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WHISPERING HOPE RANCH

By Dione Briggs

Leaving the valley and driving up to Payson, I could feel the stress leaving me. Once we went through Payson and saw all the pine trees lining the road with signs of Watch Out For Animals, the anticipation of reaching Whispering Hope Ranch was one of a child going on their first camping trip.

When we arrived I was impressed by the staff and volunteers, how helpful they were unloading our bags and setting us up with our bunks. I was so eager to get outside and smell the clean air and see the pine trees. There was a light rain and it seemed you could reach up and touch the clouds. Everything had the most wonderful scent. We saw the animals as we drove in and I was awakened every morning by the braying of the burros and the sunrise. The cabins had everything very accessible for handicapped people.

They had so many things you could sign up for, an activity for everyone: Fishing; Watching movies; Crafting; Tom Car Tours; Horseback Riding (one of my favorites) and Visits to a Fish Hatchery. We were greeted with a big bonfire on the first night we were there. Cowboy Charlie serenaded us with his guitar and told jokes. There were volunteers roasting marshmallows and making s'mores for us. Now I want some more.

I felt so laid back, it was just wonderful and made me think of what I had been missing these past years.

The rest of the time it was warm, not too hot, and Sunny. I sat out listening to the whispering wind going through the pines, while meeting new friends and helping them out when I could.

The second night, we had a Casino bring in some tables and
(Continued on page 2)

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**ARIZONA ROTARY'S
"END POLIO NOW"
AWARENESS DAY AT
D'BACK'S CHASE FIELD**

By Hal Wochholz

On Sunday, **September 20, 2009**, the Arizona Diamondbacks will play the Colorado Rockies here in Phoenix. \$10 from each ticket sold will be a tax deductible donation to the Rotary Foundation's "End Polio Now" project.

We urge you, your friends and families to attend the game and support the effort of Rotarians Internationally, along with Bill Gates, to eradicate polio from our world.

WHISPERING HOPE RANCH

(Continued from page 1)

give us free money tokens to play with. I wasn't lucky so I had Tom take my chips. He was on a winning streak. It was a lot of fun and the person with the highest chips won a prize. Sorry you didn't win Tom but we had a great time. We did win a big cup full of goodies. Tom won for relay racing and I won for horseback riding. My coffee mug says "May The Horse Be With You" I can't remember what Tom's said, but it was nice.

The third night they had a band come in and did a whole lot of wheelchair dancing. I enjoyed it from afar.

While we were sitting out in the dark the Wild Life appeared. A very large Skunk came very close, but he was used to people and didn't spray us or any place around us. Then, as I went to the dance, there was a small skunk also friendly with us. There were lots of birds in the daytime. I went and visited the animals they had there. Horses, burros, emus, cows and more animals that I didn't get to see. The Staff and



Dione enjoyed being back in the saddle again and the unique scent of the horse.

Volunteers were so great I can't begin to give enough adjectives to describe them. We ate three great meals a day and had a large assortment of every thing you can think of for snack. When we were getting ready to leave they had sack lunches for us to take with us to eat on the way home. Vegetarian sacks and Meat sacks something for everyone. Leaving and knowing we were coming back to the hot valley was not as exciting as arriving there. But, I have so many good memories to last until next year. I'm keeping my suitcases where I can reach them at a moments notice. I recommend Whispering Hope Ranch. It gives me hope until I can return next year.

PALINDROMES

by Robert J. Lynch.

Madam, in Eden, I'm Adam.

Draw putrid dirt upword.

Evil I did dwell; Lewd did I live.

Otto saw pup; pup was otto.

Able was I ere I saw Elba.

A man; A plan; a canal; Panama.

No, It is open on one position.

Was it a car or a cat I saw?

