

AONM Newsletter October 2018



Finding Solutions for PANS/PANDAS

October 9th was PANDAS/PANS Awareness Day around the world, and the landscape in the UK has certainly developed in leaps and bounds over the last year. We recently reported on the AONM conference held this last May with Moleculera, the unique PANS/PANDAS testing laboratory in the USA, and other specialists on infection-induced autoimmune disorders. This newsletter details the PANS/PANDAS UK conference held at Imperial just a month ago, featuring the work of the UK's newly established Children's e-Hospital, dedicated specifically to children with these conditions. We also cover the astounding line-up scheduled for AONM's November Annual Conference, on neuropsychiatric and pathogen-triggered disorders. An article on Cossackie gives insight into how this pernicious virus might underlie many cases of ME. We conclude with a roundup of the exciting events ahead in the last quarter of this year.

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1. PANS PANDAS UK 2018 Conference

PANS/PANDAS UK held a highly informative and inspiring conference at Imperial College, London, on Sept. 22nd, with specialists from the UK as well as the USA.



PANS PANDAS UK
awareness support education

The conference was introduced by Georgia Tuckey, founder of PANS/PANDAS UK, and Dr. Tim Ubhi, Director of the Children's e-Hospital, dedicated to supporting PANS/PANDAS children from all over the UK.

The first speaker, Tim Bouman, gave a moving patient perspective, explaining the many misdiagnoses and difficulties he had experienced on his path to correct identification of his condition and targeted therapy.

The second speaker was Dr. Susan Swedo, Chief of the Paediatrics and Developmental Neuroscience Branch at the US National Institute of Mental Health since 1988. She was the first to propose a link between Group A Streptococcal infection and rapid-

onset cases of OCD, tic disorders such as Tourette syndrome, etc., that came to be known as Paediatric Autoimmune Neuropsychological Disorders Associated with Streptococcal infections. She explained their link to basal ganglia encephalomyelitis. Her topic was “Formulation of a diagnosis: A clear outline of diagnostic process with differentials, investigations and clinical diagnosis”. She gave detailed insight into the new US diagnostic and treatment guidelines

(<https://www.pandasnetwork.org/new-era-in-pandas-pans-recognition/>) published in the *Journal of Child and Adolescent Psychopharmacology (JCAP)*, July 20, 2017, that she helped to author, alongside a wealth of further information.



Professor Jennifer Frankovich, the next speaker, is Associate Professor of Paediatric Rheumatology at Stanford Children's Hospital. Her talk entitled “PANS – A Rheumatologist's Perspective” gave an overview of PANS symptoms, concurrent/co-morbid conditions, immune markers, collaborations, and preliminary treatment results. She discussed the various brain conditions that can present with psychiatric symptoms: primary and secondary CNS vasculitis, autoimmune encephalitis and diffuse cerebritis, and basal ganglia encephalitis both with and without vasculitis. It is within the latter grouping that she categorises PANS/PANDAS. She notes a high degree of concurrent disease in these patients – including autoimmune thyroiditis, antiphospholipid syndrome, and eosinophilic esophagitis – and that 48% suffer from what she termed pain amplification syndrome.

Dr. Ming Lim discussed “PANS: Clinical, radiological and investigative comparisons to autoimmune encephalitis” – interesting, as many argue that this is precisely what PANS/PANDAS should in fact be called (such as the neurologist Dr. Elena Frid, who spoke at AONM's May conference on PANS/PANDAS, see <https://aonm.org/pans-pandas-conference-may-2018/>). He highlighted neuroinflammation and imaging abnormalities in conditions that others would call primary neuropsychiatric syndromes.

Dr. Tim Ubhi, Director of the Children's e-Hospital, described his work at the new clinic specially for PANS/PANDAS patients

(<http://www.e-hospital.co.uk/>). He explained the integrated approach that is being taken, with referrals made to nutritional therapists and other modalities as required. It is a huge achievement that a unit of this kind is now available in the UK, and their international cooperation, tapping expertise from the States in particular, was clearly apparent from this conference. He referred to the UK Physicians Network Guidelines, which are available to physicians from PANS/PANDAS UK (please scroll down to “Treatment of PANDAS” – the password needs to be applied for: <http://www.e-hospital.co.uk/resource/pandas/>).

