

TOM NEVERS CIVIC ASSOCIATION

2009 Voting Member Survey Report

**TOPIC:
Tick-Borne Diseases**

February 10, 2009

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About this Survey—

In December 2008, The Tom Nevers Civic Association conducted a survey among its members to gauge the impact of tick-borne diseases on their lives. By the January 31st 2009 cut off date, 37.1% of all voting members had responded...providing a 95% confidence level in the survey's findings.

While not projectable to the Island as a whole—especially because Town residents and transients were not included—this survey does provide a good indication of the impact of tick-borne diseases on the property-owners in Nantucket's "countryside" areas. In addition, it provides valuable qualitative data...in the form of verbatim statements from many of the survey's respondents...indicating the severity of the tick-borne disease problem and the plea that something significant be done to solve it.

The survey's detailed findings, a copy of the questionnaire, and information on the Tom Nevers Civic Association appear at the end of this report.

Other Nantucket civic associations and non-profit organizations that may wish to expand the survey to include their members are encouraged to do so. (The TNCA would be happy to provide both production and mailing services...and survey tabulating services...at out-of pocket cost.)

Summary Findings—

Conclusion #1 – The incidence of tick-borne diseases on Nantucket is far greater than the yearly statistics compiled by Nantucket Cottage Hospital would imply.

Study Finding 1a –

6-out-of-10 households have been infected with a tick-borne disease.

When asked— “Have you or any members of your family...or any of your Nantucket guests or renters ...ever had any of the following tick-borne diseases?”—survey respondents answered as follows –

Lyme disease.....	61.3 % said “Yes”
Babesiosis.....	17.2 % said “Yes”
Ehrlichiosis.....	8.6 % said “Yes”

Study Finding 1b –

On average, 2.3 people per household have been infected.

When asked— “the total number in your group (family + guests + renters) who have contracted a tick-borne disease?”—survey respondents answered as follows –

Total number of people infected.....	2.3 avg. per household*
Number infected with Lyme disease.....	1.8 avg. per household*
Number infected with Babesiosis.....	1.2 avg. per household*
Number infected with Ehrlichiosis.....	1.3 avg. per household*

* In Households that reported having had this tick-borne disease infection.

Study Finding 1c –

Local statistics totally miss nearly a third of those people infected with a tick-borne disease...because they were diagnosed and treated off-Island.

When asked— “where their tick-borne diseases were diagnosed and treated?”—survey respondents answered as follows –

Percent diagnosed off-Island.....	31.6 %
Percent treated off-Island.....	35.0 %

Study Finding 1d –

The incidence of tick-borne disease infection is even higher than reported in the above data.

- Our survey focused on the number of people infected with a tick-borne disease...and not the number of times they were infected. Based on the write-in comments from many respondents, we can see that multiple infections over time are fairly common. Reported multiple infections with Lyme disease ranged from 3 to as high as 6.
- When asked— “How many people live in, or visit, your Nantucket property in a typical year?”—survey respondents answered as follows –

Resident Family.....	2.3 people on average	(11 % of all)
Visiting Family.....	6.4 people on average	(29 % of all)
Guests.....	7.8 people on average	(36 % of all)
Renters.....	5.2 people on average	(24 % of all)

With as many as 9-out-of-10 being non-resident short-term visitors, it is more than probable that a fair number of these people were indeed infected but never diagnosed. Based on write-in comments from many respondents, we can see this concern expressed over-and-over again about some of their “guests” and/or “renters”.

Summary Findings—

Conclusion #2 – Tick-borne diseases contracted on Nantucket pose a greater long-term health threat than is generally acknowledged.

Study Finding 2a –

Due to initial mis-diagnosis, the percent of infected people with ongoing health problems is significant.

Percent reporting an initial mis-diagnosis—

Lyme disease..... 18.6 %

Babesiosis..... 15.8 %

Ehrlichiosis..... 30.0 %

Percent reporting ongoing health problems—

Lyme disease..... 10.8 %

Babesiosis..... 15.8 %

Ehrlichiosis..... 20.0 %

These verbatim comments from survey respondents provide some indication of the severity of these ongoing health problems—

“My daughter has suffered ongoing health problems, including heart problems related to an undiagnosed case of ehrlichiosis. She is currently under treatment of a Lyme disease specialist, after a mis-diagnosis at Yale University.”

