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MCFPC HIGHLIGHTS

November December 2010 Issue

The Lewiston MAINEiacs Hockey Club is hosting a prostate cancer awareness night 26 November. We have discounted tickets available but you must act fast. You will want to make the Opening Ceremony where a number of fellow prostate cancer survivors will be on the ice to help start the game which begins at 7:00 p.m. All the activities will be held at the Androscoggin Bank Colisee which is located at 190 Birch Street, Lewiston, ME 04240. The game features a great matchup with one of the series leaders from last year, so it promises to be a challenging match. Tickets for the MAINEiacs are normally \$14.50 each but we have been authorized to sell them for \$10.00 apiece. We don't know if you will have any grandchildren or family members around but this will be a great event to get everyone out of the house after all the other Thanksgiving activities. Please let us know how many tickets you would like as soon as possible. Contact Terry Kungel, TKungel@hughes.net, (207) 443-4300 with your ticket order or your questions.

The Maine Coalition to Fight Prostate Cancer relies solely on volunteers to provide all of its services free to men diagnosed with prostate cancer. The Coalition counts on gifts to carry out its mission. To help raise funds for the Coalition and to provide a once in a lifetime memory, there will be a **special VIP MAINEiacs Program** for the first 10, minimum, to 25, maximum, people to sign up. A charitable contribution of \$125 per person will entail a locker room tour, dinner in the lounge, VIP seating, a reserved table at the Post Game show, a puck autographed by the Captain and a special occasion T-

Newsletter Spotlight

If you know anyone dealing with prostate cancer recurrence please let them know that the Hormone Therapy Group meets the third Monday of every month at the Cancer Community Center, 778 Main Street, South Portland, ME, 6:00 p.m. to 8:00 p.m.

Please contact Terry Kungel, (207) 443-4300, for details.

TKungel@Hughes.net

MCFPC Web Site & Links

There is a wealth of information at the following:

www.MCFPC.org and
www.USToo.org

There is a women's page at the MCFPC site. This section recognizes caregivers also need help. There is also a printed brochure for women

shirt. Please contact Terry Kungel, TKungel@hughes.net, (207) 443-4300 as soon as possible. This is a great opportunity to help your fellow man, get a nice tax deduction, and have an unforgettable experience with a grandson, a brother, a dad, an uncle or a good friend.

The Maine Coalition to Fight Prostate Cancer is seeking volunteers to initiate a study helping newly diagnosed prostate cancer patient make better informed choices in a timelier fashion.

Your help with this project might ensure that patients who are diagnosed in subsequent years will have an easier time than you have had. This study, which is undergoing final approval, will be led by Dr. Paul Han, Maine Medical Center Research Institute, Portland, ME. Dr. Han developed tools to help colorectal cancer patients evaluate their risk when he was with the National Cancer Institute. The Coalition is seeking four general groups of men: (1) men who have been diagnosed with prostate cancer within the past 9 months who have yet to decide a treatment option; (2) men who have been diagnosed with prostate cancer within the past 12 months and who have had treatment within the past 6 months; (3) men who have had a primary treatment for prostate cancer with a Gleason level 8-10 and are now facing a recurrence of elevated PSA levels; and (4) men who have had a primary treatment within the past 36 months and who had Gleason level 6-7. The study envisions six meetings comprising 5-6 men at each meeting, so we need 36-48 volunteers to adequately fill the likely research requirements for Dr. Han. A small stipend will cover transportation charges and light snacks will be provided. This is extraordinarily important work that will benefit future generations of prostate cancer patients. Please contact Terry Kungel, TKungel@hughes.net with your email address and telephone number(s), your date of diagnosis, your Gleason score, the treatment you underwent, the date of your treatment, your PSA score at initial diagnosis, the rate your PSA level changed in the two years prior to your diagnosis, the clinical stage of your prostate cancer, for example, T1, T2, T3, and T4. All information will be held in strictest confidence.

The Maine Coalition to Fight Prostate Cancer recently submitted a grant application to the Maine Cancer Foundation to fund developing approaches to help prostate cancer patients better manage their emotional journey. MCFPC and the

partners that is available for distribution within your support group.

Checkout the Speaker's Bureau. If you would like someone to speak to a group about prostate cancer, please contact Jim Ervin, (207) 784-2086 or send an email to Jim at mjervin@roadrunner.com

If you have a suggestion for groups or events where someone could make a short presentation, please send them along as well.

