



Polio Survivors Serving Each Other

Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Survivor's Network

www.papolionetwork.org

April, 2022

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

Fatigue – It's Something that plagues almost all polio survivors. But does it have to? Last month, [Marny K. Eulberg, MD](#) wrote the very popular article: [Fatigue – It Makes Me Tired](#). As part of that article, she spoke about the importance of the self discovery that can come from going through the long but worthwhile process of completing the Post-Polio Fatigue Log. (This easily copied log was included in the March, 2022 issue and can be downloaded from our website).

[Richard L. Bruno, HD, PhD](#), Director of the Post-Polio Clinic in Englewood, NJ introduced this valuable tool as a part of his team's care for polio survivors. This month, he has given us two "Bruno Bytes" on the value of using the [log](#).

In addition to last month's newsletter, you can easily find Dr. Eulberg's article on our website under *Primary Care Perspective*. www.papolionetwork.org/eulberg-articles

She traveled the world serving those in need. Polio kept her from only one thing. Survivor Bonnie Kittle always wanted to ski with her sons. Then, for her 70th Birthday, they made it happen. Bonnie's sons found an "Adaptive" Ski and Snowboarding program. They adapted in every way, making this extraordinary gift a safe and exciting adventure for a polio survivor living with the realities of PPS.

Protecting Your Email and Online Privacy. Do you know how to avoid "Phishing" scams? Have you gotten any emails or texts that you just weren't sure about? We have information that can help.

World Immunization Week – April 24th through April 30th. The ultimate goal of World Immunization Week is for more people – and their communities – to be protected from vaccine-preventable diseases. We've brought you a beautiful poem from the World Health Organization: "Long Life for All – In pursuit of a long life well lived".

Some say that "there are NO coincidences". We accept that to be true when there were three requests in just one week regarding the ability to get Richard Bruno's [The Polio Paradox](#) in audio version. The answer? YES. With gratitude to polio survivor J. Ann Singleton, we have been learning about the [National Library Service for the Blind and Disabled](#) by the US Library of Congress.

- Any resident of the United States or American citizen living abroad who is unable to read or use regular print materials as a result of temporary or permanent visual or physical limitations may receive service through NLS.
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- Check with your own public library for more information on how to sign up for this valuable service.
- You can call Toll-free: 800-424-8567

*Note: we have no way of knowing if all titles are available in all locations. You may have to wait for some.





Bruno Bytes

[Richard L. Bruno, HD, PhD](#)

Director, International Center for Polio Education

[On the topic of Fatigue and Keeping an Activity Log](#)

Original Post: I am once again going to extoll the value of an activity log, which was recommended to me by Dr. Bruno. It was useful to help me spot the triggers which led to fatigue, so I could avoid them.

My log began in 2008, and is still going. It just paid off big time for me. Since being PPS diagnosed (and educated) in 2008, I have been able to do light hiking. I knew it was a risk. "Conserve to preserve" was always present in my mind, but was balanced by a desire to see and explore the world around me. So, I walked that knife edge, using my legs, but monitoring and logging everything that might relate to PPS in any way, noting the triggers that caused problems and avoiding those triggers, once noted.

This winter I suspected that things were changing. Reviewing my log confirmed it. In the summer of 2014, my average hike was about 4 miles, with my longest being 8.4 miles. Last winter, my hikes with a friend were 3 to 5 miles long. In 2015, my summer hike average dropped to about 3 miles with the longest being 5.5 miles. Recently this winter, our hikes have been 2 miles, more or less. Clearly my ability to walk was dropping.

If I pushed, my log would show fatigue 2 days after the hike. I didn't push, dropping distances as needed to avoid fatigue. Recently, something new showed up. I was experiencing some leg weakness in the later parts of a hike. As this was usually during descent, it was a little unexpected and almost indistinguishable from my legs being tired, but I noticed it because my log had warned me that things were changing, and I was being hyper-attentive. I logged the weakness. Over the past 2 weeks, my log shows an increase in frequency of leg weakness, and that I needed a longer recovery time. Hopefully, I will continue to be mobile, because I will not be pushing the issue. I will be conserving to preserve.

