



Parkinson Pathfinder

THE NEWSLETTER OF THE AMERICAN PARKINSON DISEASE ASSOCIATION
INFORMATION AND REFERRAL CENTER OF WASHINGTON

September/October 2008

The HOPE Conference on Parkinson's: November 1, 2008

HOPE. Parkinson's Disease

The Washington State Chapter of the American Parkinson Disease Association, in conjunction with the Northwest Parkinson's Foundation is preparing for the 3rd annual HOPE Conference on Saturday, November 1 from 8:30am – 4:00pm at the Seattle Airport Hilton Conference Center.

The 2008 Conference features national and local experts presenting the latest insights on living well with Parkinson's disease. The symposium includes sessions on medical management, the role of exercise, brain health and technology, and empowerment, focusing on practical tools that patients and caregivers can use to enhance their quality of life.

Tickets are \$25.00 which includes a continental breakfast and lunch. To register online, please go to www.nwpf.org or call 877.980.7500. Questions? Call the APDA Information and Referral Center at 206.277.5516 or email apda@u.washington.edu

Program Speakers include:

- Keynote speaker, **Dave Iverson**, Producer of the upcoming PBS/Frontline documentary special on Parkinson's. As a person with Parkinson's, Dave will discuss making this film and the some of the key questions that Parkinson's raises for science and our aging society.
- **Laurence Elmer, MD, PhD**, Medical Keynote, Director of the Parkinson's Disease and Movement Disorder Program, University of Toledo, OH. Dr. Elmer will present "The NEXT Revolution in Parkinson Therapy."
- **Jeff Shaw, Psy.D**, Neuropsychologist at the Booth Gardner Parkinson's Care Center, Kirkland, WA. Dr. Shaw will present "Playing to Keep Your Brain Working: Art, Recreation, and Technology."
- **Becky Farley, PhD, MS, PT, and Cynthia Fox, PhD, CCC-SLP** of the University of Arizona. Dr. Farley and Dr. Fox are pioneers in an integrated speech and physical therapy approach to Parkinson disease treatment. They will explain the principles behind "Big and Loud."
- **Julie Sacks, MSW, LCSW**, Director, American Parkinson Disease Association National Young Onset Center discusses the importance of reaching out and making connections within your community.
- **Sheryl Jedlinski and Jean Burns**, pdplan4life.com. Jean and Sheryl share their experience with Parkinson's on their website, pdplan4life.com. Through advocacy, humor, exercise, and personal expression, they hope inspire others to live well longer with Parkinson's disease.

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APDA Information and Referral Center

Neurology, S-127
 1660 S. Columbian Way
 Seattle, WA 98108
 Phone: 206.277.5516
 Fax: 206.277.4342
 Hours: M-F 10 am - 3 pm
apda@u.washington.edu

For information packets, literature, or other Parkinson related issues, please contact the Information and Referral Center at the above address or visit our website at www.waparkinsons.org

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Co Medical Directors

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 Ali Samii, MD

Coordinator

Marne Baca

APDA WA State Chapter**Executive Director**

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evedavis@gmail.com
 425-443-8269

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*Please Send Donations
 To The Board Address*

President's Report

September marks my one-year anniversary as president of the Washington Chapter of APDA. It has been a real pleasure to be associated with the chapter over the past twelve months. Strong leadership from Evie and volunteer effort from the board were evident throughout the year. New programs were launched and existing ones were enhanced.

The auction in May was a huge success with over 300 attendees and over \$100,000 raised for PD—both numbers are records. Everyone who attended the event had a great time. We're already looking ahead to next year.

As those of you who are careful readers of the Pathfinder remember, I said in the May issue that new and improved programs were the theme for fiscal year '08. As we finish the fiscal year and look back on the number of efforts launched during the year, set in motion for launch, and continuing from the previous year's rollouts, it is really surprising to see how many there actually were and will be—especially for an organization the size of ours.

The Taxi Voucher program (discussed by Evie in her report in this issue) is a smash hit with PD patients and partners. Being able to take a taxi to an appointment at no cost is a huge benefit for those who face transportation hurdles and have limited resources. Getting this program put in place was a big accomplishment by Evie.

