APPA News

Atlanta Post-Polio Association

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Inside this issue:

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The Current State of Health Care for People with Disabilities National Council on Disability

September 30, 2009

Letter of Transmittal

September 30, 2009

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit this report, entitled "The Current State of Health Care for People with Disabilities." NCD undertook this study in 2007 to focus the nation's attention on the health care disparities experienced by people with disabilities, and to provide information and recommendations that can help to eliminate health care inequities for people with disabilities.

Some key findings include the following:

•People with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities.

•People with disabilities frequently lack either health insurance or coverage for necessary services, such as specialty care, long-term services, prescription medications, durable medical equipment, and assistive technologies.

•Most federally funded health disparities research does not recognize and include people with disabilities as a disparity population.

•The absence of professional training on disability competency issues

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Message From The President

We are coming to the close of another year. When I was young the years seemed to creep by and I wondered if I would ever grow up, be a teenager, graduate from high school, go to college. Now, the years just fly by it seems in a nanosecond. I can't believe it is almost 2010! We have had another great year in **APPA**. I am always amazed at what talented people we have on our board and how dedicated they are. This year has been exceptional! I've had a number of personal problems that have distracted me and this Board has stepped up and supported me in every way possible. I cannot express my gratitude adequately enough for all of the assistance I have received. We have had great programs every month under the leadership of our Program Chair and First Vice President, **Cheryl Hollis**. I can't come up with enough accolades to describe what **Joe Drogan** has accomplished. Joe has completely taken over and reinvented our database, our newsletter and our member directory. In addition to being our Second Vice President, our Newsletter Editor and our Database Manager, he assists all of us with so many other small and large tasks related to our computer use. **Betty Storey** has done a stellar job as our Secretary making sure that all details of our meetings are recorded to the last word. She is our photographer and our refreshments coordinator. **Fay McCaw**, along with a little help from her husband Dennis, has taken over our books and is doing a wonderful job of keeping our financial house in order. **Charlotte Terry** has continued as our Phone Tree Captain. She keeps all of our members who do not have access to a computer updated on meetings and other announcements. **Robert Abney** and **Lynda Dillman** are working on Public Relations and Fund Raising. **Nancy Truluck** heads our Member Outreach Committee. We also call it our Sunshine Committee. Nancy certainly spreads sunshine with her beautiful cards to new members, visitors and people in our organization experiencing personal difficulties. This year she has filled in as Secretary on occasion and has taken over responsibility of fielding questions from our **APPA** phone line. **Cathy McIntire** has assisted us with a number of things including artwork and sending out quarterly meeting notices.

It is a bit unusual that our board will not change this coming year. I think it is a testament to how well we have worked together that we ALL want to stay. Because our Bylaws allow us to have eleven board members, we may add a new member. This will be determined at our annual business meeting, which is coming up fast.

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Our November meeting is our annual business meeting and I hope you will plan to attend. Not only will you have an opportunity to vote for the 2010 APPA Board, but you can place names in nomination from the floor as well. The only requirement is that you discuss it with your nominee to make sure they are willing to serve. And, their dues must be paid up to date. In addition, you will have an opportunity to ask the board everything you have ever wanted to know about APPA business. You will have an opportunity to tell us what you think about how we are doing and offer suggestions for the coming year. This is our only business meeting of the whole year. Please plan to attend and let your voice be heard. We welcome your input. After the business meeting we will have Roy Wise from the Dunwoody Rotary speak to us about their pledge to match the Bill Gates two hundred million dollar pledge to eradicate polio around the world.

I hope to see you at the November meeting as well as at our holiday party to be held at Brio's in December.

Linda Priest,

APPA President

APPA "Road Trip" to Handicapped Driver

APPA held its September meeting at Handicapped Driver in Marietta, GA.

We were treated to a scrumptious lunch and enjoyed presentations by Earl Mathews and Scott Coots from Handicapped Drivers Service and Vicki Karl spoke to us from All In One Accessibility. It's a real one stop shopping place for just about anything you would need to adapt your living space and vehicle to your individual needs. They have everything from vans to roll in showers. They told us that if you can make a circular motion with one hand they can adapt a vehicle for you to drive! They even have a "trapeze" system you can install in your home to carry you from room to room. (I can just see my sons racing around the house on that thing). They were very well informed and can help with things like Medicare approvals.

Written by Joe Drogan.

Photos by Betty Storey

(Continued from page 1)

for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care.

- The Americans with Disabilities Act (ADA) has had limited impact on how health care is delivered for people with disabilities. Significant architectural and programmatic accessibility barriers still remain, and health care providers continue to lack awareness about steps they are required to take to ensure that patients with disabilities have access to appropriate, culturally competent care.

The report offers a broad range of recommendations for reforms that will address some of the most significant obstacles to health, health care, disease prevention, and health promotion for people with disabilities. We believe that this report provides a road map for eliminating the pervasive barriers to health care for people with disabilities, which will improve the quality of life, productivity, and well-being of greater numbers of Americans as the population ages. We also believe that this report is in keeping with the Administration's goals for inclusive health care reform.

Our Council stands prepared to work with your Administration in the planning and implementation of cooperative actions on these matters.