The lesson for me, and what I hope to share, is once again that keeping a good log is invaluable in managing PPS, in spotting problems, and in avoiding them. Whether you spend your day in a comfy chair reading a book (is any hand strain occurring?), cleaning the house, doing a little walking around the house without your braces, taking a long trip in the car that tires you, or whether you take a walk in the woods, log it, and log any problems that show up.

Keep the log, and look back periodically to look for patterns. I looked back 2 years to spot the pattern and to understand what was happening to me. Without my log, I would probably have continued hiking every other day, oblivious to the harm I was doing to my neurons. Instead, I am going to sit in my recliner and read a book that a friend gave me. It is about hiking with a dog.

Dr. Bruno's Response: The Post-Polio Institute daily symptom log was found to be the single most effective tool to help polio survivors identify the triggers and treatment for muscle weakness, fatigue and pain. Yes, the log takes work, but it's work worth doing! The [Post-Polio Fatigue Log](#) is available for download in the [Encyclopedia of Polio and PPS](#).

[On the topic of PPS Fatigue](#)

Question: The most annoying aspect about fatigue is its variability. Every day is different and my reserves aren't consistent. Some days I achieve a huge amount without any subsequent fatigue. At other times a fraction of that effort will have me crashed out for days. I've noticed that today's overexertion doesn't always cause tomorrow's crash. My body's reaction can be several days later or it can be an accumulation of several weeks' worth of tiny exertions. I consciously try to listen to my body, limiting my efforts but every now & then (and increasingly), without warning my body says NOT TODAY!!

Dr. Bruno's Response: You are actually defining the predictability of Post-Polio fatigue: ". . . today's overexertion doesn't always cause tomorrow's crash. The body's reaction can be several days later or it can be an accumulation of several weeks' worth of tiny exertions."

And you are describing what we call the "48 Hour Rule": Fatigue after exertion doesn't necessarily occur the next day but commonly takes two days to reveal itself. This is why it's so important to measure steps walked and keep a daily log of activities to see how long it takes for your PPS symptoms to show up after exertion. There are many articles about Fatigue under that topic in the [Encyclopedia of Polio and PPS](#).



A 70TH BIRTHDAY TO REMEMBER! THE STORY OF BONNIE KITTLE – POLIO SURVIVOR

“Breckenridge outdoor education center (BOEC) participants come from all walks of life. They come to us from all over the world, of all ages, and with a wide array of disabilities and special needs to experience the life-changing effects of our outdoor programs. One disability that is not usually on our radar these days, however, is post-polio syndrome. Bonnie Kittle, a New Jersey native and polio survivor, skied with us for the first time on her 70th birthday this past December. This is her story of surviving the epidemic, living a very fulfilling life and experiencing something that she never thought possible.

At just two-years-old, Bonnie contracted the disabling and life-threatening disease caused by the poliovirus. It was 1952 and the area around New York City, where Bonnie lived, was in the midst of a surge in polio cases with nearly half of them resulting in its patients being paralyzed and even dying. While the polio virus can attach itself to any part of the body, Bonnie considers herself one of the “lucky” ones because she “only” contracted the disease in her right leg. Due to the fact that she was only two at the time, and naturally doesn’t remember very well, she calls on the memories of her mother as to what exactly happened.



Bonnie poses with her adaptive ski crew Bonnie (left) with her KAC crew for the day; Jim Vogel (center) and JR O’Neil (right)
Source: www.boec.org

‘From one minute I was walking and the next minute I was not,’ she recounts her mother’s experience. ‘There was, of course, a panic and my parents took me to the hospital where I was diagnosed with polio. As a child, I spent quite a bit of time in hospitals and at one point I was hospitalized for about six months.’



Bonnie (left) as a child. Source: boec.org

Bonnie was fortunate enough to be born into a family of medical professionals while being raised in the suburbs of New York City, giving her access to quality medical care and therapy that a lot of other people living with polio didn’t have at the time. There’s no cure for the disease once you have it, however, so Bonnie was forced to rely on consistent physical therapy sessions to keep mobile. When she was 12, surgery was performed on her left leg to keep it from outgrowing her right leg, but complications resulted in problems with that leg as well, leaving her with two semi-functional legs as a result. But Bonnie and her family wouldn’t let that stop them from being positive and supportive of the situation.

‘People who had polio in their chests were much worse off than I was because they had to be in iron lungs,’ Bonnie compassionately says. ‘That was really, really different from me and I was lucky that I had parents who really knew to push and encourage me to just go out and do what I could do.’

