

# Gleanings

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## Polio Outbreak in Congo



### Polio in Congo

4 November 2010 -- An acute outbreak of poliomyelitis is occurring in the Republic of Congo, with 120 cases of acute flaccid paralysis and 58 deaths. Half the cases have been reported in the past ten days, with the first case occurring in early October. Two cases have been confirmed to have been caused by wild poliovirus type 1 and laboratory testing continues.

Most cases are in young adults: among those cases for which age data is available (43) at this time, 33 are between the ages of 15-25 years. Only one is under five years old, three are between 7 and 13 and five are between 26 and 58.

The outbreak is due to imported poliovirus. Congo had recorded its last case of indigenous polio in 2000. Investigations are ongoing to determine definitively the origins of the virus.

Nearly all cases have been reported from the port city of Pointe Noire, with cases also reported from Dolisie (2), Kayes, Bouenza, Brazzaville, and Mvouiti (one each).

The Government of Congo has alerted the public to the outbreak and launched an emergency response plan, with support from key partners, including WHO, UNICEF and the US CDC. At least three nationwide vaccination campaigns are expected, using monovalent oral polio vaccine and targeting the entire population. The number, geographic extent and target age groups of further campaigns

will be determined by the Government based on the evolving epidemiology. It is anticipated that a multi-country campaign will be required to cover bordering at-risk areas. New cases continue to be reported every day.

It is important that countries across central Africa and the Horn of Africa strengthen AFP surveillance, in order to rapidly detect any poliovirus importations and facilitate a rapid response. Countries should also strengthen population immunity levels to minimise the consequences of any virus introduction. As per recommendations outlined in WHO's International Travel and Health, guidance travellers to and from Angola and DR Congo should be fully protected by vaccination.

Given the recent progress achieved in Nigeria (98% reduction in cases this year compared to the same period in 2009), very high priority is being given to rapidly controlling persistent transmission such as in Angola and stopping new outbreaks such as Congo.

### Truly Unbelievable

#### | POLIO TIPS AND TECHNIQUES

by Dr. Richard L. Bruno

Let me tell you an unbelievable story—and I mean *literally* unbelievable.

**Sweden, 2004**—“Xepol” was described in a Karolinska Institutet press release headlined “Promising anti-inflammatory treatment for postpolio syndrome.” Sixteen polio survivors with muscle weakness were treated with Xepol, which

is intravenous immunoglobulin (IVIG), a standard treatment for inflammatory diseases. “Most patients reported improvements in their physical status. However, the value of this is unclear, since this first study did not include a placebo group.” Value unclear without a placebo group? No kidding.

**Sweden, 2006**—A Xepol study was finally published in a medical journal. IVIG was given to 73 polio survivors and placebo to 69, then given again in three months. There was no improvement in fatigue, general muscle strength, pain, walking speed, balance or sleep quality. There were only four benefits: A “selected study muscle” increased in strength by 2%, a greater decrease in “significant pain,” a 10% increase in reported “vitality” and a 19% increase in physical activity compared to the placebo group.

Did Xepol help polio survivors? First, the placebo group had worse symptoms than the Xepol group to begin with, making it harder for them to show any benefit. Second, this was not a placebo-controlled study. IVIG subjects had noticeable and unpleasant side-effects as compared to the placebo group: 30% reported itching and rash with IV, 29% reported headache, 19% reported nausea and 10% reported feeling cold. Since as many as 30% of the Xepol subjects could have figured out that they were getting IVIG, any improvements could be due to the placebo effect.

**Sweden, 2008**—A press release trumpeted, “Pharmalink Reports Positive Results for Xepol,” “effective and well tolerated” in the same subjects reported in the 2006 journal article, but who were now one year post treatment. Pain, walking ability and self-report of health “all showed significant and clinically meaningful results,” the release hailed. Said Pharmalink’s managing director, “We are very excited about this data as patients in the treated group have experienced a reduction in disease symptoms after just 12 months.”

Whoa! First, the published six-month study showed no significant improvement in pain or walking ability. Second, since the new

twelvemonth data hasn’t been published, so we can’t know if any of the new results produce a “significant and clinically meaningful reduction in disease symptoms.” Third, even the release said that the placebo group also reported a decrease in pain and improved walking after 12 months. Finally, the company was “very excited” because polio survivors had a reduction in symptoms “just 12 months” after taking Xepol?” “Just 12 months?” Can you imagine any drug company excitedly proclaiming, “New Headache Medication Works Just 12 Months after Taking the Pill?”

**North America, 2009**—I received e-mails from polio survivors in the US and Mexico. Doctors were making presentations about Xepol to post-polio support groups and then asking polio survivors for donations to perform studies using Xepol.

**Sweden, 2010**—“Pharmalink AB, today announced agreement with Grifols for the acquisition of Xepol (R)...human immunoglobulin for the treatment of (PPS). This agreement marks a significant milestone in Pharmalink’s corporate development. Grifols will develop the PPS product opportunity. In several clinical trials lead by a team of physicians at Karolinska Institutet, immunoglobulin has shown significant and clinically meaningful results in pain, walking ability and quality of life by down-regulating the inflammatory process in the nervous system of PPS patients.”

