APPA News

The Newsletter of the Atlanta Post-Polio Association

Volume 20 Issue 1

www.atlantapostpolio.com

January-March 2007

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Editor, APPA News P. O. Box 250566 Atlanta, GA 30325

Letters of general interest will be published in future issues as space permits. We reserve the right to edit all letters for reasons of space and clarity. We will withhold your name upon request, but no unsigned letters will be accepted for publication. Opinions expressed in letters do not necessarily reflect the views of the Atlanta Post-Polio Association.

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Articles for next issue of APPA News are due to Linda by March 15, 2007 Please email to: lpriest3@comcast.net

President's Message

Looking Back While Focusing on the Future

This is the time of year to reflect on the past with a keen eye on the future. We have had a really productive year with a new Board of Directors and new Officers. We have accomplished a lot, in fact some would say that keeping APPA afloat was a great accomplishment!

It has been wonderful to see so many old members who left APPA, return to us. Our database is brimming full and our bank balance shows it. We actually have money for a newsletter and a Holiday party. Our future is looking bright.

We've had some great programs under the able direction of Sylvia Gray. In February Dr. Staton spoke to us about pulmonary disease and prevention. In March we traveled to Fayetteville to tour a new, accessible three-story home. In April Dr. Gandy spoke to us about heart disease and its causes. In May

we had our Annual Picnic hosted in the lovely Shepherd Garden and catered Corky's Barbeque. In June we had a rap session focusing on good doctors, and good experiences we have had with medical professionals. In August, Dr. Donald Leslie (Shepherd's Medical Director) spoke to us on Shepherd's Post Polio Clinic and the new construction and expansion underway at Shepherd Center.

In September we went on a cruise to the Caribbean aboard Royal Caribbean's Mariner of the Seas. In October we traveled to Marietta to be treated to lunch by Accessibility Services Plaza with a tour of their facility.

By the time you read this, we will have enjoyed our Holiday Party at Petite Auberge in Decatur. Not bad for a Board that started out the year with no place to meet!

Another accomplishment for which we are feeling a deep sense of pride is our new website at:

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www.atlantapostpolio.com

Plan to check this website on a regular basis. It has many interesting and new pages . . . including Meeting Notes with a synopsis of our most recent meetings and lots of pictures, Upcoming Events to keep you posted on the latest news, Marketplace where you can sell/buy used Rehab equipment, Meet the APPA Board where you can link to our contact information and our glamorous pictures, and our newest page Book Shelf where we have researched and listed the most recently published polio-related books on the market.

In addition to continuing our Sunshine Committee work under the direction of Nancy Truluck, and Very Special Arts under Barbara Forest, there are other areas where we are feeling a sense pride/accomplishment. We published a new APPA Directory and we are developing a new way to keep in regular touch with our membership. We are calling it our "Care Team". You can read about it elsewhere in this newsletter. It will be led by Charlotte Terry, and I hope you will consider becoming a part of "the team."

My hope/wish for 2007 is that you will become "a member of the team" and join us in serving and sharing with people who survived

polio. APPA is a great organization and 2007 is going to be a great year! I know there is a place for <u>you</u> in APPA. Our new membership form reflects our hope that you will join us as we unite in our common goal of serving each other. Thank you for allowing me to serve as your President this year. It has been my pleasure and my joy.

Linda Briest

Care Teams

By Linda Priest

We are elaborating on an idea from the Savannah polio group, called Care Teams. The idea is to create a support system via the telephone to reach every member of APPA. Many of our members are no longer able to attend meetings, some live alone and all of us need support and a kind word from time to time. It is a huge undertaking but Charlotte Terry has agreed to take on the task. She will be our Care Team Committee Chairperson.

How it works...We will divide the list of APPA members among Care Team Leaders. Each APPA member will be asked to contact their Care Team Leader in the event they have a polio concern, an illness, a hospitalization, death in the family, etc. Care Team Leaders will let

Charlotte know if someone is in need and appropriate action will be taken. One of the benefits of this effort is that we can send cards of support and list problems in a "Member Concerns" section of our newsletter so everyone can offer support and remember troubled members in their prayers.

We hope this will raise the level of communication among APPA members. In addition to periodically checking in with their Team Leader, members will be encouraged to contact other members on their team list to offer support and encouragement. Additionally, they will be encouraged to reach out to APPA Members who are ill or have not been attending meetings lately.

