

Rare Cancer Patient Forum from Guy's Hospital Doubles Attendance with Online Broadcast

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July 17, 2015 Prof Claire Harrison of Guy's and St. Thomas' in London is a world renowned expert in rare blood cancers called myeloproliferative neoplasms (MPNs). Fortunately, management of these cancers is improving and hundreds of patients will hear the latest from Prof Harrison, other experts, and inspiring patients this Friday evening. More people will watch the event online than attend in person.

"Patients with rare disorders like us often feel very alone and isolated and now we are using the Internet to bring even more of us together live," says event chairman Jonathan Mathias of London. Mathias is chairman of a UK patient organization, MPN Voice that is hosting the event.

<u>Patient Power</u>, a popular cancer education video channel in Europe and the US, will produce the broadcast through patientpower.info and video clips will reach thousands more after-the-fact.

"With rare conditions like MPNs it is essential patients and family members connect with specialists, learn about clinical trials, and play an active role in their care," says Prof Harrison. "We've put on many forums before, but to now make it a worldwide broadcast will help so many more."

The online broadcast will be anchored by another MPN patient, medical journalist and Patient Power founder Andrew Schorr. Given the high interest in online access to the event, Schorr sees this as a model for future events in MPNs and other rare conditions so communities from around the world can come together live.

Schorr adds, "Patients want to regain control after a terrifying cancer diagnosis. I know personally. As we come together, even virtually, it helps us learn about state-of-the-art treatments and feel part of a caring family of other patients. It makes a huge difference!"

The event begins at 6 pm Friday at Guy's and St. Thomas' Hospital. While the auditorium is filled to capacity, including with four television cameras for the broadcast, online registration is available for free viewing at http://www.patientpower.info/event/mpn-london-2015

About:

MPN Voice – is a charity based in the UK and registered under the auspices of the Guy's and St Thomas' Charity. It was formed in 2004 when patients in London with rare cancers called essential thrombocythemia and polycythemia vera were frustrated they could not find up-to-date information about treatment and research. They joined in partnership with medical specialists to fill the gap in education and community. Today MPN Voice provides forums throughout the UK and in Ireland.

Patient Power – is a pioneer in providing editorially independent, free online education and empowerment of cancer patients using video that connects experts with patients around the world. Its videos in multiple languages are seen by patients and cancer professionals on many web sites and in social media. These include patientpower.info, <u>patientpower.eu</u> and <u>oncologytube.com</u>.

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