

Summary: August 3, 1997

## PPS and the Story of Two Brothers

Speaker: Jesse Lipnik, MD

It is always a pleasure to have Dr. Burton Marsh with us for any reason. At our August 3<sup>rd</sup> meeting he introduced our speaker Dr. Jesse Lipnick, a physiatrist, who has been added to our list of post-polio network physicians treating polio and post-polio syndrome, practicing both in Ocala and in Gainesville.

Dr. Lipnick opened by saying that being with our group gave him a feeling of family. We thanked him for that, and wholeheartedly agreed with him when he said, "Thank God for Carolyn Raville," and her interest in setting up and working with post-polio support groups.

Dr. Lipnick recently had lunch with Carolyn and Jerry Raville. In their conversation mentioned that there are a number of polio survivors who do not seek medical help. She asked Dr. Lipnick to address this subject in a presentation to the Post Polio Society of North Central Florida.

Dr. Lipnick began by telling us the story of two brothers, one about four years old, and the other about nine. They both received diagnosis of diabetes within a year and a half of each other, and as we know, diabetes was more ominous then than it is today. In the 1960s a diagnosis of diabetes meant certain disability for the victim. The brothers were very different people: One did not take the diabetes maintenance very seriously. He decided that it was not worth fighting for his health, and as a result, his life was destroyed by it. He decided to enjoy the time that he had and not be limited in his thinking or in his behavior by his illness. He did not control his blood sugars. He smoked excessively and ignored the need for exercise, and he did not take his medicine properly. Eventually had to have a leg amputated and later he suffered a heart attack and died at the age of 32.

The other brother learned that there was a special relationship between exercise and his blood sugar levels. He participated in all kinds of physical activities and sports programs. He did worry about weight loss, kidney function as well as other issues that can ultimately be problems for diabetics. While he was not an outstanding athlete, he did win several varsity letters and was particularly dedicated to taking care of himself. There was an essential difference between these boys: One was oriented to life, towards growth, and to achieving what he could to help himself. The other didn't try, and eventually died at an early age. Dr. Lipnick said he told us that story because, "I am one of the brothers."

Dr. Lipnick tells us that he is not quite sure what the difference is, but it seems that adversity or personal limitation can take one of two directions in people's lives. Because of circumstance or physical disability, a person can choose to become a victim, or he can choose to be motivated by it and to do beautiful things ... to help people, build support groups, to learn about exercise, to learn about life... it is his or her decision in the end.

What causes someone to make one decision or the other? Dr. Lipnick does not have the

answer to that question. Somewhere there is a choice between life and death that all people make. They decide how they will build and pursue their daily lives. They decide where they want to go and the direction their lives will take. His story illustrates that at some point there is a choice between being as healthy and independent as possible, or just giving up. In his presentation he posed a number of thought-provoking questions to us and helped us with the answers:

Why wouldn't someone seek to see a physician? A person may feel he will not get better. Many questionable remedies have been used over the years to help polio survivors, and when people pride themselves on the level of achievement in their lives, the threat of disability lingers in the background. A person may try to deny it, and not to deal with it.

A doctor may say you are sick, or that you are not a whole person. That doctor may threaten the level of independence you have worked so hard to establish.

He may make you give up or change your life in some detrimental way. He threatens the independence that you have worked so hard to build. Dr. Lipnick says that he can relate to this, both professionally and personally.

Of course, there is also the old number one bugaboo: "It is all in your head." It was brought out in discussion that we must tell our doctors how we are feeling. Don't put up a wall, and above all be patient, because the medical community, especially in our area, is becoming more aware of post-polio syndrome. We can help in that learning process. Dr. Lipnick pointed out a frustrating phenomenon of medicine: If you can prove something through double-randomized prospective trials, then it exists. If you cannot prove it through a study that is statistically powerful, then it does not exist, and it must be in your mind.

Early on if your legs did not work as they should, you made your choices each moment. You chose a quality of personal achievement: Am I going to play with the other kids? Am I going to achieve? Am I going to college? What work will I do in my life? You needed to be as strong and as perseverant and as resourceful as possible; so much so that pain was not important. You knew that pain could not stand in your way, it is this quality that is a double-edged sword. On the one hand this can be good, because it will enable you to achieve in the face of pain. On the other hand this quality could keep you away from medical help, because you perceive a threat to lifestyle and self-image. If you understand that your life can be better when you deal with your condition from a medical standpoint, you can be more free and you can achieve things with less pain. You can deal with your problems more successfully, and somehow, your efforts will enable you to achieve your goals. In this scenario, your perseverance can be your greatest friend. It can be a wonderful quality, but it can also be a very dangerous one.