‘But there were some things that she simply could not do because of the lack of strength in her legs. Her family would go on ski vacations each year and Bonnie would miss out on the festivities to her dismay. Instead of hanging her head, though, Bonnie eventually took up horseback riding, but skiing with family wasn’t meant to be.

As Bonnie matured, whether it was directly due to her condition or not, she set her mind to helping others ... first as a volunteer in the peace corps before entering a career as a public health advisor. After obtaining degrees from Bethany College in West Virginia and the School for International Training (SIT) in Brattleboro, Vermont, at age 22 she started a 45-year journey as an International Public Health advisor that would ultimately take her around the world.

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She traveled to third world countries, first counseling community members directly; then providing technical assistance to non-governmental organizations (NGOs) on how to improve the health of mothers and children. She spent 20 years living and working in Africa, the Caribbean, South Asia and South America, and another 25 years training NGO staff in various developing countries. Bonnie had found her passion in helping others help themselves.

‘My passion is to help people live healthier lives and my focus was on mothers and children,’ Bonnie says. ‘They’re the most vulnerable, and because of my peace corps experience I decided to focus on third world countries. It’s super rewarding because I was doing something that’s really important and people really appreciate the work that one does in this field.’

While working in Burkina Faso in the 1970’s, Bonnie met her husband abroad and the couple eventually had two children, Andrew and Jason. The family traveled across the world and experienced things that most of us only dream of. Things were good.

Fast forward 45 years, and at age 65, Bonnie decided to hang up her passport and retire from her life-long career. Now it was time to switch gears and let others help Bonnie do what she did for so many others her entire life . . . live her healthiest life. But, as is the case with post-polio syndrome, the muscles in her leg continued to atrophy as she aged, so she added a set of leg braces to her arsenal, giving her a

lot more stability and generally making it much easier for her to get around. ‘During your life there’s only so much you can do to make them (muscles) stronger,’ says Bonnie. ‘You can exercise a little bit, but unlike most people where they say use it or lose it, that doesn’t apply to people who have polio. You can exercise too much and then you will lose it! That’s why I tell my boys that I’ll probably end up in a wheelchair because those muscles are going to make it so that I can’t walk even with the braces.’

While a wheelchair might be in Bonnie’s future, she doesn’t focus on such things and instead sets her sights on what she can control. The 70-year-old now lives in her RV and travels around the country, spending at least a month exploring each state, a feat she will finish by the end of this summer. She also makes Andrew and Jason a priority, visiting them in Denver every year for the holidays. And that’s where this story takes a unique and pleasant turn.

This past December, for her septuagenarian birthday, Andrew decided to do something special for his mother, something the entire family could enjoy. Knowing that she could never join in on the family ski vacations as a kid, he made this idea come true with BOEC’s program at Keystone Ski Resort, the Keystone Adaptive Center.

‘My brother and I live a pretty active life, and while my mom does pretty well for her condition, she’s never really been able to join us on anything like skiing and snowboarding,’ says the Golden Fire & Rescue volunteer firefighter. ‘I used to work for Vail so I knew about adaptive skiing and I looked into it for her 70th. It was reasonably priced so we decided to go for it.’

‘He was super excited about this because he’s a snowboarder and he loves going out on the mountain,’ says Bonnie about Andrew’s gift. ‘He asked if this was something I would be interested in and I told him it wasn’t that high on my list of things to do, but ‘ya know it might be fun.’

And fun – or more than fun – it was as Bonnie exclaims, ‘It was awesome! It was just fabulous. I loved every minute of it and the guides (JR O’Neil and Jim Vogel) who helped me were just awesome. It was just really, really great!’

One of her guides, BOEC Volunteer Jim Vogel, echoes the sentiment, ‘It was pure joy for Bonnie, a polio patient at the age of two, to celebrate her 70th birthday by skiing for the first time ever - and icing on the cake, she did so with her two sons!’