Amy Smith, Nurse Practitioner at the Open Medicine Institute, California, gave a fascinating clinician's perspective entitled “PANS and PANDAS: What I have learned and seen in practice”. She broke down the symptoms and pathology found in 333 of her patients from August 2016 - 2018. 260 of them suffered from OCD, and 128 from tics. 113 were Lyme positive, and another 54 were Lyme borderline. 96 had Mycoplasma, 67 Babesia, 76 Bartonella, 53 Epstein Barr, 34 HHV-6, and 33 Chlamydia pneumoniae. She detailed the therapies she has found to be most useful, covering antibiotics/probiotics, antivirals, antifungals, NSAIDs, steroids, EFAs, LDN, immune modulation (including IVIG), as well as extensive nutritional and supplement interventions.

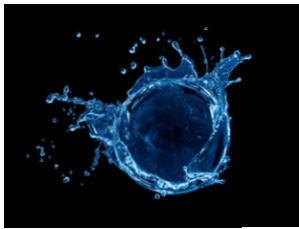


The day was filmed, and the recording will hopefully be available soon from PANS/PANDAS UK (<https://www.panspandasuk.org/>).

A special request: please sign this petition to have the NHS recognise the condition:

https://www.change.org/p/nhs-england-approve-pandas-pans-as-recognised-childhood-conditions-in-the-nhs?recruiter=522780584&utm_source=share_petition&utm_medium=copylink&utm_campaign=share_petition&utm_term=share_for_starters_page

2. Upcoming AONM Conference: Bursting the Bubble: Challenging the Misconceptions and Misdiagnoses of Neuropsychiatric and Pathogen-Triggered Disorders



The diverse mechanisms used by stealth and persistent pathogens to induce neurological and psychiatric changes are often overlooked.

Ensuing misdiagnoses can result in costly, delayed, or inappropriate treatment, leading to serious harm to patients. AONM's November 18th event features some of the most inspirational and eminent scientists in this field. The bios and synopses below profile these outstanding speakers.



DR. JUDY MIKOVITS will be chairing the conference. Dr. Mikovits earned her PhD in Biochemistry and Molecular Biology from George Washington University. After more than 20 years

researching anti-viral drug mechanisms at the National Cancer Institute, she became Research Director of the Whittemore-Peterson Institute (WPI) for Neuroimmune Disease in Nevada. In only five years she developed the first neuroimmune institute from a concept to a reality. She has published over 50 scientific papers. Dr. Mikovits continues to work on neuroimmune disease and cancer at MAR Consulting, alongside the renowned microbiologist widely regarded as the father of human retrovirology, Dr. Francis W. Ruscetti.



JENNA LUCHÉ-THAYER, Founder and Director of the Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes, and Former Senior Advisor to the United Nations, will be the keynote speaker.

Ms. Luché-Thayer has 32 years of policy and grassroots experience in 42 countries. She is a former Senior Advisor to the US Government and the United Nations and is currently assisting institutions and communities to build a humane and rights-based, patient-centered response to the global Borreliosis pandemic.



ROBERT C. BRANSFIELD, MD, Associate Director of Psychiatry at Riverview Medical Center, USA, is a highly renowned psychiatrist who is at the forefront of treating patients with

neuropsychiatric symptoms of tick-borne illness. To quote from his speech to the New York State Senate hearing on Lyme disease last year, "As a psychiatrist who has treated thousands of Lyme patients over the past 30 years, including many from New York, it is clear that inadequately diagnosed and treated Lyme disease commonly results in neuropsychiatric symptoms causing suffering, disability and death in children and young people for decades." The topic of Dr. Bransfield's talk is "Psychosomatic, Somatopsychic & Multisystem Illness".



