MYALGIC ENCEPHALOMYELITIS [ME]

The John Richardson Research Group's

THE WAY FORWARD

Sir Winston Churchill said "The longer you can look back, the farther you can look forward". He understood the importance of historical facts giving credence to those that have threatened us and then applying the correct solution. We sadly have done neither. We have ignored the past and stumbled "blindfold" into the future. For the sake of our patients this attitude must end.

Historical facts:

Myalgic Encephalomyelitis is well annotated in medical literature. It was initially mentioned, during the Polio epidemics in 1930s/40s/50s, by Dr A Gilliam then later by Dalldorf and Sickles and Dalldorf and Gifford who discovered the Coxsackie virus which they found to be the causal agent of "Benign" Myalgic Encephalomyelitis, Myocarditis and Pancreatitis. It was further defined by Melvyn Ramsay in the 1955 Royal Free Disease and in the Canadian Medical Association Journal editorial-1956. This was followed in 1969 by an excellent monograph by Luis Leon Sotomayor [Pageant Press] entitled "Epidemic Diencephalomyelitis; A possible cause of Neuro-psychiatric, Cardiovascular and Endocrine disorders". Myalgic Encephalomyelitis was recognised by the WHO in 1969 as a neurological disease [G93.3]. Throughout the second half of the 20th century there were several Enteroviral pandemics with consequential M.E. each unfortunately with its own nomenclature. M.E. became a disease with a hundred names. In 1970 the BMA published a paper by two psychiatrists Drs C P McEvedy and A W Beard who, by deception [Goudsmit EM 1987], concluded that the Royal Free outbreak was due to mass hysteria. This deception was refined by their "Successors in Title" up to and including THE PACE Trial. The effect on medical opinion was far reaching and still prevails. Sadly this gullibility of the medical profession is responsible for the catastrophic effect on patients. It is as if the medical profession believe that the polio vaccine has eradicated all Enteroviruses from nature; when obviously it has not.



The medical profession, around the world, accepted without critique, the change from WHO G93.3 to CFS. A vague concept encouraged by the State, research funding and designated clinics. Under the deceptive umbrella of CFS the latter two were funded; with resultant flawed outcomes. The Hippocratic Oath was cast aside and the "blindfold" secured.

<u>Enteroviruses</u>:- ubiquitous in nature, are responsible for a variety of human diseases ranging from mild gastroenteritis to fulminating multi-organ failure. They were and remain the cause of Myalgic Encephalomyelitis and it is no surprise that this disease has multi-organ involvement with protean manifestation.

The Enterovirus genus is comprised of Polioviruses, Coxsackieviruses A&B, Echoviruses and E71. They are members of the Picornaviridea family. The Picorna family is marked by its extremely small size. The virion is a naked icosahedron about 30 nm in diameter. The genome is comprised of single-stranded monopartite RNA. While Poliomyelitis has virtually been eradicated in the Western world, others of the genera have filled the vacuum so created. Enteroviruses, as the name implies, persist in the gut and are remarkably resistant to its harsh conditions. They mutate slowly, en passage, to re-challenge host resistance; pandemics occurring every 2-4 years. Diseases can range from relatively minor gastrointestinal upset to paralysis. The Coxsackie virus is the major cause of aseptic meningitis, encephalitis, cardiac damage and birth defects. Sub clinical and mild infections are by the far most common. They are spread from hand to mouth and have a perfect water cycle surviving freezing and chlorination. Shellfish > Seagulls > Reservoirs > Tap

	Poliovirus	Coxsackie A	Coxsackie B	Echovirus	Enterovirus 71
MENINGITIS	+	+	+	+	+
ENCEPHALITIS	+	+	+	+	+
MYELITIS	+	+	+	+	+
PARALYSIS	+	+	+	+	+
MYALGIA	+	+	+	+	+
CARDITIS	+	+	+	+	+
EXANTHEMS		+	+	+	+
GLANDULAR			+	+	

It is important, from the point of view of causality, that serological tests are performed at the outset. When Enteroviruses becomes persistent currently available tests are usually negative. At present GPs and Public Heath do zero surveillance.

<u>Enteroviral Persistence</u>: - Academia has been aware of this fact both in vitro and vivo for past 30 years.

Now we know the biochemistry underlying this persistence

- 1. Virus has an I.R.E.S which attracts and hijacks ribosomes to replicate itself." Robbing cell Peter to produce virus Paul.
- 2. Virus has an activity sense switch to instigate above. This is the reason why energetic and well motivated individuals are main sufferers of M.E.
- 3. Can encode for microproteins which inhibit the innate immune system and apoptotic pathway allowing virus to persist in situ for years.
- 4. The outcome of above is sick cells, sick organs and very sick patients.

