Hagerstown, MD and the Four-State Area

## **Monthly Newsletter**

May 2016

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

Volume 6, Issue 5

Visit us on Facebook

**May Meeting** 

#### **Local Support Group Contacts**

**This Month's Meeting** 

We had **69 people** at our April meeting, including 9 new individuals and 3 professionals.

Our speaker was Dr. Laxman Bahroo, a movement disorder specialist from the Georgetown University Hospital. Dr. Bahroo made an informative presentation and answered many questions from the attendees. Dr. Bahroo's contact info is:

Dr. Laxman Bahroo Department of Neurology Georgetown University Hospital Pasquerilla Healthcare Center 3800 Reservoir Road, N.W. Washington D.C. 20007 Phone: (202) 444.8525

Dr. Stephen Ryan also spoke briefly about his recent certification in LSVT/BIG. You can reach Dr. Ryan's office in Hagerstown at 301-797-4572.

Karl Schwanda, a pharmaceutical representative for TEVA also attended. Lunch for the meeting was provided by TEVA.

**Bob Kelley** won the \$10 gift certificate to the Western Sizzlin' Restaurant donated to the support group by Paul Romsburg and his family.

Thanks to **Ecile Shaw** for delivering our prayer.



#### MARK YOUR CALENDARS

Join us for our next
Parkinson Support Group Meeting

Western Sizzlin Steakhouse 17567 York Road, Hagerstown, MD

Thursday, May 5, 2016, 11:45 AM

Our speaker for May is Attorney Michael Day Speaking on Elder Care Law Issues and Advice

#### **Newsletter Highlights**

Tips for Making Life Easier (Page 3)
Heads Up, Caregivers! (Page 3)
Frederick Group Celebrates 20 Years (Page 4)
Parkinson's Disease Symposia (Page 5)
New Prescription for PD (Page 6)
Detailed Event Listing (Pages 7 & 8)

#### **Future Meetings**

May 5, Attorney Michael G. Day, Elder Care May 7, HPSG Yard Sale

Jun 2, Patients & Caregivers Breakout Sessions
Jun 17, Picnic in the Park

Jul 7, Candice Valencia, Trainer and Senior Yoga Aug 4, Becky Dunlop, RN, BSN, Johns Hopkins Sep 1, Shelley Steiner, Hospice of Wash. County Sep 16, Picnic in the Park

Oct 6, Dr. Kelly Mills, Neurologist from JHU Nov 3, TBD

Dec 1 Patients & Caregivers Breakout Sessions December Meeting will be Christmas Party Too

April is Parkinson's Awareness Month May 7<sup>th</sup> is our Yard Sale, See <u>Page 8</u>.

Winchester Area Parkinson's Support Group Cheryl Reames, Facilitator, 540-662-4632 winchesterparkinsons@gmail.com Facebook.com/winchesterPDsupport

Cumberland Parkinson's Support Group Toby Feddis, 301-729-5569, ianasgranny@yahoo.com Pam Dolly, 304-738-2196, pamaladolly89@gmail.com

<u>Friends in Frederick Parkinson's Support Group</u> Janet Silvious, 301-831-5609, janet@fifpdsg.org or John Kraft, 301-845-6514, john@fifpdsg.org. www.fifpdsg.org

<u>Frederick Parkinson's Disease Early Onset or Newly Diagnosed Community Support Group</u>
Deb Bergstrom, Facilitator, 301-712-5381, bergstromdf@gmail.com

Central PA PD Support Group - West Shore (Mechanicsburg, PA)
Dan Yother, 304-676-2053, oldred714@verizon.net

Gettysburg Parkinson's Disease Support Group Paula Chaplin, 717-337-4407, pchaplin@wellspan.org

<u>Cross Keys Parkinson's Support Group</u> (New Oxford, PA) Daune Wynn, 717-495-5671 wynn574@crosskeysvillage.net

Former members of the Chambersburg and Martinsburg support groups are welcome to attend the Hagerstown meetings and events.

