Apr 2006 – May 2006 Southern Arizona Post-Polio Support Group Est. 1985 P.O. Box 17556 Tucson, AZ 85731-7556 (520)-750-8608 (Message) www.polioepic.org

POLIO EPIC, INC.

General Membership Meetings Every Second Saturday of the Month 10:00 am. HealthSouth Rehabilitation Center Wyatt Road

- April 8th at 10:00

 a.m. Our own
 President-Elect,
 Karla Carr is
 going to present
 information on the
 new Medicare

 Part D
- May 13th 10:00
 a.m.
- June 10th –
 10:00 A.M. –
 This will be an important
 Meeting to go over the budget and offices for the next year.
 We need your support and guidance to make Polio Epic the group YOU want it to be.

Individual Highlights:

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Communication IS Support

Most medical application forms we encounter ask us for "the next of kin" or "responsible party" or some personal relationship in case the professionals need some approval or communication beyond that which their patient can give. We usually comply. In recent times we lost a long honored member of Polio Epic, Frank Wadleigh. We had little or no knowledge of his family. He lived alone and month after month he hosted a lunch for all who were interested or available to join him. Somehow Bill and Susie Hatton found a connection to Frank's "other life" and we learned more about his condition and visitations and ultimately his memorial. There are many persons among our friends and acquaintances who live alone or who perhaps never mentioned their offspring(s) or "next of kin". When they have passed on with little or no warning, all we can do is look for an obituary or try to grasp some remote connection to the lost person. Very often they did not know how important they were to us and how much we may wish to honor them. Years ago there was a man in Tucson who helped me run my weekly errands. He was older but much more mobile than I was. I did the driving to the stores and he did all the leg work to obtain the product, or do the

shopping or get the refund. He did all the standing in lines and I sat in my car. He was a retired health practitioner and lived a life of compassion. He knew how important his tasks were to me. When he moved away to a remote village in Montana and became ill and suddenly died, no one in that community knew him or that he helped many persons during his lifetime or of his enriched life of travel and culture...but his 3 dogs. After my letter to him returned with "DECEASED" stamped across the envelope, I traced him down thru the local postmistress who gave me the name of the county agent assigned to process the property and possessions and the body of unfamiliar persons. A sad ending for one who did so much for so many. When we spend frequent time with friends, they may not know our background, our children, our siblings or any other person to whom we are leaving a legacy. After attending a memorial service at which I heard people give great testimony and tell of the joys of that life, I come away wishing I had know that person better or longer. How important it is for us to share our lives with those around us. If in no other way than to have a list of our family members

in a prominent place or handed to a close friend or two who may never have met these family members. It's easy to be one personality in one circle of friends and another personality in another circle but how much richer I would be if all of my friends knew of each other or at the very least, knew the names and phone contact of my family.

Our application for membership to Polio Epic, Inc. will in the near future have a line requesting such a connection. When any of our members who regularly appear at meetings no longer show up we will have a connection to some responsible person in each of their lives through whom we can learn...

If they have moved away or just on a vacation somewhere or in which hospital they may be. Too often we are unaware of our importance to others until we do not show up in the usual places. It is not meddlesome to be concerned for others among us. We are polio survivors and we are unique persons...each of us.

Please stay connected, you <u>matter</u> to us.

Frank Frisina

The opinions expressed in this publication are those of the individual writers and do not necessarily constitute an endorsement or approval by **POLIO EPIC, INC**. If you have personal medical problems, please consult your own physician

and phone numbers posted

Disease couldn' t take his will to walk - Lowell Sun Times

Though it was more than a half-century ago, Robert Ziggy Burns remembers it like it was yesterday. Isolation. A stint in an Iron Lung. Pain. Paralysis. And one day, he lay surrounded by rows and rows of white lab coats, wrapped crisply around physicians and occupational therapists. His parents were there, as was the parish priest, just in case the news was as bad as his mom suspected. And the head doctor he still remembers the name, Dr. David Grice turned to Ziggy s parents. We don't think your son will ever walk again, Graves grimly told them. His mother melted into the arms of the priest. His father looked stunned. Son, the doctor asked the boy, did you hear what I said? You may never walk again. And Ziggy Burns, then 12, remembers

