Grove and River), <http://gourmetgirlsglutenfree.com/> 520.408.9000. They'll continue at the Saturday Oro Valley and Sunday St. Philip's farmers markets, too! Now, you really can "Indulge Yourself Again"! Life is good.

SACS at Tucson Meet Yourself Festival

Months of planning for *Tucson*

Meet Yourself (TMY) by a handful of dedicated SACS volunteers has paid off. Many thanks to **Jack Cohen-Joppa**, **Jerry Heintze**, **Mario Raso** and **Lee Bretan** who in conjunction with the festival's 2011 theme, *Traditions of Health and Wellness*, were successful GF advocates. They persuaded some of the festival food vendors to actually learn how to serve safe GF foods this year. How gratifying that the vendors seriously embraced cross-contamination concepts. How fitting that one of the booths which offered GF food, "*Vegetarian Soul Food*", was voted "*Smart Choices for Healthy Dining Best Food Booth*"! Smart Choices for Healthy Dining is a new program of the *Pima County Health Department's (PCHD) Communities Putting Prevention to Work (CPPW)* which TMY unveiled.

Sincere thanks go to *SACS volunteers* who manned our information booth in TMY's

Health and Wellness plaza all three days. You put a friendly face on CD/GF to the many thousands who visited our booth. How rewarding to improve the lives of so many in this way! You are the backbone of SACS. We are grateful to *Energ*, *Whole Foods*, *Basha's*, *Kinnikinnick*, *St. Juilen's Macaroons*, *Pamela's*, *Riega Foods*, *Simply Shari's*, and *Mary's Gone Crackers* who generously donated product samples for the give-away bags we distributed during the event. Thank you for your phenomenal support!

Many thanks for the cooperation and teamwork from persons and entities who helped SACS at the festival, including: all TMY board members, staff and volunteers, *PCHD*, *CPPW*, **Dr. Merrill Eisenberg** and her associates at the *UA College of Health* and **Betsy Craig** and her associates at *MenuTrinfo*.



Editors Note: Wondering what food to make for the holidays this year? Our friends over at *Living Without* magazine have some help for you. Head on over to their website at http://www.livingwithout.com/issues/4_17/gluten_free_elegant_holiday_affair-2721-1.html and try your hand at making some of their Gluten-Free recipes.



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Inside the Family of the President

By Stan Pebley

Imagine my reaction when Kim, my wife of almost 18 years at the time, was diagnosed with celiac disease, something up to that point unknown in the Pebley household. Immediately we started our Google research and found the local Celiac Support Group. We learned about separate toasters, separation of the evil gluten from the gluten-free food during preparation for cooking, and discovered that even medicine contained gluten. At that point the rest of the family led a fairly glutenous life, making fun of mom and her special toaster and cabinets until my son and youngest daughter were also placed on gluten-free diets, now I get the special cabinet. The scales have definitely tipped towards the gluten-free side in our household, with three of us gluten-free and my teenage daughter and me the only holdouts. We mostly eat gluten-free due to preparation of food and the chance of cross-contamination, but do sneak gluten containing food when we go out together; I also still eat my staple sandwich on regular bread every day at work.

Our family became involved with the Celiac Support Group shortly after we attended our first Gluten Free Food Faire and the next year Kim took it over and ran it. Two years after being diagnosed, she's the President of the support group, doing her best to help other celiacs

and educate the public on living a gluten free life.

Our family attends most of the support group's events and will be happy to share our trials and tribulations of having a split family of evil gluten people and the good gluten-free ones. We've educated ourselves in a lot of the issues concerning celiac disease and following the necessary diet. My four-year old son asks if the food being offered to him is gluten-free almost every time. When it's something he really wants, like candy or chips, he'll ask "That's not gluten-free, is it Dad?". Sometimes it is, sometimes it isn't depending on if I feel like sharing. Just a few months ago Kim convinced me to become more involved with the support group, and become editor of the very newsletter you're reading now. I mean, how hard could it really be? The answer is harder than I thought. My teenager has also been convinced to help with the support group, she has started to bring her camera to the various meetings and will be at the next potluck and gluten free food faire taking pictures of the participants. Even though two of us are not following the gluten-free diet, we do our best to support the other three in the family that must.



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**Roundtable
Resumes in January**



Mark Your Calendar

Dec. 9, 12pm, Lunch Bunch, Mr. K's BBQ, 4911 N. Stone (River & Stone). If you can attend please RSVP to Jerry@JerryHeintze.com, 975-7322.

No Roundtable Meeting In Nov. or Dec. No 4th Tuesday Dining Out in Dec.

Jan. 13, 12pm, Lunch Bunch, location TBD, please check the SACS website for updates

Jan. 14, 10am, General Meeting, Pima Community College, 4905 E. Broadway Blvd.

Jan. 24, 6pm, 4th Tuesday Dining Out, location TBD, please check the SACS website for updates

Jan. 25, 1pm, Roundtable, Ward Six City Hall. 3202 E. 1st St