Joining Together for Better Care

Friday 28 February, 2014

The theme of International Rare Disease Day 2014 is “Join Together for Better Care”. As patients and caregivers who have been impacted by peritoneal cancers (Appendix Cancer, Pseudomyxoma Peritonei, and other Peritoneal Surface Malignancies) our organizations have chosen to join together to share a simple message about these diseases.

This year’s Rare Disease Day Ambassador, Sean Hepburn Ferrer, lost his mother Audrey Hepburn to peritoneal adenocarcinoma in 1993 at a time when she was offered little treatment or hope (http://ow.ly/u1CaE). Over 20 years after Audrey Hepburn’s experience, one of the greatest challenges with these diseases continues to be correct and timely diagnosis and access to the Standard of Care: cytoreductive surgery plus hyperthermic intraperitoneal chemotherapy (CRS/HIPEC). In many cases, symptoms are misunderstood for years, and patients are thus less likely to benefit from CRS/HIPEC. This treatment, unavailable to our patient population only a generation ago, has turned what used to be an almost certain death sentence into hope for thousands of patients around the world.

We share the goal that every patient who presents with the common symptoms of these diseases – abdominal pain, increased abdominal girth, bloating, hernia,ovarian cysts or tumors, and ascites – receive correct diagnosis through tumour marker blood tests (CEA, CA 19/9, CA?125) and CT scans and be afforded the option to be treated with the Standard of Care, CRS/HIPEC, by a qualified surgical oncologist before any other counterproductive and potentially damaging treatments are attempted.

We all share the hope of achieving this goal, and by joining together in this statement and sharing this information, we strive for future patients suffering from these diseases to receive the better care that they deserve.

Signing Entities
Appendix Cancer Connection (Appendix?Cancer.com)
Be Unintimidated (BeUnintimidated.org)
The Insurance Warrior (TheInsuranceWarrior.com)
PMP Awareness Organization (PMPAwareness.org)
PMP Research Foundation (PMPCure.org)
Pseudomyxoma Survivor (PseudomyxomaSurvivor.org)

Media:

Related Sectors:

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Related Keywords:

Rare Disease Day 2014 :: Pseudomyxoma Peritonei :: Audrey Hepburn :: PMP :: Appendix Cancer :: Peritoneal Surface Malignancies :: Pseudomyxoma Survivor ::

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