Hagerstown, MD and the Four-State Area

Monthly Newsletter

September 2014

This Month's Meeting



Yes, we had 73 attendees at the August 7th meeting, including 6 new members. What a great turnout. The room was packed as we set an all-time attendance record for our featured speaker.

Becky Dunlop, RN, the Associate Director, Johns Hopkins Parkinson's Disease and Movement Disorders Center offered a discussion on gastro paresis and then took many Q&As from the group. An excellent job, Becky.

I want to thank **Dick Naugle** once again for his humorous stories and for asking the blessing.

The McSweyn's won the \$10 gift certificate to the Western Sizzlin Restaurant donated by **Paul Romsburg** and his family. **The Saterbak's** won a book donated by Becky Dunlop.

Senior Expo at Valley Mall

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About a dozen members helped staff a PD information table at the Valley Mall on Saturday, August 2, from 10 - 9. The Cravers, DeHavens, Naugles, Saterbaks, Guyers, and Dean Cook and his brother participated. The Senior Expo drew thousands of people and a large number stopped by our table to discuss PD and/or to pick up information we were displaying. **See photo on the right.**

Visit Our Website at: www.fareshare.net/Parkinsons/

Visit us on Facebook

September Meeting

MARK YOUR CALENDARS

Join us for our next Parkinson Support Group Meeting at Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, September 4, 2014, 11:45 AM

Our September Speaker is Dr. Paul Dash, a neurologist associated with Johns Hopkins

Highlights <u>What to do between Appointments (Page 3)</u> <u>Fall Picnic and MUSIC! (Page 4)</u> <u>New Treatment Strategy for PD (Page 5)</u> <u>Detailed Event Listing (Pages 7 & 8)</u>



Some of the Participating Members at the Senior Expo

Check out the new Parkinson's Events Calendar On-Line.

The Hagerstown Parkinson's Support Group
The Hagerstown Parkinson's Support Group

Group Facilitator:

Hagerstown, MD 21742

aguyer42@myactv.net

Art Guyer 22215 Troy Lane

240-625-2722



17567 York Road Hagerstown, MD Stop by for lunch or dinner to support them!

Volume 4, Issue 9

Upcoming Events

Future Meetings

September 4, Dr. Paul Dash, JH Neurologist October 2, Doug DeHaven, Fire Marshall November 6, Stephen Ryan, Physical Therapist December 4, Breakout Sessions

2015

January 8, Dr. Kelly Mills, JH Neurologist February 5, Irene Plessinger, Nutritionist March 5, Stephanie Mahan, PT, LSVT/BIG April 2, Arita McCoy, RN, BSN, Johns Hopkins May 7, Lori Markland, Assistive Tech Specialist

Caregivers' Breakfast

Third Monday of every month, 8:30 AM at the Railroad Junction Family Restaurant, 301 S. Burhans Blvd. August's breakfast is on the 18th. Call Art Guyer for information.

A detailed listing of upcoming events is included on pages 7 and 8.

Other Local Support Group Contacts

Berkeley County Parkinson's Support Group Debi Corbin, Facilitator, 304-886-8594 danicasgma@aol.com

Winchester Area Parkinson's Support Group Cheryl Reames, 540-662-4632 or <u>cwreames@gmail.com</u>

Cumberland Parkinson's Support Group Shirley McKinney, Facilitator, 301-729-1427 sjmckinney@atlanticbb.net

Chambersburg Parkinson's Support Group Kathy Smith, 717-377-8320 kathy.smith@embargmail.com

Frederick PD Support Group John Kraft and Janet Silvious, Facilitators 301-845-6514 janet@fifpdsg.org

Attend a Support Group Meeting

Thanks to Paul Romsburg, his family, and staff of the *Western Sizzlin* for supporting our group.

UNSUBSCRIBE: If you no longer wish to receive this newsletter, please contact the Group Facilitator, Art Guyer.

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Caregiver's Breakfast.

