Greetings from beautiful Yuba City. As this is written (mid-May), Leslie is hospitalized for some surgery and unable to write his column. We wish him the best and a quick recovery.

Our June 2 meeting will start at 1 p.m. at our usual meeting place, Brookfield’s Restaurant, on Madison Avenue and Interstate 80. We talked extensively at our March meeting about changing to another location that would provide us with better parking and access along with a quieter setting. Rhonda Tonkin has been working the phones and various contacts but the process has been frustrating and slow and we don’t yet have a new meeting site. We would welcome your suggestions along with contact information at the June meeting.

Speaking of the June meeting, be sure to bring your questions about Medicare as our speaker will be Carol Washington, a specialist from HICAP. The non-profit organization, part of Legal Services of Northern California, provides free information to help guide you through the intricacies of parts A, B and D. Vivian and I have used HICAP resources a couple times to sort things out and they are helpful. Read more about Carol and HICAP on Page 6 of this newsletter.

Our polio survivor profile this edition is on The Rev. Wil Nuckolls, host of our group for 15 years at the Fairvale Baptist Church, a church he founded after moving himself and his

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Ideas and suggestions printed within this newsletter are those of the individual writers and should not be considered “Medical Opinions or Advice.” Please consult your primary care physician for your health issues.

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Doctor’s listed here are for information only. Please continue to see your own primary care physician (PCP) for polio and all other health issues.

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**MISSION STATEMENT**

To provide emotional support; educate and distribute information to polio survivors, their families and the general public; and help persons afflicted by polio.

To provide information to unknowing survivors and to the medical community regarding post-polio syndrome.

Provide if possible financial support to polio survivors that are within our geographic region and membership, when specifically agreed to by a majority vote of the Board.

We may seek to collaborate with other nonprofit organizations which fall under the 501 (c) (3) section of the Internal Revenue Code and are operated exclusively for education and charitable purposes.

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**From the Editor...continued from page 1**

family from Oklahoma. I think you’ll find it interesting.

We would like to feature your story in a profile. It’s not difficult and you don’t have to be a writer. All we need is a few pictures and a few paragraphs of your journey through your life and polio adventures. See me at the meeting for more.

By the way, if there is a topic you’d like to see covered in the newsletter, let me know. The story on Page 5 of this issue, *Polio Above the Neck*, came from such a request.

That’s all for now. I’m looking forward to seeing you on June 2 at Brookfield’s.

- Larry

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Editor’s note

“Who Are You” is the popular theme song for the television series “CSI.” It’s a question we often find ourselves asking ourselves at SRPSG meetings.

Getting together monthly in the past and quarterly now, we don’t have a lot of opportunity to find out about that person sitting across from us or next to us at the meeting table. It is my hope we can answer that question to a degree with this column. Each quarter we will feature a short biographical sketch and a photo or two of a SRPSG member. You don’t have to be a writer to participate. Simply write down a little background on yourself and send it to lbadger@badsound.com along with a couple of photos and we’ll take care of the rest.

Who Are You? A Polio Survivor profile

The Reverend

Wil Nuckolls

Raised on the Oklahoma prairie

Wil Nuckolls remembers a visit from his younger brother, Charles, when he was just 18 as a “providential act of God.”

“It was a summer session at Oklahoma Baptist University in Shawnee, just east of Oklahoma City,” Wil said. “I had caught a cold and ran a fever. I said I would doctor myself but Charles said ‘No. You’re going to have a doctor look at you.’”

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Who Are You?... continued from page 3

home with me. It was a Saturday afternoon. I was tired and didn’t argue.

“Sunday morning ‘macho me’ would be okay.”

But he wasn’t okay. He was hit by violent muscle spasms and couldn’t keep his hands and arms still at the breakfast table.

“My dad took me to the hospital,” Wil recalls. “A spinal tap was made and an ambulance drove me and Dad 80 miles to St. Benedictine Heights Hospital in Guthrie.

“I don’t remember getting into or out of the ambulance or being placed in isolation on the fifth floor. Was this the end of me? How crippled would I become?”

Wil grew up in Ponca City, Okla., home of Conoco Oil, its refinery and the largest oil tank farm in the world. He had always been active in school, his church and the Boy Scouts.