Sincerely,

John R. Vaughn

Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

For more information click on the link below:
http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html

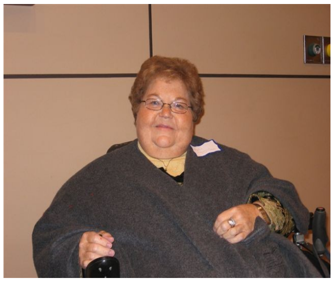
Editors Note:

We hope you are enjoying the **APPA** newsletter. As you can see a lot has changed with it. It is truly a "work in progress". The **APPA News** staff works very hard to make this publication the best it can be. We hope you are informed and entertained by it. Hopefully you enjoy reading it as much as we enjoy bringing it to you. Remember, this is your newsletter and we truly want your feedback, suggestions, praise, and complaints. Please direct positive feedback to the Editor, complaints to the **APPA** board. *Just kidding, of course!* Please send all correspondence to jdrogan@windstream.net

Joe Drogan

Meet One of Our Newest Board Members

Lynda Dillman - Public Relations



LYNDA G. DILLMAN – POLIO EXPERIENCE

I've never been a person who likes to talk much about myself so it is a little hard for me to put things down on paper. Until I became a member of **APPA** (Charter Member), I never really thought much about my experiences. I never knew anyone my age in my hometown that had polio so I always had my own thoughts of what happened. I told myself that God needed someone for this particular role and He chose me and I wanted to do the best I could. I was brought up knowing God loved everyone and that He made no mistakes. I've loved and trusted in Him all of my life and I have truly been blessed.

In August 1949, I woke up sick. I was 3 ½ years old. My mother thought I had the flu or strep throat and took me to the doctor. He thought the same thing. He never had a polio patient before so he treated me for the flu and gave me a penicillin shot. The next day my mother noticed I began dragging my left leg. She thought I'd had a bad reaction to the shot and took me back to the doctor. He said if I was his child he would take me to the Grady Clinic where they checked you for polio.

Mother said you could hear me screaming down the hall when they did the spinal tap. She even drank a Coke after me but praise the Lord she didn't get polio. The doctors confirmed I had polio and put me in quarantine for two weeks. My Mom and Dad could come to the door and talk to me but they couldn't come in. I don't remember anything until the end of my stay at Grady but then I remember crying for them. They would stand at the door and look in and talk to me but could not come in. I remember my Dad would toss me a pack of gum. The doctors told them if they went in they would not be allowed to even come back to the door. I can remember a big green machine (the oxygen) beside my bed. And those are my memories from Grady.

They wanted to send me to Warm Springs, Georgia, but there wasn't room. So I stayed at Emory's Elks Aidmore Hospital until they had a room. I had my 4th birthday at Aidmore but I don't remember much about that. I do remember having one or two birthday cakes and I had a nurse named Valentine with dark hair that rolled under. I really liked her. Whatever gifts I received were kept and burned when I left Aidmore. I remember spending Christmas at Warm Springs. I was there five months. I remember all the exercise, going up and down the stairs on the lawn and learning how to be self sufficient. I believe it was a blessing for me to be there though I didn't think that then. My parents visited every weekend. I believe there was something or someone very special at Warm Springs that encouraged you to be independent and to face life head on.

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When I was dismissed from the hospital and started home, my mother said I couldn't remember anything about home. I had been gone 8 ½ months. And while I don't remember going home, she said when we got to the top of the hill and I could see our house, I started smiling.

Every three or four months we spent the day at Warm Springs to see the doctor, the X-Ray Technician, the brace people, and the corset people. I hated that part. We had to get up by 4 a.m. to get ready to go and be there by 8 to get everything done in one day. I always dreaded the day feeling afraid the doctors would find something wrong and I'd be stuck there. Twice I did have to stay. When I was 13 and had to stay, I was not a happy camper, but I learned you had choices - make yourself and everyone around you miserable or make the best of the situation and try to enjoy yourself.

Warm Springs showed current movies twice a week, and had different things for you to do. People from all over would come to the auditorium to entertain us. Some people came from Columbus, Georgia and put on a minstrel show. Florida State University came to Callaway Gardens every year and would bring part of their show over. My brother played in a band and they came a couple of times and I must admit they were good!

But the time I was 13 the aides or nurses would ask if I wanted to go to something and I always said no. I was content at this particular time to sit in my room and be miserable. But toward the end of my stay I began to say yes. And would you believe I actually enjoyed myself. I regretted wasting a lot of time at the beginning of that stay.

I went back when I was 15 with a different attitude and had one of the best summers of my life. When they asked if I wanted to participate I said YES. I still didn't want to be there, but I learned to make the best of the situation. In the summer they added an extra bed in the rooms because so many teenagers came for treatment. My roommates were so much fun. There were three of us and I still keep in contact with one on a regular basis now. She was a great friend!

When I was in elementary school, I only stayed until lunch my first year. Then in second grade I had to have a roll-a-way bed in the classroom where I could rest for an hour everyday after lunch. I HATED THAT. I never wanted to be treated like I was sick or different. I wasn't. I just walked differently. But the doctor had told my Mom in the beginning that rest was the most important thing for me and she took every word to heart. That bed went with me through the 7th grade. And it didn't stop there. When I went to high school I had a chaise lounge chair in the library where I had to go rest for an hour every day. But I got the librarian to give me her index cards and I filed them for her - or whatever else I could do in the chair. I also had to do exercises twice a day until I was 16 - birthdays, holidays, whenever. I could probably count on one hand the times I was allowed to skip them during all those years! My mother was a real stickler for doing whatever the doctor said.

