



Frederick M. Maynard, MD

Question: *I am now 76, had polio when I was 4. Since post-polio syndrome (PPS) hit me, I needed a leg brace and walk with two canes. I can never remember a day without pain, but now it seems to have spread all over my body, not just my legs. My question is: How do you feel about the pain patch, Duragesic®, 12mcg to start. My internist feels that this will help. I would just like to get an OK from someone who has experience in treating PPS.*

A: Pain control in people with post-polio problems is highly individualized because there is no one source of pain. I would NOT endorse the use of a Duragesic patch (fentanyl transdermal system) for long-existing pain in a person with PPS because I think it is a “dead end” in regard to long lasting relief from pain. It is probably safe but can lead to dependency and less tolerance and awareness of pains that it is helpful to be aware of (so the pains can be “honored and have actions taken on.”)

I would definitely have a comprehensive evaluation by a “post-polio expert or clinic” before trying to merely “suppress your awareness of pain” by using a Duragesic patch. There are many alternatives. Maybe “giving up” regular walking and using a scooter for usual mobility would lead to a major reduction in pain levels. A thorough evaluation may tell you that and/or other alternatives.

PHI’s *Post-Polio Directory* (www.post-polio.org/net/pdirhm.html) of clinical resources for post-polio survivors can help you locate regional options for an evaluation by a post-polio rehabilitation and pain control physician, preferably a specialist in Physical Medicine and Rehabilitation.

Good luck in finding help and relief.

Question: *I had paralytic polio 64 years ago at the age of 13 months. My left leg had major paralysis and a small amount to my right leg. I always walked with a severe limp. I was diagnosed 25 years ago with PPS as I was developing new weakness in my legs. Four years ago, swallowing began to bother me and also volume when blowing breath. In the past two years, my left fingers have “clawed,” and now my tongue muscles are weak causing speech problems as are my vocal cords somewhat. I recently saw a neurologist who thinks I have ALS. Do you know of any cases of people with PPS and ALS?*

A: Yes, I know of people who are post-polio survivors who have developed ALS. The majority expert opinion on this subject is that polio people are not more likely to develop ALS than other people, but the diagnosis of ALS, as opposed to, Progressive Post-Polio Amyotrophy (Post-Polio Syndrome) is very difficult and at times impossible to distinguish with certainty. Given you have had some slow progressive weakness problems for over 25 years, your condition sounds more like a post-polio condition mimicking ALS. Unfortunately there is no definitive test for either diagnosis.

SEND YOUR QUESTIONS
FOR DR. MAYNARD TO
INFO@POST-POLIO.ORG.

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 educational, advocacy, and networking activities ...

In Memory of

Anne F. Berkes	Hal Judenfriend
Charlotte R. Boyd	Marian Moll
John "Jack" Burns	Terry L. O'Connor
Edna Cozen	Marian B. Wilson
Beverly Eisenberg	

In Honor of

Kay VanVlack

Contributions to The Research Fund ...

In Memory of

Anne F. Berkes
Alice Bindbeutel
Nancy Judkins

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

Sid Stone

Given how severe your new symptoms have become, you may be an appropriate candidate to try one of the more aggressive new treatments for progressive post-polio weakness, such as intravenous immunoglobulin therapy as shown to be helpful by researchers at the Karolinska Institute in Sweden. (See page 9, *IVIg Update*.) I suggest you consult with the neurologist who diagnosed you and together pursue possible new treatment options to slow down progression of symptoms.

There are many rehabilitation strategies to minimize risks from the swallowing and breathing problems and to maintain function and quality of life.

Also, please see *Swallowing Difficulty and the Late Effects of Polio* (Vol. 26, No. 3) and *New Swallowing Problems in Aging Polio Survivors* (Vol. 12, No. 1). ▲

PHI Thanks its Members for their support. If you are not yet a Member,

Join PHI!

Support Post-Polio Health International's educational, research, advocacy and networking mission.

PHI membership levels make it easy to start taking advantage of timely and important news and activities relating to the late effects of polio. Select your level below and return it with your check or credit card information. Memberships are 100 percent tax-deductible.

\$30 Subscriber

Newsletter of your choice:

Post-Polio Health (quarterly)

OR *Ventilator-Assisted Living* (bi-monthly)

\$55 Subscriber Plus

Both newsletters:

Post-Polio Health (quarterly)

AND *Ventilator-Assisted Living* (bi-monthly)

\$100 Contributor

ALL the benefits of Subscriber Plus AND

Post-Polio Directory AND

Resource Directory for Ventilator-Assisted Living;

discounts on special publications

and meetings sponsored by PHI

\$150 Sustainer

ALL the benefits of Contributor AND

One additional complimentary gift membership to:

Person of your choice (include name and address) or

Person who has expressed financial need to PHI

Membership at the following levels includes ALL benefits PLUS special recognition in PHI publications:

\$250 **Bronze Level Sustainer**

\$500 **Silver Level Sustainer**

\$1,000 **Gold Level Sustainer**

\$5,000 **Platinum Level Sustainer**

\$10,000 **Gini Laurie Advocate**

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

Fax (include area/country code) _____

I am enclosing a check for \$_____ made payable to "Post-Polio Health International." (USD only)

Please charge \$_____ to this credit card:

VISA MasterCard Discover

Card No. _____

Exp. Date _____

Name on Card _____

Signature _____

Send this form to: Post-Polio Health International
4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
Phone: 314-534-0475
Fax: 314-534-5070