**BAJADA TRAIL OPENS ON
SATURDAY, SEPTEMBER
26, 2009 AT 8:00 A.M.**

The ADA accessible trail at the gateway to the McDowell Sonoran Preserve, located at 18333 N. Tompson Peak Parkway in Scottsdale, will be dedicated and opened with ceremony and various activities throughout the morning. Pack lots of water and charge your power wheelchair for an enjoyable adventure on this new wilderness trail.

Orange juice will be provided by SUN ORCHARD.

For more information, call the McDowell Sonoran Conservancy at (480) 998-7971

POLIO SURGES IN NIGERIA : WHEN VACCINE VIRUS MUTATES

by MARIA CHENG

The Associated Press

Friday, August 14, 2009

LONDON-Polio, the dreaded, paralyzing disease stamped out in the industrialized world, is spreading in Nigeria. And health officials say, in some cases it is caused by the vaccine used to fight it. .

In July, the World Health Organization issued a warning that this vaccine-spread virus might extend beyond Africa. So far, 124 Nigerian children have been paralyzed this year -about twice those afflicted in 2008. ---

The polio problem is just the latest challenge to global health authorities trying to convince wary citizens that vaccines can save them from dreaded disease. For years, myths have abounded about vaccines -that they were the Western world's plan to sterilize Africans or give them AIDS. The sad polio reality fuels misguided fears and underscores the challenges authorities face using a flawed vaccine.

Nigeria and most other poor nations use an oral polio vaccine because it's cheaper, easier, and protects entire communities.

But it is made from a live polio virus - albeit weakened -which carries a small risk of causing polio for every million or so doses given. In even rarer instances, the virus in the vaccine can mutate into a

deadlier version that ignites new outbreaks.

The vaccine used in the United States and other Western nations is given in shots, which use a killed virus that cannot cause polio.

So when WHO officials discovered a polio outbreak in Nigeria was sparked by the polio vaccine itself, they assumed it would be easier to stop than a natural "wild" virus.

They were wrong.

In 2007, health experts reported that amid Nigeria's ongoing outbreak of wild polio viruses, 69 children had also been paralyzed in a new outbreak caused by the mutation of a vaccine's virus.

Back then, WHO said the vaccine-linked outbreak would be swiftly overcome -yet two years later, cases continue to mount. They have since identified polio cases linked to the vaccine dating back as far as 2005.

It is a worrying development for officials who hope to end polio epidemics in India and Africa by the end of this year, after missing several earlier deadlines. "It's very disturbing," said Dr. Bruce Aylward, who heads the polio department at the World Health Organization.

This year, the number of polio cases caused by the vaccine has doubled: 124 children have so far been paralyzed, compared to 62 in 2008, out of about 42 million children vaccinated. For every case of paralysis,

there are hundreds of other children who don't develop symptoms, but pass on the disease.

When Nigerian leaders suspended polio vaccination in 2003, believing the vaccine would sterilize their children and infect them with it, Nigeria exported polio to nearly two dozen countries worldwide, making it as far away as Indonesia.

Nigeria resumed vaccinations in 2004 after tests showed the vaccine was not contaminated with estrogen, anti-fertility agents or HIY.

Experts have long believed epidemics unleashed by a vaccine's mutated virus wouldn't last since the vaccine only contains a weakened virus strain -but that assumption is coming under pressure. Some experts now say that once viruses from vaccines start circulating they can become just as dangerous as wild viruses.

"The only difference is that this virus was originally in a vaccine vial," said Olen Kew, a virologist at the U.S. Centers for Disease Control and Prevention.

The oral polio vaccine used in Nigeria and elsewhere contains a mild version of the live virus. Children who have been vaccinated pass the virus into the water supply through urine or feces. Other children who then play in or drink that water pick up the vaccine's virus, which gives them some protection against polio.

But in rare instances, as the virus passes through unimmunized children, it can mutate into a strain dangerous enough to ignite new outbreaks, particularly if immunization rates in the rest of the population are low.

Kew said genetic analysis proves mutated viruses from the vaccine have caused at least seven separate outbreaks in Nigeria.