We are always recruiting new speakers. Please let Jim know if you can help with this important work.

medical community generally help prostate cancer patients navigate all their medical options, i.e. their medical journey, but there are few effective efforts within the prostate cancer community to address depression, anxiety, stress, loss and anger, i.e. their emotional journey. If this study is funded by the Maine Cancer Foundation it will entail meeting with all the active prostate cancer support groups in Maine to get your stories about what you have experienced and to share your ideas about helping newly diagnosed men. If you have any suggestions please forward them to Terry Kungel, TKungel@hughes.net, (207) 443-4300.

The Maine Coalition to Fight Prostate Cancer has no financial interest in any research, nor has any of its senior volunteers received any inducement, near term or long term, to endorse Dr. Han's study or the Maine Cancer Foundation's study. The sole rationale for recruiting men is to help make life easier for the brothers, sons, dads and uncles who will be diagnosed after us.

The Maine Coalition to Fight Prostate Cancer had a booth at the Maine Organic Farmers and Growers Association Fair that generated a substantial amount of awareness about prostate cancer and the Coalition's work to help men and their families deal with this disease. Attendance at the fair was in excess of 60,000 people. Look for the MCFPC booth again next year.

Science News

The FDA has recently approved two new drugs, Provenge® and Jevtana®, that are targeted towards advanced prostate cancer. The Provenge treatment currently costs in excess of \$90,000 and it has attracted the attention of the Coverage and Analysis Group at Medicare. Medicare Administrators say they will take a full year to review Dendreon Corporation's Provenge treatment and decide whether to cover the costly treatment. A preliminary decision is expected after about nine months, March 2011, and a final ruling will probably be out by June 2011. Their decision will apply to all Medicare contractors. This action by Medicare is unprecedented. It is the first time a drug approved by the Federal Drug Admini-

MCFPC Financial Support

The Maine Coalition to Fight Prostate Cancer attempts to deliver all of its services free to those in need. Please help us help others. A gift of \$10, \$25, \$50, or \$100 will be greatly appreciated. Please make your check payable to the Maine Coalition to Fight Prostate Cancer.

Please mail it to: Mr. Ole Jaeger, Treasurer, Maine Coalition to Fight Prostate Cancer, 1132 Five Islands Road, Georgetown, ME 04548.

The Maine Coalition to Fight Prostate Cancer is a 501(c)(3) not-for-profit public benefits corporation so your gift is fully tax deductible.

If you would like to help sponsor the Maine Coalition's critical work, or know someone who might, please contact Ole Jaeger, (207) 371-2740 or email to Oledk1@gmail.com.

For information concerning a deferred payment gift annuity, an IRA gift, a charitable remainder trust, a charitable lead annuity trust, a stock transfer, and estate gifts please call Terry Kungel, (617) 449-8522 or email him at TKungel@Hughes.net.

stration has been challenged solely on the basis of its cost. Provenge offers hope to men with advanced prostate cancer who historically have had little to look forward to in treatment options.

Associated Press 2 July 2010 Edited

Prostate cancer patients seeking Dendreon Corporation's new tumor fighting vaccine, Provenge, face delays of a year or more as hospital waiting lists dwarf the company's capacity to produce medicine. Dendreon can only make enough Provenge to treat about two percent of eligible patients until manufacturing increases in mid 2011, said Chief Operating Officer Hans Bishop. It takes about a month to prepare each custom-made course of doses. The company plans to make enough to accommodate 2,000 patients in the first year, falling short of the 100,000 patients with advanced tumors who may be eligible to receive it. Please see the company web site for more details, <http://www.dendreon.com/>

Bloomberg News, 28 June 2010 Edited

MCFPC 2010 CALENDAR OF EVENTS

3 November

The Bangor Area Prostate Cancer Support Group will be meeting 6:00 p.m. to 7:30 p.m. in the Lafayette Family Cancer Center, 33 Whiting Hill Road, Brewer, ME. Jon Henry is seeking someone to assist him in serving this community.

4 November

A Grand Round will be held at MaineGeneral's Thayer Campus, Waterville, ME. The principal speaker will be Andrew Hertler, MD FACP, Chief Oncologist at Harold Alfond Cancer Center, Augusta, ME.

5 November

A Grand Round will be held at MaineGeneral's Augusta Campus. The principal speaker will be Andrew Hertler, MD

MCFPC Helpline

While we encourage everyone to consider joining a support group, there are some men who are uncomfortable doing this. If you have been newly diagnosed with prostate cancer, are undergoing treatment or have suffered recurrent disease and would like to have a confidential conversation please call Nelson Leavitt, (207) 441-5374.