Another program winner is the Podcast (in Evie's report) which will be on our website and eventually lead to iPods with a selection of rotating programs featuring PD related topics to be shown in physician offices and waiting rooms in clinics.

Marne Baca and Erica Martinez have the PD Registry up to 361 fully enrolled registrants and they are working hard to add more people to the list. Anyone interested in helping to spread the word regarding the Registry's existence and why being on it would be a good thing can get information on the subject by calling a Registry coordinator at (888) 365-9901.

Under the heading of an improved program is the DVD, Managing Parkinson's: Straight Talk and Honest Hope which is now available in its second edition and has been expanded to include information on nutrition and speech and occupational therapy.

Under the heading of "Really New" will be the honor of hosting the National APDA Convention in Seattle next July. This will be a big deal and its due in large part to favorable impressions gained by national representatives who attended our May auction and were impressed with our enthusiasm and the city.

Coming events that are annual in nature and require huge amounts of organization and effort to pull off are the Retreat October 3rd and 4th, coordinated by Evie Davis, and the Symposium, November 1st, involving Marne and Evie. Please mark you calendars if you haven't done so already.

Scheduling this many events and putting in place and following through on this many programs takes organization and stamina and Evie and the board members who step forward to make them happen have our heartfelt thanks. It really has been a great year.

*Dick Dunn, President
 WA Chapter APDA*

Executive Directors Message

Well summer is now over and as we move forward towards fall there is a lot of exciting news to share with you.

Our taxi voucher program has proved to be one of the most successful programs we have initiated to-date – at this time we have issued vouchers to nearly 40 Clients and we do have funding available for some more – so if you think you qualify check out the newsletter for the information on how to apply.

Our Podcasts will be ready for release on our Web site very shortly – we have produced a podcast series featuring, medications, nutrition, speech & swallowing, exercise, DBS and other related PD topics – we will set out in our next newsletter how to access the podcasts and we look forward to your feedback once you have listened to them.

We have now distributed over 3,000 of our Educational DVD, Edition 2 Managing Parkinson's: Straight Talk and Honest Hope, if you have not received your copy

check in the newsletter for information on how to receive it.

The National APDA Convention will be taking place next July here in Seattle – the Chapter is very excited at being awarded this event and we look forward to being able to show off Seattle to all our visitors from the APDA Chapters and I & R Centers throughout the US.

November 1st is our annual Conference and we look forward to seeing you all there – more information in the newsletter.

As you can see we have a busy time ahead, but without your support we cannot continue to run all these great programs and help our PD Community, so please keep those donation envelopes coming – as I have always said, every penny we receive adds up and helps us “Ease the Burden Whilst Seeking a Cure”

Thanks and have a great fall

Evie Davis

Executive Director Washington Chapter APDA

Taxi-Voucher Program

As a reminder, the Washington Chapter is still accepting applications for its Taxi Voucher program. For qualified applicants, the APDA provides \$300 in taxi vouchers per year for people with Parkinson disease who no longer drive.

Who can participate?

Anyone with Parkinson disease who does not drive or has restrictions against night time driving. At this time, we have funding for up to 100 participants.

How do I use my vouchers?

The vouchers are used like cash and may be redeemed whenever you take a taxi ride.

Do I have to use my taxi rides just for trips to the doctor?

No. You get to decide how to best use the vouchers, whether it's for a trip to the doctor or any other destination you choose.

How do I apply for the program?

It's simple. All that is required is a letter from your health care provider, stating that you no longer drive for medical reasons. We also ask that you give us your name, address and phone number at the time your application is submitted so that we may get in contact with you.

Please contact Evelynne Davis at evedavis@gmail.com or (425) 443-8269 to get started.



The Gadget Junkie looks at Adaptive Keyboards

By Mitchell Levy, July 2008

Jess in Wisconsin writes, “Does anyone know of a keyboard that is better for people with Parkinson’s?”

Good question Jess! And the answer isn’t an easy one because as we all know Parkinson’s affects everyone differently so we need to look at many possible solutions.

