

PHI's mission is supported by its Membership.

Celia Yoder Looks Toward 99th Birthday With an Attitude of Gratitude

Exactly three years before the peace treaty ending World War I was signed in France, Celia Bell Yoder was born on November 11, 1915, on a farm in north-central Oklahoma.

In 1930, she contracted polio, which affected her left hip and leg, which is a half-inch shorter than the right. She was never hospitalized, but remembers being in pain. She was diagnosed with infantile paralysis after the fact.



Celia Yoder

Following high school and two-and-a-half years at Northern Oklahoma College, Celia earned a teaching certificate and landed a job teaching all eight grades in a one-room country school. Starting pay was \$75 a month, but it was enough to afford her own 1928 Ford.

One of her most memorable days in the classroom involved one of the many dust storms that blew through Oklahoma in the 1930s when she was teaching: “The little country schoolhouse was suddenly enveloped in an eerie darkness of dust with wind rattling the windows of the old building. I soon needed to light the Coleman mantel lamp on the piano and two kerosene lamps on the walls. Eventually, the room was so filled with dust that the students needed to intermittently blow the dust off of the work on their desks. The children were coughing and scared.”

She walked one girl, who lived nearby, to her home. “Returning I loaded the rest of the pupils into my 1928 four-door Ford sedan. Driving close to the grader ditch with my lights on, I drove to each one’s home and dropped off the remaining children.”

Celia left teaching for marriage and to raise her family. Bored after her sons were grown, she went back to work in the business office of a medical clinic, retiring in 1977 after 17 years doing bookkeeping and transcription.

“I never lamented any ‘can’t-dos,’ but enjoyed all the ‘can-dos’ – college, teaching, Cub Scout den mother and working in the clinic,” she said.

After she and her husband, a builder/contractor, retired, they enjoyed being “snowbirds,” pulling their RV to the Rio Grande Valley in the winters where they took painting classes. “My husband said many times that he took me from the farm, but couldn’t take the farm out of me.”

In 2001, her husband of 61 years died. “At the age of 86, I was alone and ill. I was living in the dream home my husband built for us in 1946.”

She and her family agreed that she should move to a retirement home in Olathe, Kansas, with two nieces nearby to look after her.

“I said goodbye to Oklahoma and hello to Kansas. I am a descendant of pioneers, so moving is an adventure. (Her maternal grandfather made The Run, the Oklahoma

PHI Post-Polio Medical Care Survey

As you may have already experienced, many physicians who dedicated part of their practice to seeing polio survivors have retired. It is more and more difficult to make a case for a post-polio clinic from a business point of view, so new ones are not springing up. To their credit, experienced practicing physicians continue to monitor their post-polio patients for many years and evaluate new patients from time to time. But, what about the future?

PHI is asking its Membership and polio survivors within the network to help us by answering questions about their post-polio medical care. How many sought out specialized care from a self-designated post-polio specialist? On the other hand, how many have never visited a post-polio clinic/specialist and utilize their local primary care physician and local health care system? PHI wants to know what you consider the benefits of each, and, lastly, what accounts for the success of each.

Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians is the name of the survey we developed to answer these questions. We ask all polio survivors, no matter where you live, to complete it. There are two ways to do so.

Online: Go to <https://www.surveymonkey.com/s/ppmedicalcare>

USPS: Go to pages 9 and 10 of this issue of *Post-Polio Health*, complete the survey and mail it to PHI, 4207 Lindell Blvd., #110, St. Louis, MO 63108, USA.

The deadline is June 23, 2014. We value your experience!

United States switch to ICD-10-CM is delayed again

The International Classification of Diseases, Clinical Modifications (ICD-CM) is used to code and classify morbidity data from the inpatient and outpatient records and physician offices. On March 31, the U.S. House of Representatives and the U.S. Senate approved a bill (HR 4302) that would delay scheduled cuts to Medicare physician payments through April 1, 2015. The bill was signed into law by President Obama on Tuesday, April 1. Within this bill, there was a provision to delay ICD-10 implementation for one year, until October 1, 2015.