Our Caregivers' Breakfasts are on the 3rd Monday of every month. In June, **Mike** Saterbak, Ecile Shaw, Barbara Harrell, Sandy Phillips, Dave DeHaven, and Art Guyer enjoyed the Caregivers' Breakfast.

This month, caregivers will meet for breakfast on August 18, at the Railroad Junction Family Restaurant, at 8:30 AM. The restaurant is located at 301 S. Burhans Blvd E, in Hagerstown.

You are encouraged to participate if possible. It gives caregivers the opportunity to seek advice in a safe environment and it allows feedback for future meetings and activities.



Birthdays in August

Happy Birthday to 6 of our members who have August birthdays: Bill Schumacker, Warren and Carol Leach, Charles Martin, dick Naugle, and Rodney Miller.

So we can celebrate your birthday at our meetings, contact Art who keeps a master schedule for the group. No years, just month and day!



Need Transportation or Just a Break?

Remember, if you need transportation to our meetings or other events, please let us know.

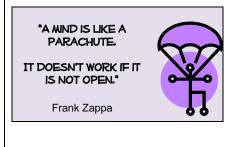
If you would like a couple of hours of free time and we can take your spouse for a short



day trip, we will be happy to try to work something out for you. Give Art a call or send him an email.

In The Hospital?

If you or your spouse, or a member you know is not doing well and/or is in the hospital, please let us know. We like to visit our friends when possible. **Barb Harrell has volunteered as the Sunshine Committee of One** and will be responsible for sending out cards as appropriate. Call her at 301-797-7845 or contact Art if you know someone in need.



Neurologist Are Important

Recent NPF research shows that expert neurologist care saves 4,600 lives per year; better access to this care could prevent the deaths of another nearly 7,000 people with Parkinson's Disease each year in the U.S. alone.

Fall Picnic

September 2014

On September 12 we will be holding our fall picnic. If you would like to attend, please contact Art by September 8 so we can order the right amount of chicken.



On Thursday, July 24th we had our second "PD Bowling Event." It was at Southside Bowls on Virginia Avenue in Hagerstown. The alleys were set up for those who have difficulty moving, lifting or even walking.

There were 9 members who showed up to participate in the duckpin fun. We split up and played several games.



We plan on doing this again on August 21st at 1:15 PM so join us for the fun and the exercise! Call **Dave DeHaven** at 301-582-2815 for more information and directions.

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WHAT TO DO BETWEEN NEUROLOGY APPOINTMENTS

DR. PAUL SHORT, THE PARKINSON'S COACH HTTP://THEPARKINSONSCOACH.COM/ FEBRUARY 28, 2014

Life is what happens between neurology appointments.

We don't talk about this much, but facts are facts. The best medical treatments for PD can do no more than relieve neurological symptoms. Your medications buy you some time without PD mounting a full assault on your daily life. Without well targeted treatments, that assault would be devastating. Your neurologists can't cure your disease but can modify its impact on you.

However, your neurologist can't give you directions for using the time treatment buys you. The quality of life that follows is entirely up to your discretion.

One way to spend the time good treatment buys you is to direct your full attention to that bright future when there will be a cure for Parkinson's. A cure will come; we all know that. All one has to do is sit and wait, doing nothing more as time passes. Monitor the Internet for the latest breakthroughs, religiously search PubMed, but most importantly, wait patiently and don't let anything move you from your chair. Life passes you by, of course, but that is just the cost of keeping one's eye on the future.

Another approach might be to keep one's eye on the symptoms that are still there rather than being reasonably satisfied that a significant number are muted. Remind yourself that you have gotten a bum deal, that Life has not been fair, and that you didn't deserve this. Spend those good moments with a chip on your shoulder and growl in your voice. Life passes you by, of course, but at least you aren't wasting it on groundless optimism.

