

FOUNDING PARTNER

MONTE SKALL



EXECUTIVE DIRECTOR, NATIONAL CAPITAL LYME DISEASE ASSOCIATION

Monte Skall is one of the founding partners and Executive Director of the National Capital Lyme Disease Association (NatCapLyme). Monte has had Lyme for over 20 years and has devoted the latter part of her life to helping Lyme disease patients and their families. She is a frequent speaker at area events and associations on the topic of Lyme disease, prevention, and treatment options.

Before she was bitten and began dealing with this devastating disease, Monte was an artist/painter, educator, and art gallery owner. In 2001, she and Lyme patients founded NatCapLyme and under her leadership and guidance NatCapLyme has grown to a membership of 3,000 people. Monte has been its support group facilitator at Sibley Hospital in Washington D.C. since 2001, helping patients and families cope with Lyme and tick-borne diseases.

The National Capital Lyme Disease Association (NatCapLyme) is an all-volunteer 501(c)(3) nonprofit organization committed to helping patients diagnosed with tick-borne illnesses. Founded in 2001 with headquarters in McLean VA, just outside the Nation's capital, NatCapLyme has fourteen chapters in 3 states and the District of Columbia and partners with other organizations throughout the country. NatCapLyme is committed to helping patients diagnosed with tick-borne infections through education, support, and advocacy and to preventing further spread of the disease. We encourage patients to advocate for themselves in their goal to regain their health. We offer patient support group meetings, information, speakers, legislative developments, and news updates. The organization's five strategic objectives are as follows: (1) build support through its network for sharing personal experiences; (2) provide public health education; (3) pursue public policy and legislation related to these diseases; (4) conduct evidence based programs to improve a patient's quality of life; and (5) support research to find a cure.

NatCapLyme has more than 3,000 members. Members of the organization and its board have either experienced the disease personally or have friends or relatives who have been bitten by an infected tick. We are dedicated to improving the plight of Lyme patients by prevention, timely diagnosis, proper treatment and finding a cure.

NatCapLyme advocates for progress in the ever-deepening health crisis surrounding Lyme and tick-borne diseases. The organization is active in legislative matters concerning the disease on both the federal and state levels in Virginia and Maryland and has conducted health and legislative education forums to discuss ways of solving the issues related to Lyme disease.

NatCapLyme has produced and disseminated valuable information to the public through its website and participation in the many annual health fairs and exhibits, including the Combined Federal Campaign and the local NBC television station's NBC4Health. NatCapLyme's tick-borne disease educational series is available in both Spanish and English and has distributed to Health Departments, schools and government offices around the county. Here is a list of some of NatCapLyme's recent activities.

1. NatCapLyme worked to pass a Virginia House Joint Resolution No. 643 in 2011 that permanently designated the month of May as Lyme Disease Awareness Month in Virginia.

2. NatCapLyme wrote and worked to pass the first “Lyme Disease Testing Information Disclosure Act” in Virginia in 2013. The law requires healthcare providers to give a written disclosure to people who are tested for Lyme disease, informing them that current laboratory testing can produce false negatives, especially in the early stage of the disease.
3. NatCapLyme was commissioned by the National Academy of Science’s Institute of Medicine to author a paper entitled, *The Human Dimension of Lyme and Other Tick-Borne Diseases: The Patient Perspective*. This paper was used as a supporting document for the Institute’s 2010 scientific workshop to assess the state of the science of Lyme and other tick-borne diseases. We partnered with Lyme organizations and patients from across the United States on this project.
4. NatCapLyme participated in the Institute of Medicine’s scientific workshop and represented the patient community on a summation panel that presented the patient’s perspective on [current gaps in the science and research of tick-borne diseases](#).
5. NatCapLyme organized a successful briefing for all the Senate and House offices of the U.S. Congress that highlighted the documentary “Under Our Skin” in 2008, followed by an educational legislative forum in 2009 that brought together Lyme groups from across the country.
6. NatCapLyme conducted a “Lyme Green Ribbon” campaign in Washington D.C. during the IDSA’s Panel Review of Lyme Treatment Guidelines as well as sponsoring a public media room for patients to view the hearing process.
7. NatCapLyme was appointed by the Governor of Virginia as a panel member of the Lyme Task Force of Virginia in 2010, an effort exemplifying state leadership in addressing a growing public menace.
8. NatCapLyme was a member of the Lyme Disease Awareness Task Force of Montgomery County Maryland and partnered with Montgomery County Department of Health & Human Services to promote a public awareness campaign on Lyme & Tick-Borne Diseases.
9. Our support groups play an important role in helping patients regain their health. Our groups provide life skills for dealing with daily challenges and illness related social problems, as well as disability and insurance issues.

The National Capital Lyme Disease Association believes that by helping people recognize, understand and cope with their disease through education, a much needed public service is provided.