OUR COMMITMENT TO LYME & TICKBORNE DISEASE

Lyme and tickborne diseases are the fastest-growing vector-borne illness in the U.S., with an estimated 476,000 new cases every year. Alex Cohen, a sufferer herself, knows how debilitating they can be. Inspired by Alex's personal journey, we launched the Cohen Lyme & Tickborne Disease Initiative in 2015 to raise awareness, advance research, and find a cure.

Today, we're the largest private funder of Lyme and tickborne disease research in the country with over $70 million disbursed to-date. We underwrite groundbreaking studies in prevention, diagnostics, and treatment, and have also made awareness and education an integral part of our mission. We show the overwhelming impact these illnesses can have on people's lives and we strive to educate healthcare providers on the latest tools to diagnose and treat them.

lymemind.org | tickssuck.org | steveandalex.org

GIVE
STEVEN & ALEXANDRA COHEN FOUNDATION

7th ANNUAL CONFERENCE

LYME MIND

November 5, 2022 | VIRTUAL

POWERED BY GIVE TICKS SUCK

AGENDA

TIMES ARE APPROXIMATE (EDT)

1:00 PM	◆ Welcome
1:02 PM	1. Shining a Spotlight on Chronic Lyme: Behind the Scenes of the Making of *The Quiet Epidemic*
1:41 PM	2. The Critical Need for Innovation: New Advancements in Lyme Disease Diagnostics
2:05 PM	◆ Break
2:11 PM	3. The Value of Partnerships: A Multi-disciplinary Approach to Addressing Perinatal Transmission of Lyme Disease
3:07 PM	4. Finding Your Voice and Fighting for the Future: Patient Advocacy, Clinician Education and Access to Care
4:06 PM	◆ Break
4:12 PM	5. What's Next for 2023: The Infection-Associated Chronic Illness Symposium
4:27 PM	6. Panelist Q&A
4:57 PM	◆ Closing Remarks

Disclaimer: The views and opinions expressed in association with this conference are solely those of the individual speakers and do not necessarily reflect the views of the Steven & Alexandra Cohen Foundation or its staff. The Foundation disclaims all representations and warranties, express or implied, of any kind with respect to any third-party resource links or information provided in connection with this conference.

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Winslow Crane-Murdoch
Director, *The Quiet Epidemic*

Winslow is a director, cinematographer and editor based in Portland, OR. Since graduating from Connecticut College in 2013 where he studied film, his work has taken him across the country and overseas. He made a multimedia project about student loan debt, hiked and filmed a 3,000 km walk across New Zealand for Outside Television and has shot and directed for large brands and political campaigns. He was diagnosed with Lyme disease in 2015 and began working on The Quiet Epidemic shortly after. *The Quiet Epidemic* premiered at HotDocs in May of 2022 and has been accepted in 20 festivals since its release. It is scheduled for a theatrical release in December of 2022.

Julia Bruzzese
Student & Lyme Disease Patient Advocate

Julia Bruzzese is a 19-year-old freshman college student in Brooklyn, New York. Ever since becoming severely ill with Lyme Disease in 2015, Julia has been a Lyme patient advocate where her primary focus is helping other patients and families find the right resources on their journeys to wellness. Julia is also a main subject in the upcoming documentary *The Quiet Epidemic*. Julia plans to pursue studies in biology on a pre-med track.

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Lindsay Keys
Director, *The Quiet Epidemic*

Lindsay is a director, producer, cinematographer and photographer based in the desert outside of Los Angeles. She has shot still and motion content for clients ranging from Bernie Sanders to The Whitney Museum. Her photography has been exhibited internationally, published in The New York Times, Time Out Magazine, Interview Magazine, and auctioned at Christie's. While attending Wesleyan University ('11), Lindsay's health began deteriorating with no explanation. Upon getting a diagnosis of Lyme disease in 2015, she began working on *The Quiet Epidemic* and spent the next seven years dedicated to its completion. This is her first feature film.

Steven Rader
NASA Center of Excellence for Collaborative Innovation

Steve currently serves as the Program Manager of NASA's Center of Excellence for Collaborative Innovation (CoECI) and the NASA Tournament Lab (NTL) which are working to infuse challenge and crowdsourcing innovation approaches at NASA and across the federal government. CoECI focuses on the study and use of curated, crowdsourcing communities that utilize prize and challenge-based methods to deliver innovative solutions for NASA and the US government.

In 2015, Steve was named as one of 20 Challenge Mentors for U.S. Government Services Administration's (GSA) Prizes and Challenges government-wide community of practice. Steve has worked with various projects and organizations to develop and execute over 100 different challenges. He speaks regularly about NASA's work in crowd-based challenges and the future of work both publicly and internally to the NASA workforce to promote the use of open innovation tools.

Steve has a Mechanical Engineering degree from Rice University and has worked at NASA's Johnson Space Center for 33 years. Prior to joining CoECI/NTL, Steve worked in mission control, flight software development for the Space Shuttle and International Space Station, command and control systems development for the X-38, and led the Command, Control, Communications, & Information (C3I) architecture definition for the Constellation Program.

