



BransonGoers Gazette

April, 2009

Volume 3, Number 8

EDITOR:

Don Hansche
bgg.editor@gmail.com

IN THIS ISSUE:

- “Getting to Know You”
(Page 1)
- Don't Forget Who's Taking
You Home (Page 2)
- The Good Hospital Visitor
(Page 9)
- Why Limbs ‘Fall Asleep’
(Page 12)
- 2009 BransonGoers Reunion
(Page 12)
- From the Editor (Page 16)

.....
 If you have articles you'd
 like to contribute, please
 contact me at the above
 email address

Articles in this newsletter cannot be reprinted without express consent of the author of said article.

This newsletter is provided for obtaining informational resources only, and not as a guide for recommendation of treatment. Recommendations for care and treatment should be obtained from your physician. BransonGoers Gazette nor Post Polio Branson Goers Association makes any representations or warranties concerning the accuracy or reliability of information contained within. The contributing authors, editor(s), production and programming staff shall not be liable for errors, omissions or inaccuracies in information or for any perceived harm to readers. Articles and other information found here are intended to share information of interest to the readers, including medical opinions. They are not intended to offer specific medical advice or act as a substitute for professional health care. Opinions, products or services mentioned herein are not necessarily endorsed by BransonGoers Gazette or Post Polio Branson Goers Association.

If you have anything you would like posted concerning your local support group, please contact me.

“Getting to Know You” featuring Dick & Phyllis Bischof



What is your name and at what age did you contract polio?

My name is Dick Bischof. I contracted polio in 1955 at age 17.

Describe your early treatment for polio :

I started out with encephalitis. When the fever broke, I became paralyzed. Hot packs were used on my legs. My muscles were stretched. I exercised in a large whirlpool pool that had a floor that lowered.

How did polio affect your teenage years?

I could no longer ice skate or square dance as I did before. I acquired a Sears Allstate Motor Scooter with a side car.

How did this affect the way people treated you in school?

I quit school after being knocked down a flight of stairs while I was on crutches.

How did polio impact your self-esteem?

I always asked myself, “Why did this happen to me?”

What is/was your occupation?

My first job was doing lawn mower repair and a truck mechanic. My employer,

Fox Valley Tree Experts in Hinsdale, IL, made a special lift to pick up lawnmowers and put them on the workbench. When I retired in 1988, I was an electronic technician for USX. I also had my own television repair business and did custom electronic work for McDonald's Hamburger University.

Do you have post-polio syndrome (PPS)? If so, when was it diagnosed?

Yes. I was diagnosed in 1993 by other PPS'ers at a support group meeting in Springfield, MO.

Do you use any mobility aids (cane, brace, wheelchair, scooter, etc)? If so, how do you feel about using these mobility aids?

I use a cane and a scooter. I am very comfortable using them because my upper legs burn when I walk any distance.

How does PPS affect your way of life (life style)?

My weakness slows me down. I can no longer carry televisions for repair or do car maintenance and overhauls etc.

What are your interests, hobbies?

I like computers, watching TV and taking care of my sugar gliders (Australian flying squirrels). I also enjoy using my Mitsubishi tractor to dig a pond, bring in firewood and plow snow.

What message would you give to someone newly diagnosed with PPS?

Remember to "conserve to preserve." Definitely use a scooter or power chair whenever possible.

Are you married, and if so, how did you meet your mate?

Yes. Phyllis and I met at a Walther League (church youth group) Christmas party.

Any comments to or from your spouse/supporter?

I am glad to have a group like the BransonGoers to be a part of and to learn from.

Don't Forget Who's Taking You Home

by Anthony Tusler

About Disability

The first song I remember about disability was "There's a Star Spangled Banner Waving Somewhere". If you haven't heard it you are probably younger than 65 years old. It was the biggest selling song of World War II. Sung by Elton Britt the lyrics combine an unabashed patriotism with a maudlin disability perspective. The singer asks, "Can the U.S. use a mountain boy like me?" because "Though I realize I'm crippled, that is true, sir, please don't judge my courage by my twisted leg". Hearing the tune as America was drafting my friends to go to Viet Nam, I marveled that someone with a disability exemption would want to go to war.

The "Star Spangled Banner Waving Somewhere" had special significance to my life. I've had a spinal cord injury since 1952 when I was five. Growing up in Pasadena I was mainstreamed and went to regular schools at a time when most kids were in Special Ed. I stayed away from other disabled people. I held the same stereotypes and prejudice against people with disabilities as other people did in the 50s. Even though I was one of "them" it didn't change my intolerance. The crippled newsie on the corner of Los Robles and Colorado Boulevards scared me to death, without consciously knowing why: that could be my fate if I didn't have my family and their resources.

The next song I noticed that was about a disabled person came out in the late 60s. It was "Ruby, Don't Take Your Love to Town". A disabled veteran begged his partner to remain faithful, "It's hard to love a man whose legs are bent and paralyzed ..." He implores her to not go to town even though he can't satisfy "... the wants and the needs of a woman your age". I don't remember being shocked the first time I heard

it, but I sure hope I was. Even as young and closeted as I was, I knew that I hadn't given up my sexuality along with my able-bodiedness. The song was so bold, so filled with self pity, anger, and revenge I was thrilled by its audacity, "... and if I could move I'd get my gun and put her in the ground" (see Wikipedia entry for Ruby, Don't Take Your Love to Town about the inspiration and writing of the song by Mel Tillis. Interestingly, Mel Tillis is a person with a disability because he has a severe stutter).