Though Nigeria's coverage rates have improved, up to 15 percent of children in the north still haven't been vaccinated against polio. To eradicate the disease, officials need to reach about 95 percent of the population.

Nigeria's vaccine-linked outbreak underlines the need to stop using the oral polio vaccine as soon as possible, since it can create the very epidemics it was designed to stop, experts say. WHO is researching other vaccines that might work better, but none is on the horizon.

Until a better vaccine is ready, WHO and U.S. CDC officials say the oral vaccine is the best available tool to eradicate polio and that when inoculation rates are nearly 100 percent it works fine.

But numerous deadlines have been missed and the number of cases has been at a virtual standstill since 2000. Critics have also wondered whether it is time to give up, and donors may be sick of continuing to fund a program with no clear endgame.

"Eradication is a gamble," said Scott Barrett, an economist at Columbia University who has studied polio policies. "It's all or nothing ...and there is a very real risk this whole thing may fall apart."

Aside from Nigeria, polio persists in a handful of other countries, including Afghanistan, Pakistan, India, Chad, Angola and Sudan.

Aylward agreed the Nigeria situation was another unwelcome hurdle, but was confident eradication was possible. "We still have a shot," he said. "We're throwing everything at it including the kitchen sink."

Addressing Habits that Cause Sleep Problems

Researchers at the University of Washington's Aging Rehabilitation Research and Training Center, Seattle, Washington.

Getting a better night's sleep may not always happen, but if your sleep problems are due to medical issues, there are ways you can manage them. Many medical problems can disrupt sleep in people with post-polio syndrome, such as breathing problems, so treating them is a first step in addressing sleep concerns. Sleep apnea, or episodes where people stop breathing during sleep, is a very important problem to discuss with your doctor if you have this symptom. Pain, which can also disrupt sleep, is a major topic that will be addressed in a future column.

Here are some physical factors that can disrupt sleep and tips on eliminating them.

Caffeine: Caffeine often plays a role in sleep problems, because it is a stimulant that affects the central nervous system. It temporarily increases alertness and wards off drowsiness, which are also the reasons it can cause sleep problems. People who drink caffeine are less likely to sleep well than those who do not. If you have sleep difficulties, it is a good idea to avoid caffeine or limit it only to the morning. Caffeine is present not only in coffee and black tea, but also in many sodas. Check labels. Decaffeinated coffee and tea are good substitutes.

Alcohol: Alcohol is a sedative. Although it may seem like it helps with sleep problems, it can actually cause them. For example, alcohol can help you to fall asleep, but it also disrupts the

sleep cycle and the quality of sleep. The sleep you get after drinking alcohol is not restful, because it interferes with the ability to achieve and stay in the deep (so-called "Stage 3" and "Stage 4") sleep cycles. It is a good idea to avoid alcohol altogether. If you have sleep problems; at a minimum, you should limit drinking it to earlier in the evening rather than right before going to bed.

Sleeping pills: Even though they are often prescribed to help people fall asleep, sleeping pills can actually worsen sleep problems over time. They also can depress breathing. However, like alcohol, most sleeping medications disrupt the sleeping cycle by interfering with our ability to achieve deep and restful sleep. Almost all sleeping medications, if they are sedatives, are recommended to be prescribed for a very short time (two weeks at most) to help someone sleep during a stressful time. Many sleep medications are addictive, and your body builds a tolerance to them. This is especially true of the benzodiazepines such as Xanax and, Librium, Valium and Ativan. If you are taking a strong sedative for sleep, you should talk to your doctor about tapering off. Getting off these drugs must be done gradually and with medical supervision. Stopping abruptly can be dangerous.

Nicotine: Nicotine, whether smoked or chewed, is a stimulant like caffeine. It causes temporary alertness or jitteriness, and raises your metabolism. These physical changes can in turn keep you from falling asleep or disturb your sleep once you've fallen asleep.

For these reasons and more, nicotine can contribute to sleep problems (another reason to quit smoking).

