

Powerful Patient #14

Host: Joyce Graff, WebTalkRadio.net

Long-Distance Travel

People with disabilities are traveling more and more these days. Thanks to legislation in some countries and heightened awareness throughout the travel and tourism industry, accessible travel is much easier to find these days, but is by no means universal. You have to plan ahead to find hotels, restaurants, and points of interest where their idea of “accessible” and your needs are a good match.

Altheada and Fred Johnson are preparing for a trip with Joyce to South Africa in March 2008. The flight alone takes 17 hours from New York.

Joyce talks with Eric Lipp, head of the Open Doors Organization, which works with hotels, airlines, and others in the travel industry to increase accessibility for handicapped travelers.



Angela D'Arezzo on the cover of Quest, a publication of the Muscular Dystrophy Association, 1999

Joyce and Altheada share the planning they have been doing in selecting a flight itinerary, and talk with Angela D'Arezzo, another wheelchair user who has made a number of long flights, about some of the particular challenges they should plan for.

1) About Our Guests

Eric Lipp is the Founder and Executive Director of the Open Doors Organization in Chicago. He consults with hotels, restaurants, and airlines to increase their accessibility for people with disabilities, and to assist them in complying with federal and state accessibility regulations. See <http://www.opendoorsnfp.org>

Angela D'Arezzo, a part-time model, was a spokesperson for the Muscular Dystrophy Association. She appeared on the cover of Quest, a publication of the MD Society, where she and other active men and women with neuromuscular diseases gave some advice on how to look your best -- and feel better in the process. Photo by Camera One. Quest 6:5, October 1999. She volunteers for the International Center for the Disabled (ICD), a nonprofit outpatient rehabilitation center in New York City <http://www.icdnyc.org/>

Altheada Johnson, a registered dietitian, volunteers for the VHL Family Alliance. She has served on their Board of Directors for nine years, and Chairs the Hotline Committee. See <http://www.vhl.org/> She also volunteers for ICD, where she and Angela made a video on low-fat cooking for disabled people that is used as part of an internal program at ICD. It is not separately available for sale.

2) More details on myoclonus

Altheada mentioned having myoclonus when she went to Hawaii in 1996. The following definition is taken from Wikipedia.

Myoclonus is brief, involuntary twitching of a [muscle](#) or a group of muscles. It describes a [medical sign](#) (as opposed to [symptom](#)) and, generally, is not a diagnosis of a disease. The **myoclonic twitches** or jerks are usually caused by sudden muscle contractions; they also can result from brief lapses of contraction. Contractions are called *positive myoclonus*; relaxations are called *negative myoclonus*. The most common time for people to encounter them is while falling [asleep](#) ([hypnic jerk](#)), but myoclonic jerks are also a sign of a number of [neurological disorders](#). [Hiccups](#) are also a kind of myoclonic jerk specifically affecting the [diaphragm](#).

3) Preparing for a long-distance flight

Laurel Van Horn, program consultant for ODO, has a number of articles on the Open Doors website that can also be helpful in planning an accessible trip or meeting: http://opendoorsnfp.org/_wsn/page8.html

4) Tips for Long-Distance Flights

- Ocean nasal spray or generic equivalent (saline solution) to use to keep your nasal passages moist. The most common illness when traveling is a cold or flu acquired during the flight, because the nasal passages dried out, cracked, and allowed other passengers' germs to enter your system.
- Artificial tears to keep the eyes and surrounding membranes moist for the same reasons.
- Avoid caffeine and alcohol, as these actually dry your system and can lengthen jet-lag. Remember that most carbonated beverages also include caffeine.
- Drink lots of water – at least 1-2 glasses of water or juice every time the flight attendant offers something to drink. If you are planning to drink less than this, check with your doctor.
- That will make it necessary for you to get up and go to the bathroom. It is best to get up and walk around at least every 1-2 hours during the flight. If you can't get out of your chair, do airplane calisthenics: flex your feet, curl your toes, raise your knees, or otherwise work your leg muscles within your allocated space at your seat. Similarly, you can work your shoulders and arms and flex your back.

- Neck pillow. An inflatable neck pillow can help a great deal to avoid neck strain from awkward positions during sleep. You can let the air out to adjust the softness and thickness of the pillow to your comfort. The airlines have cut back on pillows and blankets – you may be asked to buy a pillow or blanket on board.
- When you board the plane, set your watch for landing time and let go of your home time. Calculate your medication schedule based on landing time and the normal intervals (not time of day but hours before the next dosage). You may need to write this out, as it can be a bit complicated. Don't worry about doses-per-day when crossing an ocean, worry about those intervals. You may wind up taking one more dose during a 30-hour day, and one fewer dose during a 16-hour day when you are crossing many time zones in an airplane. Just keep the dosage intervals as consistent as possible.
- The only time I check the home time is when I want to phone home – to make sure I don't call at 4 AM their time. Other than that, it is best to think always in "local" time wherever you are.

5) Booking accessible hotels and vacation spots

Eric mentioned some resources for planning accessible vacations:

- Open Doors Organization www.opendoorsnpf.org
- Vacations to Go www.vacationstogo.com
- 101 Accessible Vacations www.101accessiblevacations.com
- Disney accessible vacations <http://disney.go.com>
- Sunset Cruises <http://www.sunset-cruises.com>

Be sure to telephone the property and double-check the specifics of any important requirements you may have. Their understanding of "accessible" may or may not be the same as yours, even in the United States, and in other countries the laws are different.

Have fun!