In the ensuing years, as I joined the disability rights movement and embraced my disability, I have researched and written about disability. I focused on self-determination and identity and didn't spend time thinking about disability and music although I kept a list of songs. Many of them had lyrics delivered with a stutter, such as "My Generation" by the Who and "Changes" by Bowie, yet few songs were explicitly about disability.

Every year the members, many if not the majority disabled, of the Society for Disability Studies (SDS) have a dance at their annual meeting. In 2003 a call appeared on the SDS listserv for song recommendations. One member posted a set list that appeared to be the soundtrack of just about every oldies radio station - good songs, but overly familiar and lacking any relevance to disability. Because SDS and I were paying more attention to disability identity, culture, and the arts I was inspired to pull together a list of songs that had some connection to disability.

I burned a CD for the dance of artists with disabilities who rocked out. To insure that the collection was danceable I engaged in a rare activity - dancing. I hopped around the living room in my wheelchair with the stereo going full volume to ensure dance-ability. I sent the CD off to the Washington DC site of the conference and waited for cheers or jeers. There was no response, positive or negative.

Yet, my interest was piqued. I began to seriously research songs, singers, and songwriters with a disability connection. The deeper I dug, the more I discovered. I continue to be surprised I was inspired to begin work on a second collection of Disability Songs, Singers and Songwriters. The criteria for inclusion in this collection were either the disability identity of the performer or songwriter, or a song that had disability subject matter. Many of the songs were performed by musicians who are blind, others were by people with a variety of disabilities, and some were by non-disabled songwriters. I eliminated emotional disabilities or addiction because those singers and songs are amply represented in music and deserve separate attention.

The material started to group around themes: society's mirror, disability imperative, and identity and meaning. Society's mirror has the hidden emotions with disability themes or images. "Ruby, Don't Take Your Love to Town" is a good example. Disability imperative includes singers and songwriters who became musicians because disability either created an opportunity for them or limited their job choices. Identity and meaning is the most exciting because it is about the back story of the music created by people with disabilities.

Society's mirror

Songs are at their core, emotional. They express ideas and feelings that we are too embarrassed to express. Where else could one say "I pledge allegiance to the heavens above tonight to you, baby" (Celine Dion, Declaration of Love) without irony or snickering. Because of the freedom to give voice to previously cloaked emotions, songs can highlight stereotypes and prejudices.

Songs like "Ruby" and "There's A Star-Spangled Banner Waving Somewhere" show disability as tragic and pitiful. There were a few other stunners. Red Sovine's tearjerker "Teddy Bear" portrayed a boy who is "... not much help with my two crippled feet" and the hard to find "Little Crippled Girl's Prayer" by the Marsh Family had a little girl who sadly "... sat alone in her wheelchair watching all the other kids play". Randy Newman may have intended "Short People" as an ironic statement, but it was adopted by bullies on playground to torment fellow students.

Disability imperative

A stronger and more interesting thread is how disability has lead musicians to create music and find a profession. Doc Watson, the justly renowned guitarist and singer, had to forego a career as an engineer when his blindness derailed his career path. Tom Jones might have followed his father into the Welsh coal mines if he hadn't contracted tuberculosis in his youth.

Marilyn Manson was lead to become every parent's nightmare by his childhood illness experiences. He and his music have been blamed for just about every evil from teen pregnancy to the Columbine tragedy. In his childhood he was in and out of the hospital. Those experiences left him feeling like an outsider and seeing the world from a disconnected perspective. He could no longer live without thinking about who he was and his place in the world. Disability in adolescence seems to have had that effect on a number of creative people.

Manson's shocking and brilliantly crafted persona, music, and stage show took inspiration from the outlook he gained when he no longer had a typical, carefree childhood. The brutal lyrics to Beautiful People, "The horrible people, the horrible people ..." take on a whole new meaning when coming from someone with a disability. The lyrics appear to mock only the jet-setting gang of beautiful people, but knowledge of his disability experiences reveals his target is a much larger group - all who are caught up in the reckless drive for youth, beauty, and physical perfection.

Alice Cooper is an earlier example. He preceded Marilyn Manson in shocking and horrifying parents. His stage show concludes with a guillotine and a phony severed head. He, too, understood how to capitalize on teenage anxiety due to his childhood illness experiences. The common denominator of Cooper and Manson's successful imagery and stage show is provided by Frank Zappa. It's been said that his sharp criticism of society was informed by his childhood illnesses. He felt like an anthropologist studying a foreign culture, e.g. the normal childhood he had left behind.

Much earlier in the 20th century, A. P. Carter dropped out of school when he was teased about his palsy. He became an itinerant salesman in the hills of Virginia where he met Sara and her cousin Maybelle. A singer and song collector, he was taken with the women's singing. The three formed what became the country music dynasty, The Carter Family. First recorded in 1927 they went on to become one of the more successful and influential groups in the 30s. Would A.P. have become a famous musician if he didn't have a disability and if he had stayed in school?