Another, perhaps better way to use that time your neurologist buys you is to focus on those precious minutes. Make a decision to use them wisely and completely. Talk with family and friends about how you can dip a toe in the stream of life again, and then do your best to wade back in. Think about those things that make your life uniquely yours, those things that give it quality. Be aware that the symptoms will come back and that the disease will become worse over time then resolve not to dwell on either fact. Envision your life as an exception to the rules of Parkinson's because you are choosing to make it so. Life passes you by, of course, but it will be a life well lived.

Life happens between neurology appointments. The gift that comes from proper treatment is yours to use in whatever way you choose.

DID YOU KNOW?

Breaking down activities into smaller segments, and setting realistic goals helps starting an activity program seem less difficult.

What goals have you set for yourself?

to Beat Parkinson's

www.parkinson.org/whateverittakes

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Fall Picnic

When: Friday, September 12, 2014, 12 NoonWhere: Martin L. Snook Memorial Park, Pavilion #4, Hagerstown, MD

Bring a covered dish or dessert and there will be fried chicken. Plates, napkins, utensils and drinks are provided.

There will be free bingo for all! Everyone should bring one or more <u>wrapped</u>, <u>inexpensive "prize</u>" for bingo winners. Prizes can be something you want to get rid of or you can pick up some items from a "dollar store."

Directions:

For those using I-81, go East on I-70 at the I-81/70 Interchange

Eastbound on Interstate 70 (from I-81), take Exit 28, turn left on Downsville Pike; turn left at first traffic light. The park entrance is 100 yards past the light, on the left. Follow the park road to the end and the pavilion will be on the right.

Westbound on Interstate 70 (from Frederick), take Exit 28, the park entrance is 100 yards past the first stop light, on the left. Follow the park road to the end and the pavilion will be on the right.

For more information or to make reservations for the picnic, contact Art by phone at 240-625-2722 or email at aguyer42@myactv.net.



Cheryl Reames & Richard Lewellen

Do You Like Music?

Last month the DeHaven's and Doris and I visited the Greater Winchester Area Parkinson's Support Group for their monthly meeting. Their featured speaker was Mr. Richard Lewellen, an accomplished musician, choir director, and a certified music therapist who is currently working on his Master's Degree in Music Therapy. The facilitator in Winchester, Cheryl Reames, has had a dream of starting a Parkinson's singing group and her contacts at Shenandoah University recommended Richard to help her. Richard explained that singing in a group has many benefits besides just being fun. For a person with Parkinson's Disease, it can strengthen the vocal cords and enhance speech, it improves breathing through special exercises, it creates a social environment with others having similar issues, and it can be a major stress reducer.

Cheryl and Richard explained the group they hope to form will be made up of persons with Parkinson's as well as caregivers. They are now trying to find a venue where they can rehearse once or twice a month with the goal of being able to perform at local functions at some point in the future. As part of the day's presentation, we sang a number of well-known songs, using lyric "cheat sheets" of course. Everyone seemed to enjoy the activity.

If you are interested in participating in this musical activity with our friends from Winchester, contact me or Cheryl Reames directly at, 540-662-4632 or <u>cwreames@gmail.com</u>.

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Trial of promising new treatment strategy for Parkinson's Disease

University of Kentucky, November 2013

A clinical trial being conducted at the University of Kentucky is investigating a new treatment strategy for Parkinson's disease that, if successful, could drastically change future treatment of the disease and possibly halt or reverse brain degeneration. UK is the first in the U.S. to conduct the clinical trial.

Dr. Craig van Horne, associate professor of neurosurgery in the College of Medicine and principal investigator of the clinical trial, is making significant contributions to research and patient care related to Parkinson's disease.

PD is one of the most common neurological disorders, affecting around one million Americans and 10 million individuals worldwide. The disease is progressive and degenerative, wherein the death of brain cells causes an array of motor and non-motor symptoms, most recognizably tremor, rigidity, slow movement and unstable posture. Despite its prevalence, there is currently no cure for Parkinson's disease, in part because its causes aren't fully understood. Symptoms are initially managed through medication, but the medication loses efficacy over time.