After high school, I went to business college. No more resting. I had been dismissed by my

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doctors and told only to come back when I needed them - which wasn't very often. Basically only when I needed new braces and crutches. I worked and enjoyed the jobs I had, but after 14 ½ years had to retire on medical disability due to a back problem. Most of my working life was for the Atlanta Army Depot and Centers for Disease Control.

After walking with crutches and braces for 43 years I totally ruined my shoulders. Now I have been dealing with PPS and am very unhappy about that. There is so much I want to do and my arms are shot. My strength is gone. I was strong as an ox. But you see what happens when you don't rest and you push yourself constantly. You pay for it. When times get rough for me, I just look back over my life and know why I've ended up like I have but I must say I had a ball getting here. I remember thinking many times about what I was doing but I always thought later I might not be able to do things so I would enjoy myself and my family now. You learn, but sometimes the hard way.

I have been very active in church since my first daughter was 1 1/2. I've taught Sunday School, Bible School, and was choir director for 30 years. I just gave that job up last year. I always had my faith and trust in God and I really wanted a husband and family. God blessed me with a wonderful husband and two precious daughters. Now I have two sons-in-law, three grandsons, and one granddaughter. We're all very close and all I can say is "Thank you, Lord, I am Very Blessed!"

Lynda Dillman

In Memoriam

Carol Dietz
Jean Brogdon
Robert Burleigh

May 2009 **APPA** Meeting

Living with Polio in the 21st Century


A large group was in attendance at our May meeting - Warm Springs conference review

As a result of the 10th Polio Health International Conference being held in Warm Springs, Georgia, on April 23-25, many of **APPA**'s members were able to attend. The theme for the International Conference was *"Living with Polio in the 21st Century."* For the May meeting, program director Cheryl Hollis asked various members who attended the Conference to report on a few items that they believed were new information. Here are some items of interest.

I. Conference Sessions

The International Conference was a very well organized meeting that utilized the various facilities of the Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). A few main topics of the 40 sessions were:

1. Your Mobility Device and Your Posture
2. Demonstration and Discussion of a Post-Polio Examination: Sorting our Secondary Conditions
3. Demonstration and Discussion of a Post-Polio Examination: Don't Forget Breathing
4. Benefits and Techniques of Aquatic Therapy
5. Demonstration and Discussion of a Seating Evaluation: Cushion and Pressure Sores

Other sessions that provided in-depth discussions were:

1. Tools to Use in Evaluating Treatment Choices
2. Making the Tough Decisions
3. Palliative Care and End-of-Life Decisions
4. Complementary and Alternative Medicine
5. What you Don't Know Can Hurt You
6. Anesthesia Update: Separating Fact from Fear
7. Housing Options: What's Out There
8. Poly Pharmacy: Making It All Work

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Each attendee received detailed handouts when registering that outlined the specific topics being discussed in each of these 40 sessions, identified the various experts from around the world leading each session, and other related information. This information is available through Post-Polio Health International's Web Site: www.post-polio.org.

II Pre-Conference Retreat

Prior to the Conference, a "Wellness Retreat" was offered from Sunday through Wednesday. This Retreat provided an opportunity for individuals to renew their mind, body and spirit under the whispering Georgia pines, while getting vital answers from medical experts in attendance to learn how to stay strong and healthy in the years ahead. Renowned polio experts Dr. Fred Maynard and Sunny Roller applied their experiences from their recent retreats held in Michigan. **APPA** members who attended this retreat (Linda Priest, Ivy Stiles, Gloria Mims, and Cheryl Hollis) raved about the value of this retreat.

Linda Priest makes an important point, while your newsletter editor contemplates yet another cookie from the refreshment table!

III Miscellaneous Comments Relating to Some of the Sessions

1. Sleep issues and Fatigue

Inadequate sleeping can produce irritability, pain, and memory problems in ***Post-Polio Patients*** (**PPPs**). It is important to begin a sleep log to identify sleep patterns and any subsequent developed problems. Also important is to get long rhythms of sleep, that is, reaching deep sleeping patterns (referred to REM type sleeping where dreaming occurs). Short patterns of sleep, commonly seen in dogs, do not relax muscles or may not allow the muscles to return to their correct length. If REM sleep is never reached the whole body becomes stressed. Both over used and under used muscles induce stress that may exacerbate achieving REM status. It was estimated that about 50% of PPPs do not get adequate rest. In addition, the immune systems of PPPs can be adversely affected. Dr. Dimayo encouraged PPPs to listen, understand, and apply the necessary information to help them resolve this potentially serious problem. He told participants to find their own way to a solution and said that resting should not be considered as wasting time! Naps are important during the day to restore the body. One **APPA** member indicated that one should develop a routine to prepare the body for sleeping. She uses aroma therapy.

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2. Acupuncture

This treatment has found some success with PPPs. Before pursuing this treatment for whatever reason, one should get a professional assessment. In addition, an independent psychological assessment should be included.

3. Benefits and Techniques of Aquatic Exercises

This form of exercise can provide passive manipulation of muscles. It can circumvent overuse of the muscles and derives added cardio benefits by having someone assist in producing additional needed body movements.

4. Dealing With Stress

Having Polio at a young age can produce trauma for the individual. Specifically, the trauma relates to being alone much of the time and the dislike of people leaving them alone again. This could result in Post Traumatic Stress in some individuals. They believe now that having an assessment by a psychologist is important in dealing with this trauma and its negative effects. It is also believed that all PPPs experience some trauma from their polio. One African American member of **APPA** had a problem obtaining proper medical attention as an African American. Specifically, she was not allowed into Warm Springs, Georgia. First Lady Eleanor Roosevelt was forced to help establish a polio treatment center in Tuskegee, Alabama, because all of her serious efforts failed to get Black Americans admitted into Warm Springs.

