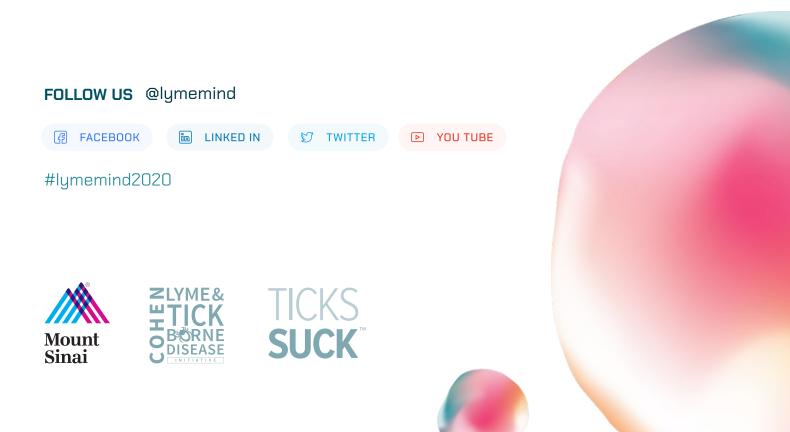
# 



# The 5th Annual LymeMIND Virtual Conference 2020

📋 🛛 Saturday, October 10, 2020 👘 📀 Virtual Event

Hosted by "Icahn School of Medicine at Mount Sinai and proudly supported by the Steven & Alexandra Cohen Foundation: Cohen Lyme & Tickborne Disease Initiative"







Since we launched the Cohen Lyme & Tickborne Disease Initiative in 2015, we knew the greatest challenges could be overcome through determination, open-mindedness and a collaborative spirit. Over the last five years, the LymeMIND conference has become a leading forum for the Lyme and tickborne disease community to hear the latest research results, share their unique stories, and generate enthusiasm to combat these formidable illnesses.

We are thrilled to bring you the 5th Annual LymeMIND Conference as a gathering place for outstanding researchers, clinicians, advocates, patients, caregivers and policymakers to share their work, new ideas, and most importantly hope for the future. Each year this forum expands our understanding of these diseases and draws us closer to prevention, diagnosis, and treatment breakthroughs.

Like many things in 2020, we've made some adjustments to normal operations. The conference has moved virtual. While we will miss the opportunity to see each other inperson, the virtual conference allows us to easily bring you the best presentations from across the public health landscape. This year, the conference features conversations on treatment approaches, mother-to-child transmission, Bartonella and co-infections, and a peek into new innovative projects to improve patient care. We thank you for participating, bring your unique perspective, and joining this collective fight.

#### Alexandra Cohen

**President** Steven & Alexandra Cohen Foundation

## Welcome

# To the 5th Annual Lyme Disease in the Era of Precision Medicine Conference

Thank you for joining us for our fifth year of discussions focused on cutting edge research, novel treatments, and community engagement, made possible through the generous sponsorship of the Steven and Alexandra Cohen Foundation: Cohen Lyme & Tickborne Disease Initiative, and the institutional support of the Icahn School of Medicine at Mount Sinai.

We mark our conference's fifth year anniversary as an inflection point not only for us on the LymeMIND team, but for the global community as well. The year 2020 has been deeply impacted by recent public health events, and as a result, instead of coming together as we have in the past, in the heart of New York City, we join together virtually. We know how important it is, this year in particular, that we embrace the power of community and shared connections. The Lyme disease community knows more acutely than others that attention to global public health is a mission that we all must take seriously. Today, as with many of these days, we miss the warm embraces and handshakes from our friends and colleagues, but we hold on to gratitude being able to share in this event through the tremendous power of technology.

The past four years of LymeMIND have forged many new connections between researchers, clinicians, patients, and patient advocates. Our events have enlightened and empowered a growing community to confront the rapidly expanding threats and challenges of Lyme and Tickborne diseases.

We hope that you share our enthusiasm and optimism for the remarkable opportunities at hand, and we kindly ask you to share your unique insights and energies with us today to help spark continued growth and community collaboration.

On behalf of the entire LymeMIND team, we thank you again for joining us at our 5th Annual Lyme Disease in the Era of Precision Medicine Conference. Your valuable time and participation are vital to moving us forward into a brighter future for the entire Lyme disease community.

Sincerely,

LymeMIND Team

**LYME**<sup>MIND</sup>

# **Event Schedule**

To the 5th Annual Lyme Disease in the Era of **Precision Medicine Conference** 

Saturday, October 10, 2020 🛛 📀 Virtual Event

9:00am – 9:10am | 10 min pre-recorded

### Chairperson – Welcome & Opening Remarks

SPEAKER Patricia (Savi) Glowe Event Chair, LymeMIND Sr. Director of Strategy & Operations, Hasso Plattner Institute for Digital Health at Mount Sinai

#### 9:10am – 9:40am 20 min pre-recorded + 10 min live Q & A

### **KEYNOTE SPEAKERS**

#### "Chronic: The Hidden Cause of Autoimmune Pandemic and How to Get Healthy Again."

Steven Phillips, MD and Dana Parish reveal striking evidence that a broad range of microbes, including the Lyme bacterium, cause a variety of recurrent conditions and autoimmune diseases. They'll discuss the science behind common infections that are difficult to diagnose and treat and provide solutions that empower sufferers to reclaim their lives.

#### SPEAKERS

Steven Phillips, MD and Dana Parish Co-Authors Bay Area Lyme Foundation

#### 9:40am – 10:10am 25 min pre-recorded + 5 min live Q & A

#### Mothers and Children

Congenital Lyme research has been on hold for 25 years. CDC just updated and acknowledged the importance of this field of study. We are interested in exploring the paradigm shifting potential of this. How can we detect and treat Lyme and TBD in children - especially infants? What are the special considerations for children? Children are most at-risk population in the US, so how do we prevent infection? What should pregnant and new mothers do if they have (or suspect they have) Lyme or TBD?

#### MODERATOR

Phyllis Rogers Bedford Executive Director/Co-Founder LymeLight Foundation

PANELIST Holly Ahern, MT(ASCP) Associate Professor of Microbiology SUNY Adirondack

PANELIST Sue Faber, RN, BScN President LymeHope

#### PANELIST

**Charlotte Mao, MD** Pediatric infectious disease specialist Spaulding Rehabilitation Hospital/Massachusetts General Hospital

#### 10:10am - 10:25am 15 min pre-recorded

#### COVID-19 in the context of Lyme disease

We've all been witness to the global rampage of COVID-19 this year and many people have gotten a crash course in terms the Lyme disease community knows all too well: inflammation, cytokines, persistent illness, etc. So, we're asking the questions: What might our experience with Lyme disease teach us about COVID-19? Or vice-versa?

#### MODERATOR

Jason Bobe, MSc Associate Professor Genetics and Genomic Sciences, Icahn School of Medicine at Mount Sinai

PANELIST Richard Horowitz, MD Medical Director Hudson Valley Arts Center

#### PANELIST

David Putrino, PT, PhD Associate Professor Icahn School of Medicine at Mount Sinai

#### 10:25am – 10:40am 15 min pre-recorded

#### Insights from Data Mining of Lyme Disease Patients by LymeMIND

LymeMIND, the data coordination center of the Cohen Lyme & Tickborne Disease Initiative at Mount Sinai, is collaborating with the Lyme Disease Research Center at Johns Hopkins University to study hundreds of Lyme disease patients that have been followed for over a year since their initial diagnosis. These patients have been profiled with genomic assays that can be used to accurately track their disease state. The talk will cover the insights from this study as well as briefly cover other activities carried out at the LymeMIND center.

