



# GLEANINGS

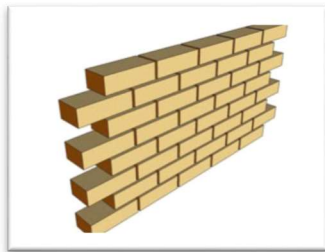
AUTUMN 2019

## Walls

By Millie Malone Lill

There has been a lot of discussion in the media about a certain wall, but that is not what I want to talk to you about today. As a polio survivor, some walls have greater impact on my personal life.

First, there's the **Polio Wall**, that thing you run into headfirst while denying you have any physical



limitations. The one that knocks you cuckoo for a few days while you recover sometimes, from just having fun. That's a very solid wall, built for a purpose: to teach you to "*Conserve to Preserve.*"

Then there's the wall many of us have built around ourselves so as not to appear vulnerable. It is the **Wall of Denial**. I've seen people lurching around, not using cane, crutch or chair in a vain attempt to appear Normal. I hate to be the one to tell you this, but you do not look Normal. You look like Pain Personified and that's because your face is scrunched up in concentration, trying not to fall. I'm so sorry to tell you this, but you do look disabled. People are far more likely to give you that Poor Pity You look than if you used your cane, your crutches or your chair.

Another wall is the **I Can Wall**. Someone will ask us to do something that is just a little bit beyond our capabilities, but because most of us are Type A people, we say, "I Can." Can you bake a couple dozen cookies for the church bake sale? "Sure, I Can." It means standing at

the counter for a couple of hours, having our backs in spasm, maybe with a few tears and gritted teeth, but that wall keeps us from saying I Can't.

The **I Don't Need Your Help Wall** prevents us from asking others to do things that we used to be able to do ourselves. I don't need someone to change the clock above the cabinet from Daylight Savings Time to Standard Time. True, it is very high on the wall, but I can stand on a chair, then go up on my tiptoes. Oops! I forgot! I don't have tiptoes anymore. I don't have a broken hip, and I don't want one, thank-you-very-much. So, I guess maybe I do need some help. (*Millie's Column: Walls, continues on p. 2*)

## Madonna Physiatrist Answers Questions at Reunion

Madonna's Rehabilitation Hospital in Omaha recently hired a physical rehabilitation medicine physician who has worked with polio survivors in the past.



Physiatrist Dr. Eugene (Yevgeny) Zadov, joined Madonna's clinical staff in mid-September, after working in Pennsylvania. Dr. Zadov graciously accepted a last-minute invitation to speak at

NPSA's 35<sup>th</sup> Annual Reunion on October 6<sup>th</sup>.

Dr. Zadov answered questions from several reunion attendees for almost an hour. During his talk, entitled "**PPS: Where YOU are the Expert**", he encouraged polio survivors to "have a human conversation" with their doctors. (*Zadov, continued on p. 3*)

## 2019 List of Donors

*Thank you to our donors who sent gifts to NPSA from August 1 through November 6. As a non-profit organization, we rely on the gifts from our members and other generous donors who support our mission.*

Fred and Eunice Jalass, Omaha, NE

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*As reported to the NPSA Foundation Board of Directors during its annual meeting, NPSA has benefited from the gifts of 19 donors in the past year. Most gifts range from \$20 - \$100, although a few have been larger than \$100.*

*We encourage our readers who value this newsletter, or those who want to honor or memorialize a polio survivor, to send a tax-deductible gift to the address listed below.*

*Your gifts to NPSA can be sent to this address:*  
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## Millie's Column: Walls

*(continued from p. 1)*

The **I'm Fine Wall** also causes a lot of problems. Here's a typical scenario: I've had a busy week and I'm exhausted and hurting all over, probably from hitting one or more of those walls. My friend asks me to go shopping or to a movie. "Are you too tired? You look a little pale." I say, "Oh no, I'm Fine!" This bad decision will very likely bring me back face-to-face with the **Polio Wall**.

I think we should start tearing down these walls. The **Wall of Denial** should become a pile of dust. We can then start using the tools that I'm always telling you about. Remember, no one asks you to pound in a nail with your fist, that's what hammers are for. Crutches, canes and chairs are just tools. Tear down that **Wall of Denial**.

The **I Can Wall** should also be destroyed. As Type A polio survivor, I've found this one very difficult. I've always been the "Go To" person and it is hard to give that up, but I must. And while I'm at it, I may as well break down the **I'm Fine Wall**. It's OK to not be Fine all the time. Other people have days when they are also not Fine.

### Post-Polio Online Resources

### Web Addresses

Exoskeleton video from Dr. Zadov's presentation	<a href="https://www.suitx.com/phoenix-medical-exoskeleton">https://www.suitx.com/phoenix-medical-exoskeleton</a>
Atlanta Post-Polio Association	<a href="http://www.atlantapostpolio.com">www.atlantapostpolio.com</a>
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PA Polio Survivors Network	<a href="http://www.papolionetwork.org">www.papolionetwork.org</a>
Post-polio Health International	PHI offers many helpful resources online. Home Page: <a href="http://www.post-polio.org">www.post-polio.org</a> Provider Directory (PDF): <a href="http://www.post-polio.org/net/PDIR.pdf">www.post-polio.org/net/PDIR.pdf</a>

**Zadov** *(Continued from p. 1)*

Based on his experience with treating polio survivors in the past, Dr. Zadov understands that polio survivors experience muscle weakness that's "a little different from normal weakness associated with aging."

He began the conversation with this question: "What matters to you?" The following are NPSA members' questions and Dr. Zadov's answers.

**Q:** What about treatment for pain?

**A:** Doctors are bad at treating pain. Pain is a message produced by your brain and, if treated as such, what needs to be done is to find what is causing the message. There's a difference between nerve and tissue-radiated pain. Medications for treating each type varies in what effects they have on the pain. For example, opioids block pain. Remember, though, that all medicines are poisons and a balance is necessary to determine how these medicines affect the individual.

**Q:** What causes polio survivors to have a sensitivity to cold?

**A:** Basically, cold sensitivity is a plumbing problem. The blood vessels don't work anymore to push blood back to the heart and lungs, where it gets warmed back up. You can solve this problem by layering. Wear thin layer after thin layer.

**Q:** Can you regain muscle after it's gone?

**A:** You don't lost muscle with polio. You lose nerves. When the nerve dies with the polio infection, the muscle withers. Basically, you are fighting an uphill battle. A big muscle developed with post-infection physical rehabilitation doesn't mean it's a strong muscle.

Zadov also discussed finding medical equipment to help with limited mobility. He presented a short exoskeleton video, explaining, "None of this is magic. Talk to someone who understands biomechanics."

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## NPSA Mission Statement

The mission of the 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.

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