5. Yoga for Post-Polio Patients

During one session, the physician said that adults may find that in terms of motion Yoga is helpful. The Conemaugh Health System (www.conemaugh.org) produced a video in conjunction with the John P. Murtha Neuroscience and Pain Institute showing the application of Yoga for PPPs. It is entitled "Yoga for Post-Polio Patients." It is 43 minutes long and demonstrates appropriate exercises. The cost for this video was not indicated, only that it accommodates those who are unable to stand.

6. Evaluation of Treatment

All **APPA** attendees were impressed with the medical staffing for discussions of treatments, as well as the participation of expert physicians from around the world to conduct the various sessions. For this session they indicated that the various evaluations of treatments can be found on two Web Sites: www.pubmed.gov and www.clinicaltreatment.gov.

7. Deceptive Ads/Secret Formulations

As the number of these ads and over-the-counter formulations are surging, they encouraged everyone to get a second opinion before buying into using these products. The reason for this caution is that it is entirely possible that polio is not the culprit. They encouraged attendees to get more involved in their own situation by actively questioning the merits of these products and to seek alternatives and all available testing results before investing in them. This decision may fall under the category of Complementary and Alternative Medicine (See number 16).

It was revealed that most PPP have low levels of Vitamin D. Low levels of this vitamin can produce fatigue. Further, absorption into the body requires taking Vitamin D pills with calcium. Although Vitamin D is produced by the human body with exposure to sunlight, it may be necessary to augment this level directly with Vitamin D supplementation. It was suggested that a daily 15-minute exposure to sunlight between the hours of 10 a.m. and 2 p.m. with the arms and legs exposed as an alternative. If intake of Vitamin D is pursued an initial level as high as 50,000 I.U. (International Units) could be prescribed and then slowly reduced to 4000 or 3000 I.U. These suggested dosages should be discussed with a physician before attempting to follow them on your own.

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8. Modifying Activities

The first recommendation is to try not to do every thing in one day or one trip. Rather, one should spread these tasks or errands over longer periods of time. The next recommendation was to move like a turtle and not like a rabbit. Utilization of labor saving devices (reachers, and/or mobility aids) should be used as much as possible. Overall, the endurance of PPPs is more important than their body strength. Modifying activities to preserve endurance is very important.

9. Exercise

How you exercise is more important than the exercise. The goal is to increase strength (where possible), flexibility, endurance and coordination. PPP must listen to their body during any exercise routine and should not be driven to exhaustion by a fixed routine or a video. Remember to apply common sense and to pace yourself. Seeking professional assistance is advised. Of primary importance when exercising with weights is that the use of lighter weights with more repetitions is preferred for maintaining endurance. Also, it is important to reduce the effect of gravity on the body. This statement relates to positioning the body to reduce any additional strain on the limbs, back or neck. Next, one needs to adopt the attitude that this effort is not a "I *have to do"* exercise (leading to fatigue) but a more leisurely attitude of "I do *not have to do*" exercise (leading to no fatigue) to maintain endurance. Doing the hardest activity on the day in your life when you are feeling good is preferable than on the day when you're feeling weak. However, stopping to rest is a good habit to adopt in all daily activities. One member learned that it is important for PPPs to eat protein about 15 minutes after exercising.

10. Demonstration and Discussion of a Post-Polio Examination

This was a two-part session with three physicians in which all of the steps were defined for a proper diagnosis. This information is important as it is believed the number of Polio Clinics is disappearing rather fast these days. The Web Sites cited above provide information on these sessions.

11. Bracing Evaluations

There is new technology involving leg bracing. They use aerospace technology of carbon-fiber, reinforced plastics to reduce the weight of the braces and new designs to make them less cumbersome. For example, leg braces having only one support brace instead of two. These new designs are being produced in the U.S.

12. Dealing With Fatigue

Two types of fatigue exist: muscle and overall body. The latter fatigue has not been closely examined. The physicians indicated that this assessment needs to be performed on all PPPs as everyone is different with respect to their fatigue symptoms.

13. Making Tough Decisions

There is a need for each PPP to describe on paper the condition of their health and known requirements for doctors to review. This includes a description of your stable condition. Everyone is unique with respect to both parts of their description. There is a Web Site that provides the form to guide you through this process. It is www.caringinfo.org. The physicians indicated that there is a new consideration being applied to DNR (Do Not Resuscitate) medical instructions. It instructs the medical staff to stabilize before acting on the DNR order. The advice of both a doctor and a lawyer are needed to advise PPPs on this legal, medical instruction. In addressing your needs as a polio patient to an anesthesiologist prior to any sur-

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gery, you must be in charge of your health and safety. PPPs should refer them to the recommendations of the Joint Commission concerning proper applications for polio patients. In following this recommendation one **APPA** member was told by the anesthesiologist that he will just switch to spinal anesthesia. She changed to another anesthesiologist. The physicians at the Conference told their audience to tell them to follow the "MD and ALS protocol." They also stated you should tell your doctor what he needs to know and to make him/her listen!

14. Flexibility Exercises
The goal is to maintain the length of the muscle. In these exercises do not wear yourself out. Remember to stretch for 5 minutes and then rest 5 minutes, or some other interval that suits your situation.

