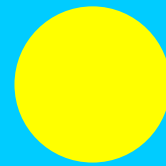


# The LincPIN

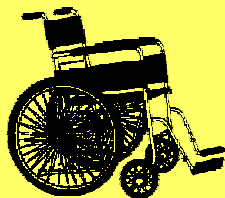
The **Lincolnshire Post-Polio Information Newsletter**  
Volume 4 - Issue 10 - June 2004

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Travels with a Wheelchair

## The Algarve



Photographs by Alan Russell  
Wheelchair graphic by Patricia Clouse  
Layout design by Chris Salter



Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

**Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

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## **Donations (Feb to June 2004) - THANKYOU for your Support.**

### **UK Account totalling £362**

Dianne Lightfoot, Angela Johnson, Michael Parkin, Jane Shaw, Margaret Horton, John Doohan, Val Scrivener, Philip Dalton, Di Brennand, Yvonne Webb, Clare Colfer, Agnes Walker, Marguerite Standing, Anne Brown, Kathleen Burrell, Maureen McAvoy, Jenni Paulger, Thomas Croker, Catherine Patterson, Hilary Davies, Raymond Owen.

**Monthly payments totalling £12** - Sylvia Fortune, Jenny Rayner, Ewan Peddie

**US account totalling \$207** - Robert Price

**Foregone expenses totalling £154** - Robin, Pauline, Jenni, Sheila, Denise Hilary

**INLAND REVENUE REBATE - £589**

Lincolnshire Post-Polio Network - UK Registered Charity 1064177  
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**Renewal dates** are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.

**Please make all denomination cheques/checks payable to 'Lincolnshire Post-Polio Network'  
Post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK**

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Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

### **Next LincPIN Newsletter - August 2004**

**Articles for publication mid July by post or** - newsletter@lincolnshirepostpolio.org.uk

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### **Editorial by Hilary Hallam.**

I apologise for the slight delay in getting this issue out due to my father being in hospital and his brothers funeral. We have been spending time in Devon where the access is bad - 11 steps and steep drive - the bungalow spread out - 40 paces from bedroom to bathroom - and visiting Dad every other day -its more energy sapping than being at home.

We also attended the Exeter ME/PPS conference where I spoke on Assessing ourselves to provide more pertinent information to health professionals. [Full report in the next newsletter] Saying 'my legs seem weaker' is not as informative as saying 'I used to be able to go upstairs stopping just once, but now run out of oomph every three steps' or 'I used to drive a manual car but have had to change to automatic, I can't lift my leg onto the clutch pedal anymore'. When we are assessed the testing most often does not test the **endurance** of our muscles. We may be able to do an action ten times and then tire, hold an action for four seconds and then tire. If the testing you are being given does not get to the level of your weakness ask if you can demonstrate an action to the level where the weakness is evident.

#### **Our AGM will be in Lincoln on Saturday 16th October 2004**

The medical speakers [Rehab Consultant/s and Physiotherapist/s] we have contacted have been unable to confirm till nearer the date if they are still free. Full information will be in the next newsletter.

Postal voting is now possible and we ask that you return the slip on page with any nominations you have for the posts available. The Charity Commission has agreed to two face to face meetings per year which we hope will entice a few more

of you to join our happy band. Meetings so far have been held on Saturdays with a start of 1.00 p.m. after a buffet lunch. If the venue is in Lincoln we have been able to offer a bed for those unable to travel and 'do' on the same day. Between meetings we keep in touch by email and if necessary arrange telephone conference calls.

As far as possible we try to spread the workload and ideally would love to have two people for every job. Taking on/ sharing/or helping with a task does not mean that you have to be on the Committee but if you would like to then you are most welcome. [See separate page enclosed with newsletter]

Would anyone else like to join the Phone Team led by Di Brennand in Merseyside. Pat is in South Yorkshire and Margaret in London. Contact Di Brennand if you would like more information on how this works. They arrange the time table between them and roughly do one week on and two off taking the calls from our Information Line. A reserve in case of illness or holidays would also be most welcome.

We have asked before but so far no-one has offered... do you take a newsletter/ magazine regularly? Why not tell us of any items that might be relevant to our members?

Mar-y-Mail will return next newsletter as Mary has taken a break from the info/ enquiry emails for a month. Taking back this task has been an eye opener for me. By the time I have checked my personal email/committee emails/ and replied to the info/enquiry emails it is time for a rest break and hence the newsletter delay. I am really grateful for Mary taking on this task and we ask is there anyone else who would like to share this job. Help is always available if you are not sure how to reply.

## **PPS and Sleep Problems One possible solution.**

An Upside View by the One-Armed Texas Bandit - Ellen Riddle.

It is 7 a.m. on a Saturday morning. I've been up since five am... singing, cooking up a nice breakfast, finished my morning email reading and here I sit writing my monthly article. What a dramatic and wonderful change from this time last month!

Every article I wrote in previous months Hilary had to nudge me, remind and coax it out of me. I wanted to do these as I love to write. But with all the fatigue my oomph, my desire to do anything, even what I love doing had flown out the window.

In previous articles I've written about finally accepting I was over fatigued from doing next to nothing. I was fearful that this was another downward step with Post-Polio and I would be soon simply sitting around passively watching the world go by. Not a happy thought for one who has always been busy with something.

I've shared about my sleep study; along with the results being that while I definitely had problems sleeping it wasn't due to any of the three possible apneas.

