

THE LATE EFFECTS OF POLIO

**Current Research in Post-Polio Syndrome
What I am Sharing with My Patients**

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First the Bad News

- **There was no new post-polio research presented at the American Academy of Neurology meeting in Seattle in May.**
- **Although the new stimulus grants offered by the National Institutes of Health will surely have attracted new interest for funding for polio research.**

Post-Polio Health International

- **THE FIFTH AWARD (2009)**
PHI awarded \$25,000 to team from University of Insubria, Varese, Italy, led by Antonio Toniolo, MD, PhD, Professor of Medical Microbiology and Virology. The study, [Persisting Noninfectious Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral Drugs](#), will complete the sequencing of the genome of persistent fragments of poliovirus strains and compare them to wild-type polioviruses.
- **THE FOURTH AWARD (2007)**
[PHI Grant Awarded to team at University of Arkansas for Medical Sciences \(UAMS\) for Pilot Study to Identify PPS Biomarker](#). The researchers propose to determine whether there is a unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome (PPS) that would enable a more definitive diagnosis of PPS. **NO PUBLICATION YET.**

Global Polio Eradication Initiative

- | | Total cases Year-to-date 2009 | Total in 2008 |
|--|-------------------------------|--|
| Globally | 416 | 1652 |
| In endemic countries (5): | 302 | 1506 |
| <u>in non-endemic countries (15):</u> | 114 | 146 (From polio being carried in) |

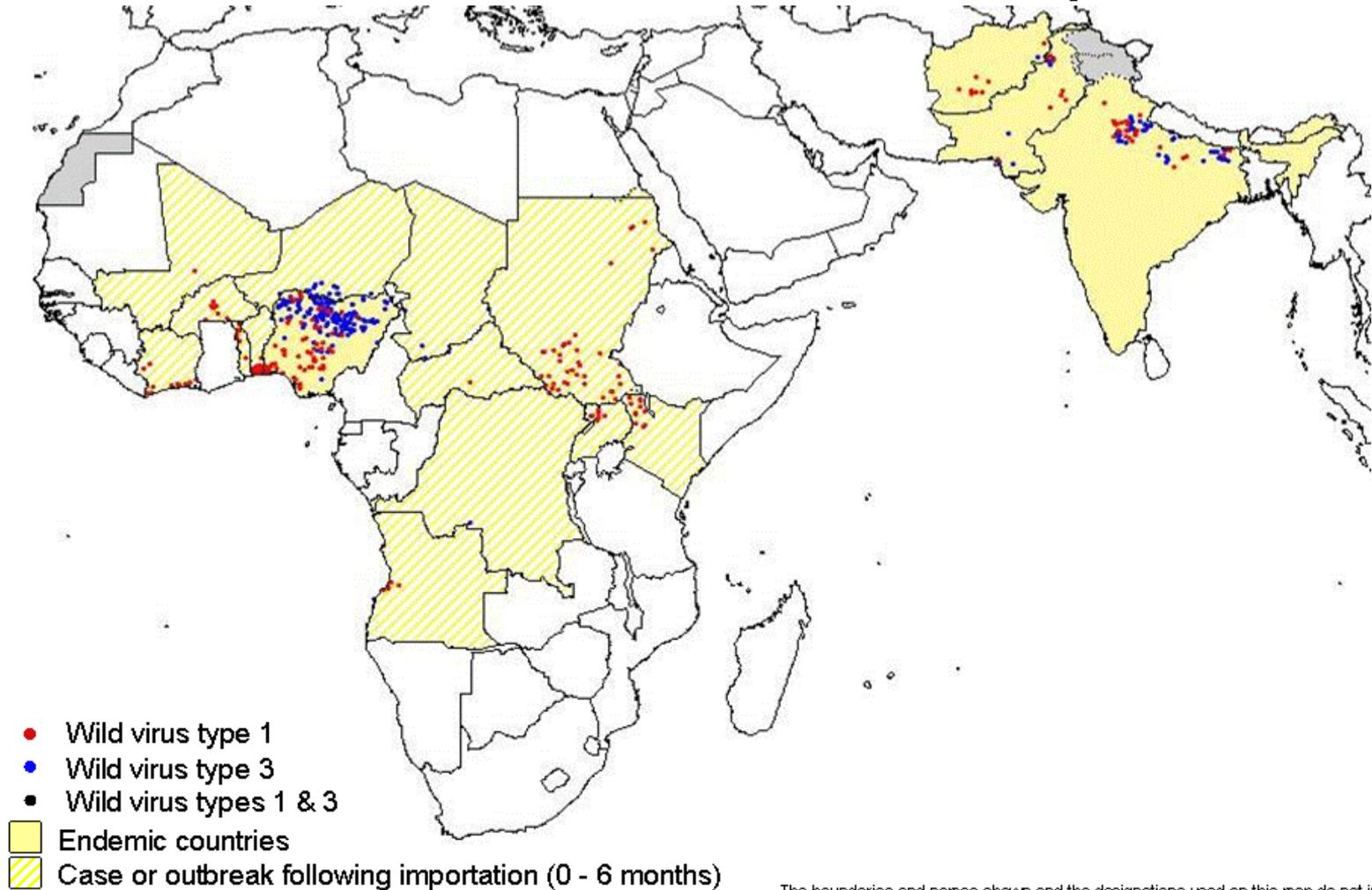
Case breakdown by country

- | Country | Year-to-date 2009 | Total in 2008 | Date of onset of most recent case |
|----------------------|-------------------|---------------|-----------------------------------|
| *Pakistan | 12 | 117 | 21 April 2009 |
| *Afghanistan | 7 | 31 | 19 April 2009 |
| *Nigeria | 243 | 799 | 18 April 2009 |
| *India | 40 | 559 | 15 April 2009 |
| Kenya | 11 | 0 | 12 April 2009 |
| Côte d'Ivoire | 10 | 1 | 6 April 2009 |
| Sudan | 33 | 26 | 4 April 2009 |
| CAR | 1 | 3 | 2 April 2009 |
| Chad | 1 | 37 | 1 April 2009 |
| Togo | 6 | 3 | 28 March 2009 |
| Benin | 17 | 6 | 25 March 2009 |
| Niger | 13 | 12 | 23 March 2009 |
| Burkina Faso | 9 | 6 | 16 March 2009 |
| Uganda | 7 | 0 | 21 February 2009 |
| Angola | 4 | 29 | 18 February 2009 |
| DRC | 1 | 5 | 10 February 2009 |
| Mali | 1 | 1 | 4 January 2009 |
| Ghana | 0 | 8 | 8 November 2008 |
| *Nepal | 0 | 6 | 15 October 2008 |
| Ethiopia | 0 | 3 | 27 April 2008 |

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Wild Poliovirus*, 13 Nov 2008 – 12 May 2009



*Excludes viruses detected from environmental surveillance and vaccine derived polioviruses

Data in WHO HQ as of 12 May 2009

The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.
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World Health Organization

<http://www.polioeradication.org/>

- **15 May 2009 Independent evaluation of major barriers to polio eradication**
- Planning for an independent evaluation of the major barriers to interrupting poliovirus transmission is now well under way. The evaluation, requested by WHO's Executive Board in January, is being conducted two years after the start of the intensified eradication effort. It will focus on the key infected areas, giving particular attention to the primary challenges identified in each. The recommendations resulting from the evaluation will lead to area-specific action plans that will be key to finalizing the 2010-2014 Strategic Plan of the Global Polio Eradication Initiative.

The work is being overseen by an Oversight Committee comprised of a senior representative of each of the GPEI spearheading partners. Members are Dr Anarfi Asamoah-Baah, Deputy Director-General of WHO; Mr Ron Burton, Vice-Chairman of the Rotary Foundation; Mr Finbar O'Brien, Director of Evaluation at UNICEF; and Dr Anne Schuchat, Acting Deputy Director for Science and Program at the United States Centers for Disease Control and Prevention.

A core evaluation team is being appointed by the Committee to lead the work. This core team will manage five sub-teams, with one team focusing on each of the endemic countries, and a fifth considering issues of international spread. The composition of this core team is expected to be finalized shortly. A senior-level national representative with a strong public health background but independent from polio eradication activities has been nominated by the Minister of Health of each of the polio-endemic countries to provide support.

The in-country work of the team is expected to take place in July and August with recommendations to be made to the Oversight Committee before the end of September.

Further information will be posted on this web site as planning progresses.

Now the Good News

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PPHI 10th International Conference at Warm Springs “Living with Polio in the 21st Century”

April 23 - 25, 2009

Conference Session-By-Session Schedule

THURSDAY, APRIL 23, 2009		
<p>1:00-2:00 p.m. Session T1 – Opening Plenary Location & Legacy – Purpose & Possibilities</p> <p>2:30 – 3:45 p.m. Session T2 Options First Things First:</p> <ul style="list-style-type: none"> • Understanding Poliomyelitis • Tools to Use in Evaluating Treatment Choices • Polio: The Legacy of Warm Springs • Modifying ADL Techniques to Accommodate New Weakness <p>4:15 – 5:30 p.m. Session T3 Options</p> <ul style="list-style-type: none"> • Demonstration and Discussion of a Post-Polio Examination: Sorting Out Secondary Conditions, Part 1 • Feel Good Food: Boosting Energy, Maintaining Weight • Meeting Other Users of Home Mechanical Ventilation • Finding Disseminating Information through Support Groups <p>5:30 – 7:30 p.m. Dinner 6:15 – 8:30 p.m. Sessions</p> <p>6:15- 7:15 p.m. Repeat 7:30-8:30 p.m. Your Mobility Device and Your Posture</p> <p>6:16-7:15 p.m.; Repeat 7:30- 8:30 p.m. Water Can Still Benefit Survivors</p> <p>6:00- 8:15 p.m.; Stop in anytime Yes, You Can Bowl</p> <p>6:45 – 8:15 p.m. Polio Narratives: Readings and Discussion of the Writing Process</p> <p>6:15- 7:15 pm; Repeat 7:30-8:30 p.m. Learn About Acupuncture</p> <p>6:15-7:15 p.m.; Repeat 7:30-8:30 p.m. Yes, You Can Practice Yoga</p>	<p>9:30-10:45 a.m. Session F1 Options Demonstration and Discussion of a Post-Polio Examination:</p> <ul style="list-style-type: none"> • Don't Forget Breathing: Part 3 • Warm Springs During the Epidemic Years: Not the Usual Story • Demonstration and Discussion of a Bracing Evaluation • PH1 Research Grant: Progress on a Biomarker for PPS • Aging with a Disability: Policy Lessons Learned from Polio <p>11:15 a.m. – 12:30 p.m. Session F2 Options</p> <ul style="list-style-type: none"> • Finding Causes of and Managing Fatigue, Part 1 • Making the Tough Decisions: Palliative Care and End-of-Life Decisions • Anesthesia Update: Separating Fact from Fear • Demonstration and Discussion of a Seating Evaluation • Benefits and Techniques of Aquatic Therapy <p>1:00-2:15 p.m. Session F3 Options</p> <ul style="list-style-type: none"> • Current Epidemics: Status, Lessons and Tasks • Using Assistive Technology for Personal Independence • Exercise: The Kinds, the Methods and the Benefits • Alimentary Matters and Bladder and Bowel Inconveniences • Communicating with your Physician: Techniques that Work <p>2:45 – 4:00 p.m. Session F4 Options</p> <ul style="list-style-type: none"> • Finding Causes of and Managing Fatigue, Part 2 • Effective Family Communication: Do We? How Can We Improve? • Exercise and Activity: How Much and What? Let's Get Practical • Complementary and Alternative Medicine: What You Don't Know Can Hurt You • Assisted Living Communities for Survivors 	<p>4:30-6:30 p.m. Story telling and pizza in Georgia Hall 7:00-9:00 p.m. Film Night in Roosevelt Hall Auditorium and Vocational Rehabilitation Unit Auditorium</p> <p>SATURDAY, APRIL 25, 2009</p> <p>8:30 – 9:30 a.m. Registration in Georgia Hall 8:30 – 9:30 a.m. Continental Breakfast</p> <p>9:30-10:45 a.m. Session S1 Options</p> <ul style="list-style-type: none"> • First Step in Pain Treatment: Finding the Cause • Surgery for Polio Survivors: What to Consider • Know Thyself: Mind as Well as Body • The Secret to Good Attendant Care • Report from the Camp Dreamers: Review of the Wellness Retreat <p>11:15 a.m. – 12:30 p.m. Session S2 Options</p> <ul style="list-style-type: none"> • Second Step in Pain Treatment: Choosing Therapies • Learning from Wise Elders • Poly Pharmacy: Making It All Work • Too Hot and Too Cold: Causes and Solutions • When are Trachs and Option? <p>1:00- 2:15 p.m. Session S3 Options</p> <ul style="list-style-type: none"> • Post-Polio Research: Progress, Possibilities and Problems • Bracing: What's New? Is Old Better? • Exercise and Activity: How Much and What? Let's Get Practical • Demystifying the Equipment of Assisted Breathing • Accessible Housing for Aging Polio Survivors: Problems and Solutions <p>2:45-4:00 p.m. Session S4 – Closing Plenary Polio: A Look Back at the Public Health Crusade that Mobilized a Nation.</p> <p>5:30 p.m. Dinner and Entertainment at Camp Dream</p>
<p>FRIDAY, APRIL 24, 2009</p> <p>8:30 a.m.-1:30 p.m. Registration in Ga. Hall 8:30 a.m.- 9:30 a.m. Continental Breakfast</p>		

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I Believe the Standard Guidelines Still Hold

- **Make sure your symptoms are polio related and not due to other neurologic, orthopedic, or medical/medicine issues.**
- **Use Rehab to develop a program of appropriate non-fatiguing exercise and reconditioning, assistive devices, pacing, and finding your limit.**
- **Do not push past the limit of pain and fatigue.**
- **No one is talking “Conserve to Preserve”.**
- **Everyone needs a good PCMD, knowledgeable PT, and attention to good general health (weight control, exercise, assistive devices, relaxation training, sleep hygiene, emotional health).**

More Good News

- In the past 12 months there have been 20 new publications about post polio in the medical literature—
 - 2 review articles of post-polio syndrome
 - 2 dealing with EMG
 - 2 dealing with biomarkers
 - 1 dealing with IVIG
 - 3 dealing with exercise treatment
 - 3 dealing with medical issues
 - 2 dealing with respiratory or ventilator issues*
 - 5 dealing with orthopedic surgeries*

Review Articles/Natural History

- **Post-polio syndrome: epidemiologic and prognostic aspects in Brazil.**
- [Conde MT](#), [Oliveira AS](#), [Quadros AA](#), [Moreira GA](#), [Silva HC](#), [Pereira RD](#), [E Silva TM](#), [Tufik S](#), [Waldman EA](#).
- School of Public Health, University of São Paulo, São Paulo, Brazil.
- Acta Neurol Scand. 2008 Dec 26. [Epub ahead of print]

- 132 patients with post-polio syndrome.
- The average age at onset was 39.4 years. The most common symptoms were fatigue (87.1%), muscle pain (82.4%) and joint pain (72.0%); 50.4% of the cases were severe.
- The following were associated with PPS severity: a ≤ 4 -year period of neurological recovery (OR 2.8), permanent damage in two limbs (OR 3.6) and residence at the time of acute polio in a city with more advanced medical assistance (OR 2.5).
- Conclusions - Health professionals should carefully evaluate polio survivors for PPS and be aware of the implications of muscle overuse in the neurological recovery period.

- **Vitality among Swedish patients with post-polio: a physiological phenomenon.**
- [Ostlund G](#), [Wahlin A](#), [Sunnerhagen KS](#), [Borg K](#).
- Department of Rehabilitation Medicine, Danderyd University Hospital, Building 39, 3rd Floor, SE-182 88 Stockholm, Sweden. Gunilla.Ostlund@ki.se
- J Rehabil Med. 2008 Oct;40(9):709-14
- Multicenter Study of 143 patients with post polio syndrome
- General fatigue accounted for 68% of the variation in vitality. Of this, 91% was accounted for by physiological indicators. After controlling for age, physiological parameters accounted for 56.6% and 25%, if entered before and after the psychological parameters, respectively. The impact of the psychological parameters decreased after accounting for the physiological parameters.
- Physical fatigue, age and sleep quality were associated with variation in pain.
- Body mass index, pain and sleep quality accounted for differences in reduced activity and physical fatigue.
- **CONCLUSION:** Vitality in post-polio patients depends on physio-logical parameters. Mental fatigue is not a prominent predictor. Subgroups with or without fatigue, independent of age, need further study

EMG

- **Electromyographic and neuromuscular analysis in patients with post-polio syndrome.**
- [Corrêa JC](#), [Rocco CC](#), [de Andrade DV](#), [Peres JA](#), [Corrêa FI](#).
- Physical Therapy Clinic, Health Sciences Department, Nove de Julho University Center-UNINOVE, São Paulo, SP, Brazil. jcorrea@uninove.br
- Electromyogr Clin Neurophysiol. 2008 Nov-Dec;48(8):329-33.

- 18 patients with post polio syndrome

- There were significant differences among the comparative analysis of EMG activity of the muscles rectus femoris, vastus medialis and vastus lateralis after maximal isometric contraction during knee extension. Initial muscle contraction and contraction after a 15 minute-rest from initial contraction decreased considerably, indicating a decreased endurance on muscle contraction, concluding that a lower limb muscle fatigue was present on the analyzed PPS patients.

- **American Association of Neuromuscular & Electrodiagnostic Medicine evidenced-based review: use of surface electromyography in the diagnosis and study of neuromuscular disorders.**
- [Meekins GD](#), [So Y](#), [Quan D](#).
- Department of Neurology, University of Washington, Seattle, Washington
- Muscle Nerve. 2008 Oct;38(4):1219-24

- Review of relevant literature published between January 1994 and February 2006
- Surface electromyography (sEMG) measures myoelectrical signals recorded from sensors placed on the skin surface.
- The present review concludes that sEMG may be useful to detect the presence of neuromuscular disease (level C rating, class III data), but there are insufficient data to support its utility for distinguishing between neuropathic and myopathic conditions or for the diagnosis of specific neuromuscular diseases.
- sEMG may be useful for additional study of fatigue associated with post-poliomyelitis syndrome and electromechanical function in myotonic dystrophy (level C rating, class III data).

Biomarkers

- **Identification of novel candidate protein biomarkers for the post-polio syndrome - implications for diagnosis, neurodegeneration and neuroinflammation.**
- [Gonzalez H](#), [Ottervald J](#), [Nilsson KC](#), [Sjögren N](#), [Miliotis T](#), [Von Bahr H](#), [Khademi M](#), [Eriksson B](#), [Kjellström S](#), [Vegvari A](#), [Harris R](#), [Marko-Varga G](#), [Borg K](#), [Nilsson J](#), [Laurell T](#), [Olsson T](#), [Franzén B](#).
- Department of Clinical Sciences, Danderyd Hospital, Karolinska Institute, Stockholm, Sweden.
- J Proteomics. 2009 Jan 30;71(6):670-81. Epub 2008 Dec 3.
- CSF from 15 patients with well-defined PPS were analyzed for protein expression profiles. The results were compared to data obtained from nine healthy controls and 34 patients with other non-inflammatory diseases which served as negative controls. In addition, 17 samples from persons with secondary progressive multiple sclerosis (SPMS) were added as relevant age-matched references for the PPS samples.
- The CSF of persons with PPS displayed a disease-specific and highly predictive ($p=0.0017$) differential expression of five distinct proteins: **gelsolin**, **hemopexin**, **peptidylglycine alpha-amidating monooxygenase**, **glutathione synthetase** and **kallikrein 6**, respectively, in comparison with the control groups. An independent ELISA confirmed the increase of kallikrein 6.
- We suggest that these five proteins should be further evaluated as candidate biomarkers for the diagnosis and development of new therapies for PPS patients.

- **Elevated serum inflammatory markers in post-poliomyelitis syndrome.**
- [Fordyce CB, Gagne D, Jalili F, Alatab S, Arnold DL, Da Costa D, Sawoszczuk S, Bodner C, Shapiro S, Collet JP, Robinson A, Le Cruquel JP, Lapierre Y, Bar-Or A, Trojan DA.](#)
- Department of Neurology and Neurosurgery, Montreal Neurological Institute and Hospital, Montreal, Quebec, Canada.
- J Neurol Sci. 2008 Aug 15;271(1-2):80-6. Epub 2008 May 12.
- **METHODS:** Serum inflammatory markers were measured (by Luminex) in 51 PPS patients and 26 normal controls.
- Clinical parameters assessed included disease duration, muscle strength (Medical Research Council sumscore), fatigue (Fatigue Severity Scale and Multidimensional Fatigue Inventory), and pain (visual analog scale scores).
- **RESULTS:** In PPS, **TNF alpha levels, as well as IL-6 and leptin** were significantly increased compared to controls (Wilcoxon rank-sum test, $p=0.03$ for TNFalpha, $p=0.03$ for IL-6, $p=0.01$ for leptin).
- The elevated TNFalpha levels in PPS were associated with increased pain due to illness (Spearman correlation coefficient $r=0.36$, 95% C.I. 0.09 to 0.57) and specifically, with muscle pain ($r=0.38$, 95% C.I. 0.11 to 0.59).
- There were no correlations between inflammatory markers in PPS and joint pain, muscle strength, fatigue, or disease duration.
- **CONCLUSIONS:** Serum TNFalpha, IL-6 and leptin levels are abnormally increased in PPS patients. **Elevated TNFalpha levels appear to be specifically associated with increased muscle pain.**

IVIg

- **IVIg in other autoimmune neurological disorders: current status and future prospects.**
- **[Dalakas M.](#)**
- Neuromuscular Division, Dept. of Neurology, 900 Walnut St., 2nd Floor, Philadelphia, PA 19107, USA. marinos.dalakas@jefferson.edu
- J Neurol. 2008 Jul;255 Suppl 3:12-6.

- For neurodegenerative diseases such as Alzheimer's disease, post-polio syndrome, pain, fibrosis, and autoimmune sleep disorders, some early promising results for the use of IVIg are emerging, but remain to be fully investigated. In conclusion, IVIg appears to be an effective treatment for a number of autoimmune disorders, however, optimal dosing and pharmacogenetic studies are necessary.

Exercise Treatment

- **Short-term effects of aerobic exercise on functional capacity, fatigue, and quality of life in patients with post-polio syndrome.**
- [Oncu J](#), [Durmaz B](#), [Karapolat H](#).
- Ege University Medical Faculty Physical Medicine and Rehabilitation Department, Izmir, Turkey.
- Clin Rehabil. 2009 Feb;23(2):155-63

- **SUBJECTS:** Thirty-two patients were divided into two groups for either hospital- or home-based aerobic exercise programme.
- **MAIN OUTCOME MEASURES:** Patients were assessed before and after the rehabilitation programme, with respect to functional capacity (pVo₂), fatigue (Fatigue Severity Scale, Fatigue Impact Scale) and quality of life (Nottingham Heath Profile).
- **RESULTS:** After the exercise programme, improvement was observed in the hospital exercise group compared to a pre-exercise period in all Nottingham Heath Profile scores (except sleep scores), pVo₂, Fatigue Severity Scale and Fatigue Impact Scale (cognitive, physical, psychosocial, total) (P<0.05).
- In contrast, in the home exercise group a decrease was observed in pVo₂ scores after the rehabilitation programme, compared to a pre-rehabilitation period (P<0.05). In addition, a significant improvement was observed in the home exercise group after the rehabilitation programme in all parameters excluding Fatigue Impact Scale-physical, Fatigue Impact Scale-psychosocial, and Nottingham Heath Profile-sleep (P<0.05).
- **CONCLUSION:** Fatigue and quality of life were both improved in the home and hospital exercise groups. An increase was also found in the functional capacity in the hospital exercise group. A regular exercise programme is beneficial to patients with post-polio syndrome.

- **Effects of resistance training in combination with coenzyme Q10 supplementation in patients with post-polio: a pilot study.**
- [Skough K](#), [Krossén C](#), [Heiwe S](#), [Theorell H](#), [Borg K](#).
- Department of Clinical Sciences, Karolinska Institutet, Division of Rehabilitation Medicine, Danderyds Hospital, Stockholm, Sweden.
- J Rehabil Med. 2008 Oct;40(9):773-5
- DESIGN: Parallel randomized, controlled, double-blind pilot study.
- PATIENTS AND METHODS: A total of 14 patients (8 women and 6 men) with post-polio syndrome participated in a 12-week muscular resistance training, 3 days/week. The patients were randomized for oral supplementation with coenzyme Q10, 200 mg/day, or placebo. Measurements used were: sit-stand-sit test, timed up & go test, 6-minute walk test, muscle strength measurement by means of dynamic dynamometer and short-form (SF)-36 questionnaire.
- RESULTS: **Muscle strength, muscle endurance and quality of life regarding mental health increased statistically significantly in all 14 patients.**
- There was no significant difference between the coenzyme Q10 and placebo groups regarding muscle strength, muscle endurance and quality of life.
- CONCLUSION: There was no effect of coenzyme Q10 supplementation during resistance training on post-polio syndrome symptoms. Thus, supplementation with coenzyme Q10 has no beneficial effect on muscle function in patients with post-polio syndrome.

- **Prolonged benefit in post-polio syndrome from comprehensive rehabilitation: a pilot study.**
- [Davidson AC](#), [Auyeung V](#), [Luff R](#), [Holland M](#), [Hodgkiss A](#), [Weinman J](#).
- Lane-Fox Respiratory Unit, Guy's and St Thomas' Foundation Trust, London, UK.
craig.davidson@gstt.nhs.uk
- Disabil Rehabil. 2009;31(4):309-17
- **METHOD:** Twenty-seven participants completed the nine-day programme and were available for re-assessment at three and six months.
- Physical outcome measures were muscle strength and endurance; psychological outcomes included illness perceptions (IPQ), depression and anxiety (HADS); functional outcomes were fatigue (HFS) and client-centred occupational performance and satisfaction (COPM).
- **RESULTS:** There was no significant change at six months for muscle strength or anxiety.
- Significant improvements were recorded for **exercise endurance, depression and levels of fatigue.**
- A shift towards an endorsement that the patient's own behaviour could be important in symptom severity of PPS was seen. Five out of 24 participants demonstrated significant clinical changes in occupational performance and satisfaction on the COPM.
- **CONCLUSIONS:** Prolonged benefits were found for physical, psychological and functional outcomes. A qualitative study is planned to investigate the patient-reported benefits of attending the programme such as the support gained interacting with others with similar disability and in lifestyle adjustment such as pacing of physical activities.

Medical Issues

- **Restless legs may be associated with the post-polio syndrome.**
- [De Grandis E](#), [Mir P](#), [Edwards MJ](#), [Bhatia KP](#).
- Sobell Department of Motor Neuroscience and Movement Disorders, Institute of Neurology, Queen Square, London WC1N 3BG, UK.
- Parkinsonism Relat Disord. 2009 Jan;15(1):74-5. Epub 2008 Mar 28

- Restless legs syndrome (RLS) has been described in association with a number of conditions including iron deficiency, neuropathy and Parkinson's disease. Here we report a patient who developed RLS concurrent with the development of classic post-polio syndrome (PPS), 40 years after recovery from an episode of paralytic poliomyelitis. PPS is still frequently encountered in neurological practice, and clinicians should be aware of the possibility of associated RLS.

- **Basal metabolic rate and body composition in patients with post-polio syndrome.**
- [Bargieri JV](#), [Quadros AA](#), [Pereira RD](#), [Oliveira AJ](#), [Lazaretti-Castro M](#), [Silva AC](#).
- Department of Physiology, Neuromuscular Diseases Division, Federal University of São Paulo, São Paulo, Brazil.
- Ann Nutr Metab. 2008;53(3-4):199-204. Epub 2008 Nov 28
- The aim of this study was to compare basal metabolic rate (BMR) of post-polio syndrome (PPS) patients with healthy individuals and to determine its correlation to body composition.
- BMR (kcal/day) was determined by indirect calorimetry and body composition by dual energy X-ray absorptiometry. BMR was lower in the PPS patient group than in the control group, although it was **similar in both groups when adjusted for body surface area, total body mass (TBM), lean body mass (LBM) and fat-free mass (FFM)**.
- **PPS patients also showed reduced TBM, LBM and FFM in relation to controls.**
- As muscle energy expenditure while at rest contributes only 20% to the BMR, a proportional reduction in BMR and FFM or LBM could suggest that **muscle mass or other factors may interfere more than predicted**. It was concluded that the prediction of BMR from the Harris-Benedict equation in PPS patients must be carefully reviewed.
- Of additional interest--

- **Factors influencing variation in basal metabolic rate include fat-free mass, fat mass, age, and circulating thyroxine but not sex, circulating leptin, or triiodothyronine.**
- **[Johnstone AM](#), [Murison SD](#), [Duncan JS](#), [Rance KA](#), [Speakman JR](#).**
- Aberdeen Centre for Energy Regulation and Obesity, Division of Energy Balance and Obesity, Rowett Research Institute, Aberdeen, Scotland, United Kingdom.
a.johnstone@rowett.ac.uk
- Am J Clin Nutr. 2005 Nov;82(5):941-8

- **CONCLUSIONS:** Our data confirm that both FFM and FM are significant contributors to BMR. When the effect of FM on BMR is removed, any association with leptin concentrations disappears, which suggests that previous links between circulating leptin concentrations and BMR occurred only because of inadequate control for the effects of FM.

There have been 17 new publications since May

- **5 dealing with vaccine related issues**
- **4 dealing with orthopedic concerns, including one that stresses the need for a baseline neurologic evaluation before a surgical procedure**
- **2 discussing osteoporosis, fractures, and bone scan**
- **1 discussing respiratory muscle training**
- **A review of post-polio in Brazil**
- **A review of non-polio enteroviruses causing acute flaccid paralysis in India**
- **And 3 dealing with fatigue and neuropsychological concerns.**

Fatigue

- **Fatigue in post-poliomyelitis syndrome: association with disease-related, behavioral, and psychosocial factors.**
- **Trojan DA, Arnold DL, Shapiro S, Bar-Or A, Robinson A, Le Cruguel JP, Narayanan S, Tartaglia MC, Caramanos Z, Da Costa D.**
- **PM R. 2009 May;1(5):442-9**

- **OBJECTIVE:** To determine the biopsychosocial correlates of general, physical, and mental fatigue in patients with postpoliomyelitis syndrome (PPS) by assessing the additional contribution of potentially modifiable factors after accounting for important nonmodifiable disease-related factors. It was hypothesized that disease-related, behavioral, and psychosocial factors would contribute in different ways to general, physical, and mental fatigue in PPS and that a portion of fatigue would be determined by potentially modifiable factors.
- **DESIGN:** Cross-sectional study.
- **SETTING:** A tertiary university-affiliated hospital post-polio clinic.
- **PATIENTS:** Fifty-two ambulatory patients with PPS who were not severely depressed were included.
- **ASSESSMENT OF RISK FACTORS:** Potential correlates for fatigue included disease-related factors (acute polio weakness, time since acute polio, PPS duration, muscle strength, pain, forced vital capacity, maximum inspiratory pressure, maximum expiratory pressure, body mass index, disability, fibromyalgia), behavioral factors (physical activity, sleep quality), and psychosocial factors (depression, stress, self-efficacy).
- **MAIN OUTCOME MEASUREMENTS:** Fatigue was assessed with the Multidimensional Fatigue Inventory (MFI; assesses fatigue on 5 subscales) and the Fatigue Severity Scale (FSS).

- **RESULTS: Multivariate models were computed for MFI General, Physical, and Mental Fatigue. Age-adjusted multivariate models with nonmodifiable factors included the following predictors of**
- **(1) MFI General Fatigue: maximum inspiratory pressure, fibromyalgia, muscle strength;**
- **(2) MFI Physical Fatigue: maximum expiratory pressure, muscle strength, age, time since acute polio; and**
- **(3) MFI Mental Fatigue: none.**

- **The following potentially modifiable predictors made an additional contribution to the models:**
- **(1) MFI General Fatigue: stress, depression;**
- **(2) MFI Physical Fatigue: physical activity, pain; and**
- **(3) MFI Mental Fatigue: stress.**

- **CONCLUSIONS: PPS fatigue is multidimensional. Different types of fatigue are determined by different variables. Potentially modifiable factors account for a portion of fatigue in PPS.**

Fatigue Management

- **Development, standardisation and pilot testing of an online fatigue self-management program.**
- **[Ghahari S](#), [Packer TL](#), [Passmore AE](#).**
- **Disabil Rehabil. 2009 May 19:1-11. [Epub ahead of print]**

How much was due to the activities and how much to the support model?

- **Purpose.** Although an effective face-to-face fatigue program is available, people with transportation, time or geographic restrictions cannot access this intervention. Therefore, the aim of this study was to develop and to evaluate effectiveness of an online fatigue self-management program (online FSMP).
- **Methods.** Key features of the face-to-face program were captured and transferred to an online FSMP prototype. Subsequently, three pilot tests were conducted for formative evaluation of the program and necessary changes were made to improve the program. During the third pilot test, the effectiveness of the online FSMP was also tested using a pre-test post-test design on a sample of individuals with multiple sclerosis, Parkinson's disease or post-polio syndrome.
- **Results.** The study resulted in a standardised 7-week online FSMP mimicking its face-to-face version. Participants were offered fatigue self-management skills through structured activities, sharing information and experiences, expressing their ideas or feelings and offering advice and support to one another.
- The participants in the third pilot study improved significantly on the Fatigue Impact Scale ($p < 0.05$) and a trend toward significance was shown on the Personal Wellbeing index ($p = 0.08$).
- **Conclusions.** The online FSMP is a viable treatment for people with neurological conditions and warrants further study.

Neuropsychology

- Fixed belief in cognitive dysfunction despite normal neuropsychological scores: neurocognitive hypochondriasis?
- **Boone KB.**
- **Clin Neuropsychol. 2009 Aug;23(6):1016-36.**

- **A subset of patients who present for neuropsychological testing report dysfunction in daily life activities secondary to cognitive deficits, but are found on formal testing to have no objective abnormalities, raising the possibility of "neurocognitive hypochondriasis."**
- **Such a case is presented, and the factors that appear to give rise to this presentation are explored.**

- **Cases of hypochondriacal overconcern regarding cognitive function are likely not rare, particularly given research showing**
- **there is little correlation between objective report of cognitive dysfunction and actual test scores in such conditions as mild traumatic brain injury, chronic fatigue syndrome, fibromyalgia, toxic mold exposure, and post-polio syndrome.**
- **ARE THEY MEASURING THE WRONG THING?**
- **IMAGING BIOMARKERS DO SUGGEST DYSFUNCTION IN TBI, WHY NOT PPS “BRAIN FATIGUE”?**

Clinical Trials

- **9 completed post-polio studies**
- **Only one active study listed—**
- **Study of Mental Fatigue in Polio Survivors**
- **This study is currently recruiting participants.**
- **Verified by Uniformed Services University of the Health Sciences, March 2007**
- **First Received: June 14, 2007 Last Updated: June 15, 2007**
- **Sponsored by: Uniformed Services University of the Health Sciences**
- **Information provided by: Uniformed Services University of the Health Sciences**
- **ClinicalTrials.gov Identifier: NCT00487487**

- **Post-Poliomyelitis Syndrome (PPS)** is the term describing the new problems affecting **polio** survivors many years after recovery from paralytic **polio**.
- Among the symptoms, fatigue is one of the most frequent and debilitating. In addition to physical incapacitation, the fatigue of PPS also affects mental function. The term “brain fatigue” is usually used by patients to express problems on the areas of attention, concentration, memory and clear thinking.
- Unfortunately, little is known about cognitive fatigue of PPS patients. This study is meant to examine if mental impairment is present in PPS patients and, if so, how it interferes on the self-function of patients. Patients will undergo an interview, clinical and neurological evaluation, and a battery of screening laboratory tests to make sure they are eligible for the study. Patients who qualify will undergo neuropsychometric tests in order to assay performance in the main areas of cognitive functioning. Through this organized approach we expect to be able to determine if mental fatigue is a significant problem affecting **polio** survivors, what areas are most affected, and how it may interfere with daily living.

Registry for Polio Survivors

- <https://www.conemaugh.org/apps/postpolio/>
- The John P. Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania, launched an [online registry of polio survivors](#) to promote research about the late effects of polio and post-polio syndrome.
5-10 minutes of on-line questions
Your identity is kept confidential

WHY THE NEED TO INCREASE AWARENESS?

- Polio survivors report poorer functional status and health-related quality of life, than non-polios.
- The life-altering effects of PPMA have not been adequately addressed by health care providers.
- Many publications indicate that polio survivors are best served in multidisciplinary clinics staffed by knowledgeable professionals.

WHAT WE ALREADY KNOW

- **New symptoms in a polio survivor are PPS only about 1/3 of the time.**
- **New symptoms may be due to another medical or neurological illness or to orthopedic problems, which must be identified and treated.**
- **Treatment of other illnesses in a polio survivor must be monitored relative to the sensitivities of PPS (eg. surgery, chemotherapy, use of cholesterol lowering medication).**
- **Polio survivors with symptoms of PPS must take care to modify lifestyle; avoid overuse; use assistive devices and bracing if appropriate; control weight gain, sleep problems, stress, and pain; and engage in non-fatiguing exercise for strength and conditioning. Many studies have shown that success in these areas can halt progression of PPS symptoms and promote improvement of 1-2% per year.**

EDUCATIONAL IMPERATIVE

- The March of Dimes has issued a report for physicians that outlines the best practices in diagnosis and care of post-polio syndrome.
- This report has been publicized by the American Medical News and has been reprinted in the Medical Board of California ACTION REPORT, which is mailed to all physicians licensed in California.
- <http://www.marchofdimes.com/files/PPSreport.pdf>
- <http://www.marchofdimes.com/files/p-psbro.pdf>

Resources

WWW.POST-POLIO.ORG

WWW.NCBI.NLM.NIH.GOV/ENTREZ
(PUBMED)

WWW.CLINICALTRIALS.GOV

Disclaimer: The following are unofficial notes which have not been read by or approved by the speaker.

- Once a year, Dr. Perlman gives a presentation to a Southern California Support Network to update them to current research in post polio.
- She tries to educate patients to take control of their conditions.

- Global Polio Eradication Initiative: Statistics from May to October 2009 increased as follows: Total cases Globally – 741, increase of 325; In endemic countries – 540, an increase of 238 cases. In the countries that are either endemic or have the virus carried into them, the increase is relatively stable.
- Conference at Warm Springs was very successful. Looking over the topics presented, the standard guidelines are still prominent:
 - Make sure your symptoms are polio related and not due to other neurologic, orthopedic, or medical/medicine issues.
 - Use Rehab to develop a program of appropriate non-fatiguing exercise and reconditioning, assistive devices, pacing, and finding your limit.
 - Do not push past the limit of pain and fatigue.
 - No one is talking "Conserve to Preserve".
 - Everyone needs a good PCMD, knowledgeable PT, and attention to good general health (weight control, exercise, assistive devices, relaxation training, sleep hygiene, emotional health).
- "Conserve to Preserve" – all the evidence suggests that you have to do a certain amount of activity in order to preserve what you have.
- If the above guidelines are followed, patients and PCPs can feel they can handle a problem that may be PPS. Therefore, no need for a patient to see a specialist.
- In the past year there were 20 new publications about post-polio in the medical literature. From May to November, there have been 17 new articles published.
- Fatigue Management study using an online self-management program suggests that the online format may be a viable program.
 - Not answered – how much improvement was due to the activity and the knowledge people got versus the support they get from other polio survivors?
 - Could online studies replace the face-to-face that people get with support group meetings?

Question: Restless Leg and how broad the presentation can be and various complaints -- individuals can have deep pain – could a diagnosis of restless leg rule out the diagnosis of post-polio?

- Article deals with fibromyalgia – polio survivors may have associated restless leg because of their motor unit disease. Restless leg and fibromyalgia are fairly common.
- Conference in Brazil in September had three presentations on the topic of Restless Leg Syndrome and periodic leg movement in post-polio. Seems that it might be correlated with sleeping disorders.
- Trying to understand the fatigue in polio survivors, sleep studies were done and evidence found of a disturbed sleep in over 80% of the subjects. Study was never published.
- Incidence of sleep disorders is high in the polio population and is a potentially treatable condition.
- Focusing on sleep disordered breathing opposed to periodic leg movement -- it is hard to know if some of the patients are polio patients with chronic pain that the general population has or polio patients with pre-disposed condition.
- Nothing in literature about polio and pregnancy. One report -- What is the effect of the Mom's polio on the infant? Nothing on what is the effect on the mom. Would be a retrospective study. Many of those individuals would have been pregnant when the post polio symptoms began. This could be one factor in the gender difference.

- John P. Murtha Neuroscience research will look at using home screening for sleep apnea – testing everyone in the clinic.
 - Hypothesis is there are significantly more people with sleep apnea that we do not recognize. Could be true with periodic leg disorder.
- Obesity always comes up as a risk factor. How do you treat the Bariatric patient who has had surgery. Is there an increase in problems after Bariatric surgery?