SPEAKER Avi Ma'ayan, PhD Professor Icahn School of Medicine at Mount Sinai

**10:40am – 11:15am** 25 min pre-recorded + 10 min live Q & A

#### Panel – Novel Treatments Making sense of all the treatment options

What are the differences in current treatment options - CDC vs. ILADS? What are the critical time points from tick bite to chronic symptoms for patients to consider? What is the latest experience and research on treatment options?

MODERATOR John Aucott, MD Associate Professor Director, Lyme Disease Research Center Johns Hopkins University School of Medicine

PANELIST Tania Tyles Dempsey, MD, ABIHM Founder AIM Center For Personalized Medicine

PANELIST Richard Horowitz, MD Medical Director Hudson Valley Arts Center

PANELIST Andrew Petersen, DO Chief of Staff Officer Forum Health



11:15am – 11:50am 30 min pre-recorded + 5 min live Q & A

#### **Bartonella and Co-infections**

Why is Bartonella important to consider as a differential diagnosis? What should patients and the public know about prevention, diagnosis and treatment? What does the latest science tell us about Bartonella? How does it interact with Lyme and other tick-borne diseases? What should patients/public know about prevention, diagnosis and treatment?

SPEAKER 5 MIN Marna Ericson, PhD Assistant Professor University of Minnesota

SPEAKER 5 MIN Monica Embers, PhD Associate Professor Tulane University

SPEAKER 5 MIN Edward Breitschwerdt, DVM

Melanie S. Steele Professor of Medicine and Infectious Diseases North Carolina State University College of Veterinary Medicine

SPEAKER 5 MIN Robert Mozayeni, MD Translational Medicine Group

#### SPEAKER 5 MIN Neil Spector, MD (posthumously)

Associate Professor Medicine, Duke University Medical Center

#### 11:50am – 12:00pm 10 min pre-recorded

#### Lyme Disease – 5 years of progress

What's new in Lyme and tick-borne disease? This talk will review highlights (and lowlights) over the past 5 years across the consortium and in key topics, including clinical medicine, fundamental knowledge, prevention, & field building.

SPEAKER Jason Bobe, MSc Associate Professor Genetics and Genomic Sciences, Icahn School of Medicine at Mount Sinai

12:00pm – 12:08pm 8 min pre-recorded

#### Call to Action: Center for Lyme Action

Center for Lyme Action. A new 501c4 and is focused on lobbying efforts in Congress. Ms. Crater will elaborate what the Center for Lyme Action does and how one can get involved.

SPEAKER Bonnie L. Crater Co-Founder and Board Member Center for Lyme Action 12:08pm – 12:10 pm 2 min pre-recorded

#### Lyme Biobank's tissue repository

A discussion of the Lyme Biobank initiative and how one can donate to the repository.

SPEAKER Liz Horn, PhD, MBI Principal Investigator Lyme Disease Biobank

12:10pm – 12:25pm 15 min pre-recorded

#### Looking towards the future

Looking towards the Future: Discussion of innovative new projects that will help translate scientific breakthroughs into improved patient care over the next four (4) years.

#### MODERATOR

Bennett Nemser, MPH, MBA Senior Program Officer Steven & Alexandra Cohen Foundation

#### PANELIST Brian A. Fallon, MD MPH

Director, Lyme & Tick-borne Diseases Research Center Columbia University Irving Medical Center

#### PANELIST John Aucott, MD

Associate Professor Director, Lyme Disease Research Center Johns Hopkins University School of Medicine





#### 12:25pm – 12:40pm | 15 min pre-recorded

#### LymeX Innovation Accelerator

"LymeX Innovation Accelerator: a public-private partnership between the Department of Health and Human Services (HHS) and the Steven & Alexandra Cohen Foundation."

INTRODUCTION

Bennett Nemser, MPH, MBA Senior Program Officer Steven & Alexandra Cohen Foundation

SPEAKER Eric D. Hargan, JD, BA Deputy Secretary of the Department of Health and Human Services (HHS)

SPEAKER ADM Brett P Giroir, MD Assistant Secretary for Health at the U.S. Department of Health and Human Services (HHS)

SPEAKER Kristen Honey, PhD, PMP Executive Director of Data Operations Office of the Chief Information Officer U.S. Department of Health and Human Services (HHS)

#### 12:40pm – 12:45pm 5 min Live

#### **Closing Remarks**

SPEAKER Patricia (Savi) Glowe Event Chair, LymeMIND Sr. Director of Strategy & Operations, Hasso Plattner Institute for Digital Health at Mount Sinai

End Time is 12:45pm



# Welcome Address and Opening Remarks



### Patricia (Savi) Glowe

Event Chair, LymeMIND Sr. Director of Strategy & Operations, Hasso Plattner Institute for Digital Health at Mount Sinai

Savi Glowe is the Senior Director of Strategy & Operations of the Hasso Plattner Institute for Digital Health at Mount Sinai (HPIMS). She leads the organization, development, and execution of research programs and directs operational efforts supporting HPIMS and the newly formed Mount Sinai COVID Informatics Center in the Icahn School of Medicine at Mount Sinai. She joined Mount Sinai's Department of Genetics and Genomic Sciences in January 2013 and began work with Dr. Joel Dudley in the Fall 2014 as a founding leader of the Institute for Next Generation Healthcare. Her work at Mount Sinai has supported research in rare genetic disorders, lab and consumer device validation, skin disorders, Lyme Disease, and precision wellness. Prior to Mount Sinai, she managed clinical research operations for the Neuro-urology research group at Stanford University.

Her personal and professional passion is to explore new ways of utilizing emerging technologies for advancements in personalized treatment models, longitudinal service for individual care, and system optimization for both patient and provider. Exciting new opportunities in precision medicine and digital health offer a path toward a future of health care that is driven by data, focused on wellness and prevention, and powered by patient understanding, while being affordable and accessible to everyone. This is Ms. Glowe's third year leading the LymeMIND event as the Event Chair. She is honored and grateful to be part of such an incredible community of dedicated and caring professionals.



### **KEYNOTE SPEAKERS**

Chronic: The Hidden Cause of Autoimmune Pandemic and How to Get Healthy Again."



### Steven Phillips, MD

Co-Author Bay Area Lyme Foundation

Steven Phillips, MD is a well-published, internationally recognized, Yale trained physician, researcher, and author, specializing in vector-borne infections. He has been in private practice in CT since 1996, where he has treated more than 20,000 of the most complex patients from approximately 20 countries.

Dr. Phillips has lectured at innumerable medical conferences and hospitals across the US and Europe, participated in closed-door health policy meetings in Sweden, repeatedly served as an invited Lyme disease expert for the states of CT, NY, RI, and VT, and was one of only a handful of medical experts from the US invited to testify at the Infectious Diseases Society of America's Lyme Disease Hearing in Washington DC. Honored by Harvard University's Dean Center as part of their 'Person Who Inspires Us' campaign, he has been an ever-present face of the Lyme disease pandemic. Having been a go-to expert for major media over the past twenty-five years, in both the US and Europe, he has been a contributing author and interviewed expert for major newspapers, television, and other major news outlets online, such as NBC and CNN.

He has also been featured in the Emmy-winning documentary "Lyme and Reason."