Another country legend is Doc Watson. He was born and still lives in Deep Gap, North Carolina. He lost his sight by his first birthday and has had a long career and significant recognition as a flat-pick guitar player and singer. In a radio interview he said that if he was not blind he would have become an engineer. I have a hard time imagining anything he could have built that would be as meaningful and significant as his music.

Identity and meaning

The most fascinating aspect of disability and music are the songs that have a greater meaning when the back stories of their disabled creators are exposed. These are stories of disabled people creating important and lasting music. Here are two examples.

"Save the Last Dance for Me"

"Save the Last Dance" is as familiar as any song can be, holding a permanent spot in the soundtrack of our lives. It was a hit by the Ben E. King Drifters in 1960. Most in my generation heard it when we were in our teens. It was not common knowledge that the lyricist, Doc Pomus, had a disability and used of braces and crutches to walk.

The power of the song is because we identify with the protagonist. We lament that the object of his affections will "... dance every dance with the guy who gives you the eye" . We are relieved at the good

news at the end of the verse, "But don't forget who's taking you home and in whose arms you're gonna be," assured the lovers will unite.

Forty-five years after it was a hit I got a shock when I began to delve into Doc Pomus' life. I knew from his 1991 obituary that he was a wheelchair user so I had included one of his moderately famous songs, "Viva Las Vegas," in my first disability music compilation.

The shock was, he wrote "Save the Last Dance for Me" for his fun-loving wife who liked to go out dancing. Those lyrics combined with my shared kinship with another non-dancing wheelchair user made my world shift. I realized, yet again, what it means to be disabled. I knew it in the old way-and the new. When I thought about Doc Pomus, a short man with an obvious disability, a man who came of age using crutches and a wheelchair in the 50s, and writing those opening lines, "You can dance every dance with the guy who gives you the eye, let him hold you tight ...". I remembered how hard and scary it was to be the only one with a disability in junior high and high school and the painful awareness of my lack of romantic desirability. I was reminded of my longing for romance, the fragility of my hopes, and my fear of able-bodied competitors.

But then, Doc Pomus' confidence comes bursting through with "But don't forget who's taking you home and in whose arms you're gonna be ...". He asserts with self assurance that the end of the dance will prove his faith in how the evening will end. His attitude is astounding. Pomus is willing to be vulnerable at one turn. He exposes his fears as a disabled outsider. Then he turns around and is assured of the upcoming eroticism. Finally, he is assertive and confident of his shared commitment and connection, "... so darlin' save the last dance for me". At the same time I am filled with disability shame, I am buoyed and excited by disability pride. Doc Pomus becomes a brother - a successful disabled brother. His words touch me in my present life. They reinforce my own commitment to my wife, my pride in our disability community, my joy in the life I am now leading. It's a life I couldn't imagine when I was young.

More importantly one doesn't need to know the disability slant to the story to be entranced by the words and tune. There is universality in his song. Everyone relates to the fear of being left. Everyone is relieved and gratified with the happy ending. I believe that the lives of disabled people, living at the margins, successfully dealing with unthinkable circumstances, can illuminate the human experience. This best selling song is a wonderful example.

Porgy and Bess

Another example of the wonder and power of the disability background is the opera Porgy and Bess. It was first performed in 1935. In 1959 it was turned into a movie in an abbreviated version, and I saw when it was released. The image of Porgy heading to New York from South Carolina to get Bess is a dim, but powerful memory. I was embarrassed by his goat cart and his pitiful leave taking. I was twelve or thirteen when I first saw the movie at the Academy Theater in Pasadena. Knowing more of the story and looking back as an aware, disabled person I now consider him as a proud, albeit poor and wheelchairless, disabled man.

The movie Porgy and Bess is an adaptation of the opera written by George and Ira Gershwin and Dubose and Dorothy Heyward. It's a love story of the title characters. It is also a story of the residents of Catfish Row, a fictional African American community. Set in 1920s Charleston, Porgy is a beggar with a disability. Without the use of his legs, he either scoots across the floor or uses a goat cart for mobility.

The opera was based on the book Porgy written by Dubose Heyward, a disabled man. He co-wrote the subsequent play with his wife, and was the librettist for the opera. He had worked on the Charleston waterfront and became familiar with the African American community there. He attempted to convey that world in Porgy. The book sold well and is considered to be one of the first American works with sympathetic African American characters. Later the production of the opera was controversial for forty years and was considered racist by many in the African American community. The first and the majority

of the performances had all black casts but characters who were dope dealers and murderers were uncomfortable to the actors and other African Americans. The 1976 revival by the Houston Grand Opera helped bring about an appreciation and revitalization of the work. Many of the songs in the opera are well known including "Summertime."

All of the attention, positive and negative, has centered on race and the legitimacy of Porgy and Bess as an opera. Little notice has been paid to the role disability plays in Porgy's life. Heyward had a bout with polio, which impaired his dominant arm and hand, affecting his ability to write. His polio also led him to contemplate and explore what it means to be a man. Porgy is Heyward's alter ego. Unlike Heyward, Porgy is robust and strong-strong enough to kill the villain, Crown.