The goal for this article is to give you a good spring board to find you a good keyboard. So let’s start with a few good websites and that should give us some ideas and hope of finding the right adaptive keyboard for your needs.

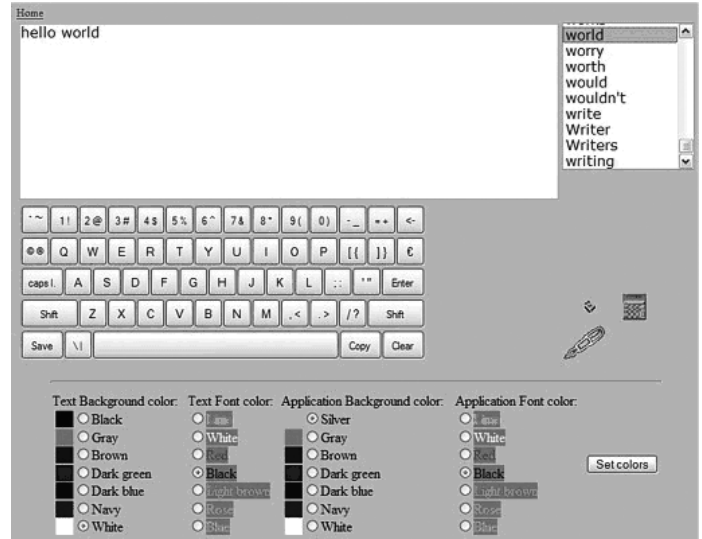
A web site called Web Accessibility In Mind (WebAIM) <http://www.webaim.org/articles/motor/assistive.php> has some good information regarding Adaptive Keyboards.

Adaptive keyboard



In cases where a person does not have reliable muscle control in the hands for precision movements, an adaptive keyboard can be useful. Some adaptive keyboards have raised areas in between the keys, rather than lowered areas, to allow the person to first place the hand down on the keyboard, then slide the finger into the correct key. A person with tremors, or spastic movements could benefit from this type of keyboard. Keyboard overlays are also available as an adaptation to standard keyboards, which achieve the same results. In some cases, adaptive keyboards come with specialized software with word-completion technology, allowing the person to type with fewer keystrokes, since typing can be rather laborious and slow otherwise.

A web-based word on-screen keyboard with word completion technology can be found at http://www.enetplanet.com/kb_fr/ - external link. In nearly all cases, people who need this technology will have it installed on their own computer, rather than using a Web-based version, but an online version can be useful when users are away from their regular computer. It can also be a useful tool to help developers understand how this particular type of technology works.



Another good web site that has adaptive keyboards is Jackson Technology Keyboard List:

<http://www.jacksontechnology.com/adaptive%20keyboard%20list.htm>

These two websites would most likely be able to provide adaptive technology at the “extreme” end and may be fairly expensive.

However there may be some other alternatives like several listed at <http://www.buypcsupplies.com> and in the search window enter “Large Print and Oversize Keyboards. These are pretty much off the shelf keyboards that range in price from \$39.95 to \$84.99. Other sources of adaptive keyboards are:

<http://www.iltsource.com>;

<http://www.assistivetechologies.com>;

<http://www.fentek-ind.com/bigkey.htm>;

<http://www.abilityhub.com/keyboard/expanded.htm> and

<http://www.sspdirect.com/large-letter-keyboard.html> to name a few.

These are just a few sources with many choices. The important issue here is it the BEST keyboard for YOU? When you contact any of these companies it is very important to find out what their return policy is. Most “discount” places do not have the personnel trained to ask you what your “keyboard issues” are. They just pack it and ship it. Some of the more “focused” companies like Jackson Technology or Assistive Technologies will tend to have better trained personnel that may “get it right” the first time.

Jess, I hope this answers your question and please let us know which keyboard works for you.

Mitchell Levy, gadgetjunkie@comcast.net

Homocysteine in Parkinson's Disease

By Laurie Mischley, N.D.

Homocysteine is an amino acid produced by the body. At normal levels, homocysteine plays an essential role in the body's functions. Elevated levels of homocysteine have been linked to Parkinson's disease, atherosclerosis, vascular disease, Alzheimer's disease, depression, and dementia. Nobody knows yet whether homocysteine directly causes or contributes to these conditions, or if it's a marker of something else, such as folic acid deficiency.

