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A B O U T U S

Parkinson's Post is published by the Northwest Parkinson's Foundation, a 501(c)(3) charitable organization.

Our mission is to establish optimal quality of life for the Northwest Parkinson's community.

We welcome comments and inquiries regarding this newsletter and all our activities. Our contact information can be found on the last page of this newsletter. We look forward to hearing from you!



NORTHWEST
PARKINSON'S
FOUNDATION

PORRIDGE FOR PARKINSON'S



Left: Porridge chef Noel MacDonald pauses for a photo with host Colleen Taucher during the Tauchers' "Porridge for Parkinson's" breakfast in January. Right: Marge Meikle with her son Mac.

'Porridge' good for body, soul and Parkinson's community

By Joanna Glickler

What do you get when you cook up a big pot of steel-cut oats, put in a little music, add a dash of levity, and throw in friends, family and neighbors?

You get "Porridge for Parkinson's," billed as "the world's simplest fundraiser."

For the second year running Marty and Colleen Taucher of Seattle discovered the power of the "Porridge" breakfast. They gathered their friends and neighbors on a Saturday morning in late January to enjoy good food and great conversation, and to support a cause near and dear to the Tauchers—the Northwest Parkinson's Foundation.

This year, the Tauchers' breakfast raised more than \$11,000 for the Northwest Parkinson's Foundation—*double* the previous year's proceeds.

And we were *doubly* impressed!

Porridge for Parkinson's was conceived in 2001 by Colleen's university friend Marg Meikle and Marg's husband Noel MacDonald of Vancouver, B.C. Marg was diagnosed with Parkinson's in 1999, and she and Noel wanted to make a difference in the community.

Marg and Noel modeled their idea on a church benefit breakfast that friends of theirs held each year. The benefit embodied a casual simplicity they thought was ideally suited to the Parkinson's cause and easy to replicate.

In November 2001, the couple hosted their first Porridge event. More than a dozen such events in Canada and a couple in the United States since then have generated well over \$100,000 for various Parkinson's causes.

Marg and Noel's website,

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www.porridgeforparkinsons.com, highlights the simplicity of Porridge. The site contains the recipe, both for breakfast and for success with the event.

Colleen confirmed that Porridge for Parkinson's is fairly easy to pull off, saying the biggest challenges are getting the porridge timing right and knowing how many people to expect.

Her advice to others interested in trying their own Porridge event: "Start small, get the timing down, practice on your family and keep it growing yearly." She offered to advise anyone who'd like to get started.

So what are you waiting for? If you're not ready to launch your own Porridge for Parkinson's, at least fix yourself a bowl of porridge. It's good for you! (See related story on this page.)

—*Joanna Glickler is development director at the Northwest Parkinson's Foundation. Learn more about Porridge for Parkinson's by calling 1.877.980.7500 or visiting www.porridgeforparkinsons.com. The Northwest Parkinson's Foundation gratefully acknowledges the efforts of the Tauchers and all their generous friends!*

Center's treatment trial in need of participants

The Booth Gardner Parkinson's Care Center seeks volunteers for a clinical study to test a new treatment's effectiveness in curbing Parkinson's side effects.

Men and women age 30 to 70 who have been diagnosed with Parkinson's are candidates for the study. All office visits, medical evaluations and medications directly connected with the study will be provided at no cost to patients.

This study will determine the effectiveness of a new form of the drug Requip in increasing the time to onset of dyskinesias in patients who have been taking levodopa (Sinemet) for less than two years.

To learn more, call Berta Leis, Ph.D., R.N., at 425.899.3123.

Nutrition role central in self-care

By Ann Settles, COTA/L



Why is nutrition so important in the management of Parkinson's disease?

In the last decade, there has been a renewed interest in nutritious

foods as a means of preventing and alleviating some of the debilitating conditions that accompany disease. With Parkinson's the risk of falls, constipation and weight change affect safety and comfort. But maintaining a healthy diet can enhance quality of life.

Risk for falls is probably one of the most prevalent problems associated with Parkinson's. Because of this, it is imperative that the body's infrastructure be sound and healthy.

The health of bones and teeth are dependent on proper intake of calcium. If there isn't enough dietary calcium available, the body "robs Peter to pay Paul," so to speak. The result can be brittle bones subject to fractures.

