

Patient Advocacy Alliance Network

NEWSLETTER



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Contact Us

1850 Samuel Morse Drive
Reston, VA 20190
outreach@snmmi.org
(703) 708-9000

Saima Hedrick
Associate Director, Outreach
shedrick@snmmi.org

Welcome to SNMMI’s Patient Advocacy Alliance Network

The Society of Nuclear Medicine and Molecular Imaging (SNMMI) is excited to launch the Patient Advocacy Alliance Network. As an organization that works to promote the science, technology, and practical application of molecular imaging and therapy, SNMMI recognizes a growing need for the patient voice to be more formally incorporated into programming and materials.

We strongly believe that the Patient Advocacy Alliance Network will help SNMMI focus on improving patient care. We have a commitment to supporting patients, partnering with patient advocacy organizations on issues of mutual interest and priority, and providing educational programs for consumers to help them understand molecular imaging and the role it can play in both diagnostic and therapeutic settings.

We would like to thank you for agreeing to partner with us to help better support patients. As a member of this network, you will receive a quarterly newsletter to include minutes from SNMMI Patient Advocacy Advisory Board meetings, updates on patient-focused activities, advocacy news, and details of upcoming programs. You will also be asked to review materials, provide input and offer insight on various matters, and promote SNMMI patient-focused programs to your constituency.

This first issue contains information about our successful Patient Advocacy Day on Capitol Hill where our Patient Advocacy Advisory Board met with 13 congressional offices from nine states, the Patient Education Day held at our Annual Meeting in Vancouver, and nuclear medicine and molecular imaging articles relevant to patients.

We hope our partnership will lead to the progress and greater understanding of our mutual interests in patient care, the safe application of nuclear medicine, and a continuing effort to educate and support each other.



June 8, 2013 - Patient Advocacy Advisory Board members from top left to right: Peter Herscovitch, MD; Gary Dillehay, MD; Andrei Iagaru, MD; Henry VanBroeklin, PhD; Josh Mailman, Fred Woodlief, Albert Sinusas, MD; Scott Williams, Fred Fahey, DSc; Saima Hedrick, Ruth Tesar, Megan Mitchell, Laurel Pracht, Virginia Pappas, CAE; Sue Bunning, Bobbi Smith

SNMMI Holds Patient Advocacy Capitol Hill Day

On October 8, 2013, SNMMI's Patient Advocacy Advisory Board (PAAB) held their Patient Advocacy Capitol Hill Day in Washington, D.C. The PAAB was created to provide SNMMI volunteer leaders, members, and staff with the patient perspective with respect to molecular imaging and nuclear medicine matters. Specifically, the PAAB helps ensure patients' concerns, ideas, experiences, and recommendations are reflected within SNMMI.

Despite the government shutdown, which closed many congressional offices, the PAAB successfully met with 13 offices from nine states, including Congressman Randy Hultgren (IL-14). The following main topics were discussed:

1. **Continued Funding from the Department of Energy (DOE):** For nearly 60 years, the DOE has funded essential, fundamental nuclear medicine research in the areas of biomedical imaging and radiotherapy that has facilitated technological breakthroughs. Only the federal government funds basic nuclear medicine research, so this DOE program is critical for training and education. Currently, the Senate has appropriated \$5 million for nuclear medicine research with human application while no funding was provided in the House bill.
2. **Preventing Cuts to Medical Imaging:** Since 2006, Medicare reimbursement for medical imaging procedures has been cut 13 times. These cuts have delayed possible innovation in medical imaging which negatively affects patients who are then denied proper care. Additionally, these cuts have caused physicians to delay updating their equipment. This could lead to patients being unable to get the most appropriate treatment. The current proposal to repeal the Medicare Sustainable Growth Rate system will cost an estimated \$175 billion, which will have to be paid for by cutting funds from other government budgets, most likely from within the health care system. We want to ensure that these cuts do not come from medical imaging.

The Patient Advocacy Advisory Board's Patient Advocacy Day was a great success. Advocacy is an ongoing effort that is strengthened by the connections made between SNMMI members and their congressional representatives. We thank all those who took time out from busy schedules to participate.



October 8, 2013 - Left: Arnold Fridland, Betsy de Parry, Josh Mailman, Henry VanBrocklin, PhD, Laurel Pracht, and Jan Manarite in the Russell Senate Office Building. Middle: Josh Mailman in front of the Russell Senate Office Building. Right: Keith Fargo with Congressman Randy Hultgren (R-IL) in his office.