Research suggests the longer you've had the Parkinson's, the higher your homocysteine level. This is most likely the result of treatment with levodopa. It appears that the break down of levodopa in the body causes an increase in homocysteine concentrations. Generally speaking, the higher your dose of levodopa, the higher your homocysteine levels.

Some studies have shown that elevated homocysteine levels are associated with worsening PD motor symptoms and dyskinesias.

Researchers are still unsure whether it is the homocysteine that is directly damaging to cells, or whether homocysteine is a reflection of underlying problem, such as deficiency of folic acid. We don't yet know whether reducing the level of homocysteine will change the course of the disease or prevent associated conditions, such as dementia or vascular disease.

What is the optimal level of homocysteine?

Ideally, blood levels should be less than 10.

How can homocysteine levels be lowered?

Folic acid	400 mcg/ day
Vitamin B-12	1000 mcg/ day (sublingual is preferred)
Vitamin B-6	10 mg/ day

This formula, virtually guaranteed to lower homocysteine levels, costs less than \$5 per month!

Do I need to have my blood level of homocysteine tested?

Not necessarily. The test is expensive and not always covered by insurance. There are many supplements available designed to lower homocysteine levels- they are inexpensive and non-toxic. One example is "Homocystrol," produced by Douglas Laboratories.

The point of this article is not to suggest that one should avoid levodopa! Rather, individuals should become familiar with the benefits and risks of the medicine, and do what they can to offset the risks. We know that levodopa raises homocysteine levels, and that homocysteine has been associated with a worsening PD course and possibly with dementia and vascular disease. We also know that homocysteine levels can be lowered very simply with supplementation of B6, B12, and folic acid. We don't know whether lowering homocysteine levels will change the course of these diseases, as the research has simply not yet been done.

This is a perfect example of integrated medicine. Supplementing with the vitamins listed above allows an individual to take levodopa, improve their quality of life, and practice a bit of preventative medicine. You get the benefits while reducing the risks and side effects!

Reference: Martignoni E, et al. 2007. Homocysteine and Parkinson's disease: A dangerous liaison? J Neurol Sci 257:31-37.

Laurie Mischley, ND is a naturopathic doctor at the University Health Clinic in Seattle.

Powerful Tools for Caregivers

Powerful Tools for Caregivers is a six-week education program developed by Legacy Caregiver Services for family and friends caring for older adults who have stroke, Alzheimer's, Parkinson's disease or similar long-term conditions. The class provides family caregivers with the skills and confidence to better care for themselves while caring for others. Many caregivers have found the class beneficial, including: those caring for a spouse or partner and adult children caring for parents.

Class participants report they:

- are better at caring for themselves,
- have fewer feelings of anger, guilt and depression,

- have increased confidence and ability to cope with the demands of caregiving, and
- take more advantage of community services.

Carin Mack, MSW, ACSW, will facilitate this program. There is no cost to participate, but you must pre-register and commit to the entire six sessions. Classes meet once a week.

When: October 16 – November 20, 2008

Time: 10:00am – 12:00pm

Location: Greenwood Senior Center,
525 N. 85th Street, Seattle, WA 98103

More Info: Carin Mack 206.230.0166



Thank you for your Greatly Appreciated Donations!

Donation Names, July 5, 2008 ~ August 31, 2008



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“Managing Parkinson’s: Straight Talk and Honest Hope,”

the DVD produced by the Washington Chapter of the APDA is now available.

Topics include medical management, support, care giving, nutrition and diet,
exercise, speech therapy, and young onset PD.

Please contact evedavis@gmail.com or (425) 443-8269 to order your free copy.

Washington State Parkinson Support Groups

APDA serves as a clearinghouse for PD Support Groups. If you know of one not listed, listed in error or would like to see one created. . .please tell the Information and Referral Center via contacts on page 2. For Support Groups in Oregon, Alaska and Hawaii, also contact the I&R Center.

Before visiting a support group, please contact the group leader to confirm schedule and location.