15. Dealing With Cardio Problems
All PPPs should attempt to do some aerobic exercises to increase their heart rate. Just doing simple and non-exertive exercises (with or without weights) will raise the heart rate. Switching to different non-exertive exercises will extend the workout period to help keep up your heart rate without over exercising your muscles. One person indicated that in aquatic exercises he swims for 1 minute and then rests for 1 minute. He strings different movements together to achieve an extended raised heart beat without exhausting himself (See Number 3). Slowly you will build up your condition. The physicians said it is important to find some program you enjoy and get into a routine of doing it.

16. Complementary and Alternative Medicine
A book entitled "Herbs At A Glance-A Quick Guide to Herbal Supplements" was available for purchase at the Conference. It is published jointly by the US Department of Health and Human Services, National Institutive of Health and National Center of Complementary and Alternative Medicine. Those considering using complementary and alternative medicines can get important information from this book.

IV. Meeting Closing Remarks

Those attending the Conference were told that if you are seeking a place to live that specifically addresses accessibility needs, you should know that "older, healthy citizens do not like living with disabled people." This attitude may present problems for PPPs and other disabled people. This situation may change with the bad news that "Baby Boomers" are becoming more and more disabled. The good news is that this situation may lead to better government consideration, and changes in the prevailing attitudes among healthy seniors.

Unfortunately, there is no centralized "support group" organization to coordinate the various efforts or to distribute important new information derived from support groups. What is needed is a central clearing house to monitor the progress of such groups so that they can advocate for themselves and distribute key information pertaining to the various needs of handicapped individuals.

The Conference physicians believe that every person with a disability has a story to be shared. Recently, **APPA** requested members to record their Polio stories and present them at meetings. Consider writing and presenting your story in the near future to share with other members.

Written by Ron Swor, Cheryl Hollis, and Ivy Stiles

Atlanta Post-Polio Association

June 2009 Meeting Summary

Ms. Amy Bohn

Ms. Amy Bohn, an occupational therapist (OTR/L) at Shepherd Center, was the featured speaker for the June meeting. Amy's experience treating Post-Polio patients (PPPs) has been extensive at the Shepherd Center, as well as treating Multiple Sclerosis, paraplegic, and quadriplegic patients. While at the Shepherd Center she developed a therapy program focused specifically on protecting the interests of her patients. This program provides for her direct interaction with all physicians administering to her patients. This interaction serves to prevent treatments or surgeries that may compromise the health and welfare of her patients. As this effort has proven effective, she has expanded it to include another major hospital. The title of her presentation was "Upper Extremity Management in Post-Polio."

Introduction

Amy's goals are to help her patients live better lives and maintain their health without damaging existing muscles or affecting mobility. Toward these goals, she focuses her patients on improving both their posture and muscle balance. She stressed that both of these concerns greatly affect a patient's ability to breathe effectively.

To breathe, three areas of our upper body are used: the upper chest, the lower chest and the two lateral areas (on the sides of our body). Improving the condition of our upper bodies, particularly the patient's posture, is crucial in facilitating effective breathing.

Amy stated that PPPs have to call on more cells in their body in order to work available muscles. Their ability to easily overwork muscles leads to loss of muscle function over time. Consequently, the regimen she uses for patients teaches them how to avoid muscle loss. Equally important is the fact that having to strain to breathe results in lower oxygen intake that affects performing needed daily routines. Amy believes that it is necessary to take a fresh look at all the knowledge and technology available and apply it to maintain the health of each patient.

Posture Maintenance

1-Towel Stretches

Amy stressed the importance of having a good posture. She defined a good posture as having all the vertebrae aligned straight from the base of the neck down to the base of the spine. Equally important for erect posture is the ability to hold the head straight up. For those patients not having erect posture, Amy demonstrated rolling up a towel into the shape of a rope that reaches from the base of the neck to the base of

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the spine. The diameter of the towel is about 1.5-2 inches. Next, Amy placed the towel on the floor and aligned her spine over the rolled-up towel to stretch the back. To prevent permanent injuries, Amy cautioned those who have curves in their back to proceed slowly and with patience in achieving a correction in their alignment. While in the desired position, Amy showed that extending the arms straight outward from the shoulder on the floor opens the shoulder positions for better breathing by the patient. Staying in this position for a brief periods of time expands the chest for a better respiratory function. Amy indicated this stretching exercise can be conducted while lying on your side. In this position the towel (not in a rope shape) can be inserted at the waistline to keep the back vertebra aligned. The arm resting on the floor is held straight outwards. Movement of the other arm induces the chest to expand.

2-Positioning
For those unable to sit upright in a chair, or who need assistance in holding their shoulders back, several photos were provided to illustrate correct sitting position. Using a patient sitting in a wheelchair, she pointed out the poor positions with the patient slumping forward and having rounded shoulders. Then, she pointed out the correct positions of a straight back and shoulders pulled back in the wheelchair. In another photo a young woman was fitted with a simple, adjustable figure-eight back support. The looped ends went over the shoulders, with the mid portion crisscrossing the back between the shoulder blades, causing the shoulders to be pulled back. Both an improved posture and better breathing were achieved.

3-Scapular (Shoulder Blade) Mobilization
To enhance mobilization of the shoulders, the patient is first positioned lying on his back. The therapist massages the front side of the shoulders. Afterwards, the patient is rotated onto his side and the back portion of the shoulders are massaged.

