

The Nightingale Research Foundation



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**Göteborg and Malmo,
Sweden
M.E. Conferences**

November 2009

I would like to discuss the following topics:

1. What is M.E. (Myalgic Encephalomyelitis)?
2. The Investigation Roadmap to Understanding any Disease Process, Including M.E. & Fibromyalgia.
3. The Recent Discovery of the Retrovirus Association with M.E.
4. What you might discover when you investigate M.E. patients.
5. What you might discover when you investigate the underlying pathology of Fibromyalgia Patients.

What is M.E.

- Acute onset post-epidemic or sporadic disease
- Incubation period of 2-6 days
- Resulting in long term chronic disability
- M.E. is due to a measurable diffuse chronic physiological brain injury.
- This diffuse injury destabilizes C.N.S. control of many body functions.
- M.E. is not CFS & the two terms should not be used as synonyms.
- Modern medicine is not equipped to handle this evolving branch of medicine.

M.E. Is Characterized By:

- a. Severely decreased stamina
- b. Very slow recovery from any physical, sensory or intellectual stressor
- c. Significant loss of cognitive ability
- d. Significant circulatory & muscular dysfunctions
- e. Non-restorative Sleep with failure of type 4 sleep
- f. Incomplete recovery from acute to dysfunctional level
- g. Measurable evidence of brain and vascular dysfunction

What does Myalgic
Encephalomyelitis mean

- a. **My:** muscle
- b. **–algic:** pain
- c. **Enceph:** brain
- e. **mye:** spinal cord
- f. **itis:** inflammation

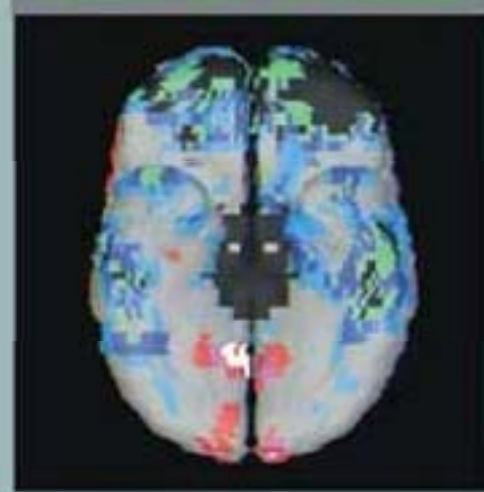
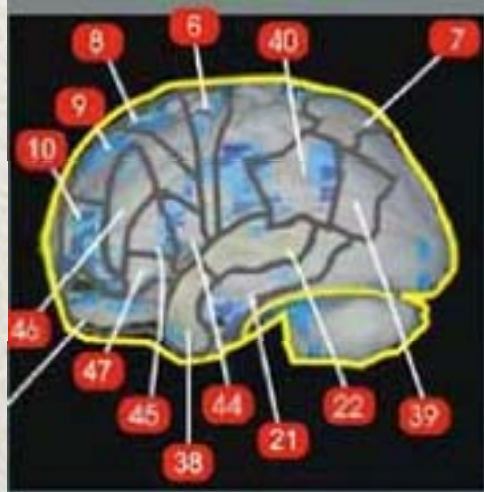
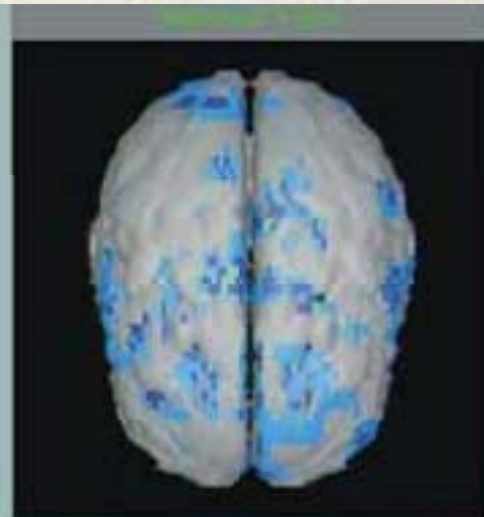
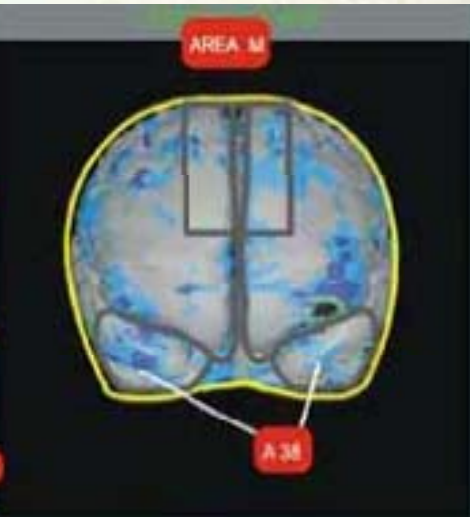
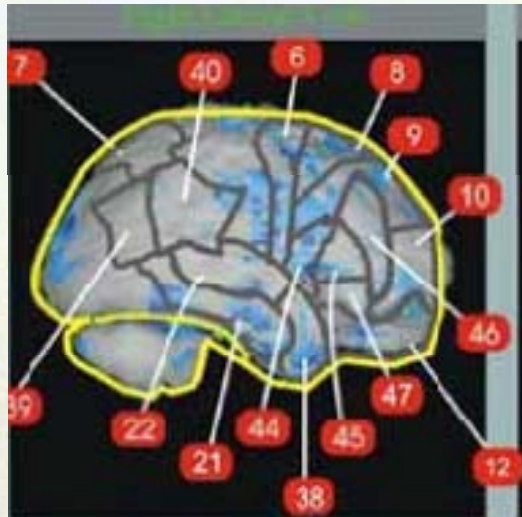
Measuring Diffuse CNS Injury:

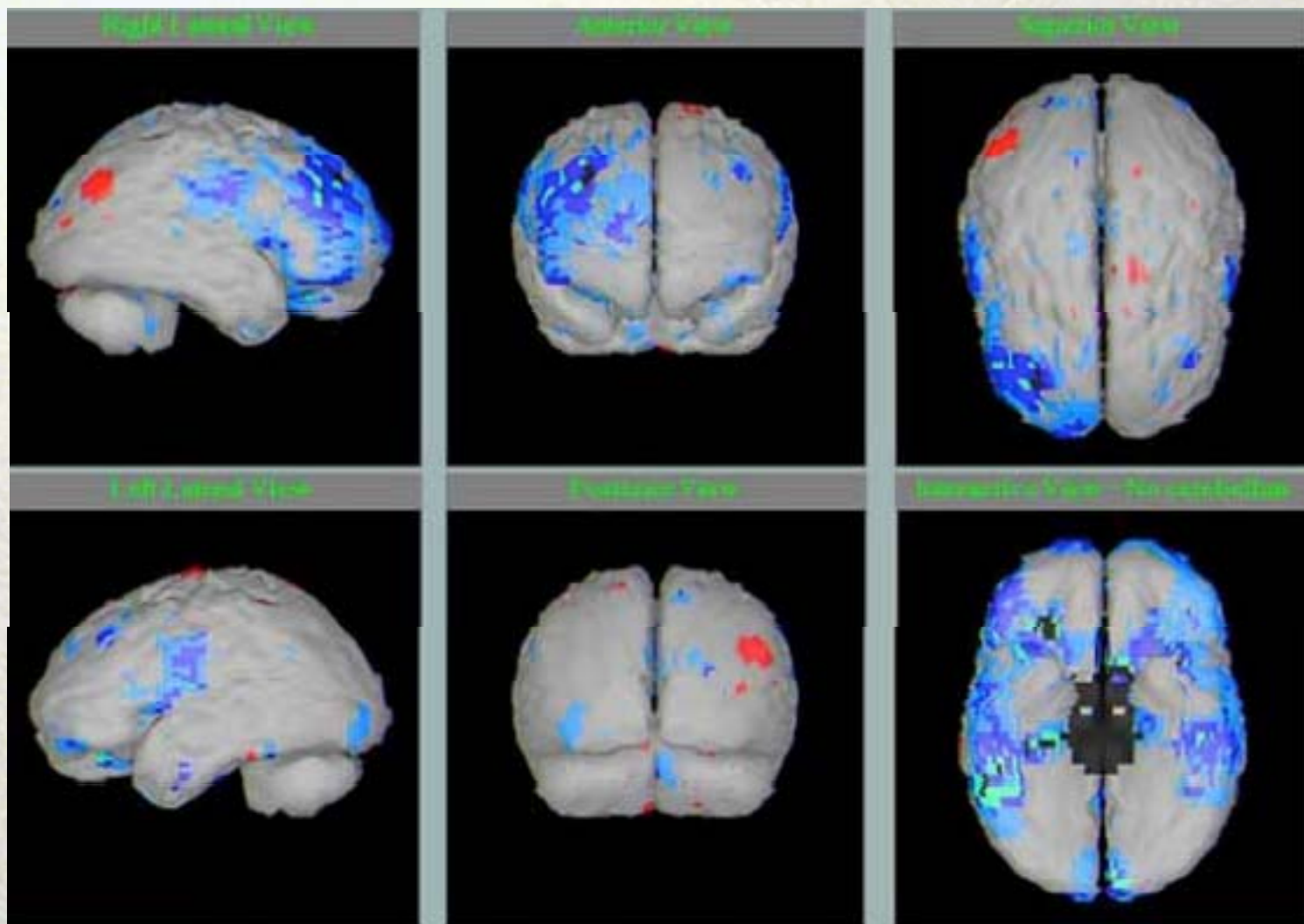
Drs. Jay Goldstein & Ismael Mena in 1998

- a. Brain SPECT (Single Photon Emission Computed Tomography)
- b. Quantitative EEG (QEEG or BEAM Scan in USA)
- c. Brain PET (Positron emission tomograph)
- d. Transcranial Doppler (Harbor View Hospital Seattle)
- e. Neuropsychological Testing (Dr. Sheila Bastien)

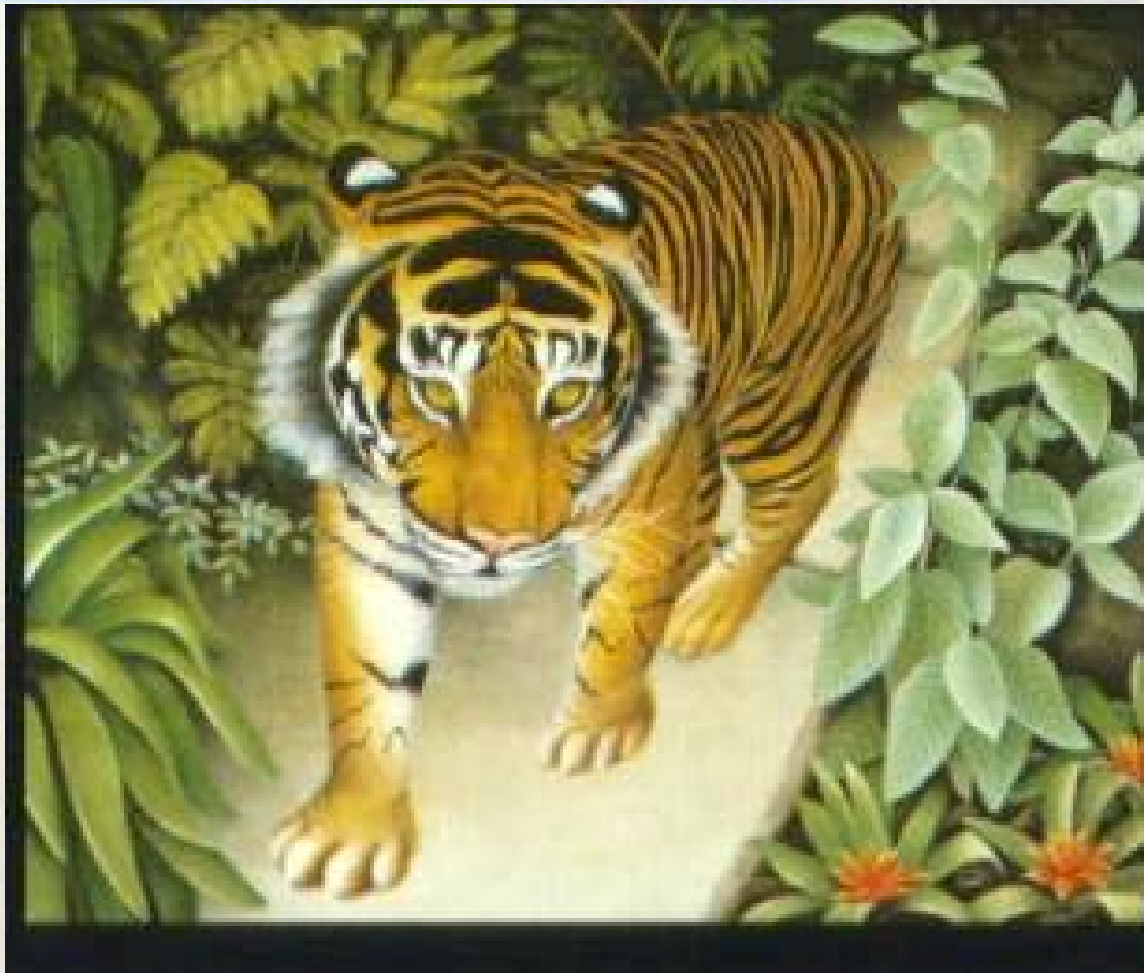
M.E. Brain SPECT With
Diffuse Hypo-perfusion Injury







Investigating Disease:



Primary Organ or System Injury:

- Gut
- Brain &
- Spinal cord.

Secondary Organ or System Injury:

- The CNS immune regulation
- Thyroid gland
- homeostasis of vascular system
- temperature change: Raynaud's
- normal physical activity.

- Severe dysautonomia, bed or house bound.
- vascular incompetence
- unable to maintain normal stable blood pressure with any activity
- POTS
- We know the pathology but almost no new or effective treatments have been marketed to treat these people during the past 20 years.

