

MEETING AGENDA

CHAIRS - Prof John (Jack) Lambert & Jenna Luché-Thayer

| 13:00 | Introduction |
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| | Prof John (Jack) Lambert, Dublin |
| 13:10 | Cryptic infections in Pregnancy |
| | Prof John (Jack) Lambert |
| 13:40 | The Value and Limitations of Serological Assays for the Diagnosis of Crypto-Infections, including Tick-Borne Infections. Includes |
| | points on how laboratory practices and policies create obstacles |
| | Michael Cook |
| 14:20 | Tick-borne Disease Diagnostics: The Good the Bad and the Ugly. |
| | Dr Leona Gilbert |
| 15:00 | Molecular biology and ecology of ticks and tick-borne pathogens: co-existence, distribution, interactions. |
| | Dr. Natasha Rudenko |
| 15:50 | Coffee break |
| 16:15 | Antigen Based Diagnostics: the value of PCR in crypto-infection diagnosis |
| | Prof Christian Perronne |
| 17:15 | Patient care in Québec and recent initiatives in Canada |
| | Dr Amir Khadir |
| 18:15 | End of Conference first day |
| 18:30 | Dinner at the Rotunda Hospital |

| MEETING AGENDA SATURDAY 1 st JUNE 2019 | | | | |
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| 8:00 | Introduction -CHAIRS Prof Christian Perronne & Fred Verdult | 11.45 | Patient groups: how to advocate for recognition and treatment of Tick-Borne Infections (lessons learned from | |
| 8:15 | Developing Effective Treatment of Persistent Lyme Disease: Where are we now? Dr Ying Zhang | | HIV, and current status with Lyme disease) Fred Verdult | |
| 8:40 | Two double blind randomized trials in Congo-Kinshasa to evaluate the efficacy of Artemisia tea versus chemical recommended drugs to treat malaria and schistosomiasis. Results and financial issues. <i>Dr Lucile Cornet-Vernet</i> | 12:15 | Lunch | |
| | | 13:15 | Biofilms: in vitro and in vivo evidence of crypto-infections and challenges with Borrelia infection Prof Niels Hoiby | |
| 9:25 | Chronic infection in Alzheimer's disease, Lyme disease and type 2 diabetes. Dr Judith Miklossy | 14:00 | Bacteriophages as diagnostic markers and therapeutic agents for predicting and treating Lyme disease Dr Jinyu Shan | |
| 10:10 | Coffee break | 14:45 | Three presentations (submitted abstracts) of 15 minutes | |
| 10:30 | Bartonella (and other zoonotic diseases) and its role in Chronic Infection, evidence of persistence and challenges of treatment Dr. Ricardo G. Maggi | 15:30 | Ross Murtagh, Vett Lloyd & Marina Golovchenko/Natasha Rundenko Conclusions: What are next steps to advance our understanding of these Crypto- infections and support patients with these 'undiagnosed' illnesses? | |
| 11.25 | The role of international advocacy in supporting patients' rights to care Jenna Luché-Thayer | | Prof Christian Perronne & Prof John Lambert | |
| | | 16:00 | End of conference | |

Prof Jack (John) Lambert

Consultant Infectious Diseases, Mater Misericordiae University Hospital/ University College Dublin, Ireland.

Dr John lambert is is a consultant in Infectious diseases and genitourinary medicine, and has been practicing in Dublin Ireland as a consultant in the Mater and Rotunda Maternity hospitals, with teaching appointment at UCD School of Medicine and Medical Science. He is director of the National Isolation Unit for Highly Infectious Diseases at the Mater Misericordiae University Hospital and a member of the National Viral Hemorrhagic Fever Committee of the HSE. He has also been involved in the Sexual Health Strategy group in Ireland and teaching GP in Ireland on the subject of STDs. He has presented widely in the field of Lyme and co infections in the last 3 years through EU and USA conferences supported by the International Lyme and Associated Diseases Society (ILADS).

Dr. Leona Gilbert, PhD

Docent in Cell and Molecular Biology, Department of Biological and Environmental Sciences, NanoScience Center, University of Jyväskylä, Jyväskylä, Finland.

