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ME/CFS:

Physical Activity & Exercise

Chronic Complex Diseases Program (CCDP)

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Pathological Fatigue

Unexplained

Does not improve with Rest

Post Exertional Malaise: "Crash"

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Original Article | Journal of INTERNAL MEDICINE

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Pain inhibition and postexertional malaise in myalgic encephalomyelitis/chronic fatigue syndrome: An experimental study

J. Van Oosterwijck[1], J. Nijs[1,2,3], M. Meeus[1,2], I. Lefever[1], L. Huybrechts[2], L. Lambrecht[4,5] & L. Paul[6]

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2010 Journal of Internal Medicine 268;265–278

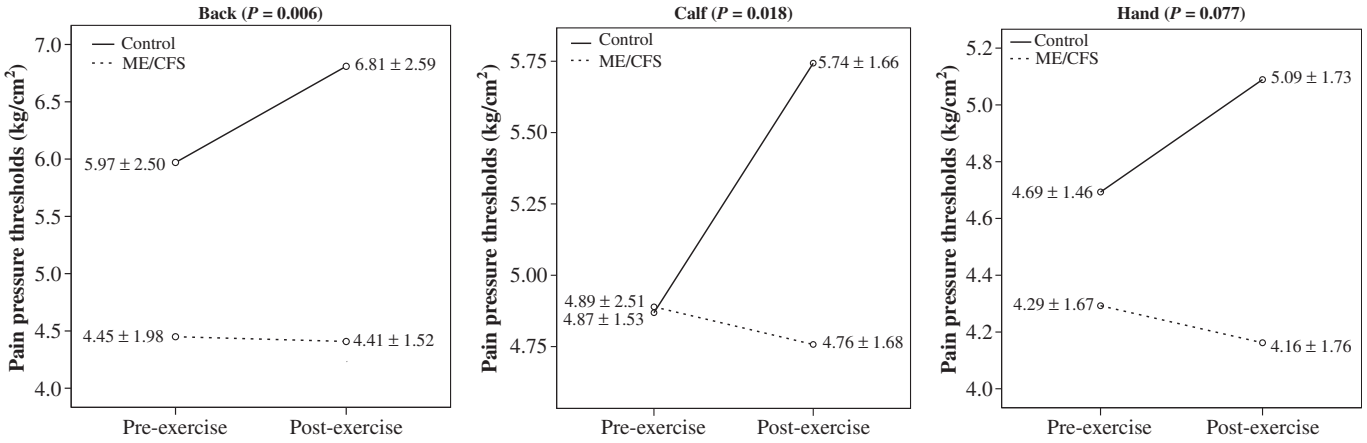


Fig. 2 *Changes in pain pressure thresholds in response to submaximal exercise in women with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (n = 22)* and sedentary women (*n = 22*).

Altered immune response to exercise in patients with chronic fatigue syndrome/myalgic encephalomyelitis: A systematic literature review

