Nebraska NPSA Polio Survivors Association

GLEANINGS

February – March 2015

CDC Statistics on the Measles Outbreak

(Source: CDC website; graphic on p. 2)

Two children in Nebraska were among the 121 people from 17 states and Washington, D.C. who were reported to have measles so far in 2015. Most of these cases are part of a large, ongoing multi-state outbreak linked to an amusement park in California.

The United States experienced a record number of measles cases during 2014, with 644 cases from 27 states reported to CDC's National Center for Immunization and Respiratory Diseases (NCIRD). This is the greatest number of cases since measles elimination was documented in the U.S. in 2000.

- Measles is still common in many parts of the world including some countries in Europe, Asia, the Pacific, and Africa.
- Travelers with measles continue to bring the disease into the U.S.
- The majority of the people who got measles were unvaccinated.
- Measles can spread when it reaches a community in the U.S. where groups of people are unvaccinated.
- One of the measles cases in Nebraska was a child who spent time at the Children's Museum in Omaha over the busy post-Christmas season.
- Five children in a Chicago-area child care center were diagnosed during the first week in February.

ON PAGE 5 IN THIS ISSUE:
- Link to PHI's Post-Polio Directory and other resources for Polio Survivors
- 2015 Meeting Dates & Topics

"If I get enough responses to warrant the travel, I might be convinced to go to the factory and lead a protest. We could "march" around in our wheelchairs with big signs stuck in our crutch holders. Let's see, what could we put on the signs? **SEQUINS FOR OUR SOAKERS!** Perhaps? Or maybe **DEPENDS ARE DRAB!**"