When I last wrote I was waiting to see my sleep doctor with a mixed feeling of relief in not needing night time venting (yet) and worry about well, what the problem could be.

The problem it turns out is simply that I was only getting an average of two hours of 'good sleep' a night regardless of how long I stayed in bed.

No wonder I was fatigued and needing to take rest breaks and lay downs from doing nothing! I would approach REM sleep only to bounce right back up to moments of being awake but without any apnea causing this.

The first week my doctor had me take Sonata (it was the only prescription sleep medication she had samples of on hand). I was to try it for the six nights and see what happens. The drug of choice though is one called Trazodone. This is one of the older anti-depressants which has been found to help with insomnia as it is very tranquilizing and only lasts 7 to 8 hours. Plus, it is better for long term use. The usual dose for sleep assistance is the small amount of 50 mg.

As soon as I got home I got on-line and checked out the pros and cons of Sonata [Zaleplon] Ambien [Zolpidem] and Trazodone [Desyrel]. I quickly came to see the whys behind Trazodone being my sleep doctor's first choice and became willing to give it a go if I found help with the Sonata.

The biggest drawback to sleep aides such as Sonata and Ambien is that both are really designed for short term use. If there is something going on in your life that has you pacing the floors these can be really helpful. They are not really meant for long term use. So if I went with either of these I could only get a prescription for 30 days at a time and would have to see my sleep doctor at least every three months or so to make sure it wasn't playing havoc with other body parts. (as opposed to an annual check-up with my sleep doctor with Trazodone.

The other is the cost. Here in the States these drugs run around \$150

for a month's supply while Trazodone comes in around \$32. As much as I longed to sleep better those amounts would have me pacing more and encourage nightmare's of doom and gloom.

The trial with the Sonata worked wonderfully well in that I slept for four to five hours solid. After that I was back to my normal routine but even this was such an improvement that I felt better. I called my doctor and obtained a prescription for a two month supply of Trazodone as I don't go back to see her until the end of this month (June).

I've been taking it now for almost two weeks. The results are unbelievably wonderful. Not only am I waking up refreshed and ready to take on the day but each one is once again more fulfilling and rich.

My mild depression has vanished. I'm my old optimistic; the glass is half full person again. I am able to plan my day and actually get some of the things I plan done. Most important for me is my muses are also happy and I am painting, writing and working with my photo programs.

As if all of this is not enough there is another unexpected perk. I was at first worried that I would go from doing nothing to over-doing as it feels so good to be able to do again and crash right into a solid fatigue wall.

This isn't happening. Since I am able to actually do things I find that I am more than happy to take my breaks and lay downs. I still don't sleep but I definitely rest and relax.

I also can hear my body saying, "its time to stop for a bit." And agree with

it because I know that after I rest enough my body will agree to go back and do something. Its literally been a few years since my body and mind had this agreement working.

I have learned through all of this that while fatigue is a very real part of Post-polio, that when resting and taking lay downs isn't working; that when one wakes up too many days in a row not feeling really refreshed that it is not something we have to just accept as inevitable and part of it.

I know that I avoided getting this checked out a few years ago when my sleep problems first became apparent as I just didn't want to face that maybe I would need night time ventilation. I kept listening to others talk about the warnings and would come back with things like not me, my nightmares aren't that bad, or that frequent. I don't have a morning headache so it's not really a sleep a problem. But, my favorite excuse is that I honestly didn't think I had insomnia because even though I was waking up a lot (I was aware of waking up 4 to 7 times a night and convinced myself this was 'normal') I didn't get up. I had this picture in my head that one with insomnia was up wandering around the house, watching TV in the wee hours of the morning and so on.

My sleep doctor very kindly laughed at all of this. She gently said that "insomnia is not getting enough quality sleep. Period. If you are waking up not feeling refreshed and are too tired during the day it's a problem."

As usual, I am delighted to have found a solution to another facet of Post-polio. Also, as usual, I am sort of kicking myself for not looking into this sooner.

This is something is working well for me at this time; remember I'm only sharing my experience. It may or may not be the solution for you; but if you suspect you aren't getting a good night's sleep and you aren't quite at the point where night time ventilation is needed this is another possible solution to consider. It is something else to discuss with your doctor to see if it may help you. Do remember that some polio survivors need much lower doses than the norm, so always discuss with your doctor the possibility of starting on a lower dose than he might normally prescribe.

Now, off to do some more singing (al-be-it off key) while I finish my latest watercolor project.

Ellen Riddle@sbcglobal.net

[Editors note:- During early pps meets in the USA I learned other polio survivors were taking Elavil [Amitryptaline] at a low dose of 5 - 25mg. I experimented with 5 to 20mg and found 5mg to be the best for me. It is one of the old anti-depressants also used for pain relief. I get into bed and read and then take my 5mg - half the tablet - and within ten minutes am asleep. I can wake and go to the bathroom and back to bed and sleep for 7 - 9 hours. That is unless my mind wakes up and starts racing about something I have to do. My father has two light switches in the bathroom, one is white light and the other is a red light for nighttime... enough light to see what you are doing without waking you up!

Other polio survivors report 5mg is good for them too. **CAUTION** - one member slept for 2 days on 10mg and 5mg was still too HIGH for her.

We have learned to discuss all drugs with the doctor prescribing them. We get home and we check on the internet pharmacy sites for drug interactions and other information. We then check with the prescribing Pharmacist before starting any new drug.

However, on local TV in Florida we saw a new website Drugdigest.org and on checking Richards drugs on the interaction list found that if he took two of them together then one stopped the other being absorbed. It did state that 'This interaction is poorly documented and is considered minor in severity.'

