



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

October 2018

Our Mission:

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

It's October. Polio Awareness is a "Happening" all over the Globe.

In anticipation of World Polio Day on October 24th, we published a series about Polio (the virus) and the Polio vaccine(s). Our goal has been to help survivors and our family members understand why the effort to eradicate this disease (that we are all SO very weary of), has been so enormously difficult. We wanted to bring to everyone's attention the history behind the raw determination to get the job done.

Has this been far more complicated than anyone realized at the start? YES.

Has any partner in the eradication initiative pulled out of this effort? ABSOLUTELY NOT.

With that comes an understanding that as survivors we are not alone in this effort. The largest Global Eradication Initiative in history is taking place right before our eyes.

We had fun bringing a different "twist" to Team Survivor this year. There couldn't be a more trustworthy reason to write a check, and so many of you have done that.

All over the US and abroad, Rotary Clubs are hosting World's Greatest Meal events to raise funds to eradicate Polio. It's not easy for survivors to get out to these marvelous events. We "cooked up" a solution to bring a tasty event to you. By purchasing pots, pans, spoons and other kitchen gadgets, you can give a significant donation to the Rotary Foundation and cook your very own WGM! The history behind this eradication effort is where our words "raw determination" came from. The amazing documentary that you can purchase through Team Survivor tells the story of those few Rotarians who had the vision back in the early 80's to Eradicate Polio. It was the producers of that video who came to us to share it with all of you for a significant discount, for these two months. How does it fit? From your own home, you can experience this history, see the world wide effort that's happening all around us, and provide the Polio vaccine for 32 children in the most war torn countries of the world.

We are survivors who are *thriving* as we become part of the solution. You can still join [Team Survivor](#) through the end of October.

To continue on our "Global" theme, [William M. DeMayo, MD](#) has given us the fourth article in his wonderful series "Lessons from Abroad".

We have enjoyed being introduced to his term "People of Determination". He was in the UAE for only a few weeks when he sent us this note: "In general, access for individuals with disabilities is very difficult here in the UAE. Even so, I saw this and I thought very determined Polio survivors might enjoy it". With this article, he has given us a marvelous collection of photos regarding the accessibility issues he is discovering during his journey abroad. Thank you Dr. DeMayo.

In September, we announced our partnership with [Richard L. Bruno, PhD](#) to publish the **Encyclopedia of Polio and Post-Polio Sequelae.**

Realizing the information is easily accessible is one issue. Accessing his amazing inventory of information may be a different story. We are optimistic that our article will help.

Accessibility Issues and Services for “People of Determination” in the UAE

Lessons from Abroad Part 4

[William M. DeMayo, MD.](#)



This article is Part IV in the series “Lessons from Abroad” and has a focus on understanding life in Abu Dhabi from the standpoint of access by individuals with disabilities. (The first 3 articles are easily accessed through DeMayo’s Q&A Clinic). The pictures really tell the story but here are a few other thoughts I have had on accessibility in Abu Dhabi:

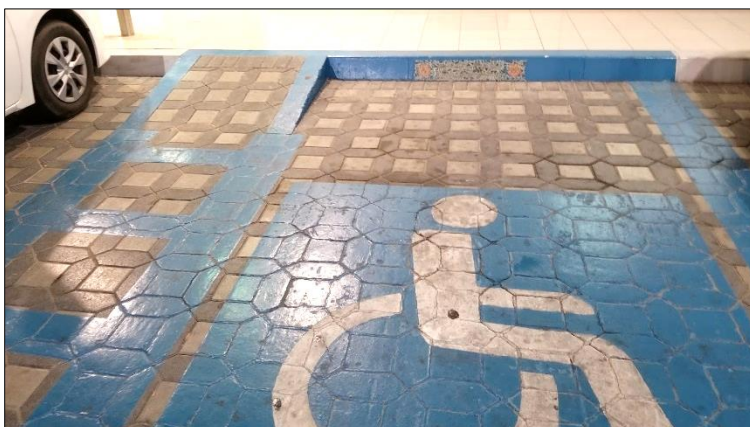
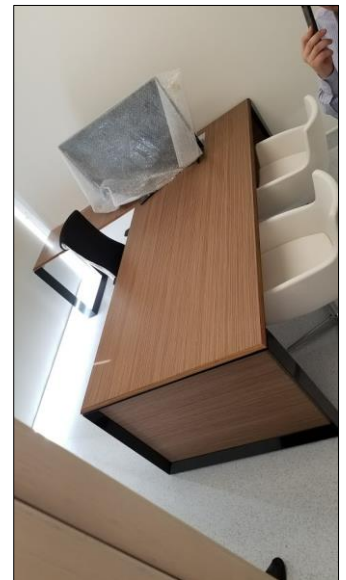
- The common theme to disability access in the UAE is that there is no common theme – the very poor accessibility that came with dramatic growth and building is rapidly changing. Newer public facilities and hotels have outstanding accessibility yet many other places are severe challenges.
- Some of the accessibility issues seen in Abu Dhabi include:
 - Ramps to nowhere are common (e.g. a curb cut leading to a side walk with no other curb cuts). .
 - Ramps are very steep.
 - Curb cuts are becoming more and more common – 12 miles along the beach, now all curbs are cut. At the same time some curbs are mountain sized – can be a 12 inch or more drop.
 - Brick and tile walkways often have hazards including cracks, dips and debris. Outdoor tile is a particular hazard if wet to anyone using an assistive device. Although it rarely rains, sprinklers or spills from pedestrians do occasionally make these surfaces wet.
 - Bathroom accessibility can be poor although excellent in hotels and many public places
 - Bathroom floors often wet from hoses in toilet stalls and can be a hazard
 - Makes one really see the amazing impact the ADA has had on the US
 - Lastly, the heat itself is an issue. During the summer temps over 110 are not rare and humidity is high. Able bodied individuals move quickly from home to car and car to work. Individuals who labor to slowly ambulate in good conditions may really struggle in this heat.
- Many individuals with disabilities simply stay home in their family compounds. Few wheelchairs are seen in malls and other public places.
 - Families don’t encourage older individuals to use power mobility. These individuals grew up in tents and would certainly have an adjustment to learn to be comfortable with a power WC but lack of family support to engage this challenge makes it all but impossible as a goal.
- There is a new movement from the top of government to facilitate rehabilitation and helping those with disabilities. The term “People of determination” has officially replaced “handicap” or “disability”.
 - *Government portal reads “The Government of Abu Dhabi offers quality care and services to people of determination. Moving away from conventional routes and methods to fulfil their needs and aspirations, and to ensure their active participation and integration in the weave of Abu Dhabi community”*

- **Also** - Federal Law No. (29) of 2006 Concerning the Rights of People of Determination
 - *His Highness Sheikh Khalifa bin Zayed Al Nahyan, UAE President, issued in 2006, the Federal Law No. (29) of 2006 concerning the rights of people of determination is the first law in the UAE to protect the rights of people of determination. The law provides for equal care, rights and opportunities for people of determination in education, health care, training and rehabilitation and aims to ensure their rights and provide all services within the limits of their abilities and capabilities.*
 - The law guarantees an unspecified job quota for people of determination in the public and private sectors and focuses on increasing accessibility to public buildings and residences. It also places emphasis on integrating people of determination into public and private schools, and takes into account retirement considerations, allowing people of determination to retire with full benefits earlier than their normal counterparts.*

In summary, accessibility in Abu Dhabi is quickly evolving. There is no question that many challenges remain but they are quickly being addressed. The new government policies for “People of Determination” are facilitating this rapid change. Rather than being critical of the limited access in many places, I personally chose to see “the cup half full” and focus on the fact that ADA level standards are quickly becoming the norm.

Abu Dhabi is much more welcoming than it used to be.

