

Ohio Polio Network Newsletter

Spring 2009 Issue

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OPN Mourns the Loss of Newsletter Co-Editor Joyce Metheny

OPN is deeply saddened by the sudden passing of Joyce Metheny. Joyce had been filled with excitement and looking forward to attending the International Post-Polio Conference. She had just returned from a trip to Disney World when she became ill with pneumonia and went into the hospital where she slipped into a coma and passed away. Joyce was very dedicated to the many areas of volunteer work she performed, including the position of Co-editor of the OPN Newsletter. She will be dearly missed by all of us, but especially by her family and close friends. We, the members of OPN, extend our sincerest and deepest sympathy to Joyce's family.



Remembering Joyce by Alice Sporar

In the early 70s, I met Joyce Metheny at a meeting of the Northeast Ohio Chapter of the National Spinal Cord Injury Association, an organization consisting of people with and without disabilities, dedicated to improving life for people with spinal cord injuries and other disabilities. Joyce served as membership chairperson.

At that time she was employed by Cuyahoga County, where she worked for most of her career.

Later, Joyce served on the Board of Linking Employment Abilities and Potential (LEAP) and was involved in many of their fundraising benefits attended by her family and friends. She was a member of the Cuyahoga County Commissioners Committee on People with Disabilities and served on the Architectural Barriers Subcommittee. She was co-editor of the Ohio Polio Network newsletter.

In addition to disability advocacy, Joyce volunteered at MetroHealth Medical Center and the Center for Therapy Through the Arts. She had many interests, including gourmet cooking, stamping, and gardening. (continued on page 2)

Remembering Joyce by Alice Sporar

(Continued from page 1)

She frequently attended live performances at the downtown theaters, enjoyed the ballet, and Browns' games. She had just returned from Disney World the week before she became ill. Joyce was a good friend to many.

Joyce loved life
and lived it to
the fullest

We'll miss her sense of humor, her way of putting people at ease, and her way of caring for family and friends. She loved life and lived it to the fullest.



Joyce Metheny - 2006 OPN Special Recognition Award

OPN Board Meeting Saturday, May 16, 2009 Noon - 3 PM

OPN members are welcome to attend. OPN is always looking for members interested in becoming Board Members. If you are interested or have agenda items for the Board Meeting, please contact Patrick Kelly, pkelly03@sprynet.com

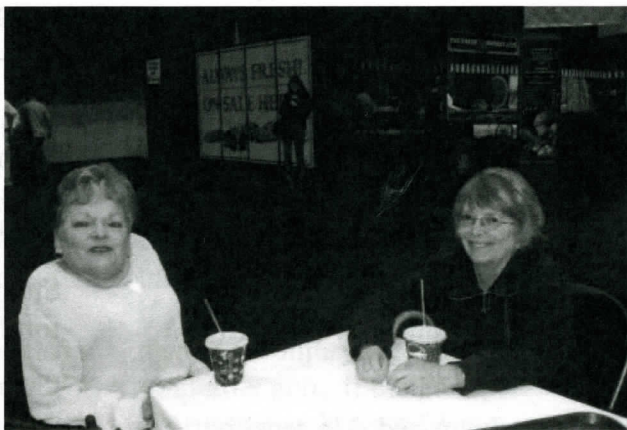
Ohio Polio Network is on the Web
www.ohiopolionetwork.org

Joyce by Teddi Gideon

When I think of Joyce many words come to mind - dependable, funny, strong, feisty, active, stubborn, loyal, upbeat. The word that means the most is friend.

She was 11 days my senior and I always introduced her as my OLDER friend. She reciprocated by calling me brat.

Joyce was very active in many disability organi-



zations and fought for our rights.

Our relationship, however, was more social. I was invited by her to many of the social functions put on by her various organizations.

We went to plays, concerts and IX Center functions together. Many of our outings included food!!! She made me feel like a part of her family.

Joyce Metheny by LEAP Executive Director Melanie Hogan

Joyce served on the LEAP board for six years and was an outstanding advocate who worked actively in support of improving the lives of people with disabilities and their families. Over the course of 15 years I have known Joyce, I developed a deep respect for her unwavering commitment to educate people about the need for equal rights and opportunity for people with disabilities—always described as normal desires that any person has: the right to live, work, learn and play in a community of one's choice. Joyce described herself as self-motivated and gently assertive. Those attributes contributed to her ability to serve the community and positively impact all of us. Joyce quietly

went about making a difference through her work with LEAP,

“Joyce was the voice of many and the impact of her work will be felt for years to come”

The Art Studio, the Cuyahoga County Commissioners Advisory Committee and various activities in Parma Heights including the library and the Garden Club. Joyce's ability

to raise awareness, create publicity, build membership, generate donations and contributions was a tremendous asset to all the organizations in which she was involved. We all benefited from her commitment to making the world a better place for all people.

