



# Parkinson's PAGES

PUBLISHED QUARTERLY by the American Parkinson Disease Association  
Information & Referral Center at the MaineHealth Learning Resource Center

WINTER 2009

## Why Tulips?

**K**AREN BARDO, AT THAT TIME AN administrative secretary with the Wiscasset School Department, conducted a search on the Internet, and stumbled upon an Internet support group called the *Parkinson's Information Exchange*. She then found a way to cope with her disease by helping others through selling tulips.

In Canada, Dr. James Parkinson's Colour Tulip Bulbs are sold by Parkinson's disease support groups as a way to raise awareness and funds for research. The red tulip with white edges was named after Dr. James Parkinson, who first described the symptoms of Parkinson's disease in 1817. J. W. S. Vander Wereld, a horticulturist with Parkinson's disease, developed and registered the Dr. James Parkinson Tulip in 1981. "Newfoundland's support groups use the Dr. James Parkinson Tulip very successfully to raise awareness and as a symbol of their hope for a cure." Bardo said. Ever since, the Maine Parkinson Society adopted the tulip as a symbol of hope and it has been selling Dr. James Parkinson Tulips. Each spring, "Gardens of Hope" bloom through out Maine and the U.S. for hope, for better lives, and a cure.



### **Why are there two Parkinson's organizations in Maine?**

As Maine Parkinson Society moved forward to become a 501 (c) charitable organization, there were several discussions with the APDA State of Maine Chapter, to merge with this organization. It became evident that each organization had a very separate mission, with MEPS focusing on patient services and APDA working "to ease the burden, find the cure." In their efforts (*continued on page 2*)

## Maine Parkinson Society Celebrates 10th Anniversary

The Maine Parkinson Society (MEPS) became Maine's first Parkinson's disease organization in 1998.

Co-founded by Karen Bardo and Gregory Leeman, both diagnosed with young onset Parkinson's disease, identified an unmet need for community services to help Mainers who are struggling with the day to day needs of people living with Parkinson's disease.

APDA INFORMATION & REFERRAL CENTER

5 Bucknam Road, Suite 1A, Falmouth, ME 04105 • (207) 781-1735 • 1-800-832-4116 • [www.parkinsonsmaine.org](http://www.parkinsonsmaine.org)

# Why Tulips?

(continued from page 1)

to preserve a collaborative spirit, both agreed that their true rival is *Parkinson's disease* – so, they joined forces! By working together, each organization could sustain its mission and further the reach of helping all Maine people and their families living with Parkinson's disease.

By 2001, this relationship accomplished its first mission to enhance the establishment of the Parkinson's Information & Referral Center (I&R Center). The I&R Center is housed at MaineHealth's Learning Resource Center in Falmouth and is a collaborative effort of the national and Maine Chapter of the American Parkinson Disease Association, MaineHealth and the Maine Parkinson Society.

Today, the Parkinson's Information and Referral Center is staffed by a full-time Professional Coordinator and part-time Administrative Support. The Center provides information about PD to the general public; coordinates educational classes and cultivates support groups throughout the state of Maine; publishes this *Parkinson's Pages Newsletter* for people with PD, their families and healthcare providers; maintains a lending library of books and literature; provides patients with assistance using the Internet to research health-related questions; maintains a specialized listing of community resources for people with PD; manages the administration of the Respite Care Reimbursement Program and conducts countless community outreach efforts to increase awareness and proper care for Maine people with Parkinson's disease.

Maine Parkinson Society has accomplished much in its ten years of existence. A proud member of Community Health Charities, MEPS has much further to go to give the Parkinson's community the advocacy and support necessary to live well in Maine with Parkinson's disease. ■



## The Southern Maine Young Onset Parkinson's Support Group

held their December meeting at the Muddy Rudder restaurant in Yarmouth to celebrate the Holidays and spread some joyous cheer. Members attending were (1st row) Elizabeth Papps, Sue Withington (co-leader), Leslie Weiner, Neal Weiner, (2nd row) Roland Sirois, Claire Sirois, Ken Nye, Kathy Hodgkins, Mark Higgins, (3rd row) Tom Meyn, and Dana Hodgkins (co-leader). The group meets the 3rd Sunday of each month 1:00pm-3:00 usually at a member's home. All are welcome to attend because "young onset" is a state of mind more than anything else. Contact Dana (207-839-7951) or Sue (207-725-0035) for more information and the next month's meeting location.