“Significant and clinically meaningful results in pain, walking ability and quality of life?” Not in the one published study. And, none of the studies, published or not, even measured “down-regulating the inflammatory process.”

What is “significant” is the “milestone in Pharmalink’s corporate development,” having sold Xepol to a company with the cash to “develop the PPS product opportunity” without polio survivors having to fund it.

I’ve been around long enough to remember an 1995 NIH study that found that high doses of prednisone, the king of anti-inflammatory drugs,

didn't decrease PPS symptoms but did cause horrible side effects. A 2007 Norwegian study found no change in polio survivors' "fatigue and muscle strength" three months after IVIG treatment."

One post-polio boat sailed long ago: Inflammation does not cause PPS. That is unless you're a corporation that "publishes" research via "very excited" press releases and happens to have a "product opportunity" that may make you a buck... or 1,500 bucks, the cost of just one Xepol treatment.

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## November Meeting

As editor of Gleanings, I feel I must apologize for the lateness of the November issue of Gleanings. My computer had some kind of seizure and had to be put down and replaced. Because of this, we had a very small turnout at our Sunday, November 7 meeting.

However, we did have an informative discussion concerning the difficulties of asking for help. Some of us can ask with no problems, while others of us were raised never to ask for help at all, the theory being that we would then learn to be independent. We discussed ways in which we might ask for the help we need without feeling we were whining. We decided that it was something we needed to work on, both on asking for help and on receiving it graciously when it was offered.

We touched on dating difficulties for the disabled, as well as numerous other subjects. All of us seemed to feel we'd had a productive meeting.

**There will be no December or January meeting, but we will meet again on February 6<sup>th</sup> at 2 PM at Bloomfield Forum, 98<sup>th</sup> and Nicholas in Omaha, NE. We are hoping for a good turnout.**

## New Book by Phillip Roth Nemesis

**FICTION:** In the stifling heat of equatorial Newark, a terrifying epidemic is raging, threatening the children of the New Jersey city with maiming, paralysis, lifelong disability, and even death. This is the startling theme of Philip Roth's wrenching new book: a wartime polio epidemic in the summer of 1944 and the effect it has on a closely knit, family-oriented Newark community and its children.

## Tipping the Scales by Millie Malone Lill

For years, I have had a feud with my body. It never seems to be quite right for the occasion. After polio, I was far too thin. Then, after a 2 month stint in a wheelchair at age 10, I was too fat. In high school, I was not pretty enough. As a young mother of three very active little boys, my body did not seem to have enough energy to get through my day. It wasn't just my muscles and skeleton that displeased me, it was my face, my figure, my hair, my fingernails. It seemed that no matter how hard my poor body worked, it just couldn't please me.

Slowly, my body and I are reaching detente. I have given up the fight to have a stylish hairdo. My hair will spitefully grow an inch immediately after being permed, resulting in a flat spot with fuzzy ends. It has no texture, is very slick, and has been known to spit bobby pins across the room in protest of my trying to force it into a French Roll.

So I wear it in a simple style that requires no perm, no curlers, no deadly bobby pins.

The fact that I'm short has also ceased to cause me great distress. I have tall grandsons who can change light bulbs for me or reach the good dishes down from the top cupboard shelf. I have heard every short joke ever told, although I am not really all that short. I know at least two people who are shorter than I am. My mother was only 4'7" when she died at nearly 98. I spend a lot of time in my wheelchair now, so height is pretty much immaterial at this point.

My fingernails, oh how I've longed for beautiful hands with long, glossy nails. Not gonna happen. I can grow hair, but not fingernails. So I keep them cut short and remember that my hands may not be beautiful, but they are capable. And which would you rather have anyway, I ask myself, pretty hands or useful hands. Both, I retort. But I'll settle for useful.

Weight. Ah, that bugaboo that haunts all women and almost all polio survivors regardless of gender. Before I moved from Canada, I had the perfect bathroom scale. It was rusted to the point that everyone, from my 6'3" husband to my little Papillon dog, weighed 160 lbs. It made everyone feel good. My husband felt svelte, my dog felt big and ferocious (something she has aimed for all her life) and I was not terribly displeased, although 160 is still too much for my smallish frame. But alas, all good things come to an end. I didn't bring that scale with me when I moved. I bought a new one, but not one of those talking ones. I hate those even more than the other kind. I step on the talking scale and it says, "One at a time, please!" So rude. The one I bought is in cahoots with my doctor's scale. They both tell me the same sad story. They lie, of course, but I'm used to that. My birth certificate tries to tell people that I'm old, too.

Losing weight is nearly impossible for a polio survivor who spends a lot of time in a wheelchair. I do try to move as much as I can but it's a tightrope

I must walk. Too much exercise and I'm so fatigued that I need to sleep for a day, thus getting no exercise at all that day. Too little and I am deconditioned and will gain weight. Therefore, I have given up all hope of being Miss America...I think you have to be tall for that, anyway...and have learned to live with my rather squat, toad-like physique. After all, if you believe my birth certificate, and I urge you not to, I'm an old woman, so who really cares how I look. I have inner beauty. "Must be," my smart aleck sons tell me. My appearance seems to please my grandchildren and great grandchildren, because they sure light up when they see me. And that makes me feel very beautiful.