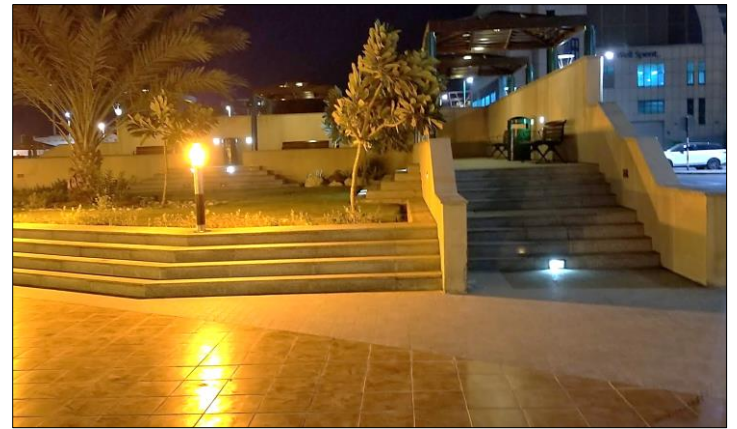
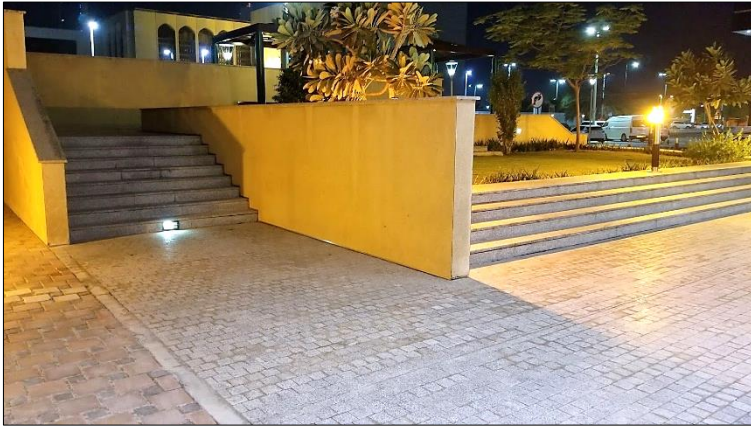
Unfortunately, accessibility issues were not considered until recent years and, even now, some projects miss the mark



The only ramp into this convenience store is located next to a clearly marked spot. But, when spaces were short, look where someone parked.....



These two steps in front of a grocery store run the entire block. At the far end is a small ramp (no handrails) and it is blocked by a stack of bricks.

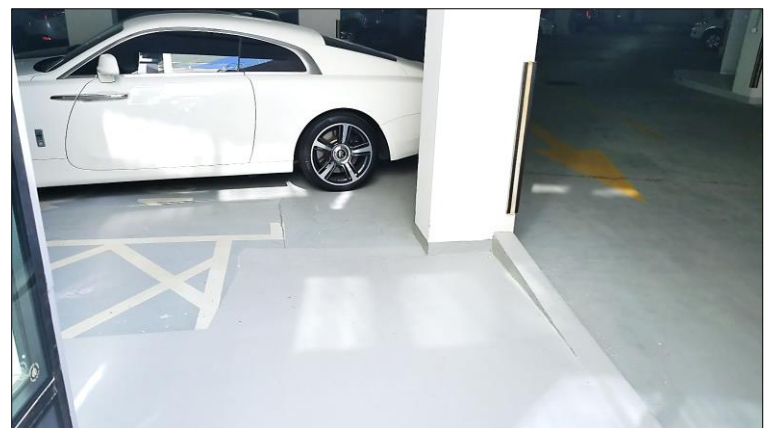
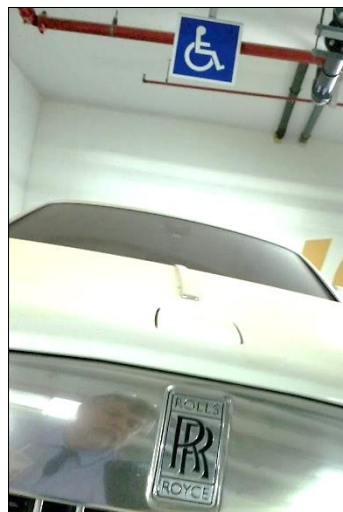


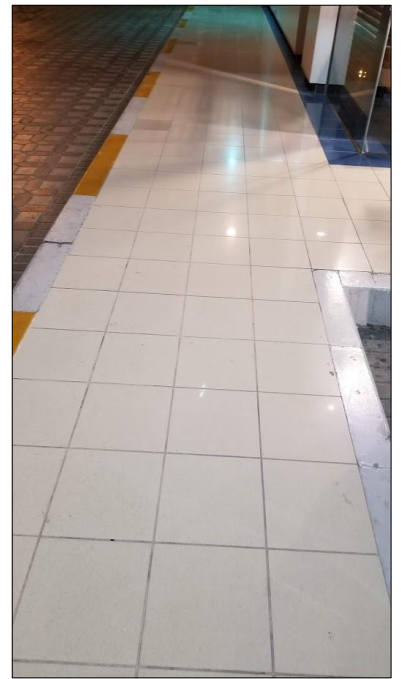
Stairs also are prevalent in older public areas, ramps are seen in newer construction.



Some beaches are becoming accessible right to the water, others are not.