## Maine Parkinson's Society BOARD OF DIRECTORS

Karen Bardo, *Co-Founder*  
 Attorney William Howison, *President*  
 Carl Barker, *Vice President*  
 Pam Saulter, *Secretary*  
 S. Andrew Smith, CPA, *Treasurer*

---

Edward Drasby, D.O.,  
 Ellen Moscinski, LCSW  
 Judy Segal  
 Karen Rajotte  
 Garrett Cole  
 Stanley Pyzynski  
 Howard Saturley

# In Loving Memory of Harold L. Jones

*Published in— part from the Kennebec Journal*

**H**AROLD L. JONES, 81, OF AUGUSTA, died Thursday, Dec. 4, 2008, at Maine General Medical Center, Thayer Unit, Waterville, after a courageous battle with heart disease.

Born in Unity, May 23, 1927, the son of Harold F. Jones and Nancy Walton Jones, he graduated from South Portland High School in 1944. He served in the Army Air Corps Pilot-Navigator training program until the war ended in Europe, and then served in the Maritime Service in 1945. He later served in the Maine National Guard from 1948 to 1952. He graduated from Gates Business School in 1946.

Harold married Winona L. Dow of Jefferson in Augusta on Sept. 11, 1948. They had lived in Augusta ever since. He was employed as an accountant by Central Maine Power Company from 1946 to 1958. He formed an accounting practice in 1958 and earned his certified public accountant's degree in 1961. He sold his practice to MacDonald Page in 1964 and joined then First National Granite Bank in Augusta. He was a senior vice president and director of First National Granite Bank and Bank of Maine N.A. until 1984. He became president of Bank of Maine before the merger with Norstar Bank of Albany, N.Y. He continued as a senior vice president of Norstar Bank, and then Fleet Bank after the two banks merged, until his retirement in 1992.



**On December 4, 2008 Harold L. Jones, former president of the Maine Parkinson Society, died after a courageous battle with heart disease. We will always be grateful for Harold's tireless efforts with Maine Parkinson Society since its inception. In addition to his family, Harold still found time for his own passions.**

Harold was treasurer and director of the American Lung Association of Maine for more than 20 years; treasurer, director and Finance Committee member at various times for more than 20 years at Good Will-Hinckley School; treasurer from 1967 to 1972, and chairman of the Maine Republican Party 1973 to 1974 (The Watergate Years); a founder, director and president of the Maine Parkinson Society; a member of the Board of Governors of the Augusta Country Club at various times and president in 1997 and 1998; a member of the Maine Seniors' Golf Association; a director of Four Square Foundation; and a member of the Augusta Kiwanis Club for more than 45 years. He was a member of various Masonic orders.

He was appointed to the Maine Board of Licensure in Medicine, as a public member, by Governor McKernan in 1991, and reappointed in 1997 by Governor King. Harold was chairman of the Personnel and Administration Committee for most of his two terms. Harold was chairman of the Capital Campaign, Kennebec Historical Society in 2006 and 2007 and was a director of Community Health Charities of Maine.

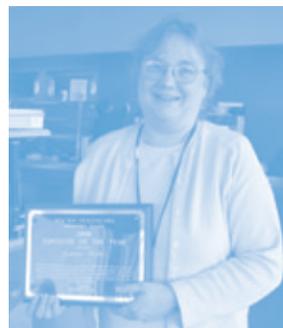
Harold loved his wife, his family and his community. He will be missed by many friends and members of the Maine Parkinson Society including his wife Winona of Augusta; his daughter, Karen Bardo of Alna; his son, Alan and his wife, Dawn, of Jefferson; his sister, Betty Potter of Augusta; three grandchildren, Steven, Kevin and Elizabeth; three step grandchildren, Jennifer, Bethany and Stephen Browne; and several nieces and nephews. ■

## Suzanne Miller, RN, CCM, *Parkinson's Support Group Leader and Health Services Coordinator* at Quarry Hill Retirement Community in Camden, has been named Pen Bay Healthcare Employee of the Year for 2008!