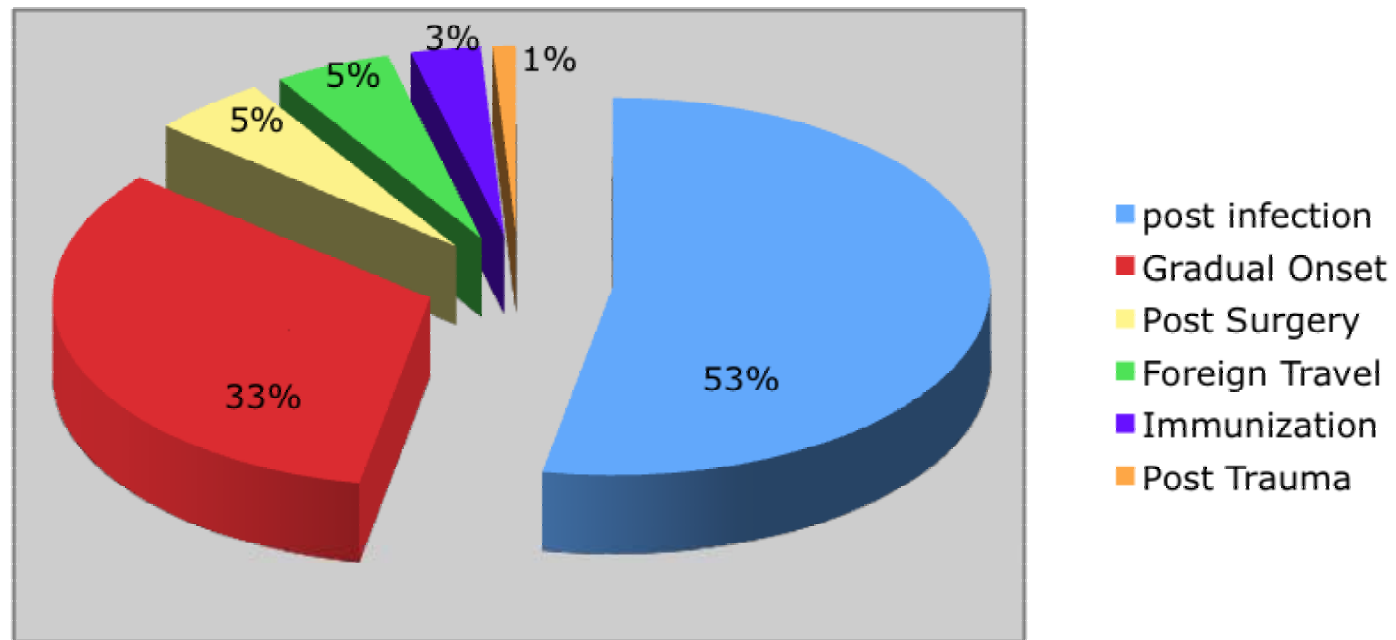
Scientific Investigation of M.E. & Fibromyalgia

- 1) Preconditions
- 2) Triggers (cause)
- 3) Primary Organ Injury
- 4) Secondary Organ Injuries
- 5) Social outcome of disease & illness

Preconditions

- Genetic,
- Prior multiple injuries or infections,
- Social conditions, deprivation, crowding
- Problem: No long-term epidemiological study

1984-92 Triggers in 2000 M.E./CFS cases

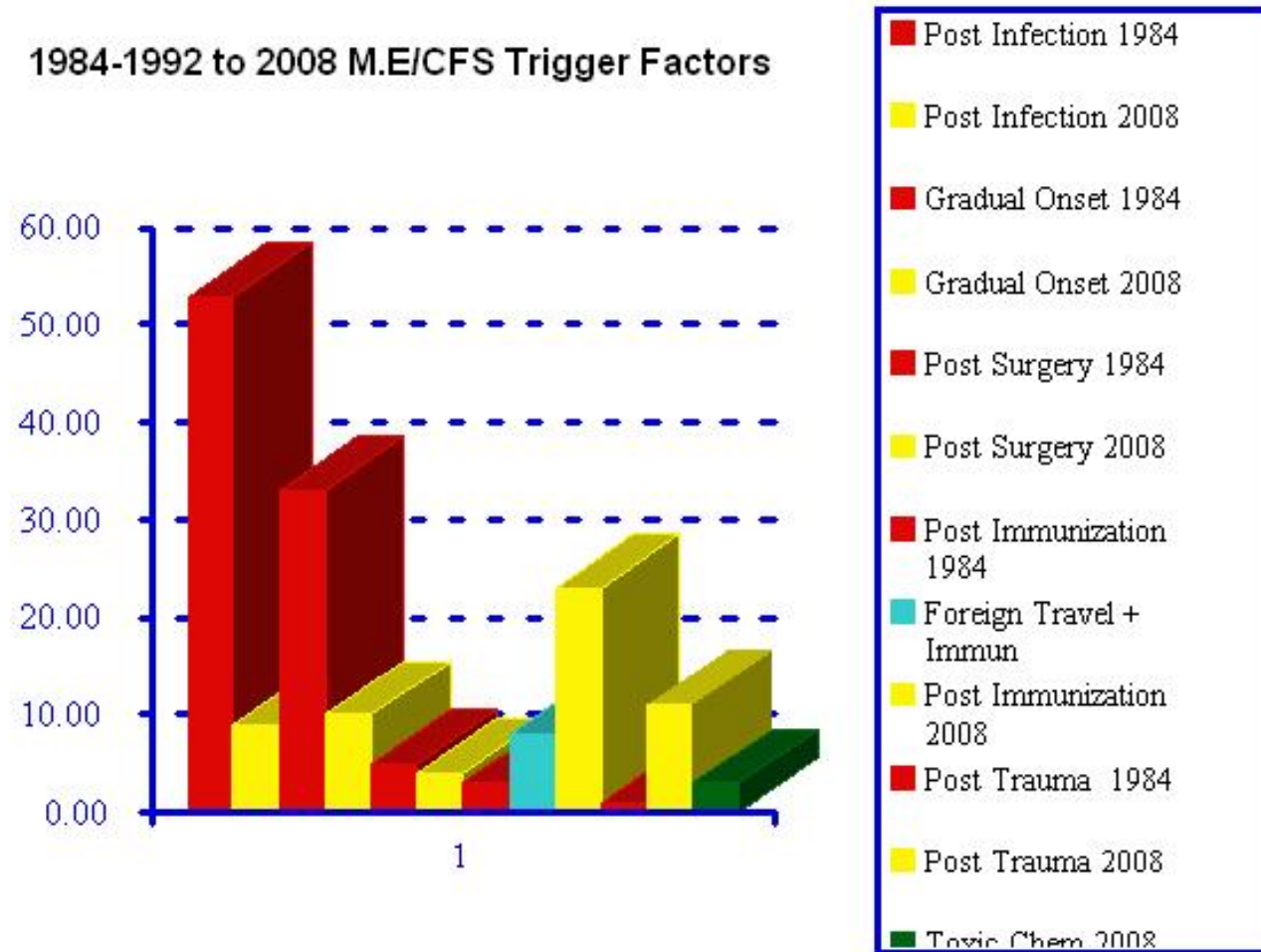


2008 Trigger Factors



- Post Hep B
- Post Influen
- Post Trauma
- Gradual Onset
- Toxic Chem +Other
- Post Infection

1984-1992 to 2008 M.E/CFS Trigger Factors



Primary Organ or System Injury:

- Brain & spinal cord.
- CNS vascular system & neurons.

Secondary Organ or System Injury:

- CNS injury immune dysfunction
- chemical & hormonal regulates all systems & organs.
- thyroid gland that in part regulates energy (slide)
- vascular system homeostasis, spasm, temperature control,
- movement BP adaptability with normal physical activity.
- Dysautonomia, POTS: Bed & Housebound patients.
- We know the pathology: no effective treatments in 20 years.