There are many ways to increase your calcium intake without taking one of those supplements the size of a horse tablet. You can drink calcium-fortified orange juice or add fortified soy products to your diet. The recommended daily amount of calcium is 1,200 to 1,400 milligrams per day. This is equal to about four glasses of milk.

Constipation is another common problem in people with Parkinson's. The first question to ask yourself: "How much water am I drinking?"

Next to oxygen, water is second in importance to the body's needs. It balances acids and moves ingredients into cells. It is a solution for holding electrolytes, which allow for the conveyance of electrical currents. It is in this fluid environment that the body's energy production takes place.

We put ourselves at significant health risk when we deprive ourselves

of this critical element of sound nutrition. The recommended amount of water is six to eight glasses per day.

Next ask yourself, "Is my diet high in fiber?" Eating enough fiber is one of the most beneficial and simple things you can do for your health. Fiber aids digestion and minimizes constipation. And fiber contributes to lower blood cholesterol, helps keep blood sugar normal, and can prevent or reduce the symptoms of bowel disease and decrease colon cancer risk.

The recommended daily amount of fiber is 25 to 35 grams. Two dried figs provide 5 grams of fiber, half a cup of lentils has 8 and one cup of oatmeal has 4. Once again, water is essential. If you have a diet high in fiber but without a commensurate amount of water, you might as well be consuming concrete!

We're always told to eat our fruits and vegetables—and for good reason. Not only are fruits and vegetables good sources of fiber, they also contain necessary vitamins, minerals and fiber.

And fruits and vegetables are an abundant source of antioxidants—your cell's protectors. Damaging byproducts, called free radicals, are created when some oxygen molecules become highly reactive. These free radicals can cause cell damage that may lead to heart disease, cancer and weakening of the immune system. That's where antioxidants come into the picture. They control the free radicals by transforming them to less damaging compounds and by repairing damaged cells.

In conclusion, fortify yourself by incorporating more calcium, water and fiber into your diet. Your quality of life depends upon your taking action!

Questions about nutrition and Parkinson's? Call the Booth Gardner Parkinson's Care Center (425.899.3123).

—*Ann Settles is a certified occupational therapy assistant at the Booth Gardner Parkinson's Care Center in Kirkland, WA.*

Yoga pluses plentiful for Parkinson's people



By Marjo Miller

What do you think a 42-year-old man with a new heart transplant, a 60-year-old woman with Parkinson's, and a 20-year-old

college student recently diagnosed with cancer have in common?

I'll tell you. They're all active participants in the Seattle Jiva Yoga Program—there because they share a desire for the support of community and for the physical, mental, spiritual and emotional benefits of yoga.

Jiva means *individual* in Sanskrit. The program is thus named because each individual who takes part responds to the program in his or her own way, depending on that person's place in life and the physical or mental challenges being addressed.

This means each student is absorbed in individual work under teacher

guidance. It also means that competition has no place in the yoga classroom.

Sessions begin with meditation and directed-breathing exercises. These can be of particular benefit to the Parkinson's person dealing with a body that vibrates with tremors and surprises us with involuntary movements.

Breathing exercises are done seated or lying down.

The breathing patterns established at the beginning of the lesson are carried through the whole hour and with each *asana*, or pose.

It's easy to forget our limitations as we follow the teacher's instructions to inhale, exhale. Breathing "opens up" each pose.

We practice twists, which tone our internal organs, standing poses with their weight-bearing characteristics to strengthen our bones and muscles, and balancing exercises, which challenge body and brain. All the while we are reminded to "breathe into the pose."

Is this for you? I hope so! If you're in the Seattle area, I encourage you to join us. Our cost is just \$5 per quarter, based on ability to pay. Our spring

WHAT?

Seattle Jiva Yoga Program

WHEN?

Spring Quarter, April 13 to June 17

Senior sessions

Tuesdays: 12:15 - 1:15 p.m.

Wednesdays: 1:15 - 2:15 p.m.

Session I

Thursdays: 11:30 a.m. - 12:30 p.m.

Session II

Thursdays: 12:45 - 1:45 p.m.

Session III

Thursdays: 6:15 - 7:15 p.m.

WHERE?