In addition to his research focused on the development of an innovative new treatment for Lyme and bartonellosis, for which he won an Emerging Leader Award from Bay Area Lyme Foundation, he has been tirelessly working to bring attention to this public



health crisis. As part of his efforts, along with Sony/ATV singer/songwriter Dana Parish, she has authored the book Chronic, slated for release 2/2/2021 by publishing giant Houghton Mifflin Harcourt. It's a thoroughly researched and highly referenced deep dive into the causal relationship of chronic infection to chronic and autoimmune illness and has been widely endorsed by university-based researchers, authors, and other authorities in the field.



### Dana Parish

Co-Author Bay Area Lyme Foundation

Dana is a chart-topping Sony/ATV Writer and New York City-based Science Journalist who penned a popular *Huffington Post* column on tick-borne diseases, read by over a million people across the globe. Parish was featured on Fox's Emmy-winning special, *Lyme & Reason: The Cause and Consequence of Lyme Disease*, and co-authored "Chronic: The Hidden Cause of the Autoimmune Pandemic & How to Get Healthy Again" with Dr. Steven Phillips set for release in Feb 2021, published by Houghton Mifflin Harcourt.

After contracting a serious case of Lyme and Bartonella in 2014, which was misdiagnosed by a dozen doctors, leading to heart failure, Parish was determined to help change the status quo. By teaming up with Dr. Steven Phillips and famed Duke oncologist, Dr. Neil Spector, she helped found a biotech company, Kyronyx, which is leading the way toward a cure for these rampant, incurable infections.

Parish has become a leading public educator on Lyme and other tick-borne diseases and sits on the board of the Bay Area Lyme Foundation, who recognized her with their first *Courage Award*. Parish and Dr. Phillips were also honored by Harvard's *The Dean Center for Tick-Borne Illness* as "People Who Inspire."



# **Mothers and Children Panel Discussion**



### Phyllis Rogers Bedford

Executive Director and Co-Founder LymeLight Foundation

Phyllis' daughter's battle with Lyme and her journey back to health inspired the creation of LymeLight Foundation. Grateful for the financial means to provide her daughter's lifesaving medical treatment, not covered by insurance, Phyllis met many parents who were forced to decide between feeding and housing their families and treating their Lyme-infected children. LymeLight Foundation was founded on the belief that this is a choice no parent should have to make.

LymeLight Foundation provides medical grants up to \$10,000 to Lyme-infected children and young adults who cannot pay for necessary medications and therapies. Phyllis has been in instrumental in achieving the foundation's accomplishments for victims of Lyme disease. Since its founding in 2011, LymeLight has provided over \$5.7M in grants to 864 individuals in 49 states.

Phyllis is a philanthropist and has devoted much of her adult life to the not-for-profit causes she believes in. She created and executed the largest sustaining fundraising initiative in the history of Today's Youth Matter, an organization serving vulnerable children in the San Francisco Bay Area. As a Governor for Opportunity International, Phyllis was an active fundraiser, hosting events and networking on their behalf. She also traveled to Honduras to observe Opportunity's microfinancing work in action. Phyllis continues to actively support several other organizations focused on social change.





# Holly Ahern, MS, MT(ASCP)

Associate Professor of Microbiology SUNY Adirondack

Holly Ahern is an award-winning professor of microbiology at the State University of New York (SUNY) Adirondack, where she teaches and mentors undergraduate students in research on small lake ecosystems in the Adirondack region of New York. As a result of her family's personal experience with Lyme disease, Ahern co-founded and is currently vice-president of Lyme Action Network, a NY-based 501-c-3 tick-borne disease education and advocacy organization. She is also the Scientific Advisor for Arizona-based Focus on Lyme, managing strategic projects aimed at improving the quality of diagnostic testing for Lyme disease and other tick-borne illnesses. As a scientist and advocate, she is involved in NYS and federal legislative initiatives to improve access and quality of care for Lyme disease patients, including the HHS-convened Tick-Borne Disease Working Group, which delivered its first Report to Congress in December of 2018.



### Sue Faber, RN BScN

President LymeHope

Sue Faber, BScN, is the Co-founder and President of LymeHope, a Canadian not-for-profit organization focused on education, public outreach, research, awareness, and advocacy, for Lyme disease. Sue is firmly committed to transparent and collaborative partnerships with Federal and Provincial 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.



Sue's specific area of expertise and research is the literature that exists on maternal-fetal transmission of Lyme and congenital Lyme borreliosis; 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.



### Charlotte Mao, MD

Pediatric infectious disease specialist Spaulding Rehabilitation Hospital/ Massachusetts General Hospital

Charlotte Mao, MD is a pediatric infectious diseases (ID) specialist at Spaulding Rehabilitation Hospital's Dean Center for Tickborne Illness and the Department of Pediatric Infectious Disease at Massachusetts General Hospital In Boston. She received her medical degree from Harvard Medical School and completed her residency and pediatric infectious diseases fellowship at Boston Children's Hospital. Her work over 25 years at Boston Children's Hospital focused primarily on pediatric HIV clinical care and research. She served as site co-investigator for numerous NIH-/NIAID-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. At Spaulding's Dean Center for Tickborne Illness, she provides consultative pediatric ID specialty care in a multidisciplinary clinic for children with complex Lyme disease and is starting a pediatric Lyme/tickborne disease clinical research program. She currently serves on the Advisory Boards of Bay Area Lyme Foundation and Ride Out Lyme and as Curriculum Director for Invisible International.



# COVID-19 in the context of Lyme disease



### Jason Bobe, MSc

Associate Professor, Genetics and Genomic Sciences Icahn School of Medicine at Mount Sinai

Jason Bobe is Associate Professor in the Department of Genetic and Genomic Sciences at the Icahn School of Medicine at Mount Sinai. His work focuses on collaborative and participatory models of biomedical research through digital platforms and participantcentered innovations in research governance and practice. At Mount Sinai, he leads the Resilience Project and N1app; he is also co-PI of LymeMIND.



### **Richard Horowitz, MD**

Medical Director Hudson Valley Arts Center

Dr. Richard Horowitz is a board-certified internist and the medical director of the Hudson Valley Healing Arts Center, an integrative medical center which combines both classical and complementary approaches in the treatment of Lyme disease and other tick-borne disorders. He has treated over 13,000 Lyme and tick-borne disease patients in the last 30 years, with patients coming from all over the US, Canada, and Europe to his clinic.



He is former Assistant Director of Medicine of Vassar Brothers Hospital in Poughkeepsie, N.Y., and is one of the founding members and past president elect of ILADS, the International Lyme and Associated Diseases Society. He is also past president of the ILADEF, the International Lyme and Associated Diseases Educational Foundation, a nonprofit organization dedicated to the education of health care professionals on tick-borne diseases. Dr Horowitz has trained over 200 healthcare providers in diagnosing and caring for patients with treatment-resistant tick-borne disorders and was previously awarded the Humanitarian of the Year award by the Turn the Corner Foundation as well as awards from Project Lyme for his treatment of Lyme Disease. He has dedicated his life to helping those stricken with this devastating illness.

He is also the author of two best-selling books on Lyme disease, Why Can't I Get Better? Solving the Mystery of Lyme and Chronic Disease (2013, NY Times Best Seller), and How Can I Get Better? An Action Plan for Treating Resistant Lyme and Chronic Disease (2017, National bestseller). These books incorporate recent scientific advances and explain in detail how healthcare providers can effectively diagnose and treat resistant chronic illness. In addition, he has co-authored peer-reviewed Lyme guidelines, and published in the medical literature on novel "persister" drugs for the treatment of Lyme disease and coinfections, as well as the role of the 16-point MSIDS model in chronic illness.