New APPA members will be assigned to a Care Team before they leave their first meeting. The Team and Team Leader should partner with the new member to offer support, encouragement and fellowship. I receive comments regularly from APPA members who tell me that they no longer are able to get out but that they look forward to receiving letters and other communication from APPA. In fact some say they read every word over and over. We hope that the Care Team approach will raise the level of communication within our

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organization and help to strengthen our support system.

Thanks to Note: those of you who have volunteered to be a Care Team Leader. We need more volunteers and hope you will consider helping with this worthwhile effort.



OBITUARIES

In recent weeks two long time members of APPA passed away.

finda Venuto and Jim Doherty

APPA sends condolences to their families.

MIAMI POLIO **GROUP**

will host a 2-1/2 day Post Polio International Conference, Partnering for a Better Tomorrow, April 9 -11, 2007, at the Radisson Hotel Downtown. Miami, Florida. Call hotel (800) 342-7499 Pilots Club of Metro Atlanta. ask for "Post Polio Interna-Conference" block tional room rate of \$119. Registration forms and fees to be available soon. Watch for more details in the near future at our www.postpolioworld.com or call (305) 652-6217 or email postpoliomiami@aol.com with questions.

A Post Polio group cruise is being offered after the conference. cruise to the Eastern Caribbean aboard Royal Caribbean's ship, Voyager of the Seas, will depart the Port of Miami on Saturday, April 14, 2007. If interested in joining them, contact Faye at:

Toll free # 1-866-447-0750 e m a i l o r fave@travelgroupint.com. Mention "Post Polio Conference Cruise" to get the group rate. To get more details on how to accommodate any special needs email Maureen of the Boca Raton Post Polio Group at BAPPG@aol.com or call 561-488-4473.

Two APPA Members Win Art Awards

APPA members, Lucille Anderson and Marie Latta have been long time entrants in the Annual Georgia Artists with Disabilities Exhibition, sponsored by the

The two-week show and awards ceremony are held annually in September. Lucille has consistently had award winning oil paintings.

This year Marie, who websites: has won awards numerous times in the past, had an award-winning photograph in 2006, her first since 1998.

Lucille's BestShow painting oil and Marie's Honorable Mention A 7-night photograph are currently a part of the juried yearlong traveling show in towns and cities throughout Georgia.

NEW APPA DIRECTORIES

The new APPA Directory was published in June 2006. It contains a list with contact information for all members whose dues were paid at that time. For those of you who have paid dues since that time, we have mailed a copy to you. Anyone else needing a copy may purchase it for \$2.00 (includes mailing charge). Our goal is to publish a new directory each June.

Thank You to Our 2006 Board of Directors

By Linda Priest

I wanted to take this opportunity to thank each member of our Board for all they have done to make 2006 a great year for APPA. They are David Jones, Nancy Truluck, Sylvia Gray, Charlotte Terry, Dave White Reynolds. and Barbara David, as our Vice President, has worked tirelessly wearing many hats and serving as support on virtually every committee. Nancy has done another stellar job as our Secretary, our Nominating Committee Chair and as our "Sunshine Committee Chair". Sylvia has done a yeoman's job as our Treasurer and our Program Chair. Charlotte has done a wonderful job keeping us all connected via the telephone and as head of our Phone Tree. Dave White has also served in many capacities and is currently answering our phone line, which rings at the Shepherd Center. Barbara Reynolds worked hard taking over the website and creating an upto-date and useful tool for everyone to enjoy.

Others who serve APPA in key positions without serving on the Board are Irvin Massey our everfaithful Librarian, Barbara

Forest our VSA contact, Ron Swor who is writing articles for the newsletter and website. Cheryl Hollis who bravely took over Social Events just prior to the picnic, and Alice Felton our proofreader. Finally. have a newsletter!!! Thanks to Bill Caudle who recently volunteered to help us. We are so excited about having him onboard. Hopefully, this newsletter will be the first of four we publish this year.

We have two new Board Members who will take office January 1, 2007 and serve a three-year term. They are **Karen Sebastian** and Shirley Duhart-Green. Please make every effort to welcome them and show your appreciation for their willingness to give of their time to APPA.

