



Dear VeteransA Message from the Network Director

Michael F. Mayo-Smith, M.D., M.P.H. **Network Director**

This issue has several articles on outdoor opportunities for our Veterans, as well as information about new prospects for our patients who are coping with cancer.

First, you'll find an article on page 3 about the Precision Oncology Program (POP). This cutting-edge program targets our Veterans with lung cancer, but it does so based on a tumor's gene mutation. State-of-the-art equipment and cutting edge technology arm our specialized staff to help Veterans do battle with cancer.

On pages 4-5, you can learn about the exciting adventures of New England area disabled Veterans who took to the water during last summer's *Sail To Prevail* event, which is scheduled for June 27-28 this year.

Disabled Veterans also took to the slopes these past months as part of the Winter Adaptive Sports program — even after record snowfalls this past winter! I hope you'll read the article on page 6 and consider signing up for one of the many upcoming opportunities when flurries fly again.

Finally, I'm delighted to announce (page 7) that the our Clinical Trials Network is now a member of the Southwest Oncology Group (SWOG), a cancer research group that will greatly benefit Veterans with cancer.

Thank you for your service. Now let us serve you!

Michael F. Mayo-Smith, M.D., M.P.H. Network Director



Secretary Bob McDonald, VISN and Bedford Leadership and distinguished guests stop for a quick photo during Secretary's visit to the Edith Nourse Rogers Memorial Hospital (Bedford VAMC) March 25, 2015.



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On the Cover:

Disabled Veterans enjoy sailing at Fort Adams State Park, Newport, RI, in specially adapted Independence 20 sailboats provided by *Sail To Prevail*.





Exciting New Program Offers Hope for Lung Cancer Patients

A groundbreaking project is underway in the VA New England Healthcare System that has the potential to help cancer patients across the country. The new Precision Oncology Program (POP) is part clinical, part research, and initially involves Veterans with lung cancer.



Dr. Louis Fiore

"Lung cancer is the most common cancer in our network—averaging about 1,000 new patients diagnosed per year," says Louis Fiore, MD, MPH, executive director of the Massachusetts Veterans Epidemiology Research and Information Center

and program director of the Veterans Integrated Service Network 1's (VISN 1) POP. "Nationally, the VA estimates the number of lung cancer patients at 7,500 and estimates the number of all VA cancer cases at about 40,000¹ a year—so there is a potential to help many Veterans."

Dr. Fiore explains that the process begins with *oncologists* (doctors who specialize in treating cancer). "Oncologists and their lung cancer patients will discuss the program and determine together if it will help the patient. This isn't a typical research program with a pre-set goal for the number of patients. We hope to test several hundred patients in the next six months, but we are very early in the process. However, all of the oncologists in the VA New England Healthcare System are aware of the program. Whether you are in Maine or Boston, we're creating ways for everyone to participate."

¹http://www.ncbi.nlm.nih.gov/pubmed/22730846

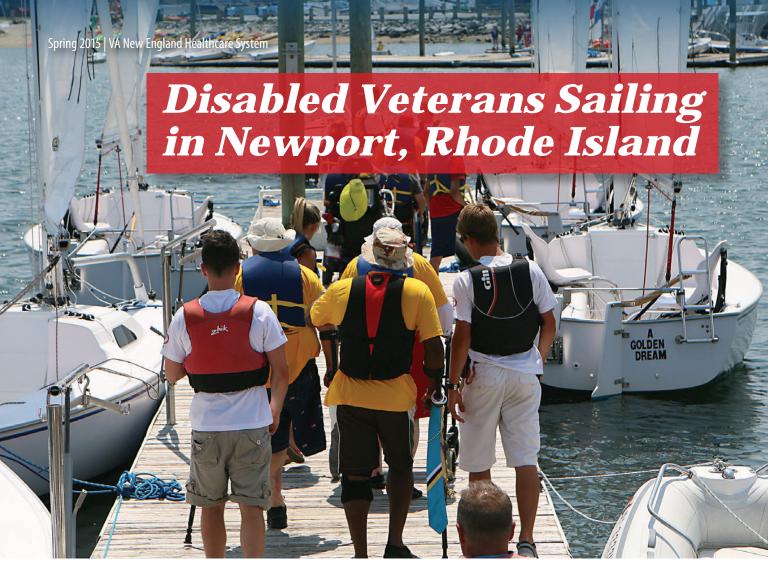
So what is POP? In simple terms, this cuttingedge program can help a Veteran based on specific genetic differences in a tumor. "Based on a tumor's gene mutation," says Dr. Fiore, "we know a patient may benefit from one type of treatment over another, which helps the oncologist provide better care. In other cases, the mutation may qualify a patient for clinical trials of experimental drugs."

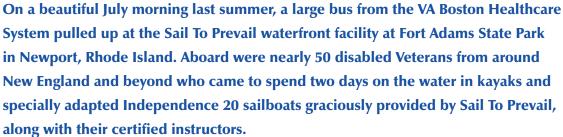
He added that drug companies are racing to develop new drugs that work with specific genetic sequencing, and that this project will give some Veterans an opportunity to participate in innovative trials they might not have access to otherwise. The results of clinical trials can go on to help many other Veterans.

