

Study Tour of United States and Canada Identifies Techniques to Better Manage the Late Effects of Polio

Post-Polio Health International, St. Louis, Missouri, was the second stop on a five-week tour of post-polio facilities in ten cities. The force behind the tour, Mary-ann Liethof, is the Community Officer of PolioNetwork, a service of ParaQuad, a non-profit organization in Collingwood, Victoria, Australia. Liethof secured funding through The Winston Churchill Memorial Trust of Australia to identify techniques to better manage the late effects of polio, with the ultimate goal of improving the services of PolioNetwork.

Liethof faithfully chronicled her visits in words and in photographs at www.polionetworkvic.asn.au/study-tour. The site also features a PDF file of the final report and *Jill's Jottings*, the impressions of polio survivor and retired occupational therapist Jill Pickering, who accompanied Liethof on the tour.

The final report lists the following as highlights of the tour:

- The incredible dedication of Jacquelin Perry, MD, and range of facilities available at Rancho Los Amigos, Downey, California.

- The historical significance of Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.
- The holistic approach to wellness being practiced at John P. Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania.
- The youthful team at Spaulding Rehabilitation Hospital's long-term commitment to provide ongoing services for polio survivors, Framingham, Massachusetts.
- The valuable clinical research being conducted by Daria Trojan, MD, at Montreal Neurological Institute and Hospital in Canada.

The following are listed as the major lessons and conclusions:

- The most effective way of managing the late effects of polio 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 post-polio syndrome with other neurological disorders in order to attract funding to continue service provision.



Liethof, at right, discussing post-polio issues with Martin B. Wice, MD, Medical Director, St. John's Mercy Rehabilitation Hospital, Saint Louis, Missouri, and polio survivor Jill Pickering.

- The apparent lack of active community outreach to younger polio survivors who may be unaware of post-polio syndrome is reflected in the decline of support groups in the USA/Canada.
- There are very few clinics, institutions or individuals doing post-polio research.

DVD to Come

While traveling to the aforementioned places, Liethof interviewed many individuals. Their opinions will be compiled on a DVD by the PolioNetwork of Victoria.

Other stops on the tour included Washington, DC; New York City; Englewood, New Jersey; and Toronto and Ottawa, Canada.

For more information:

Mary-ann Liethof,
Polio Community Officer
 208 Wellington St
 Collingwood 3066, Australia
 (03) 9418 0411
 polio@paraquad.asn.au
 www.polionetworkvic.asn.au

Disaster Planning Help for People with Disabilities at www.disability911.com

The website features televised interviews with disaster preparedness and emergency response officials, with people who were displaced by Hurricane Katrina, and with experts on issues pertaining to disaster preparedness and response. Links are provided to webcasts, books and newsletters, training materials, and other resources, which have been prepared to assist centers for independent living, public officials, emergency preparedness officials, and people with disabilities and their families. The site was developed by Lex Frieden, University of Texas Health Science Center professor and long-time disability rights advocate, and the Independent Living Research Utilization (ILRU) program at Memorial Hermann/TIRR in Houston, Texas. ▲

Development of a Polio Antiviral Drug Begins

Joan L. Headley, St. Louis, Missouri, director@post-polio.org

The Global Polio Eradication Initiative, launched by the World Health Organization (WHO) in 1988, with the help of Rotary International's PolioPlus Program, sizable contributions from the Gates Foundation, and the commitment of UNICEF and the CDC, has stepped up its activities to finish the job of eradicating poliovirus worldwide.

In 2005, the powers-that-be initiated a discussion of the role of a polio antiviral drug in the efforts to eradicate poliovirus and to explore its added benefits of maintaining a polio-free world.

Compounds belonging to the antiviral mechanistic class termed "capsid inhibitors" inhibit the function of the poliovirus capsid, the outer protein coat of the virus. The inhibitors, by integrating into the capsid at a specific site, prevent the poliovirus from releasing its RNA and block the infection that leads to acute poliomyelitis.

One anti-poliovirus compound, V-073, has promise. Consequently, investigational new drug (IND) studies will begin with V-073 and be conducted by ViroDefense, Inc., Rockville, Maryland.

Schering-Plough, Kenilworth, New Jersey, recently licensed the exclusive rights for development of a specific compound series for polio to ViroDefense. The license was provided in exchange for the purchase of compound testing supplies and potential future royalties on sales. ▲

The screenshot shows the website interface. At the top, there are two images: a peaceful outdoor scene with a bench and a scene of a fire. Below the images is the title "Disaster Preparedness for People with Disabilities". A navigation menu on the left includes: Home, Disability911 Blog, Books & Newsletters, Webcasts, Useful Resources, Preparedness Checklist, and Acknowledgements. The main content area has a "Breaking News" section with two items: "July 7th Hurricane Briefing with Lex Frieden on Fox News" and "July 1st Webcast on Hurricane Preparedness presented by Lex Frieden now available in the Archive". To the right, there is a section titled "Disaster Preparedness for People with Disabilities" with introductory text about the website's purpose and a small photo of a person in a hard hat.