Life in the prairie hamlet was punctuated in his younger years by World War II.

“I was caught up in it,” he recalls. “I played, talked, read or sang war songs.

Searchlights pierced the nighttime skies over the 20,000-resident town as the civil air patrol kept watch over the refinery and oil storage tanks. Troops aboard special trains waved as they sped through town; British airmen began training at a local airfield; and blackout drills became regular events.

Wil funneled his hard-earned dimes into buying war bonds, collected tin cans and scrap iron for the war effort and helped out in the family’s backyard Victory garden.

“There was always prayer at Second Baptist Church for our members’ relatives in the war and an update on their location,” he said.

In contrast to his vivid memories of the war in his home town were those of his second wife, Valia. She was living in Paraguay, South America, at the time and there was no radio there. The war wasn’t mentioned in her home.

Wil said he started working once he turned 12. He bought his own clothes and at 16, first car, a 1934 Ford Coupe.

When he was stricken with polio at age 18, he was a freshman at Oklahoma Baptist University, was president of the Freshman class and worked part-time at Roesch Bros. Mortuary in downtown Shawnee.

“College wasn’t much different than what I’d already spent my life doing — until I was suddenly stopped and not even given a chance to tell anybody where, what or how,” he said.

During his month-long stay at St. Benedictine Heights Hospital, Sister Alice would come to his bedside twice daily with a pressure steam kettle and, with tongs, would pull out pieces of brown woolen army blankets and wrap them onto his body.

He eventually began practicing lifting a pencil and after a month, he was moved to the Crippled Children’s Hospital in Oklahoma City where he spent another month learning to lift a one-pound weight.

Sent home wearing an arm brace and with a regime of physical exercises, he found himself reentering the mainstream of Society. But a number of unforgettables stayed with him.

“My girlfriend, Darla, who I had dated since she was 12 and I was 15, came with my parents once a week to see me at the hospital. They stood outside, five floors below my window, waved and for a few minutes lifted my spirits as we got to see each other.” He and Darla eventually married.

“At 18, being the oldest child at the Crippled Children’s Hospital, I became a natural confidante (I had been preaching, ministering, since I was 17). Two five-year olds in braces and wheelchairs — a boy and a girl — told me as they held hands going into our dining area, We’re going to get married. Their smiles and positive attitude are unforgettable.”

It was a year before Wil returned to Oklahoma Baptist. He was 21 when he graduated, was ordained and married his girlfriend, Darla — the same day.

Four years later he was in the panhandle region of Oklahoma, preaching on weekends and working another job during the week when he gathered up his wife and six-month old daughter and moved to California. It was there, along a two-lane Madison Avenue east of Sacramento, that he started the Fairvale Baptist Church.

In his 49 years at the church, he and Darla raised two-daughters and a son. After Darla died, he married Valia.

Continued on page 5
The Sacramento Regional Polio Survivors group was founded at the church which hosted its monthly potluck meetings for 15 years.

The after effects of the polio live on mostly in Wil’s arms and his ability to swallow, he said. “My arms, when extended, can’t hold a hymnal or my Bible. So when I fill in for another minister, I lay those flat on the pulpit.”

Who Are You?... continued from page 4

The Sacramento Regional Polio Survivors group was founded at the church which hosted its monthly potluck meetings for 15 years.

This report focuses on the problems of bulbar polio and other problems that are now manifested in people who have PPS. The cause of these problems is polio damage that occurred in the upper cervical spine and upward. Bulbar is defined as polio involvement of the motor nerves in the brainstem.

Early Studies

Polio autopsy reports following the epidemics of the 1940s and 1950s showed signs of acute polio infection throughout the body; it was not just restricted to the spinal cord. There were changes found in upper motor neuron pathways and there were changes found in central brain structures that control alertness, central fatigue, and autonomic functions such as temperature regulation, etc. There were also many changes seen in the brainstem itself.

Probably greater than 90 percent of a polio survivor’s motor neurons were affected to some degree during the acute stage and had some damage, even if not paralytic. Autopsy studies have shown that during the acute attack as few as 3 to 4 percent of the motor neurons remained intact.

Continued on page 6
Our June speaker

Bring your questions about the maze of Medicare

What does it take to navigate through the maze of paperwork, health care decisions and Medicare paperwork?