4-Improving Breathing
Amy demonstrated that without good posture breathing is restricted as are the mobility of the arms. She sat on the edge of a chair and leaned backwards to create a slumping shape in her back when her back contacted the back of the chair. In this position she showed that any attempt to raise the arms
above the head was severely restricted, as was breathing. Doing the same exercise with the back vertebrae straight proved to be much easier in raising the arms and expanding the lungs. Amy emphasized getting your head as close to straight back as possible for effective breathing.
Next, Amy sat in a chair leaning sideways to displace the hips to show how this creates an imbalance in the lateral body muscles. In this misaligned back position the laterals cannot assist breathing. To get more intake of air, she suggested using the neck muscles to straighten up. This raises the shoulders.

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Even when lying on your back on a hard surface with a rolled-up towel aligned to the spine, you can produce stretching of the arms and the chest and perform exercises. She suggested trying to do this for 10-15 minutes a day but build up to this level very slowly to avoid serious injuries. A similar stretching exercise while lying on your side on the floor with the towel tucked into the waist area produces a similar benefit. It also allows stretching of your trunk.

Amy related that an abdominal binder can be used to facilitate good breathing with less stress. Such devices are used by people who participate in sports. The strap is positioned just below the sternum for deeper breathing.

Cheryl Hollis, program coordinator, welcomes the group.

APPA members attend the June meeting.

Strengthening and Cardiovascular Exercises

In performing some of the stretching and other exercises demonstrated, Amy indicated that cardiovascular improvements can be achieved with exercise repetitions. These cardiovascular exercises help to provide balance of the muscles in the upper extremities as well. With most exercises, Amy indicated use of some weights may not be possible. Also, one needs to be cognizant of their body and muscle limitations and must never work to exhaustion. In exercises of the arms, for example, repetitions can be performed. To avoid overworking the arm muscles, she suggested that you need to determine when those muscles fatigue. For this reason one must proceed slowly. She also stated that it is better to do more repetitions without weights than to exercise with weights in most cases. Amy admonished never to exercise beyond any muscle fatigue level. She added that if you can exercise try to find a routine that allows you to exercise for 30 minutes without fatigue. The may mean no use of any weights and/or exercising for 4-5 minutes followed by 1 minute rest breaks to avoid overworking the muscles.

For best cardiovascular development, the goal should be to reach 25-30 repetitions in a particular exercise without using any weights and without feeling any pain or fa-

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tigue. The best approach is to start without using weights to determine how high you can go before experiencing pain or fatigue. The principle to follow is to increase the repetitions slowly over a period of time and not in one exercise session.

If you can reach 25-30 repetitions consistently without pain or fatigue, decrease the number of repetitions by 10 and try a small (one pound) weight. Listen to your body and remember to not over use your muscles to preserve their strength. The same warnings apply to swimming and use of exercise modalities.

If you are using weights (small) and you have determined that 15 repetitions can be made before fatigue occurs in the muscle, at the next exercise session reduce the number of repetitions with weights by two repetitions and continue without weights until you find the combination that produces no pain or fatigue. Again, this should not to be determined in one exercise session. *You must proceed slowly to protect these muscles*.

Upper Extremity Strengthening

1- Air Splints

Two photos showed a patient lying on his back on a mat with an air-inflated splint over the entire arm. This splint holds the arm fully extended. The patient was shown raising his arm straight upwards and, then, lowering the arm to the mat straight out to the side. This is the intended exercise pattern.

2-“Terrible 3’s”

Three photos served to illustrate the “Terrible 3’s” exercise using air splints on the arms. The first photo showed the patient on his back resting on a mat with the lower legs resting on a flat, raised surface. The upper part of the legs are supported with cushions. This position keeps the back flat on the mat. The exercise encompasses lifting and lowering the lower legs from the raised surface.

The next two photos showed the person on the mat lying on his stomach. He is resting his chest on a pillow to reduce pressure on the neck. The air splints are attached to both arms to keep them extended. The exercise is raising one arm (or both) off of the mat. This is a very difficult exercise to perform and should be attempted only under the guidance of a trained specialist (OT).

3-Theraban Exercises

Amy showed two photographs depicting the process where a patient in a wheelchair stretches a rubber strap attached firmly to the wall. The patient uses one hand at a time and stretches the band to a resistance level that is beneficial but not overworking the muscles. It appears that more than one direction for the hand/arm movements are possible in this exercise.

4-Prone on Elbows

In a photo Amy showed a patient lying on his stomach and supporting his upper body on his elbows. The exercise involves repeating the process of slowly raising the head upwards and, then, lowering it again. Use of a pillow is permitted to eliminate any dis-

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comfort from being on the stomach as needed. In addition, this exercise helps restore balance to the shoulders.

Cardiovascular Facilitation-Rotator Cuff Exercises

The four different muscles that control movement in the Rotor Cuff can be exercised independently. Many patients have problems with mobility in this area of their upper extremities. Amy discussed exercises that create better balance among these four muscles of the Rotator Cuff, and that improve scapula (shoulder blade) mobility. Exercises to stretch and strengthen these muscles were demonstrated while lying flat on her back and gripping with both hands on the a cane obtained from the audience. Amy mentioned that this exercise could be performed with the rolled up towel used to align the back vertebrae as discussed above. With hands comfortably apart on any low-weight rod, the rod is raised upwards to full arm extension over the chest area. Amy used twisting motions back and forth about the center of the rod creating an angel-wing pattern. Another exercise movement in this position is moving the rod over the head as far back as possible and back to the straight up position while keeping the arms extended. The last exercise demonstrated to exercise the Rotator Cuff was moving the rod side-to-side while keeping the arms extended above the chest as the starting position.