It has been a wonderful year serving with such a great group of people. They all deserve your praise. Please take time to thank them for their hard work and contribution to APPA.



A Big APPA "THANK YOU"

to the following people who donated additional funds to APPA in 2006

Gloria Powell
Rick & Jenny Worsham
Ann & Russell
McWilliams
Ann Coultrip
Jean Dunbar
Sylvia Bates
John Peatman

Note: Please let us know if we missed anyone.

2007 Meeting Schedule

February 17, 2007 10:00 AM Piedmont

HospitalBuilding 77, Ground Level, Classrooms 4-5

April 7, 2007 1:00 PM Emory Rehabilitation Center

First Floor, Conference room.

June 2007 Shepherd Center Garden

APPA Annual Picnic Exact date & time TBA

Starting August 2007

future meetings will resume at the Shepherd Center.

2007 PROGRAMS

As we approach 2007 your Board is trying to create new programs. We want to educate and entertain. If any of you have ideas about programs, please let us know.

We plan to do a picnic, a Christmas party, and other events. Do you know a great speaker you have heard? Have you seen a fun entertainer? We want to stress post polio information, but also have fun. Contact me or any of the Board. David Jones wdj1242@bellsouth.net 770 513 7984

DON'T FORGET! APPA Dues January 1, 2007 Membership Form on Page 11

Question?

Would you be interested in joining us for a cruise in the fall of 2007? Let us know

<u>Ipriest3@comcast.</u> net

or 404 636 2049.

Two New Books Purchased By APPA

APPA purchased <u>Polio An American Story</u> by David M. Oshinsky and <u>Living with Polio</u> by Daniel J. Wilson for the Noble Learning Center Library at Shepherd. These books are available for your use. They are dedicated to Dr. Donald Leslie and Irvin Massey, respectively, for their work and devotion to APPA.

HEY LOOK!

You can find us now at www.atlantapostpolio.com
Look for us often if you don't want to miss the latest
APPA News.

Very Special Arts

Georgia VSA of makes available to APPA members many different types of free tickets to various ven-Availability of tickets can be checked by calling the hotline at 404-221-1270 and pressing "2" when the message starts, or by checking the website www.vsaartsga.org. If you would like to receive Hotline Script via email, please send a r e q u e s t jan.truslow@VSAartsGA.org

Once you find an event you would like to attend, you may request tickets by emailing your request to <u>barbaraforest@hotmail.com</u> in the following format:

- Name of event and location
- Number of tickets
- Number of children
- How many wheelchairs or special needs
- Date of event
- Day of event
- Time of event
- Your name
- Your phone number.

If you do not have access to the Internet, you may call Barbara Forest @ 404-634-8875 between the hours of 9am. – 7pm. Please leave the above information.

There are 2 distinct ticketing programs:

Ongoing Events: Museums and exhibits that are available throughout the year including visual art, history, nature, science, and government. These tickets require 2 to 3 weeks notice.

Special Events Entertainment productions offered for a limited period of time. These include theatre productions, music events, concerts, dance productions, sports events and festivals.

Remember your past mistakes, only for what you can learn from them.

→Did You Know?

Bv Linda Priest

Did you know that in addition to APPA we have three other active post polio support groups in Georgia?

They are Coastal Empire Post Polio Survivors Association in Savannah, Warm Springs Post Polio Group in Warm **Springs and Mountain Area** Post Polio Group in Jasper.

Coastal Empire Post Polio Survivors Association (CEPSA) is lead by Diane Davis. They produce monthly newsletter, "The Lighthouse", and meet monthly in the Savannah You can find out more about this busy group at www.coastalempirepoliosurv ivors.org.

Warm Springs Post **Polio Group** is lead by *Bill* Crowell. Several years ago this group decided to divest itself of all organizational responsibility. They do not have officers, a newsletter or website. They meet monthly in Warm Springs to socialize and provide support to each other. They believe without all of the trappings of an organization they have the time and energy to care and support each other. For more information you can contact B i 11 a t williamcrowell@vahoo.com.

Our newest post polio group in Georgia is the http://www.nih.gov/news/pr/j Mountain Area Post Polio Group (MAPPG) lead by Rosemary Hendrix. Thev recently hosted a polio clinic headed by Dr. Dale Strasser of Emory University Rehabilitation Center. To find out more about this organization you can contact Rosemary at gafla@earthlink.net.