Bonnie enjoys some time at work. (Top)
Bonnie working as an international public health advisor. (Bottom) Source: www.boec.org

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Before taking the plunge, Bonnie had an idea in her head of what the experience might be like, but 'boy was I wrong,' she said. She envisioned going real slow down the bunny slopes, kind of like tubing, but in a 'sled type thing' as people helped her down the mountain. While she was partly correct in terms of people helping her down the hill, what she experienced was nothing like she envisioned. 'We went really fast going down the mountain zoom . . . zoom,' she remembers. 'I thought it was super fun going back and forth over a bunch of moguls and even catching air a couple of times. It was nothing like I expected beforehand.' And, even more importantly, she finally got that family ski vacation that had to be put on hold so many years earlier.

'It was super cool that my boys got to board alongside me,' she says. 'It was like we were going as a family for the first time! I am so very grateful that they thought it was really important to do something special and fun for my birthday and that they provided this experience for me.'

'It was really cool for both my brother and I to share that experience with her,' adds Andrew. 'It was a blast. And it wasn't like some Mickey Mouse experience either. The instructors were top-notch and from start to finish everything was really well put together.' 'Just being on top of the mountain being able to see all the mountains around me was just spectacular,' says Bonnie thinking back on her experience. 'You don't get to see that very often. And the fact that my boys were able to be with me the whole time, and that I was able to watch them board for the first time, was super fun. It was great to have an insight into what life is like for them when they tell me they're going out to the resort and go boarding.'



Wide open terrain for Bonnie and JR (top) and heading down the hill in her bi-ski (bottom)
Photo Source: www.boec.org



Bonnie on her bi-ski with Andrew, Jason and JR. Source: www.boec.org

As you can tell, Bonnie isn't afraid to throw caution to the wind and overcome her disability in any way she can. From volunteering with the Peace Corps to a 45-year career traversing the variable terrain of third world countries to hopping in a sit-ski and attacking the slopes of Keystone, it's only natural then that she would name the hypothetical book of her life, *Go For It!* The idea being don't let physical limitations dictate what you can and can't do.

That's what my parents always encouraged in me and that's what Andrew was doing,' she says. Andrew was saying 'Hey mom, here's a way for you to be on the mountain, so just go for it!' 'I could have easily said no to him, but that would've been really disappointing because I would have missed out on an incredible opportunity.'

So, the [BOEC](http://www.boec.org) has made a believer out of Bonnie and her family. Not only does she think this will become a yearly holiday tradition, she speaks to others in a similar situation that might be hesitant to get out on the hill with us. She says, 'Just go do it! You feel very, very safe and the guides are very skilled, knowledgeable, calm and collected, and just really fun. And it's wonderful at age 70 that you can look forward to learning something new and having such a really new experience. That's a really cool thing.'

It looks like we'll be seeing you again this December, Bonnie and family. Until then, keep being an inspiration to all of us and all those that are facing similar challenges as you."

[The Story Of Bonnie Kittle – Polio Survivor](#) is available in the Survivor Connections section of our website. To learn more about BOEC's [Adaptive Ski & Snowboard Program](#).

Note: Published with permission from the Breckenridge Outdoor Education Center



Thank you for your kind words and generous donations.
We genuinely appreciate it.

Protecting Your Privacy

We recently had emails from numerous survivors regarding an email solicitation for a “Study” of polio survivors that involved compensation. The email was highlighted with the words:

“POLIO VIRUS - Patient and Caregiver Compensated Research \$150”.

For some, it went right to their “Spam” folder. For others, it came to their “Inbox”. Some of the questions/comments we received were –

“How did they get my email?” “This is great – a study is finally being done.” “Should I participate?”

“What do you know about this?” “They’re going to PAY me to be a part of this !”

Please note: We have NOT researched the validity of this study. This research may in fact be credible but the way in which they are soliciting participation raised our concerns and some from you as well.

Note: Without question, know that we WILL NOT share any of your email information.

This raised the bigger question of “phishing” emails that are in fact scams. How do we know if we should be concerned? We found this article from the US Federal Trade Commission that can help.

[How To Recognize and Avoid Phishing Scams](#)

Scammers use email or text messages to trick you into giving them your personal information.

But there are several things you can do to protect yourself.

How To Recognize Phishing

Scammers use email or text messages to trick you into giving them your personal information. They may try to steal your passwords, account numbers, or Social Security numbers. If they get that information, they could gain access to your email, bank, or other accounts. Scammers launch thousands of phishing attacks like these every day — and they’re often successful.

Scammers often update their tactics, but there are some signs that will help you recognize a phishing email or text message.