Carol Washington, Education and Outreach Coordinator for HICAP (Health Insurance Counseling and Advocacy Program), will be our guest speaker at the June Sacramento Region Polio Survivors meeting.

HICAP is a program of Legal Services of Northern California, a non-profit organization that provides free unbiased information to help Medicare beneficiaries and those with disabilities, understand Medicare and decide what’s best for their individual healthcare insurance needs. The program is volunteer supported, and is part of the National SHIP program (State Health Insurance Assistance Program). It serves nine Northern California counties: Sacramento, San Joaquin, El Dorado, Placer, Nevada, Sierra, Sutter, Yolo and Yuba.

HICAP counseling and community education presentations provide Medicare beneficiaries and interested persons with professional and quality Medicare information and resources through one-on-one counseling and educational presentations.

Washington has spent 25 years in the nonprofit sector developing skills to educate individuals on how to skillfully create and implement a plan to live and thrive in their Golden Years.

Her topics include all things related to Medicare. For example; Medicare enrollment and special enrollment periods, Medicare coverage and options, original Medicare (Part A,B,D, & Medigap plans), Medicare Advantage, and one very important topic, Medicare fraud and abuse.

Above the Neck...continued from page 5

There are not many polio survivors seen now who had severe residual effects from the acute bulbar polio infection. This is probably because when there is a 50 percent loss of the motor neurons that control breathing or swallowing, a person is going to be in serious trouble. Many did not survive the acute infection.

“Those who survived severe bulbar polio truly are survivors,” said Dr. Perlman.

Respiratory Problems

People who had true bulbar polio had involvement in areas of the brainstem that trigger breathing. They needed to be assisted until those centers came back. There are some people who had only mild breathing weakness with the original polio (chest wall weakness or a little diaphragmatic weakness), but their breathing centers in the brainstem were actually intact. So, when looking at post-polio breathing problems we should include people who had primarily muscular manifestations as well as with those who had bulbar polio.

In other parts of the body, such as arms and legs, surviving motor neurons remodeled and adopted the injured or orphaned ones in order to take over function. However this was not as common in the brain and brainstem. Since the brainstem has less plasticity and flexibility, it was harder for remodeling to occur to the nerves of the pharyngeal muscles and to those of the upper part of the esophagus. For years many survivors have been using compensatory strategies, such as swallowing on one side of their throat. Those who had residual problems, such as vocal cord paralysis, may also have been able to compensate for this.

But when the muscles on the “good” side of their throat begin to weaken, they become aware of a “new” problem in that area.

Muscles that control breathing and swallowing are the same groups of muscles that are involved with speech, to some extent. These groups of muscles are

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located in the throat. So people with PPS who are having problems with swallowing, breathing, or shortness of breath during activities of daily living, might also complain of speech problems. Although facial, jaw, and throat muscles are controlled in the brain stem, they have rarely been thought of in connection with polio.

Are people who had bulbar polio going to be having increasing bulbar dysfunction?

The following criteria are used to determine increasing bulbar problems:

* Severity of residual disability
* Residual bulbar or respiratory signs
* Later age at onset of acute polio (past age 10)
* (Possibly) recent falls or injuries; or surgical procedures in the pharyngeal area; or weight gain, because it puts more pressure on the diaphragm and pharyngeal area.

Fortunately, our bodies have several safety factors to assure that breathing muscles meet our oxygen and carbon dioxide demands. The primary muscle for breathing is the diaphragm and the secondary breathing muscles are the external intercostals (the muscles between the ribs). So if a person has a fatigable diaphragm that tires out by the end of the day, the intercostals will kick in and the person will begin breathing from the chest. There are also accessory respiratory muscles that help lift the chest from the shoulders.

With post-polio breathing problems, part of the problem is going to be muscular. There may be a diaphragm or secondary assistive muscles not kicking in as well as they should. There can also be central (brain) changes contributing to this, such as decreased respiratory drive, if those centers were affected originally. There may be changes in the chemo-receptors: perhaps the sensors are not sensing carbon dioxide (CO2) buildup as sensitively as before.

Scoliosis can also cause restriction of breathing. A person who has a scoliotic spine cannot expand his chest as well so he underbreathes because of it. If scoliosis is getting worse as a post-polio symptom, it’s going to make that aspect worse and will interfere with breathing.