Attend a
Support Group
Meeting

Parkinson's Events Calendar On-Line.

The Hagerstown Parkinson's Support Group

Group Facilitator: Art Guyer 22215 Troy Lane Hagerstown, MD 21742 240-625-2722 4Parkinsons@gmail.com

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

The Hagerstown Parkinson's Support Group

is supported in part by:

STERN

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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## **Monthly Newsletter**

### May 2016

### Caregiver's Breakfast

Our Caregivers' Breakfasts are on the 3<sup>rd</sup> Monday of every month. In March, Dave DeHaven, Peg Hayzlett, Ecile Shaw, Art Guyer, Mike Saterbak, Gloria Rith, Carol Gaines, Linda Embly, Barbara Harrell, and Frank McConnell met for breakfast. Yes – there were 10 of us there!

This month the breakfast is scheduled for Monday, April 18 at 8:30 AM at the Hagerstown Family Diner. This restaurant is located at 431 Dual Highway near the Best Western Grand Venice Hotel. Contact Art if you need information or directions.

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. If you need transportation, let us know and we will take care of it.

### **Need Transportation?**

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

Give Art a call or send him an email.

Take a break!

Respite Care is important for caregivers. You need a break every now and then. Respite care is substitute care given so the regular caregiver can take a break and get some relief from the burden of caregiving. Respite care can be for a weekend or a day or even for an hour, on a regular basis or just one time.

YARD SALE, MAY 7TH: SEE PAGE 8 NOW!

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#### **MAPS Ambassador**

The Maryland Association for Parkinson Support (MAPS) has set up points of contact (Ambassadors) in each area to create visibility for MAPS in the community and to keep the Parkinson's Disease community abreast of any new activities or events planned.

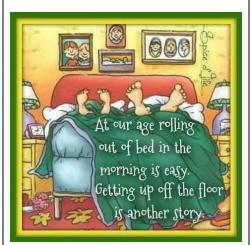
**Dean Cook** is our area's Ambassador.

We would like to enhance Dean's effort by possibly getting members of the Hager-stown Parkinson's Support Group to contact businesses, offices, schools, churches, civic groups, HOAs, etc. in other geographical areas. So, we are looking for volunteers to help distribute materials.

You can contact Dean for information or volunteer to help at 304-268-1623 or by email at home2wv@yahoo.com.

#### Senior EXPO

The <u>Washington County CARES 2016</u> Senior & Caregiver EXPO takes place this year on Monday, May 23, 2016, 10 AM – 3 PM at the Robinwood Professional Center (Blue/Silver Entrance). We have been invited to participate with an information table at this event. So, I am looking for volunteers to help staff the table during that period. Call me at 240-625-2722 or email at <u>4Parkinsons@gmail.com</u> if you are able to help out.



#### **Cards**

Contact **Dave DeHaven** at 301-582-2815 if you would like to play in the next card game. We are not scheduled to play cards in April.

#### PD Group Bowling

Our bowling group is growing slowly and we are having fun. We had a good turnout in March. Come out and join us. You do not have to be a good bowler to get in the game. In fact, newbies are welcome.

We bowl at Southside Bowl, 17325 Virginia Avenue, Hagerstown, MD. Again this year, the lanes will be charging only \$2 per line including shoes. We are scheduled to bowl on April 21 at 1:00 PM.

Call **Dave DeHaven** at 301-582-2815 for more information and directions.

### **Birthdays in April**

Happy Birthday to our members who have birthdays this month. We announced your names and sang happy birthday to you at our meeting this month.

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

### 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 is our Sunshine Committee of

One and is responsible for sending out cards as appropriate.

Call Barb at 301-797-7845 or contact Art if you know someone in need.



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#### Parkinson's Disease: Tips for Making Life Easier

Based on the Book by Shelley Peterman Schwarz (2002)

Make exercise part of your life and it will improve your quality of life. Exercise does not reverse or delay the symptoms of PD, but it does help you make full use of your potential. It also helps prevent complications, such as contractures of rigid, poorly moving limbs. Walking, range-of-motion exercise, and simple stretching regimens can do wonders for your energy level, strength and general feelings of well-being. Tai chi can help with balance, as well as providing a time for quiet meditation. Your doctor or physical therapist can suggest an exercise program that will help keep you active. Ask several friends and/or family members to be your workout buddies so you can have daily encouragement to adhere to your program.