The revelation of Porgy is in Heyward's portrayal of Porgy's disability. The book Porgy provides a closer look at who he is and his motivation. Although a beggar, Porgy is described as someone with a great deal of dignity. He is shown living successfully with a disability. But Porgy doesn't ignore or minimize the difficulties of getting around, making a living, and finding romance.

In the beginning of the book and opera, each morning Porgy catches a wagon ride to his regular begging spot. It's only when the wagon driver is jailed and Porgy loses his transportation and ability to make a living that he inventories his resources and hitches an old, smelly goat to a wooden box with homemade wheels. He then has mobility to reach his begging spot and anywhere else he wants to go. Much of one chapter of the book describes Porgy's exultant travels around Charleston in his new found freedom, made possible by the goat cart. I realized that this was not a stereotypical, poor cripple but a proud man with a disability. A man who, like the people with disability I know, uses the tools available to create a satisfying life.

Every review or analysis of the opera Porgy and Bess ignores Porgy's disability. Knowing the intent of the book, it is clear that Porgy's disability status is central to the plot. His relationship with Bess begins because he has no other choice if he wants to be with someone. As they live together she helps him to come out of his proud shell. And Porgy gives Bess his love and commitment which helps her to straighten out her life and move beyond her cocaine addiction. Eventually Porgy kills the villain, thus proving his manhood. But in the process, like the punishment of the overreaching hero in a classic Greek tragedy, he loses Bess to her addiction and the lure of New York.

I am elated glad to have gone from embarrassment to pride when I think of Porgy and his story. I'm still surprised that Porgy's status and identity as a man with disability is ignored. I never would have imagined that it was a thoughtful and proud disabled author of the 1920s who revealed the treasure of Porgy and Bess.

It's all out there in plain view. There are people with disabilities telling their stories and creating music. This is just the beginning of unearthing our history and our stories. Just the other day I heard the lyrics to "Boppin' the Blues" by Carl Perkins. I loved, "Yeah that doctor told me, 'Son you don't need no pills, just a handful of nickels and a jukebox will cure your ills." I thought it would be wonderful if he had a disability. A quick Google search reveals Perkin's closed head injury - another of my brothers telling it like it is.

Music collections

For Dancing

1. Santa's In A Wheelchair - The Kids Of Widney High, 3:13
Widney High is the Los Angeles area special school.
2. Move On Up - Curtis Mayfield, 8:56
Curtis spent the last few years of his life using a power chair.
3. I Don't Need No Doctor - Ray Charles, 2:33
Ray Charles is, of course, blind.

4. Take Me In Your Arms Tonight - Teddy Pendergrass, 5:27
A recording before his power wheelchair use.
5. What's in a Name - The Cripples, 4:12
Seattle's openly disabled punk band singing about our old favorite, semantics.
6. Short People - Randy Newman, 2:55
Will the controversy never end?
7. Mongoloid - Devo, 3:45
Easier to rhyme than Down's Syndrome.
8. Johnny's Blues - Johnny Crescendo and the P.O.P. Squad, 3:44
The U.K.'s disabled flag bearer and his Piss on Pity Squad
9. Beautiful People - Marilyn Manson, 3:38
Marilyn's early years in the hospital informs this dig at the mainstream.
10. Cowboy Brown - The Kids Of Widney High, 3:36
The Kids again.
11. Cracking Up - Nick Lowe, 3:02
The title says it all.
12. I Wanna Be Sedated - The Ramones, 2:30
Joey Ramone's OCD might have lead to this plea.
13. Spasticus (Autisticus) - Ian Dury & The Blockheads, 5:11
The disabled author of Sex and Drugs and Rock 'n' Roll writes a BBC banned anthem for the 1981 International Year of the Disabled.
14. My Generation - The Who, 3:18
Who says stuttering isn't a disability?
15. Destroy The Handicapped - Fang, 1:33
It's unclear what we did to piss off these San Francisco, hardcore skinheads. NB: The lead singer is back on the streets after serving a prison sentence for murdering his girlfriend.

Current Disability Collection

(* = disability identity determined by; ** = disability identity by song writer.)

1. T.B. Blues - Otis Spann *, 4:12
Muddy Water's long-time band mate and pianist died of TB.
2. I Have Had My Fun - Sonny Terry & Brownie McGhee *, 3:33
Since 1939 Brownie and Sonny have been instrumental in bringing country blues to mainstream audiences. Sonny lost most of his sight in early childhood.
3. Wade In The Water - The Blind Boys Of Alabama, 3:34
Singing in the blind school and gospel traditions this Grammy winning group has enjoyed mainstream success.
4. Bess, You Is My Woman Now (excerpt) - William Warfield, 1:56
Goat cart-using para celebrates love, romance, and intimacy.
5. My Little Tune - Joni Eareckson, 4:01, Joni's Song, Pop
The Christian author sings about her relationship to her disability and God.
6. In the Disability Rights Movement - Jeff Moyer, 2:11
Heart-felt, earnest folk music recognizes the struggle for Disability rights.