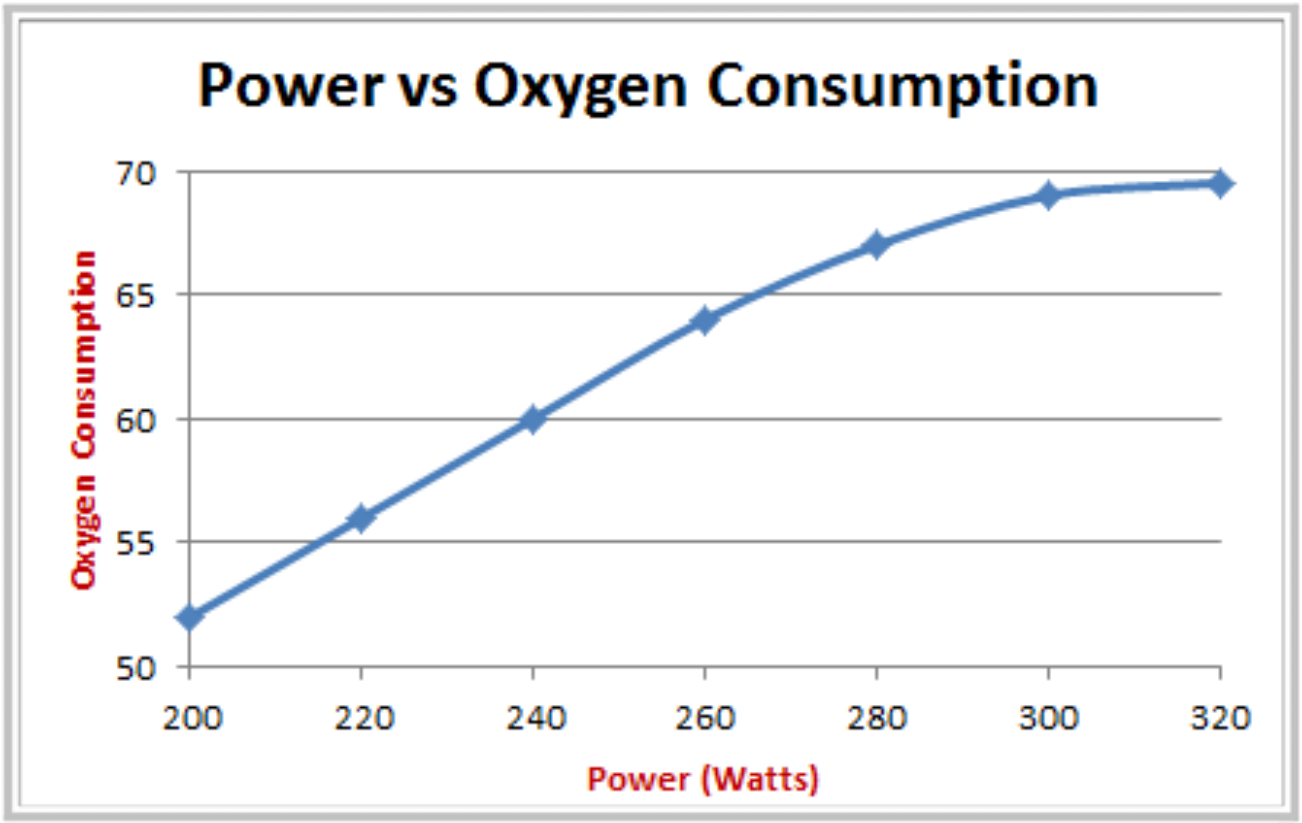
Jo Nijs[1-3], Andrea Nees[2], Lorna Paul[4], Margot De Kooning[1-3], Kelly Ickmans[1-3], Mira Meeus[1,5,6], Jessica Van Oosterwijck[1,2,5]