DR. MADELEINE W. CUNNINGHAM is a Research Professor and Microbiology and Immunology Director for the Immunology Training Program at the University of Oklahoma. She is also the

co-founder and Chief Scientific Officer at Moleculera Labs, USA. Her laboratory identifies the level of autoimmune antibodies associated with neuropsychiatric disorders and the capability they have to stimulate and trigger neurological behaviour, particularly specialising in PANS and PANDAS. She has done extensive research into the topic, and written many scientific papers. The title of her presentation is "Unlocking Neuropsychiatric Disease in Children: PANDAS and PANS."



DR. JODIE A. DASHORE, is a pioneering clinician in the all-natural, plant-based, biological treatment of autism, Lyme disease, mould/biotoxin illness, and autoimmune illness, especially PANS/PANDAS.

Dr. Dashore will talk about the neurological structural and volumetric changes seen in brain structures with exposure to biological toxins and mould, and the complex interplay between the upregulated innate immune cascade and the adaptive immune system. She will also cover the therapeutic approaches she uses. The title of her presentation is "Biotoxin Illness: Neuropsychiatric Impact, Brain Imaging, and Integrative approach to Treatment."



DR. JOSEPH G. JEMSEK is a board-certified physician in infectious disease and internal medicine. In 2000, he founded a specialty infectious disease practice with the goal of serving patients with HIV/AIDS, in addition to general infectious disease. He increasingly specialised in Lyme Borreliosis Complex, which is where his main focus is now. Dr. Jemsek sees patients from all around the world, and develops specialised treatment plans to meet each patient's unique symptoms. The title of his presentation is "Weight Change and Associated Metabolic Effects in Lyme Borreliosis Complex."



DR. SARAH MYHILL, pioneering GP and author of *The Infection Game: Life is an Arms Race* (2018), qualified in medicine (with Honours) in 1981 and has since worked in NHS and private practice. She was the Honorary Secretary of the BSEM (British Society for Ecological Medicine) for 17 years, which focuses on the causes of disease and treating through diet, supplements and avoiding toxic stress. She is particularly renowned for her work on the mitochondria together with Professor Norman Booth and Dr. John McLaren Howard. The title of her presentation is "The Somatisation of ME Patients in the UK: How Many are Actually Suffering from Infections?"



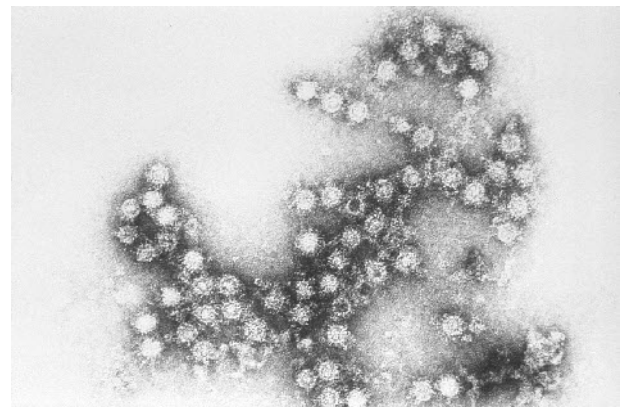
DR. ARMIN SCHWARZBACH is founder and Medical Director of Arminlabs, Germany. Dr. Schwarzbach is a Medical Doctor and specialist in laboratory medicine with three decades of experience in clinical medicine and laboratory testing. He has conducted over 50,000 tests for tick-borne disease, and has been on the board of ILADS. and serves as an expert on advisory committees on Lyme Disease in Australia, Ireland, France and Germany. Dr. Schwarzbach will describe tailored tests for pathogens in neuropsychiatric conditions.

See "Upcoming events" for details on how to register for this event.

3. Cocksackie – Doing damage to our very core: the energy delivery mechanisms of our heart?

By Gilian Crowther, NTND, mBANT, mANP, mNNA, CNHC reg., AONM Director of Research

Cocksackie (named after where it was first identified, in Cocksackie, New York) is an enterovirus that belongs to the family of Picornaviruses. These are small positive-strand RNA viruses without a lipid membrane. It falls under the same genera as polio, echovirus and other enteroviruses. Its transmission is oro-faecal, and its site of primary infection is the gut.



