



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

June, 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:

He got polio because he was too young for the vaccine. “So take it from me - everyone eligible should get COVID shots.” Just a month prior to his death, one year ago, Daniel J. Wilson, PhD was interviewed for his local newspaper. We have never shared that interview and are doing so in his honor. Always a professor, he loved teaching about both the differences AND the similarities between the 1918 Flu epidemic, the Polio epidemics and our current pandemic, COVID-19. His historical references are always interesting. We loved working so closely with him and are happy to feature a large inventory of his writings, videos, book information and interviews on our website:

[Daniel J. Wilson, PhD - Putting the Pieces of Polio History Together.](#)

Slow and steady is the pace for polio survivors. In a new [Bruno Byte](#), Richard L. Bruno, HD, PhD explains: “Being Type A makes PPS worse. Slow and steady self care, regardless of what others think and want, is the way!”

COVID-19 and Polio Survivors. We are bringing you two Q&A's that have come to [Richard L. Bruno, HD, PhD](#) regarding our immune systems and the need to vaccinate and mask up.

“WHAT IF” I hadn't had polio? It's something we've all asked ourselves at one time or another. With her marvelous writing style, survivor Milli Lill takes us into her imagination and allows herself to truly wonder about this question.

Prescription Drug Prices: It's a topic that can require the need for heartburn medication for many of us. It seems that more and more Americans are working with their physicians and pharmacies as they turn to Good Rx for help. Using the frequently prescribed medication Fosamax (Alendronate) we decided to look into it. Their website is clear and easy to use. We especially liked their willingness to assist the MANY Americans who are not online. Do you have Medicare? Medicaid? Private insurance? How does it work? They answer all of your questions.

Endemic, Epidemic, Pandemic. What's the difference?

Endemic is a disease (or condition) regularly found among particular people or in a certain area.

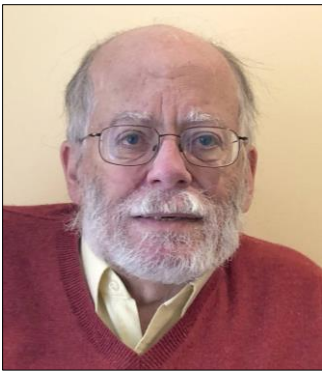
Epidemic is a disease that affects a large number of people within a community, population, or region.

Pandemic is an epidemic that's spread over multiple countries or continents.

Polio remains endemic in two countries Afghanistan and Pakistan. “Until poliovirus transmission is interrupted in these countries, all countries remain at risk of importation of polio, especially vulnerable countries with weak public health and immunization services and travel or trade links to endemic countries.” *



*Source: www.polioeradication.org



I developed polio because I was too young for Salk's vaccine.

So take it from me - everyone eligible should get COVID shots.

By [Daniel J. Wilson, PhD](#)

[The Morning Call](#)

May 05, 2021

“In 1955, polio was the most feared childhood disease in America, not unlike COVID-19 is for adults today. Every summer, cities closed their swimming pools and other places where children gathered to prevent spreading the crippling disease.

In April 1955, following a year long trial, the polio vaccine of Dr. Jonas Salk was declared both safe and effective. The nation celebrated and Salk's vaccine was quickly and widely distributed. I was 5 and living in northern Wisconsin. Unfortunately, there was a shortage of the vaccine and only children going to school received the shots. I was too young and became infected with polio instead. I was left with a weak right side which soon created a severe spinal curvature. When I was 10, I had a spinal fusion to straighten the spine, which meant a year in a body cast.

I had few problems until I was 40, when I developed post-polio syndrome. Now I use a scooter for mobility and a ventilator to assist my breathing. All because of a missed vaccination 65 years ago.

Polio and COVID-19 are different diseases, though both are caused by viruses.

- Polio is largely an intestinal disease spread by water or food contaminated by fecal material shed by individuals infected with the virus. [Over 90% of polio infections are asymptomatic](#); only 2-3% of infections result in paralysis.
- COVID-19 is a respiratory disease spread through the air. [Some 25-30% of COVID-19 infections are asymptomatic](#). Asymptomatic infections spread both diseases.
- Polio was regional, and most epidemics ended in a few months.
- COVID-19, of course, is national and global, and after a year shows no signs of ending.

