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The Most Common Message Hidden in Thousands of Patient Stories

Listening to the Healthcare Experiences of Patients Living with Alpha-gal Syndrome

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This publication summarizes voluntary survey responses collected during this period. Individual healthcare experiences described throughout the report may have occurred years before survey completion, including before Alpha-gal Syndrome became more widely recognized in clinical practice.

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Purpose of This Publication

This publication summarizes healthcare experiences reported through more than 3,000 voluntary survey responses submitted to Tick Bite Data. The report places these findings within the current scientific understanding of Alpha-gal Syndrome.

The findings presented throughout this publication are intended to support education, provide context for future research, and document healthcare experiences reported through the Tick Bite Data survey. They are not intended to establish diagnostic criteria, estimate disease prevalence, or replace individualized clinical judgment.

Copyright

Conflict of Interest

Tick Bite Data is an independent nonprofit organization. The survey, analysis, and preparation of this publication were conducted independently. No commercial entity influenced the design of the survey, interpretation of the data, or preparation of this report.

Funding

This publication was prepared using voluntary patient-reported survey data submitted to Tick Bite Data. No external funding influenced the preparation or conclusions of this report.

Ethics and Survey Participation

Participation in the Tick Bite Data survey was voluntary, and respondents were free to answer as many or as few questions as they wished.

Findings presented throughout this publication are based on patient-reported information. Survey responses were analyzed in aggregate, and representative quotations have been edited only for minor spelling and grammatical corrections where necessary to improve readability while preserving each respondent's intended meaning.

The observations presented throughout this report are intended to support education, provide context for future research, and document patient-reported healthcare experiences. They should not be interpreted as establishing diagnostic criteria, estimating disease prevalence, or replacing individualized clinical judgment.

Acknowledgment

This publication is based on voluntary patient-reported survey responses submitted to Tick Bite Data.

We thank every individual who has contributed their experience. Each response adds to a growing body of patient-reported data that supports ongoing analysis, education, and future research related to Alpha-gal Syndrome.

As additional survey responses are collected, our understanding of the healthcare experiences of people living with Alpha-gal Syndrome will continue to grow.

Understanding the Data

Data Collection Period: December 2025 – July 2026

This publication summarizes voluntary survey responses collected during this period.

The healthcare experiences described throughout this report are not limited to events occurring between December 2025 and July 2026. Many respondents reported experiences that occurred years before completing the survey, including before Alpha-gal Syndrome became widely recognized.

Accordingly, this publication should be interpreted as a snapshot of healthcare experiences reported at the time of publication rather than a record of events occurring exclusively during the data collection period.

Throughout this report, quantitative findings summarize structured survey responses, while representative quotations provide context through individual patient and caregiver experiences. Section 2 provides the scientific foundation for the report, while the observations presented throughout the remaining sections are derived from the Tick Bite Data survey unless otherwise indicated.

Abbreviations

Abbreviation	Definition
AGS	Alpha-gal Syndrome
CDC	Centers for Disease Control and Prevention
FDA	U.S. Food and Drug Administration
GI	Gastrointestinal
IgE	Immunoglobulin E
SAAT	Soliman Auricular Allergy Treatment*

SAAT is referenced only in the **About Tick Bite Data section in relation to ongoing longitudinal patient-reported data collection.*

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Executive Summary

Alpha-gal Syndrome (AGS) is an emerging allergic condition associated with tick bites that continues to challenge traditional assumptions regarding food allergy, diagnosis, and long-term patient care. As understanding of the condition has evolved, patients have also contributed valuable insight through their lived experiences.

This publication summarizes healthcare experiences reported through more than 3,000 voluntary survey responses submitted to Tick Bite Data.

The report combines quantitative survey findings with qualitative analysis of narrative responses to examine recurring themes related to diagnosis, clinical presentation, healthcare experiences, and adaptation following diagnosis. These findings are intended to support education, future research, and a broader understanding of healthcare experiences reported by individuals living with Alpha-gal Syndrome. They are not intended to establish diagnostic criteria, estimate disease prevalence, or replace individualized clinical judgment.

Patient-reported experiences included in this publication span decades. Although survey responses were collected between December 2025 and July 2026, many respondents described experiences that occurred years before completing the survey, including during the early years of Alpha-gal Syndrome recognition.

Several observations emerged from the survey.

Approximately 66.4% of respondents reported that their symptoms were initially misdiagnosed before receiving an Alpha-gal Syndrome diagnosis, while 36.3% reported that the first physician they discussed Alpha-gal Syndrome with had not previously heard of the condition. Approximately 38.6% reported receiving a diagnosis within six months, while 24.2% waited more than three years.

Survey participants described symptoms involving multiple body systems, including neurological, gastrointestinal, musculoskeletal, cardiovascular, dermatologic, and respiratory systems. Brain fog, muscle cramps, arthritis or persistent joint pain, abdominal pain, itching, and rapid heart rate were among the most frequently reported findings.

Narrative responses identified recurring healthcare experiences extending well beyond diagnosis, including medication planning, surgery, emergency care, hospital admissions, pharmacy consultations, and long-term disease management. Many respondents also described positive experiences with healthcare professionals who investigated unfamiliar questions, collaborated with colleagues, or worked alongside patients while managing an evolving condition.

Respondents from multiple countries described many of the same healthcare experiences despite differences in healthcare systems, geographic regions, and reported tick species. Recurring themes included diagnosis, medication planning, surgery, healthcare communication, and long-term management.

1. Methodology

1.1 Scope of This Report

This publication summarizes healthcare experiences reported through voluntary patient-reported survey responses submitted to Tick Bite Data by individuals living with Alpha-gal Syndrome (AGS).