Sara Holoubek
Luminary Labs

Sara Holoubek is the CEO and founder of Luminary Labs, a consultancy that develops strategies and innovation systems to help Fortune 500, government, and nonprofit organizations thrive in the face of change. She is also an active early stage investor.

Sara is a director and former chair of the Step Up National Board, a nonprofit that propels girls from under-resourced communities to fulfill their potential by empowering them to become confident, college-bound, career-focused, and ready to join the next generation of professional women. Sara's previous advisory roles include serving on the inaugural RWJF Pioneer Fund Advisory Group and the Aspen Health Innovation Project Planning Committee.

Sara has been widely quoted in publications such as Fast Company, The Washington Post and WSJ.com. She has been recognized by LinkedIn as a 2017 Top Voice in Technology, Mashable as a female founder to watch, SmartCEO magazine as a 2017 New York Brava award winner, and PepsiCo WIN for her contributions to women in technology. Her company has been profiled in business books, Geek Girl Rising, Here's the Plan, The Big Enough Company, and Stiletto Network. She also serves as a frequent guest lecturer on the subjects of technology and innovation.

Prior to founding Luminary Labs, Sara served as the Chief Strategy Officer of iCrossing and President of SEMPO, the global trade organization for the search marketing industry. Sara also brings an international perspective to her work, having lived and worked in Latin America and Europe; she is fluent in Spanish and French, and conversant in Portuguese. She holds a B.A. from the University of Iowa and an M.B.A. from HEC in France.

Kristen Honey, PhD, PMP
U.S. Department of Health and Human Services

Kristen Honey is the Chief Data Scientist and the Executive Director of the HHS "InnovationX" team in the Office of the Assistant Secretary for Health (OASH) at the U.S. Department of Health and Human Services (HHS). Her team tackles complex challenges by harnessing the power of open data, open science, open source, citizen science, crowdsourcing, prizes challenges, and innovative public-private partnerships for public health. Dr. Honey previously led the Tick-Borne Working Disease Group (TBDWG) as the inaugural Vice-Chair and co-authored the 2018 TBDWG Report to Congress. She also founded the federal Lyme Innovation initiative in 2018 to bring public and government awareness to Lyme and tick-borne diseases. Later in 2020, the HHS team launched its LymeX Innovation Accelerator (LymeX), a $25-million-dollar partnership between HHS and the Steven & Alexandra Cohen Foundation, creating the world's largest public-private partnership for Lyme disease.

Prior to joining HHS, Dr. Honey served in the White House Office of Science and Technology (OSTP) advising the U.S. Chief Technology Officer (CTO) from 2015–2017 and the White House Office of Management and Budget (OMB) advising the Federal Chief Information Officer from 2017–2018. During her three years in the White House across two administrations, Dr. Honey led innovation and open data portfolios which were codified by the Foundations for Evidence-Based Policy Making Act of 2018.

Dr. Honey earned her Ph.D. at Stanford University in the Emmett Interdisciplinary Program in the Environment and Resources, School of Earth Sciences and her Ph.D. minor in Civil and Environmental Engineering. She also holds an M.A. in Environmental Studies from the University of California, Santa Cruz, and a B.A. in Human Biology with Honors from Stanford University.

Bennett Nemser, PhD
Steven & Alexandra Cohen Foundation

Ben manages the Foundation's various health portfolios including the Cohen Psychedelic Research & Health Initiative and the Cohen Lyme & Tickborne Disease Initiative. Dr. Nemser has a PhD in Public Health with extensive experience in global health systems in developing countries and related research. Prior to joining the Foundation, Ben was a Senior Monitoring and Evaluation (M&E) Consultant for UNICEF and the World Health Organization (WHO). After receiving a Master of Public Health from Columbia University, Ben worked for Columbia University as an Epidemiologist and Data Systems Manager. In addition to his public health experience, Ben has a Master's in Business Administration and a background in governmental finance and budgeting.

LYMEX
TICK-BORNE DISEASE
INNOVATION ACCELERATOR

LymeX Diagnostics Prize Competition

Check out www.lymexdiagnosticsprize.com for more information about the LymeX Diagnostics Prize, a pledged $10 million prize competition, to accelerate the development of Lyme disease diagnostics.

The Value of Partnerships: A Multi-disciplinary Approach to Addressing Perinatal Transmission of Lyme Disease

MODERATOR: SUE FABER

Sue Faber, RN
LymeHope

Sue Faber is a Registered Nurse (BScN) and Co-founder and President of LymeHope, a Canadian not-for-profit organization. Sue's specific area of expertise and research is in the compilation and analysis of the literature that exists on maternal-fetal transmission of Lyme and congenital Lyme borreliosis; amplifying, supporting, and powering urgent research initiatives to investigate this alternate mode of transmission with the ultimate goal of opening new doors to ensure that children and families affected are able to access appropriate care, treatment, and support.