In Georgia we are truly fortunate to have so many dedicated people serving as a vital resource for people who have had polio.

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News Release from the **Public Liaison Officer** of NIH's Neurology Institute

Neurons Grown from Embryonic Stem Cells Restore **Function in Paralyzed Rats**

For the first time, researchers have enticed transplants of embryonic stem cell-derived motor neurons in the spinal cord to connect with muscles and partially restore function in paralyzed animals. The study suggests that similar techniques may be useful for treating such disorders as spinal cord iniurv. transverse myelitis, amyotrophic lateral sclerosis (ALS), and spinal muscular atrophy.

The study was funded in part by the NIH's National Institute of Neurological Disorders and Stroke (NINDS).

The full story appears un2006/ninds-20.htm or by accessing the main news section of the NINDS website (www.ninds.nih.gov)

Please note that the research was done on rats and two researchers reminded the reporters that there is a "great distance" and "long way to go" before this can be tried in humans, but the results are interesting and encouraging

Cruise Notes:

To cruise or not to cruise. that was the question. Well a group of us from APPA and some other friends decided to go to the Western Caribbean in September. I had heard a lot about the new modern ships.

My last cruise was about 30 years ago. NO they did not use oars. We booked the Royal Caribbean Mariner of the Seas for seven days. It might have been called Accessible of the Seas. From the arrival at Port Canaveral to our return, we were taken care of. I knew it was going to be good when they waived our parking fee if we had a handicap parking permit. The parking lot was across the street, close. The entry was grade level to the ship. I took my scooter, a wise choice.

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There were many on board that were disabled, and we made new friends.

We had an accessible cabin. It was large to say the least. A king bed, dressing area, large closet, roll in shower. The bath had a built in shower bench, hand held shower head, grab bars everywhere. The balcony was accessible, and we had breakfast there most days, with no extra fee!!

Many elevators were onboard. The common restrooms had push button doors. Our group sat together for evening meals, near a large picture window overlooking the Caribbean. The food was incredible. Two lobster tails.....why not. Our waiter loved zooming around the dining room on my scooter as we dined. Then he gave us a lesson on napkin folding. Some went on shore excursions; we made four ports. Those on the ship did not run out of things to do. They made getting into the pools easy with a lift.

As I am ambulatory also, the shore trips were OK. There were always fellow passengers ready to help. The ship loaned me a lightweight wheelchair for all shore excursions, very nice. In Grand Cayman the head gardener rolled me around the gardens and picked flowers. that no one else could. When I could

not board one bus trip, Royal Caribbean gladly refunded my money. The cruise was all I had hoped it would be. A great value for the money spent . I am looking forward files, as well as our own to the next cruise,

Bon Voyage



APPA Library **Changes Hands**

By Irvin Massey

Recognizing that there was very limited use of the APPA library by our members, the APPA Board voted to donate library materials -- books, videos, and audios -- to the Shepherd Center Noble Learning Resource Center. Polio materials will no longer be set aside just for use by APPA members, but will be available to Donating the everyone. APPA library to Shepherd will make it possible for anyone with an interest in polio to have access to the information. We believe it is important to provide our information to anyone who wants it.

Shepherd librarians have assured APPA that we can continue to have shelf space for our out-of-state post-polio support group newsletter APPA newsletter file. APPA materials are being catalogued with other Noble Learning Resource Center literature, but Shepherd files are alphabetically arranged by subject matter most post-polio materials will continue to be easily found in one shelf area. Of course, the Shepherd librarians -- Stacie Waddell and Mary Kay Howard will be available every weekday for assistance. The Shepherd Center has through the years been a generous supporter of APPA in many ways, and APPA can expect that to continue even more so with the completion of the large new hospital addition which will be completed next year.

DOUBLE SURGERIES AND TWIN TUBES

Marie's Mav **2006 Hospital Experience**

The first week of May 2006, I had a cold that turned to bronchitis. Before I could turn around it had gotten away from me. On May 8, 2006, I had a follow up checkup with Dr. Kenny, my

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pulmonologist. He had the nurse walk me from his office to Piedmont Hospital, where I remained until May 23. This Ms. Organized was not prepared for that!