The next line of treatment is a surgical procedure called deep brain stimulation (DBS), which works like a "brain pacemaker" whereby electrodes are surgically implanted deep into the malfunctioning part of the brain where cells have died. The electrode then emits electrical impulses to regulate the brain's abnormal impulses. For many patients with PD, DBS can be a life-changing treatment that greatly improves quality of life by reducing their symptoms and their dependence on medication, which can have drastic side effects even as its efficacy decreases. But while DBS is effective in managing symptoms, it still does not change the course or outcome of the disease.

Dr. van Horne is exploring an additional treatment option, and possibly a way to alter the course of the disease. He and his team are conducting an innovative clinical trial that builds upon the established DBS procedure by supplementing it with a nerve graft of patients' own peripheral nerves.

Peripheral nerves -- nerves outside of the brain and spinal cord -- are able to regenerate. Van Horne's trial aims to leverage the regenerative capacity of peripheral nerves to allow the brain to heal itself. As part of the study, the patients donate a small piece of their peripheral nerve tissue from just above their ankle. The nerve tissue is obtained and implanted during DBS surgery, which means the patients do not need an additional surgery for the grafting procedure and still receive all the benefits of the DBS therapy. The potential clinical effects of the implants can then be tested by simply turning off the deep brain stimulator. The hope is that the neurotrophic factors of the peripheral nerve will stimulate regeneration in the parts of the brain that have been damaged by PD.

While nerve transplantation isn't novel, van Horne's trial is the first of its kind to transplant peripheral nerve tissue into the brain in conjunction with DBS. It's an idea he has been working towards for many years. "I have been refining this concept for over 10 years," he said. "I was looking at the research field, at what worked and even what didn't work, and I was always thinking 'Why wasn't this research carried forward?' People are looking for a magic bullet. But biology doesn't work like that. And when I look at the regenerative capacity of other tissues in the body, I think "how can we take advantage of what nature has already figured out?'"

So far, five Parkinson's patients have undergone the combined DBS-nerve graft procedure, out of six allotted spaces in the trial. These patients were already candidates for standard DBS and agreed to undergo the nerve graft after being informed of the risks and benefits. "This is a beautiful example of how if you design a study correctly, it can go quickly," said Dr. Greg Gerhardt, director of the Parkinson's Disease Translational Research Center of Excellence and of the Center for Microelectrode Technology. Gerhardt assists van Horne during the DBS-nerve graft procedure.

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The use of the patient's own tissue eliminates the risk of the brain rejecting the implanted nerve, which in turn means that patients don't need to take immunosuppressant drugs to reduce the chances of rejection. The nerve graft itself only adds about 30 minutes to the standard DBS procedure, so the increased risk to the patient is minimal.

As a Phase I trial, the primary objective is to establish safety and feasibility of both the initial procedure and the long-term effects. Patients in the trial are monitored through a 12-month period that follows motor performance and psychological scores and changes in how much medication they need to manage their symptoms.

The trial is ongoing, but preliminary data indicates no increased risk to the patients, all of whom have shown consistent improvement in symptoms. To illustrate, patients who undergo standard DBS are generally able to reduce their medication one month after the surgery. By comparison, all five patients who underwent the combined DBS-nerve graft procedure in van Horne's trial were able to entirely go off the medication one month later, relying only on the DBS device to manage their symptoms. This is significant for patients because the DBS therapy provides more stable symptom management than the medications.

For the immediate future, van Horne looks to what he calls "the adjacent possible," the next possibilities that are immediately available. This could be repeating the trial with more patients, for example. Ultimately, the results of his study will be used to formulate an NIH proposal to optimize the procedure and continue to investigate the true clinical impact of the grafted tissue on clinical outcomes.

Cumberland Parkinson's Support Group Picnic

On July 11, 2014, the DeHaven's, Doris and I drove to Cumberland to attend the Support Group Picnic held there. It was a beautiful drive and our group arrived on schedule. I'm guessing there were about 25 – 30 people in attendance and the hosts and facilitators, Shirley and Ken McKinney, did a wonderful job creating a very nice event. The food, including fried chicken and freshly cooked hot dogs, was excellent. The sides and desserts were fabulous.

