

Additional AGS Resources

If you have any questions or feelings that cannot be answered, you may call the “988” dialing code to be operated through the existing National Suicide Prevention and Crisis Lifeline. This number is available 24/7 (all day, every day), is free and confidential to support people in suicide crisis or emotional distress works.

To locate an art therapist for specialized services please visit:

<https://arttherapy.org/art-therapist-locator/>

For more information on AGS (management, symptom descriptions, understanding a range of unsafe products/ingredients, tick management, and other applicable resources) please consider visiting: <https://alphagalinformation.org/> and <https://www.twoalphagals.com/>

A few possible hidden contaminants (please note there are many other contaminants which are not listed here):

- Vegan/Plant-based products (this term does not regulate all manufacturing processes and/or products as safe for individuals with AGS)
- Carrageenan (a thickening agent found in many products including: alternative cheese spreads, sauces, desserts, personal care products etc.)
- Yellow food coloring
- Natural Flavoring
 - Castoreum (berry or vanilla flavored foods, fragrances)
- Non-Organic sugar
- Glucose Dextrose (can be found in baked goods, soft drinks, candies, frosting)
- (mono-, di-, tri-) Glycerides (can sometimes come from animal fats)
- Lactic Acid (Pickles, olives, sauerkraut, candy, frozen desserts, fruit preserves)
- Casein (can be found in soy/alternative cheese, veggie burgers, condoms)
- Lecithin (can be found in breakfast cereals, candies, baked goods)
- Oleic Acid (can be found in synthetic butters, cheeses, icecreams)
- Steric Acid (found in vanilla flavoring, baked goods, beverages)
- Vitamin B12, D3, Omega-3s (unless production specifics are disclosed by manufacturers, many supplements pose risk)
- Suet, manteca (another word for butter/lard, found in baked goods, flour, tortillas, refried beans, and ready-made products)
- Clarifying agent (used to filter wine, vinegar, beer, fruit juice, soft drinks)
- Gelatin
- Lanolin (chewing gum, ointments, cosmetics, waterproof coatings)
- Myristic acid (tetradecanoic acid; chocolate, candy, jelly, desserts, baked goods)
- Sodium Stearoyl (found in baked goods unless plant source is disclosed)

- Possible cross-contamination in food preparation at restaurants/fast food chains (i.e. use of previously contaminated surfaces, workers not changing gloves, use of contaminated utensils, etc.)
- Certain brands of toilet paper, cleaners, personal care products

Some information to consider including on an emergency medical bracelet (also included on <https://alphagalinformation.org/>):

- Alpha-gal Syndrome (mammalian allergy)
- Allergic to mammalian products and by products, including heparin, gelatin-based plasma substitutes such as Gelofusin, and other medications.
- Anaphylaxis
- EpiPen in bag
- ICE 555.555.5555 (your emergency contact's phone number).
- Medical info in wallet/bag (if you have a medical card with info in your wallet or bag).

Burnout

Burnout can be referred to as resentment, anxiety, depression, or an overwhelming cycle of emotion that ultimately challenges our ability to cope and adapt with stress. Burnout can result in physical effects through how it can impact the nervous system. An individual may avoid confronting and accepting emotion in this state due to the present moment being perceived as a threat. However, avoiding accepting this cycle and recognizing your needs may also emphasize feelings of loneliness and isolation.

Specific burnout symptoms may include:

- Sense of failure and self-doubt.
- Feeling helpless, trapped, and defeated.
- Detachment, feeling alone in the world.
- Loss of motivation.
- Increasingly cynical and negative outlook.
- Decreased satisfaction and sense of accomplishment.