Sue is an active member of the Registered Nurses Association of Ontario (RNAO) and 2019 RNAO HUB Fellowship award recipient. Sue has spoken at various conferences/webinars on maternal-fetal transmission of Lyme disease and served as a subcommittee member on the current (2022) US Federal Health & Human Services Tick-Borne Disease Working Group Clinical Presentation and Pathogenesis Subcommittee. Most recently Sue and colleagues co-organized a Banbury meeting on Perinatal Transmission of Lyme Disease, sponsored by the Cohen Foundation.

Sue is firmly committed to transparent and collaborative partnerships with governments, academia, research institutions, healthcare colleagues, and industry stakeholders, to collectively identify challenges, knowledge gaps, and fresh opportunities, to examine and develop transformative health policy, best practice guidelines, and research priorities, which are anchored in patient voice, values, and priorities..

Monica Embers, PhD
Tulane University

Dr. Embers is currently an Associate Professor in the Division of Immunology and the Director of Vector-borne Disease Research at the Tulane National Primate Research Center. Her research program regarding Lyme disease and its infectious cause Borrelia burgdorferi specializes in animal models. The research is centered around three major efforts: (1) identifying treatments that can eradicate B. burgdorferi infection; (2) detection of persistent Lyme disease spirochetes in human (autopsy and surgical discard) tissues; and (3) immunodiagnosis for B. burgdorferi infection and cure. By transmitting Lyme disease to mice and nonhuman primates by tick, and studying the natural course of infection, her group aims to attain a better understanding of the clinical quandaries of human Lyme disease, including effective diagnosis and treatment. Due to the many similarities between Bartonellosis and Lyme disease, her team has begun to develop research models for Bartonella infection and assess vector transmission of this pathogen as well.

Elizabeth Darling, PhD
McMaster University

Dr. Liz Darling is the assistant dean of midwifery and an associate professor in the department of obstetrics & gynecology at McMaster University, Hamilton, Canada and is a registered midwife. Her graduate training is in epidemiology and population health. She has served in an advisory committee member for the Canadian Perinatal Surveillance system since 2008.

In addition to Lyme disease in pregnancy, her research interests include sexual and reproductive health services, health disparities, access to care, health policy, and perinatal health surveillance.

Kate Nagel
LymeLight Foundation

Kate Nagel joined LymeLight Foundation in 2018 as the Treatment Grant Coordinator. She attended St. George's University of Medicine and completed four years of medical school, but had to withdraw before graduating due to falling ill with Lyme disease. Kate has worked for several California Bay Area healthcare organizations including Sutter Health and Stanford Health Care. She has a passion for grassroots campaigns and community work

Charlotte Mao, MD, MPH
Pediatric Infectious Diseases Physician

Charlotte Mao is a pediatric infectious diseases (ID) physician with special focus on Lyme disease and associated infections. She graduated from Harvard Medical School and completed her residency and pediatric ID fellowship at Boston Children's Hospital. For 25 years, she worked at Boston Children's Hospital, focusing primarily on pediatric HIV clinical care and research and was the site-coinvestigator for numerous NIH/NIAID- and NICHD-funded multicenter pediatric HIV clinical trials.

She turned her focus to Lyme disease and associated coinfections after gaining extensive clinical experience with pediatric Lyme disease patients in the referral ID clinic there. She moved to the Department of Pediatric Infectious Disease at Massachusetts General Hospital and provided consultative pediatric ID specialty care in a multidisciplinary clinic for children with complex Lyme disease at the Dean Center for Tickborne Illness at Spaulding Rehabilitation Hospital. She is currently Curriculum Director for Invisible International, focusing on their Tick-bone Illness Education Platform, which provides free online accredited continuing medical education (CME) courses on diagnosis and treatment of Lyme disease and associated vector-borne infections.

Sue Visser, DrPH, MS
Division of Vector-Borne Diseases, CDC

Dr. Susanna N. Visser is a Health Scientist who serves as the Associate Director for Policy and Extramural Program (ADPEP) in the Division of Vector-Borne Diseases (DVBD) for CDC's National Center on Emerging and Zoonotic Infectious Diseases. Dr. Visser served as an epidemiologist for CDC's Child Development Studies Team for six years and the team's lead epidemiologist for ten years. She published more than 50 publications on child development, behavioral disorders, and pediatrics. Dr. Visser was deployed to the 2016-2017 Zika Emergency Response and served as the Response Partnerships Lead. In 2017 she was recruited to build out DVBD's policy office and help translate the Division's science for policy-makers and decision-makers. She has since served as a Senior Advisor for Policy and Partnerships within CDC's COVID-19 Emergency Response. Dr. Visser is an Adjunct Assistant Professor within the Colorado School of Public Health at the University of Colorado.

