

SECOND TIME AROUND

Publication of the Boca Area Post Polio Group

August 2018

"Sharing and Caring Together"

Volume 21 Issue 8



No August or September Meetings!!

Let's Do Dinner . . .
Tuesday, August 14 @ 5:00 PM

Chili's Grill & Bar
21078 St. Andrews Blvd., Boca Raton
561-391-2300 for directions
[East side of St. Andrews Blvd.,
just south of Glades Road]



Dining Around – September 13, 2018

JULY '18 UNMINUTES

While Jane & I are used to hot & humid weather, we hope our readers have fared well with your unseasonably hot weather!

Remember, no meetings in August & September – we look forward to seeing you at dining around during those months. So we have enough seats for you, please contact **Jane** 561-391-6850/luckycat@bellsouth.net if you will be joining us.

Second Time Around newsletters will continue all summer long.

Cruise 2019 – a few accessible & lots of regular staterooms available. A refundable deposit will hold your stateroom. See Page 2.

This time of the year we are thankful for the quiet tropics & Gulf, and we pray it continues through the end of November!

We hope you are having a wonderful summer staying cool, traveling, hobbies, enjoying family/friends, and whatever keeps you out of trouble!



Jane & Maureen

CRUISE 2019!!

\$300 onboard credit

Ocean view and above!

Join BAPPG on our sixteenth annual trip – a 7-night Western Caribbean cruise. Celebrity's *Equinox*, departs on **Saturday, February 23, 2019**, Port of Miami, docking at Key West, FL; Costa Maya & Cozumel, Mexico; & Georgetown, Grand Cayman!! This beautiful ship is **accessible** as we've cruised on it before.

Twenty-eight, various category, accessible cabins are reserved for our group.



As rooms are limited, you are encouraged to book now! Cabin rates **start at \$935** per person, which

includes all taxes & port charges.

There are plenty of non-accessible rooms. PPS is **not** a pre-requisite – so why not invite family & friends!

A \$250 per person deposit is fully **refundable until October 15, 2018**, on a cabin of your choice!

Contact Maureen at 561-488-4473 or bappg@aol.com for questions, accessibility, roommates, scooter rentals & onshore tours.

Contact Judith at 561-447-0750 x102, or judith@travelgroupint.com for booking, perks, transfers, hotels & air.

21 people have already booked!!

BAPPG appreciates the generosity of the following people who enable the printing of this newsletter.

Nicholas Kmetz

(In memory of Albert Carbonari)

Barbara Davis

WITH MANY THANKS

We wish to thank the many benefactors* who have given so generously to the Boca Area Post Polio Group.

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(In memory of Albert Carbonari)

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***Names remain for 1 year.**

POST-POLIO PROTEIN POWER: EAT WELL, BE WELL

By Richard L. Bruno, PhD

"Breakfast? Sorry, don't have the time. In the morning there's too much to do, like showering and dressing and getting to work. I grab a cup of coffee (or two or three) and maybe a donut at work..."

"Lunch? Don't think so. I'm still catching up from my late start in the morning. I grab a cup of coffee (or two or three) and maybe wolf down half a Big Mac..."

"Dinner? I'm either too tired or hungry as Patton's Third Army. I either defrost a piece of pizza and drag myself into bed or eat everything that isn't nailed down!"

"So why am I totally exhausted but can't stop gaining weight?"

Americans are not very good at taking care of themselves. Americans with disabilities are no better, and maybe a little worse, at self-care because it takes so much time to do things non-disabled folk do in a flash, like showering and dressing. There's hardly any time or energy left for planning meals, shopping, cooking ... or even eating.

However, people with disabilities pay a higher price for lack of self-care than do people without disabilities. For those who use wheelchairs, good eating habits and proper nutrition are essential; not only for general good health, but also to prevent bowel and urinary problems, to prevent weight gain, and to maintain a decent level of energy.

Polio Survivors vs. Breakfast. One group of people with disabilities shows the consequences of poor eating habits: North America's 1.8 million polio survivors. Nearly 76 percent of polio survivors experience Post-Polio Sequelae (PPS), the often disabling symptoms – fatigue, muscle weakness, joint and muscle pain, cold intolerance, and difficulty sleeping, swallowing, breathing – that occur about 40 years after their original bout with polio.

PPS requires polio survivors to use new assistive devices or aids they discarded years ago, like braces, canes, crutches, wheelchairs and scooters, to slow down and to rest during the day. The problem is, polio survivors are Type A, hard working, pressured, perfectionist super-achievers who have pushed themselves beyond their physical limits and allow no time for self-indulgent luxuries – like food.

Polio survivors don't want to slow down or rest, not only because they're afraid if they are less Type A people won't like them, but also because they are afraid of gaining weight if they become more sedentary. But they shouldn't be afraid. Food is good! Eating properly doesn't lead to becoming fat, it actually reduces PPS symptoms.

Dr. Susan Creange at the Post-Polio Institute discovered that polio survivors with blood sugar levels in the low normal range have as much difficulty paying attention and concentrating as would diabetics with blood sugars as low as if they had taken too much insulin.

"Polio survivors' 'Type A diet' – three cups of coffee for breakfast, skipping lunch and

eating pizza for dinner – is actually starving their nervous systems and causing PPS symptoms," says Creange. The relationship between diet and PPS was seen in the 1998 National Post-Polio Survey: the less protein polio survivors had at breakfast the more severe were their daily weakness and fatigue.