Relevant polio and post-polio codes from the ICD-10 are:

Z24.0 – Need for immunization against poliomyelitis

A80-A80.9 – Acute poliomyelitis

B91 – Sequelae of poliomyelitis (<http://apps.who.int/classifications/icd10/browse/2010/en#/B90-B94>)

G14 – Postpolio syndrome (<http://apps.who.int/classifications/icd10/browse/2010/en#/G14>)

The 11th version is now being developed through an innovative, collaborative process. For the first time WHO is calling on experts and users to participate in the revision process through a web-based platform. The outcome will be a classification that is based on user input and needs. The final ICD-11 is expected to be released in 2015. ■

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PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

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*PHI sends PHI Membership Memos via email.
Be sure to set your spam filter to receive emails
from info@post-polio.org.*

Moving? Change of address?

Notify PHI before you move by calling 314-534-0475
or email info@post-polio.org, and tell us your old
and new addresses.

Away temporarily?

Send us your second address and dates you will be there
and we'll do our best to send your newsletter.

Ankle Braces for Post-Polio Leg Pains

Frederick M. Maynard, MD, Chair, PHI Medical Advisory Committee, Marquette, Michigan

Greg Ramme is 52 with a history of mild weakness in his legs since developing vaccine-related paralytic polio in 1964 at age 3. He learned to walk with bilateral long-leg braces and crutches and used them until age 8 when his legs had become strong enough to walk well. After high school he studied mechanics and worked for more than 25 years as a diesel mechanic. He enjoyed many active hobbies, including fishing and hunting, around his home in the Upper Peninsula of Michigan.

At age 43, he still enjoyed frequent Nordic skiing for 10 to 12 kilometers. When he was 45, Greg developed numbness in his legs over a short period of time and began to notice gradual weakening and pain after exercise of his leg muscles.

At 49, he was diagnosed with lumbar spinal stenosis and received decompressive laminectomy surgery. After post-operative physical therapy, he was able to walk without a limp, but his leg muscle strength was only a grade of 4 to 4+ on the right and 4 to 4- on the left, which represents mild weakness.

Greg retired at age 50 on disability. In spite of further physical therapy, stretching exercises and massage therapy, he had to take pain medication and was frustrated by not being able to walk very far without more leg pains and by being unable to enjoy hobbies or sleep well because of leg muscle pains.

After evaluation by doctors and therapists at a Post-Polio and Wellness Retreat in Big Bay, Michigan, bilateral lightweight “partial ground-reaction force” ankle foot orthoses¹ were recommended. Their purpose was to assist his functional, but weakening, leg muscles that had chronic overuse pains.



Greg Ramme holding one of his braces. “Without PHI’s help I would not have been able to get my braces. The braces were the extra assistance I needed, and I am very grateful to have them.”

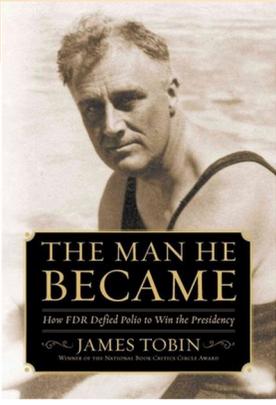
Because he had lost his health insurance and was not yet eligible for Medicare, he applied for financial assistance from PHI’s Joyce and Arthur Siegfried Memorial Fund. He received the maximum amount of \$800, which covered about half of the cost for his two braces, and he was able to obtain them a few months after they were recommended.

After using them for two months, he reports that he is mostly pain free at last and off regular pain medication. He wears the braces all day, not walking more than a quarter mile without resting, does stretching exercises, takes frequent hot baths and receives weekly leg-muscle massages from a friend who is a massage therapist. ■

Reference

1. Ottobock WalkOn® model of AFO

PHI administers the Joyce and Arthur Siegfried Memorial Fund. Polio survivors living in Missouri can apply for funds from the Gilbert Goldenhersh Memorial Tribute Fund for bracing and modified shoes. Email Brian Tiburzi at info@post-polio.org for an application for either Fund. The maximum amount given per applicant is \$800.