looking back at the doctor and saying, The hell I won t. He remembers a female assistant slyly flashed him a thumbs-up sign. And when the group of whitecoats was done collectively examining the boy 20 minutes later, the woman made sure she was last out. She leaned down and hugged Burns. Don t ever give up hope, she said. The next day, he received a Novena from a grade-school teacher who d heard about his illness. It was to St. Jude. patron saint of the hopeless, recalls Burns. I still say it to this day. Fifty years ago tomorrow, a viral reign of terror was finally on its way to being stamped out. But on April 12, 1955, when the Salk Vaccine was announced, it was too late to stave the disease off Ziggy Burns, stricken with polio in the summer of 52. For the past decade, the 65-year-old Dracut resident and veteran Lowell banking and real-estate professional has suffered from post-polio

syndrome, which has left him once again in leg braces, needing a cane to get around. It is characterized by loss of strength, increased fatigue and muscle or joint pain. Post-polio syndrome began showing up in the 1980s, when thousands and thousand of polio survivors began showing similar symptoms, says Dr. Julie Silver, director of the International Rehabilitation Center for Polio at Spaulding Rehabilitation Medicine in Framingham, and an assistant professor of physical medicine and rehabilitation at Harvard Medical School. But it s probably been around as long as polio, she adds. As many as 250,000 U.S. polio survivors suffer from post-polio syndrome, according to the March of Dimes Birth Defects Foundation. Ziggy Burns grew up on Butman Road, near Cawley Stadium, where the Lowell High School squad played and won. Still too young to play, he d run home from school and watch the older kids play on the vaunted grid. He dreamed of playing football for Lowell High, whose coach, Ray Riddick, was to high-school football what George Patton was to U.S. troops in World War II. Polio had been around in the United States for decades, and even Franklin D. Roosevelt, who would be elected president in 1932, contracted the disease in 1921. Major outbreaks occurred in New York, Los Angeles and other cities, and by 1952, there were 58,000 cases in the United States. That was a pivotal summer for Ziggy Burns. Polio was an epidemic, says Burns, sitting in his office at Lowell Co-Operative Bank. People weren t going swimming in fresh-water ponds or pools. Some people wouldn t let their kids out of the house. People were afraid. His father bought a summer home in Rye Beach, N.H., in 1951, figuring it was the safest place, with the ocean and all. He ran on the beach, played football and made friends. And then one day, near the end of July, Ziggy began to feel lethargic. I didn t have the pep I usually did, he says. My mother said, Your father didn t buy this house so you could sit around in it. Finally, his father had had enough. He drove Ziggy home to St. John s Hospital (now part of Saints Memorial Medical Center), where they took a blood test and sent him to Children's Hospital in Boston. His parents visited every day. He turned 13 there. While he was gone, his sister told him later, the family home was

quarantined. After more than two months, he left the hospital in leg braces, with a cane, a long road of physical therapy ahead of him. Football dangled like a carrot in front of him. If the therapist told him to do an exercise 10 times, he d do it 50. He was tutored at home. When he entered Lowell High School as a freshman at 14, he still needed crutches to get around. All I wanted to do was play football for Lowell High, he says. And all of a sudden, I was paralyzed and could not do it. The hard work paid off. By his junior year, he made the team. He wore number 36. He limped but was a good enough quarterback to play some of every game for the powerhouse LHS squad. He earned his

letter. Those were the days when high-school football was huge 10,000 or 20,000 people packed into stadiums for Sunday games. It's amazing. I look back now and remember clearly running out on the football field for the first time, with 12 to 15,000 people in the stadium, thinking, My God, I did it. He still keeps a football in the trunk of his car. If he sees neighborhood kids hanging around, he II grab the ball, drop his cane and play catch. Burns went on to have three children, five stepchildren and nine grandkids. Ten years ago, he was driving back from a friend s funeral in Philadelphia and was involved in a serious car accident. His back and legs ached, but the pain didn t stop. And I started falling down. And I wondered, what the hell is this? Someone told him about an article they had read in Time magazine,