7. In Northern California (Where the Palm Tree Meets the Pine) - Danny O'Keefe, 3:19
Able-bodied folkie describing a one-night-stand with a braced and crutched woman. ("Creepiest song I've ever heard." Anthony Tusler)
8. Little Crippled Girl's Prayer - Marsh Family, 3:31
Does this mean that heaven isn't accessible?
9. There's a Star Spangled Banner Waving Somewhere - Elton Britt, 2:48
World War II had its own plucky disability candidate.
10. Ruby, Don't Take Your Love to Town - Kenny Rogers
Ruby has it all - politics, anger, self pity.
11. Daddy Come and Get Me - Dolly Parton, 1:79
Forced institutionalization rears its unexpected head in thi s country weeper.
12. Disabled People Do It! - Jane Field, 2:53
Wheelchair-using folk singer tries to convince us that crips are sexy.
13. The Letter - The Medallions **, 2:49
"I was a very lonely guy at the time... 14 years old,... and I walked with crutches," Vernon Green, lead singer.
14. Save the Last Dance for Me - The Drifters, 2:30
The wheelchair-using Doc Pomus wrote this for his fun-loving, ever dancing, able-bodied wife.
15. Johnny's Blues - Johnny Crescendo and the P.O.P. Squad, 3: 44
The U.K.'s Disabled flag bearer and his Piss on Pity Squad
16. What's In a Name - The Cripples, 4:12
They should know.
17. Takin' Retards to the Zoo - Dead Milkmen, .48
What can you say? But why the crash?
18. Cretin Hop - The Ramones *, 1:18
Joey Ramone's OCD viewpoint adds another politically incorrect song title and lyrics to the genre.
19. Spasticus (Autisticus) - Ian Dury & The Blockheads, 5:11
The Disabled author of Sex and Drugs and Rock 'n' Roll writes a BBC banned anthem fo r the 1981 International Year of the Disabled.
20. Mongoloid - Devo, 3:45
Easier to rhyme than Down's Syndrome.
21. Santa's In A Wheelchair - The Kids Of Widney High, 3:13
Widney High is the Los Angeles area special school.
22. Beautiful People - Marilyn Manson *, 3:38
Marilyn's early years in the hospital informs this dig at the mainstream.

About the Author:

In the mid-1980s, Anthony Tusler assembled a show that celebrated disability and the arts and published a booklet about it called Disability and the Arts: An Exhibit Confronting Our Attitudes and Experiences (Rohnert Park, CA: Sonoma State University Office for Students with Disabilities, 1985). This groundbreaking document was the first of its kind in the U nited States. Anthony is also cofounder of the Institute on Alcohol, Drugs and Disability and active in the [disability rights and independent living movement](#).

The Good Hospital Visitor

by Jari Holland Buck

Most of us head to the hospital to visit a sick or recovering friend or family member without giving it a thought.

Give it a thought! There are many things you can and should do to make sure the experience is both positive and safe for you, the patient and your family.

What should visitors know about visiting a patient in the hospital?

1. Do not come to the hospital if you are sick. This includes having diarrhea. Patients already possess compromised immune systems due to their injury, illness or surgery. They also have to “fight off” hospital-acquired infections to which they are exposed such as MRSA (Multi -Resistant Staphylococcus Aureus) and C. diff (Clostridium Difficile). If you are ill, send your presence in spirit, by phone, through friends or prayer.

2. Wash your hands for at least 20 seconds with soap and warm water before entering any patient room and upon leaving any patient room. Hand sanitizers are not enough! According to the Mayo Clinic, “Alcohol-based hand gels, which are commonly used in healthcare institutions, may not effectively destroy C. difficile spores.” There are many, many risk factors associated with these and other hospital-acquired infections, risk factors that involve hospital procedures and personnel, building environmental factors as well as factors surrounding severity of illness. While hospital attention to minimizing risks can play a big role in the frequency of hospital-acquired infections, these are things over which we have no control. We do have control over our efforts, efforts that serve both the patient and the visitor. Therefore, scrupulous hand washing by everyone is your only hope for protection.

3. Sanitize the bottom of your purse or bag as well as the bottom of your shoes before contact with anyone following a visit to the hospital. This includes contact with your pets! Recent studies show we can “share” these pathogens with our four-leggeds. Also, change out of and launder any clothing that may have touched the patient such as a tie. This is especially important if you live with someone or visit someone who is:

- *immune-compromised;*
- *on kidney dialysis;*
- *struggling with a serious underlying illness such as inflammatory bowel disease or colorectal cancer;*
- *taking antibiotics or over-the-counter antacids;*
- *recovering from abdominal surgery;*
- *recently discharged from a hospital;*
- *living at an extended care nursing facility.*

Do so before you enter your home or the patient’s facility. MRSA lives on skin and survives on objects and surfaces for more than 24 hours. C. diff spores survive up to 70 days. Infection rates continue to increase, as do deaths from hospital-acquired infections.

What things should visitors leave at home?

1. Complaints. You are there to support the patient and family members. Having an upsetting conversation in the presence of the patient, even when heavily sedated, can have extremely negative consequences. So can whispering when the patient believes something is being withheld. State everything in the positive.