The report combines quantitative survey findings with qualitative analysis of narrative responses to identify recurring themes related to diagnosis, clinical presentation, healthcare experiences, and adaptation following diagnosis. Section 2 provides the scientific foundation for the report. Unless otherwise indicated, the observations presented throughout the remaining sections are derived from the Tick Bite Data survey.

The purpose of this publication is to document patient-reported healthcare experiences, summarize recurring observations identified within the survey, and contribute additional context to the evolving understanding of Alpha-gal Syndrome.

1.2 Survey Design

Data presented throughout this publication were collected through voluntary online surveys developed by Tick Bite Data.

The surveys include structured questions addressing diagnosis, symptoms, tick exposure, food reactions, medications, healthcare experiences, quality of life, and related topics. Participants were also invited to provide narrative responses describing their experiences in their own words.

Survey participation was voluntary. Responses reflect patient-reported experiences and were not independently verified through medical record review.

All survey questions were optional. Participants determined which questions they wished to answer and whether to provide narrative comments. Consequently, the observations presented throughout this publication reflect information voluntarily shared by respondents. Because participants were free to skip individual questions, the number of responses varies between survey questions.

1.3 Survey Population

At the time of publication, the Tick Bite Data survey had collected more than 3,000 voluntary survey responses. This publication summarizes information submitted by individuals reporting a diagnosis of Alpha-gal Syndrome, as well as parents, spouses, or other caregivers completing the survey on behalf of an individual living with the condition.

Participants represented multiple countries, healthcare systems, geographic regions, and tick species.

Because participation was voluntary, the observations presented throughout this report should be interpreted as describing the survey population rather than all individuals living with Alpha-gal Syndrome.

1.4 Quantitative Analysis

Structured survey responses were summarized using descriptive statistics.

Percentages reported throughout this publication represent responses to individual survey questions. Because respondents were free to skip individual questions, percentages are calculated using the number of responses received for each question rather than the total survey population unless otherwise indicated.

For multi-select symptom questions, percentages were calculated using the number of respondents completing the relevant symptom section rather than the total survey population. This approach more accurately reflects the frequency of reported symptoms among respondents providing symptom information.

Prior to analysis, survey responses were reviewed for obvious data-entry errors, incomplete records relevant to the analysis being performed, and implausible date values. Where appropriate, clearly erroneous entries were excluded from date-based analyses while preserving the original survey responses.

1.5 Narrative Review

Narrative responses were reviewed to identify recurring healthcare-related themes described by survey participants.

Representative quotations were selected because they reflected themes observed across multiple responses or illustrated experiences relevant to the topic being discussed. Minor spelling and grammatical corrections were made where necessary to improve readability while preserving each respondent’s intended meaning.

Patient quotations presented throughout this publication are reported as individual experiences and are included to provide context for recurring themes identified during qualitative review.

1.6 Interpretation

Patient-reported survey data provide valuable insight into the lived healthcare experience of Alpha-gal Syndrome.

The findings presented throughout this publication complement, but do not replace, clinical research. Wherever appropriate, survey findings are discussed alongside established evidence to distinguish current understanding from observations reported through the Tick Bite Data survey and to identify areas that may warrant future investigation.

2. Alpha-gal Syndrome: Current Understanding

Overview

Alpha-gal Syndrome (AGS) is an emerging allergic condition associated with tick bites. Although scientific understanding has expanded considerably over the past two decades, the condition remains an active area of clinical research.

This section provides a concise overview of the current scientific understanding of Alpha-gal Syndrome and establishes the historical and clinical context for the patient-reported observations presented throughout the remainder of this publication.

2.1 Alpha-gal Syndrome

Alpha-gal Syndrome is an allergic condition associated with immunoglobulin E (IgE) antibodies directed against the carbohydrate galactose-α-1,3-galactose (alpha-gal). In many individuals, sensitization occurs following the bite of certain tick species, resulting in allergic reactions after exposure to mammalian meat and, for some individuals, other products containing alpha-gal.[1–3]

Unlike many food allergies that produce symptoms within minutes, reactions associated with Alpha-gal Syndrome frequently occur several hours after exposure. This delayed presentation may complicate recognition for both patients and healthcare professionals.[1]

Current evidence describes considerable clinical variability among individuals living with Alpha-gal Syndrome. Dermatologic, gastrointestinal, cardiovascular, respiratory, and other manifestations have all been reported, with symptom severity differing considerably between individuals.[1–5]

2.2 Clinical Presentation

Current understanding describes Alpha-gal Syndrome as a heterogeneous condition with a broad range of reported clinical manifestations.

The patient-reported survey responses presented throughout this publication similarly describe symptoms involving multiple body systems, including neurological, gastrointestinal, musculoskeletal, cardiovascular, dermatologic, and respiratory findings.

Because symptoms frequently overlap with other medical conditions and reactions may occur several hours after exposure, recognition often depends upon careful clinical history, consideration of tick exposure, and appropriate diagnostic evaluation.

2.3 Why Patient-Reported Data Matter

Patient-reported data provide information that complements clinical research by documenting healthcare experiences outside controlled research settings.

Regulatory agencies, including the U.S. Food and Drug Administration, recognize patient experience data as an important component of healthcare research and medical product development.[6]

The survey findings presented throughout this publication are intended to complement the current understanding of Alpha-gal Syndrome by documenting recurring healthcare experiences reported by individuals living with the condition.

2.4 The Evolution of Alpha-gal Syndrome

Scientific understanding of Alpha-gal Syndrome has developed rapidly over the past two decades. Many healthcare professionals practicing today completed their medical training before the condition was recognized as a distinct allergic condition, and some respondents described healthcare experiences that occurred before a diagnostic framework existed.