Kenny Dr. more aggressive respiratory treatment and did a bronchoscopy. My muscle tone was so weak that he had difficulty swallowing, he ordered that I had no muscle tone in and around my esophagus and study, the therapist who administered it went right to my doctor with the urgency and possibility of a feeding tube. ies! After Dr. Kenny and I considpossible aspiration, we added on the tracheotomy.

On Mothers Day, May 14, 2006, in one surgical sesa feeding tube (G-Tube, also fondly known as a PEG) placement into my stomach. Both are permanent. I tell the road with this. people the hospital had a Mothers Day two for one special. I am thrilled to still have my voice (which isn't always learned to dine independently and lots of water. I do no oral eating or drinking. I don't even swallow my own sa-

social challenge.

we have averted a disaster. And I agree! I have known that these surgeries might be in my future. I just didn't started know the future was now! When I had bulbar polio in 1949, I had an emergency tracheotomy which was in about 2 ½ months. I ate through a getting the scope in. Because I nasal feeding tube for one was having increasing trouble year. I actually learned to take a the tube in and out to clean it, swallowing study. It revealed my criteria for going home two days before Christmas after almost 4 months in the windpipe. After viewing the hospital. So.... all this residual weakness stems from that time. And we know what tricks age plays on our bod-

On May 23 I was disered my limited breathing and charged and not a minute too soon. Too much time in a hospital bed is definitely detrimental to ones health. I told Dr. Kenny we had done our sion, I had a tracheotomy and job and it was time to go home. For a while I had home health services. There have been some serious bumps in

The challenges I have faced have a lot to do with a reality we all face as polio survivors. Our needs are often the case after a trach). And I out of the ordinary, and we am delighted that I have are aging. If my tubes were children, I would say I have by feeding myself the formula one easy to get along with child and one unruly one. My trach tube is no problem; the feeding tube is a high mainte-

liva... definitely the biggest nance trouble maker. My surgeries were successful. But Dr. Kenny feels that the challenges in managing my new post-surgery way of life have been almost overwhelming... mostly because of lack of information. The bottom line problems have been due to deficits in the health system.

> I must say that Dr. Kenny is a shining exception. He has been my lifeline in getting me through the maze of changing needs, even in the areas that are out of his field!

> I have started writing about my experiences and will continue to be a voice for change. So stay tuned in future months. My experience has reaffirmed that we can never let down our guard in managing our own health care. It has been alarming for me since May to see that:

- Very quickly the hospital wanted to turn my life over to "Caretakers".
- Too many nursing, therapy, technical, and support staff are still defensive with patients who expect to have a voice in their healthcare.
- There seems to be a severe disconnect between medical disciplines.

There was a dismal absence of patient instruction and education in the hospital. I went home without instruction regarding the use, care, and maintenance of my tubes.

> It is our job to keep (Continued on page 9)

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insisting that we have a voice, be treated with respect, be informed, and receive superior quality care. My fighting spirit has burned its way through my initial weakness and fatigue. We must continuously be like the "Night Watch"... never sleeping on the job and calling out warnings to each other.

© Marie B Latta 2006 with permission for use by APPA

APPA's thanks to

FODAC

AKA Friends of Disabled Adults & Children, too.

By Bill Caudle

APPA is indebted to FODAC for enabling APPA to resume publishing the newsletter again.

Recently, Sylvia Gray contacted Bill Caudle, APPA's new editor, and asked if he thought FODAC would donate a computer for APPA's use in publishing a newsletter again.

When Bill met with **Chris Brand,** President of FODAC, and asked the question, Chris' immediate response was "Let me see what I can do."

A few days later Chris called Bill and told him "it is available, pick it up."

FODAC has always been a friend to APPA and this was no exception.

APPA folks, you can thank Chris for making it possible to restore life to the letter by visiting FODAC and especially their Thrift Store, Both are located in a HUGE 64,000 sq. ft. building located at 4900 Lewis Road Stone Mountain, GA 30083 770-491-9014. (Just off Stone Mountain Freeway (Hwy.78)

Give Chris a call and make an appointment to visit and enjoy what FODAC does to enhance the quality of life for those less fortunate who must depend on others for various things to make life more pleasant on a daily basis.

It's an experience you won't ever forget!