#### This and That .... Thoughts on my Mind by Art Guyer -- Totem Pole Playhouse 2016 Season

If you want to attend one of these shows, contact me for discounted tickets.

**Lovesick Blues** May 17 – 22 (Guyer and DeHaven Not Attending)

Six Dance Lessons in Six Weeks May 27 - June 12 (Guyer and DeHaven Attending June 8 at 2:00 PM)

Forever Plaid June 17 - July 3 (Guyer and DeHaven Attending June 29 at 2:00 PM)

One Slight Hitch July 8 - 24 (Guyer and DeHaven Attending July 20 at 2:00 PM)

Funny Thing Happened on the Way to the Forum July 29 - August 14 (Guyer and DeHaven Attending August 10 at 2:00 PM) A Christmas Carol December 8 - December 18, 2016.

More information is available on line at: http://totempoleplayhouse.org/ or by phone at 717-352-2164

Take care..... Art YARD SALE, MAY 7TH: SEE PAGE 8 NOW!

### **Heads Up, Caregivers:**

Based on the Book by Shelley Peterman Schwarz (2002)

**Periodically, the person with PD may experience hallucinations or delusions**. It may be helpful to say, "I'm sure you really see the [little girl] but it's really the medication for the Parkinson's disease that's causing you to see [her]. I'll call the doctor and see how we can make [her] disappear." Then redirect the person and say something like, "Let's get a glass of ice tea. Come and help me." Or explain that you're talking about what to get Mary for her birthday and ask "What do you think she'd like?" This gets the patient thinking about something else.

Contact the local fire department about any special needs the person with PD might have should a fire emergency occur. The information will be noted and in an emergency, the dispatcher will be able to tell the firefighters where to look for the person needing assistance, and what special equipment or rescue procedures might be necessary. Communities will vary as to how they record and retrieve this information so even if your community has the 911 emergency services, it is still important to contact your local fire department before tragedy strikes. In some communities, information between the fire, police, and emergency medical services is not shared, so readers should contact each agency independently.

#### MAKE TAX-DEDUCTIBLE DONATIONS TO THE HAGERSTOWN PARKINSON'S SUPPORT GROUP

You can make tax-deductible donations to our support group through the Maryland Association for Parkinson's Support, Inc. (MAPS), a non-profit organization that can receive charitable contributions for Parkinson's support groups, issue tax-deductible receipts to donors, and administer the funds to the designated group. To contribute, make your check payable to MAPS. On the <u>memo line write Hager-stown PD Support</u>. You <u>must write that</u> to assure the money goes into the account that MAPS has set up for our support group.

Mail donations to: MAPS Treasurer, Box 450, Brooklandville, MD 21022

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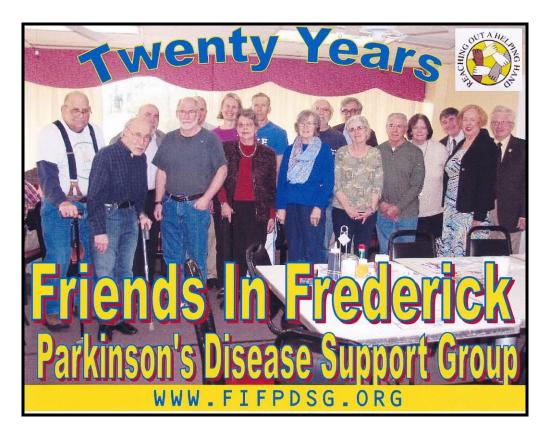
## Four-State Alliance for Parkinson's Support

Photo from the Friends in Frederick 20th Anniversary Celebration March 16, 2016

In March 2016, the Friends in Frederick Parkinson Support Group celebrated their 20th anniversary. John Kraft started the group and is still the president. He has only missed two meetings during those 20 years. Members of the HPSG helped them celebrate at the Barbara Fritchie Restaurant in Frederick. Art Guyer presented John a Community Service Award on behalf of the **Four-State Alliance for Parkinson Support.** Congratulations to our friends in Frederick.