(Source: https://en.wikipedia.org/wiki/Cocksackie_B_virus#/media/File:Cocksackie_B4_virus.JPG)

Cocksackie A virus is usually associated with fever, surface rashes, and can cause herpangia, as well as hand, foot and mouth disease⁽¹⁾. Type B typically causes internal symptoms: it can trigger illness ranging from gastrointestinal distress to full-fledged pericarditis and myocarditis (Cocksackievirus-induced cardiomyopathy)⁽²⁾. Subtypes of both A and B can cause very severe symptoms, as can be seen from the table below, such as meningitis and even paralysis.

	Poliovirus	Cocksackie A virus	Cocksackie B virus	Echovirus	Enterovirus (other)
Asymptomatic infection	yes	yes	yes	yes	yes
Meningitis	yes	yes	yes	yes	yes
Paralysis	yes	yes	yes	yes	?*
Febrile exanthems	no	yes	yes	yes	yes
Acute respiratory disease	no	yes	yes	yes	yes
Myocarditis	no	yes	yes	yes	no
Orchitis	no	no	yes	yes	no

* Enterovirus-D68 (EV-D68) can replicate in blood and may damage the central nervous system. It has been detected in cerebrospinal fluid of patients with acute flaccid paralysis.

There have been reports of children hospitalized with muscle weakness or paralysis, usually in their arms and legs. They were tested for poliovirus, West Nile virus, and enteroviruses. About half of the children had EV-D68 in their nose secretions; usually, EV-D68 affects the respiratory system and it is not yet known if this respiratory infection is linked to their muscle weakness.

Source: <http://www.microbiologybook.org/virol/picorna.htm>

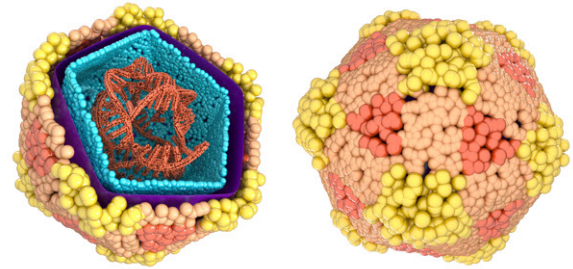
Cocksackie B virus is very common in the UK, in the experience of Dr. Armin Schwarzbach of Arminlabs, who says "The level of infection in the UK that we

are picking up in our testing exceeds that of any other country, by percentage of positive titres in those tested – especially IgA, suggesting current infection of the mucosal membranes. It is unclear why that is – we urgently need studies.” *

Coxsackie virus B can trigger an autoimmune attack on translocator protein, also called the adenine nucleotide translocator (ANT), in the heart(3). This appears to be because its VP (viral protein) capsid protein is cross-reactive to mitochondrial translocator protein(4). The ANT is the only transport system for ADP and ATP – it is the most important link of the body’s energy producing and consuming processes. Autoantibodies against the adenine nucleotide transporter were found in the sera of patients suffering from myocarditis and dilated cardiomyopathy that were capable of inhibiting nucleotide exchange activity(5). The mRNA pattern was found to be equivalent to the ANT isoform protein distribution in mitochondria(6). The importance of the virus in this process was shown by the fact that virus-positive patients had an approx. four times higher risk of isoform pattern alteration than those without enterovirus infection(7). This is a huge discovery, as mitochondria – the energy powerhouses in our cells – are rich in these translocator proteins (ANT). Cross-reactivity between the ANT protein and the calcium channel was also observed(8). ANT antibodies bind specifically at the calcium channel of the cell surface and change calcium influx into the cell(9). Raised intracellular calcium concentration causes intramitochondrial calcium overload and lowers mitochondrial transmembrane potential(10). This appears to be a frequent finding, too, in Acumen tests of patients with ME-type symptoms, and recent research from Australia is also finding calcium channelopathies in the NK cells of ME/CFS patients(11). Could it be that they are suffering from blocked/lowered mitochondrial membrane potential – at least in some cases – due to Coxsackie B?