Partial Government Shutdown

Due to Congress's failure to enact legislation appropriating funds for fiscal year 2014, the United States government was forced to partially shut down on October 1. However, the crisis was finally resolved on October 16 when Congress passed H.R. 2775, the

Continuing Appropriations Act of 2014, which President Obama then signed into law the next day. H.R. 2775 contained a continuing resolution to fund the government until January 15, 2014, and suspended the U.S. debt ceiling until February 7, 2014.

One of the driving factors behind the shutdown was a disagreement on whether the new spending bill should include provisions to defund the Patient Protection and Affordable Care Act (PPACA). While substantial debate was held on this proposal, ultimately the PPACA was not affected by the final legislation.

The government shutdown has had a direct affect of the health care industry. The Department of Health and Human Services (HHS) was forced to furlough roughly 40,000 workers, amounting to 52 percent of HHS employees. This has resulted in the delay of many services, such as federal rulemaking activities.

Following this resolution, comprehensive immigration reform once again becomes a prominent issue on Capitol Hill, though it is still unclear what will be accomplished in the remainder of 2013. While this recent shutdown has come to an end, no long term fix was put into place. As a result, similar issues will arise early in 2014. During the shutdown, more than 800,000 government workers were furloughed, and national parks, congressional offices, and more were forced to close.

Patient Education Day 2013

SNMMI held its third Patient Education Day during its Annual Meeting in Vancouver, British Columbia on June 9, 2013. The agenda was structured to help attendees better understand the history, safety, and advances in the field of nuclear medicine and molecular imaging. The event had 86 attendees.

The day's learning sessions included a keynote speech from Josh Mailman about his journey and experiences with nuclear medicine, general education sessions, and breakout sessions on the latest advances for lymphoma, neuroendocrine tumors, and dementia. Each breakout session hosted talks by leading experts in their fields; patient perspectives by Gary Murfin, Jim Mann, and Tony Hines; Q&A panels; and an opportunity for attendees to take part in focus groups and networking.

The update on lymphoma included a presentation on "Imaging and Therapy for Lymphoma, How Does it Work?" by Dr. Erik Mittra and "What to Expect for Radioimmunotherapy Procedure" by Lu Nguyen. The update on neuroendocrine tumors included a talk given by the president of the Carcinoid Neuroendocrine Tumor Society, Jackie Herman. Also presented were "Theranostics - New Perspectives on Personalized Care for NETs" by Dr. Richard P. Baum, "Treatment of NETs- a Medical Oncologists' Perspective," by Dr. Hagen Kennecke, and "Current State of Molecular Imaging and Therapies in Canada," by Dr. JeanLuc C. Urbain. The update on dementia included the following talks: "How Does Molecular Imaging Work in the Brain?" by Dr. Satoshi Minoshima, "What to Expect for Brain Imaging Procedures?" by Eileen Smith, and "Diagnosing Dementia at UBC," by Dr. Ging-Yuek Robin Hsiung.

There was a guided tour through the exhibit hall that gave attendees a first-hand look at the science and technology behind nuclear medicine. During the reception SNMMI Poster Hall, attendees were also able to directly speak to presenters about the cutting-edge research they presented at the meeting. For more information and to view videos of these talks please visit our [website](#).



Top: David Gilmore, MS, CNMT, RT(R)(N), giving a talk on Molecular Imaging 101. Bottom: 86 people attended the Patient Education Day.

Join us next year at our [Patient Education Day!](#) It will be held on Sunday, June 8, 2014 in St. Louis, Missouri.

[SNMMI Press Release](#)

Gallium-68 DOTATOC Receives FDA Orphan Drug Designation for Neuroendocrine Tumor Management

The Society of Nuclear Medicine and Molecular Imaging (SNMMI) is pleased to announce that the radiopharmaceutical Gallium-68 (DOTA0-Phel-Tyr3) octreotide (Ga-68 DOTATOC) has been designated as an orphan drug by the U.S. Food and Drug Administration (FDA) for the management of neuroendocrine tumors (NET). This designation may lead to faster approval of the agent, which would greatly benefit NET patients in the United States. Currently there are only a few small U.S.-based clinical trials for Ga-68 labeled NET positron emission tomography (PET) agents available for patients; otherwise they must travel out of the country if the scan is required to manage their disease.

In August 2013, SNMMI's Clinical Trials Network (CTN) submitted an application to the FDA for orphan drug designation for Ga-68 DOTATOC under the Orphan Drug Act. This act provides for granting special status to a drug or biological product to treat a rare disease or condition. For a drug to qualify for orphan designation the disease or condition must affect fewer than 200,000 people. With a prevalence of approximately 110,000 patients in the United States with NETs, Ga-68 DOTATOC meets this requirement. [Read More.](#)

[Molecular Imaging: The Latest Updates in Nuclear Medicine That Are Making an Impact on Patient Care](#)

Amino Acid PET Tracer Tells Brain Metastases from Radiation Injury

Delayed brain injury resulting from aggressive radiation treatment can be differentiated from recurrent brain tumors using F-18 FDOPA PET imaging, according to a study published on October 28, 2013 in the *Journal of Nuclear Medicine*.