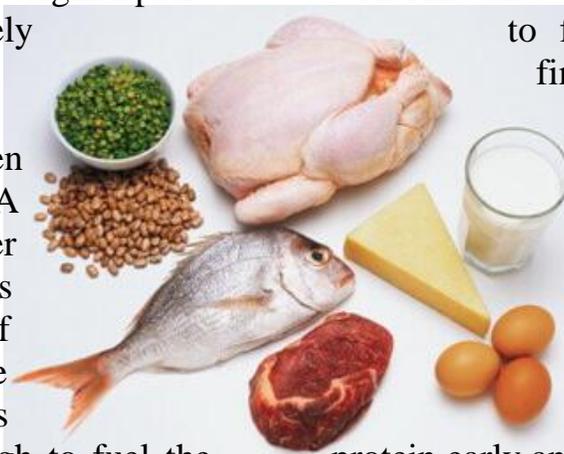
Why do polio survivors function as if they have low blood sugar and report more symptoms when they don't eat protein at breakfast? Because polio survivors are running their nervous systems on "half a tank of gas." About 50 percent of all brain stem and motor neurons were killed decades ago by the polio virus. What's worse, the metabolic apparatus, the internal power plant, of the neurons that survived the original polio virus infection was severely damaged.

So polio survivors have been running their full-tilt, Type A lives on half the normal number of neurons, neurons that are less able to use their only source of fuel, blood sugar. Dr. Creange found that even normal levels of blood sugar were not enough to fuel the remaining polio virus-damaged, metabolically impaired neurons. And that's where protein at breakfast comes in.

Protein: The fuel that keeps on giving. Protein provides a long lasting, "slow-release" supply of blood sugar throughout the day. Polio survivors who had protein for breakfast reported less PPS symptoms because their fuel tank stayed full longer. They didn't need to "fill up" throughout the day with short-lasting sugar fixes, like soda or candy bars.

When we ask our post-polio patients to eat protein every day at breakfast and have small, non-carbohydrate snacks throughout the day, they report an almost immediate reduction in nearly all the symptoms of PPS, especially fatigue. But "protein power" diet is neither a fad nor a miracle: it's just common sense. No engine can be expected to run without gas.

And having protein at breakfast isn't good only for polio survivors. Mom was right: breakfast *is* the most important meal of the day for everyone, but especially for people with damaged or compromised nervous systems. Folk with MS (for whom low energy and fatigue can be disabling) those with ALS and Guillian-Barre Syndrome need to feed their damaged neurons first thing in the morning.



Those with spinal cord injuries, CP and spina bifida, who use more energy just getting showered and dressed than does a nondisabled person who runs a mile, also need protein early and often. It's a good idea to eat breakfast *before* showering to "break your fast" and fill your tank before your neurons need the fuel.

Our patients worry that using a wheelchair, resting more *and* having breakfast will cause them to get fat and have more PPS symptoms. A four year follow-up study found that U.S. and Swedish polio survivors, living their typical "use it or lose it" lifestyles without using new assistive devices or resting, lost equal amounts of leg muscle strength, about 2 percent per year. However,

when subjects from the two countries were looked at separately, the Swedes gained only 6 ounces per year, while the Americans gained over 2 pounds; that's 220 percent *more* weight!

Although weight gain alone is not responsible for the progression of muscle weakness in polio survivors, it is Americans' high fat, Big Mac diet that causes them to get fat. You can fuel your neurons; feel stronger and less fatigued without gaining weight, if you choose low fat, low cholesterol sources of protein. In fact many of our patients, even as they slow down, sit down more, and use a scooter, lose weight (about a pound per week) if they eat more protein, reduce portion size and limit carbohydrates.

We aren't recommending one of those "all protein, no carbohydrate" diets. We aren't recommending a "diet" at all, but a method for eating healthy every day. We suggest 16 grams of protein at breakfast; that's about 1/4 of the daily protein requirement (70 grams) for a 150-pound person. (Always check with your doctor, especially if you have kidney problems, before changing your diet and ask to have your cholesterol measured at your yearly check up.)

Look at the list of protein-rich foods and select different breakfasts so you can have a variety throughout the week. Remember, you want foods that have more grams of protein than they do fat. Eat well and be well.

PROTEIN-RICH FOODS:

You need 16 grams of low-fat protein at breakfast. Note: measures in grams.

Great: Protein Fat	Protein	Fat
Cottage Cheese (lite, 1 cup)	28.0	2.3
Salmon (3 ounces)	17.0	5.4
Yogurt (8 ounces)	12.0	4.0
Tofu	10.0	5.9

2% Milk (1 cup)	8.0	3.0
2 Egg Whites	6.8	0
Bagel	6.0	1.4
Egg Beaters (1/4 cup)	5.0	0

Higher Fat:

Swiss Cheese (1 ounce)	8.1	7.8
Slim Fast "Meal On-The-Go"	8.0	5.0
Lite 'n' Lively Cheese (1 ounce)	6.4	4.3
Hard Boiled Egg	6.1	5.6
Cream Cheese (Lite, 1 ounce)	2.9	4.7

Lower Protein:

Quaker Life	5.2	1.8
English Muffin	4.5	1.1
Oatmeal (1 package)	4.4	1.7
Cheerios (1 1/2 cups = 1 oz)	4.3	1.8
Shredded Wheat (1 ounce)	3.1	0.6
Total (1 cup)	2.8	0.6

Not Great:

Bacon (3 strips)	5.8	9.4
Egg McMuffin	17.0	32.0!
Peanut Butter (1Tbs)	4.6	8.2
Coffee?	0.1!	0

PROTEIN POWER BREAKFASTS:

12 minute breakfast:

2 hard boiled eggs (12 g) and an English Muffin (4.5 g)

8 minute breakfast:

3 scrambled egg whites (10g) and a bagel (6 g)

6 minute breakfast:

Toasted bagel (6 g), lite cream cheese (3 g) and 1 glass 2% milk (8 g)

4 minute breakfast:

Yogurt (12 g) & 1 oz. of low-fat cheese (6 g)

2 minute breakfast:

1/2 cup low-fat cottage cheese (14 g)

Source:

<http://www.postpolioinfo.com/library/prodiet.pdf>

PIANO LESSONS

TRUE STORY. . .