We thought that maybe this was the cause of his bad times when his movements slowed right down. We changed timings of taking the drugs and he now has a much improved more stable level of ability.

So far we have checked with one US and one UK Pharmacy, and both were unaware of the information on Drugdigest.org. We have now on advice completed a yellow card and sent this in.

'DrugDigest is a non-commercial, evidence-based, consumer health and drug information site dedicated to empowering consumers to make informed choices about drugs and treatment options.' and 'not all drug interactions are known or reported in the literature, and new drug interactions are continually being reported. This information is provided only for your education and for you to discuss with your personal healthcare provider.']

## **Virus Seen in Muscle from Chronic Fatigue Patients**

by Will Boggs MD - Friday Jan 2nd via IMEGA-e Journal of Medical Virology, December 2003. NEW YORK (Reuters Health) - A persistent enterovirus infection in muscles may be to blame for some cases of chronic fatigue syndrome (sometimes called fibromyalgia) and others with chronic inflammatory muscle disease, a French Team reports.

They detected genetic material (specifically RNA) from enteroviruses in 20 percent of muscle biopsies from patients with chronic inflammatory muscle diseases and 13 per cent of patients with fibromyalgia/chronic fatigue syndrome, but not from healthy volunteers.

The findings favour a persistent infection involving defective viral replication as a cause of these conditions. "The persistence of defective or infectious enteroviruses is well established for a lot of organs.", DR. Bruno Pozzetto from the University Hospital Centre of Saint-Etienne, France, told Reuters Health.

Such infections have been documented in the heart, with possible involvement in heart enlargement; in pancreatic cells, possibly linked to juvenile diabetes; and in the central nervous systems in association with a syndrome that afflicts ageing survivors of polio, the researcher explained. "However, the link between these diseases, as well as chronic inflammatory muscle diseases, and viral persistence is not clear."

Pozzetto and colleagues investigated the presence of enterovirus in skeletal muscle biopsies from 15 patients with chronic inflammatory muscle disease, 30 patients with fibromyalgia/chronic fatigue

syndrome, and 29 healthy subjects to test their hypothesis that skeletal muscle may play host to persistent viral infection.

Three patients with chronic inflammatory muscle disease and four patients with fibromyalgia/chronic fatigue syndrome were positive for enterovirus RNA, the team reports in the Journal of Medical Virology. None of the muscle biopsies in this study contained a particular viral protein, the researchers note, which "suggests a defective viral replication."

It is too early to derive implications for treatment from these results, Pozzetto said.

However, he noted that so-called Coxsackie B viruses seem to play a key role in persistent muscular infections. "To prevent this persistence, an inactivated vaccine directed toward these viruses could be indicated."

Also, an anti viral agent called pleconaril, "acting during the early phase of the viral cycle, could also be useful in muscular disease clearly associated with enterovirus." This is being tried in some cases of heart muscle enlargement, Pozzetto said, "but it is too early to answer for muscular diseases".

Published in the Shropshire & Wrekin ME Support Group Newsletter.  
[www.shropshiremesupport.org.uk](http://www.shropshiremesupport.org.uk)

### **Report from ME/PPS Conference in Exeter.**

Due to time constraints a full report will be published in the next newsletter. It was excellent, more good contacts made, more information shared.

Thankyou Barbara for all your hard work.

## **Travels with a Wheelchair Alan Russell flies out to The Algarve**

First published in issue 28 (Winter 2003) of "discover", the magazine for disabled people by disabled people in Cornwall.

They say: "Better to be born lucky than rich" and I suppose given the choice I know what I would go for, but until I get that choice I am quite happy to accept the good luck I was given when we were offered a week's holiday in the Algarve for £99 each.

It started when after telling several double glazing telephone nuisances where they should place their windows - and it wasn't in my house! The phone rang again and before I could explode, the voice told me that I had been chosen to receive this holiday. The cynic in me said, another time-share promotion, and I wasn't wrong, but these people promised me the price included luxury four star accommodation, daytime flights from Bristol and all I had to do was to attend a 90 minute presentation in the hotel. I tentatively accepted, after telling them I was disabled and asked for details in writing which came in the next post, and to be truthful I was pleasantly surprised.

We paid our £198, and drove up to Bristol Airport. We had never flown from here before so it was to be a new experience. I had been recommended by a friend that a farmer near the airport stored cars for holiday makers, taking them to the airport and arranging taxis to bring them back for

less than half the airport rates. We received good directions and turned up at the farm in plenty of time. There was no need. He was there waiting and his large station wagon easily took the cases, us and the wheelchair. It was also very useful to be dropped right outside the entrance to the airport, where we were approached by a lady who directed us to the check-in area.

Although, unlike London airports, we had to use the normal check-in procedures, we were told which desk was going to be used, which made sure we were at the front of the queue.

Bristol is a lovely little airport with all the facilities anyone would need in the way of restaurants, shops and toilets, all of which were easily accessible to wheelchairs. The only problem I found was that carers did not have end of row seats reserved in the lounges, so that they can sit next to us like they have in other airports, and you have to rely on people moving to allow you to sit together if none are vacant.

Loading onto the plane was via steps, but this was no problem as they have the "ambulift" system, where you take your wheelchair into a bus with no seats and after being driven out onto the tarmac, you are lifted up to the door of the plane. We were seated and comfortable before the regular passengers arrived. The flight was only two hours, but they still had time to feed us on board, and before we knew it we were at Faro, where the "ambulift" delivered us to our cases and immigration.