Radiation injury is conventionally assessed with MR imaging, but the modality is not ideal for telling apart radiation-related injury and recurrent brain tumors, which can have similar physical symptoms. In the first study of its kind, Karlo J. Lizarraga, M.D., from the Department of Neurology in the Miller School of Medicine at the University of Miami, and colleagues reviewed PET imaging studies to assess both the diagnostic and prognostic accuracy of amino acid-based F-18 FDOPA PET for detecting late or delayed radiation injury in the brain. Delayed radiation injury crops up in as many as 24 percent of cancer patients between three to 13 months following the end of radiation treatment. [Read More.](#)

Surgical Planning Helped by 3D images Created from PET/CT

Researchers have developed three-dimensional (3D) images of a patient's organs that surgeons can use to plan surgery.

This hologram-like display application employs molecular positron emission tomography/computed tomography (PET/CT) to quickly produce a 3D image of the patient. Before entering the operating room to perform surgery, surgeons are able to use these images to visualize the detailed anatomic structure, take away layers of tissue, and move around in space to see all regions of a tumor. [Read More.](#)

Imaging Addiction: Could PET & MR End Cocaine Abuse?

Cocaine addiction can ruin a person physically and financially, and with an estimated 1.4 million cocaine users in the United States, thousands will become trapped by their habit. While previous research on the drug and its addictive potential was observational and subjective, imaging is reshaping how we see addiction—and how it will be treated.

"Neuroimaging [functional and structural MRI, pharmacological MRI, and PET] has made a huge contribution to our understanding of cocaine dependence, as it helped us to elucidate the neurobiological substrates of [addiction] and how these underpin clinical symptoms and disrupt cognitive function" explains Karen D. Ersche, Ph.D., of the University of Cambridge in the U.K. Ersche's research focuses on psychopharmacology and addiction. [Read More.](#)

Brain Imaging Agent Approved to Help Assess Patients for Alzheimer’s Disease, Dementia

A new radioactive diagnostic agent designed for use with positron emission tomography (PET) imaging of the brain in adults currently being evaluated for Alzheimer’s Disease (AD) and dementia has been approved for use in the United States.

Dementia is associated with failing brain functions such as judgment, memory, language, and complex motor skills. The dementia caused by AD is tied to the accumulation in the brain of an abnormal protein called beta amyloid and damage or death of brain cells.

However, beta amyloid can also be found in the brain of patients with other dementias and in elderly individuals without neurologic disorders. [Read More.](#)

Nuclear Medicine Therapy Increases Survival for Patients with Colorectal Cancer, Liver Metastases

For patients who fail to respond to current first-line and second-line treatments for colorectal cancer liver metastases (also known as salvage patients), radioembolization with Y-90 microspheres could extend survival according to new research published in the November issue of The Journal of Nuclear Medicine. A systematic review conducted by researchers showed that approximately 50 percent of salvage patients have an overall survival of more than 12 months after this nuclear medicine therapy.

Colorectal cancer is the third most commonly diagnosed type of cancer worldwide in men and the second in women, and it is also the third most common cause of death. In approximately 50 percent of patients, metastases to the liver are present at diagnosis or during follow-up, which accounts for a large portion of morbidity and mortality in patients. [Read More.](#)

New Scans to Detect Heart Attack Risk

The lives of patients at risk of suffering a heart attack could be saved using a new scanning technique, Scottish research shows.

A study by the University of Edinburgh found that special imaging could identify people at high risk of having a heart attack so they could be treated to prevent it happening. Experts said the technique could be used to tackle the problem of patients living with a “ticking time bomb” inside them.

Every day in the UK, about 200 people die from a heart attack and death rates from coronary heart disease in Scotland are among the highest in the country. The new test, developed by Dr. Nik Joshi and a research team, combines scanning techniques known as positron emission tomography (PET) and computed tomography (CT). [Read More.](#)

[Important Upcoming Events / Deadlines](#)

Patient Education Day – Sunday, June 8, 2014

Connect your local Missouri chapter to SNMMI to collaborate for Patient Education Day at our Annual Meeting in St. Louis, Missouri.

New Website Coming Soon – March 2014

Visit SNMMI’s new website and access information for medical professionals, our Facebook and Twitter feeds, conference videos, latest news on nuclear medicine, and our calendar of events.