New Book Asserts FDR Became President *Because* of Polio

In his new book, *The Man He Became*, James Tobin, an associate professor of journalism at Miami University of Ohio, goes much further than recounting the obvious physical limitation imposed upon Roosevelt according to the *Booklist* reviewer. Rather, Tobin convincingly asserts that the struggle to overcome the disease and to resume an active life transformed Roosevelt's character. It added steel to his personality, led to his appreciation for human suffering, and even added additional fire to his already burning political ambition. Tobin offers very useful context by describing the nature of the poliovirus, especially for those too young to recall what a terrifying and devastating malady it was before a vaccine was developed.

An Amazon reviewer notes: "Within the recounting of Roosevelt's contraction, illness, recovering and physical rehabilitation from polio, Tobin enlightens readers on a number of issues. The first is the mechanics of the poliovirus and how it became a major epidemic disease in the early 20th-century. The second is the societal attitudes towards the disabled in the 1920s and early 1930s that many faced and were amplified when Roosevelt returned to politics. The third was political dynamics that the nation and the Democratic party were facing throughout the mid-1920s. ... The fourth is Roosevelt's dealings with the press about his physical condition and how much he actually used a wheelchair."

Publisher Simon & Schuster provided this interview with the author:

Q: *You've called FDR's presidency the greatest comeback in American political history – what do you mean by that?*

Tobin: His presidency now looms so large in our memory that people don't realize that when he came down with polio, he was absolutely ruined as a politician. I mean, nobody – with the possible exception of his aide Louis Howe – thought he had a political future. By any odds, and especially in that era, he should have

spent the rest of his life sorting his stamp collection by the fireplace.

The greatest obstacle was the social stigma. In that time, it was simply unthinkable that a man who couldn't walk might be fit for an important public position, let alone the presidency. And the practical obstacles were, in fact, very great. But he did it. He had a lot of help and some good luck. But his ambition and his will were gigantic.

Q: *The conventional wisdom is that FDR deceived the public about his disability, but you say that's incorrect. What really happened?*

Tobin: FDR never pretended to be anything but a man with a significant disability. But he was allergic to pity; he didn't want to make people uncomfortable; and he was worried about falling in public, especially having a fall photographed. So, although he was perfectly frank about being disabled, his appearances in public and with company were rather carefully managed. He asked photographers not to take pictures of him walking or getting in or out of cars. And he didn't use a wheelchair in public; that was too potent a symbol of disability. But this was a very far cry from deceiving the nation about his condition.

Q: *You've said that FDR became president less in spite of polio than because of polio – how so?*

Tobin: Before polio, FDR was held back in politics by the perception that he was an aristocratic smoothie who was born with a silver spoon in his mouth. That was especially troublesome in the New York Democratic Party, which was dominated by tough types like Governor Al Smith. But polio gave him a great story to tell. Now he could present himself as the guy who had come back from a knockout punch. And by a lucky turn of fate, the years when he was rebuilding his strength were the same years when the Democratic Party was tearing itself apart over Prohibition. Polio kept him on the sidelines at the perfect time.

Q: *What did you find out about Roosevelt's initial diagnosis?*

Tobin: The key doctor who examined FDR at first – a famous surgeon – didn't even diagnose an infectious disease, which should have been obvious from his high fever. This delayed a correct diagnosis by more than a week. There's at least a slim possibility that a correct diagnosis at the outset could have led to a quick treatment and a better recovery – but since polio was probably a net plus for FDR's later career, a better recovery might also have cost him the presidency.

Q: *In researching the book, what did you learn about FDR's treatment and exercise regimen?*

Tobin: I learned that one of the hardest things anyone can face is a prolonged course of physical rehabilitation with no guarantee of recovery. It's often a matter of subjecting yourself to indefinite pain – severe pain – and failure. So it's both a physical and a psychological ordeal. FDR was not the perfect patient he has sometimes been made out to be. He slacked off sometimes. But he worked at it hard

enough to make significant progress. The most important thing he did – after several years of frustration – was to follow the advice of smart physical therapists. They showed him that learning a new way to walk was more important than sheer muscular recovery.