M.E. Thyroid Pathology



Mayo Clinic thyroid volume guidelines

Normal Male Volume Range:

7.5 - 12.5 cc's in volume

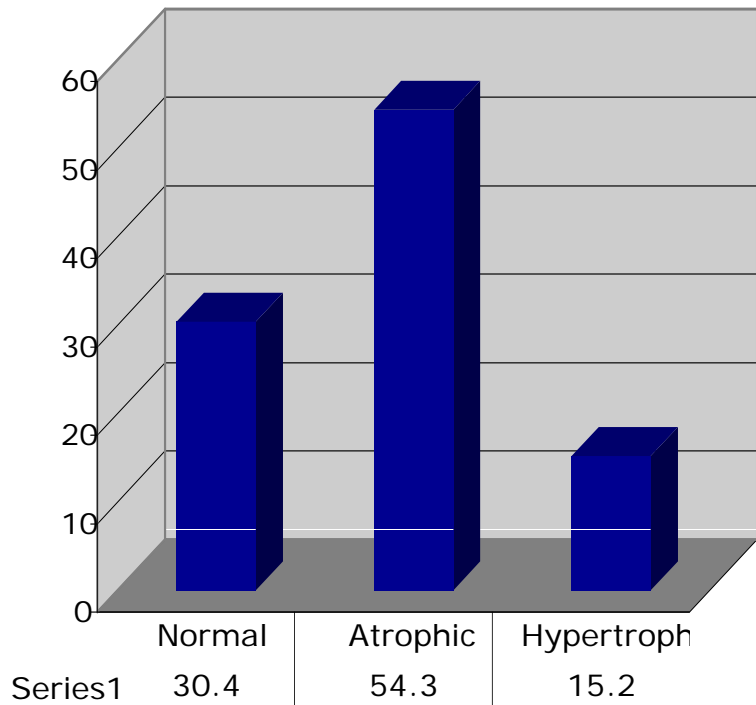
Normal Female Volume Range:

6.5 - 10.5 cc's in volume

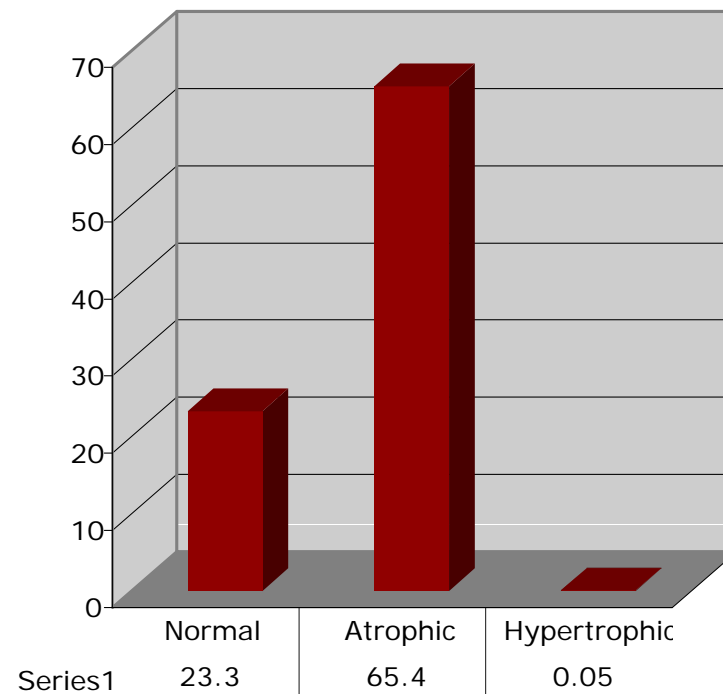
-
- 50% of all M.E & CFS patients had atrophic thyroids (Mayo guidelines)
 - Only 23% of M.E females had a normal Thyroid volume
 - TSH, FT3, FT4, were usually normal.
 - Abnormalities seen in ultrasound, sometimes thyroid antibodies

Thyroid Volume of 153 Consecutive M.E/CFS Patients

46 Male M.E/CFS F



107 Female M.E/CFS Pati



Thyroid Malignancy in M.E.

- 6 cases per 100 M.E. patients have thyroid cancer (6000/100,000)
- Normal thyroid cancer rate: 15/100,000

Social outcome of chronic illness:

- (a) Loss of ability to work or attend school,
- (b) Isolation from friends, work and community,
- (c) Unaccustomed poverty in working middle class,
- (d) Economic & social injury to spouse & children,
- (e) Scorn, ridicule, neglect of physicians, friends, colleagues & loved ones.
- (f) Personality changes in the patient
- (g) Increased risk of suicide.

A piece of textured, cream-colored paper with a blue background and a red thread. The paper has a fibrous, mottled texture and is set against a solid blue background. A thin red thread is visible at the bottom right corner of the paper. The text "Examples & Problems" is centered on the paper, underlined in blue.

Examples & Problems

Reliability of patient history.

- Professor fell with M.E. immediately after encephalitis immunization
- Examined by 5 physicians & diagnoses with CFS
- Untreated, unknown Hepatitis B
- Unknown, untreated tertiary syphilis
- Conforms to 1988 & 1994 CFS definition

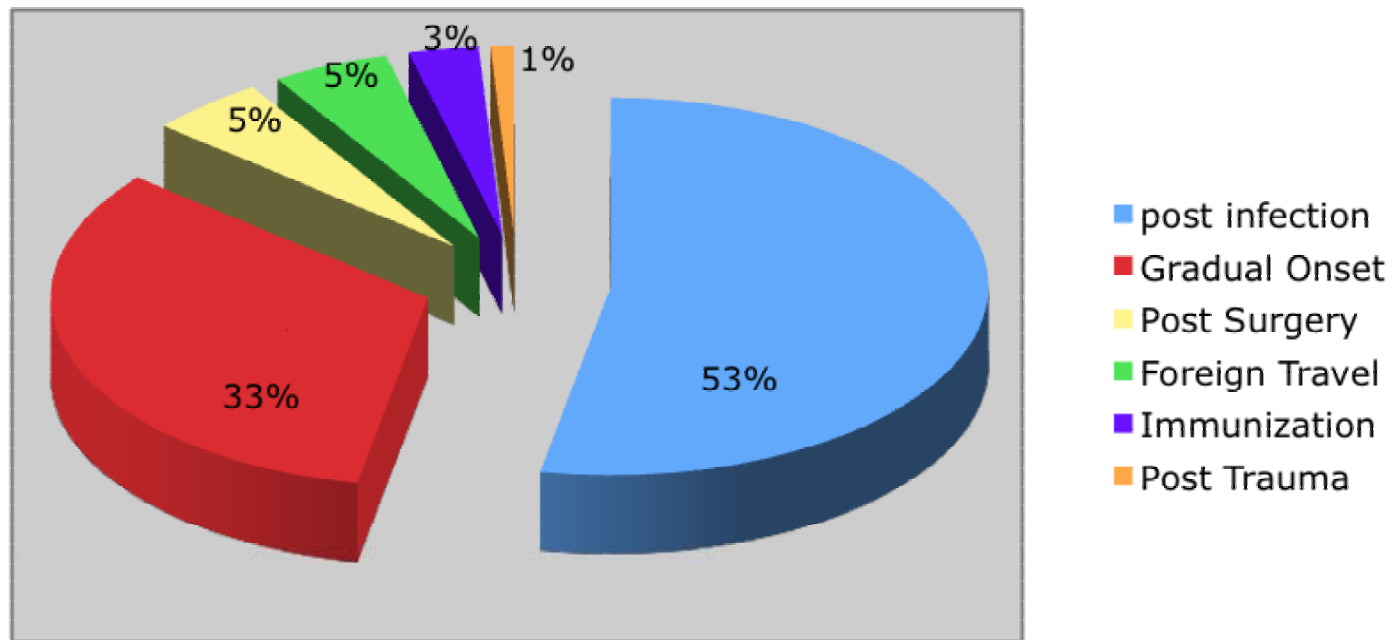
2009, Government worker:

- (a) Margaret refused private disability insurance
- (b) Why: Insurance paid U of O doctor does cursory exam, no tests & states she can work. (\$55./vs \$1000.)
- (d) Insurance co, saves \$40,000 dollars a year until she is 65.
- (e) Our clinic, finds hormone, cardiac & CNS pathologies.
- (f) 4 specialists & I agree she is unable to work.
- (g) Applies for Canadian Fed, Gov. Insurance, (\$10,000).
- (h) Fed refuses disability pension quoting the insurance doctor.