**T**he employee of the year, chosen from among the Employees of the Month in the current fiscal year, receives a gift of \$1,000 and a commemorative plaque. An article about the award is sent to the local newspapers, and the winner's photo is prominently displayed on the communications boards of the PBH organizations.

At the awards ceremony on Sept. 18, Roy Hitchings, President and CEO of Pen Bay Healthcare, addressed Suzanne directly: "You have been here since we started Quarry Hill. One of the things we knew was that we needed someone to help people navigate the system. You are one of those who understands the process, helps coordinate the services they need and works with their families."

Bob McKeown, Executive Director of Quarry Hill, pointing to Suzanne's role in counseling prospective residents and coordinating admissions at the extended-care retirement community, said Suzanne's "clinical background, communication skills, compassion and sincere belief in the value of our program inspire trust in everyone she meets." He added that her "creative solutions enrich our residents' daily lives."



In addition, he said, Suzanne enjoys a well-deserved reputation as an educator and innovator: "In designing her position, we hoped that Suzanne would have time to develop educational programming for the benefit of our residents as well as the larger community. She exceeded our expectations, developing two educational series – Adventures in Living Well and Exploring Complementary Healthcare for Seniors – designed to enhance the health and vitality of adults age 55 and older."

Suzanne is also known for helping to establish a local Parkinson's Disease Support Group. The group, which she continues to coordinate, meets monthly at Quarry Hill.

"No one achieves an honor like this in isolation," said Suzanne in accepting the award. "I think it's important to recognize the people who support you on your journey and make the things that you do possible. I thank my extended family who support me every day in being true to myself, and my co-workers and friends at Quarry Hill who support and encourage and assist me in the programs that I do." She added: "To me, the biggest honor is knowing that it was my co-workers who nominated me. They have seen me and worked with me every day – and still think I am worthy of this award." ■

### Help us verify your contact information

We hope you enjoy and learn from this Parkinson publication. We know we have some outdated contact information and ask you please return the information below. This will allow us to be more accurate and more cost effective with the dollars we have available.

**Would you prefer to receive this publication via Email?**  Yes  No

Thank you for returning this information promptly so that we may continue to send to you this important publication: I&R Center, 5 Bucknam Road, Suite 1A, Falmouth ME 04105 or by e-mail to SCENNL@mainehealth.org

NAME

ADDRESS

CITY

STATE

ZIP

E-MAIL ADDRESS

# Parkinson's STUDIES

*Are you considering becoming involved in a Parkinson's Study or Clinical Trial? There are 5 opportunities to enroll in PD studies right here in Maine! Contact PortCity Neurology for more information at 207-885-1400 or visit [www.portcityneurology.com](http://www.portcityneurology.com)*

**NEUROGEN PHARMACEUTICALS:** A Parkinson Study Group Study: Aplindore-211 (A novel partial dopamine agonist) A Randomized, Double-Blind, Placebo-Controlled Study to Assess the Efficacy and Safety of Three Doses of Aplindore MR (1,3, & 6 m g Twice Daily) in Patients with Early Parkinson's Disease

**PROGENI STUDY:** A research effort between the Parkinson Study group (a group of neurologists from throughout the United States Canada and Puerto Rico), Indiana University School of Medicine, University of Rochester, University of California, San Diego, and Cincinnati Children's Hospital Medical Center. These groups seek to identify genetic and other risk factors which may be important in the development of Parkinson's disease. The study is sponsored by the National Institute of Health (NIH).

**ACADIA PHARMACEUTICALS-STUDY:** ACP-103-015 (Pimavanserin) A Multi-Center, Open-Label Extension Study to Examine the Safety and Tolerability of ACP-103 in the Treatment of Psychosis in Parkinson's Disease.

**ACADIA PHARMACEUTICALS-STUDY:** ACP-103-012 "PD Psychosis." A Phase III Multi-center, Placebo-Controlled, Randomized, Double-Blind Trial to Examine the Safety and Efficacy of ACP-103 in the Treatment of Psychosis in Parkinson's Disease.

**PARKINSON STUDY GROUP "QE3 STUDY":** A Phase III randomized, Multicenter, double-blind, placebo-controlled, parallel group clinical trial to examine the effect of Co -Enzyme Q-10 in conjunction with Vitamin E 1200mg on delaying the progression of early Parkinson's Disease.