about re-occurences of people who'd had polio as kids. It was called post-polio syndrome. A couple of years ago, he found the book, Post-Polio Syndrome: A Guide for Polio Survivors and their Families, written by Dr. Julie Silver. It was like she was writing about me, he said. I could relate to the pain, the fatigue, where it was in the legs. He got an got appointment with Silver. There are over a million survivors in the U.S. who contracted polio before the vaccine was introduced in 1955, Silver says. And more than 20 million worldwide, generally in underdeveloped countries that did not have access to the vaccine. There s no cure for postpolio syndrome, and it is not a recurrence of polio, though the symptoms are familiar to Burns. Once stricken, he says his symptoms are expected to grow worse with age. He wears leg braces again and uses a cane. Somebody mentioned a second cane, but not now, Burns says. I m not ready for that. He undergoes water therapy at Spaulding Rehabilitation. He stretches his muscles each morning. He still lifts weights, and can bench-press 250 pounds. Here it is, years later, and I beat it once already. I feel blessed with friends and the care I m getting. Zig is a real hero, Silver says. He s one of those polio survivors who s since lived with debilitating problems. But he didn t let that stop him. He s led a tremendous life, and he s a remarkable person. He s working on a book about his experiences, mailing taped reminiscences to a writer. The last case of the wild polio virus in the United States was in 1979, thanks to the Salk vaccine and those whose previous discoveries led to it. But according to the Polio Eradication Initiative, there are 1,263 polio-virus cases in parts of the world, 789 of them in Nigeria. This year, Silver says, is not only the celebration of the halfcentury mark for the vaccine, but the target year for total worldwide eradication. Ziggy Burns remembers sitting in movie theaters as a kid, and they d pass a can around, collecting for the March of Dimes. And you d think, those poor kids. You d never think it s gonna be you. And for all his time in the hospital, all his rehabilitation, Burns remembers something those collection cans did for him. The funny thing is, my dad never got a single medical bill. For any of it. David Perry s e-mail address is dperry@lowellsun.com

POST-POLIO 101

WHAT YOU NEED TO KNOW

1. DID YOU HAVE POLIO?

- Spinal tap?
- Unexplained fever?
- Flu like symptoms?
- Paralysis?
- Severe neck pain and/or headache?
- A disease that severely affected the nervous and muscular systems?

2. WHAT IS POST-POLIO SYNDROME? (PPS) (late effects of polio) TRUTHS:

- A secondary condition to having had polio
- New symptoms approximately 10-40 years after recovery from polio
- Not everyone who had polio develops PPS
- Other conditions have been ruled out including normal aging

<u>MYTHS:</u>

- It doesn't exist
- The virus has returned
- You can't do anything about it
- Everyone gets the same symptoms
- PPS is life threatening
- All polio survivors have atrophied limbs

3. WHAT CAUSES POST-POLIO SYNDROME? (PPS)

- Decades of "overuse and abuse" of the body
- Polio damaged the nervous system, including the brain
- Motor neurons, that move muscles, weakened by polio are beginning to fail
- Triggered by a trauma, (i.e., surgery, accident, immobilization, death of a loved one)

4. WHAT ARE SOME OF THE SYMPTOMS?

- Unaccustomed fatigue either rapid muscle tiring or feeling of total body exhaustion
- New weakness in muscles both those originally affected and those unaffected by the virus
- Pain/burning sensations in muscle and/or joints
- Breathing difficulties and/or sleep problems
- Swallowing problems
- Functional decline
- Depression and/or anxiety
- Weakness and muscle atrophy

- Muscle spasms, twitching and tingling
- Nerve compression problems, (i.e. carpal tunnel and tendonitis)
- Hypoglycemia
- Hypothyroidism

5. WHAT CAN BE DONE?

To **PREVENT** new symptoms from occurring

- Awareness of type "A" behavior
- Plan frequent rest periods
- Pace daily activities
- Limit exposure to cold
- Increase protein and decrease added sugars in diet.
- Gentle exercise program as prescribed by a professional familiar with PPS

To **PRESERVE** remaining strength

- Conserve energy, "Conserve to Preserve"
- Stop overusing and abusing
- Be active, but STOP short of fatigue and pain
- Use assistive devices (i.e. braces, canes, wheelchairs, etc.)
- Use quality nutritional supplements as advised by a nutritionist
- Control your weight
- Maintain a positive attitude
- Join a post-polio support group

6. WHAT TO DO ABOUT PAIN? TIPS THAT HAVE WORKED

- Use moist heat and/or ice packs to the painful area
- Get light massages
- Try warm water therapy
- Get tested for sleeping and/or breathing problems
 - Use assistive and adaptive aids, as necessary to reduce stress to muscles and joints
- Check into need for anti-depressant prescription drugs
- Use pain medication, (i.e. ibuprofen, Celebrex, vicodin, percocet, oxycontin) as prescribed by your Healthcare provider
- Try alternative type treatments, (i.e. acupuncture, yoga, myofascial release, Reiki, Watsu, etc.)