Dr Gilbert is an Docent of Cell and Molecular Biology at the University of Jyväskylä, Finland and she is the CEO of Te?ted Oy, a university spinoff company that has a goal to get the patient tested so they can be treated. She has a doctorate in biotechnology and a very long experience in bio-innovation and biobusiness. Her numerous peer-reviewed articles span turning research results into translational value with developing novel delivery vectors that can be used for imaging and biotechnological tools as well as to developing diagnostic lab-on-chip platforms. Gilbert's research initiatives into complete diagnostic platforms and clinical profiling of patients for tick-borne diseases will allow a better understanding of how chronic conditions could be established with tick-borne pathogen infections.

Michael Cook

Independent Researcher on Tick-borne diseases since receiving a Lyme Borrelia diagnosis in 2009. Graduated of Licentiate in Chemistry from Argentina and MS and PhD from the University of Puerto Rico with over 25 years experience in Molecular Microbiology.

Prof Michael Cook has published 4 papers in medical journals, three co-authored with Professor Puri on Imperial College. The first in 2015 on transmission of the disease, the others analysing the accuracy of commercial test kits using meta analysis and Bayesian statistics. This work demonstrated the two-tier test required by most medical authorities including recently released guidelines from NICE for diagnosis generates more than 500 times more false negative tests than testing for HIV.

Dr. Natasha Rudenko, PhD.

Deputy Head of the laboratory of Molecular Ecology of Vectors and Pathogens at the Institute of Parasitology of Biology Centre Academy of Sciences of the Czech Republic

For the last two decades her research were focused on ecology, epidemiology, and distribution of arthropod-borne diseases and vector-host-pathogen interactions. The main interests are: ecology, epidemiology, genetic diversity of the causative agent of human Lyme disease, the spirochetes from *Borrelia burgdorferi* sensu lato complex, in Europe and around the world and their impact in global public health, microbial infectivity, pathogenicity, survival behaviors, and response to antibiotic treatment or capability to transform into persisting forms that cause relapsing or chronic diseases.

Prof Christian Perronne

Professor of Infectious and Tropical Diseases at the University of Versailles-St Quentin (UVSQ), France

Christian Perronne, MD, PhD, is Professor of Infectious and Tropical Diseases at the University of Versailles-St Quentin (UVSQ), France. Since 1994, he is chief of a Department of Medicine at the Raymond Poincaré University Hospital in Garches, Greater Paris University Hospitals group.

Dr Amir Khadir

Specialist in Infectious diseases and Medical microbiology practicing in Hôpital Legardeur, Quebec, Canada

Dr Amir Khadir is a specialist in Infectious diseases and Medical microbiology practicing in Hôpital Legardeur, a community hospital in the Montreal metropolitan area. He served three terms between 2008 and 2018 as a member of the Quebec national assembly and spearheaded the introduction of a petition that brought the Committee on Health of the National Assembly to recommend the implementation a Lyme disease action plan by the Quebec health ministry. He acts as an external reviewer for the plan that is scheduled to be launched in May 2019. Dr Khadir has implemented in January 2019 the first Vector borne diseases Clinic operating within the Quebec health public system.

Dr Ying Zhang

Professor at Department of Molecular Microbiology and Immunology, Johns Hopkins Bloomberg School of Public Health.

His research interests are focused on bacterial persistence and development of more effective treatments for persistent infections including Lyme disease and associated co-infections. His group has identified a range of FDA-approved drugs and some essential oils that are highly active against Borrelia persisters and is evaluating promising drug combinations for more effective treatment of persistent Lyme disease.

Dr Lucile Cornet-Vernet

DDS Paris Descartes, MSc Paris Descartes, Trial coordinator

Founder of La Maison de l'Artemisia, a humanitarian NGO, which helps to demonstrate the medical efficacy of plants against certain infectious diseases in order to provide poor people with a local, effective and cheap medicine.

Dr Judith Miklossy

Prevention Alzheimer International Foundation, International Alzheimer's Research Centre, Switzerland

Judith Miklossy has received her MD, PhD degrees and Board certificates of specialization in Neurology, then in Psychiatry and Psychotherapy, with EU and AELE conform certificates from the National Board of specialization in Neurology and Psychiatry in Hungary. She has received the university degree of Privatdozent and Master of Education and Research (MER) (equivalent of DSc and assistant Professor) and the Board certificate of specialization in neuropathology the Swiss Medical Federation (FMH) in Switzerland. She was Head of the Neurodegeneration research group at the University Institute of Pathology (CHUV, Lausanne), Switzerland, for over ten years. She has done molecular biology research and participated in the introduction of Alzheimer's research in Temple University, Philadelphia, USA. She headed the neuropathology division of Kinsmen Laboratory of Neurological Research, in The University of British Columbia, Vancouver, Canada. She is actively involved in research on Alzheimer's disease, other neurodegenerative diseases and Lyme disease for more than 25 years. She is on the board of directors or on the scientific advisory board of several international organisations or foundations. She is founder and presently Director of the Alzheimer's Prevention International Foundation and International Alzheimer Research Centre in Switzerland.