It Depends

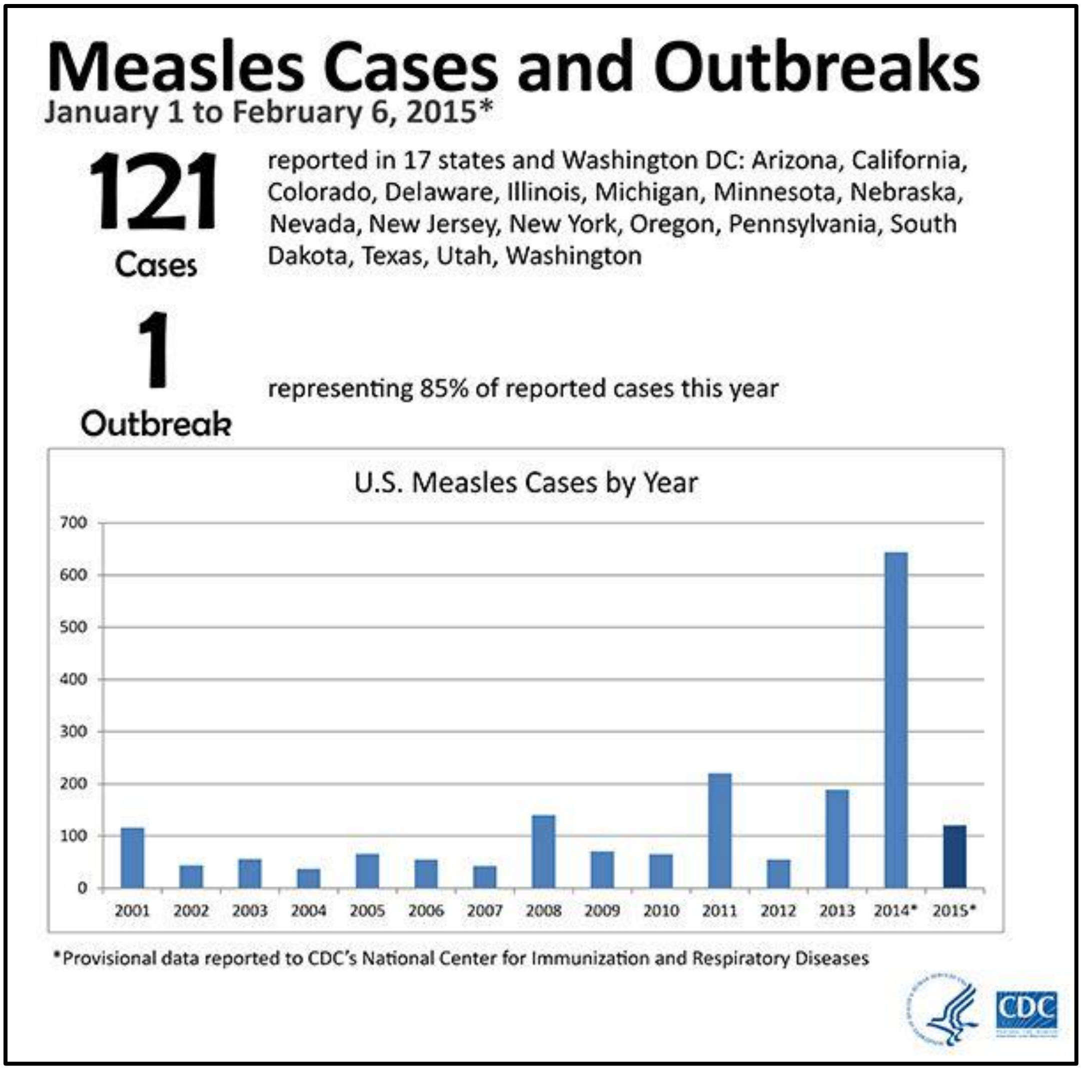
By Millie Malone Lill

This probably applies a lot more to the women in our group, but you never know. The subject is Depends...adult diapers, incontinence briefs, call them what you will. At some point in life, these things could become something we, well, Depend on.

A dear friend of mine called me the other night and said that she had had a little problem that cropped up on a trip she was taking with her husband and some friends. As my friend went to the bathroom, she noticed she was bleeding rectally, no doubt due to a pain medication she was taking. She was forced to get the adult diapers till the problem was resolved.

My friend is a beautiful woman, classy and elegant. She buys lingerie, not just undergarments, the good stuff. The lacy stuff. The Fantasy Stuff. Depends really don't fit that category. She admits they are comfortable, much more so than she had at first expected.

Millie's column (continued on p. 2)



Measles Cases and Outbreaks

January 1 to February 6, 2015*

121 Cases reported in 17 states and Washington DC: Arizona, California, Colorado, Delaware, Illinois, Michigan, Minnesota, Nebraska, Nevada, New Jersey, New York, Oregon, Pennsylvania, South Dakota, Texas, Utah, Washington

1 Outbreak representing 85% of reported cases this year

U.S. Measles Cases by Year

*Provisional data reported to CDC's National Center for Immunization and Respiratory Diseases

Millie's Column: It Depends

(Continued from p. 1)

They don't crinkle or make plastic-y sounds when she moves. But they are very utilitarian in appearance. Very Depend-able, if you will.

She explained that she immediately thought of me when she realized this issue needed to be addressed. Yes, my friends think of me when there are incontinence problems. Some people remind their friends of beautiful things, roses, moonlight, stuff like that. My friends think of me and adult diapers. At least they think of me, right? I choose to believe this is because I make them laugh so hard tears run down their legs.

As my friend sees it, the problem is that the diapers are just not pretty. If we all write to the company that makes these items, and say how we'd like a bit more bling for our buck, would it help? Gail suggested a kit you could buy, a sort of after-market add on, that contained some sequins or rhinestones or maybe a template and a magic marker so you could draw a lacy pattern on them.

If I get enough responses to warrant the travel, I might be convinced to go to the factory and lead a protest. We could "march" around in our wheelchairs with big signs stuck in our crutch holders. Let's see, what could we put on the signs? **SEQUINS FOR OUR SOAKERS!** Perhaps? Or maybe **DEPENDS ARE DRAB!**

Who is with me? Anyone want to go picket a factory? I have room for four people and one wheelchair in my van, but a walker will also fit on the lift with the wheelchair. If you wouldn't mind holding the parts on your laps in the back seat, we could probably accommodate a travel scooter that comes apart, too.