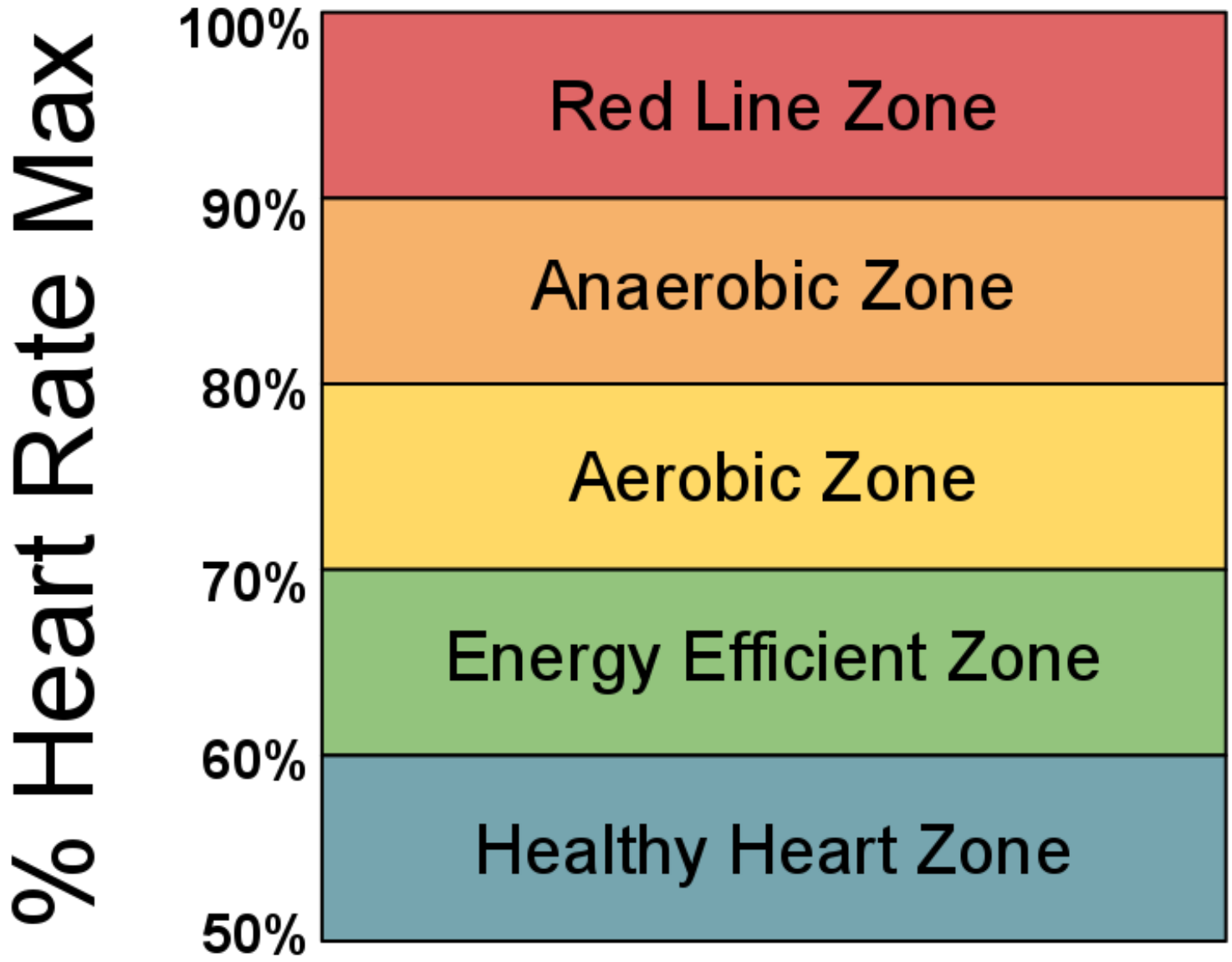
EIR 20 2014

- More pronounced response in the complement system
- Enhanced oxidative stress combined with a delayed and reduced anti-oxidant response
- More pronounced immune cell gene expression

- *"Many of these immune changes relate to post-exertional malaise in CFS, a major characteristic of the illness."*

VO2 Max


Power vs Oxygen Consumption
Oxygen Consumption
70
65
60
55
50
200
220
240
260
280
300
320
Power (Watts)


% Heart Rate Max
100%
90%
80%
70%
60%
50%
Red Line Zone
Anaerobic Zone
Aerobic Zone
Energy Efficient Zone
Healthy Heart Zone

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Loss of capacity to recover from acidosis on repeat exercise in chronic fatigue syndrome: a case–control study

David E. J. Jones[*,1], Kieren G. Hollingsworth[*,†,1], Djordje G. Jakovljevic[‡,§,¶], Gulnar Fattakhova[‡,§], Jessie Pairman[‡,§], Andrew M. Blamire[*,†], Michael I. Trenell[*,§,¶,2] and Julia L. Newton[‡,§,2]

[*]Institute of Cellular Medicine, [†]Newcastle Magnetic Resonance Centre, [‡]Institute for Ageing and Health, [§]The UK NIHR Biomedical Research Centre in Ageing and Age Related Diseases, [¶]Newcastle Centre for Brain Ageing and Vitality, Newcastle University, Newcastle, UK