### **FOUR QUESTIONS.**

First Question: You are participating in a race. You overtake the second person. What position are you in? Answer and next question on page 15



We picked up our hire car from Faro airport car park. It was a Suzuki Wagon, which had loads of headroom and room for the chair and luggage. We had extremely detailed instructions on how to get to our resort, and soon I realised why. The Algarve is totally devoid of meaningful direction signs in the rural areas. Places on the map are not signed, and places signed were not on the map, so we were not only pleased but surprised to arrive safe and well.

Portuguese drivers are fast and have no patience for first day of arrival Brits. When we turned the corner and saw this great big posh building with the sign "Alpinus Resort", I told my wife not to get too excited as we would probably be staying in an annexe somewhere due to the price we paid. But no, after checking in, a porter arrived and took our cases to our beautiful apartment. It was only one bedroom, but was enormous and fitted out superbly, together with a balcony overlooking the most beautiful view of mountains and forests. I started to get worried, for when I go to the sales talk, what excuse can I give for not buying one?

The restaurant was very nice, and although slightly informal, I felt more comfortable eating in the local outdoor restaurants where fresh fish, such as bream or sea bass, together with vegetables, dessert and very drinkable local green wine was available for about. £5 - £8 and the snack bar near the pool served a mean pizza and very cold beer!

The centre was totally accessible, with lifts, ramps, and wide doors to all the public rooms. It wouldn't be necessary to ask for a specially adapted room, as

all apartments are suitable for wheelchair users, although each had a very small 'lip' at the entrance to keep out any rain, as the corridors were all open to the elements. The pool was also well equipped with wide and shallow steps, but the sun beds were very low, which I had difficulty getting on and off. Also the pool was in the shade by about 3 p.m., so with everybody moving to the sunny spots, it got a bit crowded, though they tell me a new pool is planned for a spot that will not be shaded.

I must say that The Algarve in general is not exactly disabled friendly. The pavement surfaces are pretty uneven and great care must be taken. Most beaches are unreachable, as they are at the bottom of steep cliff paths, but there are obviously some that are not, so make sure you research this before you go. Those that are accessible, such as Albuliera, do have boardwalks on the sand, which were very useful. If you want to visit historical sites, such as Silves castle and cathedral, you will have a few problems unless you are very agile. It is possible though to get your car right up outside these places for you to see them close up without resorting to walking. It seems that traffic wardens haven't been invented yet in The Algarve, but take your blue badge with you anyway, as there are some special parking bays.

The weather was in the high 70's, this being September and sometimes ventured into the low 80s. This encouraged us to take a drive up into the mountains where I remembered from a previous visit the air is a little cooler and wonderfully fresh. What a shock we had when we got to Monchique and saw the destruction caused by the recent forest fires.

Everything was burned and in some places was still smoking. All the roadside cafes were gone, burned-out vehicles and road signs lay abandoned, and the air was thick. We really felt as though we were intruding, even though we turned up there in ignorance. The extent of the fire was indescribable. If you could imagine an area from Lands End to Truro, including the Lizard, you would be close to it, yet surprisingly, some houses survived and we could see signs of activity as the residents tried to resume their lives.

It was while trying to leave this area that I realised that my fuel was low (very low). With no chance of a filling station surviving the fires, we kept going. Have you ever tried, without knowing Portuguese, to ask a post lady, who spoke no English, up a mountain, miles from anywhere, where to buy petrol? Yet somehow we managed to get understood, and were soon refuelled. My wife reckoned I was a mime artist in another life.

Shortly after this experience, we reached an area unaffected by the fires and stopped for a drink. In The Algarve, they appear to have little roadside cafe bars at regular intervals, even if no-one lives within 20 miles! Here you can get a freshly made espresso coffee for 1 Euro (68p), but the amazing thing is that this owner held a really long and informative conversation with us without either of us being able to speak a common language. I must say I did throw in a few schoolboy Spanish words which somehow helped, and we left his company feeling we had tasted real rural Portuguese life, clutching a freshly picked bunch of his home grown grapes.

Came the day of the sales talk, and do you know what? It lasted exactly 90 minutes and when I said I wasn't interested, no pressure was put on me and we went on our way rejoicing and feeling not a little guilty. The journey home was uneventful, and on arrival at Bristol, we were taken to the farm to collect our car in a wheelchair taxi. If you prefer to get to the airport by train, there is a regular bus service from Temple Meads to the airport that is wheelchair accessible, and loads of taxis.

The area we stayed in was typical of some of the smaller resorts, and may cause a few minor problems for people with walking difficulties, but it shouldn't stop you from giving them a try. The bigger resorts are a little better; but with them you have to take the night clubs, all day breakfasts and kiss me quick hats. Personally I would recommend the smaller ones and chilling out locally, as touring is a sure way of getting a divorce if your wife is navigating on those sign-less roads.

Generally, I would advise you to research your trip well before you go, so you choose the right resort for you, but getting there is no problem, because as usual, all the help you need is there for you. Just make sure you have enough room in your case for some locally produced Portuguese wine and of course, Port.

About the Author - Alan Russell is a founder member of the Cornwall Post-Polio Support Network and a regular travel columnist for "discover".

# **Restroom Alternatives: Practical Solutions for a Private Issue**

by Linda Wheeler Donahue

Published in the January 2004 Rancho Los Amigos Post Polio Support Group Newsletter - reprinted with permission.