KIDS IN CHURCH:

A little boy was overheard praying: Lord, if you can't make me a better boy, don't worry about it. I'm having a real good time like I am.

STAY WARM

By Rick Van Der Linden

Even on mild days hypothermia can happen very quickly. It happened to me.

It was a breezy, seventy-degree day. I was cleaning my spa in a tee shirt and shorts, but I felt good and the activity seemed to keep me plenty warm until I got the front of my shirt wet.

I remember looking down and thinking how icy cold I had suddenly become and wondering why I wasn't shivering. The next thing I know I'm covered with blankets, sipping hot tea and wondering what day it is as my memory very slowly returns right up to the moment I noticed my wet shirt.

Sandy had discovered me wandering around babbling the same questions over and over and complaining about a strange thing that just happened to me. Fortunately, she figured out that I was cold and took immediate action to warm me. It had taken about and hour for me to return to planet Earth. she had not been there I may have lost my life. As it was, all I lost was about an hour. Lucky me.

Many of us are cold weather intolerant.

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When I get too cold I first experience pain in the areas with the least muscle and then, adhering to the ifit-hurts-don't-do-it policy (iihddi), I proceed to get warm as quickly as possible.

But what if you reach your low threshold and continue to get colder? Hypothermia can really sneak up on you. When your core temperature gets down to 95 degrees, memory and judgment begin to fade, you begin to lose control of muscles, and speech becomes difficult. Below 89 degrees consciousness begins to fade in and out and your heartbeat slows down to fatal levels.

To prevent this from happening, our bodies are equipped with emergency response- shivering. Shivering requires a lot of energy to be directed to the muscles as your body burns calories to create heat. If you get cold and you don't have the energy available, or if you are shivering and suddenly stop, you may be in for some serious trouble.

Complicating the situation, in my case, shivering hurts (refer to iihddi above.)

At my next visit I casually mentioned the incident to my doctor. Because of that incident and a few

other little neurological oddities (which I presume to be polio related but my doctor doubted) she referred me to a very nice neurologist. I now have an EEG printout proving that all the marbles are there. Now, if I could only use them.

I usually dress in layers and stay warm and dry but that day I slipped up. PPS requires full time management. Never let your guard down. Know your limitations. Never bite off more than you can chew. Your life is on the line.

Reprinted from PPS Manager, CA.) February 2001

If we command through intimidation, we may create followers.

But if we lead through gentle strength, we will build good leaders.

LAUGHTER IS GOOD MEDICINE

DOCTOR, DOCTOR

Two doctors and an HMO manager died and lined up together at the Pearly Gates. One doctor steps forward and tells St. Peter, "As a pediatric surgeon, I have saved hundreds of children." St. Peter lets him enter.

The next doctor says, "As a psychiatrist, I helped thousands of people live better lives." St. Peter tells him to go ahead.

The last man says, "I was an HMO manager. I got countless families cost-effective health care."

St. Peter replies, "You may enter." But, he adds, "you can only stay for three days. After that, you can go to hell."



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NEWS YOU CAN USE!

Clarity, manufacturer of Clarity Power Amplified Telephones for the hearing/visually impaired has made available a limited number of telephones, for a limited time, to be given <code>FREE_</code> to anyone willing to attend a free demonstration of a <code>Clarity</code> phone. If you are hearing impaired and would like to receive a <code>Clarity</code> amplified telephone, which will <code>enhance your quality of life while using the telephone</code>, call <code>Bill Caudle @ 404-327-3790</code> to make an appointment. After the demonstration you will receive <code>NO STRINGS</code> attached a <code>FREE Clarity Powered Amplified telephone</code>, which through modern technology will allow you to hear, and more importantly, be able to <code>UNDERSTAND</code> conversation as you talk on the phone. Don't forget, if you're hearing impaired you're only a telephone call away from a better quality of life if you will take advantage of this <code>FREE</code> offer. Remember also, it is for a limited time only.

If you take advantage of this offer, please tell your friends about the availability of Clarity Amplified Telephones for The Hearing/Visually impaired. Visit them at www.clarityproducts.com

Please let us know of your new address (including all nine digits of your ZIP code) so that we can continue to send you the newsletter. Send address changes to APPA at the address shown below.

mos.oiloqtsoqstantlan.www

Look for us....we're on the web.

1697-026-404

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