Eur J Clin Invest 2012;42(2):186–194

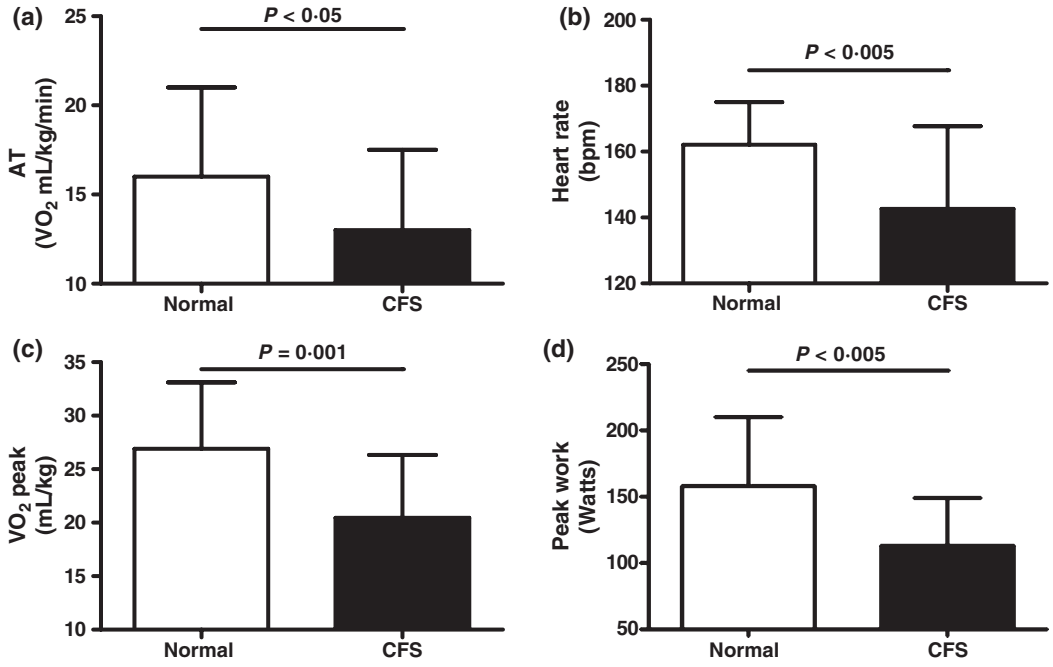


Figure 1 Chronic fatigue syndrome patients exhibit reduced (a) anaerobic threshold, (b) heart rate at anaerobic threshold, (c) VO_2 max and (d) peak work when compared with sedentary controls.

Loss of capacity to recover from acidosis on repeat exercise in chronic fatigue syndrome: a case–control study

Eur J Clin Invest 2012;42(2):186–194

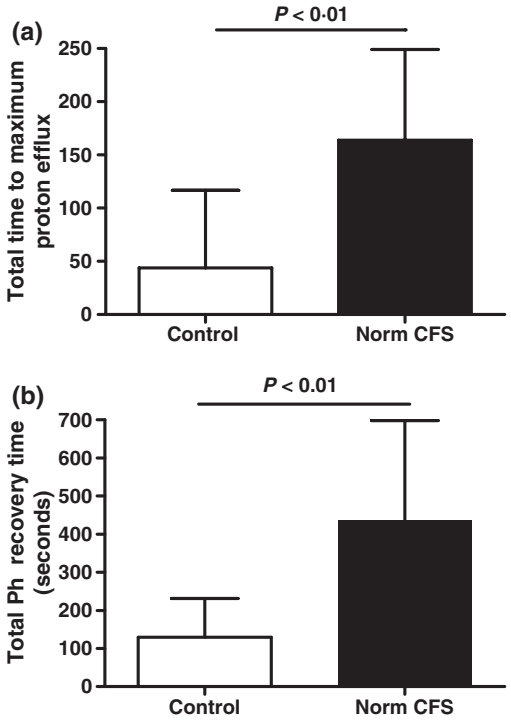


Figure 5 (a) Time taken to recover to baseline pH in group 1 chronic fatigue syndrome (CFS)/ME patients and controls (cumulative value for the three episodes). Normal PCr depletion CFS patients show significant prolongation in the recovery to baseline pH following exercise. (b) Time taken to achieve maximum proton excretion kinetics in Normal PCr deletion CFS patients and controls. Despite significantly greater acidosis, the CFS patients show significant slowing of the excretion response necessary to normalise pH.

Discriminative Validity of Metabolic and Workload Measurements for Identifying People With Chronic Fatigue Syndrome