Finally, he has served as a consultant to governmental agencies around the world, including those in China, Australia, Belgium, France, the United Kingdom, and the United States. Dr Horowitz was a member of the HHS Tick-borne Disease Working Group and Co-chair of the "Other Tick-borne Diseases and Coinfections" subcommittee from 2017-2019 which provided recommendations to Congress to help the US improve the care of those suffering with tick-borne disorders. He is presently serving as a member of the HHS Babesia and Tick-borne Pathogen Subcommittee.





### David Putrino, PT, PhD

Associate Professor Icahn School of Medicine at Mount Sinai

David is a physical therapist with a PhD in Neuroscience. He worked as a clinician in Australia, before moving to the United States to study computational neuroscience at Harvard Medical School, MIT and NYU. He has served as a faculty member at Weill-Cornell Medicine and Burke Medical Research Institute. He is currently the Director of Innovation for the Mount Sinai Health System, and an Assistant Professor of Rehabilitation and Human Performance at the Icahn School of Medicine at Mount Sinai. He works to develop innovative technology solutions for individuals in need of better healthcare accessibility. He consults with Red Bull's High-Performance division and leading NBA teams such as the Brooklyn Nets, using evidence-based technologies to enhance human performance. He is also the "Chief Mad Scientist" of Not Impossible Labs, a group that creates technological solutions for humanitarian problems. David is the author of "Hacking Health: How to make money and save lives in the HealthTech world", and his research has been featured on the ABC, Sport's Illustrated, the Wall Street Journal, the BBC, Time Magazine, Wired and the LA Times to name just a few. In 2019, he was named "Global Australian of the Year" in recognition of his contributions to healthcare.



# Insights from Data Mining of Lyme Disease Patients by LymeMIND



### Avi Ma'ayan, PhD

Professor Icahn School of Medicine at Mount Sinai

Dr. Ma'ayan is a Mount Sinai Endowed Professor in Bioinformatics, Professor in the Department of Pharmacological Sciences and Director of the Mount Sinai Center for Bioinformatics. Dr. Ma'ayan is also the Principal Investigator of LymeMIND, the data coordination center for the Cohen Lyme & Tickborne Disease Initiative. The Ma'ayan Laboratory applies computational and mathematical methods to study the complexity of regulatory networks in mammalian cells. The Ma'ayan Laboratory research team applies machine learning and other statistical mining techniques to study how intracellular regulatory systems function as networks to control cellular processes such as differentiation, dedifferentiation, apoptosis, and proliferation. The Ma'ayan Laboratory develops software systems to help experimental biologists form novel hypotheses from high-throughput data, while aiming to better understand the structure and function of regulatory networks in mammalian cellular and multi-cellular systems.



# **Novel Treatments Panel Discussion**



### John Aucott, MD

Associate Professor Director, Lyme Disease Research Center Johns Hopkins School of Medicine

John Aucott, MD, is an Associate Professor of Medicine at the Johns Hopkins University School of Medicine and Director, Johns Hopkins Rheumatology Lyme Disease Research Center, in the School of Medicine. Dr. Aucott received his undergraduate degree in molecular biology from the University of California at Berkeley and his MD from the Johns Hopkins University School of Medicine. He trained at University Hospitals of Cleveland and is a diplomate of the American Board of Internal Medicine with board certification in Infectious Diseases.

He has been involved in care of patients and research in Lyme disease since joining the Johns Hopkins faculty in 1996. He has personally diagnosed and helped countless individuals who suffer from tickborne illnesses to identify and address their unique circumstances and ultimately regain their health. Dr. Aucott's research is focused on improved diagnostic testing and health related outcomes in Lyme disease. He is widely recognized an international expert in post-treatment Lyme disease. He is currently the Principal Investigator for the *SLICE* studies, examining the impact of Lyme disease on health outcomes and the human immune system. The biorepository of blood samples from the *SLICE* studies are a nationally recognized resource that has formed the basis of numerous collaborations studying the microbiology and immune pathophysiology of Lyme disease. The *SLICE* biorepository has been instrumental in the development of several new candidate diagnostic tests for Lyme disease.

Dr. Aucott lectures widely on the accurate diagnosis of Lyme disease and the understanding of chronic illness associated with post-treatment Lyme disease. Under Dr. Aucott's leadership the Johns Hopkins Lyme Disease Research Center has instituted the Lyme Disease Annual Physician CME Course and numerous education tools to help patients and physicians in the fight against the Lyme disease epidemic (hopkinslyme.org). He has served on panels sponsored by the National Institutes of Health, the Institute of Medicine of the National Academies of Science, the National Institute of Standards and Technology, the Canadian institutes of Health Research, and the American Academy for the Advancement of Science. He has over 30 peer-reviewed publications on Lyme disease.

In 2017-2019, Dr. Aucott served as Chairman of the Health and Human Services Tick-Borne Working Group. The Working Group sent a report to Congress in December 2018 conveying gaps in disease prevention, treatment, and research and recommendations for the federal response. These recommendations were incorporated into the NIH's October 2019 Strategic Plan for Tick Borne Diseases.



Tania Tyles Dempsey, MD, ABIHM Founder AIM Center For Personalized Medicine

Dr. Tania Dempsey, MD, ABIHM is a Board-Certified Internist. She received her MD degree from The Johns Hopkins University School of Medicine and her BS degree from Cornell University. She completed her Internal Medicine Residency at New York University Medical Center. She is currently a community staff member of Greenwich Hospital in Greenwich, CT.

In 2011, she founded Armonk Integrative Medicine (AIM) which has evolved into the AIM Center for Personalized Medicine, a destination practice in Purchase, NY, focusing on complex, multi-system diseases. Dr. Dempsey is an expert in Tick-Borne Infections, Mast Cell Activation Syndrome, Autoimmunity and ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome). She is an accomplished international speaker and writer and was the Keynote Speaker in 2018 at the International Congress on Natural Medicine in Melbourne, Australia. She has been featured on Fox 5 NY News, Reader's Digest, Huffington Post, The Observer, The NY Post and countless other media outlets. She is the co-author of the chapter on "Urogynecology and Hypermobility" in the newly released book, *Disjointed Navigating the Diagnosis and Management of hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders.* She was also a co-author on the ground-breaking review article published in Diagnosis, in April 2020, titled *"Diagnosis of mast cell activation syndrome: a global "consensus-2"*. She is a member of the U.S. ME/CFS Clinician Coalition and is actively involved in their Infection Workgroup subcommittee.



Dr. Dempsey's interest in mast cell activation syndrome (MCAS) and its connection to chronic diseases began back in 2013 when she identified her first patient with MCAS. Since then, she has identified that over 75% of the patients in her practice with a history of tick-borne diseases have this syndrome.



### Andrew Peterson, DO

Chief of Staff Officer of Forum Health

Dr. Petersen is board certified in Family Medicine. He trained in Altoona Pennsylvania and shaped his treatment philosophy as a rural family physician. He now specializes in areas where he believes conventional approaches fall short. These include hormonal imbalances, hypothyroidism, chronic fatigue syndrome, fibromyalgia, metabolic disorders, neurodegenerative conditions, and of course Lyme disease.

He joined Forum Health as their Chief of Staff in order to lead integrative physicians willing to learn about and treat Lyme disease. He is passionate about the underlying cause of disease and helping people regain their health by treating the root causes of disease.

Petersen is a fellow of the American Academy of Anti-Aging Medicine. He completed the organization's fellowship in stem cell therapy. He also serves on the board of the International Lyme and Associated Diseases Society.



### **Richard Horowitz, MD**

Medical Director Hudson Valley Arts Center

Please see Dr. Richard Horowitz's biography under the "COVID-19 in the context of Lyme disease" session.