Miller Community Center
330 19th Ave. E / Seattle, WA

COST?

\$5 per quarter, waived for seniors

CONTACT?

Paul Bubak, M.D., 206.369.3057

quarter runs from April 13 to June 17.

If you're elsewhere in the region or beyond, I hope you'll consider the benefits of yoga and look for programs in your area.

—Marjo Miller is cofounder and executive director of the Seattle Jiva Yoga Program.

Get online to 'chat' with doc

Dr. Alida Griffith of the Booth Gardner Parkinson's Care Center will offer her insight and expertise through a monthly online "chat room" beginning in April.

A chat room is an online forum that allows people to "chat" with each other by typing messages that are displayed almost instantly on the screens of others signed in to the chat room at the same time.

The Parkinson's chat room will be available between 2 and 3 p.m. (PST) the second Tuesday of each month beginning April 12. During this time, the doctor will be available for live questions and answers. To register to join the chat room, visit www.nwpcf.org/chatroom.asp.

This will be an excellent opportunity for Parkinson's people and their caregivers to pose questions to this specialist and for all involved to benefit from her answers.

Griffith and her colleague Dr. Anthony Mosley are fellowship-trained movement disorder specialists at the Booth Gardner Parkinson's Care Center in Kirkland, WA.

To learn more, call 1.877.980.7500 or email info@nwpcf.org.

Genetics study seeks patients

The risk of developing Parkinson's is thought to be determined by a complex interaction between environmental and genetic factors. Identifying these factors is critical in developing more effective strategies of early diagnosis, treatment and prevention.

The Parkinson's Genetic Research Group, led by Dr. Cyrus P. Zabetian and based at the University of Washington and the Veterans Administration hospital in Seattle, is conducting a study to identify genes that increase the risk of Parkinson's and related illnesses.

Parkinson's people may be eligible to participate if they receive care from Dr. Ali Samii, Dr. Phillip Swanson, Dr. Anthony Mosley or Dr. Alida Griffith.

Individuals without Parkinson's may be eligible to participate as control subjects.

The study requires a brief assessment of family and medical history followed by a small blood draw.

To learn more, call 206.277.4594 or email pgrgroup@u.washington.edu.

Advocate role crucial during hospital stay

By David L. Cram, M.D.

An advocate is defined as “a person who pleads for or on behalf of another.” If you asked most people, “Do you need such an advocate when you visit your doctor or go into the hospital?” most would say no. Most people are not used to asking for this kind of personalized help. We think we can handle this area alone.

In reality, with today’s managed care and the increased pressures placed on nurses and doctors, nearly everyone should have an advocate, especially if you need to be hospitalized. I became acutely aware of this need when I was hospitalized a couple of years ago for a rare side effect of bromocryptine.

The person who can best act on your behalf is someone close to you who knows your condition. Preferably, it should be someone who understands how a hospital works. This can be a husband or wife, partner, friend, relative or caregiver. It also helps if the advocate has some medical knowledge or has access to such knowledge. The advocate needs to be aggressive, on top of things, and willing to question the decisions made in the care of the patient. The advocate should be prepared to ask questions like: “Why are you doing this procedure?” “Does it have risks?” “Are there alternatives?” “Can we get another opinion?”

To be most helpful, the advocate needs to be with the patient or be aware of what is happening around the clock. He or she should be available to take calls from a doctor or nurse in case of an emergency. Otherwise, important medical decisions that must be made quickly could be missed by the advocate—decisions that may have needed further discussion.

No medical condition in a hospital needs an advocate more than Parkinson’s. Parkinson’s people may not be able or willing to speak out for themselves, and they need a lot of attention and specialized care. Their medication schedule is unique and requires precision dosing. Since people with Parkinson’s are mostly over age 50, the chances are high of having or developing another illness that may require hospitalization. They also can develop complications from their basic disease as well as serious side effects from the potent medications used. It is helpful if people with this disease and their caregivers make some advance preparations and know what to do should hospitalization be required:

- ◆ Become a member of Medic Alert and wear a Medic Alert bracelet. On the bracelet are persons and physicians to be notified in an emergency, what medications you are taking, and any possible allergies to medications. (Call 1.800.432.5378.)