Immunization & M.E.

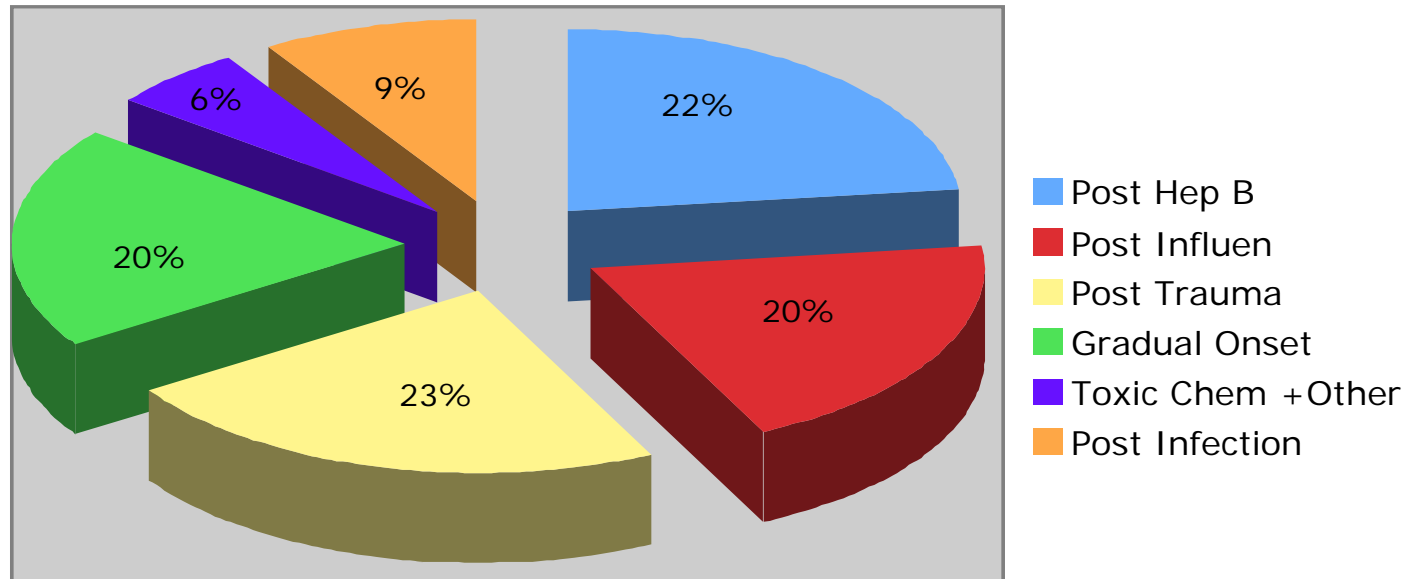


1984-92 Triggers in 2000 M.E./CFS cases



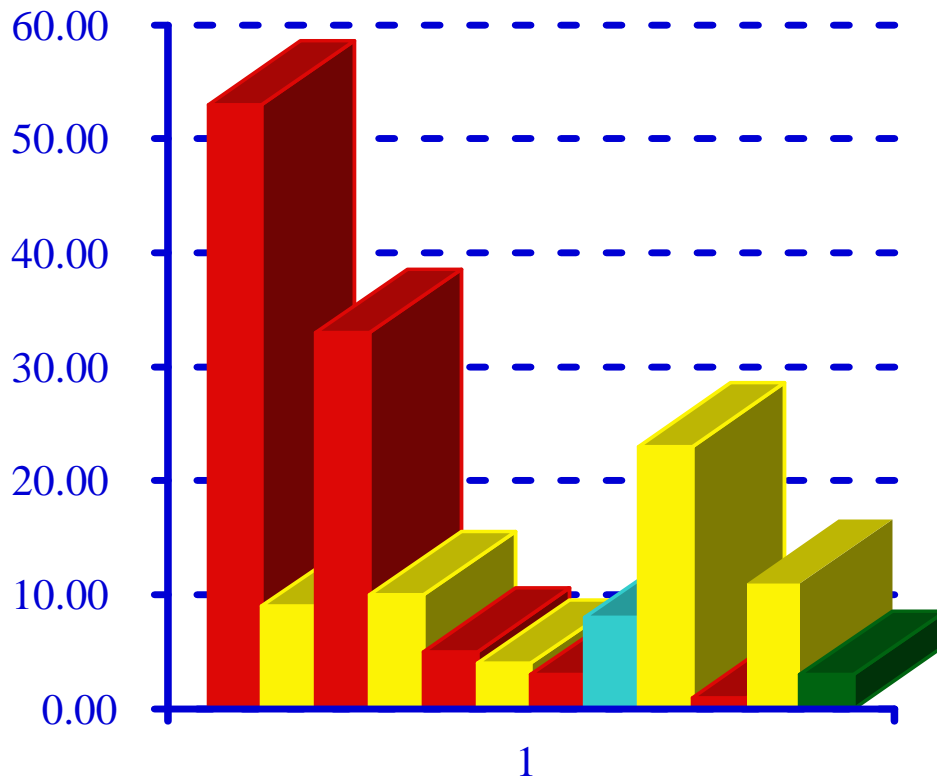
Immunization count for 3% of M.E. triggers 84-92

2008 Trigger Factors



In 2008 immunization represents 42% of M.E. triggers

1984-1992 to 2008 M.E/CFS Trigger Factors



■ Post Infection 1984

■ Post Infection 2008

■ Gradual Onset 1984

■ Gradual Onset 2008

■ Post Surgery 1984

■ Post Surgery 2008

■ Post Immunization
1984

■ Foreign Travel +
Immun

■ Post Immunization
2008

■ Post Trauma 1984

■ Post Trauma 2008

■ Toxic Chem 2008

Immunizations

Associated with M.E. like illness & even deaths:

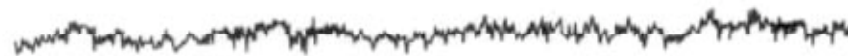
- a. 1930: BCG: Lubeck Disaster: 72 children died of TB
- b. 1934: M.E. Epidemic, Los Angeles County Hospital
- c. 1943: Hep B in 10,000 soldiers going to Pacific
- d. 1954: Salk Polio-immunization NFL & Grenada deaths
- e. 1985- Present: RHB Immunizations causes multiple CNS, M.E. & RA like pathologies
- f. 2005-6: Chiron UK, USA, Canada influenza immunizations contaminated in 10/2005 with *Serratia marcescens* & withdrawn only in 1/2006.
- f. Encephalitis immunization in Norway.