Myalgic Encephalomyelitis[ME]

Nowhere is the variety of systemic symptoms seen more often than in ME. While it is a defined entity, other organ pathology is not infrequent and can obscure the picture. Onset may be acute and be suspected when symptoms fail to clear within 14 days or may follow another acute Enteroviral illness i.e. Bornholm's Disease.

<u>Prevalence</u>: Northern Region of UK, over a ten-year period, number of cases approximately 400 per 100,000. This compares with MS prevalence over a similar period of 200 per 100,000 Internationally prevalence is unknown because of misclassification of this illness.

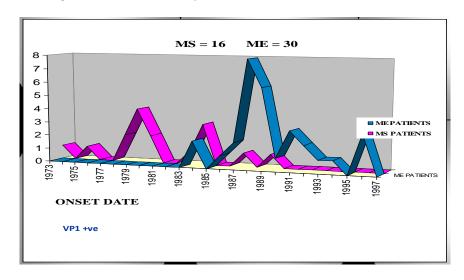
Sex ratio: Female to male 4:1.

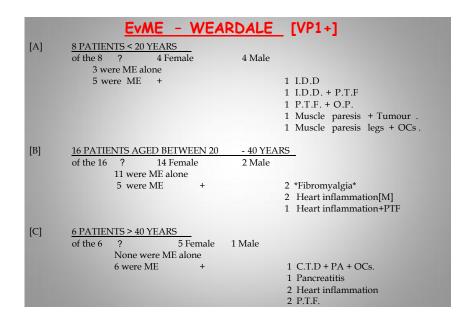
Age: 50% of cases occur between the ages of 20-40 years.

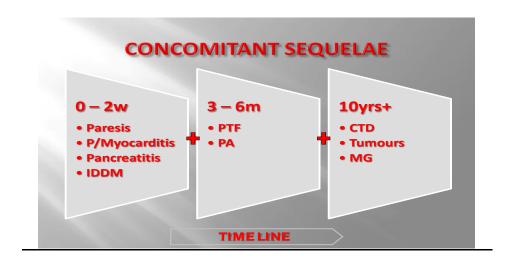
25% of cases occur during puberty.25% of cases occur after the age of 40

Survey of ME patients in the rural practice of Weardale-7,500 patients; comparing their onset dates with those of hospital verified MS. Dr J I Spurr Oct 1997

Study was undertaken between 1985 until 1997. ME patients were validated by JRRG score chart, viral titres [Newcastle General- Virology] and VP1 for Enteroviruses [Prof J Mowbray.St Marys]. All positive patients had full blood screen including auto-antibodies and pesticides [Biolab]







Observations

- Interestingly it would appear that MS has an infective trigger.
- The peak of ME occurred during a pandemic of Coxsackie B5
- At the time of the survey GPs knew their patients, their families and the environment in which they lived.
- All patients involved were well motivated and energetic with no signs of psychiatric traits.
- No of females=23. Males=7
- No. < 20yrs = 8 occurring at puberty. No. between 20-40yrs = 16. No. >40yrs = 6 mainly at menopause.
- Auto-immune diseases occurred with immune turbulence at puberty and menopause and when
 pesticides were above so called background levels [what can kill a flea could kill me]. Being a sheep
 farming area there was no indication of involvement of sheep dip. The co-factor appeared to be
 domestic insecticide sprays with one "run-off" from rape seed fields into river domestic holding
 tanks.
- Perimyocarditis [diagnosed by Dr J Richardson] occurred in >20yr olds. Was most urgent to treat and responded to IgG injection.

Having now seen over a 600 cases of Enteroviral Myalgic Encephalomyelitis my views are expressed on pages 5, 6,7 and 8. I would also encourage you to read the late Dr John Richardson's book: Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Other Organ Pathologies.