Yes, we've reached detente, my body and I. I realize that it has done a pretty darn good job over all these years, and while working with decidedly less than wonderful equipment. Mismatched legs and feet, lungs that tend to wheeze when stressed, arms that are not very strong. The legs bend to make a great lap for my great grandchildren and the arms are just right for hugs. My lungs fill up with sweet baby smells and I am content.

## **UN calls for ceasefire in Congo to expedite vaccinations following polio outbreak**

As polio reappears in 12 African countries, UNICEF officials appeal for fighting to stop in eastern Democratic Republic of Congo so that an ambitious vaccination program can proceed

United Nations officials have called for an immediate cease-fire in the Democratic Republic of Congo (DRC) to allow vaccinations to reach millions of children who are threatened by a sudden epidemic of polio.

The aggressive return of the contagious paralyzing virus comes just five years after it was declared

eradicated in most of the world. It marks a major setback in the race to make polio only the third disease, after smallpox and the cattle virus rinderpest, to be eradicated.

In the wake of an outbreak earlier this year of so-called wild polio virus, the first round of an unprecedented vaccination campaign aimed at 72 million children under five was launched in 15 African countries in November.

But vaccination teams have struggled to reach children in war zones, such as eastern DRC, where government forces, the Rwandan army and militias are fighting. "We are calling on all parties to the conflict to respect the vaccination days and cease fighting," said Pierrette Vu Thi, who represents UNICEF, the United Nations children's fund, in the DRC. "All children have the same right to health."

According to the charitable organization Rotary International, one of the main supporters of the African vaccination effort, up to 800 suspected cases of polio have been found in the past six months in 12 African countries. "As soon as we have one case of polio, we consider that we are dealing with an epidemic," said André Kasogo, a UNICEF immunization officer in the DRC. "Polio is highly contagious. One person can pass the virus to 200 others and each of those can infect 200 people."

The World Health Organization puts the number of confirmed cases of polio in Africa this year at only 139, but spokesman Rod Curtis said: "Determining numbers is complex. Multiple factors, such as the Republic of Congo not having seen polio for 10 years, or adults dying before being able to provide stool samples, mean that a significant number of early cases in the outbreak did not provide diagnostic specimens."

Poliomyelitis, which is incurable and is spread through feces, reached pandemic proportions in Europe and the United States in the early 20th century. President Franklin D Roosevelt was

among the most famous of its victims. British pop star Ian Dury was another.

It appears via a fever which kills some victims and subsides of its own accord in others. Days or weeks later some survivors wake up paralyzed, often in one leg and in the arm on the opposite side of the body.

But mass childhood vaccination campaigns begun in the 1960s made polio eradication one of the success stories of western public health systems and the WHO declared war on polio worldwide. By 2001, fewer than 500 cases were recorded in the world and in 2005 the WHO said polio remained endemic only in four countries: Nigeria, Pakistan, Afghanistan and India.

Hopes that it would soon be declared eradicated have, however, been dashed by the emergence of wild polio virus in countries with weak public health systems that fail to carry out routine vaccination of babies and toddlers.

The vast DRC has not had a functioning national civil service or health service since independence in 1960. The majority of its doctors have not been paid a salary since they qualified, and they in effect privatize their services while handing out drugs given by international donors.

Kasogo worked for the health ministry for a decade before moving to UNICEF. He said: "If polio has returned, it is firstly because of the failure of our health system. While I was at the ministry we managed to set up a line of credit for childhood vaccination but because of fears of corruption and inefficiency we never succeeded in getting the civil servants to disburse the money."

He also blamed the polio epidemic on the DRC's neighbour, Angola, which had been polio-free for several years until its own public health failures led to an outbreak in 2007 that was traced to India. "There have been recent, large-scale population

movements from our neighbor Angola, which is infected," he said.

Relations between the DRC and Angola have recently soured due to a conflict over oil extraction. As a result of a series of tit-for-tat expulsions, thousands of people have crossed the border between the two countries. Had routine vaccinations taken place in the past few years in the DRC, the virus might not have crossed over.

But the lack of routine vaccination programs is not limited to the DRC. Apart from endemic Nigeria, 11 other African countries – from Uganda in the east to Mali in the west – have recorded cases this year. The DRC, which has experienced 73 cases, is in the grip of its worst outbreak for 10 years. Its capital, Kinshasa, is threatened by a massive epidemic in neighboring Congo-Brazzaville, where

169 people have died from more than 400 suspected cases. Unusually, most of the victims in the Congo-Brazzaville have been teenagers and adults, pointing to failings in routine childhood vaccinations over a number of years.

**The Following Donations have been received:**

Up to \$100

Susan Thorson, Sioux Falls, SD

\$100-\$300

Marian Peterson and family, Joan, Jan, Joyce, and Noris, Seattle, WA, in memory of Richard "Dick" Jones.

**NPSA wishes to thank our readers for their generous donations. GLEANINGS is available online at <http://ne-polio.org> so save a tree and read GLEANINGS online!**

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