Nelson is the President of MCFPC and was instrumental in founding MCFPC. He has also developed a network, One 2 One Confidential, of prostate cancer survivors throughout Maine who have been specially trained to help other men cope with a prostate cancer diagnosis. All conversations are totally private and free.

Did You Know.....

***Prostate cancer is the second leading cause of cancer deaths among men in the United States after lung cancer.**

***African American men are 2.5 times more likely to die from the disease than Caucasian men.**

FACP, Chief Oncologist at Harold Alfond Cancer Center, Augusta, ME.

9 November

The MCFPC Board of Directors will meet today.

The South Portland Area Prostate Cancer Support Group will be meeting 6:30 p.m. to 8:30 p.m. at the Cancer Community Center, 778 Main Street, South Portland, ME 04106. Susan Ramsey, PT, MA and Ryan Bailey, DPT, both with Holistic Physical Therapy Services, South Portland, will talk about pelvic floor rehab and its role in treating incontinence, sexual issues and pelvic pain with men who have prostate cancer.

11 November

The Dancing on the Edge Group will be meeting 10:00 a.m. to 11:30 a.m. at the Cancer Community Center, 778 Main Street, South Portland, ME 04106. The Dancing on the Edge is a group of people living with recurrent, metastatic or terminal cancer diagnosis who want to stay focused on “dancing” as long as they can. This group comes together to explore how to find a place of acceptance, peace and love that does not depend on a cure. Some regularly participate by telephone.

The Ellsworth and Hancock County Area Prostate Cancer Support Group will be meeting 5:00 p.m. to 6:30 p.m. at the Beth C. Wright Cancer Resource Center, 3 High Street Ellsworth, ME 04605.

15 November

The Hormone Therapy Group will be meeting 6:00 p.m. to 8:00 p.m. at the Cancer Community Center, 778 Main Street, South Portland, ME 04106. This will be a meeting open for general discussion.

16 November

Brunswick Area Prostate Cancer Support Group will be meeting 6:30 p.m. to 8:30 p.m. at Mid Coast Hospital - Medical Office Building, 121 Medical Center Drive, Brunswick, ME 04011. Terry Kungel will present a recently completed video that was shown on Time Warner cable stations

MCFPC Feedback

The Maine Coalition to Fight Prostate Cancer is here to help you. If you have any ideas, suggestions, complaints please share them with us. If there is anything we should start doing, stop doing, or change what we are dealing, let us get the benefit of your thoughts.

We can always be reached by sending an email to: TKungel@Hughes.net or by telephone, (207) 443-4300. Alternatively, send an email to Info@MCFPC.org.

throughout Maine.

29 November

The Island Falls Area Prostate Cancer Support Group will be meeting 7:00 p.m. in the conference room, Fairpoint Communications Building, 182 Houlton Road, Island Falls, ME.

30 November

The Augusta and Kennebec County Area Prostate Cancer Support Group will be meeting 6:00 p.m. in conference rooms 1, 2, 3, Maine General Medical Center, 6 E. Chestnut Street, Augusta, ME 04330.

1 December

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MCFPC Newsletter Distribution

One of the key goals of the newsletter is to help inform everyone across Maine about prostate cancer while also hopefully linking people together. Anyone involved with prostate cancer should consider this a statewide forum for getting your events and information publicized.

The method of distribution has gone through several iterations. The current approach is to request each support group moderator, or another key person in that group, to send in material and to review the copy before it is distributed.

E-mail lists are sensitive and confidential and most support group moderators are averse to sharing this data with anyone not in the leadership of their support group. This means that the newsletter is prepared by the editor and then sent to each moderator for subsequent distribution by them.

If you would like to directly receive a copy of the Newsletter please send Terry Kungel, Editor an email to this address: TKungel@Hughes.net with the subject line, Newsletter.

Center, 778 Main Street, South Portland, ME 04106. This will be an open discussion and holiday meeting.

20 December

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28 December

The Augusta and Kennebec County Area Prostate Cancer Support Group will be meeting 6:00 p.m. in conference rooms 1, 2, 3, Maine General Medical Center, 6 E. Chestnut Street, Augusta, ME 04330.

29 December

The Lewiston and Androscoggin County Area Prostate Cancer Support Group will be meeting 6:00 p.m. to 7:30 p.m. at Central Maine Medical Center, 12 High Street, Lewiston, ME. Emily Ecker is the new co-facilitator of this group. She brings years of experience as an oncology social worker.

If your organization would like additional coverage between now and 31 December 2010 please contact the editor, Terry Kungel, (207) 443-4300 or TKungel@Hughes.net.

Prostate cancer is a significant challenge. Don't make it more difficult by trying to do it all alone.



www.UsToo.org