Christopher R. Snell, Staci R. Stevens, Todd E. Davenport, J. Mark Van Ness

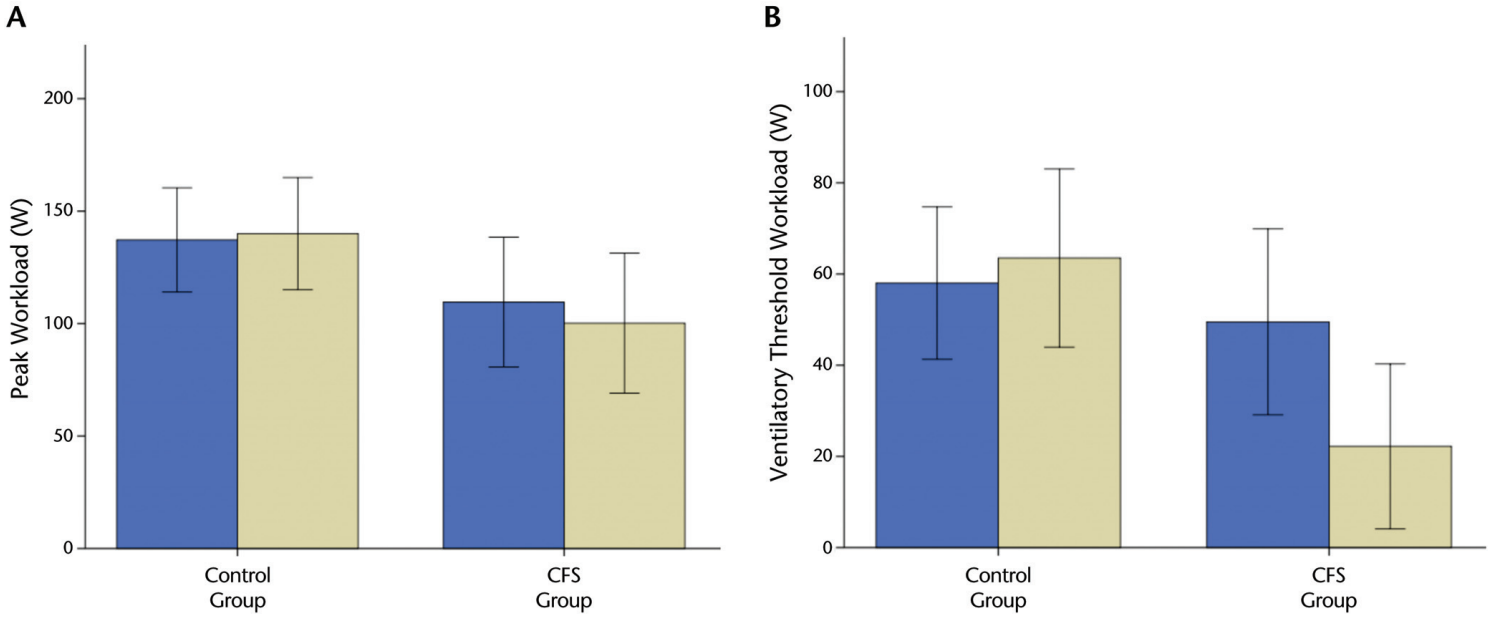
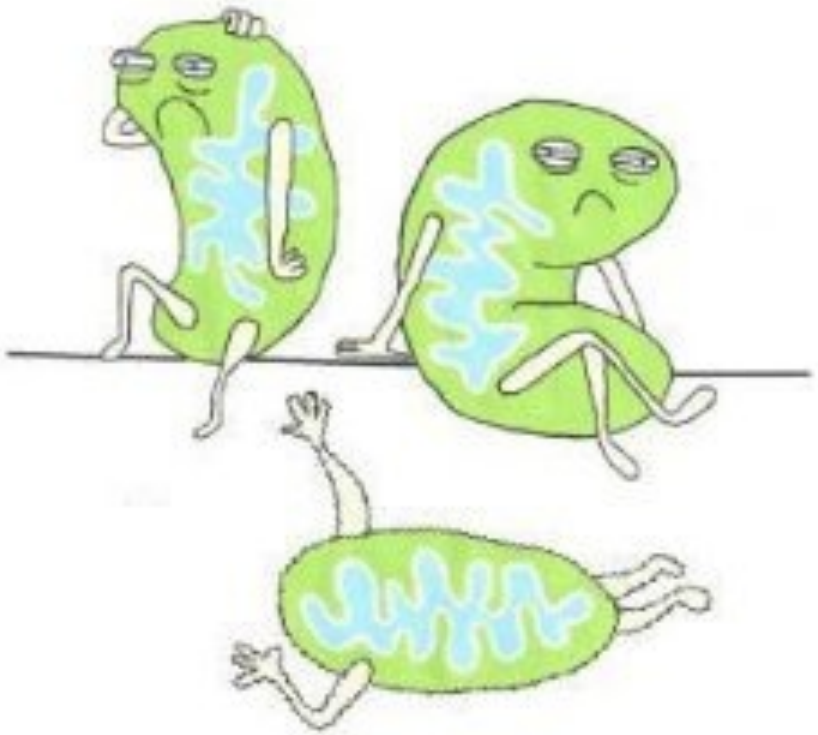


Figure 2.
Measurements of workload at peak exercise (A) and at the ventilatory threshold (B) in participants with chronic fatigue syndrome (CFS) and control participants during cardiopulmonary exercise test 1 (blue bars) and cardiopulmonary exercise test 2 (gold bars). Error bars represent 1 standard deviation.