Ken MC'd some guessing games and then the real entertainment began. Ken and Shirley and a few others shown below treated us to some great music. Shirley has a great singing voice and Ken plays a mean sax and clarinet. They had us all tapping our toes and clapping our hands, and even singing along sometimes. Also, Marshall Caton's voice is amazing.



Shirley McKinney, Vocalist, with Joe deGiovani on Keys and Ken McKinney on Sax



Marshall Caton, Vocalist with Gary Stine on Drums

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Reminders of upcoming events as of Saturday, August 09, 2014

- <u>Tuesday, August 12, 2014 (2nd Tuesday)</u>: Winchester PD Support Group Monthly Meeting at the Family Life Center, Winchester Church of God, 2080 N. Frederick Pike, Route 522 North, Winchester, VA at 11:00 AM. Speaker: Becky Dunlop, Health Educator from Johns Hopkins University Department of Neurology/Parkinson's Disease & Movement Disorders Center. Contact Cheryl Reames for more information at 540-662-4632 or <u>cwreames@gmail.com</u>.
- <u>Friday, August 15, 2014</u>: HPSG Cards at Art and Doris Guyer's at 1:00 PM. Call Dave DeHaven at 301-582-2815 for information or directions.
- <u>Monday, August 18, 2014 (3rd Monday): Caregivers' Breakfast</u> at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
- <u>Tuesday</u>, <u>August 19, 2014 (3rd Tuesday)</u>: <u>Chambersburg PD Support Group Monthly Meeting</u> at Menno Haven in Chambersburg, PA at 2:00 PM. Their speaker will be a physical therapist. Contact Kathy Smith at 717-377-8320 or <u>kathy.smith@embargmail.com</u> for information or directions.
- <u>Thursday, August 21, 2014</u>: HPSG Bowling at Southside Bowl, 17325 Virginia Ave, Hagerstown, MD, at 1:15 PM. Call Dave DeHaven at 301-582-2815 for information or directions.
- <u>Wednesday, September 3, 2014</u>: Johns Hopkins Conference Call for Support Group Leaders at 10:00 AM. Details to come.
- <u>Thursday, September 4, 2014 (1st Thursday)</u>: <u>Monthly HSPG Meeting</u> at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Dr. Paul Dash, Johns Hopkins neurologist, is the featured speaker. Call Art at 240-625-2722 for information or directions.
- <u>Monday, September 8, 2014</u>: Johns Hopkins Deep Brain Stimulation Educational Session from 6 to 8 PM. Information and discussion on the potential benefits of DBS. Call Bailey Vernon at 410-616-2811 for information and to register.
- <u>Tuesday, September 9, 2014 (2nd Tuesday)</u>: Winchester PD Support Group Monthly Meeting at the Family Life Center, Winchester Church of God, 2080 N. Frederick Pike, Route 522 North, Winchester, VA at 11:00 AM. Contact Cheryl Reames for more information at 540-662-4632 or <u>cwreames@gmail.com</u>.
- <u>Friday, September 12, 2014: HPSG Fall Picnic</u> at Snook Memorial Park in Hagerstown, MD at 12 Noon. Call Art at 240-625-2722 for information or to register.
- <u>Monday, September 15, 2014 (3rd Monday): Caregivers' Breakfast</u> at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
- <u>Tuesday</u>, <u>September 16</u>, 2014 (3rd <u>Tuesday</u>): <u>Chambersburg PD Support Group monthly meeting</u> at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or <u>kathy.smith@embarqmail.com</u> for information or directions.
- <u>Wednesday, September 17, 2014 (3rd Wednesday): "Friends in Frederick" PD Support Group monthly meeting at 1:00 PM.</u> Held at Mount Pleasant Ruritan Club in Walkersville, MD. Contact Janet Silvious at 301-845-6514 or jsilvious@yahoo.com.
- <u>Saturday, September 20, 2014</u>: Initial meeting of the Four-State Alliance for Parkinson's at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:00 AM. Leaders of the local support groups to attend. Call Art at 240-625-2722 for information or directions.