Another easy exercise for the Rotator Cuff involved the “terrible 3’s” muscles. These muscles allow the arms to rotate. In a standing or sitting positions one holds the arms slightly away from the body and the elbows bent at 90°. The exercise involves rotating the arms slowly back and forth in big movements, causing the bones to rotate at the Rotator Cuff. Additionally, this exercise can be conducted lying on the back. With both arms extended out from the shoulder and elbows bent at 90° angles to make the hands extend upwards, the hands are lowered slowly to the floor and back to the pointing upwards position, back and forth.

Amy related that these exercises have been applied to athletes where their shoulders drop down affecting the alignment and moving the shoulders forward. The prescribed exercises move the front and back muscles that control shoulder positioning to re-establish the needed balance.

Prevention for Elbows

Acquiring a short crutch and a cane from the audience, Amy showed how important it is to learn to correctly use these devices. A crutch can produce elevation of the shoulder if not properly adjusted to the height of the patient. Improper adjustments also put pressure on the wrists and elbows. The metal elbow support band on the crutch must be aligned properly so as not to put

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pressure on the complex nerve network in this area, creating painful tendonitis. Using a cane that is not properly adjusted to the patient's height can cause nerve damage. This damage occurs either to the wrist or to the triangularly-shaped bone in the hand near the wrist, depending on how the cane is held and used. There are elbow exercises to reduce the discomfort. With the arms extended forward, bend the hands at the wrists up and down with the fingers extended helps to relieve discomfort. Also, rotating the hands clockwise and then counterclockwise through 360° sweeps about the wrists provides relief.

Miscellaneous Subjects

1-Sleeping

Amy asked the audience what is the best position to sleep? Their answer was wrong and was the worse position. Their response was the fetal position. She indicated this position is bad because one moves the shoulders forward, clasps the arms tightly to the chest, folds the wrist and tightens the grip of both hands. In other words it is bad in terms of what Amy has been saying up to this point. Just moving the shoulders forward is bad enough in affecting posture and breathing. She added that football players who work out excessively develop this rounded shoulders condition that is not desirable. It turns out that the best position is sleeping on the stomach. However, as not many people can sleep this way anymore, Amy suggested sleeping on your side (as she does), using pillows to prop your head and support your arms.

2-Carpo-Tunnel Syndrome

Carpo-tunnel syndrome problems can lead to muscle loss if not corrected. She suggested getting good treatment as soon as possible after diagnosis by a hand specialist.

Elbows, Forearm, Wrist and Hand Problems

Someone in the audience indicated that excessive leaning on the elbows has created soreness in his elbows and some numbness in the hands. Amy reported that use of canes and crutches also may cause similar pain in these areas. She suggested investigating the use of elbow pads. These are similar to the ones roller blade skaters use. They come with gel now in the elbow contact area to better distribute the pressure over a larger area to relieve discomfort.

There are exercises to help relief this pain. She talked about imagining you are holding two cups of coffee in your hands with the elbow bent at 90°. While holding the cup upwards rotate it to the down position. She also mentioned that there is a Neoprene rubber strap available for purchase that helps alleviate some of the problem. There are some injections available now that may eliminate surgery. In the case of treating trigger fingers (finger joints sticking in one position), Amy admonished the audience to think through the

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problem before submitting to any surgery. Her implication was to address reducing the activities that brought on this painful problem and alternative treatments.

ROM Exercises
Amy illustrated three separate exercises for ROM (range of motion) problems. They are:
1. Extend the arms forward until they are straight and turn the palms down for forearm stretch. (Additionally, the hands can be bent slowly through the upward and downward positions, and the hands can be rotated about the wrists clockwise and counterclockwise to reduce discomfort. Spreading the extended fingers to their widest position may also produce benefits.)
2. Sit with arms resting on the arms of a chair. With the wrists slightly hanging over the edge, slowly bend the hands to the upward and downward positions to stretch these muscles.
3. For the fingers, slowly move each joint up and down. (Gentle bending and massaging of the fingers may also be applied.)

Office Worker Problems
Amy addressed the serious posture and breathing problems among workers who have desk jobs. They lean on their elbows all day and slump at their desks. They have both back alignment and muscle balance problems due to multitasking and, possibly, using bad office equipment. Those who use Blackberry telephones suffer from overused thumbs, creating great pain. They need to buy better equipment and engage in exercises to relieve them of these hand symptoms. Their wrist problems usually develop from imbalance problems between the extension and gripping movements of the fingers. This imbalance needs to be addressed.

Summary was written by Ron Swor and Cheryl Hollis

APPA is very grateful to Ms. Amy Bohn for volunteering to enlighten its members on the importance of Upper Extremity Management for Post-Polio Patients, Her special patient treatment approach, showing what is required for proper posture, muscle balances and breathing, serves to guide **APPA** members in identifying their needs and treating them accordingly. This important information was warmly received and will help the members to live better and healthier.

Tech Bits & Bytes

By Joe Drogan

I got to thinkin' about computer accessibility after our recent presentation on OT/PT. I spend a huge amount of time at my computer and have for more years than I'd care to admit. (Let's just say when I started on this computer "journey" the computers I programmed would fill the auditorium at Shepherd Center!) One weak link has always been the ability of humans to interact with the computer. Today I'd like to talk about things that make that access easier and more comfortable for us.