To help you sleep better, you can try: **Exercise:** Getting regular exercise and being aerobically fit can contribute to good sleep. Fitness helps the body naturally create healthy sleep cycles. However, people with sleep problems may want to limit exercise to the morning, since vigorous exercise late in the

day may make it difficult for your body to start winding down for sleep. If you have sleeping problems and you aren't already exercising, explore an exercise program.

Other medications: Unlike sedatives (discussed above), medications for depression can improve sleep and help you get back into a more normal sleep cycle. Talk to your doctor about this to see if a prescription would be right for you. Some antidepressants that can help with sleep are trazo- done, amitriptyline, Paxil and Zoloft.

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PULMONARY PROBLEMS IN POST-POLIO PATIENTS

Dr. Gerald W Staton, Professor of Medicine at Emory Clinic was **Atlanta Post-Polio Association's** guest speaker for its February 7, 2009, meeting. This is the second presentation by Dr. Staton, who specializes in internal medicine and pulmonary disease. The title of his presentation was "Pulmonary Problems in Post-Polio Patients." He also specializes in weaning patients off of breathing machines.

Dr. Gerald W. Staton Background Information

Citing that the first polio case observed in the United States was in 1875, Dr. Staton indicated that this and following cases of polio helped characterize the disease.

About 40% of the survivors developed some respiratory problems. However, 90% of those who experienced breathing problems during the early phase developed more serious subsequent breathing problems. After a latent period, greater than 15 years, these polio survivors experienced a gradual (usual response) or an abrupt (rare response) onset of new weakness, muscle fatigue, atrophy, and generalized fatigue symptoms. These symptoms were found to be excluded from other causes for the same symptoms. The manifestations of these symptoms in the polio survivors were as follows:

Symptom Description of Polio Survivors Affected

- a. Generalized fatigue/tiredness/exhaustion/lack of energy 85
- b. Joint pain 75
- c. Muscle pain 75
- d. Weakness in muscles previously weak 85
- e. Weakness in muscles not previously weak 55
- f. Atrophy 40
- g. Cold intolerance 40
- h. Respiratory insufficiency 40 (87.5% of which had prior respiratory problems when initially ill with polio)
- i. Dysphasia (difficulty in swallowing) 30

Respiratory Problems in Post-Polio Syndrome

Some of these problems are associated with mucous development at the bottom of the breathing tube or the lungs (Micro- and/or macro-atelectasis). Other problems include decreased lung and chest wall compliance (loss of elasticity in these areas), hypoventilation (increased blood carbon dioxide-[CO₂] levels), swallowing difficulties, poor cough, and poor secretion clearance. An inability to cough relates to breathing problems, as in having shortness of breath.

Respiratory Evaluation

A pulmonologist employs several approaches for identifying breathing problems. The first is to identify whether excess weight is a factor with this problem. Next, is the use of chest x-rays or, preferably, a CAT scan to help identify related internal problems. Another approach is Pulmonary Function testing. With the patient blowing into a tube, the physician measures the rate of air movement and total volume of air flowing in and out of the lungs. The total lung capacity is determined from this testing.

Another approach is the Arterial Blood Test. Using a syringe and needle, blood is withdrawn from the patient so that the actual CO₂ content in the blood can be determined. If a high level of CO₂ is found, there is definitely a breathing problem.

The next commonly used test procedure employed by pulmonary physicians is Walking or light Time Pulse Optometry. No further information regarding this testing was given. Maximum Aspiratory and Expiratory Pressures testing is yet another test. This instrument measures the capacity of the lungs. Dr. Staton mentioned that normal levels are 90%; however, capacity levels below 90% are serious and levels below 80% are considered very serious. Learning the Expiration Force of the lungs provides more important information.

There is another test, the Sniff Test, that measures the strength of the many muscles used in breathing. Dr. Staton mentioned that the diaphragm, abdominal or stomach, chest, and other muscles are all involved in providing air to the body during various activities. The actual functioning of the diaphragm muscles is observed using X-Ray Fluoroscopy.