It took Jonas Salk over seven years to develop the first successful polio vaccine. His research was supported almost entirely by the National Foundation for Infantile Paralysis, better known as the March of Dimes. Established in 1938 by President Franklin D. Roosevelt, a polio survivor himself, it was funded by millions of dimes and dollars contributed by Americans.

The March of Dimes contributed millions of dollars to aid polio patients and support research into the disease between 1938 and 1960. The March of Dimes also funded the 1954 trial of the Salk vaccine that in April 1955 was declared safe and effective. Unfortunately, several weeks later, a bad batch of vaccine produced by Cutter Laboratories resulted in 164 paralyzed individuals and 10 deaths. Vaccination was stopped and resumed only after other manufacturers demonstrated the safety of their vaccines.”

Research that led to the COVID-19 vaccines was funded largely by the United States government. Fortunately, medical science has advanced and companies developed safe and effective vaccines using new techniques in less than a year. “As with the polio vaccine, the rollout of the COVID vaccines has seen shortages, as it takes time to produce the millions of shots needed. There have also been complicating side effects such as blood clots that led to the recent pause of the Johnson & Johnson vaccine.

The Salk vaccine was seen as a miracle in 1955. Parents rejoiced because they no longer feared their children would be crippled for life. While many have celebrated the COVID-19 vaccines, others are skeptical or resistant. From my perspective of having missed out on the polio vaccine, we need as a nation to embrace the COVID-19 vaccine, not reject it.

Fortunately, I have had my two Moderna shots. But given my post-polio breathing problems, I am being cautious and still wearing my mask. I am looking forward to reaching herd immunity and I can go mask free in stores, in restaurants, at movie theaters and sporting events. Just as the Salk vaccine gave summer back to America's children, the COVID-19 vaccines, if widely accepted, can give us back our lives - getting together with family and friends, going out for dinner and entertainment, enjoying athletics as participants and spectators. Now that the vaccines are widely available for adults over 16, please line up and take your shots.”

Daniel J. Wilson, (was) a Bethlehem, PA resident, and a member of the Lehigh Valley Center for Independent Living board of directors. He had a doctorate in American History and was retired from Muhlenberg College, where he taught history, including history of medicine. Article [Source](#).



What If. . .

By Millie Lill

The doorbell rings. I answer the door and stare. I realize that most of my friends are, shall we say, unique, but this person has silver hair in an elaborate updo, a tutu, and ballet slippers. Also wings! Yep, those transparent fluttery things are definitely wings.

“Hello, dear!” she warbles. “I am your fairy godmother and I'm here to grant your wish!”

“OK, just one? If I talk really fast, can you count this as one wish: tall thin rich?”

“Oh, no, sweetie. You don't get to choose your own wish, and besides, really, that is three wishes anyway! It's not cool to try to fool a fairy. No, your wish is that you never had polio.” She begins waving a stick around. Well, OK, it's a wand. I know, but really this is getting to be just a tad bizarre.

“Wait! Before you grant that wish...can you show me a little preview of what that would be like?”

Sighing, she taps her toe on the floor and finally says, “Well, OK. I can do that, but you are one tough customer. The usual protocol is to say Thank You and just accept the granted wish. Here you go.”

Swish swish swish. . . and my TV comes on.

It shows me as a little girl, age four. I'm telling my Mom that my leg feels funny. Then I laugh and finish getting ready for Sunday School. Then the scene fast forwards to me, a year or so later, begging my big brother to teach me to read. I have to wait till I'm almost six to start school because of my late September birthday. “Go away, Millie. You'll learn next year in school. I'm busy.”

My mother is not a nurturing person, but I'd had the support of the entire town when I had polio. Now, it seems I am just an ordinary little girl. Mom's standards are purposely too high for any of us girls to achieve. She does not like girls, never has. Grandmother didn't like them either. Only boys have value.

As I watch my life unreel, I see myself playing softball with the other kids at recess. None of the boys are fighting over who gets to run for me in the unlikely case of my actually hitting the ball. Nope. Do it yourself time for me. I see my awkward, ungainly self with my thick eye glasses and big teeth, my crazy hair, and with no friends. I'm not good at sports. I keep trying, though, and the results are that I am failing in my classes and still not any good at sports. I'm not crazy about running around and getting all sweaty and still not being an athlete!