The beautiful Superstition Mountains of Arizona are a spectacular sight to explore on vacation. As my husband, son, and I drove through these remote windy hills, I was suddenly distracted from the painted desert colours exclaiming, "I have to **GO!**" My tolerant family was quite accustomed to these outcries, as I seem to have a small bladder that fills suddenly and urgently. My husband made a quick turn, driving offroad a ways into the desert. As he brought the car to a stop, he said, "James and I will take a little stroll and you can 'go' here." Well, that worked just fine as the only living things around were some occasional, forgiving desert jackrabbits.

## **Got to GO!**

Living in the bustling northeast, however, there are rarely such desolate places to stop to urinate outside of the car. That sentence is fair warning that this article will discuss a sensitive subject in frank and specific terms. By talking with other polio surveyors, I discovered I was not the only one with tips and techniques for discreetly urinating when a bathroom is not available. In the interest of being polite, I call these tips restroom alternatives.

For years I suffered (and suffered is

the only accurate verb) with bathroom problems. Back when I was still ambulatory, walking was extraordinarily uncomfortable to the point of exhaustion with each step. Because fast food restaurants usually had accessible restrooms, I quickly learned the location of every hamburger eatery within a 30 mile radius of my home. However, it was not sufficient to use just any old hamburger joint's bathroom. It had to be a restaurant with a ladies' room located very near to the entrance. The reason for that requisite was that walking on slick floors was difficult and dangerous for me. If the restroom was not near the entranceway, I could not use it. This requirement drastically cut down on my options, and I often had to drive in circles for miles to find a place where I could use the bathroom. My problems walking were compounded by an 'overactive' bladder'. This is an ailment where the detrusor muscle surrounding the bladder contracts spastically, which results in sustained, high bladder pressure and the sudden urgent need to urinate. Whereas normally, the detrusor muscle contracts and relaxes in response to the volume of urine in the bladder, in a person with overactive bladder, the volume of urine can be minimal. All these contractions throughout the day send signals best stated in four words: "I have to **GO!**"

## **There Had to be a Better Way.**

I knew the time had come to abandon the hamburger restaurant solution and replace it with a discreet system that I could use within my life-equipped van. There just had to be a better way!. Well, there is and here is my technique. I park in a safe, but out-of-

the-way place, such as the farthest corner of a shopping plaza parking lot. Fortunately, my van has dark tinted windows, so I am able to do my 'powder room activity' in privacy. One day I asked my daughter to do some detective work by going outside and looking at my vehicle from all angles to see what she could see, as I did my thing. She said someone might see the shadowy imagine of a person inside but they could see no detail.

For less than ten dollars, I purchased a plastic portable urinal, which I nicknamed 'the duck'. I zipped it into a sturdy travel tote, securing the shoulder strap of the tote around the headrest of a seat in the back of my van. I added other supplies such as tissues, plastic bags, and baby wipes. The process is easiest when I am wearing a skirt. However, since I usually wear slacks, I keep a beach towel in the van to cover my lap.

Disposing of the urine is another issue to consider. I seem to imagine that someone will wander by and know exactly what I am doing. Therefore, the filled duck sometimes has to take a ride in the tote for a while before I can conveniently empty it. This style urinal does not have a lid so I place a plastic baggy over the opening and firmly secure the baggy with an elastic band. When I get home, the duck cleans easily with soap and water. This routine would work equally well for men as women.

### **High-Tech Ducks.**

In addition to my plain 'duck' I have discovered some higher tech products that are very efficient. One is a personal urinal, compressed to about the size of a lemon, and called 'Travel

John' [loo]. It fits conveniently into a pocket or purse [handbag]. Even though it is small, it unfolds to hold a capacity of up to 24 fluid ounces. Its high-tech feature is an absorbent, biodegradable polymer substance within the pouch. This material converts liquid into a solid, odorless gel. Since the contents are spill proof, disposal is a simpler task than with my low-tech duck. With a bit of practice, this style of personal urinal can be used while seated and has a spill guard to prevent back flow during use.

Another bathroom alternative is called the Freshette system. This involves a small funnel attached to a flexible tube. It is compact and lightweight and comes with a convenient travel pouch that fits neatly into your purse [handbag] or pocket so you can carry it wherever you go.

### **Bladder Disorders and PPS**

When I decided to seek medical help for my overactive bladder, I did some research to discover if my symptoms might be connected to polio. It took some digging, but I did find a number of medical studies showing that bladder disorders are indeed common among persons with Post-Polio Syndrome.

When I finally made an appointment with a urologist, I brought with me a study by Dr. Jonathan S. Vordermark and associates titled 'Urologic Manifestations of Post-Polio Syndrome.' In this research, Dr. Vordermark writes that PPS can affect bladder function. He did a study of randomly selected polio survivors and found that respondents with post-polio syndrome had a significantly greater prevalence of urologic symptoms than

did the respondents without post-polio syndrome. No dominant pattern of voiding dysfunction was noted. [Vordermark].

Another study states that there are numerous causes for neurogenic bladder dysfunction and symptoms vary depending on the cause. An overactive bladder is caused by interruptions in the nerve pathways to the bladder. This nerve damage may be a complication of having had polio. [Hendrick] Neurogenic bladder is a dysfunction that results from interference with the normal nerve pathways associated with urination. Normal bladder function is dependent on the nerves that sense the fullness of the bladder [sensory nerves] and on those that trigger the muscle movements that either empty or retain urine [motor nerves]. The bladder, internal sphincter, and external sphincters may all be affected by nerve disorders that create abnormalities in bladder function. My urologist said he believes my overactive bladder is caused by nerve damage from polio. No generalized conclusions should be drawn, however, as many people who had polio have normal bladder function.