The Display: (ya gotta be able to see what you're doing)
For me, the bigger and clearer the screen is the better. It is a $ issue though. Here's a shopping tip, you can buy a Hi-Def TV (780 or 1080 resolution) with pc input and it'll work great as a monitor, it's cheaper, and you can watch Oprah on it too! It needs to have a VGA input connector on it that looks like this. (unless you have a HDMI video card in which case you probably know all this already).

Here are some tips on display settings:
You can change the screen resolution to make things bigger, good for text stuff like email, or smaller so you can get more things on one screen. Right click on a blank area on the screen, select properties, select settings tab, adjust the slider, and click apply to try the setting.
In your browser (IE7/8) in the lower right corner you'll see a 100% dropdown box, Clicking on it cycles thru the zoom modes 125%, 150%, and 100%.
In Outlook and Outlook Express you can click on the view button on the menu bar (that's the one at the top with File Edit View Tools......Help) It drops down to reveal Text Size > click it and select size text you want. This won't work for everything as some emails are viewable only in the senders format. In Windows you can set up a user account for each user on the computer that saves different settings for each.

Note: Click Start/Programs/Internet Explorer means click Start, then click Programs then click Internet Explorer.

There is also some other neat things to play with, click Start/Programs/Accessories/Accessibility there you'll see a magnifier program and an on screen keyboard (OSK). Click on the magnifier and it opens a new magnified window. Wherever you move your cursor the contents are REALLY BIG. Great for graphics! (or makin' that SSDI check look really huge!) Right click on its title bar (the colored bar at the top) and you can change magnifier options. The OSK is neat when you are sitting back in your chair, browsing with your mouse, and you just need to enter a few characters without reaching for your keyboard. There is a narrator program that can read text to you. A lot is being done these days with narration and voice typing software. You talk and it types for you, or it can read to you in various voices. I've done work in this area and amazing things are out there and getting better. It is however a whole subject in itself. If there is interest I

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can write an Tech Bits & Bytes article on it.

<u>Hardware:</u>
Keyboards – Wireless ones are convenient, you can put them in your lap and give your shoulders a break. You can buy extension cords for the wired ones that will allow you to put it in your lap. I use a fancy wired one (a Logitech G15) that has keys you can setup for entering strings of info you enter over and over like your email/street address. You hit one key and bingo! <u>Not recommended for passwords though</u>. It's got tons of other cool features like a volume control, skip, pause/stop for CD's, it lights up, has a little LCD screen on it that shows info about my system, weather, #emails unread, etc. (yep you CAN get carried away with this stuff!). They also make large keyed ones with large letters on them too. (our eyes aren't getting' any younger)

Mice – Where to start? Once again wireless is nice. If you're not typing, just browsing around, you can sit back and "drive" your computer from your lap!
They make them with wheels for fast scrolling, extra buttons that can be set to suit you. I have buttons set on mine that do "copy" and "paste", zoom in/out, delete, so I don't need to reach for the keyboard as often. They even have "air" mice that move with your hand in the air. You tilt your wrist up, down, left, right to move the cursor around.

Laptops – For many of us a laptop is best. It sits on our laps and makes access easier plus it travels easily. A few things to note. You can get "cool pads" (no, not some groovy apartment in "Little Five Points") that keep your lap cool. Some even have little fans in them that run off the USB ports on the laptop. A laptop can be hooked up to a regular monitor, keyboard, and mouse too so you can have it either way. A portable system when you need it and the comforts of home when you're there. I carry a little wireless mouse with mine 'cause those little touchpad things make me $%^'ing crazy.(er)! Size DOES matter when it comes to some things. (oh boy here we go again with the **APPA** censors ;-) If your laptop is too big they get kinda' heavy to lug around or won't fit well in a storage pocket. If they are too small they are hard to read/use. The netbooks are getting popular. They are small and light. They are a little pricey for a minimal laptop but they will come down as production increases.

Other - Voice control is getting better & better. Someday it <u>will</u> work like Star Trek. Intelligent switches that let you switch your mouse, keyboard and monitor between computers. Yeah I have several. Still need to buy a McIntosh someday - don't I Alice;-)

New cool stuff is being developed all the time. I'll try to keep you informed. Look around, ask questions, there's something out there that can help you be more comfortable and productive and have fun too!

Until next time - **Happy Computing!!!**

APPA wishes to thank the following for their donations to APPA:

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APPA UPCOMING EVENTS

Nov. 7 Business meeting - plus **Roy Wise** from Rotary International "End Polio Now" campaign will have a short presentation
1 PM @ Shepherd Center

Dec. 5 Holiday Party
11:30 AM @ Brio Tuscan Grille - 2964 Peachtree Road NW
Atlanta, GA 30305

Shepherd Center Auditorium, 7th Floor
2020 Peachtree Road, Atlanta, GA

Very Special Arts Update!!
The contact information for VSA has changed ---
It now is Barbara Forest barbaraforest@gmail.com

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Return TO: **APPA**, P. O. Box 250566, Atlanta, GA 30325
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Please **CHECK** one.

☐ I am a new member. ☐ I am renewing my membership.

☐ I've already sent my tax-deductible annual membership contribution, but my contact information has changed as shown above.

☐ I am unable to contribute at this time but would like to receive the **APPA** News.

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☐ Program planning
☐ Assist with answering **APPA** phone line

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Barbara Reynolds	**APPA** Webmistress!!
Barbara Forest	VERY SPECIAL ARTS Ticket Coordinator
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Thanks, Your **APPA** Board

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