My few friends graduate from school and move away. I marry to get out of the house and to limit the amount of time my mother can spend telling me that I am big, ugly, clumsy and lazy. Soon I have children, but they are no excuse to keep me from learning to drive the tractor.

I can feel how lonely I am in this scenario because my husband and his family are all beer drinkers and I can't stand the taste. I am not invited along to any parties. I'm only there to work. Chores, housework, child raising.

I grow old, my husband dies. I have no fun hobbies to fill my time. My time was spent working, eating or sleeping. I never heard of post-polio, so I am not writing my column, I'm not going to support group meetings. I am very bored and very lonely.

“Wait! Don't grant that wish! Having polio was not fun, but it led to a lot of things that were. I met so many wonderful people through my polio groups. Not being able to be so active, I spent my time reading and studying, making good grades, writing and doing other sedentary things. I don't want to lose that!”

Swish, swish, swish, I hear and I start screaming, “NO! NO! NO!” and wake up to find the swishing was Fiona wagging her tail as she tried to wake me up from my nightmare. Whew. Yes, my legs are their usual mismatched, barely functioning selves, but that's OK. My life would only have been different, not necessarily better had I not had polio.



Bruno Bytes

From [Richard L. Bruno, HD, PhD](#)
Director, International Centre for Polio Education

On the topic of Polio Survivors and Type A Personalities

TYPE A? NO WAY! SLOW AND STEADY IS THE PACE FOR POLIO SURVIVORS.

There are some who refuse to believe that polio survivors are Type A. These folk won't hear what we have found again and again: polio survivors are more Type A on average than the general population, 18 points more Type A than people who have had heart attacks.

Why is it such a problem to be Type A? Way back in our 1985 National Post-Polio Survey, we found that the more Type A polio survivors were, the more PPS symptoms they had and the more severe the symptoms were.

Our surveys of more than 2,000 polio survivors, as well as decades of clinical data, support the thesis that polio survivors show more Type A behavior because being Type A protected them from the emotional and physical abuse they experienced as children. What are the rules polio survivors painfully learned?

- “Do for others before they do unto you.”
- “I can’t just be as good as everyone else. I have to be BETTER than everyone else to survive.”

In treating polio survivors, I feel deeply the fear many have when giving up their Type A, self-protective behavior. That's why we say feeling guilt and anxiety show that polio survivors have stopped being Type A and are finally doing for themselves, no longer doing only for others and trying to be “better than the best.”

Bottom Line: Being Type A makes PPS worse. Slow and steady self care - regardless of what others think and want - is the way!

From Dr. Bruno's Article: Type A Behavior and Polio Survivors:

“It is exactly because of everything polio survivors have already experienced that they will survive in spite of PPS. To do this, polio survivors need to read these words again and again and take in the full depth and breadth of their meaning:

“I am a polio SURVIVOR!”

If polio survivors can acknowledge the truth to their suffering they have survived, there is no question that they can cope with the past and make the physical and emotional changes necessary to survive and thrive with PPS.”

For more articles on this subject, look under the topic “Psychology” in the [ENCYCLOPEDIA of POLIO & PPS](#)

On the topic of Compromised Immune System and Viruses

Question: Weren't polio survivors' immune systems compromised when we got the poliovirus? Why else would it take hold rather than being fought off, as would be the flu?

Dr. Bruno's Response: Being infected with and having neurons damaged by the poliovirus does not mean that your immune system was compromised. Unlike the flu viruses, to which people are exposed at least yearly, you were a "poliovirus virgin" having never before been exposed to any of the three polioviruses. Your immune system (as with COVID today) had no antibodies or B cells or T cells to fight them. But your immune system learned quickly to attack the poliovirus. Had you been immune compromised during the acute polio infection you quite likely would have died. The purpose of the polio vaccines was to expose the immune system to the polioviruses without causing neuronal damage, to teach it to attack the polioviruses before they could cause neuron damage and death.