Yes, that is a Rolls Royce parked permanently in a spot for People of Determination. It also blocks the only ramp to get in the building.





Some older sidewalks are hard for an able bodied person to negotiate. Some new walkways can be very slippery when they are wet (it rarely rains here but sprinklers and spills by pedestrians do occur).



Some sidewalks are way too narrow for a wheelchair. Often, if you do find a wide sidewalk, there is no curb cut out to get to the next block.

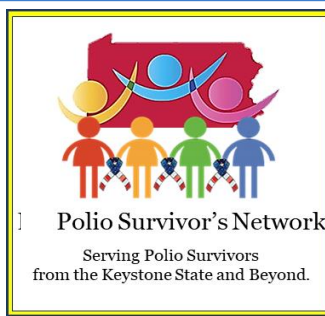
Empowering the
People of Determination in UAE

20%
 discount on tuition fees
 أصحاب الهمم

There have been huge strides by the government to foster accessibility. This includes everything from parking to lower tuition fees.



“It is an exciting time in the UAE for those of us in the rehabilitation field and I feel privileged to be a part of the process.” William DeMayo, MD.



Working Together to Publish the Encyclopedia of Polio and Post-Polio Sequelae

The [Encyclopedia of Polio and Post-Polio Sequelae](#) contains all of Dr. Richard Bruno's articles, monographs, commentaries and "Bruno Bytes". The Forward and his commentary about this work is on the main Encyclopedia page.

Published on September 15, 2018 this Encyclopedia contains Dr. Bruno's articles in an easy to access format, by Subject. In addition, it contains a complete Index (by subject), current and previous month's Bruno Bytes, a video library and links to purchase books he has authored. You can easily download and share the information.

Bruno Bytes: These monthly Q&A's are now in the Encyclopedia section of our website. The current month is easily visible. Current AND previous months are available from that page in PDF format for easy sharing.

Index: This document created with Dr. Bruno's input, is edited by our Network. We update it whenever Dr. Bruno publishes any new articles (including Bruno Bytes). It contains a "search" ability by simply holding down the "Control" key and the letter "F" at the same time. You will see a box appear (probably at the top of your screen) that will allow you to enter the words, topics, etc. you are looking for. You will see your entry "highlighted" on the page. Just "click" on it. If you are not familiar with using this format, try it a few times. This Index is sorted alphabetically by Subject.

Inventory of Articles: Dr. Bruno's *entire* inventory of articles have been reviewed, edited and updated. These edited articles are only available on our website. Note: His amazing work is still available on his website (www.pospolioinfo.com) but you will see that he has noted those articles as "Classics" and are *not* the edited, updated versions.

- This article page is sorted by "Subject", thus placing all articles (Research, General and "short" articles) about "Fatigue" in the same section.
- The article page also has the "Control" "F" search option mentioned above.

Navigating the Encyclopedia: The primary Encyclopedia page is easily located in the Post-Polio Syndrome section of our website. Beneath Dr. Bruno's Forward, you will see Red "buttons". Just "click" to go to your area of interest. (This format is used throughout our website).

Direct Links:

polionetwork.org/encyclopedia *

*Note: The Direct Access to the Index is from this main Encyclopedia Page.

polionetwork.org/bruno-bytes

ENCYCLOPEDIA INDEX (By Subject)

ARTICLES

BOOKS

BRUNO 'BYTES' by MONTH

VIDEO LIBRARY

From the World Health Organization (WHO)

Eradicating polio is hard and complicated. It requires committed, hardworking frontline healthcare workers to deliver doses of the oral polio vaccine to every single child, multiple times, so that they develop full immunity.

It relies on community leaders, parents, medical personnel, traditional healers and surveillance officers to search for symptoms of polio – most often a floppy arm or leg – and to make sure that the child is tested for the poliovirus.

These two tactics – reaching every last child and finding every last virus – are the pillars to success, giving the virus no place to hide. Once no children remain under-immunized, the virus will die out – and the world will be free of polio.

To end polio, WHO works alongside Rotary International, UNICEF, the US Centers for Disease Control and Prevention, and the Bill & Melinda Gates Foundation. Rotary International had the vision of a polio-free world nearly three decades ago, and millions of Rotarians have committed over US \$ 1.6 billion to the effort to date.