8. How is PPS diagnosed?

Having a physician exclude all other possible causes for new symptoms, (i.e. normal aging, ALS, MS, MD, Guillen-Barre, etc.)

9. HOW TO COMMUNICATE WITH YOUR HEALTHCARE PROVIDER?

A. <u>BEFORE</u> you visit your Healthcare provider

- Keep a journal of progression of symptoms, making simple entries concerning:
 - Daily living
 - Physical
 - Emotional
 - > Time of day most affected
 - Positive and negative changes
- Note current symptoms, (i.e. tired, fatigue, exhaustion)
- From journal, make a list of questions and concerns to present to your healthcare provider

B. <u>DURING</u> the visit with your Healthcare Provider

- Describe all current symptoms and when/how they have changed over time.
- Be specific about what you need, if known
- Avoid giving "Yes" and "No" answers
- Describe HOW: (i.e. <u>much</u>, <u>long</u>, <u>in what</u> <u>way</u>). ("I can climb <u>3 steps</u> in <u>5 minutes</u> with assistance.")
- Clarify what you hear by asking, "Did you say...?"
- Bring written post-polio information
- Build a relationship with your Healthcare provider
- REMEMBER, some symptoms are not PPS related, (i.e. normal aging, heart disease, diabetes, etc.)

C. <u>AFTER</u> your Health care provider's visit

- Request copies of all reports and test results
- Call if you have further questions

10. DID YOU KNOW?

- There are Post-polio Clinics and support groups all over the world
- Rotary International goals are to:
 - 1. Eradicate polio worldwide
 - 2. Assist polio survivors
- People still get polio
- Polio survivors are likely to develop post-polio symptoms
- "No Pain No Gain" DOES NOT apply to post-polio syndrome
- Many resources are available

11. WHERE DO YOU FIND MORE INFORMATION?

Polio Epic, Inc.
 P.O. Box 17556
 Tucson, AZ 85731-7556
 (520) 750-8608 (message)

www.polioepic,org

 Polio Echo, Inc. Phoenix, AZ P.O. BOX 61024 Phoenix, AZ 85082-1024 (480) 545-1147

www.polioecho.org

 Post-polio Health International (314) 534-0475

www.post-polio.org

 International Rehabilitation Center Julie Silver, M.D. (508) 872-2200

www.polioclinic.com

- International Centre for Post-Polio Education and Research Dr. Richard Bruno, Ph.D. (201) 894-3000
 - www.postpolioinfo.com
- The Lincolnshire Post-Polio Network www.ott.zynet.co.uk/polio/ lincolnshire

TAKE CHARGE OF YOUR MEDICAL CARE. YOU KNOW YOUR OWN BODY BEST!



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WE NEED YOU

I encourage everyone reading this newsletter to consider what their own individual "part" of the solution truly is in making Polio Epic a valuable support group. During the previous meeting, we all participated by listing the things we wanted Polio Epic to do in the coming year. Our President-Elect, Karla spent hours going through every item and comparing the times that each individual voted for each project. One of the items that came up more often than any other was the "support" issue. During the 2005 year, a lot of our meetings were very business like, as we prepared the Post Polio 101 document, and fulfilled the demands of our grant.

Now is the time to re-focus our energies on what we want and need from Polio Epic. The only

way that can happen, is to have every single member be heard from. The only way to hear from every member, is to have every member speak up!