(Diagnosed and treated for Ehrlichiosis off-island)

“We have had 3 cases of Lyme disease. One case was diagnosed at a very advanced state and resulted in rather extensive cardiovascular problems, as well as vulnerability to other viral infections.”

(Diagnosed and treated for Lyme disease both on-island and off-island)

“I almost died when my spleen ruptured as a result of Babesiosis complications...and would have where it not for the heroic efforts of the EMTs, Dr. Lepore and Nantucket Hospital. This can happen to anyone.”

(Diagnosed and treated for Babesiosis both on-island and off-island)

“Mis-diagnosed Lyme disease shortened my father’s life. The result was strokes, total deafness, blindness in one eye, neuropathy in extremities, eventual confinement to wheelchair, etc. etc.”

(Diagnosed and treated for Lyme disease off-island. Initially mis-diagnosed and treated un-successfully.)

“Two of us contracted Lyme disease and Babesiosis. One of us was diagnosed and treated successfully on-island. But the other was initially mis-diagnosed off-island, delaying successful treatment significantly.”

(Diagnosed and treated for Lyme disease and Babesiosis both on-island and off-island)

“I was mis-diagnosed for Lyme disease in the 1980s, which led to the onset of early arthritis.”

(Diagnosed and treated for Lyme disease off-island. Initially mis-diagnosed.)

“I have 2 friends in PA with chronic Lyme, which they may have contracted here (not sure). It’s a huge problem for them. To date, 4 of our family members have contracted Lyme disease and I’m getting more and more concerned.”

(Diagnosed and treated for Lyme disease both on-island and off-island)

“Lyme has definitely affected my well being. I attribute it to my first case in ’83 which was treated after-the-fact (2-3 months after the rash) and only for 2 weeks. The problem is confounded by...1. The difficulty of diagnosis and unreliability of tests...2. Treatment duration (spirochete has 4 week life cycle, yet local physicians treat for 3 weeks only and resist requests for longer treatment...3. Local physicians seem to negate concept of “chronic Lyme”...even though periodic antibiotic treatment (myself as example) provides relief of specific symptoms.”

(Diagnosed and treated for Lyme disease and Ehrlichiosis on-island)

“Six years after my treatment for suspected Lyme disease, I still have some neurological issues. Our yard never has less than three deer in it, despite our efforts to make it less attractive. We don’t fertilize any grasses. Our few shrubs are fenced off and only native plants are accessible as a food source. It doesn’t matter. Our whole area is covered with droppings and is tick infested.”

(Diagnosed and treated for Lyme disease off-island. Initially mis-diagnosed.)

“Initially, I was mis-diagnosed and didn’t respond to the original medications. But I was very lucky in that my internist got me to a communicable disease specialist.”

(Diagnosed and treated for Lyme disease off-island)

Summary Findings—

Conclusion #3 – The growing threat of contracting a tick-borne disease on Nantucket is having a serious negative impact on both the quality-of-life and future economic health of the Island.

Study Finding 3a –

More than 8-out-of 10 are now apprehensive about engaging in outdoor activities.

- 88.2% say they now worry more about outdoor activities like gardening, hiking, picnics, etc.
- 83.9% say they now warn their visitors to be more cautious about exposure to ticks.

Study Finding 3b –

More than 5-out-of 10 now worry that unless something is done to solve the tick-borne disease problem, Nantucket will lose its appeal to visitors...and decrease their property values.

- 59.1% say “they worry that the problem, if left unchecked, will make Nantucket less attractive to their visiting family members, guests and/or renters.”
- 51.6% say “they worry that the problem, if left unchecked, will affect Nantucket property values.”

These verbatim comments from survey respondents provide some indication of their concerns—

“I don’t want my grandchildren exposed to the potential of a serious illness from a tick-borne disease. If this problem is not addressed, it will cause me to recommend that my family discontinue coming to Nantucket.”