Burnout Management / Prevention Tips:

- Prioritize Self-Care:
 - Sleep habits
 - Nutrition
 - Exercise
 - Social connection
 - Meditation
 - Journaling
 - Enjoying your “happy places”

- Understand how you are delegating and spending your time, documenting in your notes how your mood and energy feels before/after activities to find what is most beneficial for you and what exposures may not be essential/decrease your mood (1 being angry/drained, 10 being joyful/energized)
- Make space for yourself to optimize rest and positive self-filling activities
- Reframe self-talk
 - Remove judgment and approach yourself with curiosity, kindness, and understanding
 - Imagine talking to yourself in the way you would communicate to someone you love and/or respect
 - Reduce Stressors
 - Understand what relationships, expectations, and work adds unhealthy stress into your day.
 - Seek to uncover what is controllable, where boundaries can be set, and what needs may need to be met in order to shift things in a positive direction.
 - Seek Connections
 - Prioritize the relationships and activities that align with your values and increase your sense of connection opposed to obligation, inefficacy, and cynicism. This can be found within personal and professional contexts.

Types of Boundaries:

- **Emotional:** may entail inappropriate topics, holding space for emotional unloading, and emotional limits. *"This is not something I am willing to discuss."*
- **Time/Energy:** having to do with time or availability, contact needs, favors and efforts. *"Please text me back to confirm or let me know if you will be late."*
"I will check my phone at ____ (select a convenient time for yourself) and check for a response for you then!"
- **Material:** boundaries around possessions, when they can be used, and how they are treated. *"My car cannot be used on weekends."*
- **Mental:** freedom to have your own thoughts, beliefs, values, and opinions. *"I respect that you disagree with my opinion, but don't force your own."*
- **Physical:** Proximity, touch, PDA, unwanted comments regarding appearance or sexuality. *"I don't find comments like that funny."*

Communicating when a response feels urgent:

"I will need to get back to you on this"

"I need some space with myself to process my emotions"

"I am unable to commit to this right now"

"I have seen your message and will response when I have the space to"

"I will know when the time is right for me to do x)"

How to say no and make room for self-care:

"That sounds fun and I really appreciate you thinking of me. I've been a little overwhelmed lately and have been planning for that time to be used for self-care. I am worried that if I push and overextend myself that I will hit a point of burnout."

It is *NOT* Selfish to:

1. Take time for doing "nothing" to simply exist without explanation.
2. Prioritize yourself, happiness, needs, self-care, etc.
3. Say "no" to something that you feel a resistance to
4. Change your mind, decision, perception
5. Set boundaries and respect them
6. Re-evaluate relationships, obligations, commitments that feel overwhelming or confusing
7. Have activities and interests that you are excited about but may feel uninteresting or misunderstood by others

Signs of Emotional Healing:

1. Understanding humans are imperfect and individuals can only love on their own level of awareness.
2. Behavior *does not* define you, it is information for understanding and reflecting on yourself.
3. You have the ability to support yourself and control how you choose to extend yourself to others in their own healing.
4. You take responsibility in embracing your growing perspective and understanding of self with compassion, patience, and respect.
5. You accept fluctuating emotion without judgment and feel more at peace with yourself.

Things to say to yourself to provide emotional reassurance:

You are enough

I see you

You are worthy & can create your life experience

I understand

You live in a new reality now

It wasn't your fault

I forgive you

You are a warrior

I am here to guide you

The present moment is safe

I am here, I am breathing, I am alive

(See: [instagram.com/somaticexperiencingint](https://www.instagram.com/somaticexperiencingint) for more information)

Alpha-Gal Allergy Hospital Information Handout Example

Alpha-Gal Allergy Alpha-gal syndrome (AGS), or mammalian meat allergy, is a tick-induced allergy to galactose- α -1,3-galactose. This sugar, commonly known as alpha-gal, is found in non-primate mammals and foods, medications, and other products with ingredients derived from mammals. Reactions, which can be life-threatening, are delayed up to 10 hours after exposure and often occur in the middle of the night.

My EpiPen is located: _____


Below is a list of the most common binders/fillers in medications that are derived from mammals. Please note this is not a complete list. If you are unsure that a medication is safe for me please call the Robert Woods Johnson Pharmacy Hotline at (732) 937-8842 (they will need the NDC number and that I am reactive to Dairy).