My urologist was very interested in the articles I brought to him. As a result of the recommendation of Dr. Vordermark, my urologist conducted a urodynamic assessment. He then prescribed a medication to relax the bladder called Ditropan [oxybutynin], which tends to suppress the unwanted urgent bladder contractions. This has been only mildly effective in my case. However, my trusty ducks are always one hundred per cent successful.

### **Polio Survivor Share Tips.**

My problems of overactive bladder combined with difficulty walking were my motivation to find a better way... a restroom alternative.

Not all PPSers have urologic dysfunction, but many have mobility problems. I wanted to know how others deal with the need to use a bathroom when none is around or is too difficult to reach. Therefore, I asked my friends who had polio for their tips and techniques and discovered this collection of ingenious inside information. Here are the comments from others who had polio:

- Some public toilets are too hard for me to rise up from. I bring my urinal and use it in the stall. Then I do not have to struggle or ask for help.
- I brought my personal urination equipment from a catalogue called MOMS. I paid \$17.99 for the urinal plus \$2.49 for the female adapter. I just love it. I keep it in a plastic bag in my car and use it when I visit my son. His bathroom is upstairs. With the urinal, I just step into his cloak closet and do my business. It does not spill or leak.
- We have a bedside commode in our vacation cabin in the upstairs bedroom. I find it easier and more convenient to use my little urinal rather than the commode.
- Our friends invited us for an afternoon on their boat. That goodness I brought my 'duck' since the bathroom onboard was too teeny tiny to use.

- I purchased a urinary device from Allegro Medical called 'Travel John'. It is a disposable urinal bag containing Liqisorb, a product that absorbs liquid and turns it into a biodegradable, spill proof gel. After use, you dispose of the bag in a any waste receptacle. If you can stand, or lift yourself to the edge of your chair, this product works well.
- The 'Freshette' system works for me. It looks like a funnel attached to a tube and then to a container. Try it first in the shower to get accustomed to it.
- For long airplane trips, I use a urinary catheter. An incontinence nurse taught me how to do this. A soft tube is placed into the urinary bladder to drain urine. The catheter is inserted into the urethra and is connected to a urinary drainage bag.
- There is nothing quite as good as a dill pickle jar. Save your next pickle jar, wash it out, and keep it in your car. The screw-on lid is wonderfully leak-proof and odorproof.
- The Rolli mail order catalogue showed a collapsible urinal that looked good.
- Some of the female urinals do not have lids. Therefore, I carry a plastic coffee jar with me and empty the urine from the urinal into the jar for safe-keeping until I can conveniently empty it.
- My home health store sells a portable 'John' and a portable 'Jane'. These disposable pouches will not spill.

We have all been in situations where a sanitary restroom is unavailable or too difficult to walk or roll to. Perhaps we are at a restaurant or conference center and the bathroom stalls are too small for wheel chair use. Most of the time, we are not in a remote desert as I was in those beautiful Superstition Mountains. I hope that some of these solutions to a common problem will work for you. We polio survivors have dealt with many trials and tribulations more difficult to manage than discreet urination. We should not be embarrassed about this intimate topic. We just have to get resourceful!

#### References.

Agency for Health Care Policy and Research. **Urinary Incontinence in Adults: Acute and Chronic Management.** Rockville, MD, U.S. Department of Health and Human Services, 1996.

Bahnson, Robert R. **Management of Urologic Disorders.** London: Wolfe Publishing Ltd., 1994.

Department of Neurology, West Virginia University. **Muscle and Nerve Journal**, July 1996;811-818.

Hendrick Medical Center. Health Information Library; AccessMed Resource Center. Abilene, Texas. <http://www.hendrickhealth.org/healthy/index.html>

**Overactive Bladder.** A program of the Bladder Health Council of the American Foundation for Urologic Disease. <http://www.afud.org/oab/index.html>

Vordermark, MD, Jonathan S, and Associates. 'Urologic Manifestations of Post-Polio Syndrome.' **Journal of Wound, Ostomy, and Continence Nursing**, July 1996; 23(4):218-23

#### **About the Author**

Linda Wheeler Donahue, Professor Emeritus of Humanities, is a polio survivor, writer and speaker. She is President of **The Polio Outreach of Connecticut** and is a frequent presenter at conferences, focusing on the social, emotional, and

psychological complexities of disability.

Linda's essays on subjects of disability dignity, positive thinking, and living with the aftermath of polio, have been published worldwide. She welcomes feedback and can be reached at

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#### **Linda's Sources for Personal Hygiene Products.**

Home health stores, camping/hiking stores, and retail mail order catalogues frequently carry these products. In addition, if you have internet access, you can purchase most of the merchandise in this article online. Here are the websites.