Table 1. The Evolution of Alpha-gal Syndrome

Scientific Milestones	**Patient-Reported Observations**
Before 2008 – Alpha-gal Syndrome had not yet been formally recognized as a distinct allergic condition.	Survey respondents reported tick bites dating back to 1972. More than 160 respondents reported tick bites before 2008, indicating that many healthcare experiences documented in this report occurred before Alpha-gal Syndrome was widely recognized.
2008 – IgE antibodies to alpha-gal were identified as the cause of severe allergic reactions observed in some patients receiving cetuximab.[7]	Respondents described healthcare experiences spanning the period before and after formal scientific recognition of Alpha-gal Syndrome.
2009 – The association between tick bites and delayed allergic reactions to mammalian meat was first reported in 2009.[1]	Respondents continued to report prolonged diagnostic delays during the early years of clinical recognition.
2010–Present – Research expanded to include delayed reactions, gastrointestinal presentations, multiple tick species, medication considerations, perioperative management, and global distribution.[2–5]	Survey responses reflect increasing recognition of Alpha-gal Syndrome across multiple countries and healthcare systems while continuing to identify new healthcare experiences and clinical questions.

The scientific framework summarized in this section provides the historical and clinical context for the patient-reported observations presented throughout the remainder of this publication. Unless otherwise indicated, the observations described in subsequent sections are derived from the Tick Bite Data survey.

References

The following publications provided historical and scientific context for the development of this report. Patient-reported observations presented throughout the publication are derived from the Tick Bite Data survey unless otherwise indicated.

1. Chung CH, Mirakhur B, Chan E, et al. *Cetuximab-induced anaphylaxis and IgE specific for galactose-α-1,3-galactose.* N Engl J Med. 2008.

2. Commins SP, Satinover SM, Hosen J, et al. *Delayed anaphylaxis, angioedema, or urticaria after consumption of red meat in patients with IgE antibodies specific for galactose-α-1,3-galactose.* J Allergy Clin Immunol. 2009.

3. Centers for Disease Control and Prevention. *Alpha-gal Syndrome.* U.S. Department of Health and Human Services.

4. U.S. Food and Drug Administration. *Patient-Focused Drug Development Guidance Series.*

3. The Unexpected Finding

The healthcare experiences presented throughout this report were identified through recurring themes that emerged during qualitative review of the narrative survey responses.

The Tick Bite Data survey was developed to better understand the experiences of individuals living with Alpha-gal Syndrome. Structured survey questions focused on diagnosis, symptoms, tick exposure, reactions, treatment experiences, medications, and quality of life.

Participants were also invited to provide written comments describing their experiences in their own words.

Review of these narrative responses identified a recurring theme that extended beyond the original objectives of the survey.

3.1 Survey Overview

The survey was designed to collect both quantitative and qualitative information.

Structured survey questions provided measurable information regarding diagnosis, symptoms, food reactions, medications, healthcare experiences, and other aspects of living with Alpha-gal Syndrome.

Narrative responses provided additional context by allowing participants to describe experiences that could not be fully captured through structured questions alone.

Narrative responses were reviewed to identify recurring healthcare-related themes.

Table 2. Selected Healthcare Findings Reported by Survey Respondents

Survey Finding	**Survey Result**
Symptoms initially misdiagnosed	66.4%
First physician had not previously heard of Alpha-gal Syndrome	36.3%
Diagnosed within 6 months	38.6%
Diagnosed after more than 3 years	24.2%

Percentages represent responses to individual survey questions and should not be combined across unrelated survey questions.

3.2 Geographic Distribution of Reported Tick Bite Exposure

The Tick Bite Data survey had collected more than 3,000 voluntary survey responses at the time of publication. Survey participants reported tick bite exposures across multiple regions of the United States.

The geographic distribution summarized below reflects the reported location of tick bite exposure rather than the respondent's state of residence. Tick species listed in the table represent patient-reported identifications recorded through the Tick Bite Data survey. These identifications were not independently verified and are presented to summarize reported tick bite exposures within the survey population rather than establish vector competence or causation.

Table 3. Reported Tick Bite Exposure by Geographic Region

Geographic Region	**Representative States/Territories Reported in Survey**	**Tick Species Reported by Respondents***
Pacific Northwest	Washington, Oregon	Blacklegged Tick, Chiggers
Southwest	Texas, New Mexico	Lone Star Tick, Blacklegged Tick
Mountain West	Colorado, Idaho, Montana, Utah	Lone Star Tick, Blacklegged Tick, Seed Ticks (breed unknown)
Midwest	Missouri, Kansas, Illinois, Indiana, Iowa, Ohio, Michigan, Minnesota, Wisconsin, Nebraska	Lone Star Tick, American Dog Tick, Blacklegged Tick, Asian Longhorned Tick, Gulf Coast Tick, Brown Dog Tick, Rocky Mountain Wood Tick, Chiggers, Seed Ticks (breed unknown)
Northeast	New York, Pennsylvania, New Jersey, Connecticut, Massachusetts, Rhode Island, Vermont, New Hampshire, Maine, Delaware, Maryland	Blacklegged Tick, American Dog Tick, Lone Star Tick, Western Blacklegged Tick, Seed Ticks (breed unknown)
Southeast	Virginia, West Virginia, North Carolina, South Carolina, Tennessee, Kentucky, Arkansas, Oklahoma, Georgia, Florida, Alabama, Mississippi, Louisiana	Lone Star Tick, American Dog Tick, Blacklegged Tick, Gulf Coast Tick, Brown Dog Tick, Rocky Mountain Wood Tick, Chiggers, Western Blacklegged Tick, Seed Ticks (breed unknown)

3.3 Healthcare Experiences

Healthcare experiences became one of the most frequently discussed topics within the narrative responses.