(Diagnosed and treated for Ehrlichiosis off-island)

“More and more family and visitors have heard of the “Lyme disease epidemic” on Nantucket. People have become skeptical about taking walks anywhere but on the beach. We believe this is a problem that is doing to grow. We recently watched the movie “Jaws” again. Nantucket’s politicians remind us of the politicians depicted in Jaws, in that they refuse to accept the obvious data and act.”

“We check ourselves thoroughly for ticks every day. And several have been found on our grandchildren. Fortunately they were easily found before attachment...but the whole process brings fear to the children.”

“I worry that our family or guests may get infected but not understand that it is Lyme disease before it is too late for effective treatment.”

(Diagnosed and treated for Lyme disease off-island.)

“After their 3rd bout with Lyme disease, the couple who had rented our house for 3-weeks every summer for the past 14 years decided that they had finally had it with Nantucket. They’re now vacationing in the Pacific Northwest.

(Diagnosed and treated for Lyme disease and Babesiosis on-island.)

“Those of us who have contracted a tick-borne disease here are at least quickly diagnosed and treated. Unfortunately, visitors and renters may not be as readily diagnosed off-island...especially in areas where there is less knowledge and awareness of tick-borne diseases. I worry about my grandchildren playing on the lawn and near beach grass.”

(Diagnosed and treated for Lyme disease on-island.)

“It’s a real issue...and with all the wildlife and deer in my yard (I border conservation), it makes me even more concerned.”

“I was diagnosed and treated for Lyme disease over 20 years ago. How successfully, I’m not sure. You never know what long-term problems are attributable to Lyme disease.

(Diagnosed and treated for Lyme disease off-island.)

Summary Findings—

Conclusion #4 – While growing numbers are taking major steps to reduce their personal tick exposure, most believe it will require an Island-wide initiative to counter the growing tick-borne disease problem.

Study Finding 4a –

About 3-out-of-10 plan to take steps to reduce the number of ticks on their properties—

- 29.0 % say “they plan to increase preventive measures like fencing, Damminix, etc.”
- The vast majority believe that Nantucket’s tick-borne disease problem must be addressed on an Island-wide basis.

These verbatim comments from survey respondents provide some indication of their actions and attitudes—

What people are doing to reduce their tick exposure—

“We now have our property sprayed for ticks every year.”

“This is a very serious problem! We are currently spending \$15,000 to build a deer fence.”
(Diagnosed and treated for Lyme disease off-island)

“We’ve owned our cottage for 1 ½ years. We don’t know what previous owners did about ticks. We are entering our 2nd year of using Damminix tubes. We do not bring our pets to Nantucket, and we do not allow friends or tenants to bring pets. We’re eager to learn whatever else we can do to help with this very serious problem.”

“The number one reason that I’ve had all 3 tick-borne diseases many times is due to being a volunteer for the ASPCA feral cat program. My feeding and trapping of cats requires me to go into the woods weekly. Since I’ve all 3 tick diseases and find many ticks on my body, I now take doxycycline (2 pills) on discovery of a tick. So far this year, which was a bad one for ticks, I avoided all the tick diseases...which I assume was due to the medication.”

(Diagnosed and treated for Lyme disease, Babesiosis and Ehrlichiosis on-island)

“Almost all my gardening and landscaping is now done when the temperature is near or below freezing. This eliminates my tick concerns.”

“We check everyone for ticks, everyday. It’s a rule in our house that everyone must check one’s self.”

(Diagnosed and treated for Lyme disease off-island. Initially mis-diagnosed.)

“My feeling is stay vigilant... i.e.-check yourself after outdoor activity and inform visitors of same. It’s part of life here.”

“We conduct overall body checks on an ongoing basis. And we encourage the use of native plantings—i.e.-bayberry—and discourage plants that deer won’t eat. Why tease the deer with flowers they will feast on? One saves money, time and headaches if these are not planted. Also leashed dogs help cut down on ticks being brought into the home. If dogs are allowed to roam through tall grass, they bring ticks into the house. Also, light colored fur on dogs makes ticks more visible and easier to detect and remove. Sidewalks on Tom Nevers Road would help too...we now need to walk on the grass verge to be safe from passing cars.”