As ADPEP, Dr. Visser leads DVBD's budget initiatives, directs public and private partnership activities, coordinates and conducts partner and congressional briefings, and coordinates the execution of extramural activities. Dr. Visser led the development of a cross-Departmental national framework for vector-borne disease prevention and control to help coordinate federal efforts and bring awareness to the work that must be done to decrease vector-borne disease-related morbidity and mortality. She is currently leading the build-out of a full national strategy, built upon the National Public Health Framework. She is the director of the Public Health Entomology for All (PHEFA) program, an internship and fellowship partnership with the Entomological Society of America.

Dr. Visser received her Doctorate in Public Health (2014) and Master of Science in Epidemiology (2001) from the University of Illinois at Chicago. She teaches Public Health Leadership as an Adjunct Assistant Professor within the Colorado School of Public Health at the University of Colorado.

TICKS SUCK™

Check out the Ticks Suck™ public service announcement (PSA) on www.tickssuck.org to help build awareness for children and adults on preventing tick bites and what to do after someone has been bitten.

Finding Your Voice and Fighting for the Future: A Discussion on Patient Advocacy, Clinician Education and Access to Care

MODERATOR: BENNETT NEMSER

Lorraine Johnson
LymeDisease.org

Lorraine Johnson, JD, MBA, is the Chief Executive Officer of LymeDisease.org and the principal investigator of its patient registry and research platform, MyLymeData--which has enrolled over 17,000 patients. She has published over 50 peer reviewed articles on Lyme disease and patient centered healthcare, including three big data patient driven research studies on which she served as Principal Investigator.

She has served on five federal advisory committees related to big data, patient centered research, and patient registries. She served as the Chair of the Patient Council for the Patient Centered Outcomes Research Institute and sat on both the Steering Committee and the Executive Committee of its big data project, PCORnet. She participated in the White House Precision Medicine Summit.

Elizabeth Maloney, MD
Partnership for Tick-Borne Diseases Education

Dr. Elizabeth L. Maloney is a Minnesota family physician whose current focus is on tick-borne diseases education and policy. She began providing comprehensive, evidence-based, accredited continuing medical education courses for physicians in 2007 and subsequently became the founder and president of Partnership for Tick-borne Diseases Education, a non-profit organization providing online and live evidence-based continuing medical education programming and materials on tick-borne diseases for physicians and other healthcare professionals. The hallmark of her teaching is that it represents a broad-based and detailed evaluation of the evidence.

Dr. Maloney also acts as a consultant to government agencies and private organizations. She is currently a member of the federal advisory committee, the Tick-borne Diseases Working Group. Dr. Maloney frequently speaks to the general public on tick-borne diseases, emphasizing the need for primary and secondary prevention.

Pat Smith
Lyme Disease Association

Pat Smith, a Monmouth University graduate, is in her 26th year as President of the volunteer run national non-profit Lyme Disease Association (LDA). She is a member of Columbia University's Lyme & Tick-Borne Diseases Research Center Advisory Committee and a member of the Food & Drug Administration's (FDA) PESP Partnership to promote avoidance of tick exposure. She has served on several panels for LymeX, the public-private partnership between the Cohen Foundation and HHS. She served 4 years as a public member of the HHS Tick-Borne Disease Working Group in Washington, DC, where she co-authored the TBDWG Group Report to Congress 2018 and the TBDWG Report to Congress 2020 and wrote several minority reports contained in those documents. She also co-chaired 2 subcommittees while on the Working Group and co-authored 2 reports.

Ms. Smith was a 4 year member of the US Army Medical Research and Materiel Command Tick-Borne Disease Research Program Programmatic Panel. She has twice testified before Congress on Lyme disease. She is also former Chair, (NJ) Governor's Lyme Disease Advisory Council and was EPA's PESP 2011 Lyme prevention conference session co-chair with CDC. Ms. Smith is a member & former officer of ILADS, International Lyme & Associated Diseases Society, a professional medical and research organization. She was a member of the on-line journal, Contagion Infectious Disease Today, Chronic Lyme Expert Panel on video.

Bennett Nemser, PhD
Steven & Alexandra Cohen Foundation

Please see Dr. Nemser's biography under "The Critical Need for Innovation: New Advancements in Lyme Disease Diagnostics."

Julie Liao, PhD
The National Academies of Sciences, Engineering, and Medicine

Dr. Julie Liao is a Program Officer for the Board on Global Health within the division of Health and Medicine at the National Academies of Sciences, Engineering, and Medicine. She joined the National Academies in 2020 and now directs the Forum on Microbial Threats. Prior to arriving at the National Academies, she worked in infectious diseases research including early stage vaccine platform development and antimicrobial resistance. She received her Ph.D. from Binghamton University and completed post-doctoral training at Boston Children's Hospital.

Sue Visser, DrPH, MS
Division of Vector-Borne Diseases, CDC

Please see Dr. Visser's biography under "The Value of Partnerships: A Multi-disciplinary Approach to Addressing Perinatal Transmission of Lyme Disease."

Bennett Nemser, PhD
Steven & Alexandra Cohen Foundation

Please see Dr. Nemser's biography under "The Critical Need for Innovation: New Advancements in Lyme Disease Diagnostics."