Art & Doris Guyer and Dave & Patsy DeHaven attended the celebration. More photos are on their website at: <a href="http://www.fifpdsg.org/20th\_anniversary">http://www.fifpdsg.org/20th\_anniversary</a> - 1996 - 2016.





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### Parkinson's Disease Symposia

Patsy and Dave DeHaven and Doris and Art Guyer attended the Parkinson Foundation of the National Capital Area (PFNCA) Symposium on March 19, 2016, in Falls Church, VA, and the University of Maryland (UM) Annual Parkinson's Disease Symposium on April 1, 2016, at the BWI Marriott near Baltimore, MD. In conjunction with the UM Symposium they attended the *Spring Support Group Leader Networking Meeting* the afternoon before the meeting, March 31, 2016.

The <u>PFNCA Symposium</u> was an excellent educational opportunity featuring well known speakers such as Drs. Linda Sigmund, Pritha Ghosh, Howard Weiss, Zoltan Mari, Paul Fishman, Stephen Grill, and Larry Dalton. It was also a great opportunity to renew some old acquaintances, meet some new people, and set up some possible speaker opportunities for next year. The networking is an invaluable part of these meetings. Seven members of the Winchester PD Support Group attended also.



Dave and Patsy DeHaven – PFNCA Symposium



Art and Doris Guyer – PFNCA Symposium



Waverly and Cheryl Reames - PFNCA Symposium

The <u>Support Group Leader Networking Meeting</u> which took place on March 31<sup>st</sup> at the BWI Marriott near Baltimore, the day before the UM Symposium, was also a success. About 10 support groups were represented from Pennsylvania, Virginia, and Maryland. In addition, Todd Hebb, from MAPS, and Dr. Lisa Shulman, Director of the UM Movement Disorder Center, were in attendance.

The <u>Symposium sponsored by the University of Maryland</u> was formatted differently but equally excellent, allowing for much more participation by the attendees. It also featured expert speakers such as Drs. Lisa Shulman, Stephen Reich, David Glovinsky, and Paul Fishman. Other noted speakers included Michelle Cines, Ellen Talles, Lynette Chambers, and Debbi Shpritz. We made some new contacts and talked with some people we had not seen for a couple years. This resulted in a number of good leads for speakers for 2017.



Doris Guyer and Patsy DeHaven – UM Symposium



Patsy and Dave DeHaven, and Cheryl Reames

– UM Symposium



Dr. David Glovinsky, and Lorraine and Bill Garret – UM Symposium

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#### The New Prescription for Parkinson's: Puttering

Michael J. Fox Foundation: FoxFeed Blog

Posted by Maggie McGuire Kuhl, September 29, 2015

Research pours in on the negative health effects of a sedentary lifestyle. And exercise may not be answer enough — even marathon runners who sit at a desk all day may be hurting their health.

People with Parkinson's are no exception. A recent paper from The University of Michigan shows that more everyday physical activity, perhaps more so than vigorous exercise, is associated with less severe motor symptoms. The Michael J. Fox Foundation supported the study.

Motor difficulties are a trademark of Parkinson's disease (PD), but many people assume the deterioration seen in advanced stages is solely from dopamine loss. "It is also plausible that lack of physical activity worsens motor symptom severity in PD independent of the degree of brain degeneration," the authors wrote. Their study investigated that relationship.

The study team enrolled 48 people with PD, most with moderate severity of disease. Each had an imaging scan to measure brain dopamine change and completed a survey that asked about time spent doing various physical activities — both exercise and other actions such as housework and visiting local events.