When doctors are looking at respiratory problems of PPS patients, they should look at not only peripheral problems and muscular problems, but also central dis-

regulation of breathing as well.

Recent Findings

Dr. Perlman cited a report (“Epidemiology of the Post-Polio Syndrome” by J. Ramlow, et al. American Journal of Epidemiology, October 1, 1992) that involved 77 subjects with non-paralytic polio and 474 subjects with paralytic polio. A change in breathing was observed in 10 percent of the non-paralytic subjects and in 12 percent of the paralytic ones. Swallowing problems were noted in 6 percent of the non-paralytic subjects and in 7 percent of the paralytic ones.

In the larger ongoing studies at polio centers such as Mayo Clinic, Rancho Los Amigos, and centers in Canada, possibly as many as 40 percent of the people with PPS are having new respiratory complaints.

About 80 percent of PPS patients complain about fatigue.

Another study of 74 polio survivors who were having shortness of breath found two good measuring devices for patients with increasing respiratory problems:

Forced expiration (a pulmonary function test) can be a very helpful monitor. This test shows how hard it is for a person with PPS to breathe out and it requires the use of some of the intercostal muscles and the abdominal muscles. Dr. Perlman recommends this test every year or so for her patients who have significant breathing complaints.

Monitoring CO2 levels in the blood is another good measuring device. The question is not how much oxygen is a person inhaling, but how much CO2 is a person retaining? Is a patient not breathing fast enough? Is the person fatiguing so that he cannot ventilate? It is the amount of ventilation a person gets that clears the CO2. So if you are ventilating less efficiently, your CO2 levels are going to go up slowly.

For patients at risk, these researchers felt that anything that was in danger of happening could be detected by measuring maximum expiratory pressure and carbon dioxide levels on a regular basis.

Swedish research on cardio-respiratory parameters in PPS patients found a significant incidence of deconditioning. This goes back to the old thought that everybody should be doing some exercise. Dr. Perlman says doctors are no longer saying people with PPS should do no exercise; some exercise, conditioning or aerobic exercise, is important. Survivors can improve
Above the Neck…continued from page 7

heart function, circulation, and breathing to some extent by doing something that increases the heart rate. These researchers suggested increasing the heart rate to 70 percent of maximum by using a pool or other equipment. They felt these were tolerable levels for their PPS patients.

Researchers in Toronto looked at 3 areas of muscles, (respiratory, diaphragm, chest wall), bulbar symptoms, the control rate, and scoliosis. They found that the control panel in the brainstem was the least important of the group. These people were having problems because of the diaphragm, chest wall fatigue, or due to progressing scoliosis.

A few of Dr. Perlman’s patients have experienced increased breathing problems at higher altitudes. Adjustments can be made so those patients can travel at higher altitudes and not feel short of breath all the time.

Swallowing

The motor neurons that control swallowing are located in the brainstem. In order to have an effective swallow, groups of muscles are used to insure that the food is chewed, forms into a bolus, and goes down properly. The swallowing center coordinates other activities related to swallowing: chewing, licking, gagging, coughing, sneezing, vomiting, belching, and breathing to some extent (when a person is swallowing, he doesn’t breathe). It is hard to eat or swallow at the same time as breathing, because the two groups of muscles and nerves are competing against each other.

There are at least a dozen places in the body where a post-polio patient who had some pharyngeal problems or brainstem related swallowing problems could begin to have trouble now with swallowing – either in the steps or in the sequence of swallowing. For example, people who have weakness in the jaw muscle as a complication of PPS will find it hard to chew when fatigued. Or people who have a weak soft palate will find that food is slipping into their throat before it is fully chewed, and food or drink - especially drink - may be coming out their nose.

Swallowing problems have been identified in recent studies. However it is rare to see a PPS patient who is having constant choking. Most people can think about it and use their conscious mind to control what is going on, thereby preventing swallowing problems from occurring. Any part of the gastro-intestinal tract - from the mouth all the way to the bottom - could be slowed, weakened, or not working properly due to PPS. But don’t assume that every symptom a polio survivor gets is due to PPS.