Q: *Your research draws on many primary sources – what was the most difficult part of the research?*

Tobin: Robert Caro said an editor once told him: “Turn every page.” Maybe Caro turned every page at the Lyndon Johnson Library; I know I didn't turn every page at the FDR Library at Hyde Park. But in the papers that cover these years in FDR's life, I turned an awful lot of pages. I had to, because FDR revealed very little about his private thoughts and emotions about his condition. It was a process of looking for a hundred needles in a thousand haystacks. But after a while, patterns started to emerge, and I realized that his silences about the disease – and his happy pronouncements about getting better, even when he wasn't – were essential parts of the story. ■

Celia Yoder continued from page 1

Land Rush of 1889 where 50,000 people lined up for a race to lay claim to unoccupied public land.)

“In Olathe, I have made many friends. I am a member of the Olathe Visual Artists, and I became a member of the local chapter of the Daughters of the American Revolution at age 90.”

Celia has written four family histories and two books – *Memories of a Farmer's Daughter* and *Memories of a Carpenter's Wife*.

“I now help people write their memories and teach a landscape painting class in the senior apartment building where I am in independent living. I still paint landscapes, although I am struggling with macular degeneration. My hearing is failing even with expensive aids.”

Post-polio problems in her left leg caused a fall that has left her with stasis ulcers exacerbated by poor circulation and antibiotic allergies.

“But I feel I am still blessed and I am proud to be a polio survivor,” Celia says. “It has made me aware of and empathetic to people with any handicap or disability. I always felt blessed to enjoy a good life even with problems. Now I realize it was with an ‘attitude of gratitude,’ I enjoyed understanding and helpful parents, sisters and brother, a loving husband, two sons, valued nieces, nephews, cousins and friends.” ■



QUESTION: *My husband is a post-polio survivor who will be 75 later this year. He started to experience new weakness at the age of 70. I recognize his weakness, as I am 70 and have degenerative disk problems so weakness is not new to me. I have told him to go to your website and read Post-Polio Health so that I am not always the “bad guy” bringing him information. He needs to see things himself and remain informed. Do you have other ideas as to how to approach the subject with him?*

Response from Rhoda Olkin, PhD:

I can empathize with your position of wanting to save your husband time and energy and move him further along in his discovery of weakness management. As a therapist, I often find myself wishing I could give clients the benefit of my own disability experiences and save them much time and aggravation. But I cannot do this because it is not helpful to them; I have to respect their pace and development. It is a truth universally acknowledged that it is hard, if not impossible, to change another person. So change yourself:

1. Make “I” statements. Most people do not want or like advice. So rather than make suggestions for your husband, you might read *Post-Polio Health* yourself, and then leave it lying around, without mentioning it. Or talk out loud about how you are managing your own weakness. Not in a “Look how great I am” way, but just musing out loud (e.g., “I don’t think I can manage the grocery shopping and laundry in one day. I’m doing the shopping today, so the laundry will have to wait.”). Rather than saying “It is helpful to rest in the afternoon,” say, “I hope we can have dinner out tonight. I’m going to rest up first.”

2. Go about your life, inviting your husband but not insisting. For example, you could say, “I want to go to the movies tonight. I do hope you will come with me, but I will understand if you do not.” And then ...

3. ... go to the movies with or without him. Don’t diminish your activity level to match his.

4. Talk about your fears. There is a reason you want your husband to manage his weakness. Perhaps it is a fear of being alone either because he becomes housebound or more disabled or because he dies before you do. Perhaps you had dreams of traveling together and now that dream is gone. Perhaps you fear he will get increasingly depressed as his functioning decreases. Perhaps you worry he will lose out on being with his grandchildren. Whatever the fears, talk about them (remembering to use “I” statements).

5. Ask him about his fears. In a neutral place and time, say that you notice he seems reluctant to read about post-polio, and you wonder what that is about. Be curious, not critical. It can be hard to read about symptoms (I always get symptomatic when reading about



Rhoda Olkin, PhD

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology.

She is a polio survivor and single mother of two grown children.

breathing problems!). And scary to face uncertainty in potentially diminishing functional capacities. Join with your husband around these issues; do not try to talk him out of them, but empathize with them. Sometimes when a person feels validated then he or she becomes more ready to problem solve.