In the future, a patient-centered website will give participating Veterans an opportunity to provide input that is critical to scientists. The hope is that many of these targeted drugs will offer a longer survival rate; if a drug works but isn't improving a patient's quality of life, scientists want to know that.

Although POP is starting in VISN 1 by working with lung cancer patients, it may later extend to other types of cancer in the network and ultimately to other VA regions. "It is just beginning here in VA New England, but we hope to roll it out nationally if it is as successful as we think it will be," adds Dr. Fiore.

If you are interested in learning more, talk to your local VISN 1 provider, call 1-857-364-3387, or visit http://www.newengland.va.gov/research/ precisiononcologyprogram/index.asp.





VA Boston Healthcare System's Adaptive Sports Program, whose motto is *Rehabilitation through Recreation*, sponsored the event. This was the fifth weeklong Summer Sports Clinic, the first to offer sailing in a weeklong clinic, and the first year in Rhode Island.

"We have enormous respect for the professionalism and dedication of the people from the VA New England Healthcare System," said Paul Callahan, CEO of Sail To Prevail. "They are top notch, and we are proud to collaborate with them. Whether Veterans are in a wheelchair, are an amputee, or have some other hidden disability, sailing is a sport that levels the playing field for all to participate equally."

Arn Manella, Sail To Prevail Waterfront Coordinator and retired Marine Corps commander, agreed. "It's not a vacation. You're here to try and experience." Manella



kept a watchful eye on the boats while they sailed the Lower East Passage. "We never insist," he said. "We assist."

Participants included paraplegics, quadriplegics, and amputees. "That special little piece of a skill clicks in," said Ralph Marche, the 2014 Director of the VA Adaptive Sports Program. "Veterans say, 'You know, this isn't so hard. I have control over my life, and I know how to do this thing.' It's an AHA moment."

One participant, paraplegic George St. Hilaire, summarized his experience. "Ah, this is the life right here! Look at this! I'm sailing! If it weren't for organizations like this, I would probably be home . . . miserable! I have a life, you know! I do things! It's great!"

New England Paralyzed Veterans of America (PVA) Vice President Wayne Ross described his experience in the July VA event. "Newport Harbor is beautiful, and I had a blast. The wind was perfect and the temperature ideal, not too hot or too cold, and 'Speedy' was the fastest boat. I can't wait to do it again."

Callahan said Sail To Prevail weekend events allow Veterans wounded in combat and active



For more information go to www.sailtoprevail.org/disabled_veterans.html.

To see photos of the June 2014 events, go to www.sailtoprevail.org/photos.html.

duty military personnel with any type of disability to enjoy the camaraderie and fun of sailing together. "The results are astonishing," he said. "Without question, the Veterans, the VA New England Adaptive Sports Program, and Sail To Prevail all derived a much higher level of impactful outcomes than anticipated."

Sail To Prevail, a non-profit 501(c)(3) charitable organization founded in 1982, has helped more than 15,000 individuals with disabilities overcome adversity through therapeutic sailing. Each year, Sail To Prevail teaches approximately 1,000 people with disabilities the skills of sailing, including self-confidence, teamwork, and leadership. These skills translate to their everyday

lives to conquer the challenges of living with a disability. Sail To Prevail was named a Paralympic Sport Club in 2011 by U.S. Paralympics, a division of the U.S. Olympic Committee.

Sail To Prevail will host two Veterans events this summer. The VA Boston Healthcare System will repeat the successful disabled Veterans program July 21-22. To sign up, Veterans can contact Jenny McLaughlin, the Recreational Therapist who coordinates all of VA Boston's Adaptive Sports Programs at (774) 826-1955 or jenny.mclaughlin@va.gov. No experience is needed!

There is also PVA Weekend June 27-28. Sailing is FREE to individual sailors!



The **VA Boston Adaptive Sports Program** holds events throughout the year, including air rifle, cycling, cross-country skiing, kayaking, surfing, downhill skiing, fishing, snowshoeing, and water skiing. In January, VA Boston Healthcare System partnered with New England Handicapped Sports Association for its 18th Annual Winter Sports Clinic at Mount Sunapee, New Hampshire, for Veterans with disabilities.

Winter Adaptive Sports: A Prosthetic for the Soul

Parts of New England saw harsh winter weather this year, but heavy snowfall allowed many area Veterans to hit the slopes.

The winter of 1998 was no picnic, either. That was when Veteran Tony Santilli, who suffered from PTSD and disability, teamed up with Boston VA's Chief of Voluntary Service Ralph Marche to establish the first New England Winter Sports Clinic for Disabled Veterans. Despite an ice storm that year, 10 Veterans braved the elements to experience skiing.

