Sean Hepburn Ferrer becomes Rare Disease Day Ambassador

Wednesday 7 August, 2013

Sean Hepburn Ferrer has become a Rare Disease Day Ambassador for EURODIS, the European organisation for rare diseases. Sean Ferrer's mother, the actress Audrey Hepburn, died from pseudomyxoma peritonei. He was nominated for the position by Pseudomyxoma Survivor's Dawn Green.

Sean Ferrer commented: "On January 20, 1993, my mother, Audrey Hepburn, passed away from a rare type of cancer – Pseudomyxoma adenocarcinoma. When we found out that the only tentative treatment was a chemotherapy (5 fu leucovorin) available since the 60s, we, her family, truly connected with the fact that this disease was not a priority for Big Pharma. The most precious person we knew could not be saved.

"So, when Dawn Green, CEO and founder of the ‘Pseudomyxoma Survivor’ Charity and herself a one in a million cancer survivor, nominated me to be the ambassador for rare disease day 2014, I knew that, not only did she have this rare cancer but also a rare ability to transform darkness into light and smile in the face of adversity.

"‘Rare’ is a word most often used to convey the same values as ‘precious’… unique… valuable. And if one adds up all of us precious beings that suffer from a ‘rare’ disease, the number is staggering – 60,000,000 and counting. The way each of us deals with what ails us is always unique and therefore, I feel it is quite easy for any of us to relate to ‘rarity’… that rarity that comes in those moments when we must truly face life and adversity by ourselves."

Pseudomyxoma Survivor is a UK based charity which aims to raise awareness of the condition and to provide emotional and practical support to those affected by the disease, worldwide. Pseudomyxoma Survivor founder and CEO, Dawn Green added: "We are excited that Sean has taken up this ambassadorship and will be collaborating with both Pseudomyxoma Survivor and EURODIS to raise awareness of pseudomyxoma peritonei and other appendix cancers, as well as rare diseases more generally."

Pseudomyxoma peritonei is a rare cancer that usually starts as a small growth (adenoma) in the appendix comparable to a polyp. This adenoma will eventually break through the appendix wall and into the peritoneum (abdominal cavity lining). The tumors secrete a jelly-like mucus in the abdomen, which causes the abdomen to swell and compress other vital organs.

If left untreated, this mucin will engulf the abdominal cavity producing a characteristic "jelly belly". It is this build up of mucin that generally causes symptoms.

PMP is not like other types of cancer in that it is seldom spread through the blood stream or lymphatic system, it generally remains contained within the abdomen and spreads along inner surfaces. Presently, it is thought to affect between one and two million people worldwide per year.

PMP symptoms usually appear after some time and are caused by the build up of resulting mucus within the abdomen. Some sufferers do not show any symptoms for some years.

Symptoms are often initially misdiagnosed as a hernia or ovarian cancer and include but are not limited to:

- Changes in bowel habit
- Loss of appetite
- Pelvic pain or pain within the abdominal area
- Appendicitis
- Swelling of the abdomen
- Weight gain and or increase in waist size
- Bladder discomfort

These symptoms can be caused by a variety of medical conditions which are not necessarily PMP. However, due to the nature of this cancer it is imperative to rule out PMP as a cause. Any unexplained

Related Sectors:

Charities & non-profits :: Health ::

Related Keywords:

Pseudomyxoma Peritonei :: PMP :: Pseudomyxoma Survivor :: Appendix Cancer :: EURODIS Ambassador :: Rare Diseas ::

Scan Me:

symptoms should always be discussed with your doctor.

Pseudomyxoma Survivor is a charity established primarily to provide emotional and practical support to those affected by the disease but also to raise awareness and to raise funding to support research. Pseudomyxoma Survivor is completely dependent on voluntary donations. It is too small to have offices or staff; the charity is run entirely by volunteers.
http://www.pseudomyxomasurvivor.otr

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe.
http://www.eurodis.org

Company Contact:

_

Pseudomyxoma Survivor

T. 03003020050
E. press@pseudomyxomasurvivor.org
W. https://www.pseudomyxomasurvivor.org

View Online

Newsroom: Visit our Newsroom for all the latest stories:
https://www.pseudomyxomasurvivor.pressat.co.uk