Although participants were not asked to evaluate physicians, hospitals, pharmacists, nurses, emergency departments, or the healthcare system, many chose to describe those experiences in detail.

Comments frequently addressed delayed diagnosis, emergency care, medications, surgery, hospital admissions, pharmacy, communication among healthcare professionals, and long-term disease management.

Many respondents also described positive experiences with healthcare professionals who investigated unfamiliar questions, consulted colleagues, coordinated care, or worked collaboratively with patients while managing an evolving condition.

Narrative responses were reviewed to identify recurring healthcare-related themes.

Approximately 66.4% of respondents reported that their symptoms were initially misdiagnosed before receiving an Alpha-gal Syndrome diagnosis.

Approximately 36.3% reported that the first physician they discussed Alpha-gal Syndrome with had not previously heard of the condition.

These findings represent responses to separate survey questions and should be interpreted independently.

Table 4. Themes Identified During Narrative Review

Theme	**Examples Described by Respondents**
Diagnostic Delay	Delayed testing, multiple evaluations, self-advocacy, prolonged time to diagnosis
Healthcare Communication	Conversations with physicians, referrals, shared decision-making, provider awareness
Medications	Ingredient questions, excipients, pharmacy consultations, medication planning
Surgery & Hospital Care	Procedure planning, hospitalization, perioperative discussions, emergency care
Long-Term Management	Diet, follow-up care, quality of life, ongoing symptom management

3.4 Themes Identified During Narrative Review

Review of the narrative responses identified several healthcare-related themes that appeared repeatedly across respondents. These themes emerged independently of the structured survey questions and were identified through qualitative review of the written comments.

Each of these themes is explored in the sections that follow using structured survey findings and representative patient narratives.

4. “I Had to Ask for the Test”

Overview

This section summarizes patient-reported experiences related to diagnostic delay, time to diagnosis, and the healthcare experiences that preceded an Alpha-gal Syndrome diagnosis.

4.1 Diagnostic Experience

Approximately 66.4% of respondents reported that their symptoms were initially misdiagnosed before receiving an Alpha-gal Syndrome diagnosis.

Approximately 36.3% reported that the first physician they discussed Alpha-gal Syndrome with had not previously heard of the condition.

Together, these observations provide context for many of the diagnostic experiences described throughout the narrative responses.

Table 5. Diagnostic Experience Reported by Survey Respondents

Survey Finding	**Survey Result**
Symptoms initially misdiagnosed	66.4%
First physician had not previously heard of Alpha-gal Syndrome	36.3%

4.2 Conditions Reported Before Alpha-gal Syndrome Was Considered

Narrative responses described evaluations or diagnoses for a broad range of conditions before Alpha-gal Syndrome was considered.

Respondents frequently described gastrointestinal disorders, gallbladder disease, anxiety, chronic urticaria, autoimmune conditions, neurological disorders, and other conditions with overlapping clinical features.

These observations are presented qualitatively because the survey did not collect structured data regarding specific prior diagnoses.

One respondent wrote:

> *"Doctor thought gallbladder. We chased that for months and every test, scan, ultrasound showed I was fine. I finally told her I felt like no one was listening to me. She read through my chart and asked if I had ever been tested for Alpha-gal Syndrome. Turns out, she also has Alpha-gal Syndrome and recognized the symptoms."*

Another shared:

> *"Doctors kept treating me for diverticulitis. CT scans never showed diverticulitis, but my reactions continued until Alpha-gal Syndrome was considered."*

Table 6. Time to Diagnosis Reported by Survey Respondents

Time to Diagnosis	**Survey Result**
Less than 6 months	38.7%
6–12 months	16.3%
1–3 years	17.5%
More than 3 years	24.2%

Percentages are based on respondents who reported receiving an Alpha-gal Syndrome diagnosis. Respondents indicating they had not yet received a diagnosis at the time of survey completion are not included.

The findings illustrate considerable variability in the diagnostic experiences reported by survey participants.

4.3 Time to Diagnosis

Survey respondents reported considerable variation in the time required to receive an Alpha-gal Syndrome diagnosis.

Table 7. Relative Patient-Reported Symptom Burden by Time to Diagnosis

Time to Diagnosis	**Observation**
Less than 3 months	Lowest reported symptom burden
3–12 months	Greater reported symptom burden
1–3 years	Greater reported symptom burden
More than 3 years	Highest reported symptom burden

4.4 The Cost of Waiting

Analysis of the survey responses identified an association between longer diagnostic delays and greater reported symptom burden.

Respondents diagnosed earlier generally reported fewer persistent symptoms than those whose diagnosis occurred later. As diagnostic delay increased, respondents described a broader range of neurological, gastrointestinal, musculoskeletal, cardiovascular, dermatologic, and respiratory symptoms.

Because these findings are based on patient-reported survey data, they identify an association rather than establishing causation. The consistency of this association identifies an important area for future clinical investigation.

4.5 Patient Narratives

Several respondents described lengthy diagnostic journeys before Alpha-gal Syndrome was considered.

One respondent wrote:

> *“I had to seek out a laboratory and pay out of pocket for testing because no physician would listen after a friend suggested Alpha-gal Syndrome.”*

Another commented:

> *“I don’t know how many doctors’ appointments I had before someone finally considered Alpha-gal.”*

These narratives illustrate the wide variation in diagnostic experiences reported throughout the survey.

5. Clinical Presentation

Overview

Clinical presentation varied considerably among survey participants.

Respondents described symptoms involving neurological, gastrointestinal, musculoskeletal, cardiovascular, dermatologic, and respiratory systems. No single symptom characterized every respondent, and many participants described symptoms affecting multiple body systems.