THANK YOU

Thank you to all the panelists and participants of the 7th Annual LymeMIND Conference. We hope you enjoyed the event.

All sessions will be available for replay on www.lymemind.org in the coming weeks.

LYME MIND

SUPPLEMENTARY MATERIALS

The following slides are resources related to panel discussions.

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LYME MIND

SESSION 3

The Value of Partnerships: A Multi-disciplinary Approach to Addressing Perinatal Transmission of Lyme Disease

Monica Embers, PhD | Tulane University

Elizabeth Darling, PhD | McMaster University

Charlotte Mao, MD, MPH | Pediatric Infectious Disease Specialist

Sue Visser, DrPH, MS | Division of Vector-Borne Diseases, CDC

Kate Nagel | LymeLight Foundation

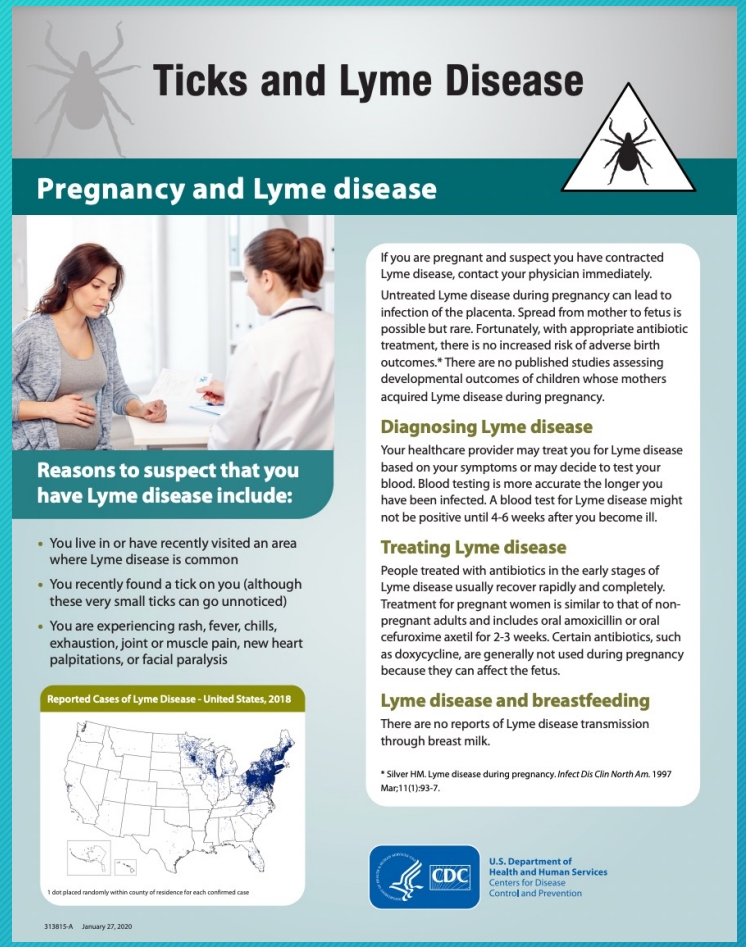
Moderator: **Sue Faber, RN** | LymeHope

Followed By

Session 4	Finding Your Voice and Fighting for the Future: A Discussion on Patient Advocacy, Clinician Education and Access to Care
Break	5-minute break

Up Next

CDC: Pregnancy and Lyme Disease



Ticks and Lyme Disease

Pregnancy and Lyme disease

Reasons to suspect that you have Lyme disease include:

- You live in or have recently visited an area where Lyme disease is common
- You recently found a tick on you (although these very small ticks can go unnoticed)
- You are experiencing rash, fever, chills, exhaustion, joint or muscle pain, new heart palpitations, or facial paralysis

Reported Cases of Lyme Disease - United States, 2018

1 dot placed randomly within county of residence for each confirmed case

If you are pregnant and suspect you have contracted Lyme disease, contact your physician immediately.

Untreated Lyme disease during pregnancy can lead to infection of the placenta. Spread from mother to fetus is possible but rare. Fortunately, with appropriate antibiotic treatment, there is no increased risk of adverse birth outcomes.* There are no published studies assessing developmental outcomes of children whose mothers acquired Lyme disease during pregnancy.

Diagnosing Lyme disease

Your healthcare provider may treat you for Lyme disease based on your symptoms or may decide to test your blood. Blood testing is more accurate the longer you have been infected. A blood test for Lyme disease might not be positive until 4-6 weeks after you become ill.

Treating Lyme disease

People treated with antibiotics in the early stages of Lyme disease usually recover rapidly and completely. Treatment for pregnant women is similar to that of non-pregnant adults and includes oral amoxicillin or oral cefuroxime axetil for 2-3 weeks. Certain antibiotics, such as doxycycline, are generally not used during pregnancy because they can affect the fetus.

Lyme disease and breastfeeding

There are no reports of Lyme disease transmission through breast milk.