At the prodding of my friends, I am writing this story. My name is Mildred Honor. I am a former elementary school music teacher from Des Moines, Iowa.

I have always supplemented my income by teaching piano lessons... something I have done for over 30 years.

During those years, I found that children have many levels of musical ability; and even though I have never had the prodigy, I have taught some very talented students. However, I have also had my share of what I call 'Musically Challenged Pupils'.



One such pupil being Robby. Robby was 11 years old when his mother (a single mom) dropped him off for his first piano lesson.

I prefer that students (especially boys) begin at an earlier age, which I explained to Robby. But Robby said that it had always been his mother's dream to hear him play the piano, so I took him as a student.

At the end of each weekly lesson, he would always say, 'My mom's going to hear me play someday.' But to me, it seemed hopeless; he just did not have any inborn ability. I only knew his mother from a distance as she dropped Robby off or waited in her aged car to pick him up. She always waved and smiled, but never dropped in.

Then one day Robby stopped coming for his lessons. I thought about calling him, but assumed that because of his lack

of ability, he had decided to pursue something else. I was also glad that he had stopped coming. He was a bad advertisement for my teaching!

Several weeks later I mailed a recital flyer to the students' homes. To my surprise, Robby, (who had received a flyer), asked if he could be in the recital. I told him that the recital was for current pupils and that because he had dropped out, he really did not qualify.

He told me that his Mother had been sick and unable to take him to his piano lessons, but that he had been practicing. 'Please, Miss Honor, I've just got to play,' he insisted. I don't know what led me to allow him to play in the recital – perhaps it was his insistence or maybe something inside of me saying that it would be all right.

The night of the recital came and the high school gymnasium was packed with parents, relatives and friends. I put Robby last in the program, just before I was to come up and thank all the students and play a finishing piece. I thought that any damage he might do would come at the end of the program, and I could always salvage his poor performance through my 'Curtain Closer'.

Well, the recital went off without a hitch; the students had been practicing and it showed. Then Robby came up on the stage. His clothes were wrinkled, and his hair looked as though he had run an egg beater through it. 'Why wasn't he dressed up like the other students?' I thought. 'Why didn't his Mother at least make him comb his hair for this special night?'

Robby pulled out the piano bench, and I was surprised when he announced that he had chosen to play Mozart's Concerto No.21 in C Major. I was not prepared for what I heard next. His fingers were light on the keys, they even danced nimbly on the ivories. He went from pianissimo to fortissimo, from allegro to virtuoso; his suspended chords that Mozart demands were magnificent! Never had I heard Mozart played so well by anyone his age.

After six and a half minutes, he ended in a grand crescendo, and everyone was on their feet in wild applause!!! Overcome and in tears, I ran up on stage and put my arms around Robby in joy.

'I have never heard you play like that Robby, how did you do it?' Through the microphone Robby explained: 'Well, Miss Honor, remember I told you that my mom was sick? Well, she actually had cancer and passed away this morning. And well... she was born deaf, so tonight was the first time she had ever heard me play, and I wanted to make it special.'

There wasn't a dry eye in the house that evening. As people from Social Services led Robby from the stage to be placed into foster care, I noticed that even their eyes were red and puffy. I thought to myself then how much richer my life had been for taking Robby as my pupil.

No, I have never had a prodigy, but that night I became a prodigy ... of Robby. He was the teacher and I was the pupil; for he had taught me the meaning of perseverance and love and believing in yourself, and maybe even taking a chance on someone and you didn't know why.

Robby was killed years later in the senseless bombing of the Alfred P. Murrah

Federal Building in Oklahoma City in April, 1995.

So many seemingly trivial interactions between two people present us with a choice. Do we act with compassion or do we pass up that opportunity.

If God didn't have a purpose for us, we wouldn't be here! Live simply. Love generously. Care deeply. Speak kindly. Leave the rest to God.

Contributed via email, Bruce Sachs, MI, 3/5/17.



SHOE EXCHANGE 

'Newbie' member Anne wears right 4 M, left 6½ M & would love to find a home for her mismatched shoes. If you are the opposite & interested in her athletic Easy Spirit, Van Eli flats, Naturalizer flats, Mar K Lemp, low heels & a pair of black boots. Contact Anne – 954-434-0895 Cooper City, FL.

RED SKELTON'S RECIPE FOR THE PERFECT MARRIAGE

1. Two times a week we go to a nice restaurant, have a little beverage, good food and companionship. She goes on Tuesdays, I go on Fridays.



2. We also sleep in separate beds. Hers is in California and mine is in Texas.

3. I take my wife everywhere, but she keeps finding her way back

4. I asked my wife where she wanted to go for our anniversary. "Somewhere I haven't been in a long time!" she said. So I suggested the kitchen.

5. We always hold hands. If I let go, she shops.

6. She has an electric blender, electric toaster and electric bread maker. She said "There are too many gadgets, and no place to sit down!" So I bought her an electric chair.