# Bartonella & Co-infections



### Dr. Marna Ericson, PhD

Assistant Professor University of Minnesota and Thought Leadership & Innovation Foundation

Our goal is to decipher the complex nature of vector-borne diseases and importantly, co-morbidities. Over the past 15 years, we have used our knowledge, experience and skill with advanced imaging methodologies, coupled with new molecular detection techniques, to improve our understanding of the complexities of vector-borne diseases. Advanced imaging techniques we have successfully applied and adapted include single and multi-photon microscopy, second harmonic generation, super-resolution microscopy, correlated X-Ray electron microscopy and correlative light electron microscopy (CLEM). The tissue and blood imaging analyses are coupled with advances in molecular biology and nanotechnology including development of direct genome sequence methodologies of tissues/blood, imaging with quantifiable mRNA probes and development of nanopolymers to alter pathogen biofilm growth. This proposal offers a new, cutting-edge team approach to detect vector-borne pathogens in our blood supply using intelligent design hyperspectral imaging. This approach is a point-of-care technique that could be scaled to use in many environments.

Working with local, national and international collaborators, we characterized the vectorborne infections, Bartonella spp. and Borrelia spp. bacteria, in skin, brain, bone, blood, appendix, synovial fluid etc, in patients with a range of life-altering co-morbidities (a–d). Recently, we detected and visualized Bartonella spp. and Borrelia spp. in a small cohort of melanoma patients (7/8) by blood PC, serology and culture and in a subset of this group we detected the same pathogens using advanced imaging analysis, tissue PCR and direct deep sequencing using the MinION. We co-cultured melanoma and Bartonella henselae, and discovered B. henselae within the melanoma cells, as well as altered melanoma growth, and expression of VEGF. Future plans involve investigations into mechanisms of Bartonella biofilm and analysis by cutting-edge cryo-EM at the Hormel Institute.



Our highly collaborative, multi-pronged approaches have provided us with exciting insights and improved methods for detection and diagnosis for vector-borne diseases and lifealtering co-morbidities. This proposal can have wide-spread implications, improving blood safety.

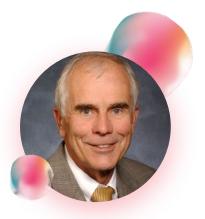


### Monica Embers, PhD

Associate Professor Tulane University

Monica E. Embers obtained her Ph.D. in the Department of Microbiology and Immunology at the Pennsylvania State University College of Medicine in Hershey, P.A., where she studied immune responses to Papillomaviruses. She made the transition to the study of bacterial pathogenesis when performing her postdoctoral research on the Lyme disease spirochete at the Tulane National Primate Research Center (TNPRC). She subsequently joined the faculty at the TNPRC. Dr. Embers is an Associate Professor in the Division of Immunology and the Director of Vector borne Disease Research at the TNPRC. Her research program regarding Borrelia burgdorferi and Lyme disease specializes in animal models and is centered around three major efforts: (1) identifying treatments that can eradicate B. burgdorferi infection; (2) identification of Lyme disease spirochetes in human tissues; and (3) immunodiagnosis for B. burgdorferi infection and cure. The first research goal is to use animal models of persistent infection to evaluate new therapeutic strategies. The second goal is to evaluate humans for persistent infection with B. burgdorferi. The third goal is to develop a quantitative multi-antigen test that expands detection limits and helps to distinguish persistent infection from clinical cure. By transmitting Lyme disease to mice and nonhuman primates by tick, and studying the natural course of infection, her group hopes to facilitate a better understanding of the clinical guandaries of human Lyme disease, including effective diagnosis and treatment.





### Edward B. Breitschwerdt, DVM

Melanie S. Steele Professor of Medicine and Infectious Disease North Carolina State University College of Veterinary Medicine

Edward B. Breitschwerdt is a professor of medicine and infectious diseases at North Carolina State University College of Veterinary Medicine. He is also an adjunct professor of medicine at Duke University Medical Center, and a Diplomate, American College of Veterinary Internal Medicine (ACVIM). Dr. Breitschwerdt directs the Intracellular Pathogens Research Laboratory in the Comparative Medicine Institute at North Carolina State University. He also co-directs the Vector Borne Diseases Diagnostic Laboratory and is the director of the NCSU-CVM Biosafety Level 3 Laboratory.

A graduate of the University of Georgia, Breitschwerdt completed an internship and residency in Internal Medicine at the University of Missouri between 1974 and 1977. He has served as president of the Specialty of Internal Medicine and as chairperson of the ACVIM Board of Regents. He is a former associate editor for the Journal of Veterinary Internal Medicine and was a founding member of the ACVIM Foundation.

Breitschwerdt's clinical interests include infectious diseases, immunology, and nephrology. For over 30 years, his research has emphasized vector-transmitted, intracellular pathogens. Most recently, his research group has contributed to cutting-edge research in the areas of animal and human bartonellosis. In addition to authoring numerous book chapters and proceedings, Dr. Breitschwerdt's research group has published more than 450 manuscripts in peer-reviewed scientific journals. In 2012, he received the North Carolina State University Alumni Association Outstanding Research Award and in 2013, he received the Holladay Medal, the highest award bestowed on a faculty member at North Carolina State University. In 2017, Dr. Breitschwerdt received the American Association of Veterinary Medical Colleges Outstanding Research Award and the American Canine Health Foundation Excellence in Research Award. In 2018, he was named the Melanie S. Steele Distinguished Professor of Medicine at North Carolina State College of Veterinary Medicine.





### Bob Mozayeni, MD

Translational Medicine Group

Dr. Mozayeni is a physician scientist with a particular interest in Translational Medicine, the science and art of advancing medical science, quickly, safely and efficiently. After graduating from the 6yr BS-MD program of Union College and Albany Medical College, he completed his Internal Medicine Research Residency at Yale-New Haven Hospital and completed Rheumatology Fellowships at Yale and NIH. As a Senior Staff Fellow in NHLBI Laboratory of Biophysical Chemistry, he conducted research in the biophysics of antigen recognition by the immune system.

He is a Fellow of the non-profit Think Lead Innovate Foundation. He is the Medical Director of Galaxy Diagnostics, LLC. He is a co-founder of the Foundation for the Study of Inflammatory Diseases. And, he is a founding Board member of the Human-Kind Alliance. He also serves as a consultant to Pharma- and Nutra-ceutical companies.

He is the President of ILADS until Fall 2021. His main objective with ILADS is the same as with his professional career – to advance the science of translational medicine. His career passion is to find the fastest path for advancing medical science in diverse areas of patient need to validate and continuously improve best clinical practices – all to alleviate medical suffering faster while reducing the cost of care. By studying how to advance best practices, while understanding and navigating the controversies in diverse areas of medical need, insights are gained in one arena that can inform translational medical science in another.

Recently, Dr. Mozayeni launched T Lab Inc., a research and clinical laboratory engaged in research using advanced microscopy to understand better the pathogenesis of disease in inflammatory conditions associated with persistent infections.