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- <u>Tuesday, September 23, 2014 (4th Tuesday)</u>: <u>Berkeley County Parkinson's Support Group</u> monthly meeting at 6:30 PM at the Otterbein United Methodist Church of Martinsburg WV. Contact Debi Corbin at 304-886-8594 for more information.
- <u>Thursday, October 2, 2014 (1st Thursday): Monthly HSPG Meeting</u> at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Doug DeHaven, Hagerstown Fire Marshall, is the featured speaker. Call Art at 240-625-2722 for information or directions.
- <u>Sunday, October 12, 2014: Partners in Parkinson's Seminar</u> in Washington, DC. Time is 7:45 AM to 3:45 PM. Information and registration is available on this website: <u>https://www.partnersinparkinsons.org</u>.
- <u>Monday, October 20, 2014 (3rd Monday): Caregivers' Breakfast</u> at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
- <u>Tuesday, October 21, 2014 (3rd Tuesday)</u>: <u>Chambersburg PD Support Group Monthly Meeting</u> at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or <u>kathy.smith@embarqmail.com</u> for information or directions.
- <u>Wednesday, October 22, 2014 (3rd Wednesday): "Friends in Frederick" PD Support Group monthly meeting at 1:00 PM. Held at Mount Pleasant Ruritan Club in Walkersville, MD. Contact Janet Silvious at 301-845-6514 or jsilvious@yahoo.com.</u>
- <u>Tuesday, October 28, 2014 (4th Tuesday)</u>: <u>Berkeley County Parkinson's Support Group</u> monthly meeting at 6:30 PM at the Otterbein United Methodist Church of Martinsburg WV. Contact Debi Corbin at 304-886-8594 for more information.
- <u>Thursday, November 6, 2014 (1st Thursday): Monthly HSPG Meeting</u> at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Dr. Stephen Ryan, Physical Therapist, is the featured speaker. Call Art at 240-625-2722 for information or directions.
- Friday, November 7, 2014: Support Group Leaders Dinner and Meeting: BWI Airport Marriott, in Baltimore, MD. Details to come.
- <u>Saturday, November 8, 2014</u>: Johns Hopkins Movement Disorders Symposium, BWI Airport Marriott, in Baltimore, MD. Call Bailey Vernon at 410-616-2811 for information and to register. Details to come.
- <u>Monday, November 17, 2014 (3rd Monday): Caregivers' Breakfast</u> at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
- <u>Tuesday, November 18, 2014 (3rd Tuesday)</u>: <u>Chambersburg PD Support Group Monthly Meeting</u> at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or <u>kathy.smith@embarqmail.com</u> for information or directions.
- <u>Tuesday, November 25, 2014 (4th Tuesday)</u>: <u>Berkeley County Parkinson's Support Group</u> monthly meeting at 6:30 PM at the Otterbein United Methodist Church of Martinsburg WV. Contact Debi Corbin at 304-886-8594 for more information.
- <u>Thursday, December 4, 2014 (1st Thursday): Monthly HSPG Meeting</u> at the Western Sizzlin' Restaurant in Hagerstown, MD, at 11:45 AM. Holiday gift exchange and breakout sessions. Call Art at 240-625-2722 for information or directions.
- <u>Monday, December 15, 2014 (3rd Monday): Caregivers' Breakfast</u> at the Railroad Junction Family Restaurant, 301 Burhans Blvd, Hagerstown, MD, at 8:30 AM. Call Art at 240-625-2722 for information or directions.
- <u>Tuesday, December 16, 2014 (3rd Tuesday)</u>: <u>Chambersburg PD Support Group Monthly Meeting</u> at Menno Haven in Chambersburg, PA at 2:00 PM. Contact Kathy Smith at 717-377-8320 or <u>kathy.smith@embarqmail.com</u> for information or directions