7. My wife told me the car wasn't running well because there was water in the carburetor. I asked where the car was. She told me, "In the lake."

8. She got a mud pack and looked great for two days. Then the mud fell off.

9. She ran after the garbage truck, yelling, "Am I too late for the garbage?" The driver said, "No, jump in!".

10. Remember: Marriage is the number one cause of divorce.

11. I married Miss Right. I just didn't know her first name was 'Always'.

12. I haven't spoken to my wife in 18 months. I don't like to interrupt her.

13. The last fight was my fault when my wife asked, "What's on the TV?" I said, "Dust!"

Can't you just hear him say all of these?

These were the good old days when humor didn't have to start with a four-letter word. It was just clean and simple fun. And he always ended his programs with the words, "And May God Bless" with a big smile on his face.

Contributed via email, Jo Hayden, member, 3/12/18.



THE KEY TO WEIGHT LOSS IS DIET QUALITY, NOT QUANTITY, A NEW STUDY FINDS

By Anahad O'Connor

Anyone who has ever been on a diet knows that the standard prescription for weight loss is to reduce the amount of calories you consume. But a new study, published Tuesday in *JAMA*, may turn that advice on its head. It found that people who cut back on added sugar, refined grains and highly processed foods while concentrating on eating plenty of vegetables and whole foods

– without worrying about counting calories or limiting portion sizes – lost significant amounts of weight over the course of a year.

The strategy worked for people whether they followed diets that were mostly low in fat or mostly low in carbohydrates. And their success did not appear to be influenced by their genetics or their insulin-response to carbohydrates, a finding that casts doubt on the increasingly popular idea that different diets should be recommended to people based on their DNA makeup or on their tolerance for carbs or fat.

The research lends strong support to the notion that diet quality, not quantity, is what helps people lose and manage their weight most easily in the long run. It also suggests that health authorities should shift away from telling the public to obsess over calories and instead encourage Americans to avoid processed foods that are made with refined starches and added sugar, like bagels, white bread, refined flour and sugary snacks and beverages, said Dr. Dariush Mozaffarian, a cardiologist and dean of the Friedman School

of Nutrition Science and Policy at Tufts University.

“This is the road map to reducing the obesity epidemic in the United States,” said Dr. Mozaffarian, who was not involved in the new study. “It’s time for U.S. and other national policies to stop focusing on calories and calorie counting.”

The new research was published in *JAMA* and led by Christopher D. Gardner, the director of nutrition studies at the Stanford Prevention Research Center. It was a large and expensive trial, carried out on more than 600 people with \$8 million in funding from the National Institutes of Health, the Nutrition Science Initiative and other groups.

Dr. Gardner and his colleagues designed the study to compare how overweight and obese people would fare on low-carbohydrate and low-fat diets. But they also wanted to test the hypothesis – suggested by previous studies – that some people are predisposed to do better on one diet over the other depending on their genetics and their ability to metabolize carbs and fat. A growing number of services have capitalized on this idea by offering people personalized nutrition advice tailored to their genotypes.

The researchers recruited adults from the Bay Area and split them into two diet groups, which were called “healthy” low carb and “healthy” low fat. Members of both groups attended classes with dietitians where they were trained to eat nutrient-dense, minimally processed whole foods, cooked at home whenever possible.

Soft drinks, fruit juice, muffins, white rice and white bread are technically low in fat, for

example, but the low-fat group was told to avoid those things and eat foods like brown rice, barley, steel-cut oats, lentils, lean meats, low-fat dairy products, quinoa, fresh fruit and legumes. The low-carb group was trained to choose nutritious foods like olive oil, salmon, avocados, hard cheeses, vegetables, nut butters, nuts and seeds, and grass-fed and pasture-raised animal foods.

The participants were encouraged to meet the federal guidelines for physical activity but did not generally increase their exercise levels, Dr. Gardner said. In classes with the dietitians, most of the time was spent discussing food and behavioral strategies to support their dietary changes.



The new study stands apart from many previous weight-loss trials because it did not set extremely restrictive carbohydrate, fat or caloric limits on people and emphasized that they focus on eating whole or “real” foods – as much as they needed to avoid feeling hungry.

“The unique thing is that we didn’t ever set a number for them to follow,” Dr. Gardner said.

Of course, many dieters regain what they lose, and this study cannot establish whether participants will be able to sustain their new habits. While people on average lost a significant amount of weight in the study, there was also wide variability in both groups. Some people gained weight, and some lost as much as 50 to 60 pounds. Dr. Gardner said that the

people who lost the most weight reported that the study had “changed their relationship with food.” They no longer ate in their cars or in front of their television screens, and they were cooking more at home and sitting down to eat dinner with their families, for example.

“We really stressed to both groups again and again that we wanted them to eat high-quality foods,” Dr. Gardner said. “We told them all that we wanted them to minimize added sugar and refined grains and eat more vegetables and whole foods. We said, ‘Don’t go out and buy a low-fat brownie just because it says low fat. And those low-carb chips – don’t buy them, because they’re still chips and that’s gaming the system.’ ”

Dr. Gardner said many of the people in the study were surprised – and relieved – that they did not have to restrict or even think about calories.

“A couple weeks into the study people were asking when we were going to tell them how many calories to cut back on,” he said. “And months into the study they said, ‘Thank you! We’ve had to do that so many times in the past.’ ”

Calorie counting has long been ingrained in the prevailing nutrition and weight loss advice. The Centers for Disease Control and Prevention, for example, tells people who are trying to lose weight to “write down the foods you eat and the beverages you drink, plus the calories they have, each day,” while making an

effort to restrict the amount of calories they eat and increasing the amount of calories they burn through physical activity.

