

POSTER PRESENTATIONS

Pharmacologic and non-pharmacologic treatment advances Virology/microbiology Research

WORKSHOPS

These topics are generally of interest to medical professionals; please address any queries, in the first instance to Info@anzmes.org.nz.

A large number of posters were presented with a wide range of topics from around the world. I was not able to view them all, but those I did manage to see are described:

Pharmacologic and non-pharmacologic treatment advances

Effectiveness of oral NADH in the treatment of CFS - Jose Allegre (Barcelona Spain) concluded that oral NADH does not seem to modify clinical variables, but some benefits were seen in anxiety levels, but depression increased. In effort tests there was some significant reduction of maximum FC.

Partner relationship influence on functional capacity in CFS women – A.Blazquez (Barcelona,Spain) – Neurocognitive dysfunction correlated positively with the relationship and significantly influenced ventilation and supramaximal exercise.

Role of erythrocyte aggregation and deformability in CFS – Ekua Brenu (Gold Coast<Australia) – found that there were no abnormal changes in the rheological characteristics of erythrocytes in CFS. Deformability and aggregation are not therefore likely to be markers for CFS.

Post-Cancer Fatigue (PCF) is not associated with altered cytokine production – Barbara Cameron (Sydney,Australia) – findings argue strongly against the notion that PCF is mediated by peripheral inflammation.

Pacing as a dynamic embedded, embodied treatment/prevention strategy in CFS – Bruce Carruthers (Vancouver,Canada) – Pacing is a strategy that patients learn gradually to adjust their activity/rest sequences and treat their fatigue in a preventative way.

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Oxygen toxicity as a locus of control for CFS – Paul Cheney (Ashville, USA) – Concluded that CFS is an oxygen toxic state. This is less a cause of CFS but a final common pathway downstream from etiologies, but which may determine outcome.

Cell associated therapy for CFS – Paul Cheney (Ashville,USA) – has found that therapy with low molecular weight peptides from cell-associated mammalian tissue homogenates (porcine) appear to offer significant benefit in CFS. Use of several tissue extracts appears to be more successful than only one.

Oxymatrine for the treatment of CFS associated with chronic enterovirus infection – J.Chia (Lomita,USA) – This treatment showed significant benefit, with a shift in immune response in the Th1

direction, which correlated with symptomatic response. Oxymatrine maybe an effective immune modulator in CFS before definitive antiviral therapy becomes available.

Serving Students with CFS and other chronic illnesses – Patricia Fennell (New York, USA) – described a workshop for educators to discuss the needs of those with chronic illnesses. As a result educational services can be improved for students using the Fennell Four Phase Model.

US Government strategy and funding of CFS research compared to similar illnesses – Kenneth Friedman (Newark, USA) – Of the US Government research effort into neuro-endocrine-immune disorders (NEIDs), Lyme disease has shown the most progress. Despite the government spending more on GWI there is still no diagnostic test or specific medication. New research strategies and funding mechanisms are needed for illnesses such as CFS.

Amygdala retraining techniques may improve outcomes for patients with CFS – Ashok Gupta (London,UK) – had done a clinical audit of subjective outcomes. This revealed higher rates of improvement in comparison to remission rates in other intervention studies. No control or placebo group was used and future studies will incorporate this.

Treatment of *Cryptosporidium parvum*, a new parasite found in CFS – Lawrence Klapow (Santa Rosa,USA) – This is a chronic roundworm parasite found in a number of patients studied. It reproduces in the lungs and GI tract. It appears to trigger CFS symptoms during its reproductive stage. Symptoms were relieved with Ivermectin, weekly inhalations with nebulised ethanol and treatment of the GI tract with anthelmintics.

Predictors of fatigue in patients with MS – Anners Lerdal (Drammen,Norway) – The main predictors of fatigue were fatigue scores and fatigue caseness at baseline. Poor general health and perceived cognitive impairment also predicted higher levels of fatigue.

Is there an association between exposure to chemicals and CFS? – Luis Nacul (London,UK) – existing evidence remains inconclusive as to the association between exposure to chemicals and CFS, and there is need for well designed epidemiological studies.

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Similarities of CFS and autism spectrum disorders: comparison of blood co-infections – Garth Nicolson (Huntingdon Beach,USA) – Chronic infections are similar in both those with CFS and a large subset of patients with neurobehavioural disease. The 3 infections seen were mycoplasma species, Chlamydia pneumoniae and HHV6.