While this project might not, at first glance, seem very appealing to our male members, I would like to point out that a happy spouse is always a good thing. If you happen to be married to a disgruntled female Depends wearer, it might be in your best interests to go along with this business. If you don't want to march with us, I'll gladly provide paint and brushes so you can paint some signs for us. Remember, if Momma ain't happy, ain't nobody happy.

"Could I have gotten polio from the live vaccine?"

(Reprinted from an email, with permission)

I am wondering whether there is any way to know for sure whether I had polio, and if so, whether that might be responsible for problems I encounter today. I know it sounds crazy – but here's my situation.

I was born in 1967, so was one of the last groups to receive the oral polio vaccine, which I understand is a live virus. When I was three, I was living with teen parents who were drug abusers, and I was a neglected child. I was given the OPV and developed a very high fever (103 for several days) and my mother was having trouble keeping it at that level. She phoned the doctor's office, which told her to bring me in if my temp went OVER 103.

I'm hoping that, as polio survivors who are familiar with what happens during the illness, maybe you can give me some insight as to whether my symptoms at the time did match up with having polio.

Since my mom was a very literal sort, she didn't take me in. I remember being in extreme pain – too much to play. Even too much to move. Any movement at all sent waves of pain down my body to the point that I sat on the sofa (couldn't breathe if I lay down) and just cried every time I accidentally moved. There were involuntary muscle movements too, where the muscles would just jump, which was why I was trying so hard to stay still – muscles would jump, pain would run through my body from the movement, cry, repeat. Several days along, my leg started to misbehave. I couldn't get it to work right. Over a few days I went from being able to walk normally to dragging it behind me. My parents noticed, but again, didn't know what was wrong, so they didn't take me to the doctor. Gradually, I got the movement back in it, but it stayed weak for months and it is still weaker than the other leg today. Additionally, both my thigh muscles are atrophied, according to doctors who have examined me – the first time this was discovered I was fifteen, thin and fit, doing a lot of exercise. The doctor blamed it on a birth defect in my legs and said that I use other muscles to compensate in order to walk, but today I am told that medical science has learned more and that the birth defect is definitely not the reason for it. Doctors now look at me and just assume it is due to my inactivity today, but it's been like this for decades, well before I began having the pain that has made me inactive.

I have a Primary Immune Disorder (CVID) with good immune response to unencapsulated bacteria such as tetanus, and no immune response at all to encapsulated bacteria such as bronchitis or pneumonia. Response to viral agents is unknown, although it's suspected that we won't react normally. Immunologists have us vaccinated for the flu annually (with a dead virus only) just because it "can't hurt". Obviously, people like me don't develop reliable indicators, such as antibodies, to produce positive medical tests on many illnesses.

I have had a few incidents of MS-like muscle weakness. The last time, a few years ago, was the worst, and my ability to swallow was affected – I kept choking on my own saliva, even to waking up choking at night and whenever I tried to drink. It was very frightening, but I didn't have insurance, and couldn't get in to see my doctor. It has affected my back, my arms, and my upper legs I think, although it's hard to be sure. Then, it just goes away. The first time this happened, I was in my 20s, and was given an MRI looking for MS, but the symptoms were gone by the time my appointment came up (it took months) and no scar tissue was found in my brain. They didn't look at my spinal cord. I ran across a description of post-polio syndrome, but without knowing whether I probably had polio or not, it's hard to know whether it should be considered.

"Could I have…." (continued on p. 4)

"Could I have… "

(Continued from p. 3)

My rheumatologist sent me to a neurologist, but he poo-pooed the idea that I might have had polio in the first place. The idea that parents would be that neglectful was too incredible for him to believe. And I got the impression that he wasn't accustomed to thinking in terms of polio generally. My memory doesn't seem to be any match for the lack of medical records, and I can't prove anything, obviously, since my parents never took me to the doctor about it. My mother remembers the incident, but says I always ran high fevers after vaccinations (which makes sense, since with the defective immune system, I probably just got the illnesses that used a live virus in the vaccines), so she didn't realize anything unusual was going on at the time.