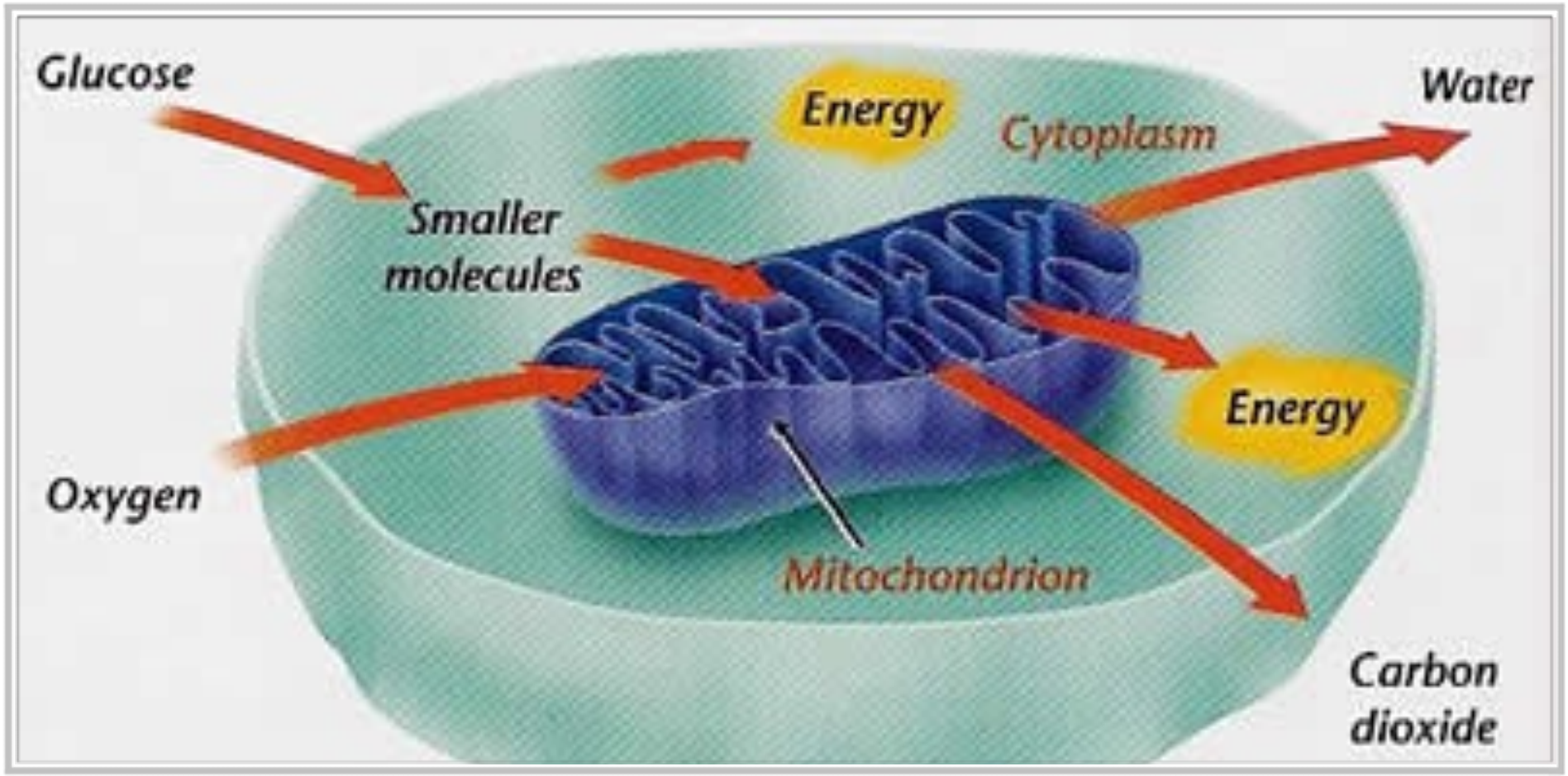
Diagnosis and Treatment of Chronic Fatigue Syndrome