Post-polio is an illness that primarily affects lifestyle. It affects your independence and your ability to move your body in one way or another. Certain physicians may not consider post-polio an issue for their medical practices because polio is no longer an active disease in America. Rather, many people consider it to be a third world disease.

Dr. Lipnick then told us of how he became interested in post-polio syndrome. He said he was fortunate to have Dr. Justine Vaughen and Dr. Burton Marsh as mentors. After coming to Gainesville to join a medical practice, Dr. Vaughen, then in the process of retiring, talked to him one day and stated, “Jesse, there is a population of people very near and dear to my heart. I have cared for people with this illness for many years and I am looking for a young physician who can carry this work on for me.” Dr. Lipnick decided that: There are no people that I am aware of who are more kindred in spirit; who believe in independence; who refuse to yield and who have a need to achieve.”

Dr. Lipnick feels that it comes down to what kind of role you wish to play in your life. Do you wish to be a mother? A banker? An accountant? A lawyer? A father? Whatever you want, if you cannot do it, then maybe Dr. Lipnick can do something to help. So much of medicine is directed toward blood pressure or studies of the bone, the heart, the liver, whatever component of us may be studied in a scientific way. Dr. Lipnick feels that we cannot afford to lose track of the healer who serves as the basis for the art medicine. We also cannot ignore the scientist. He further stated: “To me it is all about freedom to do what you want to in life, and if medicine can help you to do that, great. If it can’t so be it.”

What is the message of post-polio? “Do, but don’t overdo.” Pay attention to pain. It is a very threatening thing. Be in control of your pain; don’t let your pain control you. Rules are different now. The medical establishment is asking you to pay attention to pain and to limit your activity based on it.

Dr. Lipnick pointed out that there is a need to demystify the physical exam, and as a doctor specializing in post-polio care he asks, “What am I looking for when you come to the office for an examination? What kind of issues am I going to be dealing with?” First is making the diagnosis of post-polio. He had to first separate the late effects of polio from many other things because the differential diagnosis is extensive. How can you separate the late effects of polio from old age, arthritis, spinal disease, muscle disease of other illnesses? The list of things that we use in diagnosing post-polio syndrome: The key is that there was a period of stability after surviving polio. People argue about the number of years; 20 to 25 is most common, and then there may arise a certain group of symptoms. Old age does not just hit you, and so there is a difference in time course. In addition, electromyography can define nerve injury. There are physiologic reasons for post-polio syndrome, and the bottom line is that your nerves are not healthy.

The number one problem is fatigue. Somewhere during the day there comes a wall, and all of a sudden you just cannot go on. This point is difficult for most polio survivors because they have learned not to pay attention to pain. There are strategies: Get out of the limelight. You need to “get out of the blender.” Lie down in a dark place; close your eyes and get some honest rest, for half an hour or so. Learn to push yourself so hard. Park closer to the building. Don’t clean the whole house today, but rather do it a little bit at a time.

The next most common difficulty is increasing weakness. “I use to be able to lift up this pan, to clean the house, but now I just don’t have the strength.” Along with weakness

comes muscular atrophy. Exercise helps, but at some point you will do yourself harm, and this is where “do, but don’t overdo” comes into play. The idea is that post-polio is an overuse syndrome. You have one nerve doing the work of five because polio has killed some nerves. This constant over-stressing makes the nerve wear out. At some point, you must stop and rest. Dr. Lipnick recommended exercise to increase your limits. It is important to say that fast changes can hurt you. If you can walk only a few steps and you try to walk five blocks you will hurt yourself. Make changes slowly. If you can go three steps, tomorrow go four. In three weeks go five; in three months go ten. This will ultimately benefit you.

Sleep is a major issue, and the most threatening issue, not in a physical sense, but in a psychological way, is breathing. If you cannot sleep because of shortness of breath the images come back... iron lungs, loss of independence and even death. Remember that if this is a problem there are things that can be done to restore a normal sleep pattern and to promote independence. People who sleep well do better than people who do not.

Loss of mobility is a key factor. If you do not have the same strength in your leg and you continue to use the leg and the ligaments in that leg to support you, you may have a breakdown in the joints. If you favor your strong leg, it can also suffer. The doctor is looking to see why you have lost mobility. Do you have arthritis? There are helpful things that can be done and you have to pursue them.

Look for answers and ways to make your life better. Try harder. Remember that fear can be debilitating and limiting. If you fear what you will find, you may choose not to look. Fear can be worse than looking at the problem and dealing with it. If you can reach deep down and come up with the gumption and the nerve to deal with the issue, the rewards can be great.

**Jesse A. Lipnick, M.D.**