Please make whatever effort you are capable of, and make your voice heard. At the end of every newsletter are contact phone numbers and e-mails to all of the board members. Make use of these communication tools. If you can't attend a meeting, then call one of us and let us know what you want! All the members of the board are volunteers that want to make sure that you get the kind of support group that is important to you! I also encourage all of you to try to search your heart and

abilities to find out what service you can provide, as well as the ones that you want to be able to receive. At the last general membership meeting I talked with a wonderful lady, who doesn't speak English, and needs her scooter to get around. This lady knew she could take part, and searched for something which she could do within her abilities. Polio Epic was that important to her. To many of us, stuffing envelopes doesn't seem like much, but it is a HUGE service, and each of us need to find that service within us, to be a part of the solution, not part of the problem. Micki Minner, Webmaster, Treasurer, and Newsletter Editor. P.S. Dave Marsh is taking over the Website! (Hooray!)

CONTRIBUTIONS POLIO EPIC expresses Appreciation for the following contributions...

Phyllis Andersen
Dana Vincil
*BUILDERS
Betty Pudlo

Jeannette Haugrud & Mary Anderson
William and Eunice Schultz
*FRIENDS
*BUILDERS \$100 and OVER
*FRIENDS UP TO \$99

Directories are now available

We have had directories printed of all of our members, and associates for polio epic. If you wish to have one mailed directly to your home, please submit \$2.00 for mailing. We will be issuing updates to the address directory in a separate page that you can keep with your directory. You can contact Nannoe Westbrook at

Nannoe1@aol.com, or Joanne Yager to get your copy today!

Our condolences, from Polio Epic, go out to all the families and friend who have lost a loved one. In Memory of . . .



Frank Wadleigh

Frank was a long-time member, and monthly sponsored "Lunch at Frank's". Frank was a long time support of Music and the arts, as well as a one-time member of Senator John Kyl's staff. Frank was also a veteran of WWII, and served in Burma. Frank will be missed by all of us, and we hope that his spirit stays with us.

Your Dues...How to tell when your Dues are due!

If your label says 2005 or earlier, then you owe for this fiscal year. Many of you have already paid your current dues. If your label says 2006 or later, then you are paid for this fiscal year, or up through whatever future year is listed on your label. Remember, even though postage and supplies have gone up we are still able to continue with our low \$5.00 yearly dues. Please send in your dues. If you are not sure what you owe, please contact a board member. Note: The printer did not print the year (for unknown reasons) on last month's mailing labels. We apologize for the confusion.

A BOARD MEMBER of Polio Epic has a term of one year.

- 1. A BOARD MEMBER attends the monthly general meetings and the monthly Board of Director's meetings.
- 2. Each BOARD MEMBER will take on at least one (1) committee and/or responsibility for the fiscal year.
- 3. The following are examples of duties you could take on as a Board Member!
 - a. Greeter/hostess at General Meetings
 - b. Refreshment Reminder
 - c. Call HealthSouth to verify room and drinks 2-3 days before General Meeting.
 - d. Check Polio Epic's telephone messages weekly.
 - e. Sunshine Person Keeps track of member's important dates (special birthday's, anniversary's, illness, surgery, deaths, send cards and/or notify members/editor.)
 - f. Prepare and mail out Information Packets
 - g. Board Member Reminder
 - h. Librarian
 - i. Goodwill Caller
 - j. Anniversary/Holiday Committee
 - k. Conference Committee
 - I. Speaker's Bureau
 - m. Fund Raiser
 - n. Any other program/activity that may develop in the fiscal year.



Personal Growth Is Possible By Ana Blum

When I was child in Ecuador, I contracted Polio from the vaccine that was supposed to protect me. I grew up handicapped, condemned to asking for help for everything, feeling desperately different, wrong, and out of place. I spent most of my life facing difficulties and anger. Anger possessed my soul in an implacable way.

Years passed, and in a search for a rational spirituality, I learned to understand my body. I learned to help myself. I acknowledged, without despair, that I am different and that I always will be. I began to feel right and not out of place. Anger still visits me. I am sure it will continue doing so, but now it doesn't possess me - I possess it, and I transform it into strength, into power.

Personal growth IS possible! It is a long path, an everyday path, but a sure path. When I deeply realized that nothing has more certainty than my own self, and that I didn't have the power to change my body, but I did have the power to change my thinking - that was when I started walking the road to a better life, to a joyful life, to a loving life.

You spend every second of a 24 hour day with yourself. Why not try to make that a pleasant experience instead of a frustrating one? You can escape from everybody else but never from yourself.