The observations presented in this section are derived from structured survey responses and representative patient narratives collected through the Tick Bite Data survey.

5.1 Neurological Findings

Neurological symptoms were among the most frequently reported observations within the survey.

Table 8. Body Systems Represented in Patient-Reported Symptoms

Body System	**Examples Reported by Survey Participants**
Neurological	Brain fog, mental fatigue, headaches, tremors
Gastrointestinal	Abdominal pain, diarrhea, nausea, vomiting
Musculoskeletal	Muscle cramps, arthritis, joint pain
Cardiovascular	Rapid heart rate, dizziness, blood pressure changes
Dermatologic	Itching, hives, rash, swelling, hair loss
Respiratory	Shortness of breath, throat swelling, wheezing

Table 9. Neurological Findings Reported by Survey Participants

Finding	**Reported by Participants***
Brain fog	80.1%
Mental fatigue	72.6%
Anxiety	66.9%
Headaches	64.2%
Depression	36.1%
Tremors	33.2%

**Percentages calculated using respondents completing the neurological symptom question.*

Brain fog, mental fatigue, headaches, anxiety, and tremors were among the most frequently reported neurological findings. Respondents often described neurological symptoms occurring alongside gastrointestinal, musculoskeletal, cardiovascular, or dermatologic symptoms, reflecting the involvement of multiple body systems.

> *"The brain fog has been one of the hardest symptoms to explain."*

5.2 Gastrointestinal Findings

Gastrointestinal symptoms were also frequently reported.

Table 10. Gastrointestinal Findings Reported by Survey Participants

Finding	**Reported by Participants***
Abdominal pain	88.2%
Diarrhea	79.7%
Nausea	75.4%
Vomiting	43.3%

**Percentages calculated using respondents completing the gastrointestinal symptom question.*

Many respondents described prolonged gastrointestinal evaluations before Alpha-gal Syndrome was considered.

> *"I had every GI test imaginable before anyone mentioned Alpha-gal."*

5.3 Musculoskeletal Findings

Musculoskeletal symptoms were frequently reported throughout the survey.

Table 11. Musculoskeletal Findings Reported by Survey Participants

Finding	**Reported by Participants***
Frequent or unexplained muscle cramps	69.4%
Arthritis or persistent joint pain	64.5%
Tremors	33.2%

**Percentages calculated using respondents completing the musculoskeletal symptom question.*

Approximately seven in ten respondents reported frequent or unexplained muscle cramps, making it one of the most frequently reported musculoskeletal observations in the survey. Nearly two-thirds reported arthritis or persistent joint pain, and approximately one-third reported tremors.

Several respondents described musculoskeletal symptoms that affected mobility, physical activity, daily routines, and sleep.

> *"I developed severe joint pain and bursitis and ended up having to retire early as a police officer due to the pain and inability to climb stairs and get out of my police vehicle."*

> *"This is a nightmare. Seems like every day is something new. Shaking, hives, itching, headaches, joint pain, muscle aches that never go away."*

> *"Anaphylaxis twice resulting in ER visits. I then began having headaches and severe joint pain in my hands that prevented me from lifting weights and sleeping… And the muscle cramps! Ouch!"*

Others described tremors occurring alongside muscle cramps, fatigue, dizziness, or neurological symptoms, suggesting that musculoskeletal findings were frequently reported as part of a broader clinical presentation.

5.4 Cardiovascular Findings

Cardiovascular symptoms were commonly reported.

Table 12. Cardiovascular Findings Reported by Survey Participants

Finding	**Reported by Participants***
Dizziness	62.4%
Rapid heart rate	57.6%
Low blood pressure	35.5%
High blood pressure	23.7%

**Percentages calculated using respondents completing the cardiovascular symptom question.*

Respondents frequently described dizziness and rapid heart rate, often occurring alongside symptoms involving other body systems.

5.5 Dermatologic Findings

Table 13. Dermatologic Findings Reported by Survey Participants

Finding	**Reported by Participants***
Itching	83.4%
Hives	65.9%
Rash	56.5%
Swelling	52.0%
Hair loss	46.5%

**Percentages calculated using respondents completing the relevant symptom question.*

Respondents frequently described itching, hives, rash, swelling, and other skin-related symptoms.

Nearly half of respondents also reported noticeable hair loss. Although hair loss is not traditionally emphasized in descriptions of Alpha-gal Syndrome, it emerged frequently enough within the Tick Bite Data survey to warrant additional investigation.

5.6 Respiratory Findings

Table 14. Respiratory Findings Reported by Survey Participants

Finding	**Reported by Participants***
Shortness of breath	60.4%
Throat swelling	37.9%
Wheezing	34.6%

**Percentages calculated using respondents completing the relevant symptom questions.*

Respondents frequently described respiratory symptoms including shortness of breath, throat swelling, and wheezing. These symptoms were often reported alongside findings involving other body systems.

Some respondents also described respiratory symptoms associated with reported airborne exposure to mammalian products, including cooking vapors or smoke generated during the preparation of mammalian meat. These individuals frequently reported avoiding restaurants, cookouts, grocery store meat departments, or other environments where they believed airborne exposures could trigger symptoms.

> *"When around fumes within minutes my throat swells and breathing becomes difficult. This makes going to malls or even driving around the city during meal times very difficult."*

5.7 Clinical Variability

No single symptom characterized every respondent.

Instead, survey participants described symptoms involving multiple body systems that varied considerably between individuals.

Collectively, these findings demonstrate the diversity of healthcare experiences documented through the Tick Bite Data survey.