“Weight management is all about balancing the number of calories you take in with the number your body uses or burns off,” the agency says.

Yet the new study found that after one year of focusing on food quality, not calories, the two groups lost substantial amounts of weight. On average, the members of the low-carb group lost just over 13 pounds, while those in the low-fat group lost about 11.7 pounds. Both groups also saw improvements in other health markers, like reductions in their waist sizes, body fat, and blood sugar and blood pressure levels.

The researchers took DNA samples from each subject and analyzed a group of genetic variants that influence fat and carbohydrate metabolism. Ultimately the subjects’ genotypes did not appear to influence their responses to the diets.

The researchers also looked at whether people who secreted higher levels of insulin in response to carbohydrate intake – a barometer of insulin resistance – did better on the low-carb diet. Surprisingly, they did not, Dr. Gardner said, which was somewhat disappointing. “It would have been sweet to say we have a simple clinical test that will point out whether you’re insulin resistant or not and whether you should eat more or less carbs,” he added.

Dr. Walter Willett, chairman of the nutrition department at the Harvard T. H. Chan School of Public Health, said the study did not support a “precision medicine” approach to nutrition,

but that future studies would be likely to look at many other genetic factors that could be significant. He said the most important message of the study was that a “high quality diet” produced substantial weight loss and that the percentage of calories from fat or carbs did not matter, which is consistent with other studies, including many that show that eating healthy fats and carbs can help prevent heart disease, diabetes and other diseases.

“The bottom line: Diet quality is important for both weight control and long-term well-being,” he said.

Dr. Gardner said it is not that calories don’t matter. After all, both groups ultimately ended up consuming fewer calories on average by the end of the study, even though they were not conscious of it. The point is that they did this by focusing on nutritious whole foods that satisfied their hunger.

“I think one place we go wrong is telling people to figure out how many calories they eat and then telling them to cut back on 500 calories, which makes them miserable,” he said. “We really need to focus on that foundational diet, which is more vegetables, more whole foods, less added sugar and less refined grains.”

Source: <https://www.nytimes.com/2018/02/20/well/eat/counting-calories-weight-loss-diet-dieting-low-carb-low-fat.html?rref=collection%2Fissuerecollection%2Ftodays-new-york-times&action=click&contentCollection=todayspaper®ion=rank&module=package&version=highlights&contentPlacement=1&pgtype=collection>

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THE LAST OF THE IRON LUNGS

By Jennings Brown, 11/20/17

Part 1 of 2

Martha Lillard spends half of every day with her body encapsulated in a half-century old machine that forces her to breathe. Only her head sticks out of the end of the antique iron lung. On the other side, a motorized lever pulls the leather bellows, creating negative pressure that induces her lungs to suck in air.

In 2013, the Post-Polio Health International (PHI) organizations estimated that there were six to eight iron lung users in the United States. Now, PHI executive director Brian Tiburzi says he doesn't know anyone alive still using the negative-pressure ventilators. This fall, I met three polio survivors who depend on iron lungs. They are among the last few, possibly the last three.

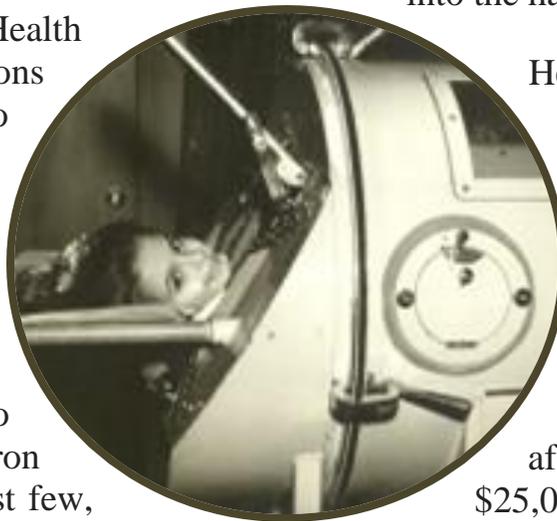
Their locations form a line that cuts directly through the heart of the country—one in Dallas, one outside Oklahoma City, and one in Kansas City, Missouri—what some call tornado alley.

The human battery

Storms have always been especially difficult for Lillard because if the iron lung loses power, she could die in her sleep. She lives alone, aside from three dogs and 20 geckos that she keeps in plastic terrariums filled with foliage and wool. “They like to sleep in the

fleece, wrapped up like a burrito,” she said as she introduced me to a few of her favorites.

Lillard sleeps in the iron lung, so it is in her bedroom. Even though the tank is a dull canary yellow it pops in the room, which is painted chartreuse—like the rest of the house, inside and out—and filled with toys and dolls that she has collected throughout her lifetime. On the walls hang a crucifix, a plush Pink Panther, and mirrors strategically placed so she can see around the room and into the hallway.



Her iron lung has portholes and windows on the side; a pressure gauge at the top. The machine is actually cobbled together from two iron lungs. One, the March of Dimes gave her when she was a child. The other, she bought from someone in Utah, after she haggled him down from \$25,000 to \$8,000. The body has also been modified over the years. Her grandfather invented a motorized pulley system that closes the bed tray into the tank after she climbs in. He also replaced the brushed aluminum mirror above the neck slot with a real mirror so that she could have a clear view to the rest of the room when she's locked in the canister. A local engineer used a motor from an old voter registration device to build a mechanism that tightens the collar around her neck after she slips her head through the portal. The fan belts and half-horsepower motor have been replaced about ten times.