2. Plants and flowers for ICU patients. They are not allowed as they grow mold and some patients have allergies to them.

3. Questions about the patient's condition. Use the services of caringbridge.org. The purpose of this organization is to keep all friends and family with Internet access updated on the condition of the patient and needs of the family. With the assistance of caringbridge.org, the family can set up a blog and make comments/requests as well as expressions of gratitude. There is no reason 24/7 advocacy needs can not be placed on this blog, asking for assistance. These postings eliminate the need for the family to personally contact everyone in their network whenever there is a change. It also gives those friends and loved ones who have an interest in specifics the information they crave without bothering the family.

What things can families or visitors do to improve the “care” of a patient?

1. Have someone with the patient, in the room, 24/7. This means twenty-four hours a day, seven days a week. The patient needs a guardian. Maintain that post or pass it to someone else. This is especially true in Intensive Care. A-W-O-L could mean D-E-A-D.

2. Create a Care Team Notebook. By asking friends, neighbors and family to assist in advocacy, the family's personal burden is not only reduced but the patient benefits from “new eyes.” This Notebook passively “coaches” advocates in what should be observed and, as necessary, negotiated with hospital care providers. In order to stay organized and keep track of everything, this Notebook should be set up prior to or immediately upon hospital admission if the patient's stay is expected to be anything more than a short, overnight visit! In that way, whenever well-meaning and caring individuals ask what they can do, the family is ready to request help. It should include:

- *Sign-up Sheets* – in which a sheet of paper exists for each day with four-hour shifts. Make sure that advocates do NOT have a change in personnel at the same time there is a shift change at the hospital! This is a particularly vulnerable time for the patient and the uninterrupted presence of a healthcare monitor is critical;
- *Doctor Visits* – in which each care team member is asked to record every doctor visit/outcome that occurs during their shift;
- *Procedures* – in which each care team member is asked to record any procedures done and the expected and actual outcomes;
- *Notes* – in which each care team member is asked to record any observations during their shift;
- *Questions* – in which each care team member lists any questions they have for medical personnel for future shifts;
- *Outside the Hospitals Tasks and Chores* – in which are listed things that need to be done to keep the patient's family and household functioning, divided into categories such as personal care for the patient, transportation, household chores, childcare, pet care, etc.;
- *Legal Documents* – including a copy of the Durable Medical Power of Attorney and Living Will (Advanced Directives);
- *Emergency Contact Information* – for the family, the advocate(s), the trusted medical advisor(s) and all key medical personnel.

(For downloadable forms, visit www.hospitalstayhandbook.com.)

3. Ask the patient if s/he has executed a Durable Medical Power of Attorney and a Living Will, also called Healthcare Directives in some states. If not, help the patient complete them. If you need copies of these documents, go to the Legal or Patient Advocacy office in the hospital to secure the forms. No one wants to believe anything bad could happen to them, the very issue that confronted the spouse and parents of Terri Schiavo whose case went to the Supreme Court because she lacked these documents. Regardless of what course of action you believe should have occurred, the fact remains that this painful experience could have been totally avoided had she executed these two documents. With these documents in place, everyone, including the medical community, will know the desires of the patient. This action spares the patient's family from the agony of one of life's greatest and most difficult decisions. Place copies of each document in the Care Team Notebook and give a copy to the legal department of the hospital.

How can families and friends better coordinate visits?

1. Honor the visitation hours and policies, especially in the Intensive Care Units (ICU's). Visits should be staggered and not exhaust the patient. There are good reasons for limiting the number of people in the patient's room at any one time.
2. Ask the assigned advocate to manage the flow of visitors. Have visitors contact the advocate ahead of time and determine the best time to visit. Patients get tired, even when there is not a lot of activity. So do family members who have to answer questions over and over again.
3. Find out when nursing shifts change and procedures are scheduled and avoid these hours. Some hospitals/units even disallow visitors during these vulnerable periods of time.

What top things can families or visitors do to make the jobs of hospital caregivers and professionals easier?

1. Offer to assist the nursing staff. There is a tremendous shortage of nurses that is only going to get worse as "baby boomer" nurses continue to retire and fail to be replaced. Many things can be done by a visitor to assist the nurse such as securing bedding, running errands for the staff or patient, filling water pitchers, assisting with patient food intake, notifying the nurse when alarms sound (do NOT touch the equipment!), securing supplies, etc.
2. Give the family members a break! They get tired and crabby, too, making the nurse's job harder to handle. Do not step into this role without learning what needs to be done or attended to while you are taking the family member's place if they are operating as the advocate.
3. Learn to speak "hospital" speak, even just a little. Machines have names. So do nurses. Doors will open — with the doctors, with the staff and with the patient, who will want to understand what is happening or what has happened to him or her. Calling people and things by their right name supports speedy and compassionate care.

Any other visiting dos and don'ts?

1. Take care of yourself. You are of no value to a family member or friend if you go down for the count. Sacrificing your own health for another is not what anyone who loves us would want us to do. Drink lots of water before and after your visit.
2. Manage your own stress, about the patient as well as about your personal fear of hospitals, disease and death. If you can't, don't visit. World-renown shaman, Sandra Ingerman, says that "All healing is done by creating space from the heart. Anxiety occurs when you are in a state separate from spirit. If you can't get emotionally detached, you can't let spirit through." This cannot be done when you are operating out of or spilling fear.
3. Don't stop visiting hospitalized patients! They need our support. Just do so in a thoughtful and compassionate way. Robert Hénri said in his wonderful book, *The Art Spirit*, written in 1923, "Do not let the fact that things are not made for you, that conditions are not as they should be, stop you. Go on anyway. Everything depends on those who go on anyway."