M.E. & Sleep Pathology

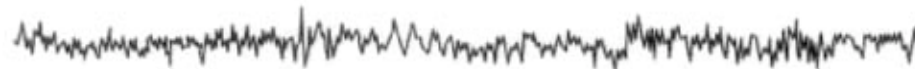


Normal Electric Sleep Waves

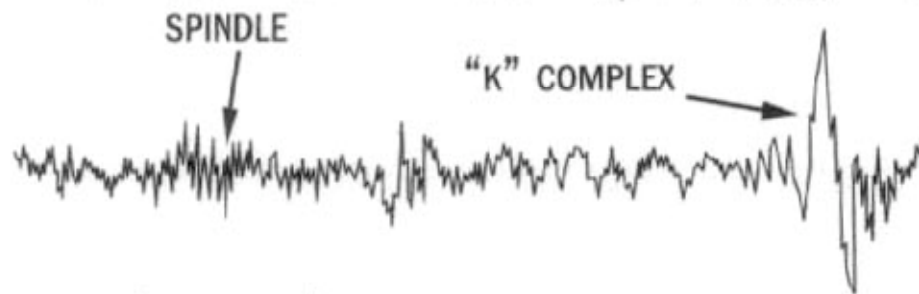
THE ELECTRICAL SIGNATURES



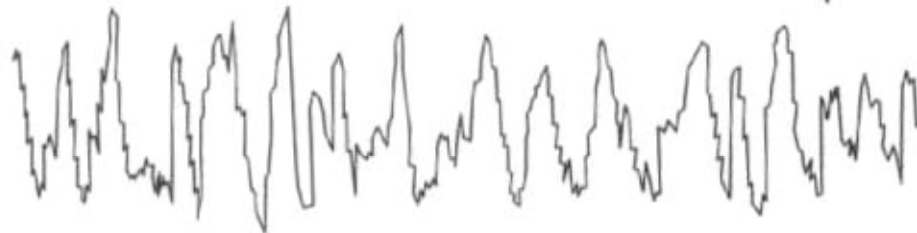
Awake



Stage 1



Stage 2



SWS



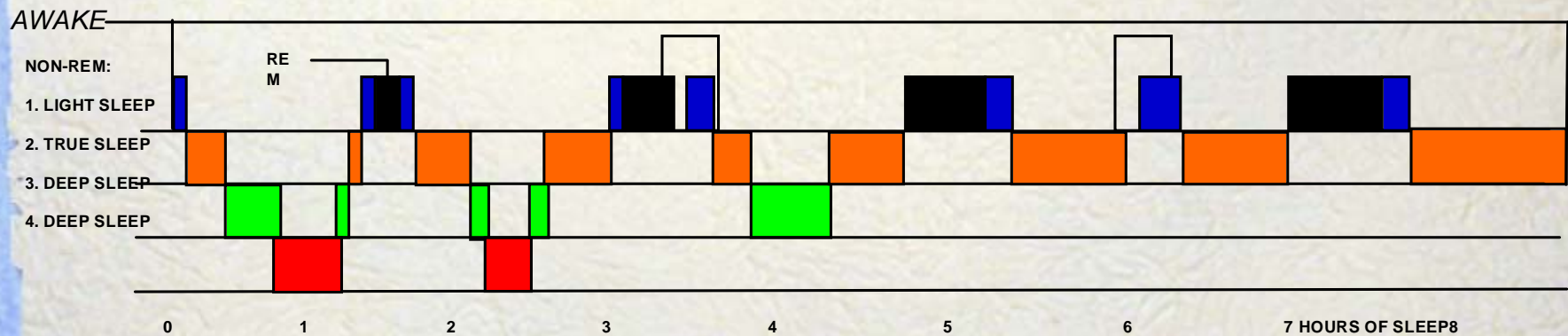
REM sleep

Normal Sleep Pattern

The New York Times

By NATALIE ANGIER

SUNDAY, OCTOBER 28, 2007



Stage 3 & 4 Sleep- Repair Stage & Memory Storage

- Production of Cortisol (stress hormone) ceases. Catabolic processes that produce metabolic waste is stopped.
- Pituitary revs up production of Growth Hormone (G.H.) that repairs routine catabolic cell damage.
- New information is implanted as memories.

Stage 4 Sleep- Growth Hormone

- Growth Hormone is the repair hormone & synthesis protein, metabolizes fat, particularly cholesterol & CHO.
- Growth Hormone restores tissue, decreases stress, builds new synapse chains that implant new information as memory.

Stage 5- REM SLEEP & Memory Preservation

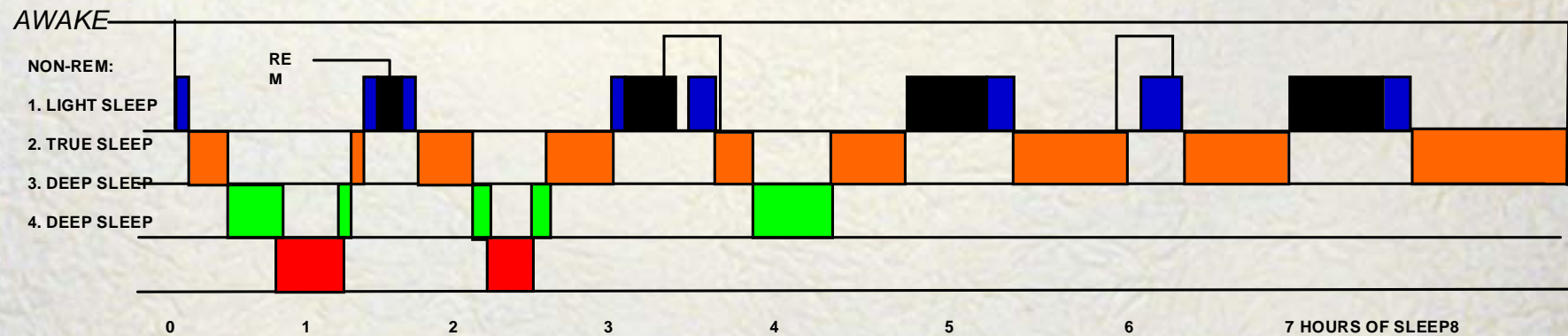
- Body temperature falls, brain temperature & blood flow in brain rises significantly.
- Heart speeds up, B.P increases, brain blood vessels dilate, neuron firing increases, brain metabolites flushed out clearing the brain for new brain function. Neural networks are soldered into place.
- REM potentiates higher learning functions.

Normal Sleep Pattern

The New York Times

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Testable
Cardiovascular M.E. Abnormalities



Autonomic Testing & POTS:

Damage to the autonomic nervous system interferes with the body's ability to regulate blood pressure, heart speed & vascular proprioception. (see Roy Freeman: Beth Israel Harvard)

Multiple Cardiac Abnormalities:

It is essential to do complete Holter Monitor, Stress ECG, Echocardiogram on each M.E. patient simply as a base line since cardiac irregularities are very common. (see Dr Paul Cheney, Florida Jan. 2007)