“It seemed like forever because you weren’t breathing. You just laid there and you could feel your heart beating.”

When Lillard is outside of the tank, she can breathe using a positive-pressure ventilator, a smaller device that pushes air into her lungs. But that instrument doesn’t provide the same relief as when she puts her entire body into the 640-pound, 7-and-a-half-foot-long apparatus. Plus forcing air into the lungs can cause inflammation or damage the air sacs. When she’s sick, she can only heal if she spends full days in the iron lung. She calls herself “a human battery” because she has to recharge every day.

Lillard is 69, 4-foot-9 and weighs 98 pounds. Her back is arched from scoliosis. She didn’t get surgery when she was a child because doctors didn’t expect her to make it to her teenage years; and she never had an operation as an adult because polio survivors can stop breathing when they’re on anesthesia.

She was infected with polio at her 5th birthday party at the Joyland Amusement Park on June 8th, 1953. Nine days later, her neck ached so bad she couldn’t raise her head off the pillow. Her parents said it was probably just a summer cold, but Lillard could tell they were afraid. They took her in for a spinal tap, which confirmed it was polio.

Lillard asked me to take out a photo album so she could show me snapshots of her youth as she sat on a blanket on the floor of her living room, where it’s more comfortable for her to sit when she’s out of the machine. “I wanted to be a ballerina. That was my big wish. I

started walking on my toes when I was one, and I just constantly was after ballerina dolls. We didn’t have a dance school in town until I was five, and my mom was going to enroll me that year, but I got sick,” she told me. “I think now of my life as a ballet. I have to balance so many things. It’s a phenomenal amount of energy I have to use to coordinate everything in my life.”

Polio is a silver bullet

“All the mothers were just terrified because people were just getting it right and left,” Lillard said. “They didn’t know if it was a virus or bacteria or how you caught it.”

Poliomyelitis is a highly contagious disease that can cause paralysis of legs, arms, and respiratory muscles. “The polio virus is a silver bullet designed to kill specific parts of the brain,” Richard Bruno, a clinical psychophysicologist, and director of the International Centre for Polio Education said. “But parents today have no idea what polio was like, so it’s hard to convince somebody that lives are at risk if they don’t vaccinate.”

When Lillard was a child, polio was every parent’s worst nightmare. The worst polio outbreak year in US history took place in 1952, a year before Lillard was infected. There were about 58,000 reported cases. Out of all the cases, 21,269 were paralyzed and 3,145 died. “They closed theaters, swimming pools, families would keep their kids away from other kids because of the fear of transmission,” Bruno said.

Children under the age of five are especially susceptible. In the 1940s and 1950s, hospitals across the country were filled with rows of

iron lungs that kept victims alive. Lillard recalls being in rooms packed with metal tubes – especially when there were storms and all the men, women, adults, and children would be moved to the same room so nurses could manually operate the iron lungs if the power went out. “The period of time that it took the nurse to get out of the chair, it seemed like forever because you weren’t breathing,” Lillard said. “You just laid there and you could feel your heart beating and it was just terrifying. The only noise that you can make when you can’t breathe is clicking your tongue. And that whole dark room just sounded like a big room full of chickens just cluck-cluck-clucking. All the nurses were saying, ‘Just a second, you’ll be breathing in just a second.’”

In 1955, Americans finally had access to the polio vaccine developed by Jonas Salk. “It was hailed as a medical miracle, and the excitement about it was really unparalleled as far as health history in the United States,” Jay Wenger, director of the Bill & Melinda Gates Foundation’s polio-eradication effort told me. “No one who remembers the 1950s, in terms of polio, wants to go back there and be in that situation again.”

By 1961, there were only 161 reported cases in the US. But in 1988, there were still an estimated 350,000 cases worldwide. That year, the World Health Organization, UNICEF, and Rotary International began an aggressive campaign to end polio everywhere. Last year there were 37 cases reported in Afghanistan, Nigeria, and Pakistan.

According to Bruno, if an infected person in either of those countries visited family in an

area like Orange County, California, where many parents are opting out of vaccinating their children, “then we could be talking about the definition of a polio epidemic.”

Wenger said that’s why the Gates Foundation recently joined the other organizations in the global effort to eradicate polio. “If there’s a virus anywhere in the world, it could just come back in,” Wenger said. “Some little kid could get on a plane and fly in and reinfect an area. And if the kids in that area are not vaccinated, you could start the virus circulating again.”

But even though the last wild case of polio in the US was in 1979, it still haunts this country. “A lot of people think of polio as a disease of the past and don’t realize there are people here today that are still suffering the effects of polio.” said Brian Tiburzi, executive director of Post-Polio Health International (PHI), an advocacy group for the estimated 350,000 to 500,000 polio survivors living in the US.

“If there’s a virus anywhere in the world, it could just come back in.”

Some polio survivors were only partially impaired or got better. For instance, Mia Farrow only had to spend eight months in an iron lung when she was nine, before going on to become a famous actress and polio advocate. And golfer Jack Nicklaus had symptoms for two weeks as a child, but as an adult only had sore joints.

But many polio victims have breathing difficulties for the rest of their lives, or have issues later in life when overworked neurons burn out, a condition called post-polio

syndrome. “I breathe 20 percent of what you breathe with every breath,” Lillard explained to me. “You still have the neurons that work the muscles that you breathe with.” Let it breathe for you.