Phishing emails and text messages may look like they’re from a company you know or trust. They may look like they’re from a bank, a credit card company, a social networking site, an online payment website or app, or an online store.

Phishing emails and text messages often tell a story to trick you into clicking on a link or opening an attachment. They may:

- say they’ve noticed some suspicious activity or log-in attempts
- claim there’s a problem with your account or your payment information
- say you must confirm some personal information
- include a [fake invoice](#)
- want you to click on a link to make a payment
- say you’re eligible to register for a [government](#) refund
- offer a coupon for free stuff

Here’s a real world example of a phishing email:

Imagine you saw this in your inbox.

Do you see any signs that it’s a scam? Let’s take a look.

The email looks like it’s from a company you may know and trust: Netflix.

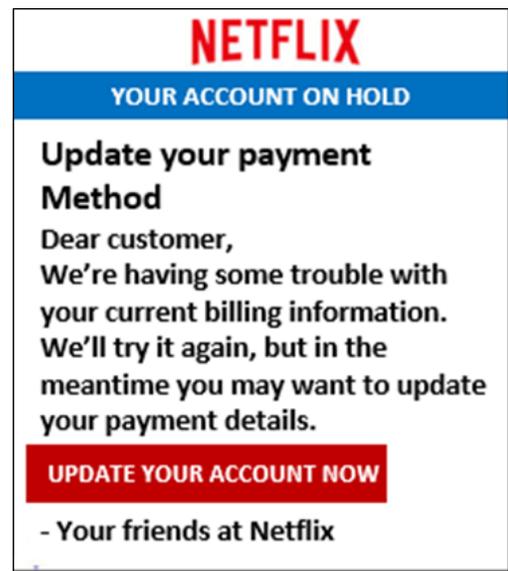
It even uses a Netflix logo and header.

The email says your account is on hold because of a billing problem.

The email has a generic greeting, Hi, Dear Customer etc. If you have an account with the business, it probably wouldn’t use a generic greeting.

The email invites you to click on a link to update your payment details.

While, at a glance, this email might look real, it’s not. The scammers who send emails like this one do not have anything to do with the companies they pretend to be. Phishing emails can have real consequences for people who give scammers their information. And they can harm the reputation of the companies they’re spoofing.



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How To Protect Yourself From Phishing Attacks

Your email spam filters may keep many phishing emails out of your inbox. But scammers are always trying to outsmart spam filters, so it's a good idea to add extra layers of protection. Here are four steps you can take today to protect yourself from phishing attacks.

Four Steps To Protect Yourself From Phishing

1. Protect your computer by using security software. Set the software to update automatically so it can deal with any new security threats.

2. Protect your mobile phone by setting software to update automatically. These updates could give you critical protection against security threats.

3. Protect your accounts by using multi-factor authentication. Some accounts offer extra security by requiring two or more credentials to log in to your account. This is called multi-factor authentication. The additional credentials you need to log in to your account fall into two categories:

- Something you have - like a passcode you get via an authentication app or a security key.
- Something you are - like a scan of your fingerprint, your retina, or your face.

Multi-factor authentication makes it harder for scammers to log in to your accounts if they do get your username and password.

4. Protect your data by backing it up. Back up your data and make sure those backups aren't connected to your home network. You can copy your computer files to an external hard drive or cloud storage.

Back up the data on your phone, too.

What To Do if You Suspect a Phishing Attack

If you get an email or a text message that asks you to click on a link or open an attachment, answer this question: Do I have an account with the company or know the person that contacted me?

- If the answer is "No," it could be a phishing scam. Go back and review the tips in How to recognize phishing and look for signs of a phishing scam. If you see them, report the message and then delete it.
- If the answer is "Yes," contact the company using a phone number or website you know is real. Not the information in the email. Attachments and links can install harmful malware.

What To Do if You Responded to a Phishing Email

- If you think a scammer has your information, like your Social Security, credit card, or bank account number, go to IdentityTheft.gov.* There you'll see the specific steps to take based on the information that you lost.
- If you think you clicked on a link or opened an attachment that downloaded harmful software, update your computer's security software. Then run a scan.

How To Report Phishing

- If you got a phishing email or text message, report it. The information you give can help fight the scammers.
 - If you got a phishing email, forward it to the Anti-Phishing Working Group at reportphishing@apwg.org.*
 - If you got a phishing text message, forward it to SPAM (7726).
- Report the phishing attack to the FTC at ReportFraud.ftc.gov.*
- Note: This reporting information is for the US. Check locally for your country's reporting information.