On the topic of the COVID Vaccine and Polio Survivors

Question: I feel as though I have been pressured heavily into both

- wearing a mask and
- getting vaccinated for COVID

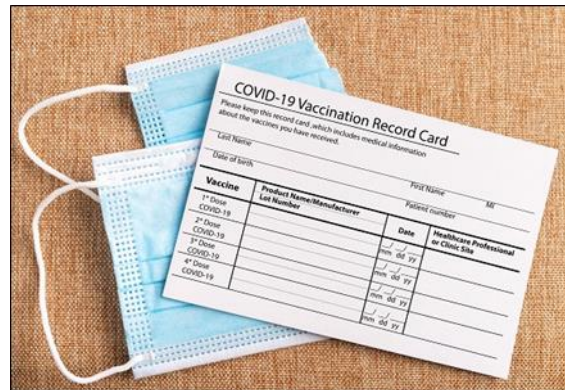
I think I already am immune, having contracted COVID earlier this year would give me a natural immunity.

What you're your thoughts on polio survivors being forced to get the vaccine.

Dr. Bruno's Response: You are not being forced to get the COVID vaccine or wear a mask. But you are doing yourself a tremendous disservice to yourself and others if you don't do both.

Antibodies levels are lower after you have had the COVID virus than they would be if you also were vaccinated. This is no different than the situation with the polio vaccine. Polio survivors received boosted immunity, plus immunity against the types of polio they did not have, when they were given the vaccine. Now, especially with so many of the unvaccinated allowing the development of COVID variants, everyone needs as many antibodies as possible.

As for wearing a mask, since COVID is a respiratory virus that grows in your throat, you are protecting yourself against reinfection and, even if you are re-infected without symptoms, the mask prevents you from passing the virus growing in your throat to someone else.



GoodRx How Do I Use It to Compare Prescription Drug Prices?

It's Easy.

All you need is a [GoodRx card](#) (it's free). If you're not online, that's OK.

You can pick one up at many doctors offices (or) call (855) 723-1225

We decided to test it out, using a common prescription medication – Fosamax (Alendronate). For a location to check prices? We looked at a map of the US and chose Omaha, Nebraska – right in the center of the country.

We went online to: www.goodrx.com and entered the drug name (Fosamax).

- It describes the medication, shows a photo of it and explains what it's used for.
- Then, it asks you to “match your prescription” and you can see both the brand and generic names along with the dosage information (as prescribed by your physician).

We entered our location and sorted by price. It quickly showed a significant difference in pricing along with coupons, savings plans and mail order information.

Then, we went back up to “match your prescription” and checked out the generic - Alendronate. We kept the same sorting (by low price).

The differences in pricing were significant (comparing 3 dose packs of 4 tablets per dose) for the Brand Name and for the Generic brand *

<u>Pharmacy</u>	<u>Generic (Alendronate)</u>	<u>Brand (Fosamax)</u>
Costco	\$9.99	\$408.90
Hy-Vee	\$10.14	\$383.55
Walmart	\$18.78	\$424.10
Walgreens	\$25.00	\$410.17
CVS	\$53.22	\$410.41
Target	\$53.33	\$410.41

*Note these prices are being used as examples only. Always enter YOUR location and seek current information. Pricing can change.

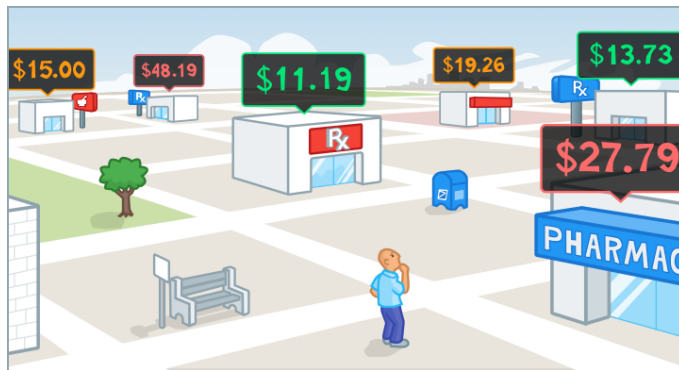
If you're not online, present your GoodRx card to the pharmacist when you drop off your prescription. They'll help you.

This article continues with additional information and helps clarify: Medicare, Insurance and Deductible information.

Why do I need GoodRx?

Prescription drug prices are not regulated. The cost of a prescription may differ by more than \$100 between pharmacies across the street from each other!