Effects of a dietary weight supplement on fatigue, appetite suppression and weight-loss: implications in CFS – Garth Nicholson (Huntingdon Beach,USA) – The product used was an amylase inhibitor plus NT factor (HealthyCurb). Notable appetite suppression occurred coupled with significant weight loss. The group showed an overall decrease in fatigue, with improvement in lipid profiles and cardiovascular health. There were no adverse effects clinically or biochemically. This seems a safe option for those with CFS wanting to lose weight.

Improved renal function in CFS patients with IV immunoglobulin treatment – Tae Park (Seoul,Korea) – Improved renal blood flow as a result of this trial may be evidence of corresponding cerebral blood flow, as patients on treatment experienced improved cognition. A further poster looked at the risk of CFS patients developing chronic kidney disease. The risks showed decreased glomerular filtration rate in many CFS patients, and recommendations are that kidney function should be checked regularly in CFS. Cognitive function was further investigated in another poster with positive outcome in those treated with IV immunoglobulin.

Lymphatic drainage of the neuroaxis and the central rhythm impulse – Ray Perrin (Preston,UK) – hypothesized a model for pathological links to CFS. Cranial rhythm impulse may be the rhythm produced by a combination of cerebrospinal drainage of the neuroaxis and sympathetic induced pulsations of the central lymphatic drainage. Osteopathic manual treatment can reduce the severity of CFS.

Muscle fatigue in CFS and its response to a novel manual therapeutic response – Ray Perrin (Preston,UK) found that post-exercise muscle function in CFS is improved following specialized osteopathic intervention. Fatigue in this disorder is considered not due to myopathic changes, but a consequence of other extrinsic causes, such as a reduction in lymphatic drainage.

VDR receptor competence induces recovery from CFS – Amy Proal (New York,USA) – has a working model of CFS in which a microbiota of chronic pathogens accumulate a metagenome that is able to dysregulate the innate immune response, and cause the systemic inflammation characteristic of the disease. The process has been reversed using a VDR agonist (olmesartan medoxomil) and sub-inhibitory antibiotics.

A parent advocacy guide advising how to obtain educational services for children with neuroimmune disease – Laura Baker (Santa Barbara,USA) and Karla Rogers (Nevada City,USA) produced a comprehensive resource guide to assist parents meet their child's educational needs.

Utilization of CFS continuing medical education courses – Hao Tian (Atlanta,USA) – this course was described and confirmed as an important online source for continuing medical education. There is a well utilized Primary Care course and one for allied health professionals. In a 5 month period, 283 participants received CME certificates.

The self-regulatory model in women with CFS and MS: illness representations, coping strategies and outcome - Elke van Hoof (Brussels,Belgium) – Patients were shown to determine the degree of dysfunction and illness related behaviours in relation to their subjective experience of the disease. Findings in the study will help determine what strategies may be effective in improving function.

Treatment study of methylation cycle support – Richard van Konynenburg (Springfield, USA) – Treatment designed to support the methylation cycle appears very promising and seems worthy of a more controlled study. Results are consistent with the glutathione depletion-methylation cycle block hypothesis for CFS. Treatment included hydroxocobalamin, 5-methyltetrahydrofolate and folic acid, with nutritional support.

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Virology/microbiology Research

Post-infectious fatigue syndrome following giardia infection – an ongoing multidisciplinary five-year follow-headed by Prof Harald Nyland – presented by Eva Stormorken – (Vaaler, Norway) – Findings support the existence of PIFS following giardiasis. Interventions consisted of medical care, clinical assessment and an educational course. Currently a work-related rehabilitation programme is taking place. Prospective studies are required to determine functional outcome.

6 years experience in a specialized unit in the diagnosis of CFS – José Alegre (Barcelona,Spain) – The SFC is the main tool for diagnosis in this specialized unit. A variety of diagnoses of fatigue are described. Analytical, imaging and psychiatric assessment did not provide diagnostic tools adequately.

Family response when a parent has CFS – Julie Donalek (Chicago,USA) – A wide range of effects on the family are presented such as “a changed life”, “a shrinking exterior world”, reorganizing family management”, “struggle for normalcy” etc These issues need to be addressed for the family as well as the patient.

Socio-demographic variables, depression, sleep quality and functioning, and the relationship to fatigue in the acute phase of a stroke - Anners Lerdal (Oslo,Norway) – Symptoms of depression and poor general health are related to the experience of fatigue in these patients, suggesting the need for further research into the complex nature of fatigue.

Prevention of CFS – Phillipe Tournesac (Dijon,France) – A questionnaire has been developed to identify patients described as “hypersensitive” and more likely to develop illnesses such as CFS and FM. This could provide a means of identification and preventing the evolution of toward CFS and related syndromes. Many simple preventative approaches can be included such as sleep, nutrition and exercise.