Although common pathways are used for breathing and swallowing, not everyone who has swallowing problems has breathing problems and not everyone who has breathing problems has swallowing problems. Bulbar muscles can slowly dysfunction and there can be silent swallowing problems. In a 1991 swallowing study by Dalakas he concluded “…in bulbar neurons there is a slowly progressive deterioration similar to that in the muscles of the limbs.”

Blood Pressure and/or Variable Heart Rate

Can high or low blood pressure be a result of polio and PPS?

Can variable pulse rate be made worse, not because of heart disease, but because of post-polio symptoms affecting the area?

The average internist may be hard pressed to believe it possible for polio to be related to current blood pressure or pulse rate problems. However, vaso-motor centers that control blood pressure and pulse rate are located in the medulla (in the lower brainstem) and also in the autonomic area of the brain. Since polio damage has been seen in the brain and in the brainstem, this is an area that needs further study.

As we understand what was involved in acute polio and the amount of brain that was involved, recovered motor neurons that might have looked quite complete on the surface could actually be functioning on very shaky ground. “The majority of motor neurons, in whatever region the poliovirus got to, were probably affected in some way or another,” said Dr. Perlman.

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Please submit your request to: RanchoPoli-oGroup@hotmail.com - or send it to 12720 La Reina Ave., Downey CA 90242
Word finding difficulty in post-polio patients

Of all Post-Polio Sequelae, fatigue is the most commonly reported and most debilitating symptom. In the 1985 National Post-Polio Survey, 91 percent of respondents reported new or increased fatigue, 41 percent reported fatigue interfering with performing or completing their work and 25 percent reported fatigue interfering with self-care activities. Importantly, polio survivors differentiate between physical tiredness and what they describe as "brain fatigue" associated with thinking difficulties. In the 1990 National Post-Polio Survey, between 70 percent and 96 percent of respondents with fatigue reported difficulty with concentration, focusing attention, mind wandering, memory, thinking clearly and word-finding, with 77 percent reporting moderate to severe difficulty with these problems. Of these cognitive symptoms, word finding difficulty was least expected. Of all polio survivors surveyed, 79 percent reported difficulty "thinking of words I want to say," with 37 percent reporting frequent, moderate to severe word finding difficulty. Further, the frequency and severity of word finding difficulty were significantly correlated with all of the other subjective cognitive difficulties listed above.

We studied 33 polio survivors and administered the Post-Polio Fatigue Questionnaire, Animal Naming and FAS Tests, plus tests of attention and information processing speed. Plasma prolactin was also measured as a marker for brain dopamine secretion since, as prolactin increases in the brain, dopamine decreases:

1) Subjects reporting high fatigue severity and word finding difficulty had clinically abnormal or significantly lower Animal Naming Test scores as compared to subjects with low symptom severity;

2) Impaired performance on the most difficult tests of attention and information processing speed were also associated with lower scores on the word finding tests;

3) A significant inverse relationship between Animal Naming Test scores and plasma prolactin suggests that a reduction in brain dopamine secretion is related to reduced animal naming ability. These data support the hypothesis that decreased dopamine secretion, possibly secondary to poliovirus damage to the basal ganglia, may underlie not only fatigue and impaired attention but also word finding difficulty in polio survivors.

Clinically, polio survivors report a "tip-of-the-tongue" phenomenon characterized by difficulty naming familiar objects and people (sometimes even family members), difficulty that increases as fatigue worsens. This complaint is similar to that in Parkinson's disease patients, who also report "tip-of-the-tongue" word finding difficulty as well as "excessive" and sometimes disabling fatigue.

To see the article in its entirety, go to:

The Exchange

Welcome to The Exchange, a place where you can look for a mobility device, or list mobility devices that need new homes. Do you have something you would like to list? It's free. Contact the SRPSG Newsletter editor at lbadger@badsound.com.
We thank EASTER SEALS SUPERIOR CALIFORNIA for contributing postage costs.

SACRAMENTO REGION POLIO SURVIVORS GROUP:

Meets quarterly the first Saturday of the month at 1:00 p.m., at Brookfield’s Restaurant, 4343 Madison Avenue (at I-80 Freeway), Sacramento, CA. 95842

June 2, 2018
Guest speaker Carol Washington from HICAP will speak about Medicare and you.

September 8, 2018

ADDRESS CORRECTION REQUESTED