6. Try to distinguish reluctance and fear from depression. If you think your husband might be clinically depressed, take action to seek couples therapy together.

7. Utilize social support – friends, family, community. This is good advice for everyone as they age.

Uh oh, I just violated my own tenet, and I am giving advice!

Response from Stephanie T. Machell, PsyD:

You say you recognize your husband's weakness. You refer to his "need" to see this and inform himself. You also say that you are the "bad guy" for bringing him the information, which I assume means he is reacting negatively to you when you share what you've learned with him.

All this implies that your husband isn't ready to recognize his own weakness, or to inform himself about PPS. Until he is, efforts to push him to do so are a step ahead of where he is.

How do you make him ready? You can't. And the more you force the issue the more he may resist. As long as he is not putting himself or someone else in danger

he has the right to take whatever time he needs to be ready – and the right never to be ready at all.

You've already expressed concern and shown him where he can find out more. If he is falling more as a result of his weakness, or if he is unable to participate in activities that matter to him, or if there are other consequences of his weakness that you observe, you can share your observations with your husband. If others he respects and listens to have observed his weakness and its consequences you can encourage them to share their observations and concerns with him as well. Suggest he share your observations with his doctor, and recommend he share resources with him as well, including the PHI website.

To avoid being the "bad guy," share your observations in a neutral manner, at times when you are both calm. Use "I" statements and encourage whatever positive changes you see, no matter how small. Avoid blame and judgment, including the phrase, "You need to ..." It doesn't work. Guilt doesn't either.

It's frustrating and hard to wait for someone to be ready to see something that is so clear to you. But it's up to your husband to decide what he wants to do next. ■



Stephanie T. Machell, PsyD

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.



Frederick M. Maynard, MD

Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/edu/askdrmay.html.

Question: I am a 68-year-old paralytic polio survivor from the 1955 polio epidemic. I use two leg braces and a variety of assistive devices. My arms were also totally involved but recovered well. My main problem now is increased weakness and pain in my arms as I depend on them more for transfers. My primary care physician recommended using 600 mg. of ibuprofen three times a day to reduce inflammation and alternating ice and heat. A cortisone injection has also been suggested. Is a cortisone injection advisable for people with post-polio syndrome?

Answer: Cortisone injections are safe and often helpful for polio survivors who have developed inflammation problems in shoulder tendons (tendonitis), bursa (bursitis) or joints (arthritis). Their success in eliminating pain depends on an accurate diagnosis of inflammation in a structure and accurate localization of the injection into that structure. Many practitioners now use ultrasound to accurately guide the injection into the desired structure. Cortisone injections will not be helpful for pain in post-polio weakened muscles that are being overused. You may also find it helpful to read one of my previous Q&A's about this subject. www.post-polio.org/edu/pphnews/PPH29-2spr13p4-5.pdf and www.post-polio.org/edu/pphnews/PPH29-2spr13p4-5.pdf.

Note: SOS – Save Our Shoulders: A Guide for Polio Survivors from Moss Rehabilitation Research Institute (www.mossrehab.com/index.php?option=com_docman&task=doc_view&gid=67&Itemid) is a 34-page booklet compiled in 2003. It discusses shoulder problems of polio survivors and offers advice and exercise possibilities. The colorful booklet includes diagrams and photos. Also see www.polioplacelive.org/living-with-polio/living-polio (Scroll down to exercises.)

Question: I'm interested in finding out if polio survivors should or should not take beta blockers. I have atrial fibrillation and the doctors keep trying me on beta blockers and I have trouble taking them. Do they work for atrial fibrillation?

Answer: Some polio survivors can tolerate, and benefit from, taking beta blockers, but many are unable to tolerate them because of severe weakness and fatigue. If you are one of those with significant side effects, you should not take them. There are other drugs that can be used for your heart condition. Beta blockers are not essential for the successful management of atrial fibrillation. I would suggest seeking a second opinion from a cardiologist if your current doctor insists you take them.

Question: My husband had polio at age 8. He is now 71. His left leg has started giving out on him and he falls. He goes to a special trainer, but I'm afraid the trainer doesn't know how to treat this. What type of exercises should benefit him, and what should he avoid?