Since then, the clinic has grown to include over 40 Veterans annually from many states amputees and those with spinal cord injuries, neurological afflictions, vision impairments, and other disabilities. Tony has changed, too. Now a certified instructor and an expert skier, he tells fellow Veterans "What you need is a willingness to learn and a sense of humor," adding that if he can ski, anyone can. Cofounder Marche aptly considers the adaptive sports and activities a 'prosthetic for the soul' to help Veterans live life.

This is a life-changing experience. An opportunity to realize you're not done, you're not over, and you're not broken.

Kristian Cedeno

Adaptive sports have become quite popular, with numerous winter sports clinics allowing Veterans to discover a new sense of freedom,

independence, and confidence

on the slopes, as well as a feeling of camaraderie with fellow Veterans.

If you'd like to join the fun, these resources can help get you started.

- New England Handicapped Sports Association (NEHSA) at Mount Sunapee Resort in Newbury, New Hampshire, serves those who want to enjoy active and independent lives through participation in sports. NEHSA proudly welcomes disabled Veterans, whether for therapeutic reasons or just to relax. NEHSA provides stand-up skiing and sit skiing, plus adaptive snowboarding, and cross-country skiing. http://nehsa.org/disabled-veterans-program
- The U.S. Olympic Committee's Paralympic Division has over 20 New England sports clubs that provide adaptive sport and recreation for those with physical or visual impairments. The program combines funding from the Department of Veterans Affairs support from the U.S. Olympic Committee and partner organizations to provide Veterans with Paralympic sports programs.

 http://paralympicsportnewengland.org/ne-paralympic-sports-club
- The New England Nordic Ski Association (NENSA) runs weekly Nordic ski programs through the winter for anyone with physical disabilities. Equipment, instruction, and trail passes are free. NENSA also coordinates with adaptive organizations throughout the region. https://www.nensa.net/page.php?id=5761
- New England Paralyzed Veterans of America is interested in all issues affecting the lives of persons with disabilities. Each year, the VA New England Healthcare System invites Veterans with spinal cord injuries, orthopedic amputation, visual impairments, certain neurological problems, and other disabilities to participate in the New England Winter Sports Clinic for Disabled Veterans. This look at the past years' activities can help you start planning for winter. http://nepva.org/downloads/sports/Winter%20Programs_13.pdf
- Maine Adaptive Sports & Recreation is the State's largest year-round adaptive recreation program. It provides opportunities to alpine and Nordic ski, snowboard, and snowshoe at multiple locations. Its Veterans No Boundaries program provides Veterans and active duty personnel with disabilities free activities, and the New England Blind & Visually Impaired Ski Festival provides lessons to visually impaired skiers. www.maineadaptive.org

You can learn more about the benefits of adaptive sports and find one that is right for you at www.va.gov/adaptivesports/va_groups_main.asp



The VISN 1 Clinical Trials Network achieved membership to the National Cancer Institute's (NCI) Southwest Oncology Group (SWOG) in November 2014.

SWOG is a cancer research cooperative group that designs and conducts clinical trials to help prevent, detect, and treat cancer, and to enhance the quality of life for cancer survivors. It is also one of the largest groups of its kind in the United States.

The Clinical Trials Network's goals are to provide New England Veterans broader access to emerging therapies through clinical investigation targeting diseases relevant to our population. In addition, increasing research opportunities in the VISN and implementing key findings from these trials into clinical practice will translate into better healthcare.

"Admission into SWOG will give VA researchers greater access to the latest innovations happening in oncology," said Dr. Mary Brophy, M.D., M.P.H., VISN 1 clinical trials director.

SWOG has more than 4,000 researchers at more than 650

institutions, including 24 NCI-designated cancer centers, as well as cancer centers in almost a dozen other countries. At any given time, there are around 100 cancer clinical trials open through SWOG.

Since the group's founding in 1956, more than 200,000 participants have enrolled in SWOG-led clinical trials. Membership in SWOG allows us to take part in these trials, as well as other cooperative group trials.

The Clinical Trials Network applied and was accepted as a consortium of six New England VAs with oncology departments; Boston VA will serve as the administrative and logistical hub. The other five VAs are Providence, White River Junction, Togus, Manchester, and West Haven.

"Membership in SWOG will allow for greater and easier access to many more innovative cancer trials for Veterans than are currently available through the VA because it's a wider network of researchers and physicians for VA clinicians to learn from," said Sara Turek, M.P.H., project manager, VISN 1 Clinical Trials Network.

VA researchers will benefit, as well. "We will have access to a huge network of other SWOG researchers to learn from and can attend SWOG meetings where new research is presented," adds Turek. "This provides the potential for collaborative activities between VA researchers and others in the SWOG network."

Charles D. Blanke, M.D., SWOG chair, says that SWOG will benefit from the partnership, too. He posted on the SWOG website: "Bringing together these multiple VA institutions within SWOG could allow us economies of scale and consistency in addressing VA-specific challenges, providing opportunities to pilot and refine our VA Task Force's approaches on a smaller scale, then expand the collaboration to include another 12 facilities, and then to consider systemwide VA participation. If we are successful, the other Cooperative Groups would no doubt like to open their trials with the VA system as well, benefiting the entire Clinical Trials Network."



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