The group of doctors and scientists around Professor Malcolm Hooper (The John Richardson Research Group, including Dr. Irving Spurr, sadly just recently deceased) have long contended that Coxsackie B underlies many cases of so-called ME/CFS. The ME/CFS researcher Professor Peter Behan suggested that the ANT autoantibody might be the cause of many symptoms of the condition as far back as the 80’s. One guinea pig study found that the measured energy output from hearts impacted by the ANT autoantibody was five times less than the energy output from healthy controls, and the hearts

of the former animals produced more than twice the amount of lactate(12). The 2009 energy metabolism studies of Dr. Sarah Myhill, Professor Norman Booth (†) and Dr. John McLaren-Howard also found that ME/CFS patients have major disruption of their ANT protein – in both transport of ATP from the mitochondria into the cytosol and ADP from the cytosol into the mitochondria(13). Blocking of the translocator proteins is often found in Acumen tests by heavy metals, pesticides and other contaminants: that they have been disabled by the Coxsackie B virus certainly also appears another possibility in light of these studies.



Coxsackie virus

A 2010 mouse study found that in Coxsackie B myocarditis, a reduction in IL-17 reduced ANT autoantibodies(14). Th17 cells produce IL-17, and have been associated with the promotion of viral replication. N-acetyl-glucosamine has been shown to reduce Th17 and IL-17, as can several other agents. Interestingly, the article that found this is entitled “N-acetylglucosamine inhibits T-helper 1 (Th1)/T-helper 17 (Th17) cell responses and treats experimental autoimmune encephalomyelitis”.

This would appear to bring us round full circle to the PANS/PANDAS pathology that many specialists have said should really be renamed autoimmune encephalitis. Perhaps the underlying drivers of these merciless diseases are not so different after all.

***Dr. Schwarzbach suggests also testing for Echo-virus where there is a suspicion of Coxsackie virus, as this is also frequently found. See the next newsletter for an item on the Echovirus (enteric cytopathic human orphan virus).**

NB Three of the specialists mentioned in this article, Dr. Armin Schwarzbach, Dr. Sarah Myhill and Professor Malcolm Hooper, will all be speaking at AONM’s Annual Conference on Nov. 18th this year (Dr. Myhill and Dr. Schwarzbach will be giving presentations, Professor Hooper will be on the plenum for Q & A)..

(References mentioned in this article are available from AONM, please contact info@aonm.org)

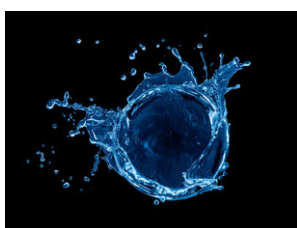
4. Upcoming events



ANNUAL INTERNATIONAL CONFERENCE

NOV 18th 2018 9.00 am - 6.00 pm

Bursting the bubble: Challenging the misconceptions and misdiagnoses of neuro-psychiatric and pathogen-triggered disorders



Chair: Dr. Judy Mikovits

Keynote: Jenna Luche-Thayer

Dr. Robert C. Bransfield

Dr. Madeline W. Cunningham

Dr. Jodie A. Dashore

Dr. Joseph G. Jemsek

Dr. Sarah Myhill

Dr. Armin Schwarzbach

Holiday Inn London Regent's Park

Carburton Street, London W1W 5EE

<https://bursting-the-bubble.eventbrite.co.uk>



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BSEM Spotlight on treating allergies

Friday, 2nd November 2018

Hallam Conference Centre

<https://www.tickettailor.com/events/bsemevents/195090/r/web>

BSEM Conference 2018

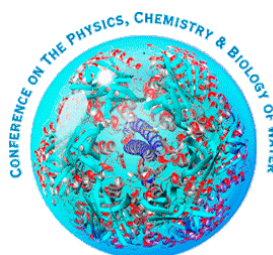
Friday, 16th November 8.30 - 17.15

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<http://www.melisa.org/register/>



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