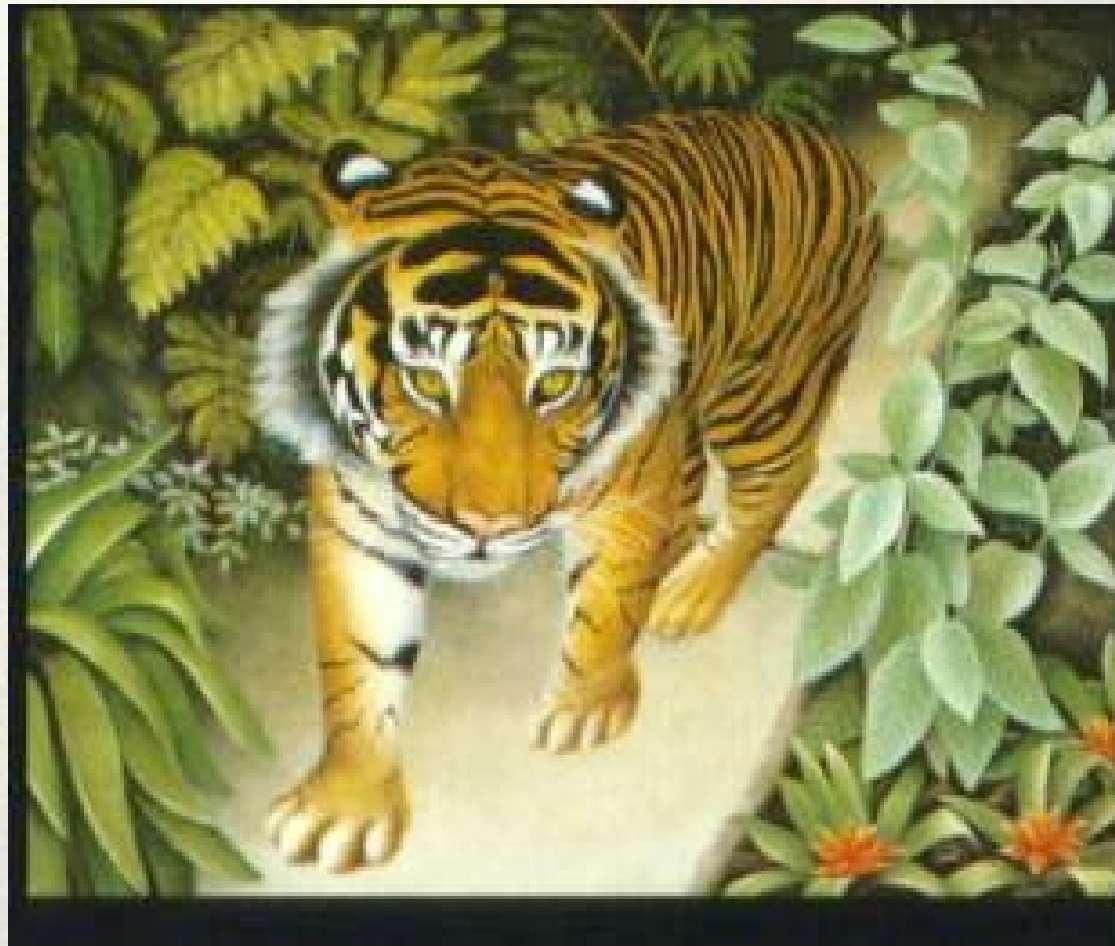
Autonomic Nervous System Dysfunctions Include:

- a. Raynaud's Phenomenon
- b. Circulating blood volume decrease
- c. Acquired Ehlers-Danlos Syndromes
- d. Multiple medication adverse effects
- e. Persistent Pain Effect in M.E.
- f. Diabetes Insipidus-Like Bladder Dysfunction
- g. Marfan Syndrome

Abnormal Blood Clotting Defects

- a. Abnormal clotting factors occur in 1-5% of of population. This genetic defect is made worse by M.E. vascular anomalies.
- b. This is a treatable defect.
- c. M.E. populations have a significantly higher percentage of clotting abnormalities.
- d. Clotting defects are associated with brain dysfunction, early death, M.I. & stroke.

Pain Syndromes & M.E.



History of Fibromyalgia

- a. 1800's: muscular rheumatism.
- b. 1904: Sir Edward Gowers fibrositis (1904-1989)
- c. 1989: ACR: Fibromyalgia (FS)
- d. Pain in at least 11 of 18 b tender points
- e. Problem: varies hour to hour & from day to day.
- f. Problem: other than measurable sleep dysfunction no scientific tests

Primary generalized non-articular pain disorders:

- a. Fibromyalgia Syndrome
- b. Polymyalgia Rheumatica
- c. Hypermobility Syndrome
- d. Ehlers Danlos

Regional Pain Syndromes:

a: Myofascial Pain Syndrome.

Fibromyalgia can occur secondary to:

- a. Systemic Lupus Erythematosus,
- b. Rheumatoid Arthritis,
- c. Osteoarthritis,
- d. Scleroderma,
- e. Polymyositis
- f. Generalized Spinal Arthritis due to genetic, traumatic or infectious origin &
- g. Psoriasis/ Psoriatic arthritis
- h. HLA B27 & HLA B 60 positive patients despite absence of ankylosing spondylitis.

Fibromyalgia Syndrome can occur
secondary to chronic infectious disease
including:

- a. Tuberculosis,
- b. Tertiary Syphilis,
- c. Bacterial Endocarditis &
- d. Subacute & chronic viral infections.

Fibromyalgia can occur secondary to:

a. Malignancy

Hormonal dysfunction

b. Hypothyroidism &

c. Hyperparathyroidism

d. PMS induced or aggravated.

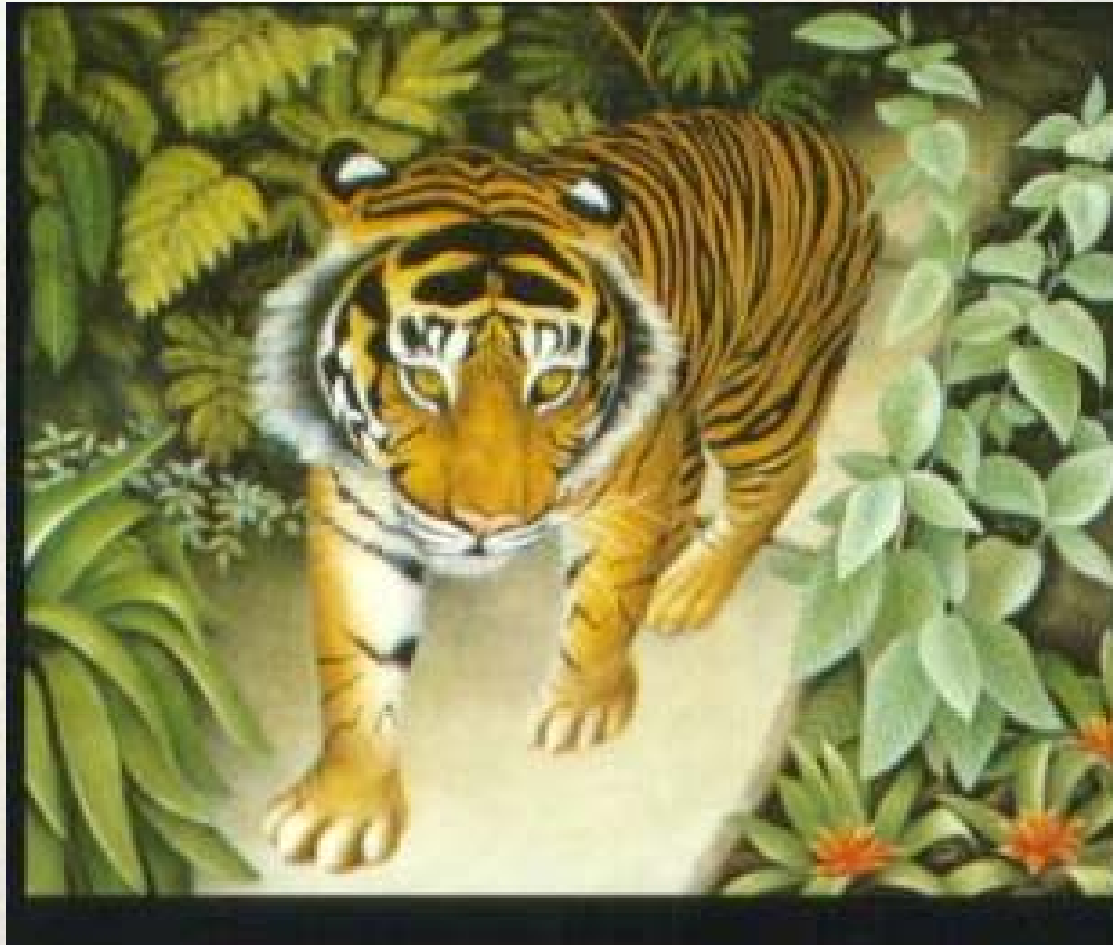
Fibromyalgia Syndrome can occur
secondary to or made worse by
multiple pharmacological agents
including:

- a. Excessive use of non-steroidal antiarthritic agents: NSAIDS
- b. Analgesic & narcotic addiction, corticosteroid withdrawal

Fibromyalgia Syndrome made worse by:

- a. sleep dysfunction,
- b. stress,
- c. depression or anxiety,
- d. or created by use of ongoing NSAIDS.