Joyce was the voice for many and the impact of her work will be felt for years to come.

Various Types of Pain Defined

Reprinted from Florida East Coast Post-Polio Support Group—Vol. 15 #4 Jan/Feb 2009
Reprinted from San Joaquin CFIDS/ME/FMS Support Group September 2008 Newsletter

Neuropathic Pain

Pain is often assumed to be caused by physical injuries such as a broken bone or skin cut and once the injury is healing the pain subsides and eventually disappears. However, nerves can also produce pain and this type of pain can be difficult to manage. It is called neuropathic pain.

Pain caused by nerve damage can be agonizing and often fails to improve with time. It can originate from the peripheral and/or central nervous system. Neuropathic pain is often used as an umbrella term to include:

- Phantom limb pain
- Peripheral neuropathy
- Post herpetic neuralgia
- Trigeminal neuralgia
- Complex Regional Pain Syndrome (CRPS)

With neuropathic pain the nerves may be damaged or injured and they send incorrect pain messages to the brain. The cause is often difficult to discover. This sort of chronic pain may result from conditions such as Diabetes, Shingles, and multiple Sclerosis or from injury, surgery or amputation. Although it can also occur without any of these factors.

Nerve pain is often described as:

- Shooting
- Stabbing
- Burning
- Searing

These pains may be accompanied with:

- Increased skin sensitivity
- Changes in skin temperature and color
- Muscle weakness
- Loss of Feeling
- Swelling and stiffness in the affected joints

In some types of neuropathic pain the diagram shown below may help to establish the area of nerve damage or injury.

Phantom Limb Pain

Pain in a limb that no longer exists is a common phenomenon after amputation. For some people the phantom limb pain gets better without treatment but for others the management of this pain can be difficult. Phantom pain is more common after the loss of an arm or leg but can also occur after the removal of any body part such as an eye or breast.

To receive the correct treatment for your condition it is important for your doctor or specialist to determine whether you are experiencing phantom limb

pain or stump pain.

Phantom limb pain: is pain that feels as if it is in the area of the lost limb.

Stump pain: is pain or discomfort felt at the site of amputation.

Phantom limb pain is an unfortunate term as it seems to imply that the pain is a psychological rather than a physical problem. In fact the pain may not have a psychological component at all. Although the longer pain continues it is more likely that physical and psychological influences are involved.

Contributing factors to phantom limb pain are thought to be:

Nerve damage or injury

Existing pain prior to amputation

Neuroma, which is a growth containing nerve cells. This can form on the nerve endings in a stump after amputation.

If you are experiencing phantom limb pain you may benefit from a pain management programme.

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Various Types of Pained Defined

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Peripheral neuropathy

The peripheral nervous system includes nerves in the face, legs, arms, torso and some nerves in the skull. It often affects people with diabetes and auto-immune diseases. Certain vitamin deficiencies and alcoholism can also damage the peripheral nerves.

Symptoms will depend upon the cause of a persons' neuropathy and on which nerve or nerves are involved.

These can often begin gradually and are sometimes barely noticeable but for others the symptoms are constant and may be almost unbearable especially at night.

Symptoms may include:

- Pain
- Numbness
- Tingling
- Muscle weakness
- Burning
- Loss of feeling
- Sharp, stabbing pain
- Extreme sensitivity to touch
- Lack of coordination

If you experience any of these symptoms you should consult your doctor.

For others with a diagnosis but who have poor pain control a pain management programme may be beneficial.

Post herpetic neuralgia

This type of nerve pain often happens after a viral infection such as shingles. The pain manifests itself as listed under neuropathic pain. Consult your doctor if you think that you have nerve damage or injury caused by a viral infection. If the pain persists you may benefit from a pain management programme or a review of your medications by a pain specialist.

Trigeminal neuralgia

This type of nerve pain affects the forehead, nose, cheeks, lips, teeth and jaw and can affect the most basic of daily activities such as eating, swallowing, teeth brushing and face washing.