it's mitochondria, not hypochondria

MITOCHONDRIA

THE CELL'S POWERHOUSE



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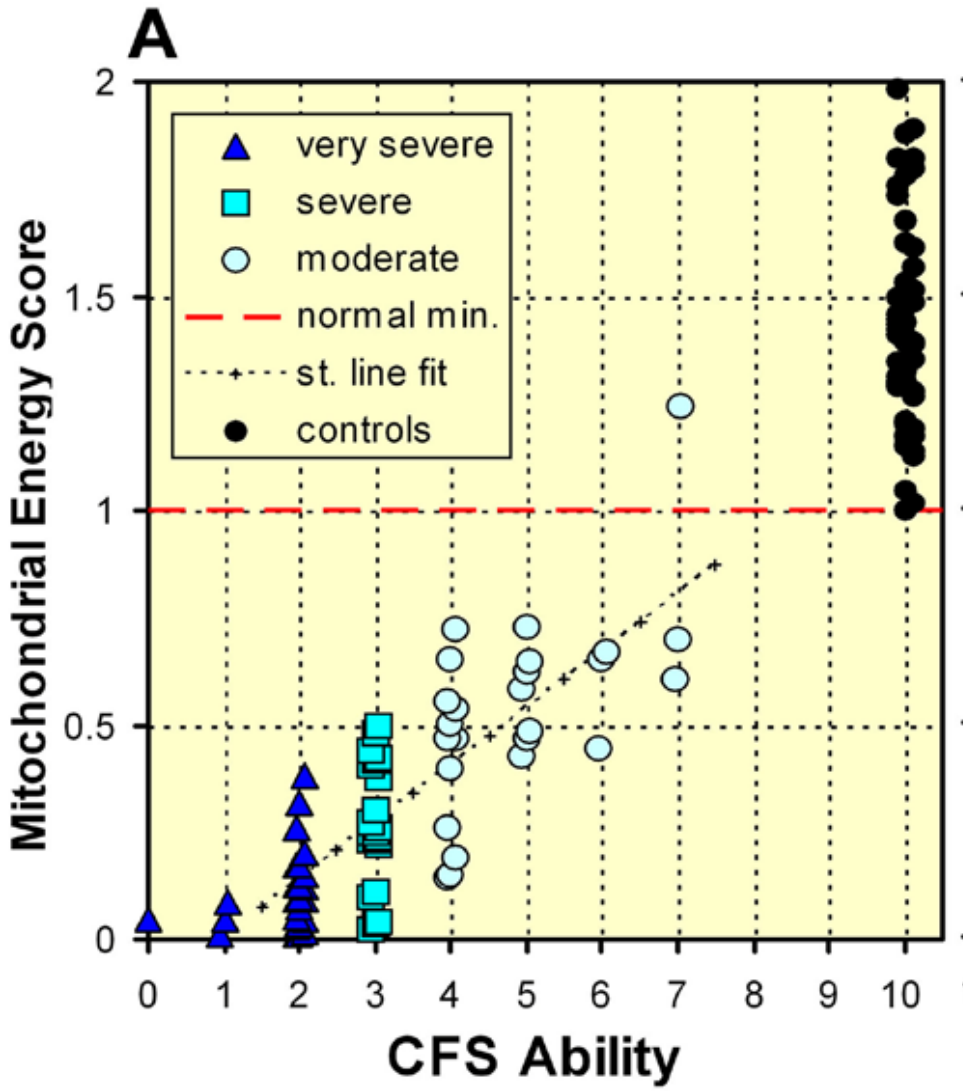
Int J Clin Exp Med (2009) 2, 1-16

Chronic fatigue syndrome and mitochondrial dysfunction

Sarah Myhill[1], Norman E. Booth[2], John McLaren-Howard[3]



Medical Hypotheses 79 (2012) 607–613

Increased nuclear factor-κB and loss of p53 are key mechanisms in Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS)

Gerwyn Morris [a], Michael Maes [b,*]

[a] Tir Na Nog, Pembrey, Llanelli, UK
[b] Maes Clinics @ TRIA, Bangkok, Thailand

Activation of immuno-inflammatory pathways

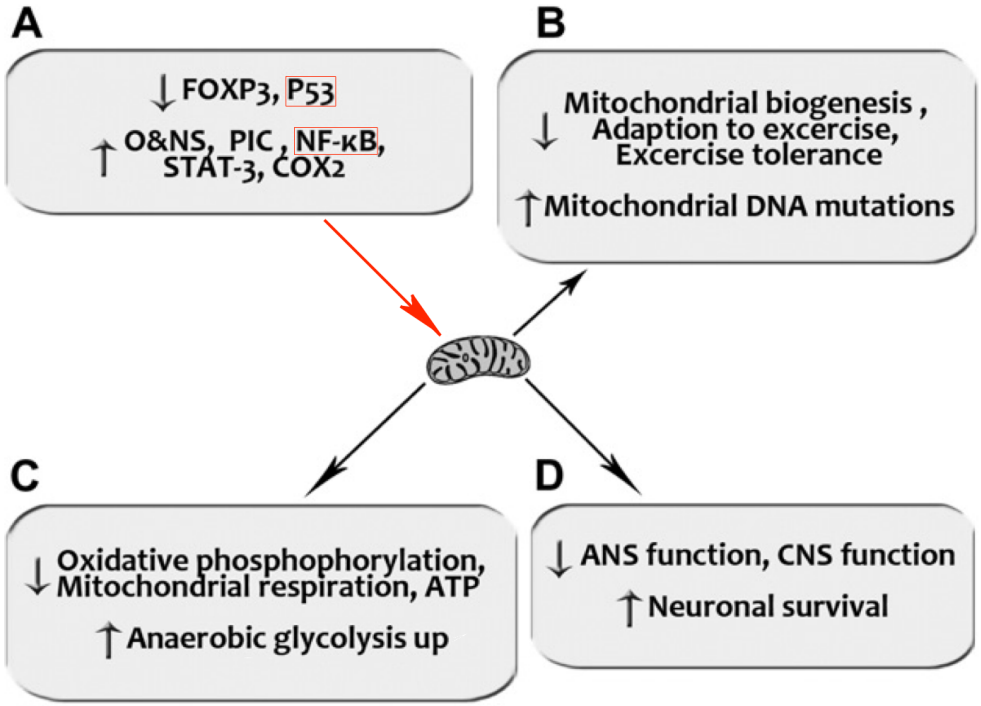


Fig. 2. This Figure shows the functions of p53 in conditions characterized by activation of immuno-inflammatory pathways. FOXP3: forkhead box P3; O&NS: oxidative & nitrosative stress; PIC: pro-inflammatory cytokines; NF-κB: nuclear factor κB; STAT-3: signal transducer and activator of transcription 3; COX2: cyclo-oxygenase 2; ANS: autonomic nervous system; CNS: central nervous system.

Low p53
High NF-ƙB
Low ATP
Mitochondrial dysfunction

Leads to…

- neurocognitive symptoms
- greater muscle fatigability
- reduced exercise capacity due to the inability of mitochondria to increase respiration rates according to increases in demand

REVIEW ARTICLE

Fear of movement and avoidance behaviour toward physical activity in chronic-fatigue syndrome and fibromyalgia: state of the art and implications for clinical practice

Jo Nijs · Nathalie Roussel · Jessica Van Oosterwijck · Margot De Kooning · Kelly Ickmans · Filip Struyf · Mira Meeus · Mari Lundberg

Clin Rheumatol (2013)32:1121–1129

- Fear of worsening symptoms
- Can lead to deconditioning
- 40% of FM patients have a high level of fear
- Likely less in ME/CFS but prevalence unknown
- CBT strategies can be helpful

Practical Advice

- All physical activity should be thought of as exercise
- Before you can start a formal exercise program, you need to…
  - Know your current activity tolerance
  - Define your energy envelope and be living within it
  - Know your Anaerobic Threshold (AT) and Target Heart Rate (THR)
  - Create a detailed plan

Pacing by the Numbers

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Pacing by the Numbers

- Maximum Heart Rate (MHR) = 220 - age
- Anaerobic threshold (AT)
  - The point at which you stop using oxygen to metabolize fuel
  - AT usually occurs at 65% - 95% of MHR (depending on fitness)
  - AT is reduced in ME/CFS (happens at a lower heart rate)
    - Want at "buffer": use 50% - 60%
  - Target Heart Rate = (220 - age) x 0.5

Exercise Guidelines

- **Frequency > Duration > Intensity**
  - Increase the frequency of exercise before increasing the duration
  - Increase the duration of exercise before you increase the intensity
- More is not better
- Avoid the "no pain, no gain" approach
- Individualize your program
- Set realistic goals
- Start low and go slow
- Monitor yourself

When to move up or down a level

- Your doing too much if…
  - If you're experiencing post-exertional malaise
  - If your energy envelope is contracting
  - If your participation in your exercise plan is at the expense of your activities of daily living or socializing,
- Otherwise, consider an increase in level

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