Tests to diagnose M.E. pain syndromes:



X-ray & MRI of the spine & HLA B27 or HLA B60:

- a. Ankylosing spondylosis,
- b. Missed compression & other fractures,
- c. Genetic variations,
- d. TB of the spine,
- e. Metastatic malignancy
- f. Spinal cord compression

ANA, ENA, dsDNA, Russel Viper
Venom, Rheumatoid factor:

- a. Lupus,
- b. Scleroderma or
- c. Early rheumatoid arthritis

IgM, IgG Anti-cyclic Citrullinated Peptide, Lp (a) Lipoprotein:

- a. So called seronegative rheumatoid arthritis
- b. Mixed connective tissue diseases Not apparent with dsDNA, anti-ENA, ANA

Hughes-sticky blood Syndrome

- a. Anti-cardiolipin antibodies (ACA),
- b. Factor V Leiden,
- c. Prothrombin mutation VIII levels,
- d. Protein C & S,
- e. Lupus anticoagulant,
- f. Hughes is one of a multitude of clotting defects that can cause pain & brain dysfunction, mimicking M.E. & also coronary & CNS arterial obstruction

hsCRP or C Reactive protein:

a. Multiple inflammatory diseases

Polymyalgia Rheumatica (usually over 60 years)

- a. Elevated C Reactive Protein,
- b. Elevated Sedimentation
- c. Rheumatoid Factor

Comment: *I have seen this in 30 year old patients,
but rheumatologists believe this is not possible.*

Miscellaneous Pain & Fatigue Problems

- a. Smooth Muscle Antibodies,
- b. Mitochondrial antibodies:
- c. Suspect NSAID induced FS, pain syndromes & Lupus:

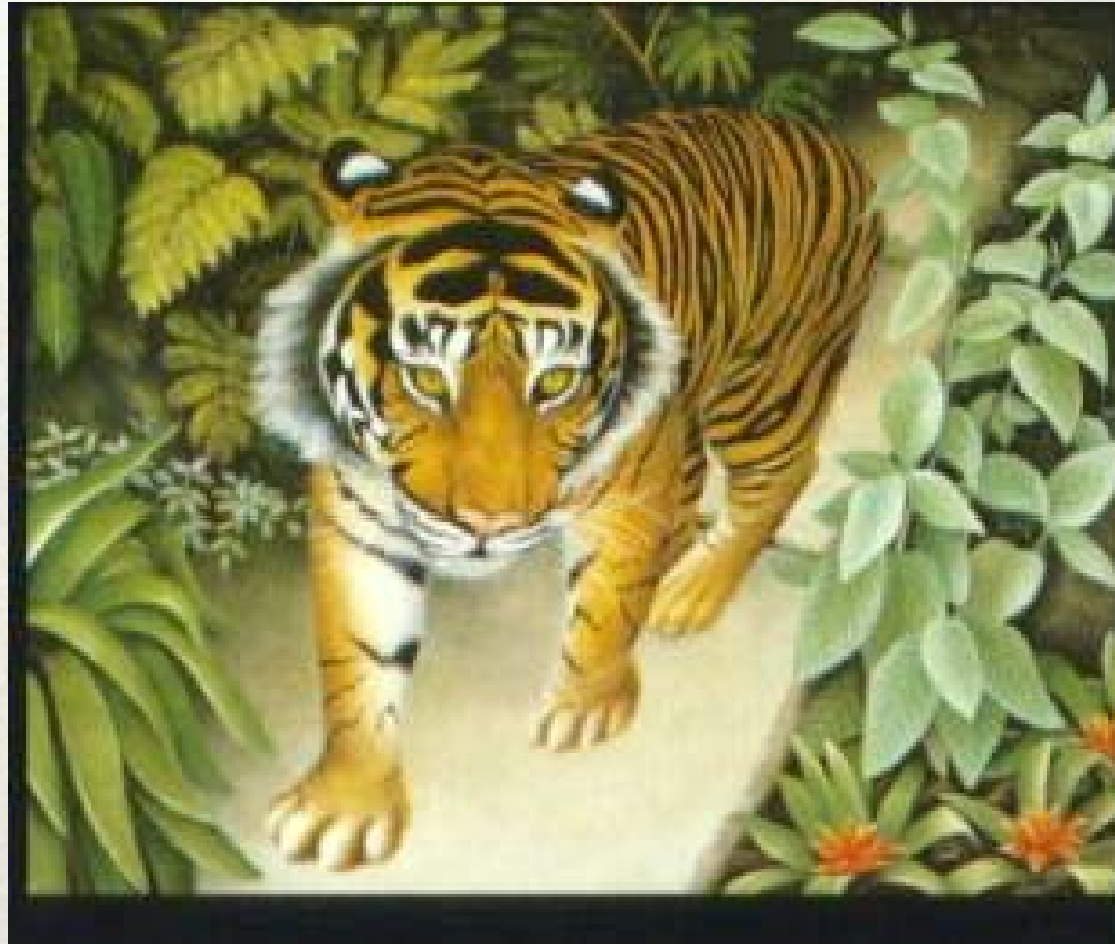
Last Resort: Nuclear Bone Uptake Scan When Tests Are All Normal

- a. Significant inflammatory disease
- b. Rheumatoid or interstitial disease
- c. Generalized tendon disease
- d. Ciproflox induced tendon disease
- e. Metastatic or bone malignancy
- f. BELIEVE THE PATIENT WHO SAYS THEY HAVE PAIN
- g. Repeat Tests if pain persists: Palindromic Arthritis

Pathological conditions in 30 of our M.E. patients with pain:

- a. 11 significant spinal arthritis, 2 positive for HLA B27:
- b. 9 Rheumatoid arthritis with serological markers:
- c. 4 with significantly elevated ESR:
- d. 2 with polymyalgia rheumatica
- e. 2 with severe Raynaud's (see Thermogram)
- f. 1 with NSAID induced arthritis,
- g. 1 with prescription induced Lupus
- h. 1 with reflex Dystrophy
- i. 1 with elevated mitochondrial Ab.
- j. 3 with Cipro induced tendon injuries

Raynaud's is not a minor
pathology



QuickTime™ and a
decompressor
are needed to see this picture.

Father with normal circulation in hands and arms

QuickTime™ and a
decompressor
are needed to see this picture.

Daughter with severely decreased blood circulation

Thermogram

QuickTime™ and a
decompressor
are needed to see this picture.

QuickTime™ and a
decompressor
are needed to see this picture.

Healthy Father

Daughter with severe
Raynaud's

Thank You Very Much

- These slides were prepared by Irina Statch, University of Ottawa Student at Nightingale, part time Researcher
- Nightingale is a clinical research charity examining Myalgic Encephalitis & CFS & Fibromyalgia patients since 1985
- Nightingale published The Clinical & Scientific Basis of M.E. & CFS