6. Healthcare After Diagnosis

For many respondents, receiving an Alpha-gal Syndrome diagnosis marked the beginning of a new phase of healthcare rather than the end of the diagnostic process.

Narrative responses described ongoing healthcare considerations related to medications, surgery, emergency care, hospital admissions, pharmacy, and long-term disease management. The observations presented in this section are derived from structured survey responses and representative patient narratives collected through the Tick Bite Data survey.

6.1 Preparing for Medical Care

Preparing for healthcare encounters was one of the most frequently discussed topics in the narrative responses.

Respondents described reviewing inactive ingredients, contacting manufacturers, consulting pharmacists, preparing medication lists, and discussing Alpha-gal Syndrome before medical appointments or procedures.

One respondent wrote:

> *"The effort needed to check everything you consume, put on your skin, or use during medical procedures is unbelievable."*

Another commented:

> *"The lack of transparency in medications is the most difficult part. There is no reliable way to check medications without contacting the manufacturer."*

Survey findings also identified frequent reactions to gelatin-containing foods and medications, providing context for why medication review appeared repeatedly throughout the narrative responses.

Table 15. Selected Medication-Related Findings

Survey Finding	**Reported by Participants**
Reactions to gelatin-containing foods	78.9%
Reactions to gelatin-containing medications	67.9%

6.2 Hospital and Emergency Care

Hospital admissions and emergency care were recurring topics throughout the survey.

Respondents frequently described concerns regarding medications, dietary accommodations, allergy communication, and continuity of care during hospitalization.

One respondent wrote:

> *"After an outpatient procedure at the hospital I was given a red allergy bracelet and was still offered a blueberry muffin containing dairy while waking up from anesthesia."*

Another commented:

> *"I had to be hospitalized. Not one care worker had heard of AGS. I could not eat the food they brought, nor take many of the medications because of gelatin or milk additives."*

Several respondents also described uncertainty about seeking emergency care because of concerns regarding medications or provider familiarity with Alpha-gal Syndrome.

These narratives describe healthcare experiences reported following diagnosis and emphasize the importance of communication across the healthcare team.

6.3 Surgery and Procedures

Many respondents described surgery and medical procedures as situations requiring additional planning.

Comments frequently referenced medication review, communication with surgeons and anesthesiologists, review of surgical products, and discussions regarding mammalian-derived ingredients before procedures.

One respondent wrote:

> *"Tried to give me heparin for an emergency surgery and told me it wouldn't matter because it was medicine."*

Another commented:

> *"Before having surgery for a hiatal hernia, I tried to educate my surgeon and asked for no mammal products. I still received heparin, experienced an anaphylactic reaction, and remained hospitalized for several additional days."*

These comments represent patient-reported experiences and illustrate why respondents frequently described surgery as requiring additional preparation following diagnosis.

6.4 Pharmacy and Nursing

Respondents described pharmacists reviewing medication ingredients, contacting manufacturers, and answering medication-related questions before treatment.

One respondent wrote:

> *"Luckily the pharmacies in my area are very helpful in finding medicine that has no mammal."*

Nurses were also frequently mentioned in relation to allergy documentation, medication administration, emergency care, and communication with physicians.

One respondent wrote:

> *"The second nurse I had told me about Alpha-gal and suggested I speak with my allergist. Testing later confirmed the diagnosis."*

Together, these narratives illustrate the important role pharmacists and nurses played in helping respondents navigate healthcare after diagnosis.

6.5 Healthcare Considerations Frequently Described by Survey Participants

Table 16. Healthcare Considerations Frequently Described in Narrative Responses

Healthcare Setting	**Examples Described by Participants**
Medications	Ingredient review, gelatin, excipients, manufacturer questions
Surgery and Procedures	Medication review, pre-operative planning, anesthesia discussions, heparin concerns
Hospital Care	Dietary accommodations, medication review, allergy communication
Emergency Care	Acute reactions, repeated visits, delayed recognition, diagnostic evaluation
Pharmacy	Ingredient verification, manufacturer consultation, medication planning
Nursing Care	Allergy documentation, medication administration, communication with physicians

Across healthcare settings, respondents consistently emphasized communication, preparation, and collaboration while navigating care after diagnosis.

7. Healthcare Experiences Across Countries

Survey responses included participants from multiple countries representing different healthcare systems, geographic regions, and tick species. Although tick species, geography, and healthcare delivery differed, many respondents described similar experiences related to diagnosis, healthcare communication, medications, and long-term disease management.

7.1 Geographic Representation

Although most survey responses were submitted by participants reporting tick bites in the United States, the survey also included respondents from Australia, Canada, Europe, Africa, the Caribbean, South America, the Middle East, and Southeast Asia.

Together, these survey responses demonstrate that Alpha-gal Syndrome is being reported across multiple geographic regions and healthcare systems.

7.2 Shared Healthcare Experiences

Despite differences in geography, healthcare systems, and tick species, respondents frequently described many of the same practical healthcare questions following diagnosis.

Questions regarding medications, surgery, healthcare communication, access to reliable information, and long-term disease management appeared repeatedly throughout the narrative responses regardless of country of residence.

Canada — Survey Respondent

> *"Thank God for all the information coming out of the States, because without it I would have been screwed and never get screened. It's just not on the radar here."*

Australia — Survey Respondent

> *"Joint pain after dairy exposure. Difficult with medications—magnesium stearate is in many tablets. I have to contact the manufacturer before taking any new medication and take precautions with everything, even medical tests."*

South Africa — Survey Respondent

> *"I suffered through three years of reactions because of misdiagnosis. Education across doctors, pharmacies, and clinics needs to improve. The worst part is trying to find mammal-free medications. There is no alternative for some medications here in South Africa."*

Although these respondents described different healthcare systems and geographic regions, they frequently raised many of the same questions regarding diagnosis, medications, and long-term management.