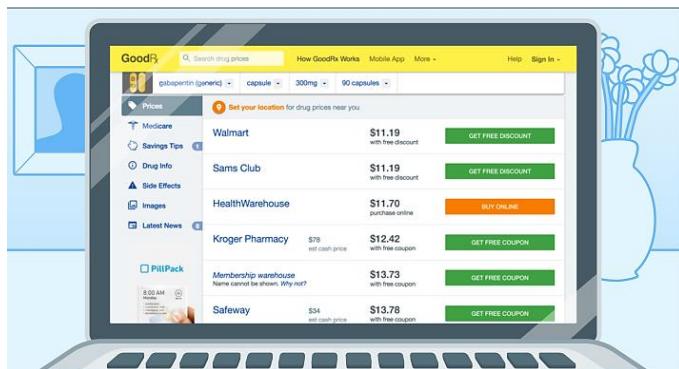
Insurance isn't helping like it used to. In the past 10 years, insurance companies started passing 25-80% more of the cost of drugs onto patients.



How can GoodRx help me?

GoodRx gathers current prices and discounts to help you find the lowest cost pharmacy for your prescriptions.

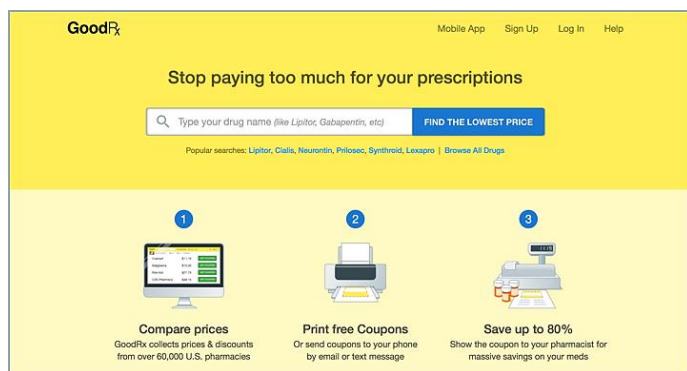
GoodRx is 100% free. No registration required.



How do I find discounts for my drug?

It's easy. Just go to the home page, type in your drug's name in the search field, and click the "Find the Lowest Price" button.

We'll even help you spell the name of your prescription.



What are GoodRx coupons?

GoodRx coupons will help you pay less than the cash price for your prescription. They're free to use and are accepted at virtually every U.S. pharmacy.

Your pharmacist will know how to enter the codes on the coupon to pull up the lowest discount available.



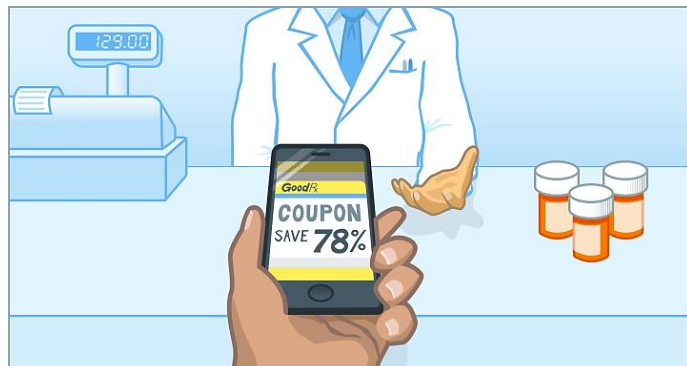
How do I use a GoodRx coupon?

It's similar to using a coupon at a grocery store. Simply print the coupon and bring it with you to the pharmacy when you pick up your prescription. The pharmacist will enter the numbers on the coupon into their system to find the discount.

Don't have a printer or want to save paper and ink cartridges? You can show the coupon on your phone by:

- A) Sending the coupon to yourself via email or text
- B) Or using our [mobile app](#)
- C) Or visiting our mobile website

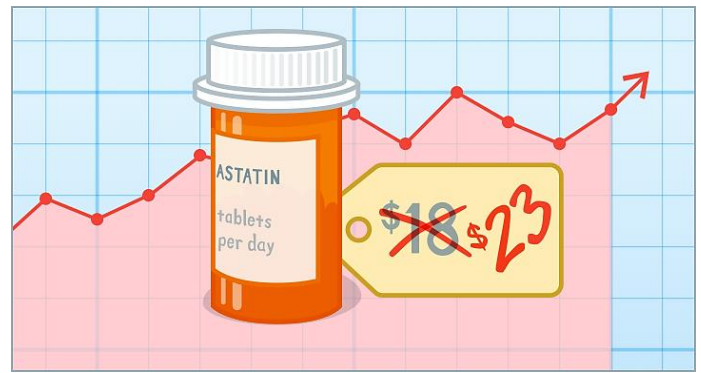
[Learn more about using a GoodRx coupon](#)



What if I have insurance or Medicare?

