Alpha-gal Syndrome Surveillance in Rhode Island

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BACKGROUND

Alpha-gal syndrome (AGS) is an emerging tick-associated condition causing an allergic reaction to galactose-alpha-1, 3-galactose, a carbohydrate found in mammalian meat and mammalian products such as milk, dairy, and pharmaceuticals containing mammalian products.[1] AGS is primarily caused by the bite of the lone star tick (*Amblyomma americanum*), a tick known to be prevalent in the southeastern United States, but now increasingly identified in Rhode Island as its geographic range expands northward.[2,3] AGS allergic reactions can be severe and possibly life threatening. Mild symptoms include hives, itching, abdominal pain, nausea, vomiting, and diarrhea; with more severe reactions including acute hypotension, swelling of facial structures, shortness of breath, and anaphylaxis.[4]

AGS is not a nationally notifiable condition to the Centers for Disease Control and Prevention (CDC) and is not legally required to be reported under Rhode Island's Reporting and Testing of Infectious, Environmental, and Occupational Diseases (216-RICR-30-50-1) regulations; therefore, its incidence in Rhode Island was unknown prior to this investigation. The Rhode Island Department of Health's (RIDOH) Center for Acute Infectious Disease Epidemiology (CAIDE) sought to determine the presence of AGS in the Rhode Island population. CAIDE obtained hospital emergency room and inpatient data for calendar years 2022 and 2023, and selected records that included the ICD-10 code Z91.014, allergy to mammalian meats. Analysis of the hospital records identified 43 individuals who met the inclusion criteria, providing evidence of human illness potentially consistent with AGS in Rhode Island. This finding supported the likelihood that AGS was present in the state and warranted further investigation, leading to the development of a voluntary AGS surveillance system.

METHOD

In January 2024, RIDOH issued a Healthcare Professional Advisory to licensed allergy and asthma specialists within the state of Rhode Island requesting voluntary reporting of AGS. In addition to the advisory, targeted outreach was conducted in February 2024 to laboratories known to perform serologic testing for alpha-gal-specific immunoglobulin-E (IgE). Electronic communication provided the laboratories with the background and justification for the development of CAIDE's AGS voluntary surveillance system for human illness. CAIDE requested that laboratories voluntarily report positive alpha-gal IgE results retrospective to January 1, 2022, and continue to report these results prospectively. All agreed to participate and submitted positive laboratory reports.

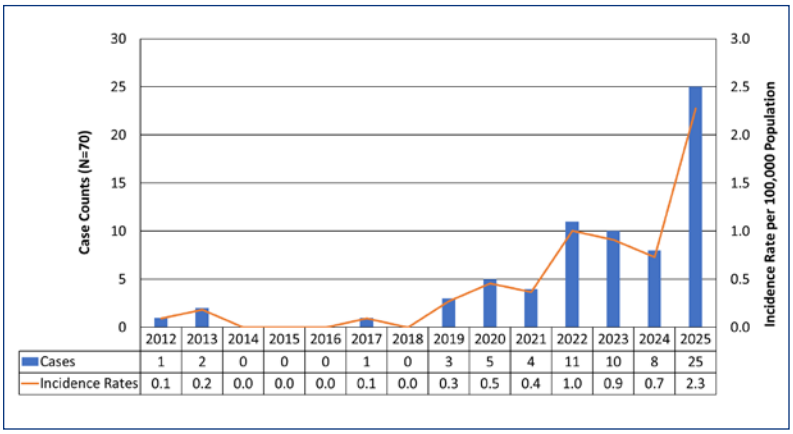
The CDC case definition for AGS was utilized to determine case status.[5] Individuals with an allergy skin test consistent with an alpha-gal allergy based on sensitivity to one or more mammalian meats or a serum or plasma IgE laboratory test specific to alpha-gal ≥0.1 IU/mL or ≥0.1kU/L were considered suspect cases. CAIDE investigators used an adapted CDC AGS case report form to interview individuals and collect a history of symptoms experienced following consumption of mammalian foods or administration of mammalian-derived products or medications. The interview results were reviewed to assess whether each individual experienced a clinically compatible illness and met criteria for classification as a probable or confirmed case.

An investigation module, adapted from the CDC AGS case report form, was incorporated into the Rhode Island National Electronic Disease Surveillance System (RINEDSS) and used for the entry and storage of laboratory and investigation data. RINEDSS is the Rhode Island instance of the CDC-developed National Electronic Disease Surveillance System (NEDSS), an integrated surveillance system used to manage and exchange public health data.[6] Data was extracted from RINEDSS and analyzed using Microsoft Excel 365.