The cause is not completely understood although it can occur when the trigeminal nerve becomes irritated or trapped causing pain to the face. Dental work has been identified as being the most common trigger for trigeminal neuralgia.

Symptoms include:

- Sharp, 'electric shock' type pain
- Dull ache
- Sensitivity to touch

If you have any of these symptoms you should consult your doctor who will advise you of the treatment options.

Complex Regional Pain Syndrome (CRPS)

This is a chronic pain condition. The key symptom of CRPS is continuous intense pain which may appear to be out of proportion to the severity of the injury. The pain commonly worsens with time.

CRPS I is often triggered by tissue injury but has no apparent nerve damage.

CRPS II has the same symptoms but is also associated with a nerve injury.

Symptoms include:

- Burning pain
- Increased skin sensitivity
- Changes in skin temperature
- Sweating and swelling of the affected area
- Changes in skin colour and texture
- Changes in nail and hair growth
- Decreased ability to move the affected body part
- Muscle spasm

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F. D. R. TALKS ABOUT HIS PARALYSIS

Reprinted from Second Time Around March 2009 Publication of Boca Area Post Polio Group, Boca Raton, FL

Contributed by Anne Berkes, BAPPG member, 2/2005.

Reprinted from *Polio Heroes of TN*, July 1996.

Source: Jane Hath, Portland, TN., June 1996.

Warm Springs, Georgia

October 11, 1924

My Dear Dr. Egleston:

Please excuse my delay in replying to your letter which has been forwarded to me down here in your neighboring state where I am spending a few weeks swimming and getting sunlight for my legs. I am very glad to tell you what I can in regard to my case, and as I have talked it over with a great many

doctors can, I think, give you a history of the case which would be equal to theirs. First symptoms of the illness appeared in August, 1921, when I was thoroughly tired from overwork. . . .

In February, 1922, braces were fitted on each leg from the hips to the shoes,

and I was able to stand up and learned gradually to walk with crutches. At the same time, gentle exercises were begun. . . The

recovery of muscle paralysis began at this time, though for many months it seemed to make little progress. In the summer of 1922, I began swimming and found that this exercise seemed better adapted than any other because all weight was removed from the legs and I was able to move the legs in the water far better than I had expected. Since that time I have carried out practically the same treatment with the result that the muscles have increased in power to a remarkable extent .

. . .

One year ago, I was able to stand in fresh water without braces when the water was up to my chin. Six months ago, I could stand in water up to the top of my shoulders and today can stand in water just level with my arm pits.

To sum up, I would give you the following "Don'ts":

Don't use heavy massage but use

light massage . . . toward the heart.

Don't let the patient overexercise any muscle or get tired.

Don't let the patient feel cold, especially the legs, feet or any other part

affected. Progress stops entirely when the legs or feet are cold.

Don't let the patient get too fat.

The following treatment is so far the best judging from my own experience and that of hundreds of other cases which I have studied:

1. Gentle exercise especially for the muscles which seem to be worst affected.
2. Gentle skin rubbing – not muscle kneading – bearing in mind that good circulation is a prime requisite.

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Various Types of Pained Defined

(continued from page 5)

Reduced muscle tone

Continuous pain

The cause of CRPS remains unknown and it is very difficult to diagnose. Diagnosis is usually achieved by ruling out other con-

ditions.

There is no cure for CRPS but pain can be reduced or controlled by using a mixture of symptomatic pain management therapies. If you have been diagnosed with CRPS you and your

doctor may decide that you could benefit from consulting a pain specialist. There are many treatment options available which can help you to gain control over this debilitating pain.

<http://www.thepainclinic.co.uk>

F. D. R. TALKS ABOUT HIS PARALYSIS

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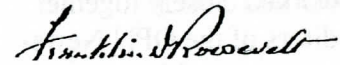
3. Swimming in warm water – lots of it.
4. Sunlight – all the patient can get . . .
5. Belief on the patient's part that the muscles are coming back and will eventually regain recovery of the affected parts.

I hope that your patient has not got a very severe case. They all differ, of course, in the degree in which the parts are affected.

If braces are necessary, remember that [they] are only for the convenience of the patient in getting around – a leg in a brace does not have a chance for muscle development. This muscle development must come through exercise when the brace does not have a chance for muscle development. This muscle development must come through exercise when the brace is not on. . . .

I trust that your own daughter is wholly well again.

Very truly yours,



William Egleston, M.D.,

Hartsville, S.C.