Answer: Your husband's leg weakness is most likely a result of post-polio syndrome. If his knee extensor muscle (quadriceps) has weakened to the point that he is falling, I would recommend he be evaluated by a physical medicine and rehabilitation physician before he continues on with his trainer. The question to be evaluated is: How intense and frequent should he be exercising the weakening muscles? See links at left. Your husband should share these with his trainer, and until he is evaluated by a knowledgeable post-polio physician he should limit exercise on his weakening leg muscles to only non-fatiguing and low resistance types of exercise. ■

Here are links to PHI's statement on Exercise for Polio Survivors Health (www.post-polio.org/edu/pphnews/pph19-2a.html), written by the Medical Advisory Committee of Post-Polio Health International and endorsed by 29 post-polio experts, and Articles about Exercise for Polio Survivors, collected from past issues of *Post-Polio Health* (www.post-polio.org/edu/pphnews/BrochExercise.pdf).

Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians

Please complete this survey online at <https://surveymonkey.com/s/ppmedicalcare>, if possible. If not, complete it below and mail to Post-Polio Health International. Deadline: June 23, 2014.

PHI wants to find out how many of its Members have seen a post-polio specialist and how many depend on their primary care (family/general) physician for guiding them in their post-polio care. We also want to learn why survivors visit a post-polio specialist and the benefits. If survivors depend on their primary care physician, we want to know what makes the relationship successful.

Before you start:

- 1) On some questions it is possible to click more than one answer.
- 2) If responding with "other," please explain.
- 3) The survey will take about 5-7 minutes.

Have you had an appointment with a post-polio specialist?

- Yes Skip to the following page ⇨
 No Please continue below.

Who manages your medical care that is polio related? Choose all that apply.

- no problems to manage
 primary care (family/general) physician
 physical therapist
 pulmonologist
 local physiatrist, not a post-polio specialist
 orthopedist
 neurologist
 manage my own polio-related problems
 Other (please specify) _____

How many providers did you see before you found the healthcare professional you depend on now?

- 0 1 2 3 4 5 or more

How often do you discuss post-polio problems with your primary care physician?

- at every visit
 annually
 only when a problem arises
 less than once in a five-year period

How do you rate your satisfaction with the post-polio care you receive from your primary care physician?

- Poor Fair Good Excellent

What accounts for their good/excellent rating? Choose all that apply.

- years of experience as my physician
 newly trained and open to ideas
 thorough (looks for the causes/symptoms)
 refers when needed
 up to date on research
 problem solver; good analytical skills
 not in a hurry straightforward good communicator
 support staff involves my family
 Other (please specify) _____

Personal Information:

Name (optional) _____ City (required) _____

Thank you for completing this survey from Post-Polio Health International.

If you have had an appointment with a post-polio specialist, please complete the following:

How did you learn of this specialist?

- PHI's Post-Polio Directory other internet source primary care physician referral
 at a support group meeting from a post-polio friend

What factors lead you to go to this specific post-polio specialist? Choose all that apply.

- closest geographically family in the area heard they were the best accepts my insurance
 Other (please specify) _____

When did you first see this specialist?

- 0-2 years ago 3-5 years ago 6-10 years ago 11-15 years ago more than 15 years ago

How far did you travel?

- less than 10 miles 11-100 miles 101-200 miles 201-500 miles more than 500 miles

Do you visit them on a regular basis? Yes No

Why not?

- no longer in practice no benefit no insurance
 Other (please specify) _____

Did you visit this specialist in 2013? Yes No

Did they/do they communicate with your primary care physician?

- No Yes, before the visit Yes, after the visit Yes, anytime he/she requests a consultation
 Other (please specify) _____

What has been part of your post-polio evaluation? Choose all that apply.