### Neal Spector, MD (posthumously)

Associate Professor Medicine Duke University Medical Center

Neil Spector, M.D. has an endowed faculty position, the Sandra Coates Associate Professor of Medicine, Duke University Medical Center. Dr. Spector's work has focused on elucidating molecular mechanisms underlying therapeutic resistance to therapies targeting the Human Epidermal Growth Factor Receptor (HER) family of receptor tyrosine kinases that promote the growth, survival and metastatic dissemination of breast cancers and other commonly occurring solid tumors. He directed the translational research program for lapatinib, the first small molecule inhibitor of the HER2 and EGFR tyrosine kinases that was FDA approved for the treatment of advanced stage HER2 overexpressing (HER2+) breast cancers. His lab developed the first models of therapeutic resistance to lapatinib, which identified a novel mechanism of resistance that was published in the Proceedings of the National Academy of Sciences, and served as the scientific basis for a clinical development program that led to the FDA approval of lapatinib in combination with the aromatase inhibitor letrozole as a first line therapy for patients with HER2 positive and Estrogen Receptor positive metastatic breast cancer. His work is widely regarded as a model for how precision oncology can transform treatment of cancer patients and facilitate the development of targeted cancer therapies. Dr. Spector also oversaw the early phase clinical development of nelarabine, an ara-G prodrug that was FDA approved for the treatment of pediatric acute lymphoblastic leukemia. His work with Dr. Tim Haystead (Professor, Duke Cancer Biology and Pharmacology) has led to the identification of novel small molecules that target cell pathways involved in the earliest stages of tumorigenesis, providing an opportunity to prevent breast and other cancers in high risk individuals. Dr. Spector was recognized by his peers through his selection as a Komen Research Scholar, a group representing the top breast cancer researchers from around the world. He was the recipient of the R. Wayne Rundles Award recognizing outstanding research accomplishments by a Duke investigator, and the Wendell Rosse Teaching Award recognizing excellence in teaching as determined by Duke medical oncology/hematology fellows. Dr. Spector also detailed his personal 17-year journey with Lyme disease and the life-threatening cardiac complications that ensued, leading to heart transplant in 2009 in his book, "Gone In a Heartbeat: A Physician's Search for True Healing".



He delivered a TEDxNashville talk in which he discussed the growing impersonalized nature of modern precision-based medicine. Dr. Spector is the principal investigator on a multi-institutional grant that includes Drs. Monica Embers (Tulane), Tim Haystead (Duke) and Ed Breitschwerdt (NC State University) that was awarded by the Steven and Alexandra Cohen Foundation to discover and develop non-antibiotic, molecular targeted therapies for the treatment of infections related to Borrelia and Bartonella. Dr. Spector completed his internal medicine residency training at Parkland Hospital, University of Texas-Southwestern Medical Center in Dallas and a Medical Oncology/Hematology and Bone Marrow Transplantation fellowship at Massachusetts General Hospital and Dana-Farber Cancer Institute, Harvard Medical School.

# Lyme Disease – 5 years of progress



### Jason Bobe, MSc

Associate Professor Genetics and Genomic Sciences Icahn School of Medicine at Mount Sinai

Please see Jason Bobe's biography under the "COVID-19 in the context of Lyme disease" session.





# **Call to Action: Center for Lyme Action**



### Bonnie L. Crater

Co-Founder and Board Member Center for Lyme Action

Bonnie Crater is co-founder and board director at Center for Lyme Action. As co-founder and co-chair of Bay Area Lyme Foundation and chair of the BAL science committee, she led the team that drives the research agenda, champions innovation, and seeks partners to chart new paths in Lyme research. Bonnie is currently the president and CEO of Full Circle Insights and is a multi-time vice president of marketing in Silicon Valley. She currently serves on the board of the CB Wellness Foundation and on the Town of Portola Valley's Nature and Science Committee. Ms. Crater holds an AB in Biology from Princeton University.



### Liz Horn, PhD, MBI

Principal Investigator Lyme Disease Biobank

Liz has spent the past 17 years building research initiatives and collaborations with non-profit organizations, with a focus on registries and biobanks. She has worked in Lyme disease since 2013 and was part of the team that launched the Lyme Disease Biobank. The Lyme Disease Biobank, a project of Bay Area Lyme Foundation, was created to provide much-needed samples to researchers studying Lyme disease and other tick-borne infections, and each participant's sample donation supports up to 50 different research projects. More than 900 participants (representing early Lyme disease, later stages of Lyme disease, endemic controls, and ill controls) have been enrolled at sites in endemic areas, including Long Island, Martha's Vineyard, Boston, several regions in Wisconsin, and California. Currently, the biobank supports 55 research projects across academia and industry. For more information about the biobank visit www.bayarealyme.org/our-research/biobank/



A tissue bank has also been created to collect samples from patients with Lyme disease and other tick-borne infections to understand the impact of these infections on the body. This program is in partnership with the National Disease Research Interchange (NDRI) to collect surgical and post-mortem tissues and LymeDisease.org, so that participants in the MyLymeData patient registry can link their MyLymeData profile with their tissue samples. This program is provided at no cost to patients and families. Interested individuals can register at ndriresource.org/lyme-disease

Liz earned her doctorate in molecular pharmacology and cancer therapeutics from SUNY at Buffalo, was a National Library of Medicine fellow in biomedical informatics and received her MBI from Oregon Health & Science University. She has mentored and trained more than 75 advocacy organizations in the translational research enterprise, and helped these groups initiate collaborations with academia, other non-profits, and industry. Liz is passionate about building tools and resources to move research forward that helps people, improves lives, and reduces suffering.

# Looking towards the future



### Bennett Nemser, MPH, MBA

Senior Program Officer Steven & Alexandra Cohen Foundation

Mr. Bennett Nemser is the Senior Program Officer for the Steven & Alexandra Cohen Foundation and manages the Cohen Lyme and Tickborne Disease Initiative. He has been a caregiver for a family member suffering with Lyme and tickborne disease since 2013. Prior to joining the Foundation, Ben was a Senior Monitoring and Evaluation (M&E) Consultant for UNICEF and the World Health Organization (WHO), where he directed M&E efforts for various projects and initiatives including the UN Commission on Life-saving Commodities for Women and Children as well as the \$200-million Reproductive, Maternal, Newborn and Child Health (RMNCH) Trust Fund. After receiving a Master of Public Health from Columbia University's Mailman School of Public Health, Mr. Nemser worked for Columbia University as an Epidemiologist and Data Systems Manager. His research portfolio includes coauthorship of more than ten (10) publications on various issues facing developing countries including malaria, HIV, TB, nutrition, child survival and access to life-saving commodities for women and children. In addition to his public health experience, Ben has a Master's in Business Administration and a background in governmental finance and budgeting.





### Brian A. Fallon, MD, MPH

Director, Lyme & Tick-borne Diseases Research Center Columbia University Irving Medical Center

Brian A Fallon, MD, MPH is director of the Lyme and Tick-borne Diseases Research Center at Columbia University Irving Medical Center and Professor of Clinical Psychiatry. He is author with Dr. Jennifer Sotsky of Conquering Lyme Disease: Science Bridges the Great Divide (Columbia University Press 2018). Current research at the Center focuses on adults and children, spanning brain imaging, treatment, and biorepository building to facilitate biomarker and diagnostic advances.



### John Aucott, MD

Associate Professor Director, Lyme Disease Research Center Johns Hopkins School of Medicine

Please see Dr. John Aucott's biography under the "Novel Treatments Panel Discussion".





# LymeX Innovation Accelerator



### Bennett Nemser, MPH, MBA

Senior Program Officer Steven & Alexandra Cohen Foundation

Please see Bennett Nemser's biography under the "Looking towards the future" panel.



### Eric D. Hargan, JD, BA

Deputy Secretary U.S. Department of Health and Human Services (HHS)

Eric D. Hargan is the Deputy Secretary of the Department of Health and Human Services (HHS). HHS is dedicated to promoting and enhancing the health and well-being of the American people, and as the largest department in the federal government has an annual budget in excess of \$1.3 trillion and over 80,000 employees across 26 divisions. As Deputy Secretary, he is the Chief Operating Officer and is responsible for overseeing the day-to-day operations and management of the department in addition to leading policy and strategy development.