Lillard offered to let me try out her iron lung about an hour after I met her. She showed me how to operate the ad hoc mechanisms that would lock me into the tank and tighten the collar around my neck like a camera shutter – tight enough that no air can escape, but loose enough that I don’t choke myself.

I climbed into the bed tray, slipped my head through the hole, tightened the collar, then flipped the switch that controls the pulley that closes the tray into the main canister. As the system locked me in, I had a quick wave of claustrophobic panic and my instinct was to take deep breaths, but a motor was controlling that. I tried to describe the feeling to Lillard, but the machine was inhaling for me, so no sound came out. I had to wait a moment for the release.

“Let the air out of your lungs and let it breathe for you,” Lillard said. “Imagine if you were real tired of breathing, how good that would feel – if you were struggling to take a breath.”

Being in an iron lung was the most relief and discomfort I have ever felt at the same time. I slowly got used to the mechanical rhythm and began feeling a little relaxed. I tried

closing my mouth, and air still rushed in through my lips. I felt like a vacuum cleaner.

As I climbed out, Lillard warned me to be careful and not break any of the switches or pulleys. If I damaged anything, and she wasn’t able to get someone to repair it within a few hours, she might not have made it



through the night. A few weeks earlier, the collar-opener broke and she was trapped inside. Fortunately, her housekeeper was there to help her force it open, and a friend who does custom metal fabrication for motorcycles, planes, and other machines, Tony Baustert, came a few

hours later to repair it.

Recently, an ice storm knocked her power out for three days and the generator malfunctioned. The fire department came over but they wouldn’t run a power line from down the street or provide a temporary generator, Lillard said. Fortunately, one of the firefighters came by when he was off-duty and fixed the generator. During the panic, Lillard thought about Dianne Odell, a polio survivor who died in her iron lung in Memphis in 2008, after she lost power during a storm. Her father and brother-in-law took turns pumping the bellows by hand but couldn’t sustain the rhythm long enough to keep her alive.

Understandably, Lillard lives in a constant state of anxiety over the functionality of her iron lung. But she said the company

responsible for servicing the device, Philips Respironics, hasn't been much help. She recalls one time when a repair person disassembled the machine to make a repair, then tried to leave before putting it back together. Another technician took it apart and couldn't figure out how to fix it, so Lillard had to call another mechanically skilled friend, Jerry House, to help.

These days her biggest concern is the canvas spiral collar that creates the seal around her neck. She used to have to replace them every few months after they wore out and stopped keeping a seal. Back then she could get them for a few dollars each, but she recently bought two from Respironics for a little more than \$200 each. She said the company wouldn't sell her anymore because they only have ten left. For years she's been trying to find someone to make a new collar. She uses Scotch guard on her current supply and tries not to move her neck around, hoping to make them last as long as possible.

I asked her what happens if she runs out. "Well, I die," she said, in a matter-of-fact tone.

Iron lungs became the responsibility of Philips through mergers and acquisitions. The March of Dimes supplied and serviced iron lungs until the end of the '60s, around the same time the J.H. Emerson Company stopped manufacturing the product. Once Salk's vaccine diminished the need for polio support and advocacy, March of Dimes handed off iron lung responsibilities to Lifecare Services. Medical supply company Respironics acquired Lifecare in 1996, then merged with Philips in 2007.

Over the years, Lifecare and Respironics have tried to get more polio survivors to use alternative breathing aids – devices that were newer, cheaper, easier to service, and didn't require parts that were no longer manufactured. In 2004, Respironics gave iron lung users three options: transition to another ventilator device, keep using the iron lung but know that Respironics may not be able to repair the device, or accept full ownership and responsibility of the iron lung and find someone else to repair it. According to Post-Polio Health International, responses "ranged from 'it is understandable that repairing a device made that long ago would be difficult' to 'a multi-million dollar company should be able to just make parts.'"

Philips Respironics denied multiple requests to comment for this story. But polio advocates believe the company can do more to help polio survivors who have struggled with the effects of polio their entire lives.

"It would be helpful if the people who are contractually responsible and morally and ethically responsible for polio survivors did something to help these people," said International Centre for Polio Education director Richard Bruno. "It would be like if you bought a used car, you drove it a block and the car stopped working. Then you go back to the car dealer and you say, 'Hey, the car stopped working.' And they say, 'Well too bad, you bought it and that's the way life goes.' Except instead of a car it's a machine that you need to live."

Source:
https://l.facebook.com/l.php?u=https%3A%2F%2Fgizmodo.com%2Fthe-last-of-the-iron-lungs-1819079169&h=ATO1sAUQN5NweW5tRiNnXdzuW1e0gI2tIRbsESo_yq2y3WbYnXmuRkRyqM7aiQKDHv0Ifq9VrL3M_UpGa7KsgXNOpLGm0l7vX1bg1bG7ydwRKG4bAoVbhW6kL9PGZpCx10&s=1&enc=AZOdb7csK4vjHJl-qt2OmpadNBJ4BG97RpX35bgN-F29cXywulBLer4xSUHlsqaDc468s3XZ34jRFTbuulSnk1d

Posted on FaceBook by Jo Caywood, GA, 11/21/17.

HOW UP-TO-DATE ARE YOUR “HEART SMARTS”?

Medical knowledge is constantly evolving. What was once common wisdom is changed or even turned upside down by new research. When you act on dated information, you could be putting your heart at risk.

How savvy are you?

True or False...

1. A heart attack feels like an elephant on your chest.

It's TRUE for many people. But at least one-third of heart attack victims have atypical chest pain – or none at all. They may have back pain, extreme fatigue, or a feeling of indigestion.