* Silver HM. Lyme disease during pregnancy. *Infect Dis Clin North Am.* 1997 Mar;11(1):93-7.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

313815-A January 27, 2020

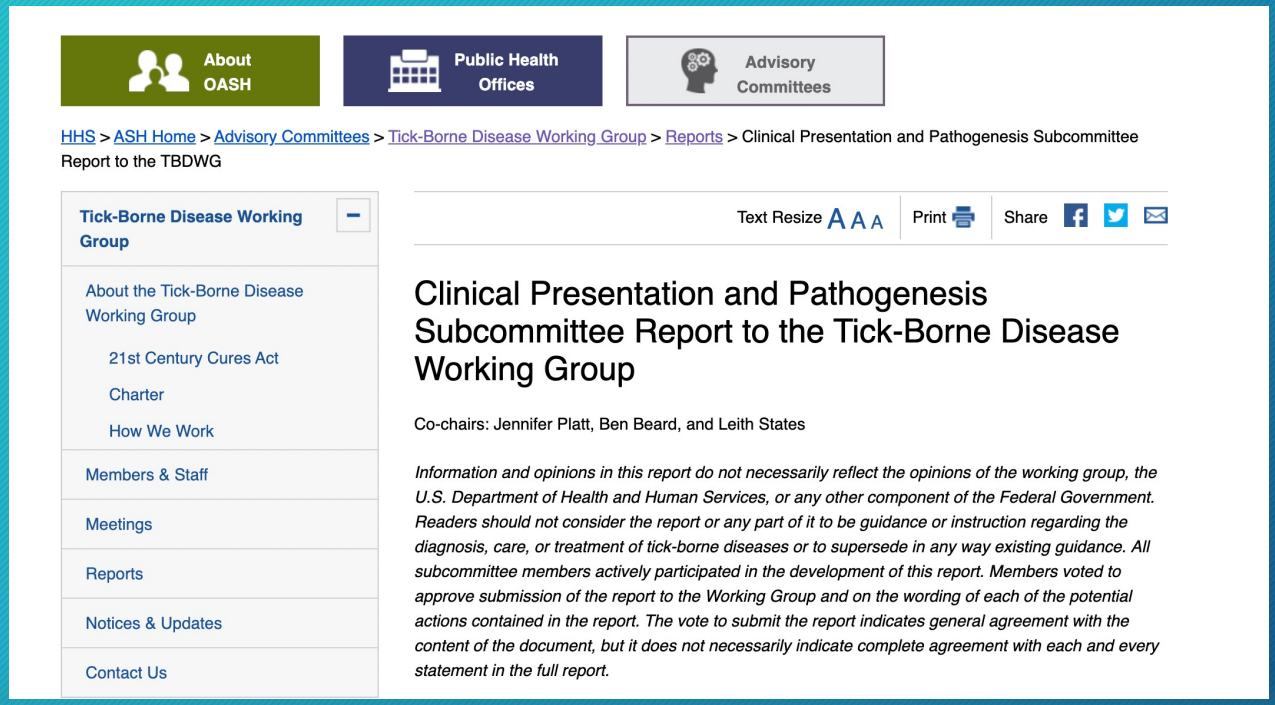
If you are pregnant and suspect you have contracted Lyme disease, contact your physician immediately.

Untreated Lyme disease during pregnancy can lead to infection of the placenta. Spread from mother to fetus is possible but rare. Fortunately, with appropriate antibiotic treatment, there is no increased risk of adverse birth outcomes.* There are no published studies assessing developmental outcomes of children whose mothers acquired Lyme disease during pregnancy.

https://www.cdc.gov/lyme/resources/toolkit/factsheets/Pregnancy-and-Lyme-Disease-508.pdf

Clinical Presentation and Pathogenesis Subcommittee Report to the HHS Tick-Borne Disease Working Group, 2022

https://www.hhs.gov/ash/advisory-committees/tickbornedisease/reports/clinical-presentation-pathogenesis-2022/index.html



Priority 4: Pregnancy and Lyme Disease

Background

Lyme disease and pregnancy is an issue of special concern and importance given that both mother and baby are at a particularly sensitive time for health and development. The Lyme disease bacteria, *B. burgdorferi*, can be transmitted vertically, from mother, across the placenta, to offspring. This has been documented in animals [1][1] and humans [2], with many experts providing reviews, professional opinion, and analysis on the subject matter [3]. In the current edition of a leading medical reference textbook on the subject matter of infectious diseases of the fetus and newborn infant, experts recommend expansion of “TORCH” the well-known medical acronym for the group of diseases that are known to cause congenital infections to “TORCHES-CLAP” with “L” representing Lyme disease (Wilson et al., 2014). Transplacental transmission of *B. burgdorferi* may invariably challenge and expand what is known regarding the pathogenesis and resulting clinical spectrum of Lyme disease (Hamilton, 1989; Harvey & Salvato, 2003; Jasik et al., 2015).