Could CFS be caused by allergen-induced immune activation in individuals who respond with excessive and prolonged cytokine production due to variant genes, and who have enhanced susceptibility to cytokines. – Gina Watkins (Sydney,Australia). A literature search was presented together with further study from the Dubbo infection outcomes. This confirmed that further research is needed looking at the immune response and cognitive function following allergen exposure.

Remodeling of lymphocyte-cytokine networks in GWI under challenge – Gordon Broderick (Edmonton,Canada) – Characteristic immune responses occur spontaneously in these patients after exercise challenge, and resolve once the challenge is removed. Results suggest a potential shift in the regulation of body fat and energy metabolism in GWI and a bias toward Th2 mediated humoral immune response.

A comprehensive analysis of serum cytokines in PIFS: a masked case control study – Barbara Cameron (Sydney,Australia) – The data did not support the hypothesis of ongoing cytokine activity in the circulation in the pathogenesis of CFS or PIFS.

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Comparison of immunoperoxidase staining of stomach biopsy, neutralizing enterovirus antibody and whole blood viral RNA testing, for the diagnosis of chronic enterovirus infection in patients with CFS – John Chia (Lomita,USA) – EV VP1 staining of stomach biopsy is more sensitive than either commercially available neutralizing antibody test or qualitative enteroviral RNA determination of the blood, for the diagnosis of chronic enteroviral infection. Elevated EV antibody titre can confirm the particular serotype involved.

Decreased perforin and granzyme protein expression of cytotoxic T cells and NK cells from CFS patients – Deborah Goetz (Reno,Nevada) – this study corroborated the Klimas et al study. NK cells showed altered expression of PRF1 and GZMB not due to increase in CD56 subset. T cell abnormalities suggest prior antigen exposure and possible impaired memory function.

A re-analysis of the Dubbo Infections Outcomes Study post infective fatigue cytokine dataset. – Brian Gurbaxani (Sydney,Australia) – Cultured cytokine values do appear to oscillate over time. The oscillations may help distinguish PIFS cases from controls within each infective group, and appear to be different for each of the 3 infections studied. (EBV,Ross River Virus and Q fever)

Ion channel function and CFS – Susan Hagan (Glasgow,UK) – Identification of changes in gene expression of a number of ATPase enzymes and ion channels using DNA microarray indicates a potential role for ion channels and ATPase function in the pathology of CFS. This may help formulate a rational hypothesis for the pathogenesis of CFS.

The RNaseL antiviral pathway and its role in chronic inflammation and CFS – Vincent Lombardi (Reno,USA) – Results confirm that proteosomal degradation of RNaseL is triggered by PMA in human cell lines, and this inflammatory response can be prevented by anti-inflammatory agents that block NF- κ B.

TGFβ-1 in the treatment of autoimmunity in CFS associated with HLA DR by PCR – Ritchie Shoemaker (Pocomoke,USA) – The ability of losartan (up to 50mg daily), an angiotensin receptor blocker, labeled for treatment of hypertension, to lower TGFβ may affect TH17 cells that in turn affect T regulatory cells. Losartan may have a role in the innate immune abnormalities in CFS.

Assessment issues from Biological to Behavioural

Measuring fatigue pre and post exercise using SF-36, MFI-20 health and wellbeing surveys – Katie Baroni (Stockton,USA) – the SF-36 and MFI-20 clearly differentiate between CFS and controls. The SF-36 did not detect significant pre to post test changes in the CFS group.

Functional impairment in an environmental clinic sample – Alison Bested (Toronto,Canada) – a wide representation of the profiles of 128 CFS patients diagnosed with CFS,FM and MCS. Results were consistent with findings in other countries and patients' reported difficulties working and caring for homes and families. Early comprehensive assessment and medical management, social support, and assisted non-discriminatory access to consistent financial means could avoid deterioration associated with prolonged illness.

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Diagnosis of CFS – Bruce Carruthers (Vancouver,Canada) – describes clinical experience with comments regarding the influence of different attitudes on the process of diagnosis of CFS and other syndromes. 3 issues are covered: nominalist attitude, complementary attitude and causal influences felt directly in everyday life. He comments that we do need to pay more attention to the earlier phases of diagnosis not just the end point.

Unusual dietary intake among CFS patients – Alexandra Caspero (Stockton,USA) – a diet history questionnaire (NIH) was used. Dietary interventions maybe efficacious as adjunct therapy.