[The Howarth Medical Press. 10 Alice St, Binghampton, NY]

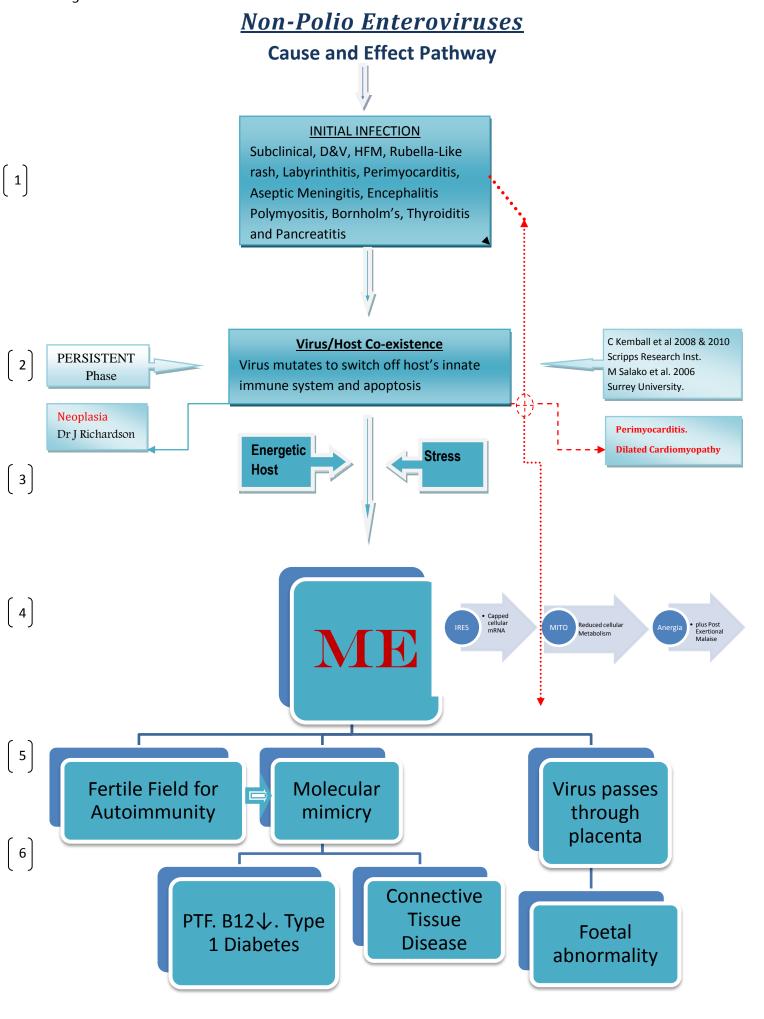
[5] Enteroviral cause and effect flow chart

[6] Common major symptoms which are amplified in the <u>JRRG ME score chart</u>. It is rapid to score both by patients and medical staff saving doctor/patient consulting time. According to Prof James Mowbray, Emeritus Professor of Immunology. St Marys. London it has been validated by VP1, Buspirone/prolactin challenge and SPET hypoperfusion brain scan.

[7] Common major neurological signs. With a positive NRRG ME score and at least 2 major neurological signs GPs can refer rapidly and correctly.

[8]Inclusion criteria for valid research.

There should be but one aim for doctors and that is to understand the causality of M.E. and to instigate the correct treatment. This aim needs to be underpinned by precise effective research. We know that in The Western World polio has been eradicated by vaccination. What would be the benefits of a Coxsackie B vaccine?



JRRG ME SCORE CHART

Consultation Dates

1	Has there ever been any evidence, either illness or titre, of past infection	1		
2	ENERGY BATTERY			
	Are you less than 33% efficient per day (i.e. this relates to a full day with hobbies and			
a)	social activities after work)	2		
b)	Do you need a period of bed or settee rest during each day	3		
or	Do you need a period of bed or settee rest on 2 or 3 days each week	2		
c)	Have you excessive fatigue and muscle pain after work effort	2		
	WALKING DISTANCE			
d)	Do you feel fatigued upon waking?	1		
3	CARDIAC/VASOMOTOR EPISODES			
a)	Do you have chest pain	1		
b)	Do you tend to have faint attacks and lose consciousness	3		
or	Do you have attacks without loss of consciousness but have to sit or lie down	2		
	Either accompanied by abnormal heart beat Y / N			
4	THERMODYSREGULATION			
a)	Do you have nocturnal sweats or cold feelings	2		
	Is your appreciation of temperature the same as other family members?			
5	SLEEP			
a)	Owl1 - Not asleep by 1 a.m. or Owl2 - Not asleep by 2 a.m.	1		
or	Owl3 - Not asleep by 3 a.m. or Owl4 - Not asleep by 4 a.m.	2		
b)	Do you have bizarre dreams	1		
6	EVIDENCE OF DISTURBED MENTAL ACTIVITY			
a)	Do you have difficulty finding the correct words	1		
b)	Can you write a long letter with uniformity of words?	1		
	Does your voice become hoarse or weak Y / N			
7	GAIT			
	Is your gait consistent with your age or unsteady	1		
8	Do you have tingling or numb or cold feelings in extremities or face	2		
9	Do you have disturbed vision or disturbed hearing	2		