Resources

CDC Lyme disease and Pregnancy Factsheet:
https://www.cdc.gov/lyme/resources/toolkit/factsheets/Pregnancy-and-Lyme-Disease-508.pdf

Banbury Meeting on Perinatal Transmission of Lyme Disease.
https://www.cshl.edu/banbury/meeting-agendas/

Clinical Presentation and Pathogenesis Subcommittee report to the 2022 HHS Tickborne Disease Working Group
https://www.hhs.gov/ash/advisory-committees/tickbornedisease/reports/clinical-presentation-pathogenesis-2022/index.html

LymeHope:
https://www.lymehope.ca/lyme-disease-and-pregnancy.html

LymeLight Foundation:
https://lymelightfoundation.org/congenital-lyme/a-call-to-action/
https://lymelightfoundation.org/lyme-and-pregnancy/

LivLymeFoundation:
https://livlymefoundation.org/

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SESSION 4

Finding Your Voice and Fighting for the Future:
A Discussion on Patient Advocacy, Clinician Education and Access to Care

Lorraine Johnson | LymeDisease.org

Elizabeth Maloney, MD | Partnership for Tick-Borne Diseases Education

Pat Smith | Lyme Disease Association

Moderator: **Bennett Nemser, PhD** | Steven & Alexandra Cohen Foundation

Followed By

Break
Session 5

5-Minute Break
What's Next for 2023: The Infection-Associated Chronic Illness Symposium

Up Next

EDUCATION & ADVOCACY RESOURCES

MyLymeData

- Visit www.lymedisease.org

Continuing Medical Education (CME) platforms

LymeCME

- Visit www.lymecme.info

Invisible International / Montecalvo Foundation

- Visit learn.invisible.international/

Lyme Disease Association

- Visit www.lymediseaseassociation.org

LYME MIND

SESSION 5

What's Next for 2023:
The Infection-Associated Chronic Illness Symposium

Julie Liao, PhD | The National Academies of Sciences, Engineering, and Medicine

Sue Visser, DrPH, MS | Division of Vector-Borne Diseases, CDC

Moderator: **Bennett Nemser, PhD** | Steven & Alexandra Cohen Foundation

Followed By

Session 6 : Panelist Q&A
Session 7 : Closing Remarks

Up Next

Infection-Associated Chronic Illnesses

Reflects a Growing Public Health Concern

- Long COVID or post-COVID-19 conditions: Between 10 to 30% of patients infected with SARS-CoV-2 develop chronic symptoms that lead to a diagnosis of long COVID (Proal and VanElzakker, 2021)
  - Disease burden of between 7.7 million and 23 million patients who will be living with long COVID by February 2022
- Myalgic encephalomyelitis/chronic fatigue disease (ME/CFS): ME/CFS onset is often associated with a prior, unidentified infectious episode (O'Neal et al., 2021; Komaroff and Bateman, 2021)
  - ~1.7 to 3.3 million patients in the U.S. are diagnosed with ME/CFS and experience chronic, multi-organ symptoms (Valez et al., 2019)
- Persistent or post-treatment Lyme disease: Between 10-20% of Lyme disease patients develop persistent and debilitating symptoms after standard antibiotic treatment (Marques, 2009; Rebman and Aucott, 2020)
  - ~2 million patients in the U.S. living with persistent or post-treatment Lyme disease syndrome (DeLong et al. 2019; Kugeler et al., 2021)
- Multiple sclerosis: A strong association with of multiple sclerosis with Epstein-Barr virus infection was recently reported (Bjornevik et al., 2022; Lanz et al., 2022)
  - In the US, more than 700,000 patients are living with multiple sclerosis (Wallin et al., 2019)

NASEM Workshop Discussion Could Consider:

1. Overlapping clinical and biological factors underlying infection-associated chronic illnesses
2. Current practice and novel technologies to develop urgently needed diagnostic tests for different stages of illness
3. Identification of therapeutic targets and strategies to prevent or impede chronic illness progression
4. Coordination and collaboration among various stakeholders and practitioners that will increase research and enhance care across different patient populations

Forum on Microbial Threats

National Academy of Medicine > Health and Medicine Division > Board on Global Health

Established in 1996, the forum is charged with facilitating cross-sector dialogue and collaboration to stimulate new thinking that address *scientific and policy issues related to research on and the prevention, detection, surveillance, and responses to emerging and reemerging infectious diseases* in humans, plants and animals as well as the microbiome in health and disease.

This workshop is a collaboration between the Forum on Microbial Threats (lead) and the Forum on Neuroscience and Nervous System Disorders.

https://www.nationalacademies.org/microbialthreats
https://www.nationalacademies.org/neuroforum

Toward a Common Research Agenda in Infection-Associated Chronic Illnesses – a workshop

June 29-30, 2023 | Washington, DC

Exploring the current understanding and future research opportunities for:

- Overlapping clinical and biological factors underlying infection-associated chronic illnesses (with a focus on long COVID, ME/CFS, persistent Lyme disease, and MS).
- Current practice and novel technologies to develop urgently needed diagnostic tests for different stages of illness and/or the potential underlying infectious agent.
- Identification of therapeutic targets and strategies to prevent or impede chronic illness progression.
- Coordination and collaboration among various stakeholders and practitioners that will increase research and enhance care across different patient populations.