Idaho

Coeur D'Alene

Lake City Senior Center
Contact: Karen Goodson 208.689.3109
1st Friday of the month 1:00PM

Washington

Anacortes

Island Hospital
contact: Jerry Ramsey 360.293.2185
3rd Thursday of the month 1:00PM

Auburn

Wesley Homes
Contact: Geri Montoya 253.876.6014
1st Friday of the month 10:00AM

Bainbridge

PD Young at H.E.A.R.T. Group
Contact: Steve Bohannon 206.842.0226
sbohann@msn.com
1st Monday of the month 1:00PM

*Bellevue

Young Onset ~ Bellevue Senior Center
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
1st Wed. of the month 7:00PM

Bellingham

Parkway Chateau
Contact: Debra Ivanovich 360.724.3382
2nd Monday of the month 2:00PM

*Bothell

North Shore Senior Center
Contact: Susy Favaro 425.486.4564
suzyf@seniorservices.org
2nd Tues. of the month 10:00AM

Bremerton

Harrison Rehabilitation Services
Canterbury Manor
Contact: David Hull 360.895.6220
1st Tues. of the month 1:30PM

Chehalis

Dayspring Baptist Church
Contact: Gwen Moor 360.858.1206
happygp@juno.com

Des Moines

Wesley Homes
Contact: Rita Lambert 206.870.1302
rlambert@wesleyhomes.org
3rd Wednesday of the month 10:00AM

Edmonds

South County Senior Center
Contact: Kathy McNutly 425.774.5555
njbeeler@comcast.net
2nd Wed. of the month 1:00PM

Everett

Rainier Room, Colby Campus,
Providence General Hospital
Contact: Karen Painter 425.327.9401
KPainter62@aol.com
4th Sat. of the month 2:00PM

Gig Harbor

Rosedale Fire Station
Contact: Doug Manuel 253.858.8741
2nd Tuesday 7:00 PM

*Issaquah

Our Savior Lutheran Church
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
2nd Monday of the month 1:30PM

Lakewood

St. Mary's Episcopal Church
Contact: Doris Gilmore-Sherwood
253.582.8421
dbgilmore1212@aol.com
2nd Tues. of the month 1:00PM

Langley

Contact: Carolyn Hansen
360.279.1785
2nd Tuesday of the month 10:00AM
Bay View Senior Center

Longview

Canterbury Inn, 3rd and Hudson
Contact: Barbara Sudar 360.423.7012
bnsudar@msn.com
3rd Wed. of the month 1:30PM

Kirkland Caregiver Support Group

Tan 138 at Evergreen Hospital
4th Monday of the month 12:30-2PM

Mercer Island

Community Center at Mercer View
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
1st & 3rd Tues. of the month 2:00PM

*Mercer Island

PD Partners -- Community Center at Mercer View
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
2nd Thurs. of the month 1:30PM

*Mercer Island

Adult Children of Parents with PD --
Community Center at Mercer View
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
3rd Mon. of the month 7:00PM

North Seattle/Shoreline

Shoreline Senior Center
Contact: Scott Tieson 206.268.6761
scottth@seniorservices.org
4th Tues. of the month 11:15AM

*Oak Harbor

North Whidbey Fire Station
Contact: Carolyn Hansen 360.279.1785
1st Friday of the month 1:00PM

Olympia

Westwoods Assisted Living
Contact: Karen Williams 360.956.3396
kwilliams@alcco.com
3rd Tues. of the month 11:00AM

Port Angeles/Sequim

Port Angeles Senior Center
Contact: Jan Yates 360.457.9746
4th Wednesday of the month 10:30AM

Port Townsend

Jefferson Healthcare/Telehealth
Contact: Mark Cherniack 360.385.2200
mcherniack@jgc.org
3rd Mon. of the month 2:00PM

Puyallup

United Methodist Church
Contact: Shannon Tait 253.697.8533
shannon.tait@goodsamhealth.org
3rd Thurs. of the month 1:30PM

Puyallup

Caregivers Support Group (Not Only PD)
Good Sam Community Services
Contact: Kathy McCormick 253.697.8400
2nd Monday of the month 1:30PM