About the Author:

Jari Holland Buck is a business consultant, medical layperson, Reiki Master and Shamanic Practitioner who spent 7-1/2 months in four hospitals with her critically ill husband. During 6+ months on life support, every organ in his body failed, yet he survived. Learn more about how to be an advocate in her book, *Hospital Stay Handbook: A Guide to Becoming A Patient Advocate for Your Loved Ones*, winner of the 2006 Parent to Parent Adding Wisdom Award and finalist in the Fresh Voices of 2006 Health category. www.hospitalstayhandbook.com.

Why Limbs 'Fall Asleep'

by Matt Soniak

You know how it goes. You sit too long with your legs crossed or lie with your arm under your head, and when you go to move the limb, it's tingling with a "pins and needles" sensation; But why?

We've got nerves running through our bodies that act as lines of communication between the brain and the other body parts, transmitting commands from the brain and relaying sensory information back to it for processing. What's happening with a sleeping limb is that your nerves are going a little haywire because prolonged pressure has actually cut off communication between that limb and the brain. (The tingling sensation is technically called paresthesia.)

Pressure puts the squeeze on nerve pathways and blood vessels, so the nerves can't transmit signals properly, and the blood vessels can't bring oxygen and nutrients to the nerves. The cut-off interferes with the normal flow of information between the limb and the brain and the signals going back and forth get jumbled. Some nerve cells stop sending info entirely, while others send impulses erratically.

The problem is compounded by the fact that our nerves are pretty specialized and different kinds of nerves and sensory receptors receive different stimuli and transmit different information (last year, we talked about another bodily oddity caused by this). When the various signals get scrambled and aren't transmitted normally, the brain starts to misinterpret the info it's getting and generates an array of sensations, like warmth, numbness and that tingling feeling.

When a limb falls asleep, we usually try to "wake it up" and change positions. Blood flows back to the limb, giving a little boost to the misfiring nerves and making the tingling seem worse, but eventually the nerve signals begin to flow properly again. The pins and needles sensation is annoying for a few minutes, but it's a nice little prompt for us to relieve the pressure on a limb before serious nerve damage occurs.

When you come to the end of your rope, tie a knot and hang on.

2009 BransonGoers Reunion

Dates

The 2009 BransonGoers Reunion dates are Friday, June 12th through Sunday, June 14th. Many will come early to eat at Lambert's Café and will stay until Monday (or even later) to visit, tour the Branson area, see shows, etc. You are welcome to come earlier and stay later if you like. Those of you arriving on Thursday, June 11th, around 4:30pm to eat at Lambert's Cafe will get a free meal if you are in a wheelchair or scooter, or a reduced meal if you use a cane. They have lots of good food and everything is '*all you can eat*'. We guarantee you won't leave hungry! You can visit their website [here](#).

Accommodations

Those of you, who have not yet made reservations, *PLEASE make your reservations now!* You can always cancel them later, if your plans change. The hotel's phone number is 1-800-677-6906. Please let the person you're making reservations with know you're with the Post-Polio group; Group #PP6109. They will need your credit card number to hold your room, but *nothing will be charged until you arrive*. If you need special adaptive equipment, please tell them when you make your reservation and ask that they put it in the "comments" section. If you have portable equipment at home, bring it with you. Also, please let the front desk know if you'll be bringing a pet or service animal.

Our hospitality room (The Stonehenge) is in building "C", so if you need to be in that building, specify that

when you make your reservation! All handicap-accessible rooms are set aside for us, but they go quickly ; so reserve yours *NOW!* Waiting any longer may result in not getting an accessible room and/or the building you desire.

Kathy is in charge of accommodations and is happy to arrange for special equipment through local DMEs. If you have a question or problem with the hotel, please *let her know ASAP!* She will handle any problems you may have. You can call her at 1-417-336-8663. She has unlimited long distance, so she can call you back if you need her to. After you make your reservation, please [email](#) Kathy or contact her through our Yahoo Group with your special equipment needs, special room requests, etc., so she can make sure your needs are met.

Staying in Stonehenge is a necessity for us. We have access to the kitchen and the ice machine, and have LOTS of room for our 40+ power chairs and scooters. Plus, we have the PA system.

Pets / Service Animals

Pets are welcome at the Settle Inn. However, *only* service animals are allowed to stay in rooms in building "C" where our hospitality room is. Again, please let the front desk know you have a pet when you check in. We know you love your pet, but, if for any reason you bring a pet into the Hospitality Room (Stonehenge) that is not a service animal, please control him or her. If he or she gets loud or does any other distracting act, you will politely be asked to remove him or her from the room.

Registration Fee

\$45 per person registration fee includes lunch and supper on Friday, Saturday and Sunday. Also includes soft drinks, bottled water and snacks (which will be in the Stonehenge all weekend), VCR or CD of the reunion, our Polio Stories book (bring yours from last year to be updated; newcomers only will receive a complete new book), use of the Stonehenge room and any miscellaneous charges.