The entire world has been turned upside down once again.

The GPEI (Global Polio Eradication Initiative) has been on top of a circulating vaccine derived polio outbreak in the Ukraine and have issued a statement regarding their efforts to assist with vaccination through this crisis.

GPEI deeply concerned for health of Ukrainian people amid escalating crisis

Insecurity and displacement increase risk of diseases such as polio

“The Global Polio Eradication Initiative (GPEI) is extremely concerned about the unfolding effects of the current crisis in Ukraine on the country’s health system. A functioning health system must be kept neutral and protected from all political or security issues affecting countries, to ensure that people have continued access to critical and essential care.”

“At the same time, we have seen time and again that large-scale population movements, insecurity and hampered access contribute greatly to the emergence and/or spread of infectious diseases, such as polio.”

“The GPEI has a long history of working in a variety of complex environments, and will continue to adapt its operations to the reality on the ground, to the degree possible, without compromising on the safety and security of health workers. At the same time, immunization and surveillance is being assessed in neighbouring countries, to minimize the risk and consequences of any potential infectious disease emergence/spread resulting from the current large-scale population movements. It is critical that necessary resources are mobilized and made available to assist with the humanitarian needs, including relief, disease response/prevention efforts both in Ukraine and in neighbouring countries.”

[Source: www.polioeradication.org/news-post/global-polio-eradication-initiative-deeply-concerned-for-health-of-ukrainian-people-amid-escalating-crisis](http://www.polioeradication.org/news-post/global-polio-eradication-initiative-deeply-concerned-for-health-of-ukrainian-people-amid-escalating-crisis)



A Long Life for All is not a promise, it's an ambition.
Because everyone deserves a chance at a fulfilling life.
One where we're free to pursue happiness.
And look back without wondering "What if?".
Vaccines have been indiscriminately saving lives since 1796.
The first Smallpox immunization was a fight back against disease.
For the first time, it gave everyone a chance.
And hundreds of vaccines later,
Across two and a quarter centuries.
Billions of people have lived longer lives.
Grown up to become firefighters. Doctors. Musicians.
Fathers. Mothers. Brothers. Sisters.
Vaccines might not get credit for that first kiss.
That winning goal.
That special day.
That final hug.
But their worth isn't just measured in doses given.
It's in minutes given back.
And lives prolonged.
Vaccines provide opportunity and hope for all of us to enjoy
a more fulfilling life. And that's something we should all be
fighting for.
Vaccines, in the pursuit of a long life well lived.
Long Life for All.

Our Professional Contributors

Physicians everywhere are struggling with patients bringing in information that they “got from the internet”.

In his article – [The Role of the Primary Care Physician in the Life of a Polio Survivor](#), Dr. William DeMayo, MD reminds us that “. . . a polio survivor’s health is not solely dictated by their history of polio. They are just as susceptible to the same medical conditions as everyone else.” “Most PCPs willingly admit to a lack of expertise in this area and, sometimes, this creates a dynamic that their opinion on other matters is also downgraded. In fact, from my standpoint, it is unreasonable to expect that a PCP have extensive post-polio knowledge.”

This makes it even more important to make sure we document the SOURCE of information when we are sharing it with our trusted physicians. We all want to feel better and no one wants to help us do that more than our physicians. We are grateful for outstanding professionals who are happy to help bring you their best advice/work regarding the late effects of polio.

When you see an article(s) on our website that applies to you, you can easily download it (or) give your physician the link from our website. Of greatest importance – you can also download (or) give your physician the link to the [biography](#) of the author(s) as well. Any time you see an professional contributor’s name highlighted – whether it be on our website, in our newsletters, in an email or in an article, just “click” and you will find easy access to their biographical information. Perhaps this is even more important for us to do after the complex issues that have surrounded our medical community over the last two years.

You can easily find all professional background and contact information in one place on the [“Our Network Team”](#) page our website.



“More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google.”

April



Always feel free to contact us.

Unless noted with the article, feel free to copy and share what you see. Always give credit to the original source, include a visible, working link to our website: www.papolionetwork.org and email us a copy of what you “share”. THANKS.



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