Puyallup - Young Onset

Bethany Baptist
Contact: Jeff Magin 253.445.7399
2nd Tuesday of the month 7:00PM

Redmond

Emerald Heights
Contact: John Waltner 425.556.8100
3rd Thursday of the month at 1:30PM

Renton

Merrill Gardens at Renton Centre
Contact: Barbara Shull 425.235.6400
3rd Wed. of the month 1:30PM

Richland

Neurological Research Center
Contact: Heidi Hill 509.943.8455
hillh@kadlecmed.org
2nd Thurs. of the month 1:30PM

*Seattle

Seattle PD Partners --
Greenwood Senior Center
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
2nd Tues. of the month 1:00PM

Seattle

Well Spouse -- Greenwood Senior Center
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
1st Mon. of the month 4:00PM

Seattle

Young Onset -- meets in members homes
Contact: Suzanne Cameron 206.286.8149
2nd Tues. of the month 7:00PM

Seattle First Hill

Virginia Mason Medical Center
Contact: Laurel Beck
206.652.7373 x64553
laurel.beck@vmmc.org

Spokane

St. Lukes Rehab Institute
Contact: 509.473.2490
3rd Mon. of the month 2:00PM

Spokane (Dystonia)

St. Lukes Rehab Institute
Contact: Denise Gibson 509.891.9131
denise@designnden.com
2nd Sat. of the month 1:00PM

Spokane (Women's)

Location changes -- contact group leader
Contact: Julie Willis 509.467.2240
1st Thurs. of the month 1:00PM

Tacoma

Tacoma Lutheran Home
Contact: Sharon Jung 253.284.4488
3rd Friday of the month 11:30AM

Vancouver

Legacy Salmon Creek
Contact: Lynda Forbes-Cramer
360.546.1763
lfcramer@comcast.net
3rd Sat. of the month 1:00PM

Vancouver

Locations and time varies
Contact: Jeanne 360.892.0686

Vashon island

Contact: Kate Lanigan 206.463.3140

Walla Walla

Congregational Church
Contact: Darlene Lambert 509.382.4012
4th Sat. of the month 6:00PM

Washington Peninsula

Ocean park Lutheran church
Contact: Patti Pellerin 360.665.3284
4th Fri. of the month 1:30PM

West Seattle

Admiral Congregational UCC
Contact: Katie Stokely 206.933.5931
3rd Thurs. of the month 1:30PM

Yakima

Park Meadows
Contact: Jaci Rice 509.248.9963
2nd Thurs. of the month 2:00PM

PD Partners

Parkinson disease is a complex disorder that impacts the whole family. PD Partners support groups are open to spouses and significant others supporting a loved one with PD. Share concerns, learn more about PD, find out about resources and network with other PD partners.
Call Carin Mack
MSW for more information
206.230.0166
socialwkr@earthlink.net

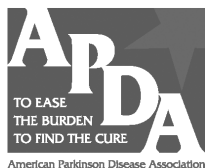
*Denotes APDA Affiliation

APDA Event Calendar

For more information about any events listed below, contact Marne Baca (206) 277-5516 or apda@u.washington.edu

Location	Date	Event
Renton Merrill Gardens	September 29 1:30pm	Adam Hebb, MD “Deep Brain Stimulation for PD”
Mercer Island Community Ctr.	October 7 2:00pm	Laurie Mischley, ND “Nutrition and PD”
Longview Canterbury Inn	October 15 1:30pm	Ann Zylstra, PT “Exercise helps but only if you do it”
Lynnwood Community Ctr.	October 23 11:00am	Charles David, MD “Deep Brain Stimulation for PD” Laurel Beck, PT “Exercise and PD”
SeaTac Airport Hilton	November 1 8:30am	HOPE conference (see page 1 for more info)
Mercer Island Community Ctr.	November 4 2:00pm	Debbie Hanson, DPT “Being Fit with PD”
Seattle Greenwood Community Ctr.	November 6 7:00pm	Dennis McCullough, MD “Elders, Families and the Healthcare System Working Together”

University of Washington
Department of Neurology
 Box 358280
 Seattle, WA 98195
 Attention: Marne Baca (S-127)



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