Treatments That Might be Needed For Respiratory Problems

The treatments for these conditions relates to overcoming Oxygen (O₂) deficiencies with exercise or with O₂ therapy. In the latter therapy, support breathing at night using a CPAP or BIPAP to feed O₂ into the lungs is a way to help the patient. With a minority of PPS patients, a tracheotomy may be needed.

One member of the audience suggested the O₂ therapy is applied during the day just to give all the breathing muscles a needed rest.

Using proper conditioning exercises, when possible, can also improve O₂ intake in the patient.

Sleep Apnea is a common and serious breathing disorder that requires medical attention. With Sleep Apnea, weight gain is a contributing factor. This statement applies to

Post-Polio patients too. Sleep Apnea tends to be worse for Post-Polio patients.

Finally, Dr. Staton said it is important to separate breathing problems from heart problems and treating the identified problem or both problems. For this testing Dr. Staton monitors respiration and heart functions at rest and during exercise modes. A bicycle apparatus is used that can be pedaled with the feet or with the hands to accommodate patient exercise limitations. This was discussed further in the Questions and Answers section.

Other treatments available include Bronchodilators for Asthma or COPD, Speech therapy for swallowing problems, Incentive spirometry, Learning cough techniques, Chest physical therapy (percussion and postural drainage), and Feeding tube usage.

Questions and Answers

Q1: In swallowing food, a member reported the food stopping part way down the esophagus. Is this related to Post-Polio? A: It is important to get it evaluated but it could be related to a change in the tube diameter and be independent of Post-Polio.

Q2: A member has a similar swallowing problem with taking a Barium pill and is having to deal with a lot of mucous. A: You need to get a swallowing test with a liquid contrast to look for any narrow spots that could stop the pill. Also, an X-Ray Fluoroscopy test can detect spine intrusions that may produce a narrow spot in the tube. Skeletal muscles were affected by the polio virus and so the

sleeping study too. BIPAP also keeps acid reflux from annoying a patient.

Q3: Can involvement of chest muscles affect swallowing? A: Yes.

Q4: Do Post-Polio patients need to be concerned with anesthesia during surgery? A: Yes. Specific procedures must be followed. It is important to talk to your Surgeon and Anesthetist to prepare them.

Q5: What is the difference between CPAP and BIPAP? A: CPAP provides a constant back pressure with the air flow. With BIPAP, the machine senses you taking a breath and helps in taking air into the lungs. It adds more support to exhaling. In essence, BIPAP is a form of an artificial respirator. If your CO₂ levels are high during the day you should be using BIPAP therapy. But you must have a physician-monitored sleep study, too.

***Dr. Staton indicated there are physical therapy exercises that will help remove the mucous buildup from the chest. He recommended daily, simple exercises of taking deep breaths as a treatment. Also, BIPAP O₂ therapy will help to clear lungs. Not smoking or being exposed to cigarette smoke is definitely a must. Getting an influenza vaccine shot each year is an important safeguard, as well as getting a pneumonia shot every 5 years. Finally, swallowing safe foods that will not get caught in the esophagus is important to not overly tax the body.

Dr. Staton stressed that if you suspect that you may have Sleep Apnea get it checked out immediately with a physician and properly treat it. He reported that there exist what are termed "de-conditioning ef-

fects" pertaining to breathing problems. These de-conditioning effects are the result of other health problems a patient may be experiencing that need to be addressed before any reconditioning treatments, such as exercise and other approaches, can be prescribed by the physician.

Q6: Did the Sugar Cube vaccine have all three virus strains? A: Not for sure.

Q7: A member having an airway problem wants to know if it is polio related? A: A floppy airway - the voice box is skeletal muscle related and could be affected by polio. A floppy airway below the voice box is smooth muscle and not skeletal muscles, thus not affected by polio.