Through these efforts, more than 16 million people are walking today who would otherwise have been paralyzed for life. More than 400 million children are vaccinated every year. In 2016, nearly 220 000 stool samples were tested for polio in WHO-accredited laboratories.



Vaccinators in the Syrian Arab Republic deliver polio vaccines to children despite conflict.



In Karachi, Pakistan, hard working vaccinators have won the hearts of communities as they vaccinate children against polio.

The Complete article is available [HERE](#)

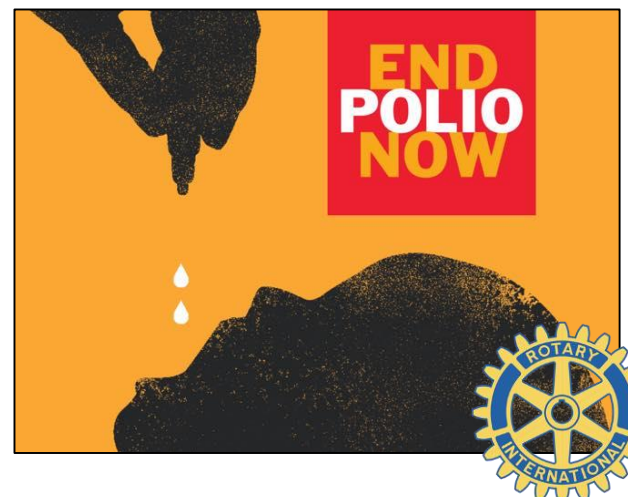
World Polio Day – October 24, 2018
One Day. One Focus: Ending Polio

<https://www.endpolio.org/world-polio-daya>

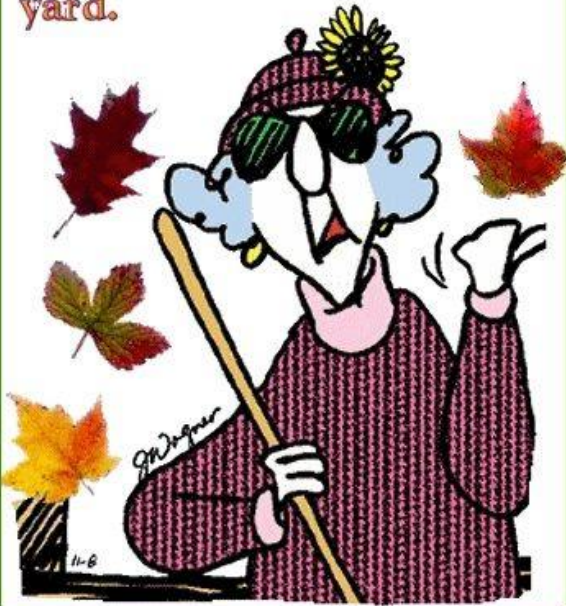
No child should ever have to face the pain and disability from this completely preventable disease. All children must be vaccinated.

Polio workers are responding to other health needs. Polio eradication paves the way to meet a plethora of other health needs. Since last year, polio workers have contributed to fighting cholera in Nigeria, responded to Meningitis outbreaks, strengthened routine immunization, and brought broader benefits to communities.

“Until polio is eradicated everywhere, every country remains vulnerable,” says Zaffran. “To build a world where future generations are free of polio, much work remains, all of it needing continued political and financial support: we must find every last virus and vaccinate every last child.”



I love a brisk fall breeze,
especially when the leaves
blow into the neighbors
yard.



How do you mend a broken pumpkin? —
With a pumpkin patch!

What's the best thing to put into a pumpkin pie? —
Your teeth.

What do you get when you drop a pumpkin? —
Squash.

Why do birds fly south in the Fall? —
Because it's too far to walk.

What has ears but can't hear a thing? —
A cornfield.

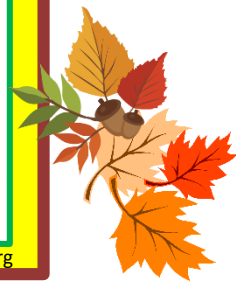
What reads and lives in an apple? —
A bookworm.

What did one leaf say to another? —
I'm falling for you.

Why shouldn't you tell a secret in a cornfield? —
Because the corn has ears.

Without question, the one
thing we ALL share is the
prayer that with world wide
vaccination; death and
disability from the
Polio virus will
soon be gone . . . **Forever.**

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Do you have a topic you would like us to cover? Please let us know.
Always feel free to contact us.

[The Polio Network Team](#)

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THANKS.



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