Mr. Hargan was sworn into office as Deputy Secretary of the Department of Health and Human Services on October 6, 2017. He immediately served as Acting Secretary of HHS from October 2017 to January 2018.

From 2003 to 2007, Mr. Hargan served at HHS in a variety of capacities, including holding the position of Acting Deputy Secretary. During his tenure at HHS, Mr. Hargan also served as the Department's Regulatory Policy Officer, where he oversaw the development and approval of all HHS, CMS, and FDA regulations and significant guidances.



He received his B.A. *cum laude* from Harvard University, and his J.D. from Columbia University Law School, where he was Senior Editor of the *Columbia Law Review*. In between his tours of duty at HHS Mr. Hargan taught at Loyola Law School in Chicago, focusing on administrative law and healthcare regulations.

Mr. Hargan was born and raised in Mounds, Illinois, a small town of approximately 800 located in the southern county of Pulaski. He currently lives in Virginia with his wife and their two sons.



### ADM Brett P Giroir, MD

Assistant Secretary for Health U.S. Department of Health and Human Services (HHS)

ADM Brett P. Giroir, M.D., was sworn in as the 16th Assistant Secretary for Health at the U.S. Department of Health and Human Services (HHS) on February 15, 2018. The Assistant Secretary for Health leads development of HHS-wide public health policy recommendations and oversees several of the Department's core public health offices — including the Office of the Surgeon General. His office leads many critical national initiatives, including an historic new plan to end the HIV Epidemic in America, the Physical Activity Guidelines for Americans, the revised Common Rule and a cross-agency effort to improve the outcomes of patients living with sickle cell disease.

In addition, ADM Giroir serves as Senior Adviser to the Secretary for Opioid Policy, responsible for coordinating HHS's efforts across the Administration to fight America's opioid crisis.

ADM Giroir is a pediatric critical care specialist and physician-scientist, who has served in a number of leadership positions in the federal government as well as academia.

He was executive vice president and CEO of Texas A&M's Health Science Center from 2013-2015, and professor of pediatrics and engineering, having earlier served as vice chancellor of strategic initiatives (2011-2013) and vice chancellor for research (2008-2011) for the Texas A&M University system. Prior, he was professor of pediatrics and endowed chair at the University of Texas Southwestern Medical Center from 1993-2003, and was the first chief medical officer of Children's Medical Center of Dallas (now Children's Health).



ADM Giroir's federal service includes directing the Defense Sciences Office of the Defense Advanced Research Projects Agency (DARPA) from 2006-2008. He joined the office in 2004 as deputy director, and also served on the Department of Defense's Threat Reduction Advisory Committee both during his tenure at DARPA and thereafter. From 2014-2015, he chaired the Veteran's Choice Act Blue Ribbon Panel to reform the U.S. Veterans Health System.

ADM Giroir has authored or co-authored more than 100 scientific publications, editorials and book chapters. He is the recipient of numerous honors and awards, including the U.S. Secretary of Defense Medal for Outstanding Public Service, the American Heart Association's President Lyndon Baines Johnson Research Award, and the American Society of Nephrology's President's Medal. ADM Giroir was the nation's high school debate champion in 1978. He received a bachelor's degree in biology, magna cum laude, from Harvard University, and a medical degree from the University of Texas Southwestern Medical Center.



### Kristen Honey, PhD, PMP

Executive Director of Data Operations Office of the Chief Information Officer U.S. Department of Health and Human Services (HHS)

Dr. Honey is the Executive Director of Data Operations at the U.S. Department of Health Services (HHS) in Washington D.C. Prior to joining HHS, Dr. Honey worked in the White House and led the federal Open Data portfolio for three years across two Administrations. She is passionate about data-driven partnerships and emerging technologies that empower patients and caregivers with lived experience as equal partners to co-create solutions with M.D. clinicians, Ph.D. researchers, and D.C. policy makers. Dr. Honey founded and leads the HHS Lyme Innovation initiative. She served as the inaugural Vice Chair of the Tick-Borne Disease Working Group (TBDWG) and co-authored the 2018 TBDWG report with 28 recommendations to the U.S. Congress and HHS Secretary. Dr. Honey 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. Dr. Honey earned her Ph.D. at Stanford University (interdisciplinary biology) with a Ph.D. minor in Civil and Environmental Engineering.



# **Closing remarks**



# Patricia (Savi) Glowe

Event Chair, LymeMIND Sr. Director of Strategy & Operations, Hasso Plattner Institute for Digital Health at Mount Sinai

Please see Savi Glowe's biography under "Welcome Address and Opening Remarks".











# Art Expo

# Yanin Ruibal

Yanin Ruibal's illustrations and paintings are bold in their vibrancy, whether decorating her Mexico City apartment or public spaces in various countries. Conceptually, her art explores what's inside of us. Hidden softness, hidden ferocity or hidden pain – the last one Yanin knows well through her own battle with Lyme disease. But what's inside always spills out. The natural explodes into our everyday like weeds between pavement cracks. Her work overflows with lushness, combining an interest in flora and fauna with a uniquely Mexican understanding of vivid color.

WWW.YANINRUIBAL.COM INSTAGRAM

# **Tracey Grumbach**

Tracey Grumbach is a digital and photo artist working out of Northern Harford County, Maryland. Her ongoing fight with Chronic Lyme Disease forced her to give up a career as a real estate photographer but led her into a career as a digital artist. Much of her art has a direct connection to her struggle and triumph over this difficult illness. Tracey's artistic passion and focus is creating dream-like or surreal visual worlds that convey a deeper meaning and emotion to the viewer. Her work has been seen in venues throughout Maryland including art galleries in Harford and Cecil County. Tracey's photography and digital artwork has been used by ad agencies, and has been published in popular local, national, and international magazines and newspapers including Baltimore Magazine, Artful Blogging, and Somerset Digital Studio. Mrs. Grumbach lives on a small farm with her husband and their four children. She is passionate about the health, Lyme disease awareness, organic living, and the environment. During her free time, she likes to garden, read, and hike.

NINEACRESDESIGNS.ZENFOLIO.COM INSTAGRAM FACEBOOK

# Josh Tiessen

Josh Tiessen was born in 1995 in Moscow, Russia, and is now based near Toronto, Canada. He was listed as one of the world's top ten prodigy artists (Huffington Post) and recognized as the only known male art prodigy in North America (Dr. J. Ruthsatz, international child prodigy expert). Tiessen has exhibited his work for the past 14 years in over 100 exhibitions including the National Gallery of Canada. He has been featured over 200 times in the press and media, receiving over 60 awards and honors such as Canada's Top 20 Under 20, the Queen Elizabeth II Diamond Jubilee Medal, and Art Renewal Center's youngest Associate Living Master designation. New York based gallery Jonathan LeVine Projects awarded him First Place from 2000 artists in their international competition Search for the Next Great Artist. LeVine presented the emerging artist's debut international solo exhibition in May of 2019. Tiessen is best known for his hyperreal shaped oil paintings, which take 400-1200 hours to complete and reflect the interaction between the natural world and manmade structures, drawing upon his studies in philosophy, theology and intercultural aesthetics.