Table 17. Commonly Reported Healthcare Topics

Region Represented in Survey	Examples Described by Participants
North America	Diagnostic delay, medications, surgery, emergency care
Australia	Medication planning, provider awareness, long-term management
Canada	Access to information, diagnosis, specialist referral
Europe	Tick exposure, provider awareness, diagnosis
Africa	Diagnosis, healthcare access, long-term management
Other regions*	Medication planning, healthcare communication, ongoing management

**Includes respondents from South America, the Caribbean, the Middle East, and Southeast Asia.*

7.3 Expanding Recognition

Survey responses collected through Tick Bite Data demonstrate that respondents from multiple countries frequently described similar healthcare experiences following diagnosis.

Although healthcare systems, geographic regions, and reported tick species differed, respondents consistently described many of the same questions regarding diagnosis, medication planning, healthcare communication, and long-term management.

Together, these findings demonstrate that many of the healthcare experiences documented through the Tick Bite Data survey were shared across international borders, highlighting opportunities for continued collaboration, education, and future research.

8. Adapting After Diagnosis

Receiving an Alpha-gal Syndrome diagnosis marked the beginning of a new phase for many survey participants. Beyond medical care, respondents described adapting to ongoing healthcare decisions, medications, daily routines, family responsibilities, and an evolving understanding of the condition.

The observations presented in this section are derived from structured survey responses and representative patient narratives collected through the Tick Bite Data survey.

8.1 Learning About the Condition

Many respondents described continuing to learn about Alpha-gal Syndrome after receiving their diagnosis.

Narrative responses frequently referenced scientific publications, healthcare professionals, patient communities, nonprofit organizations, and conversations with other individuals living with Alpha-gal Syndrome as important sources of information.

Several respondents described continuing to learn as new information became available regarding medications, medical procedures, diet, and long-term management.

One respondent wrote:

> *"You included more than I ever correlated with this illness. You helped me realize why I feel the way I do. Thank you."*

These observations reflect the evolving understanding of Alpha-gal Syndrome and the importance respondents placed on access to reliable information.

8.2 Self-Advocacy

Many respondents described becoming active participants in their own healthcare following diagnosis.

Narrative responses frequently discussed preparing for medical appointments, reviewing medication ingredients, contacting manufacturers, carrying emergency medications, discussing Alpha-gal Syndrome before surgery, and asking additional questions during healthcare encounters.

These observations suggest that many respondents viewed self-advocacy as an important part of managing Alpha-gal Syndrome within an evolving healthcare landscape.

8.3 Family and Caregiver Perspectives

Although most survey responses were completed by individuals living with Alpha-gal Syndrome, a portion were submitted by parents, spouses, or other family members responding on behalf of someone with the condition.

Caregivers frequently described coordinating medical appointments, reviewing medications, researching ingredients, preparing for medical procedures, managing dietary restrictions, and communicating with healthcare professionals.

One caregiver wrote:

> *"As a mother and caregiver, this diagnosis has not only significantly impacted my life but also the people I cook and care for."*

These narratives illustrate that adapting to Alpha-gal Syndrome frequently involved family members participating in healthcare planning and daily management.

8.4 Adapting Daily Life

Following diagnosis, many respondents described adapting daily routines in ways that extended beyond healthcare.

Narrative responses frequently discussed planning meals before travel, reading ingredient labels, carrying emergency medications, preparing for medical appointments, and modifying daily routines to reduce the risk of unintended exposures.

Respondents also described adapting social activities and community participation.

Restaurants, cookouts, family gatherings, workplace events, holidays, and travel were frequently mentioned as situations requiring additional planning or, in some cases, avoidance because of concerns regarding food preparation, cross-contamination, or uncertainty surrounding ingredients.

One respondent wrote:

> *"It just changes your whole lifestyle. Can't go to restaurants, cookouts or any food events…"*

Another commented:

> *"It has affected my overall mood and is mentally challenging. I'm afraid to eat out and do less socially."*

Some respondents also described modifying daily activities because they reported reactions to cooking vapors or other airborne exposures associated with mammalian products. These individuals described avoiding restaurants, cookouts, grocery store meat departments, shopping centers, or other environments they believed could trigger symptoms.

Collectively, these observations illustrate how Alpha-gal Syndrome influenced everyday decision-making long after diagnosis.

8.5 Contributing to Knowledge

A substantial majority of respondents answering the relevant survey question indicated they would be willing to participate in future research studies.

Many respondents explained that they completed the survey because they believed sharing their experiences could contribute to a better understanding of Alpha-gal Syndrome and improve the experience of future patients.

"I hope my experience helps someone else."

Table 18. Examples of Adaptation After Diagnosis

Theme	**Examples Described by Survey Participants**
Learning about the condition	Scientific publications, healthcare professionals, patient communities
Self-advocacy	Medication review, manufacturer contact, preparing for appointments
Family and caregiver involvement	Medical appointments, household planning, healthcare communication
Adapting daily life	Meal planning, travel, emergency preparedness, social activities
Contributing to knowledge	Survey participation, sharing experiences, future research participation

Collectively, these observations describe how respondents adapted to Alpha-gal Syndrome while continuing to navigate healthcare, family responsibilities, and everyday life after diagnosis.

9. Key Observations

9.1 Symptoms Involved Multiple Body Systems

Survey participants described symptoms involving neurological, gastrointestinal, musculoskeletal, cardiovascular, dermatologic, and respiratory systems. No single symptom characterized every respondent, and many participants described symptoms affecting multiple body systems.

9.2 Diagnostic Delay Was Associated with Greater Reported Symptom Burden Over Time

Analysis of the survey responses identified an association between longer diagnostic delays and greater reported symptom burden.