“I do all my own gardening and take all the precautions I can...tick spray, long sleeved clothes, tick check, etc. All very important.”

(Diagnosed and treated for Lyme disease on-island.)

“Ticks are found throughout the northeast and beyond. Wearing the proper clothing can help prevent a tick encounter. Thus far we have had no problem with tick-related diseases. Our renters have been coming here for years and I have heard of no concerns.”

“I am 73 years old and have spent some time at east coast beaches each summer. My family and I have been on Nantucket yearly for at least 20 years, and own our own home in Tom Nevers, We are careful to watch for ticks, and if exposure to tall grass or wooded areas is unusual, we may wipe down with alcohol. As a physician, I have made special efforts to educate my family and guests as to risks, and how we might avoid tick-borne diseases on Nantucket. I haven’t seen the data on the incidence of tick-borne illnesses, nor the data of recent increases. While awareness and preventive measures are important, I’d like to caution the Association to avoid alarmist or frantic-sounding statements in the newsletter. I have great respect for Dr. Lepore and the efforts he has made over the years to educate vacationers and islanders to the presence and risk of these illnesses. Lastly, 380 confirmed cases of tick-borne illness are certainly significant, but how many tens of thousands of visitors spend time on Nantucket each year? And who are the people who contracted these illnesses? ...residents or guests? ...children or adults? ...activities in which they engaged? ... and whereabouts on the island? This information might be helpful in understanding the risk of infection and how to prevent it. Finally, what is the annual incidence of disease vs. total number of visitors?

(Spends less than one-month on-island in a typical year.)

What people want Nantucket to do—

“I was very unhappy when the extra deer hunt was abandoned after one season. Obviously, there were difficulties, but it would have been far better to improve the hunt management and get the number of deer down to a less dangerous level. Now there are so many that I feel I am “riding shotgun” (i.e. - lookout) every time we drive on Milestone Road or Tom Nevers Road after dark.”

(Diagnosed and treated for Lyme disease off-island)

“One deer is one too many on Nantucket.”

(Diagnosed and treated for Lyme disease on-island)

“Although I have had Lyme disease 3 times, I have been diagnosed successfully by Dr. Pearl and seem to have suffered no serious consequences. However, the prevalence of this disease and other tick-borne diseases is a serious health threat and something should still be done by the authorities.”

(Diagnosed and treated for Lyme disease on-island)

“We are surrounded by deer. I’m not a hunter, but I think that hunting and other methods to control the deer population should be expedited. The Board of Selectmen should be vigorously prodded to approach this problem with urgency from all arenas.”

“Nantucket deer population must be drastically reduced or sterilized.”

“Having to inspect your body every day for tiny bugs may be standard fare if you’re visiting a third-world country—but we should expect far more from a world-class resort like Nantucket. Why do we settle for the health-risk and indignity of living with a deer tick infestation? Why are we letting the few block the obvious solution? We should get rid of the deer...or at the very least, reduce the number and move them to an enclosed compound on conservation land.

(Diagnosed and treated for Lyme disease on-island.)

“If something can be done to reduce the problem, I certainly support it.”

“Definitely a serious concern that needs to be addressed.”

“The deer population must be decreased...winter hunts...specialists...etc.”

“The negative reaction to additional hunts is not realistic. The thought of Nantucket becoming the Lyme disease capital should wake up the people that are opposed to additional (REGULATED) hunts.”

“Nantucket should do something about this problem, as it is increasing every year. Sooner or later, it will require more than local action. Perhaps that is the only way that proper actions will take place.”

(Diagnosed and treated for Lyme disease and Babesiosis off-island)

“Kill the deer, or at least reduce the population by infertility methods.”

(Diagnosed and treated for Lyme disease both on-island and off-island)

“A big problem is that people in our area feed the deer, thus keeping many close at all times. Should we ban feeding and attracting deer?”