Many insurance plans have high deductibles or limited formularies that don't cover the drugs you need. GoodRx may be able to find you a lower price than your insurance co-pay. Hundreds of generic medications are available for \$4 or even free without insurance.

[Learn more about how to use GoodRx if you have commercial insurance or Medicare](#)



Can I use GoodRx if I have insurance? Yes!

Anyone (in the US) can use GoodRx, regardless of whether they have insurance or not - and this is true if you have commercial insurance, Medicare, Medicaid, or any other type of insurance. To use GoodRx, just let your pharmacy know that you'll use a GoodRx discount instead of your insurance when you pay for your prescription medication.

When using GoodRx instead of your insurance, the amount you pay will not automatically be applied toward your deductible.

Do purchases with GoodRx count towards my deductible?

When using GoodRx instead of your insurance, the amount you pay will not be automatically applied toward your deductible.

You may want to contact your insurance company to find out if you can submit receipts for prescriptions purchased using GoodRx. Many insurance plans will allow you to submit receipts for potential reimbursement and/or credit toward your deductible and other policy limits.

Article Source: www.goodrx.com

You're standing in your local pharmacy or in the medicine aisle of your neighborhood grocery store, and you're hurting. Maybe you have a headache or twisted your ankle during your morning workout. Whatever the case may be, you need some relief.

You scan the rows of medications. There are boxes and bottles; tablets and capsules. Which one do you choose? Which one is safest? Aren't they all the same?

With so many different options and types of medication, a seemingly simple choice can get complicated quickly. Let's take a look at Advil and Tylenol and learn how they compare.

7 Things to Know About Over-the-Counter

Advil vs. Tylenol

	ADVIL	TYLENOL
1 What's the active ingredient?	IBUPROFEN	ACETAMINOPHEN
2 What's the maximum daily dosage?	1200 mg/day	4000 mg/day*
3 What forms does it come in?	TABLET, CAPSULE, LIQUID	TABLET, CAPSULE, LIQUID, RECTAL SUPPOSITORY
4 What are the side effects?	STOMACH UPSET, DIZZINESS, AND HEARTBURN	RARE**
5 What organs does it affect?	STOMACH, KIDNEYS	LIVER
6 Can you alternate them?	YES!	
7 How often can you take them?	EVERY 4 TO 6 HOURS	

* A lower maximum dose of 3,000 mg/day is often recommended for some groups of people, including older adults and those with liver problems.

** Headache and nausea are possible.

GoodRx

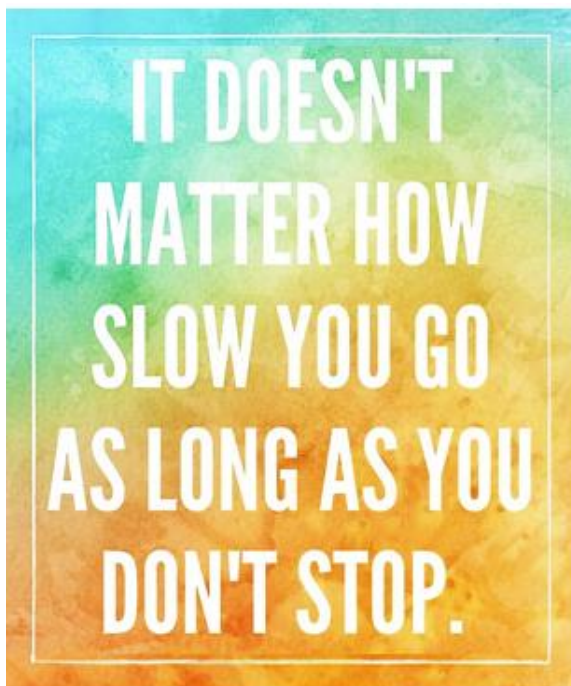
Just For Fun . . .



“...No movies, no music, no text messages ... you just talk!”



Thank you for your kind words and generous [donations](#). We treasure each an every one.



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