Respondents diagnosed earlier generally reported fewer persistent symptoms than those whose diagnosis occurred later. These findings identify an association rather than establishing causation and represent an important area for future investigation.

9.3 Healthcare Experiences Extended Beyond Diagnosis

For many respondents, receiving an Alpha-gal Syndrome diagnosis represented the beginning of a new phase of healthcare rather than the end of the diagnostic process.

Narrative responses frequently described medication planning, surgery, hospital admissions, emergency care, pharmacy consultations, and ongoing communication with healthcare professionals as part of long-term disease management.

9.4 Similar Healthcare Experiences Were Reported Across Multiple Countries

Respondents from different countries, healthcare systems, and geographic regions frequently described similar healthcare experiences following diagnosis. Many also described similar questions regarding medications, surgery, healthcare communication, and long-term disease management despite differences in geography and healthcare delivery.

9.5 Adaptation Extended Beyond Medical Care

Respondents described adapting healthcare decisions, family responsibilities, daily routines, travel, social activities, and emergency preparedness following diagnosis.

Many also indicated that they completed the survey because they hoped their experiences would contribute to a better understanding of Alpha-gal Syndrome and support future research.

This publication documents healthcare experiences reported through the Tick Bite Data survey and represents a snapshot of patient-reported observations available at the time of publication. Many respondents described experiences that occurred years before completing the survey, including experiences that preceded the broader clinical recognition of Alpha-gal Syndrome. Together, these historical and contemporary observations provide additional context for understanding the evolving healthcare experience of individuals living with Alpha-gal Syndrome. As scientific understanding continues to advance, future patient-reported data and clinical research may further expand upon the observations presented in this report.

Appendix

Clinical Considerations Informed by Patient-Reported Survey Data

This appendix summarizes recurring patient-reported observations documented through the Tick Bite Data survey. It is intended as a concise reference for clinicians, researchers, and public health professionals. The information presented here provides additional context for the findings described throughout this publication and is not intended to establish clinical guidelines or recommendations.

Table A.1. Frequently Reported Clinical Findings by Body System

Body System	**Frequently Reported Findings**
Neurological	Brain fog, mental fatigue, headaches, tremors
Gastrointestinal	Abdominal pain, diarrhea, nausea, vomiting
Musculoskeletal	Muscle cramps, arthritis or persistent joint pain
Cardiovascular	Dizziness, rapid heart rate, blood pressure changes
Dermatologic	Itching, hives, rash, swelling, hair loss
Respiratory	Shortness of breath, throat swelling, wheezing

Table A.2. Healthcare Experiences Frequently Described by Respondents

Healthcare Setting	**Commonly Reported Topics**
Primary Care	Diagnostic delay, referrals, recognition
Emergency Care	Acute reactions, recognition, communication
Hospital Care	Dietary accommodations, medication review, allergy documentation
Surgery & Procedures	Medication review, perioperative planning
Pharmacy	Ingredient review, manufacturer consultation

Table A.3. Questions Frequently Raised During Healthcare Encounters

Topic	**Example Question**
Diagnosis	Could Alpha-gal Syndrome explain these symptoms?
Medications	Does this medication contain mammalian-derived ingredients?
Surgery	Should medications and mammalian-derived products be reviewed before surgery?
Hospital Care	How should Alpha-gal Syndrome be documented during admission?
Long-Term Management	What healthcare considerations should be discussed during future appointments?

Table A.4. Recurring Themes Identified Throughout the Report

Theme	**Primary Report Section**
Diagnostic delay	Section 4
Clinical presentation	Section 5
Healthcare after diagnosis	Section 6
Healthcare experiences across countries	Section 7
Adapting after diagnosis	Section 8

Table A.5. Clinical Considerations Reported by Survey Participants

Clinical Situation	Patient-Reported Considerations
New diagnosis	Respondents frequently described delayed recognition, careful clinical history, and tick exposure as important parts of the diagnostic journey.
Medication review	Respondents frequently described reviewing inactive ingredients and consulting pharmacists before starting new medications.
Surgery & procedures	Respondents frequently described discussing medications and mammalian-derived products before planned procedures.
Hospital admission	Respondents frequently described discussing dietary accommodations, medication review, and allergy documentation during admission.
Follow-up care	Respondents frequently described ongoing adaptation, education, and symptom management after diagnosis.

This appendix provides a concise reference to recurring patient-reported observations identified through the Tick Bite Data survey. It summarizes healthcare experiences discussed throughout this publication and is intended to complement—not replace—individualized clinical judgment or established clinical guidance.

About Tick Bite Data

Tick Bite Data is an independent nonprofit organization dedicated to collecting, analyzing, and communicating patient-reported information related to **Alpha-gal Syndrome (AGS).**

Through voluntary survey participation, Tick Bite Data documents patient-reported healthcare experiences, clinical presentation, diagnosis, and adaptation following an Alpha-gal Syndrome diagnosis. These observations are intended to document recurring patient-reported experiences that may inform future research, education, and public health discussions.

In addition to the survey presented in this publication, Tick Bite Data is developing longitudinal patient-reported research initiatives examining treatment experiences, symptom progression, and quality of life among individuals living with Alpha-gal Syndrome. Current initiatives include ongoing patient-reported outcome collection related to **Soliman Auricular Allergy Treatment (SAAT).**

As additional survey responses are collected, future publications will continue to summarize recurring patient-reported observations and expand upon the findings presented in this report.

Tick Bite Data is committed to advancing the understanding of Alpha-gal Syndrome through careful analysis of patient-reported observations and transparent communication of survey findings.

Website

https://tickbitedata.com