[www.valuemedicalsupplies.com/incont.htm](http://www.valuemedicalsupplies.com/incont.htm)

[www.comforthouse.com/comfort/porjoh.html](http://www.comforthouse.com/comfort/porjoh.html)

[shop.store.yahoo.com/buyinprivate/femurthispor.html](http://shop.store.yahoo.com/buyinprivate/femurthispor.html)

[www.caregiving-solutions.com/urinalfemale.html](http://www.caregiving-solutions.com/urinalfemale.html)

[www.acespilotshop.com/pilot-supplies/safety/travel-john.htm](http://www.acespilotshop.com/pilot-supplies/safety/travel-john.htm)

[www.dansmobility.com/convcarepersonalhygiene.html](http://www.dansmobility.com/convcarepersonalhygiene.html)

[www.allegromedical.com/Home/search.asp](http://www.allegromedical.com/Home/search.asp)

[www.freshette.com/](http://www.freshette.com/)

#### **UK websites.**

Boots the Chemist - [www.boots.com](http://www.boots.com)

Smith+Nephew - [www.smith-nephew.com/UK/](http://www.smith-nephew.com/UK/)

Later Life - [www.laterlife.com](http://www.laterlife.com)

**HAVE YOU FOUND GOOD SPECIALISTS, AIDS, SUPPLIERS, MAGAZINES, NEWSLETTERS, ORGANISATIONS, WebSites? - LET US KNOW PLEASE.**

#### **FOUR QUESTIONS CONTINUED.**

Q. 1 - Answer: If you answered that you are first, then you are absolutely wrong! If you overtake the second person and you take his place, you are second.

Try not to screw up in the next question. To answer the second question, don't take as much time as you took for the first question.

Second Question: If you overtake the last person, then you are...?

Answer and next question on page 17

## **Polio and Post Polio News.**

The following are a selection of items from around the World. The full article can be read by going to <http://mt.lincolnshirepostpolio.org.uk/archives/pandpp-news/> and adding the number at the end of each item

**June 21, 2004**

### **Lennie Bush: Dependable jazz double-bassist and early bebop enthusiast.**

Leonard Walter Bush, double-bass player: born London 6 June 1927; married (one son); died 15 June 2004.

An old jazz-world maxim used to be "If you are forming a band, always start by hiring a really good double-bass player. Another word of advice often passed on to aspiring jazz improvisers was "If you get into trouble during your solo, listen to the bass line." Lennie Bush totally understood and unfailingly provided the instrument's primary functions in ensemble performance.

Lennie Bush was born in 1927 at Shepherd's Bush in west London and was a childhood victim of polio. It left him with a permanent limp, but in his adult years his arrival at a gig, with rolling gait and handsome, craggy smile, gave musicians and fans a feeling of pleasant expectation. He studied violin as a youngster, but, as Louis Armstrong put it, "the doggone thing grew up on him". 000104.html

**June 20 2004**

### **Botswana Races to Immunize Children in Polio Scare.**

Tue Jun 15, 2004 11:08 AM ET GABORONE (Reuters) - Health

workers backed by helicopters and dugout canoes raced on Tuesday to immunize children across Botswana against polio after the first case in a decade raised fears of a resurgence of the deadly disease.

"Botswana was polio free, but the virus moves extremely fast -- just one case can mean 100,000 people exposed to the disease," said the head of U.N. children's agency UNICEF in Botswana, Gordon Jonathan Lewis. 000102.html

### **South Africa launches polio vaccinations after Botswana outbreak.**

JOHANNESBURG (AFP) - South Africa will next month launch a polio immunisation campaign targeting five million children after an outbreak of the crippling disease in neighbouring Botswana, the health ministry revealed.

Health spokeswoman Joanne Collinge said the 23-million-rand (3.5 million dollars / 2.9 million Euro's) campaign was part of efforts to have South Africa declared polio-free by next year. 100101.html

**April 29, 2004**

### **PM tells students of brush with polio.**

OTTAWA --- Prime Minister Paul Martin used the poignant tale of his own brush with polio --- and of friends lost in an epidemic --- to encourage Canadians to get immunized against disease.

Martin visited Vincent Massey Public School in Ottawa yesterday morning to



mark national immunization awareness week. He told a group of students how he contracted the disease in 1953 at age 8. 10093.html

**April 23, 2004**

**HIV Not Linked to Polio Vaccine.**

LONDON (Reuters) - Scientists reported new research Wednesday which they say is further proof that the AIDS pandemic was not sparked by polio vaccines used in Africa in the 1950s that were contaminated with a chimpanzee virus.

The controversial theory on the origins of AIDS has been dismissed by many medical experts who say there is no scientific evidence to support it. 10090.html

**April 14 2004**

Patrick Nuttgens, Architect, broadcaster and founding Director of Leeds Polytechnic.

Patrick John Nuttgens, architect, broadcaster, writer and educationist: born Whiteleaf, Buckinghamshire 2 March 1930; Lecturer, Department of Architecture, Edinburgh University 1956-61; Director, Institute of Advanced Architectural Studies, York University 1962-68, Professor of Architecture 1968-69, Honorary Professor 1986-2004; Hoffman Wood Professor of Architecture, Leeds University 1968-70; Director, Leeds Polytechnic 1969-86; CBE 1983; married 1954 Bridget Badenoch (six sons, three daughters); died York 15 March 2004.

Brought up as a Roman Catholic, he

was influenced and formed all his life by his Catholic faith, though subject to crises of doubt and questioning. At the age of 12, he contracted polio and was confined to hospital bed for a year. It left him partially crippled and thereafter he was troubled by pain and discomfort, borne with remarkable courage and good cheer. 10075.html

**April 13, 2004**

**First Presumed West Nile Virus Patient in U.S. Responds to GenoMed's Treatment.**

ST. LOUIS, April 12 /PRNewswire-FirstCall/ -- GenoMed, Inc. (OTC Bulletin Board: GMED), a Next Generation Disease Management(TM) company that uses its expertise in genes to improve patient outcomes, said today that its protocol has helped the first patient in the U.S. in 2004 who is presumed to have West Nile virus encephalitis. This patient represents the ninth success out of ten consecutive patients to be treated with GenoMed's protocol. 10072.html

**FOUR QUESTIONS CONTINUED**

Q 4 Answer: Nunu? NO!  
Of course not. Her name is Mary.  
Read the question again.