- ◆ Make a legible (preferably typed) list of all the medications you are taking, including the exact time of the day you take each drug. Give this list to your partner or spouse, your advocate, and your

doctors for your medical files. Also, keep a copy in your wallet or purse and be sure to keep it current. The benefit of having your drug regimen readily available in an emergency situation is obvious.

- ◆ Because some hospital pharmacies may not stock certain medications, bring all your medications to the hospital in their original bottles to insure dosages are not missed.

- ◆ If an elective surgical procedure is to be performed, selegiline (Eldepryl) should be stopped at least two weeks prior to surgery as it can interact adversely with the pain medication merperidine (Demerol). Also to be avoided because of potential drug interactions are the gut motility drug metoclopramide (Reglan) and the anti-nausea drug perchlorperazine (Compazine). While observing the patient in the hospital, the advocate should be alert to the possibility of a drug interaction or side effect when the patient’s medical or mental status suddenly changes. The advocate should immediately alert the attending physician of his or her suspicions. Drug reactions are more frequent in the elderly.

- ◆ Support hose should be fitted on the legs to help prevent blood clots. (The advocate may need to remind the nursing staff of this as well as getting the patient to ambulate as much as possible.) Leg and foot exercises by the patient in bed should be encouraged. Bedside physical therapy should be started immediately after surgery, especially if the patient is debilitated.

One of the most important problems for the hospitalized Parkinson’s patient is his or her medications. Unless the attending physician is a neurologist or a doctor familiar with these medications, errors in proper dispensing can occur. Doctors write hospital medication doses using Latin abbreviations such as TID (three times a day) and QID (four times a day), and all of the medications on the medical ward are dispensed by nurses at specific intervals during the day.

People with Parkinson’s, however, take their medications at various but *precise* times during the day and sometimes at night. The dosing times need to be exact as failure to do so can result in periods when the patient’s disease is no longer in control, resulting in severe motor fluctuations with reduced mobility.

This is another area where an advocate can be helpful.

Continued on next page

On arrival at the hospital, the advocate should present the patient's medication list to the nurse in charge and explain why the drugs must be taken at specific times. The advocate may also wish to discuss the drug list with the attending physician, who may not be familiar with some of the medications used.

As careful as they try to be, doctors and nurses can sometimes make mistakes. With the introduction of managed care, nursing and physician demands have increased and only the sickest patients are admitted to the hospital. This increases the importance of an advocate.

The advocate should try to establish some rapport with the attending physicians and nurses. This means the advocate should not act like a police officer but more like a spokesperson for the patient, someone who asks questions and is looking out for your interests when you are least able to do so. If the advocate is not happy with the way things are going and questions the quality of care, he or she should discuss all concerns with the medical staff. If things don't improve the advocate should try to change doctors or even hospitals, if this is possible.

In discussing the advocacy situation with patients and medical personnel alike, there is general agreement that the advocate plays an important role in helping insure the patient is getting the safest and most effective treatments at all times during the hospital stay.

If you or a loved one has Parkinson's, be prepared. Appoint someone now whom you can trust to be a good advocate should hospitalization become necessary.

—Dr. Cram has had Parkinson's for 14 years. A retired dermatologist, he is the author of many scientific articles and was appointed clinical professor emeritus by the University of California, San Francisco, in 1991. He has authored the books, "The Healing Touch" and "Understanding Parkinson's Disease, A Self-Help Guide."

Free online tool geared to caregivers

Don't forget the Parkinson's Educator, an online learning tool for caregivers. Any Parkinson's caregiver—family or professional—may complete the eight-module program, developed by a panel of Parkinson's experts. There is no cost to complete the program. Learn more at www.parkinsonseducator.org.

Professional facilities whose staff caregivers complete this training have an opportunity to be listed as "Parkinson's friendly" by Total Living Choices (www.tlchoices.com), which provides information and referrals nationally to assist seniors looking for living options.

Facilities can find details on the Parkinson's Friendly program at www.parkinsonsfriendly.org.

Caregiver conference will inform, inspire

Family and professional caregivers will be the focus of the daylong conference, "Challenges in Caregiving: Giving Care, Taking Care." Sponsored by the Aging and Disability Services Administration,

American Heart Association, and AARP Washington along with numerous community organizations, the conference is set for June 7 at the Tukwila Community Center in Tukwila, WA.