If you are unable to attend, you can still order a DVD or VHS, shirts, caps, totes, a PPBG Recipe Book and/or a 'Men of Branson' Calendar by contacting [Sharon](#).

Shirts, Caps and Tote Bags

Color: Green

T-shirts: \$10 each. Available in all sizes.

Caps: \$5 each

Polo shirts: \$12 each

Tote bags: \$7 each. 18x16x4¼ deep with 28" handles.

Payment Deadlines

By April 30, please submit your order for shirts, caps and totes to [Sharon](#). By May 5, mail your money for your shirt, cap and tote order (and registration fees if you want).

You can pay your registration fee in advance or make installment payments on it. If it will help you to spread the costs of the trip over the next couple months, I suggest you take advantage of this option. A record of all payments is being kept. Please make out your check or money order to Post-Polio Branson Goers Association and mail to:

PPBGA

@ Sharon Hansche

1404 Kingsdown Drive

Granite Shoals, TX 78654

Again, please make your check payable to Post Polio Branson Goers Association. DO NOT make your check payable to any individual! It will be returned to you with a cordial note to send another check made out to correctly to Post-Polio Branson Goers Association! If something changes and you can not

come, everything you ordered will be mailed to you along with the refund of your registration fee, less shipping charges.

Activities:

The Eddingtons (Gospel singers who were at the Settle Inn in 2008) will be in the Knights of the Round Table room (next door) on the same dates as our reunion. Along with them will be Joie Christensen, Brian Keith Pendergrass and Miss Keely. Plan on having a great time listening to some of the best Gospel music and singing in the area!

As over the past few years, we will again have karaoke which also includes *The Bransoneers!* We have acquired another karaoke CD for a wider range of music and plan to add another each year.

Special Dinner Gifts

Everyone is asked to bring a gift; inexpensive, used, gag gift, etc. , etc. – remember... *inexpensive!*

Kitchen

Pat Grimes is in charge of the food. If you are interested in helping, please [contact her](#).

Book / CD / DVD / VCR / Audio Book Exchange

If you have any you'd like to get rid of, bring them along!

Crafts Etc.

If you have crafts or other things you'd like to sell, please feel free to bring them. If you do bring things to sell, please remember, many live on fixed incomes, so you may have a better chance to sell something if it's priced inexpensively.

Phyllis is handling the exchange and the crafts table. Any questions, please contact her by clicking [here](#).

Branson Shows

If you decide you want to go to a show while you're at the reunion, the following web sites offer coupons WITHOUT timeshare tours:

www.sunnydayguides.com Click on Branson on the left column and coupons along the top of the page.

www.bestreadguide.com Click on Branson on the map, click on the booklet cover, then on coupons as each click takes you to a new page.

Branson also has a 2 for 1 ticket outlet that is NOT a timeshare. They do not have a web site. A list of the shows they offer will be available at the reunion. They do not offer tickets to the major shows such as Shoji, Andy Williams, etc.

Feel free to email [Linda DeRyke](mailto:Linda.DeRyke) if you have any questions regarding free Branson vacation guide s.

We look forward to seeing each of you at the 2009 Post -Polio BransonGoers' 11th Annual Reunion on the second Friday of June (June 12th). That is the weekend *before* Father's Day weekend.

April Sudoku

		5	1		8		6	
		6		4				2
						3	1	
		1		8			7	
		7	3		2	6		
	5			7		2		
	4	2						
6				5		1		
	1		6		9	4		



Worry is like a rocking chair;
It'll give you something to do but won't get you anywhere.

Answer to March Sudoku

3	8	7	9	1	2	6	4	5
2	6	5	8	4	7	3	1	9
4	1	9	6	5	3	2	7	8
9	4	1	7	3	8	5	6	2
8	5	3	4	2	6	1	9	7
7	2	6	1	9	5	8	3	4
1	3	8	5	7	9	4	2	6
6	7	4	2	8	1	9	5	3
5	9	2	3	6	4	7	8	1

From the Editor

We will continue to post deadlines and related information for the 2009 reunion here and on the PPBGA website (www.ppbga.org) at the '2009 Updates and Deadlines' link. Please check there often so you don't miss anything and are not late on any fees and dues that have deadlines connected to them.

The BransonGoers Gazette is published and placed online on the first day of each month. Although articles are managed to be found to include in the publications, it does take a lot of time. Your help and contributions are much needed and appreciated! If you have articles you'd like to contribute, please send them to bgg.editor@gmail.com. All articles or edits must be received by the 20th of the month prior to publishing.

What lies behind us and what lies before us are tiny, compared to what lies within us.

A note about third-party links – By selecting links in this newsletter, you may leave the Post-Polio BransonGoers' web site and enter a web site hosted by an organization separate from Post-Polio BransonGoers. We encourage you to read and evaluate the privacy policy and disclaimer of any site you visit when you enter the site. While we strive to only link you to companies and organizations that we feel offer useful information, Post-Polio BransonGoers Association does not directly support nor guarantee claims made by these sites.

*This Newsletter ©Copyright 2009 Post-Polio Branson-Goers Association (www.ppbga.org)
All Rights Reserved.*