2. Everyone over 50 should take a daily baby aspirin.

Not so fast! For people with coronary artery disease, daily aspirin helps prevent clotting and heart attacks. But if you don't have heart disease, the danger of serious bleeding outweighs the potential benefits.

3. Women don't get heart disease as much as men.

FALSE. In fact, heart disease is the leading cause of death for women of all ages – the same as it is for men. So being proactive about your heart health is a great project to share with your spouse.

4. Exercise is risky if you have heart disease.

FALSE. Exercise is essential for all of us...and it has the special benefits for heart patients. A mere 30 minutes a day of brisk walking can lower your blood pressure, im-

prove cholesterol levels, help control your weight, and much more.

5. The healthiest heart diet is ultra-low fat.

Good news! You actually need some fats in your diet. Just make sure you're eating the healthy kind – found in olive and canola oils, avocado, fish, flaxseed, and some nuts.

Reprinted from *Cleveland Clinic Heart Advisor*, OCTOBER 2017.

Contributed by Jane McMillen, Member

TAKE A FEW CLEANSING BREATHS

By Judith Orloff, MD

“I stress to my friends how important it is to create your own positive, protective bubble against the world to maximize your energy. In order to feel physically and mentally powerful throughout your day, you need to replenish yourself constantly. A great way to do this: Sit quietly for a few minutes. Now take a deep breath in for a count of six, and let it back out for a count of six. Repeat this for a total of six cycles. This exercise will quickly reduce levels of the stress hormone cortisol in your body. Plus, it produces endorphins, which, as you know, make you feel happy and energized. It's a great way to reboot! One night I was totally exhausted, but I had to speak at an event before hundreds of people on my book tour. I did this breathing exercise, it replenished my energy, and I was able to speak clearly and really enjoy the evening.”



Reprinted from *Redbookmag.com*, July/August 2017.

Contributed by Jane McMillen, member.



COMMENTS

Barbara Davis, Boynton Beach, FL: Your newsletter gets more interesting with each edition. Mainly because you have come closer to what I need that helps me the most and thank you very much. I had Polio at age 21; did work for years; but it gives me a lot of trouble now.

Alice Handal Baeza, Davie, FL: Will definitely join one of your meetings! Informative website! Thank you for all you do.

Alfred Gorlick, Boynton Beach, FL: Great article: Exercise: Use It or Lose It. Very informative. Thanks.

Doris Austerberry, Farmington Hills, MI: Thank you for the July Newsletter. I'm amazed that even though you don't have meetings in the summer, you and your wonderful, dedicated staff continue to write and distribute very interesting and helpful and fun newsletters! Regarding how much physical activity we PPS people should do, I think it's strictly an individual decision, and subject to challenge and innovation to change one's routine. Happy Summer to you!

Marilyn, Rowan, Clifton, NJ: Loved reading this [July] month's newsletter.

Meenu Khanna, Toronto, Canada: Thank you Eddie [Rice] for sharing this newsletter. There was tons of useful information.

SUCCESS

At age 4 success is not piddling in your pants.

At age 12 success is having friends.

At age 17 success is having a driver's license.

At age 35 success is having money.

At age 50 success is having money.

At age 70 success is having a driver's license.

At age 75 success is having friends.

At age 80 success is not piddling in your pants.

Contributed via email, Nancy Saylor, member, 8/5/17.



MARK YOUR CALENDAR

Colorado Post-Polio 2018 Rocky Mountain Getaway, Sunday, August 19-23, Rocky Mountain Village Camp, Empire, CO. Contact Nancy Hanson, 303-233-1666, x237 or nhanson@eastersealscolorado.org

Bay Cliff Post-Polio 2018 Wellness Retreat, September 10-15, Big Bay, MI. Christy 906-345-9314 or www.baycliff.org/bay-cliffs-post-polio-wellness-retreat.

Ohio Polio Network will host a one-day conference, Sat., September 15, 2018, Tuscora Park, New Philadelphia, OH. For info contact Brenda 330-671-7103 or jdbafergie@aol.com.

Polio Australia will host *Polio Health and Wellness Retreat – Body, Mind & Spirit* for polio survivors/family members, Thursday, October 11 - 14, 2018, Stamford Grand, Glenelg, South Australia. Email – office@polioaustralia.org.au.

MISSION STATEMENT

- To help polio survivors become aware that they are not alone and forgotten.
- To share our thoughts and feelings with others like ourselves.
- To network with other support groups.
- To share information and encourage each other to carry on.
- To educate the medical profession in diagnosing and treating Post Polio Syndrome.
- To always maintain a positive attitude.

Boca Area Post Polio Group collects no dues and relies on your donations. If you would like to make a contribution, please make your check payable to **BAPPG**.

Thank you for your support!

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Flattery will get you everywhere!
Just give us credit:
Second Time Around, Date
Boca Area Post Polio Group, FL



SPREAD THE WORD. We would love to hear from you. If you know of someone who would like to receive our newsletter, send us the information below and we will gladly add them to our growing mailing list.

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11:30 – 1:30 PM

Second **Thursday** of each month

Except June, July, August & September

Spanish River Church

2400 NW 51 Street, Boca Raton
(corner of Yamato Rd. & St. Andrews Blvd.)

Sunset Room of Worship Center
Entrance and parking on west side

E-mail: bappg@aol.com

Website: www.postpolio.wordpress.com

Printing: **R & C Mgmt., Inc., Miami, FL**

BOCA AREA POST POLIO GROUP

A Ministry of Spanish River Church

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