When I was a young girl I listened to people behind doors, saying: "Poor little thing. She is so cute, but with that crippled body how is she going to make it in life," and "Poor girl - she never is going to have a husband," and "Poor Ana. She's going to need someone to assist her forever." They might have been right if I had let them be, but I didn't. I changed my destiny and I found a way. There are always ways.

Self growth is possible! I could have chosen the path of self pity, isolation and anger. If I had, I probably would be living a bitter life in my old bedroom at the home of my parents in my native Ecuador. Instead, I chose to fly, and I actually did. Now I am living in the United States, working as a Spanish teacher, writing a book of poetry and happily married with a wonderful and intelligent man.

So, don't give up. Keep trying, keep looking for a way. Your strength is there, inside you. Personal growth really is possible

Editors Note: This is our very own Ana expressing a wonderful and powerful sentiment. We ARE capable of so much more than we think. Besides the fact that Ana is beautiful inside and out, her husband is indeed a handsome fellow!

Bashas' Thanks A Million

Bashas' "Thanks a Million" program is back, offering a way for Polio Epic to raise money. All you need to do is take your Bashas' "Thank You Card" into any Bashas' and ask the cashier to enter our group number – **27169**. The program runs from <u>September 1, 2005 to March 31, 2006</u>. Polio Epic will receive 1% of the total dollars attributed to our group identification number – up to \$2,500. Don't forget to tell **all your friends & relatives** that shop at Bashas' about this program. Again our group number is:

27169

NEW BOOKS FOR OUR LIBRARY

Polio: An American Story (Hardcover)

by David M. Oshinsky Copyright - 2005

Splendid Solution: Jonas Salk and the Conquest of Polio (Hardcover)

by Jeffrey Kluger Copyright – 2005

Living with Polio: The Epidemic and Its Survivors (Hardcover)

by Daniel J. Wilson Copyright - 2005

Polio and Its Aftermath: The Paralysis of Culture (Hardcover) \$

by Marc Shell Copyright – 2005

Walking Fingers: The Story of Polio and Those Who Lived With It (Paperback)

by Helen D'Orazio Copyright – 2004

Polio: A Dose Of The Refiner's Fire: Surviving Polio (Paperback)

by Jeane Curey L. Dille Copyright - 2005

Dues Form

POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES ARE RENEWABLE THROUGH THE FISCAL YEAR 0F SEPTEMBER 1, 2005– AUGUST 31, 2006

Name	Spouse	Date		
Address	Phone ()			
C CityState	Zip			
Emergency Contact info:				
EmailI am sending in my/our annual dues of \$5.00 per person for 2005-2006 fiscal year. I am sending in a <i>tax-deductible</i> donation in the amount of \$ POLIO EPIC, INC. is a 501(c)(3) non-profit corporation. Tax ID # 74-2477371 I am UNABLE TO PAY dues at this time, but wish to continue my membership and receive the newsletter. Please remove my name from the mailing list. I no longer wish to receive the newsletter. Check here if you do not want your name, address, phone number and email listed in the POLIO EPIC DIRECTORY.				
I would like to be more involved in Polio Epic. Please contact me at the number above.				

Make checks payable to POLIO EPIC and return this form to Polio Epic, P.O. Box 17556, Tucson, AZ 85731-7556

Board of Directors

Cathy Bleyer	520-572-0599	CatBley@aol.com
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Charlie Minner	520-743-1556	Canthmin@msn.com
Carol Phelan-Smith	520-579-0078	Handthx82@cs.com
Alice Smedley	520-792-2758	
Barbara Stough	520-887-4731	chasbarstough@juno.com
Joanne Yager	520-296-1471	jyager@mymailstation.com

MARK YOUR CALENDAR

General Meetings: April 8th-10:00 A.M. May 13th - 10:00 A.M. Board Meetings: First Thursday of each month at DIRECT on Tyndall

ALL ARE WELCOME!

Executive Board Officers 2005-2006

President, Frank Frisina 327-3252 Shinybear@msn.com
President Elect, Karla Carr 318-1219 KarlaKrazies@aol.com
Recording Secretary Virginia Roberts 886-2236 Virgaz1@cox.net
Treasurer, Micki Minner 743-1556 Micki Minner@msn.com
Correspondence Secretary, Nannoe Westbrook 797-6898 Nannoe1@aol.com