Conference sessions are designed to provide information attendees can use in their day-to-day caregiving roles. Caregivers will learn practical tips for managing medications and talking with doctors. They will see homecare products on display, and be able to talk to representatives from local resource agencies about respite care, Medicaid and other services.

Other topics will include:

- ◆ Managing stress
- ◆ Understanding depression
- ◆ Legal and financial planning
- ◆ Coping with feelings of anger, guilt and grief

The fee for individual caregivers is \$25, and scholarships are available. The fee for agency-based caregivers is \$50. Fees include workshops, lunch and resource exhibits. Space is limited and pre-registration is required.

To learn more or to receive a brochure and registration packet, call 1.800.422.3263 or 1.360.725.2544.

Need support?

Having Parkinson's can be an isolating experience. Its puzzling physical symptoms are often accompanied by depression—the result of the brain's reduced dopamine production.

These disease effects can make you want to withdraw. But being part of a group of others facing what you're facing can mean better quality of life for you.

Think about it: Other people with Parkinson's will have practical ideas for managing this complex disease. Maybe you can learn from

them. They'll have stories to share that you'll no doubt identify with. Maybe they've discovered resources you don't know about. And surely you'll make some new friends.

To find out if there's a support group in your area, visit our website at www.nwpcf.org or call us toll-free 1.877.980.7500. Our website links to almost 80 groups in Washington and Oregon and directs you to a resource for other groups regionally and nationally.

No support group near you? We can help you connect to others in your area who might join you in forming one!

It's no exaggeration to say that the Northwest Parkinson's Foundation could not exist without your support. We rely on donations to carry out our services for the Northwest Parkinson's community. Gifts support our programs of awareness, education, advocacy and care. If Parkinson's has touched you or someone you care for, please consider making a gift today. Those listed here gave between Jan. 10 and March 17, 2004. (We have made every effort to list donors correctly. Please advise us of any errors.) To each and every one of you, we extend our heartfelt thanks!

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Personal challenge or labor of love: Team needs you!

By Craig Howard

Three years ago I was challenged to ride my bicycle from Seattle to Portland. It was the end of gray, rainy February in Seattle. The Northwest Parkinson's Foundation was starting to take the Cascade Bicycle Club's Seattle-to-Portland (STP) bike ride seriously—we found out it was a terrific way to raise money and awareness for our cause.

But with a cursory check of my list of Things I'd Least Like to Do, I found none that could beat this.

If I wanted to get in shape, I could join a gym—it's warm there! There's even CNN playing in view of the treadmills!

But this challenge was about much more than just my fitness. I perceived my real challenge to be that I hadn't broken a sweat on a bicycle in more than 15 years. Could I really be ready to ride 200 consecutive miles by July?

In early March I decided to find out.

The first 6-miler (to my local bike shop and back) was an eye-opener. I just had no idea the little uphill near my house were so long, nor the downhill so short. But a week later I rode the 13 miles around Mercer Island. I could feel my body getting used to the machine again.

Without belaboring this too much (I'm making it

sound like Sylvester Stallone in "Rocky"), I'll tell you that four months after getting on the bike for the first time, I crossed the finish line in Portland. It was a great moment for me, and I'd also raised \$1,500 for Parkinson's disease care and awareness.

If this has piqued your interest, either as a rider or as a supporter, I urge you to find out more. Here are some things to know:

- ◆ This year's Group Health Seattle-to-Portland Bicycle Classic is July 17 and 18.
- ◆ More information about Team Parkinson's can be found by visiting www.pedalforparkinsons.org, emailing joanna@nwpf.org, or calling 1.877.980.7500. We can also send you an information packet by mail.
- ◆ Along with your own training, Team Parkinson's has five planned training rides, and the Cascade Bicycle Club offers more still.
- ◆ We welcome corporate and other workplace teams. Contact us for details on how to motivate your coworkers to join you on Team Parkinson's.
- ◆ Not going to ride? You can pledge in support of your favorite rider (visit www.pedalforparkinsons.org to see our growing rider list), to Team Parkinson's overall, or to your own "virtual ride."