- | | |
|--|--|
| 1. Heparin! | 11. Some Antivenoms (Snake/Spider) |
| 2. Stearic Acid | 12. Some recombinant human Coagulation Factors |
| 3. Magnesium Stearate | 13. Catgut sutures |
| 4. Lactose Anhydrous | 14. Biologic Mesh |
| 5. Lactic Acid | 15. Bovine Pericardium |
| 6. Lactose | 16. Some Hemostatic agents |
| 7. Gelatin (Example Gel capsules) | 17. Lactated Ringers |
| 8. Glycerin | 18. Plasma-Lyte 148 (manufacturer dependant) |
| 9. Numerous Vaccines including Influenza | 19. Tube Feedings (Nustrison-Soya is safe!) |
| 10. Some Volume Expanders | |

Due to the fact I am also reactive to cross contamination I will not be eating any food from the cafeteria; my family members will be bringing me food. Please keep them informed of any specially ordered diets by the DR. Thank you.

Please check out this article <https://alphagalinformation.org/hospitalization-and-surgery-with-ags/>

Wallet-Sized AGS information card to be used for reducing restaurant risks (to be handed to servers, managers, restaurant workers, etc.). Front:



ALERT!

FOOD ALLERGIES

**Memo To: The Restaurant Owner, Chefs,
Food Preps and Wait Staff**

ALPHA-GAL SYNDROME - SEVERE MAMMAL MEAT ALLERGY

**I have Galactose-alpha-1,3-galactose,
aka Alpha-gal Syndrome**

It has also been called the Mammal Meat Allergy (MMA)

Allergic reactions are often delayed, severe & can be fatal.

Allergens include, but are not limited to: beef, bovine, pork, ham, bacon, sausage, lamb, goat, bison, venison, gelatin, milk, cream, butter, cheese, sour cream, yogurt, whey, casein, carrageenan, collagen, etc.

**Safe Foods Include: Poultry, Chicken, Turkey, Duck, Quail, Eggs,
Fish, Shrimp, Fruits and Vegetables**


Please do not think I am being difficult or shunning the mammal based menu items offered. I am overly cautious and avoid them in order to stay out of the hospital and quite possibly, save my life.

Please avoid cross contamination with my food and use only clean utensils for preparation and serving.

Please do not cook my food on the same grill, fry in the same oil or use the same pans, preparation, cooking or serving utensils that have been used with mammal foods without being washed / sanitized.

Please verify only safe vegetable cooking oils, marinades, sauces, seasonings and ingredients are used in my meal.

Thank you in Advance for a Safe Dining Experience.



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Wallet-Sized AGS information card to be used for reducing restaurant risks (to be handed to servers, managers, restaurant workers, etc.). Back:

What is Alpha Gal Syndrome ?

Alpha-gal Syndrome is caused from a Lone Star tick bite.

If the tick carries the alpha-gal epitope in its saliva and bites a person, it transfers the 'alpha-gal' into the person's bloodstream. Since humans don't naturally have galactose-alpha-1,3 galactose in their system, the body can start producing antibodies against it. Once enough antibodies accumulate, the immune system responds to the alpha-gal in the meat or meat by-products they eat or use with severe, sometimes life-threatening allergic reactions.

Unlike other food allergies, alpha-gal allergic reactions are typically delayed 4 to 10 hours; making it difficult to properly diagnose and pinpoint the actual cause. Alpha-gal is also different in that not everyone's reactions are the same nor do we all react to all of the same mammalian sources. These delayed reactions may include, but are not limited to: nausea, vomiting, diarrhea, bloating, stomach cramping, rashes, gastrointestinal distress, all over itching and/or hives, deep epidermal urticaria, angioedema (swelling of face, lips, tongue, throat) and anaphylaxis (airway blockage).

There is no cure and although some may go into remission, many of us may never be able to eat mammal meats or use mammal products for the rest of our lives. Most people who have been diagnosed with Alpha-gal carry an EpiPen, antihistamines, a medical alert card and will probably wear an allergy alert bracelet or pendant.

Please understand, we are not trying to be difficult, we're just trying to live a somewhat 'normal' life.

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Printable QR code with link to AGS advocacy film:

