What's New In PPS?

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Churchill Fellowship Study Tour

- The purpose of my study tour was:
  - *"To identify techniques to better manage the late effects of polio"*
- Travelled to 10 cities in the USA and Canada

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Churchill Fellowship Study Tour (Cont'd)

- Los Angeles, California

- Richard Daggett
  President - Polio Survivors Association

- Dr Susan Perlman
  Director – Post Polio Clinic
  University of California, Los Angeles (UCLA) Medical Center

- Dr Sophia Chun
  Chief - Post Polio Center
  Rancho Los Amigos National Rehab Center

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Churchill Fellowship Study Tour (Cont'd)

- Los Angeles, California
  - Los Angeles Post Polio Support Group

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Churchill Fellowship Study Tour (Cont'd)

- St Louis, Missouri
  - Joan Headley

    Director – Post-Polio Health International

    Board of Directors – ParaQuad Inc.

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Churchill Fellowship Study Tour (Cont'd)

- Warm Springs, Georgia
  - Greg Schmieg
    Executive Director, Roosevelt Warm Springs Institute for Rehabilitation

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Churchill Fellowship Study Tour (Cont'd)

- Washington, DC
  - The Polio Society

    Wendy Wilmer, President / Elver Ariza, Board Member

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Churchill Fellowship Study Tour (Cont'd)

- Washington, DC
  - Dr Lauro Halstead

    Director, Post-Polio Program, National Rehabilitation Hospital

(author of Managing Post-Polio: A Guide to Living and Aging well with Post-Polio Syndrome)

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Churchill Fellowship Study Tour (Cont'd)

- Johnstown, Pennsylvania
  - Dr William DeMayo
    Medical Director, Post-Polio Center
    John P Murtha Neuroscience and Pain Institute

Staff photo by Michael Kuhne

Australian visitors

Dr. William Demayo, director of the neuroscience specialty clinic, talks with Australian visitors Maryann Liethof, a community development worker, and retired occupational therapist and polio survivor Jill Pickering at the John P. Murtha Neuroscience and Pain Institute in Richland Township. Liethof and Pickering were provided with funding to go on a study tour in the United States and Canada. Their goal is to identify the latest research in managing post-polio symptoms and learn about the resources and equipment available.

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Churchill Fellowship Study Tour (Cont'd)

- New York, NY

- Dr Richard Bruno
  Director, The Post-Polio Institute (author of The Polio Paradox)

- Dr Margaret Backman
  Clinical Psychologist (author of The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families)

- Susan Fish
  Physical Therapist

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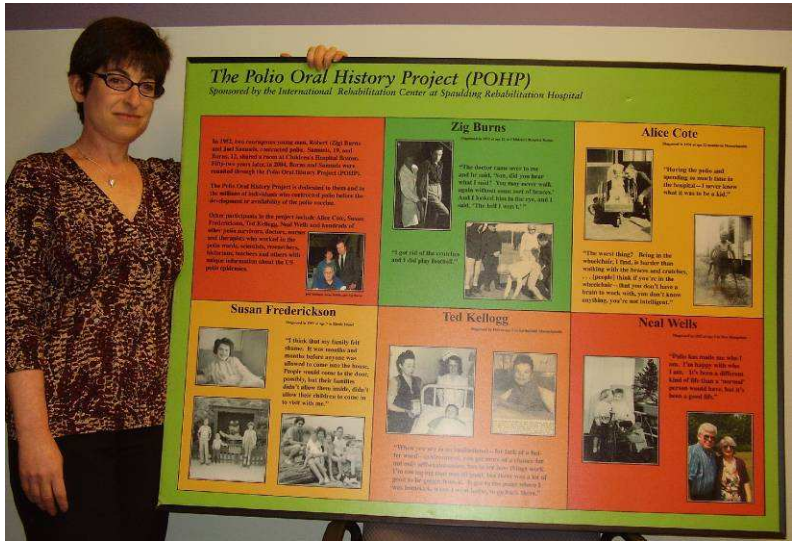
Churchill Fellowship Study Tour (Cont'd)

- Framingham, Massachusetts
  - Dr Darren Rosenberg
    Medical Director, Spaulding Rehabilitation Hospital Network
  - Anna Rubin
    (former) Education & Outreach Co-ordinator, SRHN



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Churchill Fellowship Study Tour (Cont'd)

- Toronto, Ontario, Canada
  - Sheila Casemore

    Group Development and Support Coordinator, National Programs, Ontario March of Dimes

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Churchill Fellowship Study Tour (Cont'd)

- Ottawa, Ontario, Canada
  - Dr Marcia Falconer
    Virologist, Researcher and Polio Survivor

  - Dr Douglas McKim
    Medical Director, Respiratory Rehabilitation Services,
    The Ottawa Hospital Rehabilitation Centre
    and
  - Carole LeBlanc
    Registered Respiratory Therapist, RRS

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Churchill Fellowship Study Tour (Cont'd)

- Montreal, Quebec, Canada

  - Dr Daria Trojan
    Director, Post Polio Clinic,
    Montréal Neurological Institute and Hospital

  - Mr Gilles Besner
    President, Association Polio Quebec

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PPS Clinics

- No two Post-Polio Clinics operated with the same combination of therapists.
- This was influenced by the qualification and experience of the individual/team who instigated the clinic, i.e. Neurologist, Physiatrist (Physical Rehabilitation Specialist), Psychologist or Respiratory Specialist.

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PPS Clinics (Cont'd)

- Standard treating specialists consisted of a Physiatrist or Neurologist, Physiotherapist and Occupational Therapist.

- Additional specialists that may either be on site or referred back to the community were:
  - Nurse for clinical, education and/or research work
  - Speech Therapist for swallowing problems/memory techniques
  - Seating Specialist (usually an OT) for cushions/wheelchairs
  - Psychologist for coping strategies
  - Social Worker for specific case work, e.g. employment/housing
  - Nutritionist/Dietitian for weight management
  - Orthotist for bracing (if required)
  - Orthopedic Specialist for corrective surgery (if required)
  - Respiratory Specialist (if required)

PPS Clinics (Cont'd)

- An assessment with Dr Lauro Halstead at NRH in Washington DC takes 1½ days and involves consultations with the following health professionals:
  - Physiotherapist
  - Occupational Therapist
  - Clinical Nurse
  - Physiatrist
  - Orthotist (if required)
  - Electromyogram (EMG) (if required)
  - Social Worker

- Finally, a 'wrap up' meeting is held with the patient, their 'significant other' and all disciplines to discuss integrated management techniques.

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PPS Clinics (Cont'd)

- At John P Murtha Neuroscience & Pain Institute in Johnstown, the:
  - Physiatrist discusses mind, body and spiritual wellbeing
  - Nurse discusses aromatherapy, meditation, yoga, massage and acupuncture
- Spaulding Rehabilitation Hospital, Framingham includes referrals to additional on-site therapists such as:
  - Psychologist
  - Speech Therapist for swallowing & cognitive function
  - Dietitian
- Referrals to sleep, respiratory and orthopedic specialists are made as required.

Respiratory Clinic

- Dr Douglas McKim and Carole LeBlanc at The Respiratory Rehabilitation Services at The Ottawa Hospital work with a number of polio survivors experiencing respiratory problems.
- Important to keep the airway supple as with other muscles.
- Lung Volume Recruitment (LVR) is proving to be a simple and successful management technique for polio survivors.
- Improves chest movement, prevents small areas of the lung from collapsing, improves cough, and increases speaking volume.

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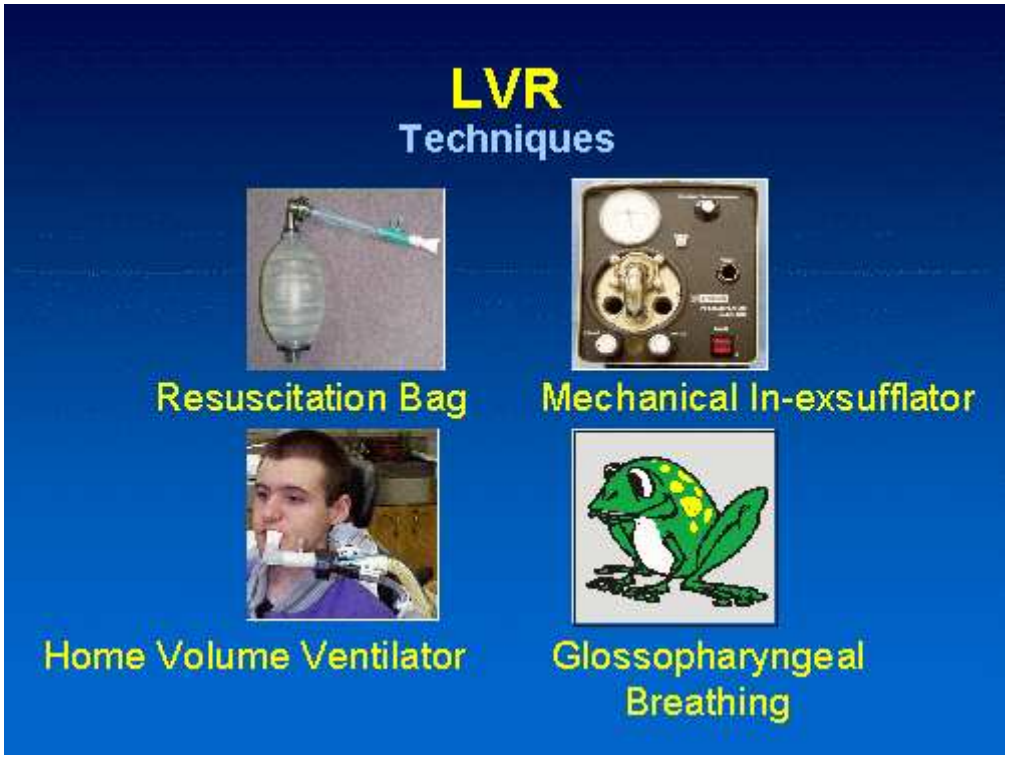
Respiratory Clinic (Cont'd)

- A full step-by-step explanation of LVR can be found on line: www.irrd.ca/education/presentation.asp?refname=e2r4



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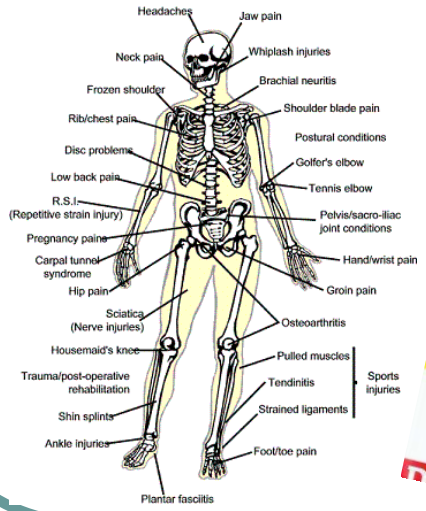
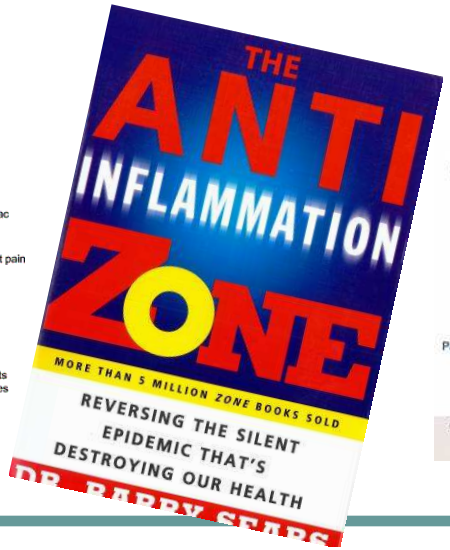
PPS Clinics (Cont'd)

- A model clinic might include access to all these therapists, as well as:
  - An expert in inflammation management, incorporating strategies for relaxation and diet
  - An Osteopath for realignment
  - A Podiatrist to monitor foot health
  - A range of Complimentary and Alternative Medicine (CAM) therapies





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PPS Clinics (Cont'd)

- USA clinical services are paid through a variety of insurance programs.
- International patients can pay for clinical assessments ranging from $1,500 to $3,000US.
- As there is only one PPS clinic in Canada - which has a 6 month waiting list - many Canadians travel to the USA for clinical services.
- Canada, like Australia, has no clear statistics on numbers of people living with PPS.

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Key lessons (Cont'd)

- All health professionals visited believed it was important to have knowledge of the late effects of polio (LEOP) and Post Polio Syndrome (PPS) – or be willing to learn.
- These same health professionals stated they were fully prepared to share their expertise with peers if contacted. Staff at Polio Services Victoria share this philosophy.
- Dr William DeMayo at John P Murtha Neurological & Pain Institute hosts a monthly teleconference at 8.00am (Australian EST) on the third Wednesday of each month - anyone interested in the treatment of PPS can join in.

Key lessons (Cont'd)

- All PPS clinics visited indicated they were consistently busy with local, national and international patients.
- As western world polio survivors age, it was generally agreed that services would increasingly be required for at least another 20-30 years.
- In addition, younger polio survivors are accessing USA services from parts of the world where the poliovirus was more recently eradicated, or is still active.

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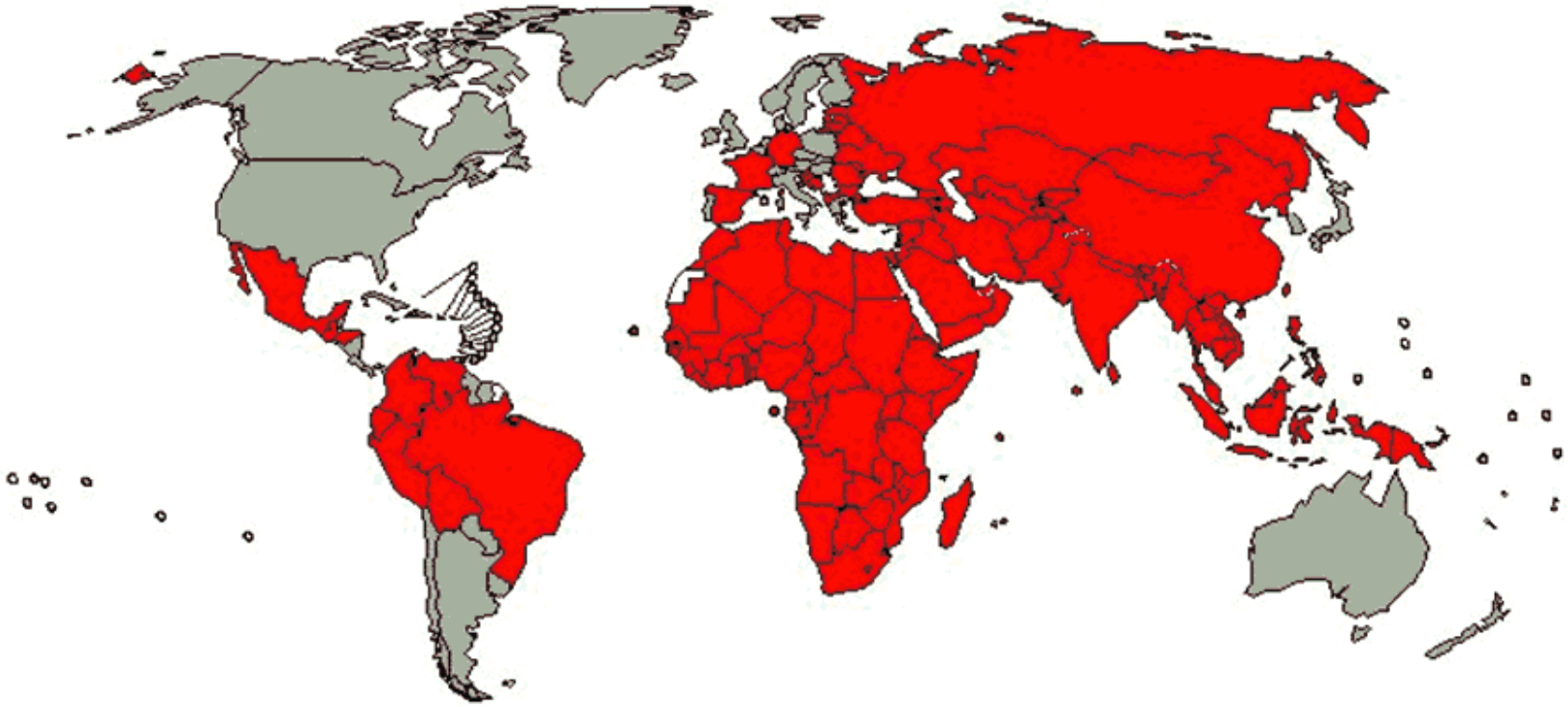
World Scene

Global Status 1988



endemic
non-endemic

Source: Polio Eradication Website / www.polioeradication.org

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World Scene (Cont'd)

World Polio Cases as at 30 July 2008

Total cases	Year-to-date 2008	Year-to-date 2007	Total in 2007
Globally	896	337	1315
- in endemic countries	844	278	1208
- in non-endemic countries	52	59	107

Headlines

In northern Nigeria, the wild poliovirus type 1 (WPV1) outbreak is intensifying, as 59 new cases were reported for the last 2 weeks, and the high season (rainy season) for polio transmission begins.

Source: Polio Eradication Website / www.polioeradication.org

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World Scene (Cont'd)

Case breakdown by country

Country	Year-to-date 2008	Year-to-date 2007	Total in 2007	Date of onset of most recent case
India	331	124	874	11 July 2008
Pakistan	17	11	32	3 July 2008
Afghanistan	13	5	17	3 July 2008
Niger	12	5	11	3 July 2008
Nigeria	483	138	285	1 July 2008
Angola	19	6	8	1 June 2008
Chad	6	2	22	1 June 2008
Nepal	4	0	5	28 May 2008
Ethiopia	2	0	0	27 April 2008
Benin	1	0	0	17 April 2008
CAR	1	0	0	6 April 2008
DRC	2	27	41	24 March 2008
Sudan	1	0	1	2 March 2008
Myanmar	0	11	11	28 May 2007
Somalia	0	8	8	25 March 2007

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Service Provision

- Polio vaccines became available in 1955/56 but many people in North America and Australia were still contracting polio into the 1960's. Many survivors are still only in their 40's & 50's.
- In spite of the ongoing need for specific polio services, established USA clinics are progressively diminishing or diversifying into treating other conditions.
- Reasons include:
  - Natural attrition of PPS expertise due to general ageing, illness, retirement and/or career change with no succession planning.
  - Lack of funding to run the clinic – nowadays often supplied by drug companies. No specific drug treatment for PPS equals no money.
  - Clinics that choose to diversify can utilise drug company and other funding to support PPS services. Will this dilute expertise?
  - Perception by government/general population that polio-related conditions are no longer an issue.

Service Provision (Cont'd)

- According to the Post-Polio Directory 2008, there are 32 Post Polio Clinics operating in the USA and only 1 in Canada: *(the '*' denotes specifically allocated PPS clinics whereas the other rehabilitation clinics manage a variety of neurological/physical conditions)*
  - Alabama = 1 *
  - California = 3 *
  - Colorado = 1
  - Washington DC = 1 *
  - Florida = 3 **
  - Georgia = 4 **
  - Illinois = 1
  - Massachusetts = 1 *
  - Michigan = 3 *
  - Minnesota = 1
  - Missouri = 1
  - New Hampshire = 1
  - New Jersey = 1 *
  - New York = 1
  - North Carolina = 1
  - Ohio = 1
  - Pennsylvania = 4 *
  - South Carolina = 1 *
  - Texas = 1
  - Washington State = 1
  - Montreal, Canada = 1 *

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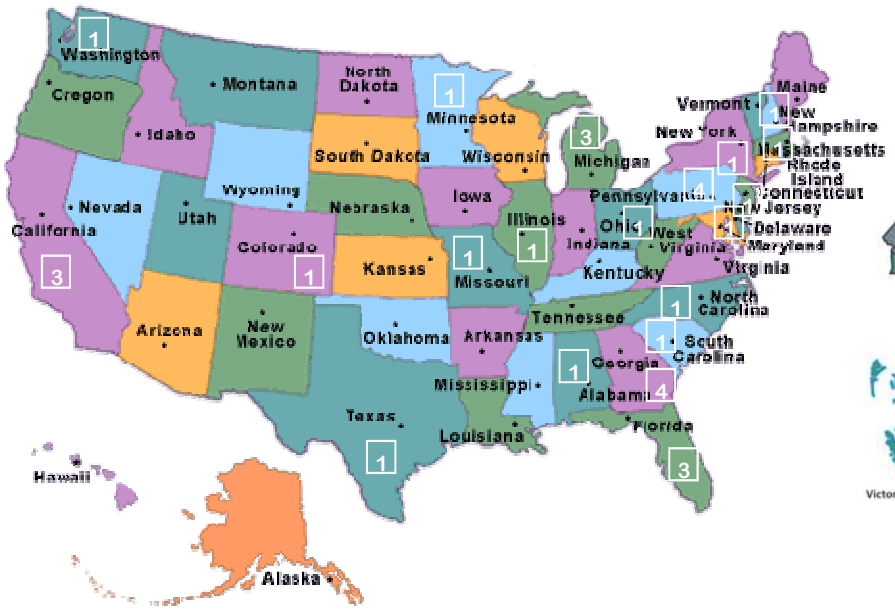
Service Provision (Cont'd)

USA comprises 50 states and 1 district – population 301,139,947



Canada comprises 10 provinces and 3 territories – population 33,390,141

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Service Provision (Cont'd)

- The USA 1994-1995 National Household Interview Survey statistics made available by the National Center for Health Statistics identified 445 polio survivors. Based on this sample size, the estimate of polio survivors in the United States is 1,000,000 with 433,000 reporting as paralytic polio survivors.
  (Source: Post-Polio Health International)

- Therefore, if all USA polio survivors were to seek services from the 32 PPS clinics available, each one would have 31,250 patients!

A typical afternoon in our Out-Patient Department, illustrating the crowding and congestion at present prevailing.

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Service Provision (Cont'd)

- As knowledge of LEOP and PPS can sometimes be difficult to find within the health sector, polio survivors need to ensure they are well informed about their own condition.

- Information is readily available from the Polio Networks throughout Australia and there is extensive library material available on-line.

- Many health professionals now specialising in LEOP and PPS first learned about the condition through their patients.

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PPS Research

- Dr Daria Trojan, Montreal Neurological Hospital has completed the following 'clinical' based research:
  - **Osteoporosis in a Postpolio Clinic Population** (2007)
    - Conclusions: In this retrospective, cross-sectional study, we found that osteoporosis and osteopenia at the hip occur commonly in postpolio clinic patients referred for bone densitometry in men, premenopausal women, and postmenopausal women compared with the general population.
  - **Sleep-Disordered Breathing in Fatigued Postpoliomyelitis Clinic Patients** (2006)
    - Conclusions: In our retrospective, cross-sectional study, we found that SDB, especially obstructive hypopnea, was very prevalent among postpolio clinic patients referred for sleep evaluation.
  - **Predictive Factors and Correlates for Pain in Postpoliomyelitis Syndrome Patients** (2002)
    - Conclusion: Our study provides insights on the pathophysiology and possible management of muscle and joint pain in PPS . . . Because pain is associated with significant reduction in Quality Of Life in PPS, further study of this important symptom is indicated.

PPS Research (Dr Trojan - Cont'd)

- **A multicenter, randomised, double-blinded trial of pyridostigmine in postpolio syndrome** (1999) (pyrodostigmine (Mestinon) is often used to decrease muscle weakness in other conditions)
  - Conclusion: This trial did not show a clear benefit of pyridostigmine.
- **Fibromyalgia Is Common in a Postpoliomyelitis Clinic** (1995)
  - Conclusions: (1) Fibromyalgia occurs frequently in a postpolio clinic. (2) Fibromyalgia can mimic some symptoms of postpoliomyelitis syndrome. (3) Fibromyalgia in postpolio patients can respond to specific treatment.")

- Dr Trojan has also just completed another study to compare inflammatory markers in PPS patients to normal controls. The study also included MS patients with PPS patients, and normal controls. They have presented the MS inflammatory marker results (with the PPS and normal control results) in abstract form but not in the published paper.

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PPS Research (Cont'd)

- Post-Polio Health International funded: Regulatory T Cells as a Biomarker of Post-Polio Syndrome (2007/08):
  - Rahnuma Wahid, PhD, Department of Microbiology and Immunology, University of Arkansas for Medical Sciences, Little Rock, Arkansas
    - The ability of a physician to diagnose a specific disease can be significantly aided by the availability of one or several disease biological markers (biomarkers).
    - No biomarker/s has/have been identified for PPS as yet.
    - Data suggests that PPS individuals have higher levels of antibodies and regulatory T cells circulating in their blood than healthy age-matched individuals.
    - 'Stable polio' (SP) individuals have variable levels of these immune components, which overlap with both the PPS and the healthy individuals.

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PPS Research (Regulatory T Cells Biomarker - Cont'd)

- This was a very small study with only 4 SP donors.
- Not enough to make a final conclusion about whether the regulatory T cells can be used to diagnose only PPS.

- The observations from this study suggest that there is some kind of problem with the immune responses in polio survivors which could contribute to PPS.

- Whether immune components have a direct role in the initiation and progression of PPS or just indicate the presence of a problem with the immune system is unclear at this time.

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PPS Research (Cont'd)

- **Post-polio syndrome patients treated with intravenous immunoglobulin (IvIg): a double-blinded randomized controlled pilot study**
  - Department of Neurology, Haukeland University Hospital, Norway (2007)
    - Patients with PPS lose more motor neurons than expected and surviving neurons fail to maintain neurogenic supply to enlarged motor units.
    - Some studies suggest an ongoing inflammation in the spinal cord in these patients. From this perspective, intravenous immunoglobulin (IvIg) could be a therapeutic option.
    - A double-blinded randomized controlled pilot study was performed with 20 patients to investigate the possible clinical effects of IvIg in PPS.

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PPS Research (IvIg - Cont'd)

- Patients receiving IvIg reported a significant improvement in pain during the first 3 months, but no change was noted for subjective fatigue and muscle strength.
- Cerebrospinal fluid (CSF) levels of tumour necrosis factor-alpha (TNF-alpha) were increased compared with patients with non-inflammatory neurological disorders.

- Conclusion:
  - In this small pilot study no effect was seen with IvIg treatment on muscle strength and fatigue, however IvIg treated PPS patients reported significantly less pain 3 months after treatment.
  - TNF-alpha was increased in the CSF from PPS patients.
  - The results are promising, but not conclusive because of the low number of patients studied.

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PPS Research (Cont'd)

- John P Murtha Neurological & Pain Institute
  - In 2004, JPMNPI was funded to do a research project on "Hatha Yoga and Meditation in Patients with PPS"
  - 23 patients participated in a 5 day retreat
  - Conclusion: Results showed significant improvements in a patient population where a lack of deterioration is often viewed as success. These patients improved in areas of fatigue, weakness and pain and continued to practice their skills. At the end of 12 weeks they were actively involved in self-care.
  - Results printed in "Alternative Therapies", Mar/Apr 2004, Vol 10, No 2

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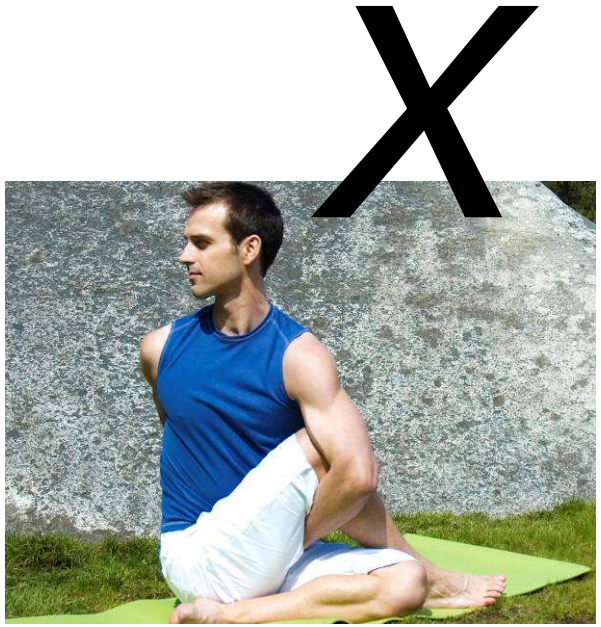
PPS Research (Cont'd)



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PPS Research (Cont'd)

- John P Murtha Neurological & Pain Institute
  - Currently doing research on Cognitive Fatigue: *Cognitive Function Status in Polio Survivors With and Without Post Polio Syndrome*
  - Hypothesis/Objectives:
    - The original infection with poliovirus "weakens" neurons throughout the central nervous system. As with age-related degenerative changes involving remodeled motor units in polio survivors causing weakness and atrophy, our central hypothesis is focused on the likelihood that a similar process may take place at supra-spinal neural relays responsible for cortical activation and information processing. If so, late-life neuronal losses over these "repaired' circuits might contribute to the impaired cognitive function often complained of by aging polio survivors.

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Why Research?

- Well designed, recorded and published clinical and/or scientific research validates the myriad symptoms experienced by polio survivors.
- Health professionals can use research data, conclusions and recommendations to more confidently diagnose and treat patients who have a history of polio.
- Research can also exclude ineffective treatment options.
- Research is the key to finding answers to our questions about what causes PPS, and how we can most effectively manage it.

Inflammation & PPS

- Dr Marcia Falconer is a virologist, researcher and polio survivor. The following points are excerpts of a presentation she made in Melbourne and continues to explore:
  - Little research has been done on PPS, probably because polio survivors are considered a “dying breed”.
  - Poliomyelitis continues to cause paralysis although now the virus causing the illness is not only the polio virus but the West Nile Virus, or enterovirus 71, or one of several Coxsackie viruses.
  - The nerve damage caused by these viruses is virtually identical to that caused by the polio virus and therefore it is likely that PPS, perhaps by then called Post-Viral Syndrome, will continue to bring new limitations to survivors many years after they thought they had recovered.

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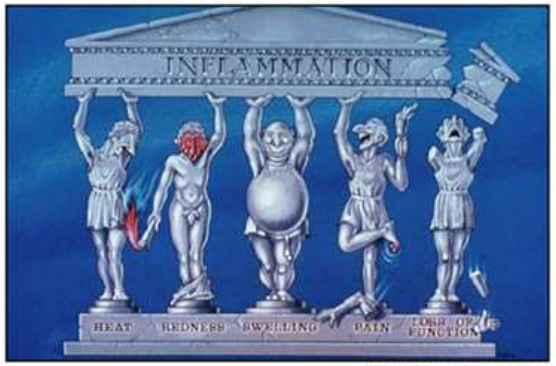
Inflammation & PPS (Cont'd)

- It remains important to examine the underlying cause of new muscle weakness, central fatigue, pain, memory and word finding problems and other symptoms that accompany PPS.

- Fortunately, current research in other areas holds great promise for explaining what is happening to so many polio survivors. The cause of virtually all PPS symptoms can be explained by one word: inflammation!

- Front line research in the fields of neurology, immunology, physiology and virology is coming together and our understanding of how inflammation is related to almost all chronic diseases; PPS, MS, ALS, CFS, Parkinson's, irritable bowel syndrome, and many others.



Nature Reviews | Immunology

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Inflammation & PPS (Cont'd)

- Treatments to reduce PPS symptoms may be based upon traditional anti-inflammatory medicines such as aspirin, ibuprofen, indomethacin and others.

- All these treatments would have to be done under the supervision of your doctor.

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Inflammation & PPS (Cont'd)

- However, there are some things you can do that are known to minimise inflammation in the body – and with that you might have a reduction of PPS symptoms.

  - *Meditation* – This works if you do it consistently.
  - *Exercise* – Appropriate exercise, under the guidance of a knowledgeable physiotherapist, will definitely lower inflammation levels.
  - *Omega 3* – laboratory studies suggest that diets rich in omega-3 fatty acids (and low in the inflammatory omega-6 fatty acids) may benefit people with inflammatory disorders.
  - *Pacing* – Pace yourself and don't overdo it. This is easier said than done but if you understand that seriously overusing muscles will start the proinflammatory cascade of events that will bring on or intensify PPS symptoms, perhaps you can justify resting before going too far.
  - *Weight loss* - Adipose tissue – commonly known as fat – is also a producer of inflammatory cytokines. (*cytokines are chemical messengers that tell specialised cells to protect you from invading organisms)*

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Support Groups

- It was surprising to note that polio support groups in the USA have been reduced from well over 300 in the 1980/90's to approximately 150 today.

- Reasons?
  - Natural attrition
  - Ageing / decreased mobility / illness
  - People stop attending support groups because:
    - Nothing more to gain/learn
    - Group has become 'stale'
    - Group dynamics / Age demographic
    - Leadership style / Lack of succession planning
    - Other priorities
  - 'New' people don't know about support groups
  - 'Younger' polio survivors don't know about the late effects of polio/PPS – even if they are experiencing symptoms

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Support Groups (Cont'd)

- Although many polio services & groups have excellent websites and extensive information available for people who contact them, they are not actively 'outreaching' to these new and/or younger polio survivors.

- How do you find out more about the late effects of polio / PPS if you are unaware of it existence?

- As older polio survivors tire and withdraw from the 'active' polio community, it is vital that younger survivors are identified, informed and encouraged to continue the campaign for more and better services for their own future needs.

Questions & Answers

- So, what IS new in PPS?
- Are there techniques to better manage the late effects of polio?
- What did this study tour reveal?
- How does this apply to Australia?

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What IS new in PPS?

- Increasing indications that PPS symptoms are not exclusively associated with general ‘wear and tear’ of fragile motor neurons over the years.
- Inflammation may play a much greater role in exacerbating symptoms.
- Studies in inflammation may offer a broader range of treatment and management options to polio survivors.

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Are there techniques to better manage the late effects of polio?

- Pacing activities of daily living is still one of the most effective means of self-management.
- Meditation / yoga / tai chi
- ***Appropriate*** exercise
- Omega 3 supplements
- Anti-inflammatory diet
- Lose weight (if overweight)
- Glossopharyngeal or 'Frog' Breathing to keep airways supple
- Aromatherapy
- Continue to follow IvIg research

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What did this study tour reveal?

- The most effective way of managing PPS symptoms and ensuring polio survivors remain as active and independent as possible is through self-management techniques coupled with regular specialist clinic assessments and intervention strategies.
- Services for polio survivors will be required for at least another 20-30 years.
- Services are merging PPS with other neurological disorders in order to attract funding to continue service provision.
- There very few clinics/institutes/individuals doing PPS research.
- The apparent lack of active community outreach to younger polio survivors who may be unaware of PPS is reflected in the decline of support groups in the USA/Canada.

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How does this apply to Australia?

- With the impending start up of 'Polio Australia', lessons learned could inform some of its' operations, i.e.:
  - Discuss models of service provision with funding bodies/service providers.
  - Arrange for further discussions with organisations representing other neurological conditions.
  - Make available list of PPS medical specialists who expressed an interest in being contacted for peer-to-peer email consultation.
  - Promote participation in the monthly "Post-Polio Clinics Directors Network" teleconference among Australian health service providers.
  - Compile a kit of self-management strategies and techniques provided by the various clinics to give to polio survivors.
  - Continue to provide outreach to polio survivors currently unaware of PPS in the community via community education programs, media opportunities, support group activities, electronic and hard copy information resources.

Your Questions?

- Handouts available:
  - Slides
  - Aromatherapy
  - Inflammation
  - Omega 3
  - Aromatherapy
  - Suggested Reading
  - Recommended Websites

PolioNetwork
A SERVICE OF PARAQUAD VICTORIA

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Post-Polio Clinics Directors Network
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Disclaimer: The following are unofficial notes which have not been read by or approved by the speaker.

- A full copy of the study tour is on the website: www.polionetworkvic.asn.au under Churchill Study Tour.
- Churchill Fellowship Study Tour to 10 cities in the U.S. and Canada in April and May of 2008 to identify techniques to better manage the late effects of polio. Jill Pickering, polio survivor, traveled with Mary-ann.
- There are limited services for polio survivors and no PPS research currently in Australia. The purpose of this study tour to the US and Canada was to: identify the latest research being carried out into the cause and management of PPS symptoms; observe a variety of "best practice" services for polio survivors; learn about the range of resources and equipment available; understanding the implication of emotional and psychological issues that impact polio survivors and family members; open networks and links with clinicians for Polio Services Victoria to pursue.
- The six-week tour began on the west coast, then to St. Louis and Warm Springs, Georgia and then north.
- Los Angeles, California
    - Mr. Richard Daggett, President, Polio Survivors Association
        - Editor of the Rancho Los Amigos Post-Polio Support Group Newsletter. Sends out over 700 monthly newsletters to people in the area.
    - Dr. Susan Perlman, Director, Post-Polio Clinic, University of California, Los Angeles (UCLA) Medical Center
        - After 20 years at the Post-Polio Clinic, Dr. Perlman and Melinda Guttrey, physiotherapist, are referring patients out to professionals in the community where they will receive effective treatment and services.
    - Dr. Sophia Chun, Chief, and Dr. Jacquelin Perry, Consultant, Post-Polio Service, Rancho Los Amigos National Rehabilitation Center.
        - Dr. Perry has been on the staff since the 1950s. She has an awareness of what muscles work as people are walking.
        - Dr. Sophia Chun now heads up the Post-Polio clinical team.
- St. Louis, Missouri
    - Joan Headley, Executive Director, Post-Polio Health International
        - Joan is on the board of ParaQuad, Inc.
        - PHI actively promotes networking between survivors and communities.
        - PHI is putting together a conference next year in Warm Springs, GA.
        - One program of ParaQuad, Inc. is Recycled Durable Medical Equipment. Donated scooters, walkers or other equipment are repaired and are offered to people who cannot afford to purchase new items. All proceeds go back into the program.
- Warm Springs, GA

    - Greg Schmieg, Executive Director and Michael Shadix, Librarian/Historian, Roosevelt Warm Springs Institute for Rehabilitation
        - Location for next year's Post-Polio Conference.
        - Explained the "Roosevelt Way" – an effective "hands on" approach to physical therapy.
        - Braces are made on site. People come from across the U.S. and Canada to have their braces repaired here.
- Washington, D.C.
    - Dr. Lauro Halstead, Director, Post-Polio Program, National Rehabilitation Hospital and Editor of Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome)
        - Currently there is no successor for Dr. Halstead when he retires.
    - Wendy Wilmer, President, The Polio Society; Elver Ariza, Board Member
        - Independence Square – area where people can practice walking up and down steps, driving simulator.
        - Clinic is conducted over 1-1/2 days and significant others are encouraged to attend.
    - Elver Ariza is on a student visa. He doesn't have access to medical coverage other than what he can pay for himself.
- Found that a number of clinics have 2-3 day clinics. Only services in Australia run for an hour.
    - Australian polio survivors would love to have 1-1/2 day of services including time with specialists who know that is going on in Post-Polio.
- Johnstown, PA
    - Barbara Duryea, Director, Research and Development, John P. Murtha Neuroscience and Pain Institute
    - Dr. William DeMayo, Medical Director, Post-Polio Clinic
        - Very impressed with this clinic; they blend traditional and alternative methods to treat PPS.
        - JPMNPI looks at the whole mind, body, spirit for total well-being and part of the healing process.
        - A lot can be taken back to Australia: Research into Cognitive Function Status; Yoga and Meditation.
        - Spent time with nurse on therapeutic use of essential oils.
- New York, NY
    - Dr. Richard Bruno, Director, The Post-Polio Institute and International Centre for Post-Polio Education and Research
    - Susan Fish, Physical Therapist
    - Dr. Margaret Backman, Clinical Psychologist
        - Spoke about vaccinations. At least one million U.S. children have not been vaccinated for polio.
        - Dr. Bruno has no successor for the Post-Polio Institute once he retires.
        - Susan Fish, PT, is very humble although she worked on numerous polio survivors. In her 60's and possibly retiring soon.
        - Dr. Backman's book "The Post-Polio Experience" – for people who have had polio and their families – will be her legacy.
        - The aging process is the most troubling problem for people.
- Framingham, MA
    - Dr. Darren Rosenberg, Medical Director, Spaulding Rehabilitation Hospital
        - Believes there is a need to provide services to post-polio patients after his retirement.

        - All staff have prescribed reading on the experience of polio survivors, including Dr. Julie Silver's book.
        - Mary-ann is thinking of doing something similar in Victoria.
        - Philosophical belief is that the patient is the expert on their own body.
- Toronto, Ontario, Canada
    - In Australia, an organization has been established – Polio Australia. Hopefully will be up and running soon. All states have signed MOU.
    - Polio Canada aligns itself with Stroke Canada. Stroke Canada can attract quite a bit of money from medical companies.
    - Polio Australia hopes to align itself to do the same thing.
    - Dr. Marcia Falconer, Virologist and Researcher
        - Has done research on inflammation and post-polio syndrome.
        - Inflammation might be exacerbating PPS symptoms.
        - Living proof of how dealing with inflammation through diet, pacing and meditation for three years has helped her feel better.
    - Dr. Douglas McKim, Medical Director, Respiratory Rehabilitation Services
        - Discussed the respiratory issues that polio survivors face.
        - Respiratory problems are a condition of PPS .
        - Lung Volume Recruitment (LVR) technique to keep the airway supple.
        - Explanation of the LVR method can be found on the website: www.irrd.ca/education/presentation.asp?refname=e2r4. This is something for those in medical practice to teach their patients.
- Montreal, Quebec, Canada
    - Dr. Daria Trojan, Director, Post Polio Clinic, Montreal Neurological Institute and Hospital
        - Post-Polio clinic encompasses three areas: clinical care of patients, education of health care professionals and lay groups, and clinical research on post-polio syndrome.
        - There is a six-month waiting list because it is the only post-polio clinic in Canada's eastern provinces.

- Conclusions:
    - No two post-polio clinics operated with the same combination of therapists.
    - Standard treating specialists consisted of a Physiatrist or Neurologist, Physiotherapist and Occupational Therapist. Additional specialists may either be on site or referred back to the community.
    - A model clinic might include access to all these therapists as well as an expert in inflammation management, incorporating strategies for relaxation and diet; an Osteopath for realignment; a Podiatrist to monitor foot health, a range of Complimentary and Alternative Medicine therapies.
    - It is important to have knowledge or be willing to learn of the late effects of polio and Post Polio Syndrome.
    - A monthly teleconference is held on the third Tuesday of each month, hosted by Dr. William DeMayo of the John P. Murtha Neuroscience and Pain Institute.
    - All PPS clinics visited indicated they were consistently busy with local, national and international patients.
    - It was generally agreed that services would be required for at least another 20-30 years as polio survivors age.
    - Younger polio survivors are accessing services from parts of the world where the polio virus was more recently eradicated or still active. Australia sees a lot of people from India and Pakistan.

- After returning from her trip, Mary-ann gave many presentations. Whenever she would go out to do an information session in the community, there would be at least 20 survivors who did not have any indication from their physicians that what they are experiencing is brand new for them. She has reached approximately 800 polio survivors, their families, health professionals and other community services providers.
- Question: The issue of self-management education – was there anything you saw that stood out – an approach or written material – how did you see that managed?
    - It needs to be something palatable to the patient. Compliance is the biggest issue. Looking at the aspects of health and well-being are important. To help them understand that they are achieving with disabilities, what it means to their families and facing decisions and issues as they age. They understand that if they overdo it, they will be fatigued. They need to know what that means for the long haul. Seems to be the biggest thing that people are struggling with is the psychological aspects of aging with a disability and how they treat their bodies at the end of the day.
- Question: How are we going to encourage younger health professionals to get involved to follow through with what has been started and going on since the 80's? At the conference will there be a lot of therapists and physicians in their 20's?
    - One of the things Mary-ann mentioned on how polio fits with other diagnoses is part of the way. We are a clinic of adults with childhood onset disabilities. We have orthotics, speech, OT, etc. under one roof and we can be very efficient. Need to build interest as to how people use their professional skills and are able to serve those who need these services.
    - Mary-ann said they don’t have anything like that in Australia but it is a way they need to consider going.