WWW.JOSHTIESSEN.COM INSTAGRAM

# Kristin Thornton

Kristin Thornton is a disabled Maine artist. Her doctors believe she was both born with and re-infected with Lyme disease and co-infections. Her Lyme disease went undiagnosed for 23 years and triggered an autoimmune disorder which then lead to Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). Kristin believes creating art has the power to heal and bring peace. Her goal is to reach out to others with Lyme and chronic illnesses to help them feel a little less alone. Kristin's relationship with nature changed when she was diagnosed with Lyme disease and much of her art is inspired by the places she once found peaceful, which have taken on an ominous air due to the unseen threat of living everyday with Lyme.

KRISTINTHORNTONART.WIXSITE.COM INSTAGRAM FACEBOOK

# Jivan Lee

Jivan Lee is an oil painter based in Taos, NM. He grew up in Woodstock, NY, and studied painting at Bard College. His work – which is primarily made outdoors in all seasons – explores the nature of paint as raw material, creator of image, and catalyst for emotional response, and is increasingly addressing the complexities of how humans see and shape the environment. Jivan's paintings have been exhibited nationally and covered in publications such as Fine Art Connoisseur, The Denver Post, Hyperallergic, Southwest Art, Phoenix Home and Garden, and Two Coats of Paint among others. His work is represented by LewAllen Galleries in Santa Fe, NM; William Havu Gallery in Denver, CO; and Altamira Fine Art in Scottsdale, AZ, and Jackson Hole, WY. Jivan overcame debilitating Lyme disease in 2009 after a climactic cross-country odyssey and has been symptom-free since.

WWW.JIVANLEE.COM/ INSTAGRAM FACEBOOK

# Jennifer Scott

"From broken and lost; to purpose and identity – my work is a visual diary of reinventing myself and rebuilding my life. When a diagnosis of a life-altering illness left me bedridden and searching for my lost identity, a childhood passion resurfaced. In frustration, I dragged out old supplies and started drawing the symptoms that I couldn't seem to verbally express. In that moment, my passion for art was reborn!" Jennifer Scott is a self-taught artist who started using art to express what it feels like to live with chronic illness and chronic pain. She found that "showing" people her symptoms was easier than struggling to communicate the pain and frustration through words alone. Over the years, the subjects of her pieces have expanded far beyond her original "Expressions of Lyme Disease," and now includes cityscapes inspired by her hometown of Chicago, spiritual pieces inspired by her own walk with God, people, landscapes, florals, and abstracts. Unlike most artists, Jennifer admits that she does not have a standout "signature" style or technique. Instead, she loves to explore with all different media, styles, and subject matter. In 2017, Jennifer developed and implemented "Created to Create Ministries," a local ministry that facilitates the exploration of individual creativity through various art projects and culminates with discussions of spiritual importance - teaching the values of kindness, thoughtfulness, empathy, and beautiful acceptance of self and others. It is her deepest desire to help others connect with God and community through the freedom and joy of creativity! Jennifer is an Artist Member of the Oak Park Art League and Niles Art Guild.

# Vicki Favilla

Vicki Favilla began her love of art as a child, winning many competitions and had some work published at an early age. After studying art at Montgomery College, she decided their art disciplines were not for her. She channeled her creative energy into renovating houses, refinishing furniture and her love of gardening. It was only in the last several years that she discovered she was an abstract artist. Vicki's work has been in countless juried exhibits in Maryland, DC, Pennsylvania and New York City.

VICKI FAVILLA INSTAGRAM FACEBOOK

# Justin Lefty Lefkowitz

Life's full of tales that have yet to be written they say... well this one has yet to be fully painted. Born in Staten Island in 1991, Justin did not start perfecting his craft until mid 2016 when faced with horrific health issues at the time. Although it would not be learned until several months later when he would officially be diagnosed with chronic Lyme Disease, Justin continued experimenting, creating, and producing new pieces of art that would expand boundaries and push his artistic limits as if there were no issues. Painting was the perfect outlet for Justin as he was unable to process audio and visual imagery due to the ongoing issues with his illness. By meshing some ideas from modern culture in an apolitical way, Justin is able to channel a style that is truly his own. In mid-2019, Justin was diagnosed with Bartonella, one of the main and most brutal co-infections of Lyme. Justin, who was named "Staten Islander of the Week" by NY1 in 2017 for the work he has contributed so far, looks to serve as an inspiration to not only the Lyme world, but to the local community as well, working with organizations such as the Heart Society and the Islanders Children's Foundation. Remember, when life hands you lemons, take it, but when life hands you Lyme, paint it!

WWW.JLEFTYART.COM/ TWITTER



# About Mount Sinai Health System

The Mount Sinai Health System is an integrated health care system providing exceptional medical care to our local and global communities.

Encompassing the Icahn School of Medicine at Mount Sinai and eight hospital campuses in the New York metropolitan area, as well as a large, regional ambulatory footprint, Mount Sinai is internationally acclaimed for its excellence in research, patient care, and education across a range of specialties. The Mount Sinai Health System was created from the combination of the Mount Sinai Medical Center and Continuum Health Partners, which both agreed unanimously to combine the two entities in July 2013.

The Health System is designed to increase efficiencies and economies of scale; improve quality and outcomes; and expand access to advanced primary, specialty, and ambulatory care services throughout a wide clinical network. The Health System includes more than 7,200 physicians, including general practitioners and specialists, and 13 free-standing joint-venture centers. Mount Sinai also features a robust and continually expanding network of multispecialty services, including more than 400 ambulatory practice locations throughout the five boroughs of New York City, Westchester, and Long Island. With an extraordinary array of resources for the provision of compassionate, state-of-the-art care, the Mount Sinai Health System is poised to identify and respond to the health-related needs of the diverse populations we serve.







# Note from the Foundation

The Cohen Lyme & Tickborne Disease Initiative is working to combat some of the fastestgrowing vector-borne disease in the U.S. Inspired by Alex Cohen's personal struggle with Lyme disease, the Initiative reflects her commitment to raising awareness, advancing research, developing better diagnostics, and finding a cure for these complex illnesses.

It is estimated that over 300,000 people are infected by Lyme and tickborne disease each year and incidence rates are on the rise throughout the country. When diagnosed early, most cases can be successfully resolved through a course of antibiotics. However, between 10 to 20 percent of treated cases remain unresolved, resulting in life-altering symptoms that can linger for years. The cause of these ongoing symptoms in unclear and treatments for those who suffer are highly debated within the medical community. Lyme and tickborne disease are also often hard to diagnose, and many of those at risk are unaware of the potential dangers, proper methods of prevention, and signs of infection. The Foundation is addressing these challenges through an investment strategy designed to bring more funding and greater attention to this growing problem. With a comprehensive, mission-driven strategy, encompassing research into prevention, diagnosis, and treatment as well as awareness and education, the Cohen Lyme & Tickborne Disease Initiative is attracting new talent to Lyme and tickborne disease research and demonstrating the impact of these illnesses on vulnerable communities. Over time, we hope to help educate healthcare providers on the latest tools to diagnose and treat patients.

Central to the Initiative is an unwavering commitment to collaboration. When building its investment portfolio, the Foundation worked closely with over 80 Lyme experts and other respected figures in the scientific community who represent a spectrum of medical disciplines and perspectives. The foundation is also requiring collaboration among grantees to ensure everyone is learning from one another and increasing the overall impact of these efforts. Since 2015, the Cohen Lyme & Tickborne Disease Initiative has committed over \$80 million to more than 30 research projects. To learn more about the Initiative and specific grants, please visit www.steveandalex.org/ticks-suck/

We look forward to actively supporting this community and discovering innovative solutions for patient care in the coming years.

# **LYME**MIND

# The 5th Annual

# LymeMIND Virtual Conference 2020