There is also a call for greater information—

“Not aware of what Babesiosis and Ehrlichiosis are...or what their symptoms are. There should be greater awareness of this.

(Diagnosed and treated for Lyme disease off-island. Initially mis-diagnosed.)

“I need more information on prevention methods like fencing, Damminix, etc.”

“I was not aware that the problem was getting worse.”

“It would be helpful to have additional info about preventive measures. For instance, what is Damminix, how does it work, where can it be purchased? Are there proven medications/treatments that can reduce the infection of deer with the deer tick? I do not favor hunting as the solution to eradication or reduction of tick-borne diseases.”

And some just feel helpless—

“When you build houses in what used to be just woods, why would you expect ticks not to affect you? They were here first.”

(Diagnosed and treated for Lyme disease, Babesiosis and Ehrlichiosis on-island.

3 people were infected with Lyme disease a total of 10 times. Of these, 5 were initially mis-diagnosed...and I was treated un-successfully.)

“Never saw or felt the tick that did me in.”

(Diagnosed and treated for Lyme disease on-island)

TOM NEVERS CIVIC ASSOCIATION

2009 Voting Member Survey Report

Tick-Borne Disease Survey

Appendix—

- Detailed Findings
- Survey Questionnaire
- About the Tom Nevers Civic Association

Detailed Findings: 2009 Tick-Borne Disease Survey

Q. 1-- Have you or any members of your family...or any of your Nantucket guests or renters...ever had any of the following tick-borne diseases?

Lyme disease	Yes	61.3 %
Babesiosis	Yes	17.2 %
Ehrlichiosis	Yes	8.6 %

Q. 2-- If you answered “Yes” to any of the above tick-borne diseases...please tell us the outcomes, based on the TOTAL NUMBER in your group (family + guests + renters) who have contracted a tick-borne disease.

	Lyme	Babesiosis	Ehrlichiosis	Average
■ <u>Total number</u> of people infected	1.8 per HH*	1.2 per HH*	1.3 per HH*	2.3 per HH*
■ Percent diagnosed <u>on-Island</u>	60.8 %	94.7 %	80.0 %	66.2 %
■ Percent diagnosed <u>off-Island</u>	38.2 %	5.3 %	20.0 %	31.6 %
■ Percent with diagnosis still uncertain	2.9 %	0.0 %	0.0 %	2.3 %
■ Percent treated <u>on-Island</u>	60.8%	94.7 %	80.0 %	65.0 %
■ Percent treated <u>off-Island</u>	40.2 %	10.5 %	20.0 %	35.0 %
■ Percent not yet being treated	0.0 %	0.0 %	0.0 %	0.0 %
■ Percent treated <u>successfully</u>	95.1 %	94.7 %	80.0 %	93.9 %
■ Percent treated <u>un-successfully</u>	4.9 %	10.5 %	20.0 %	6.9 %
■ Percent initially mis-diagnosed	18.6 %	15.8 %	30.0 %	19.1 %
■ Percent with <u>ongoing health problems</u>	10.8 %	15.8 %	20.0 %	12.2 %

* In Households that reported this tick-borne disease infection.

Q. 3-- How has the growing problem of tick-borne diseases on Nantucket affected you? (Check all that apply.)

- 88.2 % ...say they worry more about outdoor activities like gardening, hiking, picnics, etc.
- 83.9 % ...say they warn their visitors to be more cautious about exposure to ticks.
- 59.1 % ...say they worry that the problem, if left unchecked, will make Nantucket less attractive to their visiting family members, guests and/or renters.
- 51.6 % ...say they worry that the problem, if left unchecked, will affect Nantucket property values.
- 29.0 % ...say they plan to increase preventative measures like fencing, Damminix, etc.
- 20.4 % ...say the problem has had no impact on them, to date.

Q. 4-- How many years have you been coming to Nantucket?

More than 20 years... 76.3%

10-to-20 years..... 20.4%

5-to-9 years..... 3.2%

1-to-4 years..... 1.1%

Q. 5-- How many months do you spend on Nantucket in a typical year?

Less than 1 month... 11.8%

2-to-3 months..... 36.6%

4-to-5 months..... 25.8%

6 or more months... 24.7%

Q. 6-- How many people live in, or visit, your Nantucket property in a typical year?

Resident Family... 2.3 Avg.