Q8: Do Post-Polio patients need to get the polio vaccine? A: Yes, even though there is a very low incident of polio in the U.S. If you are planning to travel to areas of the world where there is a high exposure to polio virus you must get the inoculation.

Q9: Do you always have to observe the patient with breathing problems while exercising? A: Yes, this is sometimes necessary.

10. How many people affected by polio get paralytic polio? A: 1 in a 100.

Q11: Will polio survivors that used an Iron Lung have swallowing problems? A: They may not have involvement of swallowing muscles.

Q12: One member has always had to

deal with high blood pressure and inquired if it was polio related? A: Polio could affect the autonomic nervous system.

Q13: What about breathing exercises? A: A good program of aerobic-type exercises is beneficial to our breathing process. Even ordinary daily deep breathing exercises while being seated are beneficial.

Q14: What can you do for an elevated CO₂ level versus O₂ levels? A: Excess O₂ will increase CO₂ levels. This counter intuitive response is not understood as being due to the patient's breathing ability but more as being a result of a chemical interaction taking place in the patient. This anomaly becomes an issue only if the patient is very sick. It never occurs in someone not sick. A blood gas test is used to measure these levels. Use of an O₂ flow rate of 1-3 liters/minute is a safe level. If higher flow rates get the concentration of O₂ in the blood up to 50-75% levels, then this is an issue.

Summary written by Ron Svor, Cheryl Hollis and Ivy Stiles. Material taken from an article in the Atlanta Post Polio Association's APPA NEWS, Volume 22, Issue 2—September 2009.

Cut out form and mail to Polio Echo

Please take the time to fill in the registration form below. If you cannot afford the membership fee it doesn't mean you cannot receive the newsletter. We need everyone on our mailing list to send in their registration. Memberships are due in January for current calendar year. If you have questions about membership status, contact the Treasurer, Roger Buel at (602) 493-7242.

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With the increase in U.S. postage please let us know if you want us to remove your name from the Polio Echo Mailing list. (The Polio Echo News is available from our web site.)

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Make checks payable to Polio Echo Inc. and send to: Polio Echo, P.O. Box 61024, Phoenix, AZ 85082-1024

Chapter Activities

East Valley Chapter Meets (and eats) at 1:00 pm on 3rd Wednesday of each mo.

September 16 - Meets at King's Fish House, 35 S. McClintock Dr. in Tempe Market Place (not just seafood). Contact Joan DeRenzis at 480-895-8238 for RSVP or more information.

October 21 - Meets at Coco's, 1862 Baseline Rd. (NE Corner Baseline and Dobson) in Mesa. Possible speaker. For information, contact Joan DeRenzis at 480-895-8238. RSVP to Joan or Jane Crawford at 480-899-5857.

Scottsdale Chapter

Thursday, September 3 and October 1 meetings will begin at 11:30 a.m. in the Gold Room of the Scottsdale Civic Center, which is located at 3839 N. Drinkwater

Blvd. lower level. Bring your own brown-bag lunch.

Call Carol Pranka for details at 480-946-6669.

West Valley Chapter Meets informally in September and October. Contact Jim Bley (623) 972-9102 or Jim LaBenz (623) 972-3499, for details.

Annual contributions help to educate the public and health care community concerning polio. We respond to the needs of individuals who suffer from post-polio syndrome through group meetings, educational programming, newsletters and web-site. Polio Echo, Inc is a 501(c)3 Non-profit Arizona Corporation. All contributions and voluntary dues are tax deductible.

To contribute news to Polio Echo News call (480) 820-3358 or E-mail: ringhofer@aol.com



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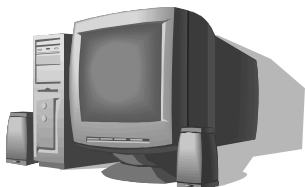
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polio_echo@polioecho.org



Information/Message Line

(602) 376-7581

If you have questions concerning projects or programs of the post-polio support group, please call and leave a message. The person best able to serve you will call back.