The emergence of fatigue science – Fred `Friedberg (New York,USA) – A study of literature on pain and fatigue were reviewed. The study provides encouraging signs of increased scientific attention to fatigue. The future direction of fatigue research is uncertain as there is no clearly delineated domain of fatigue with respect to both peer review journals and federal funding.

Replication of an empirical approach to delineate heterogeneity of CFS – Brian Gurbaxani (Sydney,Australia) – Data support the contention that chronic medically unexplained fatigue is heterogenous and can be delineated into discrete endophenotypes, and this should be pursued further. This could help understand etiology and provide more patient focused treatments.

Frequency and content analysis of CFS in medical textbooks – Leonard Jason (Chicago,USA) – Findings suggest that CFS is underreported in medical textbooks. There is a need for CFS to be more represented in text books, with more comprehensive coverage provided to include etiology, prevalence, criteria and treatment options.

A closer examination of cardio-pulmonary test-retest effects in CFS – Kylie Kumasak (Stockton,USA) – Reductions in VO2 max were similar to previous studies, The reductions seen in VO2 max on test-retest were not due to differences in maximal effort. Future test should include prescreening criteria of post exertional malaise to increase the likelihood of observing metabolic abnormalities in CFS.

Prevalence and risk factors for CFS in women in S Brazil – Luis Nacul (London,UK) – CFS and probable CFS are not uncommon in the study. Different factors were identified in these 2 groups, and the importance of using specific diagnostic criteria and subgrouping of cases in research and clinical practice was emphasized.

Trends in knowledge about CFS by Brazilian doctors – Luis Nacul (London,UK) – the ability of doctors in Brazil to diagnose this illness remains poor, but there is a trend towards a move from psychological to medical interpretations of a typical patient with CFS. Education of health professionals and the population about CFS is thus warranted.

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Trends and predictive value of CFS diagnosis labels given by GPs in England – Luis Nacul (London,UK) – Diagnostic labels vary in time and across GP practices. This needs to be taken into account when estimating prevalence of CFS in primary care.

A survey of the health needs and experiences of people with CFS in a NHS specialist service in England – Sue Pemberton (Leeds,UK) – These patients have varied needs, necessitating the importance of a multidisciplinary team. The interpersonal skills and engagement with the patient are as important as the intervention itself. A model is being developed to guide professionals dealing with this illness.

An audit of the clinical outcomes of a multi-disciplinary service for CFS – Sue Pemberton (Leeds,UK) – Minimum data set was used in this audit done at one year from entry into the service. There was a positive overall effect, particularly in symptom related outcomes. Functional outcomes did not show significant change, but this may be due to patients being asked to balance out activity levels initially.

WORKSHOPS

Before the formal conference 4 workshops were available and well attended:

WORKSHOP 1

Treating pain, sleep and fatigue – Charles Lapp and Lucinda Bateman

This presentation was divided into the 3 parts and gave an excellent overview of the 3 topics and included case studies. Much discussion was generated.

PAIN

Treatment of pain was addressed non-pharmacologically and pharmacologically.

Non pharmacological approaches included:

Pacing

CBT

Counselling, hypnotherapy, biofeedback

Restoration of sleep

Gentle physical conditioning (stretching, strength, aerobic)

Massage therapy, physical therapy etc.

Pharmacological tools included:

Anticonvulsants: Pregabalin, gabapentin, topiramate, zonisamide

Serotonin norepinephrine reuptake inhibitors: Duloxetine, milnacipran, venlafaxine

Dopamine agonists under study: pramipexole, ropinirole,

Hypnotics under study: sodium oxybate

Opioids: (a last option) – less effective for chronic than acute pain, severe side effects, withdrawal problems. Tramadol, methadone, hydrocodone, oxycodone, morphine, fentanyl,suboxone

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SLEEP

No specific sleep disorder is characteristic of defining CFS/ME/FM, but sleep disorders are highly prevalent. Management of sleep seems to be the key to improvement.

Characteristic sleep patterns:

Non-restorative sleep

Difficulty in initiating and maintaining sleep

RLS/PLMS

Nocturnal myoclonus

Vivid dreams/nightmares

“Tired but wired”

Phase shifting

Dysania

Undiagnosed sleep disorders should be considered. Upper airways resistance disorder (UARS), when patients do not meet criteria for obstructive sleep disorder is common in CFS. This is accompanied by erratic breathing, drop of oxygenation, frequent arousals and daytime fatigue plus other symptoms. Treatment may relieve some symptoms.