This letter is part of a letter FDR wrote to a physician while taking treatment at Warm Springs.

Dr. Wold says it will probably become one of most famous "medical case reports" written by a layman.

A MESSAGE FROM THE DIRECTOR

WHATEVER HAPPENED TO WARM SPRINGS

By Greg Schmieg

Reprinted from Second Time Around March 2009 Publication of Boca Area Post Polio Group, Boca Raton, FL
Reprinted from *Post-Polio Chronicles*, GA, March 10, 2008.

Polio certainly doesn't get the attention it used to during the 1930's, 40's and 50's. It has all but faded from the front page of newspapers and medical journals, and if you were to ask most school children about it, they wouldn't know what you were talking about. But that doesn't mean polio has gone away. Not only are there thousands of polio survivors and people living with the symptoms of post-polio, but there are still new cases diagnosed around the world every day. To the very contrary, polio may have been forgotten by many, but it is not gone. That is understandable. Times change, the world moves on, and one epidemic is replaced by another

and then another. Even the polio exhibit at the Smithsonian Museum of American History was called "Whatever Happened to Polio".

At the height of the polio epidemic, the drive to eradicate the disease was embodied by none other than the President of the United States, Franklin Delano Roosevelt. FDR and polio became almost interchangeable, you could not think of one without thinking of the other. The same was true for the little town in Georgia that FDR fell in love with and spent much of his time, Warm Springs. He purchased and created what was then called the "Georgia Warm

Springs Foundation" as a place of healing. . . a place of healing for polio, because that was the illness that he and so many other "polios" struggled with, suffered through and endured. Without polio, most likely there never would have been a Georgia Warm Springs Foundation, which later became known as the Roosevelt Warm Springs Institute for Rehabilitation; and the history of rehabilitation would have been completely different. Warm Springs has always been a place of healing, and polio made it the birthplace of rehabilitation as we think of it today.

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Pat Kelly's Message

We are all still in a state of shock over the sudden passing of Joyce Metheny. Joyce and Alice Sporar worked closely together as Co-editors of the OPN Newsletter. Joyce worked in many areas as a volunteer. We will miss her. We have included a few articles about Joyce and photos too. Alice has volunteered to stay on as Co-editor and gather material for the newsletter articles. I will also be working on the newsletter until a new Co-editor can be found.

As we go to press, the Post Polio community, as well as many of us personally, suffered another tremendous loss with the passing of Fran Willemsen. Fran was Treasurer of the Akron Post Po-

lio Support Group and Treasurer of OPN, both, for a number of years. Fran brought many members into the Post Polio organizations and was very dedicated to these organizations as well as others where she volunteered her talents and efforts. We will have more about Fran on the OPN website and the next newsletter. OPN extends its sincerest and deepest sympathy to Fran's daughter, Sandie, and the entire family.

Our appreciation goes to Ruth McCort who has volunteered to be the OPN Treasurer.

On our website and the upcoming newsletter, we will be reporting on the recent International

Post Polio Conference which was held in historic Warm Springs, GA.

Several of us attended the Conference and we will provide our thoughts, observations and what we learned.

Our next OPN Board Meeting is on May 16th at the Westerville Library. As always, our Board Meetings are open to OPN members or those who wish to become a member. Please let me know if you plan to attend. If you are interested in being on the OPN Board, please contact me as well. We continue to look for ways to serve our members and we want your ideas. Please send us your ideas!

WHATEVER HAPPENED TO WARM SPRINGS

(continued from page 7)

Although the numbers of polio patients served by the Institute has decreased considerably since the advent of the vaccines, to this day the Roosevelt Warm Springs Institute for Rehabilitation continues as a place of healing for all kinds of disabilities. The mission hasn't changed even though the nature of the illness has. But that doesn't mean that Warm Springs has forgotten about polio. To the contrary, the Institute is still focused on serving those living with polio. The names and faces of the doctors and thera-

pists may have changes, but the desire to continue to be the "living legacy" of FDR is still strong. Polio is part of the Institute's DNA, and it will always be. This past year, the Institute acquired the Smithsonian polio exhibit

which is proudly displayed in Roosevelt

Hall, and plans are currently underway to be

the "host" site for the 10th International Polio Symposium in

April 2009. As the Institute continues to move forward in this new century, and serve individuals with spinal cord injuries, the blind and deaf, and returning wounded warriors, it does so with its undying commitment to polio . . . That will never change.

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