



July 8, 2024

Dear Mr. Mailman.

As dedicated patient advocates, we understand the role and importance that nuclear medicine plays in our lives. We also understand the role that promoting nuclear medicine can play in improving millions of patients' lives. But we also recognize that there are risks in nuclear medicine when these lifesaving drugs are not administered correctly. We are writing to express our concerns regarding your lack of soliciting and sharing input from patients who share this perspective during your ACMUI and Nuclear Regulatory Commission (NRC) meetings.

Your role as the ACMUI Patient Advocate is essential, as you represent the voice of patients who have experienced or may one day experience an extravasation. However, it appears that there is a significant gap in how patient input is being solicited and shared. Specifically, it appears that you have done a nice job soliciting feedback from neuroendocrine patients, but there is a lack of direct engagement with patients and members of PSNM. This engagement is essential to ensuring that patient experiences, particularly those involving medical events like extravasation, are adequately represented.

One such patient, Pam, who has experienced an extravasation, has valuable insights that could inform better practices and improve patient safety. Her experience, and those of others like her, are critical in shaping effective patient-centered policies. It is imperative that their voices are heard and considered in your recommendations to ACMUI. You did not mention Pam's experience during the June 17 ACMUI teleconference. In fact, you did not mention the patient perspective at all during the meeting.

Through comments during the June 17 meeting and an earlier meeting this year with the Commissioners, we are aware of several factual mistakes you have made regarding the role of SUV's in care and in the frequency of extravasations. Furthermore, we have never heard you address the perspective of cardiovascular patients. These patients make up the vast majority of nuclear medicine patients. Recent estimates suggest that of the 20 million nuclear medicine studies performed every year, 10 million are cardiovascular studies. Many of these studies involve two injections of radiopharmaceuticals and in many cases, IVs are left in a patient between injections; sometimes for hours at a time while patients are carrying on their daily routine. An extravasation during either the rest or stress exam, can compromise the study in a way that is clinically important.

Rather than rely on conflicted members of the society for your information, we strongly encourage you to actively solicit input from experts who have no conflicts of interest and from patients who have firsthand experience with the issues at hand. It is also crucial that you engage with patients of color to understand their perspectives, especially given the persistent health inequities and systemic racism within the healthcare system. By doing so, you can ensure that you are truly representing all patients' perspectives and advocating for their needs and safety.

We believe that to fulfill your role effectively, it is essential that you engage directly with patients. This engagement will not only enhance your understanding of their experiences but also empower you to advocate more effectively on their behalf.

Thank you for your attention to this matter. We would be happy to meet with you anytime and to connect you with experts who can share unbiased information with you. It is time for more robust and inclusive engagement with patients. Your efforts in this regard will undoubtedly contribute to better outcomes and improved safety for all patients.

Sincerely,

A handwritten signature in black ink that reads "Simon Davies". The signature is written in a cursive, flowing style.

Simon Davies
Executive Director, Teen Cancer America
Member, Patients for Safer Nuclear Medicine Coalition