- | | |
|---|--|
| <input type="checkbox"/> polio history | <input type="checkbox"/> physician examination |
| <input type="checkbox"/> examination by therapist(s) | <input type="checkbox"/> evaluation of muscle strength |
| <input type="checkbox"/> examination of joints | <input type="checkbox"/> gait evaluation |
| <input type="checkbox"/> blood tests | <input type="checkbox"/> EMG |
| <input type="checkbox"/> sleep study | <input type="checkbox"/> pulmonary function tests |
| <input type="checkbox"/> evaluation of psychosocial issues | <input type="checkbox"/> referral to a rehabilitation therapist(s) |
| <input type="checkbox"/> referral to another specialist (physician) | |
| <input type="checkbox"/> Other (please specify) _____ | |

Please rate the specialist's knowledge of post-polio issues and research related to evidence-based guidelines (2000 March of Dimes Statement) specific to post-polio problems.

- Poor Fair Good Excellent

What were/are the benefits of visiting a post-polio specialist? Choose all that apply.

- | | |
|---|--|
| <input type="checkbox"/> eliminated other neurological/musculoskeletal conditions | <input type="checkbox"/> provided assurance to me |
| <input type="checkbox"/> answered my questions fully/satisfactorily | <input type="checkbox"/> provided assurance to my family |
| <input type="checkbox"/> access to assistive technology (brace, wheelchair, etc) | <input type="checkbox"/> referral to other specialists (physician) |
| <input type="checkbox"/> specified optional exercises/activity modifications for me | <input type="checkbox"/> referral to rehabilitation therapist(s) |
| <input type="checkbox"/> provided new and/or needed education | |
| <input type="checkbox"/> Other (please specify) _____ | |

How do you rate your satisfaction with the post-polio care you received with the specialist?

- Poor Fair Good Excellent

Personal Information:

Name (optional) _____ City (required) _____

Thank you for completing this survey from Post-Polio Health International.

Thank You

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

Contributions to PHI's education, advocacy and networking activities ...

In Memory of

Rev. Margaret Brown
Joseph F. Flasch
Robert Thomas Hutcheson
Ronald Russell
Ronald S. Thier, DDS

In Honor of

Norma Braun, MD
Shannon Flasch

Contributions to The Research Fund ...

In Memory of

Arnold Dimond
Joseph F. Flasch
Robert Thomas Hutcheson

Dale LeCornu
Thomas A. Mahon
Jeffrey Pollard

Major Employment Law Change Took Effect in March

Beginning Monday, March 24, 2014, a new rule went into effect requiring businesses that work with the federal government to set goals to employ people with disabilities at a rate of 7 percent and in doing so, keep track of their progress. This may mean many changes in personnel departments and workplaces.

The rule was finalized last August when Labor Department's Office of Federal Contract Compliance Programs made changes to Section 503 of the Rehabilitation Act of 1973.

The new law permits companies to invite employees to self-disclose a disability, allowing the company to conduct an internal census. With this data, companies can make sure their recruiting and hiring practices do not inadvertently exclude qualified candidates with disabilities. But, no employee has to disclose a disability unless he or she wants to.

This rule change stems from an effort to combat chronic unemployment of people with disabilities. Most recent data from the U.S. Bureau of Labor Statistics shows that in 2012:

- ❖ The unemployment rate for non-disabled Americans stood at 8 percent, but almost doubled to 15 percent for people with disabilities.
- ❖ The workforce participation rate for non-disabled Americans was 31.6 percent, while 76.5 percent of people with disabilities in the same age group were out of the work force entirely.
- ❖ Median household income for a person reporting a disability was \$25,420, compared to \$59,411 for someone without a disability.

Not yet a Member?

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POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2930 USA



May 31 – June 3, 2014
Hyatt Regency St. Louis at The Arch

Can you meet us in St. Louis? There is still time!

Reserving a room: Deadline for conference rate is May 7, 2014. After this date, rooms will be based on availability and the prevailing rate. To reserve a hotel room at the conference site, call 888-421-1442. (Rooms are \$119 plus taxes before deadline.)

Registration: Deadline for reduced rate is May 1, 2014. (Full registration fee is \$280 per person plus \$155 for spouse/attendant. Lunch is included. After May 1, add \$30.)

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PHI's website Polio Place (polioplacel.org) has been upgraded for improved viewing on smart phones. Information from Promoting Healthy Ideas will be added this summer. Check often or watch PHI's *Membership Memo* for news about updates to Polio Place.