They found that increased motor severity (measured by the Unified Parkinson's Disease Rating Scale) was associated with decreased duration of non-exercise physical activity even when accounting for brain dopamine change, levodopa medication dose, age and duration of disease. Translation: those people who did more puttering and low-impact activity had less severe motor symptoms. Further analysis showed the biggest impact on slowness, gait and balance, more so than rigidity and tremor.

"The study indicates that disability of Parkinson's is not just from the brain disease itself but also a consequence of a sedentary lifestyle. Non-exercise physical activity has an independent outcome on patients' motor impairments," says lead researcher Nicolaas Bohnen, MD, PhD.

Interestingly, they did not find the same association between motor severity and duration of exercise activity. More time spent exercising did not mean less severe motor symptoms in this study. Dr. Bohnen's paper suggests this may be because exercise uses a different brain region than is used for daily movement. Non-exercise physical activity also may contribute to habit formation, where the brain knows how to build motor routines to better meet the demands of daily life.

While beneficial, building in more activity is easier said than done. Poor peer support, lack of motivation, fear of social stigma and barriers to activity (geographic location, for example) make it difficult to get up and go. That inactivity breeds more of the same, though, as people have decreased muscle strength, deconditioned reflexes and fear of falling, the researchers write.

"A vicious cycle of worsening parkinsonism and increasingly sedentary behavior may explain decreasing physical activity in advanced PD," they said.

 $Starting \ small \ -- \ tracking \ your \ steps \ with \ a \ pedometer \ and \ setting \ incremental \ goals \ or \ working \ with \ a \ physical \ therapist \ to \ gain \ strength \ -- \ can \ help \ increase \ activity.$ 



"A person with Parkinson disease will be best off when medical management, such as taking medications, will be combined with behavioral interventions that reduce a sedentary lifestyle. The good news here is that this does not require intense or vigorous exercise efforts but can be done right at home while cooking, doing this dishes, cleaning the house, working in the garden or walking the dog," says Dr. Bohnen.



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#### Reminders of upcoming events as of Sunday, April 10, 2016

View our local Parkinson's Support Groups Calendar at: https://www.localendar.com/public/HPSG

#### **REGULAR EVENTS:**

Event	Date, Time, Location	Contact for Information
Hagerstown Parkinson's Support Group Meeting	1 <sup>st</sup> Thursday @ 11:45 AM Western Sizzlin Restaurant, Hagerstown , MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Cumberland PD Support Group Meeting	1 <sup>st</sup> Friday @ 4:00 PM Grace Memorial Church, Cumberland , MD	Tobby Feddis, 301-729-5569 Pam Dolly, 304-738-2196
Winchester PD Support Group Monthly Meeting	2 <sup>nd</sup> Tuesday @ 11:00 AM Winchester Church of God, Winchester, VA	Cheryl Reames, 540-662-4632 winchesterparkinsons@gmail.com
Central PA PD Support Group Meeting	2 <sup>nd</sup> Wednesday @ 1:30 PM Health South Rehab Hospital, Mechanicsburg, PA	Dan Yother, 304-676-2053 oldred714@verizon.net
Hagerstown Parkinson's Support Group Caregivers' Breakfast	3 <sup>rd</sup> Monday @ 8:30 AM Hagerstown Family Diner, Hagerstown, MD	Art Guyer, 240-625-2722 4Parkinsons@gmail.com
Frederick PD Support Group Monthly Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM Mount Pleasant Ruritan Club, Walkersville , MD	Janet Silvious, 301-831-5609 janet@fifpdsg.org
Gettysburg PD Support Group Meeting	3 <sup>rd</sup> Wednesday @ 1:00 PM WellSpan Adams Health Center, Gettysburg, PA	Paula Chaplin, 717-337-4407 pchaplin@wellspan.org
Frederick County Parkinson's Early Onset or Newly Diagnosed Community Support Group	3 <sup>rd</sup> Saturday Time and Location Varies	Deb Bergstrom, 301-712-5381 bergstromdf@gmail.com
Cross Keys Parkinson's Support Group	Time and Location Varies Cross Keys Village, New Oxford, PA	Daune Wynn, 717-495-5671 wynn574@crosskeysvillage.net