Our goal this year is to have 100 riders on Team Parkinson's. Join us for a ride on Sunday, April 18. It will be followed by a barbecue for the team, with lots of information about riding, raising money and staying motivated. Not to mention it's a fun bunch of people!

—*Craig Howard is co-founder of the Northwest Parkinson's Foundation, and he'll be on the trail to Portland again this year.*

Mr. and Mrs. James G. Thumlert
Mr. and Mrs. Scott Webber
Mr. and Mrs. Robert E. Yarr

In memory of Freida Foster
Mr. and Mrs. Robert Diemert

In memory of William A. Gissberg
Mrs. Helen M. Gissberg

In memory of Gerry Graham
Mr. and Mrs. James I. Taylor

In memory of Daniel Woodrow Grefthen
Mr. and Mrs. John E. McDevitt

In memory of Wayne Hunter
Mr. Jeffrey Fehr
Mrs. Wayne Hunter
Ms. Elizabeth Stowell

In memory of Hap James
Mrs. Leona M. Burgess
Ms. Ellen D. Cooke

Mr. and Mrs. D. G. Jewett
Ms. Maxine Kraemer
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In memory of Len Kanser
Laird Norton Family Fund

In memory of Jacob Kessler
Mr. and Mrs. Edwin S. Bean
Mr. and Mrs. Alfred E. Kessler
Mr. David Kessler
Mr. and Mrs. Ernest Kessler
Mr. and Mrs. Ken S. Kessler

In memory of Walter Kessler
Mr. and Mrs. Ernest Kessler

In memory of Ken Knight
Mr. and Mrs. Gordon D. Barnes
Mr. and Mrs. Norman M. McCrea

In memory of Robert Knight
Mr. and Mrs. Stephen J. Bigg
Mr. William B. Pauls
Ms. Arlene L. Sund

In memory of Robert Kendal Knight
Mr. and Mrs. Barry R. Fahlstedt

In memory of Robert Konigson
Mr. and Mrs. Todd A. Konigson

In memory of Bill Kraemer
Mrs. Leona M. Burgess

In memory of Mel Light
Mr. E. Ronald Cohn
Mr. and Mrs. Richard E. Nicholl

In memory of George Lindahl
Ms. Elaine Howe
Ms. Pauline H. Kirkman
Ms. Kaye Kooistra
Mr. and Mrs. Donald W. Rea
Mr. and Mrs. Merl Zigler

In memory of William Maraist
Mrs. Mary Echis

In memory of Margaret T. Marter
Ms. Anne Loustau

In memory of Mary C. Martinell
Mr. W. M. Martinell

In memory of Rick McIntosh
Ms. Janet Zema

In memory of Walter Nissen
Mrs. Evelyn Nissen

In memory of Evelyn Patterson
Mr. Kenneth Patterson

In memory of Barbara E. Phillips
Mr. John Phillips

In memory of Jo Ann Plihal
Mr. and Mrs. Ivan G. Eines

In memory of Gilbert Surface
Mrs. Edna Surface

In memory of William Torrance
Ms. Anne A. Moldrem

In memory of Violet Yario
Ms. Dorithe E. Herriges



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Tiptoe through tulips for Parkinson's cause

On April 9, a group of volunteers will host an all-day bus tour of the tulip fields of Skagit Valley, WA, to raise awareness and funding for Parkinson's care.

The tour—a nod to the red-and-white tulip recognized as the flower of hope for Parkinson's—is timed to coincide with Parkinson's Awareness Month.

The cost to take the tour is \$25 per person, which includes the bus ride, a salmon barbecue, a tulip tour and refreshments along the way. Participants and others may also purchase a tulip lapel pin for \$5 plus postage.

Proceeds will be donated to the Northwest Parkinson's Foundation and the Parkinson's Action Network.

To learn more, call Judi Baker at 425.396.4469 or visit www.tulips4u.org.

DBS organization conducting survey

DBS-STN.org, an affiliate of The Parkinson's Alliance, is conducting a survey to learn more about the day-to-day experiences of patients and caregivers of patients who have had deep brain stimulation (DBS) surgery.

If you or someone you know has had this surgery, DBS-STN.org wants to hear from you. To take part in the survey, you must have had your surgery at least six months ago.

DBS-STN.org can be reached toll free at 1.800.579.8440 or online at www.dbs-stn.org.

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