Treatment of sleep disorders associated with CFS

Rule out sleep disorders

Sleep hygiene

CBT

Medication:

Reduction of pain (as above)

Dopamine agonists: ropirinole, pramipexole (RLS,PLMS)

Simple measures: antihistamines, melatonin (watch for rage reactions at high dose)

Non-benzodiaepines: zolpidem, eszopiclone, zaleplon, ramelteon

Clonazepam: (myoclonus, restlessness)

Tizanidine: may enhance sleep and reduce self talk

Tricyclics: amitriptyline, cyclobenzaprine

Sleep maybe disturbed by benzodiazepines, some opiates, some SSRIs and DOPAs,Alcohol

FATIGUE

This session covered general causes of fatigue, and there seems no way to really define or measure it. There are many different types of fatigue reported. Fatigue may be physical, mental/cognitive or motivational. The nature and severity of fatigue must be addressed, and this includes: Interference with daily activities, post-exertional effects, diurnal effects and relief or not by rest. Mood disorders have a complex association with fatigue.

A number of fatigue measuring instruments were evaluated.

Management of Fatigue:

Elimination of sedating medication

Treatment of depression

Structured schedule

Activity/exercise plan

Stimulants: caffeine, amantidine, methylphenindate, modafinil

Antidepressants: Bupropion, fluoxetine

CBT

Self care techniques: books, CDs etc, coping skills, Campbell course

Gupta course

Emotional support

Cognitive techniques (distraction, prioritization, reframing)

WORKSHOP 2

Behavioural assessment and treatment of ME/CFS – Fred Friedberg and Leonard Jason

This workshop focused on the understanding of ME/CFS and the management from a behavioural point of view. Leonard Jason began with a good overview of the history, biological, social and psychological factors in this illness, the importance of accurate diagnosis and how to distinguish the illness from anxiety and depression. This was followed by a presentation covering the behavioural assessment and treatment

of CFS by Fred Friedberg. Sleep management, pacing, behavioural intervention, coping skills and the importance of emphasizing pleasurable feelings were all covered in depth.

This was a session in which audience participation and much interaction was involved. There was a wide range of participants from disciplines of general medicine, psychiatry, research, psychology and complementary medicine.

Questions and areas of interest were posed by the audience, which were then ably covered by the 2 leaders, with their background of wide experience, expertise and research work. Many different techniques were discussed among the audience looking at CBT, simple strategies to improve coping skills, the importance of social support and relaxation approaches.

By the end of the workshop, after much interactive discussion, most people came away feeling there were plenty of simple options to offer patients with this perplexing illness.

I was not able to attend the following 2 other workshops, as one had to make a choice, and I hope these will be covered by another attendee.

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WORKSHOP 3

How to apply for grants – Eleanor Hanna.

I did not attend this informal workshop with Dr. Hanna on a speaker phone from NIH, as she was unable to attend in person.

WORKSHOP 4

Research 101 – Suzanne Vernon

This workshop presented research approaches for how genomics could inform clinical practice of CFS. Suzanne Vernon first provided evidence that chronic diseases are some of the most common maladies of the 21st century and how genomic approaches could improve diagnosis, treatment and ultimately prevent chronic diseases.

We discussed how CFS puts the aspirations of genomic medicine to the test since CFS is a complex phenotype controlled by many genes and whose inheritance does not follow the simple rules of Mendelian genetics. This means that genes and gene products are context dependent and in the case of CFS, potentially affected over time by other diseases and comorbidities, infection, trauma, and behavior.

We then discussed how high-throughput genomics will influence medical practice. With new biology and technology, we now can identify gene-environment causes of CFS, we can develop early detection methods and we can determine of molecular basis CFS taxonomy.

Genomic profiling has been used to identify “subtypes” of CFS that are related to both pathophysiology and etiology. There are examples of several examples of using genomics to customize therapeutic interventions in a variety of diseases and there is recent evidence to support this approach for CFS.

The greatest opportunity to inform medical practice as it relates to CFS will come from applying new technologic and computational tools to well designed human observational and clinical studies that include collection of rich and relevant data.

Suzanne emphasized the need for good study design and stressed that new technology should be used to identify early detection markers as well as diagnostic and subtype and treatment markers for CFS. We discussed a genomic medicine model for CFS and how adaptation of this model will influence not only the diagnosis and treatment of CFS, but will allow for the design of smaller, focused clinical trials and the tailoring of treatment to the biological profile of the patient and CFS.

Suzanne provided all participants with a USB drive that had a copy of her presentation as well as a file on personalized medicine. The session lasted for 3 hours and seemed to hold the interest and attention of the participants.

ROSAMUND VALLINGS, MB BS

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