## JOIN A CLASS

### A Good Start: When the Diagnosis is Parkinson's

If you or someone you love has been recently diagnosed with Parkinson's disease, you may be faced with new challenges and decisions. You don't have to face them alone. Join **Lillian Scenna, LSW, APDA Information & Referral Center Program Manager**, as she explores the journey from symptoms to diagnosis including helpful information for newly diagnosed persons with Parkinson's disease, their family members, caregivers and friends.

**Friday, February 6**

**10:00 – 11:30 a.m.**

**MaineHealth Learning Resource Center –**

**5 Bucknam Rd, Falmouth**

### Living Well

This six-session course is designed to help adults with chronic conditions, and their caregivers, deal with problems such as frustration, fatigue, pain and isolation, appropriate exercises, medication use, nutrition and communicating effectively with family, friends and health professionals.

**Fridays, March 6 – April 10**

**1:00 – 3:00 p.m.**

**MaineHealth Learning Resource Center –**

**5 Bucknam Rd, Falmouth**

### SAVE THESE DATES

The APDA State of Maine Chapter is part of our country's largest grassroots organization, the American Parkinson Disease Association, serving the 1.5 million Americans with Parkinson's disease and their caregivers. The APDA Maine Chapter sponsors a wide variety of exciting events to help improve the quality of life for individuals with Parkinson's disease and their families throughout the State of Maine. Contact APDA Chapter at 207-781-1738 for more information about our exciting 2009 events, or visit our website [www.parkinsonsmaine.org](http://www.parkinsonsmaine.org)

**Saturday, March 7, 2009**..... **Harlem Basketball Super Stars**

**Saturday, April 11, 2009**..... **April Awareness Day Conference entitled; In It Together**

**Saturday, April 25, 2009**..... **Parkinson's Unity Walk**

**Monday, June 8, 2009**..... **First Annual Golf Tournament**

**TBA, August 2009**..... **APDA Maine Walk-A-Thon**



American Parkinson Disease Association

# State of Maine Parkinson's Disease Support Groups

## **CAPITOL AREA – AUGUSTA & WATERVILLE**

Meetings are held on alternate months at the Prince of Peace Lutheran Church on 209 Eastern Avenue in Augusta and St. Mark's Episcopal Church on 60 Eustis Parkway in Waterville on the second Sunday of each month at 2:00 PM. Contact Cam Weaver (207) 293-2667 or Debbie Roberge (207) 872-5446 for more information.

## **GREATER BANGOR – BANGOR**

Meetings are held at Acadia Hospital, 268 Stillwater Avenue, on the third Sunday of each month at 2:00 PM. Contact Bonnie Bragg (207) 843-5908 or Michele McDonald (207) 262-5095 for more information.

## **SOUTHERN MAINE – BIDDEFORD**

Meetings are held at Southern Maine Medical Center, One Medical Center Drive (second floor classroom next to cafeteria), on the Second Sunday of each month, at 2:00 PM. Contact Sherwood & Nancy Treadwell (207) 985-2431 or Al & Mary McLaughlin (207) 967-8971 for more information.

## **BLUE HILL PENINSULA – BLUE HILL**

Meetings are held at the Parker Ridge Retirement Community, 63 Parker Ridge Lane, on the third Wednesday of each month at 2:00 PM. Contact Anne Cushman (207) 348-6611 or Alvion Kimball (207) 469-1144 for more information.

## **BATH – BRUNSWICK**

Meetings are held at Mid Coast Hospital, 123 Medical Center Drive, on the fourth Sunday of each month at 1:30 PM. Contact Jessica Loney (207) 373-6592 for more information.

## **CAPE ELIZABETH**

Meetings are held at Village Crossings, 78 Scott Dyer Road, on third Monday evening of each month at 4:00 PM at Village Crossings in Cape Elizabeth. Contact Fran Bagdasarian (207) 799-7832 for more information.

## **CAMDEN**

Meetings are held at Quarry Hill, 30 Community Drive, on the first Tuesday of each month at 12:00 PM. Contact Suzanne Miller (207) 230-6224 or Gordon Guist (207) 236-8475 for more information.