Dr. Ricardo G. Maggi

Associate Professor and Co-Director, Intracellular Pathogens Research Laboratory, College of veterinary Medicine, North Carolina State University, USA

Graduated of Licentiate in Chemistry from Argentina and MS and PhD from the University of Puerto Rico with over 25 years experience in Molecular Microbiology. Co-Directing the Intracellular Pathogens Research Laboratory that specializes in the development of diagnostic tools (molecular, serological, and culture) and the characterization of vector-borne zoonotic pathogens. Founder and CTO of Galaxy Diagnostics, a CLIA accredited diagnostic Company in the USA focusing on the diagnosis of vector-borne diseases (Rickettsiosis, Mycoplasmosis, Borreliosis, Bartonellosis, Ehrlichiosis, and Anaplasmosis).

Jenna Luché-Thayer

Jenna Luché-Thayer, MIA. Jenna is a uniquely qualified expert on the vital issues of transparency and accountability, human rights and the political representation of marginalized groups. She has over 30 years of policy and grassroots experience in 42 countries representing all regions throughout the world and over 75 publications. She was the first woman to hold critical Senior advisory posts in both United Nations and US Government, has dedicated years combatting gender-based violence, trafficking and gender-based inequities. Jenna established the Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes, an international, professional and all voluntary group that successful added many codes to signify Lyme borreliosis complications to the globally utilized ICD11. Awards include: International Woman's Day Award for Exemplary Dedication and Contributions to Improving the Political and Legal Status of Women, Highest Ranking Technical Area in Accomplishment, Innovation and Comparative Advantage for United Nations Capital Development Fund, the International Lyme and Associated Diseases Society Power of Lyme Award 2018. She is the Founder of the Global Network on Institutional Discrimination, a non profit that helps institutions remedy entrenched practices of discrimination and cruelty towards vulnerable groups.

Fred Verdult

Chairman of the Dutch Lyme Patients Association

In December 2018, Fred Verdult received the royal decoration as Knight for his 20 years of commitment to people living with HIV, and in particular for bringing the patient perspective into research on HIV cure. Since 2018 he is chairman of the Dutch Lyme Patients Association, as well as founding father of the Dutch Lyme Fund (Lymefonds) in formation. 'Partly due to the efforts of activists, I now only take one HIV pill per day, and I have never been ill because of HIV at all. The contrast with Lyme couldn't be greater: my struggle to obtain a diagnosis, the disabling symptoms and my 37 daily pills, powders and drinks.'

Prof Niels Høiby

Professor of Medical Microbiology, University of Copenhage, Department of Clinical Microbiology, Rigshospitalet, and Costerton Biofilm Center, Institute of Immunology and Microbiology, Copenhagen, Denmark

Prof Niels Høiby graduated from the University of Copenhagen Medical School in 1968 and completed his training as specialist in clinical microbiology in 1979. In 1980 he became Chairman of the Department of Clinical Microbiology at Rigshospitalet and in 1988 also a professor of medical microbiology.

Prof. Høiby was the first president of the European Cystic Fibrosis Society and is the Founder and Chairman of multiple societies, including the Scandinavian Society for Antimicrobial Chemotherapy, the ESCMID Study Group for Biofilms and the Biofilm Study Group of the Danish Society for Clinical Microbiology. He has published extensively in the area of chronic lung infection in CF and other biofilm infections. Prof. Høiby has won multiple awards and honours throughout his career. He is also member of the Regional Council of The Capital Region of Denmark (Liberal Alliance Party)"

Dr Jinyu Shan

Research Fellow, Department of Genetics and Genome Biology, University of Leicester, Leicester, UK

Jinyu Shan earned his PhD in molecular microbiology at University of Warwick, UK. He has been working with pre-clinical development of bacteriophages (viruses infecting bacteria) targeting pathogenic bacteria for over ten years. Since 2015, Jinyu has been driving a project on exploiting phages as diagnostic markers and therapeutic agents for detecting and treating Lyme disease and co-infections.