RESULTS

CAIDE received 121 alpha-gal serology laboratory results with specimen collection dates ranging from January 1, 2022, to December 31, 2025. No reports of individuals with a positive allergy skin test consistent with AGS were received. All serology laboratory reports met the suspect case definition and were assigned for interview. Of the 121 suspect cases, 70 (57.9%) had a clinically compatible illness and were

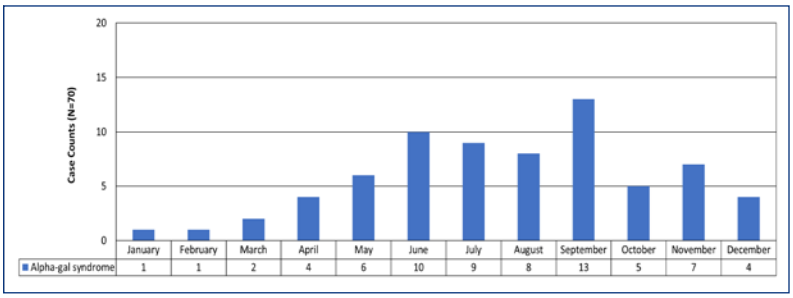
Figure 1. Case counts and incidence rates of Alpha-gal syndrome, Rhode Island, 2012–2025*



	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Cases	1	2	0	0	0	1	0	3	5	4	11	10	8	25
Incidence Rates	0.1	0.2	0.0	0.0	0.0	0.1	0.0	0.3	0.5	0.4	1.0	0.9	0.7	2.3

*Rates were calculated using the 2020 Rhode Island population as reported by the U.S. Census.

Figure 2. Aggregate cases of Alpha-gal syndrome by month, Rhode Island, 2012–2025



	January	February	March	April	May	June	July	August	September	October	November	December
Alpha-gal syndrome	1	1	2	4	6	10	9	8	13	5	7	4

classified as confirmed cases. Of the 51 cases that were not confirmed, 33 (27.3%) remained classified as suspect cases. Twenty-three (19.0%) of the 33 suspect cases refused interview or were unable to be contacted, and 10 (8.3%) had a clinically compatible illness, but no reaction after exposure to a mammalian-derived product. Sixteen (13.2%) suspect cases were reclassified as not a case because they did not have symptoms consistent with AGS, and 2 (1.7%) were not included in this analysis because they were out-of-state residents.

To assess the annual and monthly occurrence of AGS in Rhode Island, the initial illness onset date, specimen collection date, and provider diagnosis date of the 70 confirmed cases were reviewed. The earliest of these three dates for each case was used to create a graph illustrating the annual occurrence of AGS in Rhode Island [**Figure 1**]. The earliest cases identified in Rhode Island occurred in 2012 and 2013, with consistent annual reporting from 2019 through 2025, peaking at 25 cases. Similar to other tickborne infections, an increase in case counts was observed during the summer months. However, this seasonal pattern was modest and may reflect the small number of cases available for analysis, as well as the potential delay between tick exposure and reported illness onset [**Figure 2**].

Due to small numbers, confirmed cases were analyzed in aggregate to summarize demographics, symptoms experienced, and products consumed within 2 to 10 hours prior to symptom onset [**Table 1**]. Males (52.9%) were found to make up a slightly higher percentage of cases compared to females (47.1%). The highest percentage of cases occurred in those 60–69 years of age (27.1%), followed by 40–49 years of age (21.4%), and then by both 50–59 years of age and 70 years of age or older (17.1% each). AGS was less common in the younger age groups. Geographically, the highest percentage of cases were in Washington County residents (41.4%) followed by Providence County residents (30.0%).

Eight cases (11.4%) reported either being bitten by a lone star tick or found one on their body before symptom onset. Overall, 48 cases (68.6%) reported experiencing a tick bite of any species at any time prior to developing symptoms consistent with AGS. Of those cases, 31 cases (64.6%) recalled being bitten by a tick within Rhode Island, 12 cases (25.0%) recalled being bitten while out of state or traveling, and 5 cases (10.4%) did not recall the geographic location of the tick bite.

Cases were questioned about their ingestion of mammalian foods as well as the consumption and administration of mammalian-derived products or medications within 2–10 hours prior to symptom onset. Overall, more than one-third of cases (68.6%) reported AGS-related reactions after the consumption of products from multiple product categories, while the remaining cases (31.4%) reported an allergic reaction to a single product category. Beef was the most commonly reported product consumed by cases (81.4%), followed by pork (48.6%), and milk or milk products, including cheese, yogurt, butter, and ice cream (40.0%). The remaining categories, including gel-cap medication and glycerin-containing foods, were reported by 10 or fewer cases.