I GOT THEM ALL WRONG

TRY THIS ON THE "SMART  
PEOPLE" IN YOUR LIFE

# Thought Provoking Statements

A man's home is his castle, in a manor of speaking.

A pessimist's blood type is always b-negative.

My wife really likes to make pottery, but to me, it's just kiln time.

Dijon vu - the same mustard as before.

Practice safe eating - always use condiments.

Did Noah keep his bees in archives?

I fired my masseuse today. She just rubbed me the wrong way.

A Freudian slip is when you say one thing but mean your mother.

Time flies like an arrow. Fruit flies like a banana.

A gossip is someone with a great sense of rumour.

She criticized my apartment, so I knocked her flat.

Without geometry, life is pointless.

When you dream in color, it's a pigment of your imagination.

Condoms should be used on every conceivable occasion.

Reading whilst sunbathing makes you well-red.

When two egotists meet, it's an I for an I.

Energizer Bunny arrested - charged with battery.

Shotgun wedding: A case of wife or death.

If electricity comes from electrons... does that mean that morality comes from morons?

Marriage is the mourning after the knot before.

A hangover is the wrath of grapes.

Corduroy pillows are making headlines.

Is a book on voyeurism a peeping tome?

Dancing cheek-to-cheek is really a form of floor play.

Banning the bra was a big flop.

Sea captains don't like crew cuts.

Does the name Pavlov ring a bell?

Accept that some days you're the pigeon, and some days you're the statue.

Always keep your words soft and sweet, just in case you have to eat them.

Always read stuff that will make you look good if you die in the middle of it.

Eat a live toad in the morning and nothing worse will happen to you for the rest of the day.

## ENGLISH

In what other language do people drive in a parkway and park in a driveway?

In what other language do people play at a recital and recite at a play?

Why does night fall but never break and day break but never fall?

Why is it that when we transport something by car, it's called a shipment, but when we transport something by ship, it's called cargo?

Why does a man get a hernia and a woman a hysterectomy?

Why do we pack suits in a garment bag and garments in a suitcase?

Why -- in our crazy language -- can your nose

run and your feet smell?

Why is it that a woman can man a station but a man can't woman one, that a man can father a movement but a woman can't mother one, and that a king rules a kingdom but a queen doesn't rule a queendom? How did all those Renaissance men reproduce when there don't seem to have been any Renaissance women?

In what other language do they call the third hand on the clock the second hand?

Why is phonetic not spelled phonetically? Why is it so hard to remember how to spell mnemonic? Why doesn't onomatopoeia sound like what it is?

Why is the word abbreviation so long? Why does the word monosyllabic consist of five syllables? Why is there no synonym for synonym or thesaurus? And why, pray tell, does lisp have an s in it?

A writer is someone who writes, and a stinger is something that stings. But fingers don't fing, grocers don't groce, hammers don't ham, humdingers don't humding, ushers don't ush, and haberdashers do not haberdash.

If the plural of tooth is teeth, shouldn't the plural of booth be beeth? One goose, two geese -- so one moose, two meese? One index, two indices -- one Kleenex, two Kleenices? If people ring a bell today and rang a bell yesterday, why don't we say that they flang a ball? If they wrote a letter, perhaps they also bote their tongue. If the teacher taught, why isn't it also true that the preacher praught? Why is it that the sun shone yesterday while I shined my shoes, that I treaded water and then trod on the beach.

Why is it that when the sun or the moon or the stars are out, they are visible, but when the lights are out, they are invisible; that when I clip a coupon from a newspaper I separate it, but when I clip a coupon to a newspaper, I fasten it; and that when I wind up my watch, I start it, but when I wind up this essay, I shall end it?

A waiter. Why do they call those food servers waiters, when it's the customers who do the waiting?

A hot water heater. Who heats hot water? This is similar to garbage disposal. Actually, the stuff isn't garbage until after you dispose of it.

I'll follow you to the ends of the earth. Let the word go out to the four corners of the earth that ever since Columbus we have known that the earth doesn't have any ends.

It's neither here nor there. Then where is it?

Extraordinary. If extra-fine means "even finer than fine" and extra-large "even larger than large," why doesn't xtraordinary mean "even more ordinary than ordinary"?

Put on your shoes and socks. This is an exceedingly difficult maneuver. Most of us put on our socks first, then our shoes.

The bus goes back and forth between the terminal and the airport. Again we find mass confusion about the order of events. You have to go forth before you can go back.

Keep a stiff upper lip. When we are disappointed or afraid, which lip do we try to control? The lower lip, of course, is the one we are trying to keep from quivering. I'm speaking tongue in cheek. So how can anyone understand you? They do things behind my back. You want they should do things in front of your back?

Why do six, seven, eight, and nine change to sixty, seventy, eighty, and ninety, but two, three, four, and five do not become twoty, threety, fourty, and fivety. Why is first-degree murder more serious than third-degree murder and a third-degree burn is more serious than a first-degree burn. Why can we open up the floor, climb the walls, raise the roof, pick up the house, and bring down the house.

[This article played havoc with my spell check!]

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