A decade of scientific breakthroughs for patients with GIST

In the past decade, some life-threatening diseases have evolved from being untreatable diseases to chronic conditions with the help of significant medical advances.

Gastrointestinal stromal tumors, or GIST, are a rare and life-threatening cancer of the gastrointestinal tract. The advances in the treatment of this cancer exemplify the leaps and bounds in scientific innovation and improvements in patient care that are possible within a 10-year span.

People living with a rare disease such as GIST - a condition which affects approximately 10 to 20 people per million worldwide each year - can often feel isolated and overlooked. Patients diagnosed a decade ago found little information about the disease, encountered underdeveloped support networks and faced an uncertain future given the limited treatment options.

“I remember several weeks after my own diagnosis I went to the National Cancer League to try and get some information about my cancer, and the only definition I was given was that GIST was an orphan cancer. And you can imagine it was a terrible and a painful moment, because at this moment you think that no one has ever heard about your disease,” said Estelle Lecointe, Founder & President of the French GIST Patient organization, Ensemble contre le GIST.

In the last decade, there has been significant clinical research focused on understanding the specific pathway of the disease.

“We have really made remarkable progress over the past ten years. GIST was hardly ever known as a tumor entity in the 1990s. But now within the last decade we have gained a lot of information about GIST,” Heikki Joensuu, M.D., Ph.D., Professor, Oncology, University of Helsinki.

But despite the significant advances made to date, scientific understanding of the disease continues to be a priority for researchers and clinicians. A key area of focus is to further improve patient outcomes by working to improve the measurement of risk of recurrence in patients – a challenging task given that multiple factors are associated with risk for relapse or decreased survival after surgery, including the size and location of the tumor, the occurrence of tumor rupture and the proportion of tumor cells undergoing cell division (mitotic rate).

In addition to the difficulties in assessing chances of recurrence, the initial treatment of the disease also presents challenges. All gastrointestinal stromal tumors have the potential to be malignant and approximately 10% to 25% of cases of GIST have spread to distant parts of the body (metastasized) at the initial stage of diagnosis, with data estimating that the 5-year survival rate for these patients is about 13%. And although complete surgical removal is possible in most patients with primary GIST (tumors at the original site of development before any spread to other locations), many patients develop tumor recurrence or metastasis following surgery, with poor chances of survival following recurrence. For those reasons, researchers and physicians continue to strive to find ways to improve patient outcomes.

For more information about GIST, speak with a healthcare professional or local advocacy organization. To learn more about the advancements in the treatment of GIST, please visit http://www.youtube.com/novartis.

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