The AGS case report form included a standardized question assessing each case's experience with 12 symptoms commonly associated with AGS. **Table 1** provides a summary of the symptoms experienced by AGS cases. The number of symptoms experienced in the past by a case ranged from 1 to 12, with each case experiencing an average of 4.2 symptoms. The most reported symptom was itching (71.4%), followed by hives (67.1%). Forty-five cases (64.3%) experienced at least one gastrointestinal symptom (diarrhea, vomiting, nausea or abdominal pain). Each case was provided with the definition of anaphylaxis and then asked to self-report whether they experienced anaphylaxis. Fifteen cases (21.4%) self-reported experiencing anaphylaxis, six of whom were hospitalized. In contrast, of the 55 cases who

Table 1: Characteristics of Alpha-gal syndrome cases, Rhode Island, 2012–2025

Characteristic	Number of Cases (N=70)	Percent of Cases
Sex		
Male	37	52.9
Female	33	47.1
Age Range (Years)		
0–19	5	7.1
20–39	7	10.0
40–49	15	21.4
50–59	12	17.1
60–69	19	27.1
≥70	12	17.1
Patient County		
Bristol County	<5	†
Kent County	<5	†
Newport County	12	17.1
Providence County	21	30.0
Washington County	29	41.4
Signs or Symptoms Reported by Cases During Interview		
Itching	50	71.4
Hives	47	67.1
Abdominal pain	31	44.3
Nausea	31	44.3
Diarrhea	26	37.1
Swelling of lips, tongue, throat, face, eyelids, or other associated structures	26	37.1
Acute episode of hypotension	19	27.1
Vomiting	16	22.9
Heartburn/Indigestion	16	22.9
Shortness of breath	14	20.0
Wheezing	9	12.9
Cough	7	10.0
Product Categories Consumed within 2–10 Hours of Symptom Onset		
Beef	57	81.4
Pork	34	48.6
Milk or milk products (cheese, yogurt, butter, ice cream)	28	40.0
"Red meat", not specified	10	14.3
Lamb/mutton	9	12.9
Gel-cap medications	6	8.6
Gelatin/glycerin-containing food products (such as gelatin dessert, pudding, gummy candy, marshmallows)	5	7.1
Game meat (venison, boar, bison, elk, rabbit)	4	5.7
Goat	2	2.9

† Suppressed due to small numbers.

did not report ever experiencing anaphylaxis (78.6%), only one case reported being hospitalized in the past for an AGS-related allergic reaction. For five of the seven cases with available data, the average length of hospital admission was 2.8 days.

DISCUSSION

The spread and establishment of a self-sustaining lone star tick population in Rhode Island, together with case interview data, provides evidence that Rhode Island residents are at risk of developing Alpha-gal syndrome following a tick bite. Continued voluntary reporting by laboratories of individuals with reactivity to galactose-alpha-1,3-galactose will facilitate identification of additional cases in the future. Given the marked increase in cases observed in 2025, enhancing AGS surveillance in Rhode Island is essential to fully assess its impact. To support this, CAIDE proposes that AGS be added to Rhode Island's Reporting and Testing of Infectious, Environmental, and Occupational Diseases (216-RICR-30-50-1) regulations during the next revision. Inclusion of AGS to the testing and reporting regulations would require clinical laboratories and healthcare professionals to report individuals with positive laboratory or skin tests, as well as those that are suspected of having AGS.

The number of confirmed cases reported here likely underestimates the true burden. Laboratories were requested to voluntarily submit positive AGS laboratory tests since January 1, 2022, yet one of the cases reported an onset of AGS in 2012. This suggests that expanding laboratory reporting to earlier dates could have identified additional earlier cases. Additionally, CAIDE did not receive any reports from healthcare professionals of positive skin tests; however, interviews revealed that nine (12.9%) cases reported they had undergone skin testing, seven (10.0%) of whom reported positive results. Although self-reported and therefore subject to recall bias or misunderstanding, these findings indicate that skin testing occurs, but the overall volume of testing is unknown. Had positive skin tests been systematically reported, these individuals could have been investigated and counted as probable cases if they experienced symptoms consistent with AGS.

CAIDE's investigation into AGS in Rhode Island has established the foundation for an ongoing surveillance system. Although AGS is not yet officially reportable in Rhode Island, commercial laboratories continue to submit positive laboratory reports and suspect cases are actively investigated. Case

interview data indicate that individuals with positive skin test results, but no serology testing, are currently not being captured. Transitioning from voluntary to required reporting by including AGS in Rhode Island's Reporting and Testing of Infectious, Environmental, and Occupational Diseases (216-RICR-30-05-1) regulations will help improve case identification. Strengthening AGS reporting and surveillance will provide a more accurate estimate of disease burden and guide the development of targeted public and healthcare professional education, as well as funding to inform resource allocation for monitoring this.

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