I'm hoping that, as polio survivors who are familiar with what happens during the illness, maybe you can give me some insight as to whether my symptoms at the time did match up with having polio. I've never heard that it was painful, for example, but what I remember certainly was! I don't have medical insurance today, but hope to qualify in the future and it would be very helpful to my rheumatologist to be able to either rule out polio or to know whether she should consider it as a serious likelihood, based on my memory of events. It's not as good as a medical record, of course, but knowing might help untangle a very complex medical situation. I realize this is probably far beyond the scope of your organization, but any information you can give would be very helpful and much appreciated.

Thanks so much for your attention and help,

Phoenix Caladrius

Editor's note: *Obviously you cannot make a diagnosis or offer medical advice, but if you had experience with the live vaccine and would like to respond to Phoenix, please send us an email at npsa.org@hotmail.com and we will forward your email to her. Or, if you grant us permission, we will print your response in the next issue of Gleanings.*

NPSA Mission Statement

The mission of Nebraska Polio Survivors Association is to educate the public and the health care community concerning polio and post-polio syndrome and to respond to the needs of individuals who suffer from the syndrome through group meetings, educational programming and newsletters, financial and other support of research concerning the syndrome and the circulation of research results.

Thank You to Our Donors

No matter the amount contributed, each gift helps NPSA achieve its mission. All gifts are fully tax-deductible because we are a 501(c)(3) non-profit organization. Please consider NPSA in your charitable giving for 2015.

We're grateful for gifts received from December 9, 2014 to February 15, 2015:

Barbara J. Stenning, Portsmouth, RI
James V. Zeman, Deadwood, SD
Marie R. Galda, Omaha, NE

IN THE NEWS & RESOURCES

Polio Health International's Post-Polio Directory: For a list of post-polio resources, including health care providers, enter this web address or click this link to download the order form: www.post-polio.org/net/pdirhm.html

Hotline for Disability Services
301 Centennial Mall South
Box 94987
Lincoln, NE 68509
Toll-Free Number: 1-800-742-7594
Web: www.cap.ne.gov/hotline_services
Email: shari.bahensky@nebraska.gov

Nebraska Chapter of the March of Dimes:
Mary Larsen
Director Program Services/Advocacy
Government Affairs
11640 Arbor St. Suite 102
Omaha, NE 68144
Phone 402-496-7111
Email: MCLarsen@marchofdimes.com

History of Polio website:
http://86735198.nhd.weebly.com/

NPSA's 30th Anniversary Video:
https://vimeo.com/105055161

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2015 NPSA Meeting Dates and Topics

March 1: Skype call with Robert Emmett, author of Three Quick Steps
April 12: Domesti-PUPS: Service dogs
May 3: Deacon Eldon Lauber: Ministering to Caregivers
June 7: To be announced **July 12:** Ice Cream Social
August 2 & September 13: To be announced **October 4:** Annual Reunion
November 1: To be announced

Our meetings are held on the first Sunday of each month from February through November, unless it's a Sunday before or after a national holiday. We meet between 2:00 – 4:00 p.m. at the Bloomfield Forum Community Room, 9804 Nicholas Ave., Omaha, Nebraska. Everyone is welcome to attend. Coffee and refreshments are served during the social hour.

If you're in the Omaha metro area, please join us!

Nebraska NPSA Polio Survivors Association
PO Box 6076
Omaha, NE 68106

Are you moving? Do you have a friend or family member who survived polio and who would like to receive *Gleanings*? Return this form with your address changes or the name and address of your friend/family member.

Name: ____

Street Address: ____

City/State/Zip: ____

If you'd prefer to receive an **email** version of *Gleanings* instead of a mailed paper copy, please send us an email. In your message, include your name and postal address with your email address to npsa.org@hotmail.com. Thank you for helping us to keep our mailing list current and accurate.