## **GREATER PORTLAND**

Meetings are held at the Parkinson's Information & Referral Center, 5 Bucknam Road, in Falmouth on the fourth Sunday of each month at 2:00 PM. Contact Mary Sontz (207) 781-1738 or Louise Paulin (207) 892-5651 for more information..

## **LEWISTON**

Meetings are held at St. Mary's Regional Medical Center, 318 Sebattus Street entrance at Parking Lot G, in Lewiston on the first Friday of each month at 1:00 PM. Contact Kate Adams (207) 376-3031 for more information.

## **OXFORD HILLS**

Meetings are held at Western Maine Health at Stephen's Memorial Hospital, 181 Main Street, Norway, on the last Thursday of each month at 2:00 PM. Contact Social Worker (207) 743-7086 for more information.

## **YARMOUTH**

Meetings are held at Bay Square at Yarmouth, 27 Forest Falls Drive in Yarmouth on the fourth Wednesday of each month at 1:00 PM. Contact Mary Willson or Minie Poleshuk at (207) 846-0044.

## **YORK**

Meetings are held at York Hospital, 15 Hospital Drive, York on the first Sunday of each month at 2:00 PM. Contact Gail Anderson (207) 363-6039 or Shaaron Hendry (207) 967-5400 for more information.

## **SOUTHERN MAINE YOUNG ONSET GROUP**

Meetings are held on the third Sunday of each month at 1:00 PM. Contact Sue Withington (207) 729-0035 or Dana Hodgkins (207) 839-7951 for meeting location.

## **PARKINSON'S PLUS SUPPORT GROUP**

Meeting are held at various locations through out the state. Janet Edmunson (former caregiver of husband, Charles, with CBD) and author of *Finding Meaning with Charles*, invites you to attend a new gathering to meet others other's dealing with PSP, MSA and CBD to learn from each other. Contact Janet Edmunson (207) 799-4963 for more information and a support group meeting nearest you.

**WE LOOK FORWARD TO SEEING YOU!**

## MEMORIALS, HONORS and DONATIONS PROGRAM

Individuals, families and organizations who would like to contribute to Parkinson's disease research, Maine patient services or the APDA Parkinson's Information & Referral Center are now given an opportunity to allocate their funds towards a specific purpose. Contributions can also be made to the memory of a relative or friend or honoring birthdays, anniversaries or other noteworthy events. Please remember to indicate the name and address of the family. The I&R Center will notify the family that a memorial or honor contribution was made. Acknowledgement of the contribution will be sent to the donor.

**THANK YOU FOR YOUR NEEDED SUPPORT!**

DONOR NAME(S)

ADDRESS

CITY

STATE

ZIP

IN MEMORY OF (DECEASED)

IN HONOR OF (LIVING)

PLEASE NOTIFY: NAME

ADDRESS

CITY

STATE

ZIP



American Parkinson Disease Association

- APDA Chapter**  
(Support, Research & Education)
- Maine Parkinson Society**  
(Maine patient services)

**PLEASE SEND TO:**

APDA Parkinson's Information  
& Referral Center  
5 Bucknam Road, Suite 1A  
Falmouth, Maine 04105

SAVE THIS DATE!

Saturday, April 11, 2009

## 7th Annual Parkinson's Awareness Conference

*In it Together: Understanding the many aspects of life with Parkinson's disease*

8:30 a.m. – 2:30 p.m.

Wyndham Hotel  
(formerly the Sheraton)  
South Portland**\$25/person****(includes lunch)****Pre-registration preferred**

**Designed to educate, inform and inspire** those living with PD as well as those who care for them, In It together will address the role that Parkinson's disease plays in our everyday life situations. We will provide topics to educate employers, families, friends, health care providers, and others on how daily life goes on – with Parkinson's.

**The conference features internationally-recognized** author and speaker, Janet Edmunson, former caregiver of husband with CBD and author of *Finding Meaning with Charles*. In addition, the event will offer a distinguished panel of presenters as well as showcase a large number of vendor booths with helpful exhibits and resources. Whether you attend all or a portion of this day conference, you are sure to leave enlightened and inspired!

All material related to Parkinson's Disease contained in this newsletter is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the Editors, the APDA I&R Center, the Medical Director, MaineHealth, MEPS or APDA.



American Parkinson Disease Association

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at the MaineHealth Learning Resource Center

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