Visiting Family.... 6.4 Avg.

Guests..... 7.8 Avg.

Renters..... 5.2 Avg.

Q. 7-- Any comments you'd like to add? 41 % wrote-in comments

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TOM NEVERS CIVIC ASSOCIATION / Voting Member Survey

TOPIC: Tick-Borne Diseases

Please complete and mail to -- Tom Nevers Civic Association, c/o Jack Warner, 706 Hillcrest Road, Ridgewood, NJ 07450

Q. 1-- Have you or any members of your family...or any of your Nantucket guests or renters...ever had any of the following tick-borne diseases?

- | | | |
|--------------|------------------------------|-----------------------------|
| Lyme disease | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Babesiosis | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Ehrlichiosis | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If you answered "No" to ALL of the above, please skip to Q. 3 below.

Q. 2-- If you answered "Yes" to any of the above tick-borne diseases...please tell us the outcomes, based on the TOTAL NUMBER in your group (family + guests + renters) who have contracted a tick-borne disease.

	Lyme Disease	Babesiosis	Ehrlichiosis
■ <u>Total number</u> that were infected	-----	-----	-----
■ Number diagnosed <u>on-Island</u>	-----	-----	-----
■ Number diagnosed <u>off-Island</u>	-----	-----	-----
■ Number with diagnosis still uncertain	-----	-----	-----
■ Number treated <u>on-Island</u>	-----	-----	-----
■ Number treated <u>off-Island</u>	-----	-----	-----
■ Number not yet being treated	-----	-----	-----
■ Number treated <u>successfully</u>	-----	-----	-----
■ Number treated <u>un-successfully</u>	-----	-----	-----
■ Number initially mis-diagnosed	-----	-----	-----
■ Number with <u>ongoing health problems*</u>	-----	-----	-----

* If you'd like to elaborate, please do so on the back of this questionnaire.

Q. 3-- How has the growing problem of tick-borne diseases on Nantucket affected you? (Check all that apply.)

- Worry more about outdoor activities like gardening, hiking, picnics, etc.
- Warn our visitors to be more cautious about exposure to ticks.
- Worry that the problem, if left unchecked, will make Nantucket less attractive to our visiting family members, guests and/or renters.
- Worry that the problem, if left unchecked, will affect Nantucket property values.
- Plan to increase preventative measures like fencing, Damminix, etc.
- Has had no impact on me, to date.
- Other (please specify) -- _____

About the Tom Nevers Civic Association—

The Tom Nevers Civic Association is the “official neighborhood organization” for the Greater Tom Nevers Area—one of the largest neighborhoods on Nantucket...both in terms of size and number of residential properties.

Geographically, the Greater Tom Nevers Area stretches from the western boundary of ‘Sconset to the eastern border of Nantucket Memorial Airport...and from Milestone Road to the Atlantic Ocean on the south. It encompasses not only all the areas flowing into Chuck Hollow and Tom Nevers Roads, but also all the areas flowing into New South Road, Madequecham Valley Road and. Russell’s Way.

The Greater Tom Nevers Area is home to more than 550 families, with more than 30-percent of them year-round residents. Many of the property-owners (both seasonal and year-round) rent out all or part of their property during the summer season, and have family and friends come to visit on a regular basis. In these regards, the views of the members of the TNCA can provide a good glimpse into the general views of property-owners Island-wide.

To more effectively serve its members, TNCA conducts periodic surveys...this survey being the most recent example. To assure the greatest possible reliability, 100% of TNCA’s Voting Members are surveyed, with response rates of 25% or higher typical.

Founded in 1976, and the official area representative in the Island-wide “Nantucket Civic League”, the Tom Nevers Civic Association, Inc. is a non-profit organization under IRS Code: 501(c) (4).

You can learn more about the Tom Nevers Civic Association, and the “Tom Nevers Area Plan” that is now being implemented, by visiting the TNCA website at— www.tomnevers.org

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