#### **OTHER EVENTS:**

- Saturday, April 16, 2016, 11:00 AM 4:00 PM, Hagerstown Lioness Club, Paddle & Quarter Auction. Contact 301-790-0076
- Monday, April 18, 2016, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.
- Wednesday, April 20, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series Subject: Voice Health (Dr. Celia Bassich, PHD, CCC-SLP)
   St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
   Contact: Phone 410-955-8795 Email rdunlop@jhmi.edu. Register
- Thursday, April 21, 2016, 1:00 PM 4:00 PM, Parkinson Bowling: Duckpins at the Southside Bowls at 17325 Virginia Avenue in Hagerstown, MD. For directions or carpooling, contact Dave DeHaven at 301-582-2815 or by email at hagdehaven@aol.com.
- Thursday, April 28, 2016, Noon 1:00 PM Memory Café: Free lunch and meeting at Hurrikane Taphouse, 29 N. Burhans Blvd, Hagerstown. Contact David Kukor for information and reservations at 301-639-3166 or dkukor@ahcglobal.com.

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- Thursday, May 5, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Speaker is Attorney Michael G. Day on Elder Care.
- Monday, May 16, 2016, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at 4Parkinsons@gmail.com or 240-625-2722.
- Wednesday, May 18, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series Subject: Vision (Dan Gold, DO)

St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD Contact: Phone 410-955-8795 Email rdunlop@jhmi.edu. Register.

 Monday, May 23, 2016, 10 AM – 3 PM, Washington County CARES 2016 Senior & Caregiver EXPO, Robinwood Professional Center (Blue/Silver Entrance). We will be having an information table at this event.

- Thursday, June 2, 2016, 11:45 AM, Hagerstown Parkinson's Support Group Meeting: Breakout Discussion Sessions
- Wednesday, June 15, 2016, 7:00 9:00 PM, Johns Hopkins PD Community Education Series Subject: Depression and Anxiety (Dr. Greg Pontone, MD)
   St. Thomas Episcopal Church, 1108 Providence Road, Towson, MD
- Contact: Phone 410-955-8795 Email rdunlop@jhmi.edu. Register
- Friday, June 17, 2016, Noon 3:00 PM, HPSG Picnic. Bring a dish and a Bingo Prize. For directions or information, contact Dave DeHaven at 301-582-2815 or by email at <a href="mailto:hagdehaven@aol.com">hagdehaven@aol.com</a>.
- Monday, June 20, 2016, 8:30 10:00 AM, Caregivers' Breakfast: Hagerstown Family Diner, Hagerstown, MD. Contact Art Guyer for information at <u>4Parkinsons@gmail.com</u> or 240-625-2722.

# Hagerstown Parkinson's Support Group Yard Sale May 7, 2016

Spring is just around the corner and we're moving forward to have our first ever Hagerstown Parkinson's Support Group Yard Sale, tentatively scheduled for May 7<sup>th</sup>, weather permitting. The proceeds will be used to support our own group. We plan to make this a <u>Parkinson's Awareness Event</u> also.

Several members have told us they are putting aside items to contribute. Please talk to your neighbors and friends and family members and see if they have items to donate. If it is something they want to get rid of immediately, we can arrange for pick-up and storage. If anyone knows of a secure storage place, either a vacant garage or shed, in the Hagerstown area that we could use for a couple of months to store items, that would be greatly appreciated. The owners of the Western Sizzlin' Restaurant have graciously offered us part of their parking lot and grassy shaded area for the event. Signs are being prepared.

If you want to be part of the Yard Sale Committee, contact Dean or Carol Cook at 304-267-7819 or at <a href="mailto:home2wv@yahoo.com">home2wv@yahoo.com</a>.

THIS YEAR PICNICS ARE ON JUNE 17 AND SEPTEMBER 16, NOON UNTIL 3 PM BRING A DISH AND ENJOY THE SOCIAL HIGH POINTS OF THE YEAR