Positive score if greater than 15/25

No 2e equates with Post Evertional Malaine	Patient Score		
No 2c equates with Post Exertional Malaise			

Vacs:
Toxin contact [pesticides]:
Viral Serology – date:
Other blood tests:

PATIENT No

<u>COMMON CLINICAL SIGNS</u> –

ROMBERG.	+ 1
JITTER IN QUADRICEPS	+ 1
MOTOR-SERVO [cogwheel	ing] + 1
PRONATOR	+ 1
PUPIL REACTION. [converse Argyl-Robertson	n] +1
Score/5	

The above signs should be performed within a full physical examination

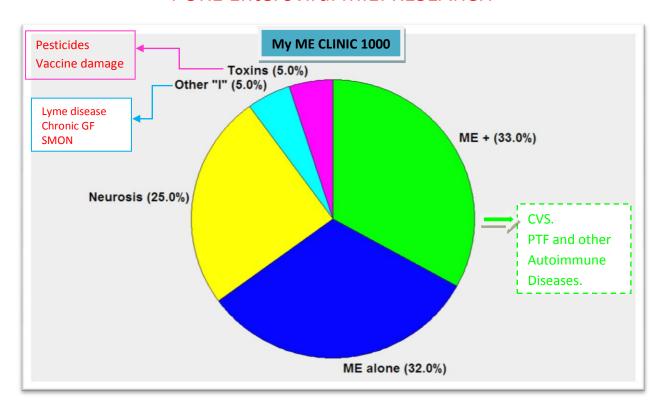
^{**} x2 turns for Romberg

^{**} Jitter of quads after x20, seated, leg elevations then hold leg out at 90*. Palpate quads for tremor as leg lowered slowly.

^{** [}R] and [L] upper limbs, in turn, flexed against resistance for 10secs then passively extended checking for cogwheeling.

^{**} Elevation of upper limbs above head – palms forward. Check for Supinator/Pronator imbalance

PURE Enteroviral M.E. RESEARCH



From above pie chart one can appreciate that research can unwittingly be flawed

RESEARCH_Subjects should comply with the following inclusion criterion:-



If research is conducted without complying with the above criterian it cannot claim to represent WHO. G93.3

GP page

DIAGNOSIS. When a patient presents with an infective disease which does not clear within 28 days and the main symptom is fatigue with post exertional malaise. The doctor should use the John Richardson Research Group ME score chart and do a full Nervous System [Pg.7] and Cardiovascular assessment. Serology should also be performed for EBV, Enterovirus and Borrelia

INVESTIGATIONS

- 1. At onset [within first 4 weeks] Viral serology including Elisa IgM for Enteroviruses Auto-immune screen CRP or Esr Standard blood test[FBC, LFTs, U&Es etc]
- 2. fMRI or SPET hypoperfusion brain scans if able; or at referral.
- 3. Other investigations are same as those for research inclusion.

To wait for 6 months before treatment is in breach of the Hippocratic Oath. Treatment should commence as soon as possible.

TREATMENT

- 1. It is a proven scientific fact that Enteroviruses replicate because they possess an Activity Sense Switch and an Internal Ribosome Entry Site; resulting in "Robbing cell Peter to pay virus Paul". The end result of which is a sick cell, potentially sick organ[s] and extremely sick patient. It is common sense therefore to rest the patient and only adopt a flexible activity regime when the patient has little or no post exertional malaise. Because the patient is naturally well motivated and energetic, strict self discipline is required.
- 2. Immunoglobulin i.m. injections to modulate the immune system in favour of the patient. The John Richardson Research Group has used this treatment for the past 30years with energy levels increasing over time from 20% up to 80%. Also heart and autoimmune sequellae have been minimized. Unfortunately, the proponents of the misnomer CFS have prevented genuine research into this treatment of ME for at least 30years.
- 3. Patients should not be exposed to the CFS NICE regimen. Forced activity will result in viral replication and patient deterioration.
- 4. Similarly patients should avoid any drugs which suppress their immune/virus balance in favour of the virus. E.g. Intravenous Steroids, Rituximab or Etanercept
- 5. Nor should patients be exposed to unnecessary stress which, as with the above, suppresses their immune system; causing deterioration of their illness.

An Esr or CRP together with a full Autoimmune screen should be monitored annually as 20% of patients develop auto-antibodies; particularly thyroid.