Goal: Convene researchers toward a more coordinated community to share knowledge, identify future research directions, and build evidence base to inform policies

Workshop Proceedings

Staff will engage a professional rapporteur to author a written proceedings of the workshop.

- A factual accounting of what is presented and discussed at the workshop.
- No consensus official findings or recommendations.
- Expected release in 2024.
- Will be available to read online or download as a free PDF at www.nap.edu

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Stay updated for when registration opens:

https://bit.ly/NASEM-chronic-illnesses OR

LYME MIND

BREAK

5-Minute Break

The conference will display Lyme & tickborne disease-related informational resources during the break.

Followed By

Session 5 : What's Next for 2023: The Infection-Associated Chronic Illness Symposium
Session 6 : Panelist Q & A

Up Next

TICKS SUCK™

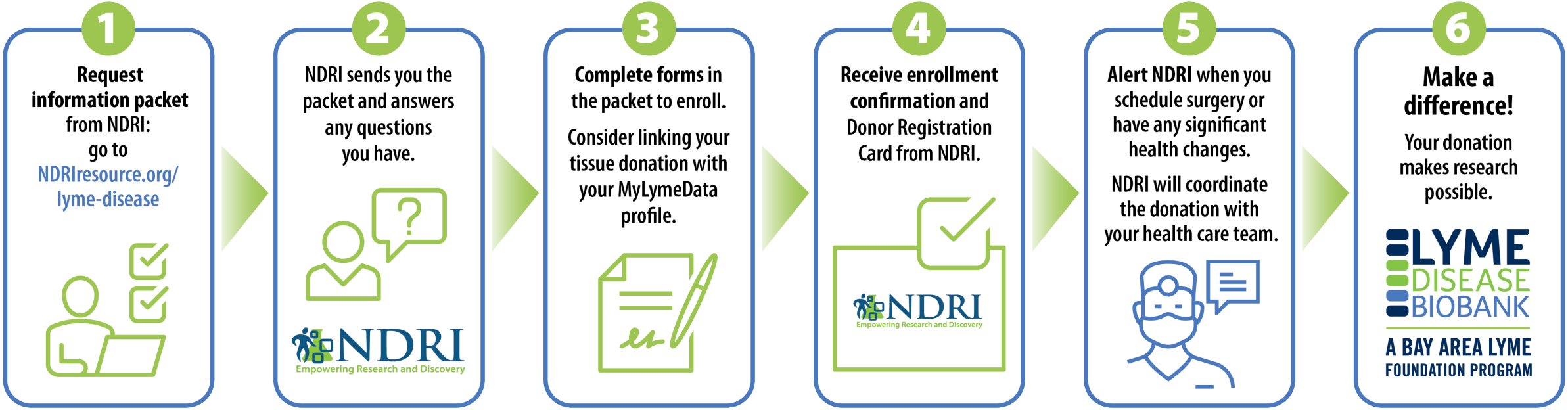
Visit www.tickssuck.org

For more information on TICKS SUCK™ public service announcement (PSA) that helps build awareness for children and adults on preventing tick bites and what to do after someone has been bitten.

Information

Got Lyme? Having Surgery?

- Adults with Lyme disease needed to donate tissue from knee replacements and other surgeries
- You can help researchers study this complex disease and how Lyme bacteria invade tissues
- Participants may choose to link their tissue sample to their MyLymeData profile
- Visit https://www.bayarealyme.org/biobank/patient-information/ or call (800) 222-NDRI (6374), Option 5 to learn more






LymeLight FOUNDATION

Raising Hope for Families with Lyme

LymeLight Foundation provides treatment grants of up to $10,000 per individual for children and young adults with Lyme disease through age 25.

LymeLight has enabled treatment for over 1,000 individuals by awarding $7M in grants.

- To learn more, visit LymeLightFoundation.org

Looking for a **support group**?

- Visit www.lymedisease.org

www.lymedisease.org/lyme-disease-support-groups/

Lymedisease.org empowers patients through education and patient-centered research. Lymedisease.org provides tools like a Symptom checker, Physician Directory, and the MyLymeData patient registry and research platform.

CLINICIAN TRAINING RESOURCES

Center for Disease Control (CDC)

- Visit www.cdc.gov/lyme/healthcare/index.html

Continuing Medical Education (CME) platforms

LymeCME

- Visit www.lymecme.info

Invisible International / Montecalvo Foundation

- Visit learn.invisible.international/

Fellowship program in Lyme and Tickborne Disease

Two-year clinical and research training program at Johns Hopkins University

- Visit www.hopkinslyme.org/about-the-center/johns-hopkins-medicine-fellowship-program/