

Introduction

A web-based survey of cognitive dysfunction and other patient-reported outcomes in people with gastrointestinal stromal tumor (GIST)

This research initiative started after hearing patients with GIST complain about long-term negative symptom experiences following treatment, particularly with respect to cognitive function (similar to “Chemo brain”).

Cognitive symptoms and memory problems have been widely reported among survivors of certain cancers, particularly breast cancer. These memory problems may be mild or moderate but can nevertheless interfere with daily life. Memory difficulty has also been associated with mood disturbances that can affect quality of life.

Very little is known about cognitive dysfunction (difficulties with thinking and memory) for patients with GIST, particularly those who are taking tyrosine kinase inhibitors (TKIs), like Gleevec (Glivec). Most patients treated with TKIs (like you) have to maintain this therapy for an extended period of time and take it on a regular basis. This is different from patients with other cancers who are undergoing chemotherapy or radiation therapy. Their therapy is typically given in bouts over a few weeks or months.

We are asking current GIST patients and survivors to complete an online survey to help us identify possible problems with memory and cognitive function. Those who complete the survey must be 18 years of age or older. The survey can only be offered in English at this time and includes questions about your background (e.g., age, race, years of education, occupation), your medical history and treatment regimens, your perceived cognitive problems and other symptoms as well as your quality of life. If you are willing to participate, the survey will take about 30 to 45 minutes to complete. You will not receive any payment for completing the survey.

There are no foreseeable risks associated with this project, nor are there any direct benefits to you. This is an anonymous questionnaire, so your responses will not identify you in any way. All responses will be kept confidential, with results kept in password-protected files behind an institutional firewall. It is possible that your research data may be shared with investigators conducting other research; however, this information will be shared in a de-identified manner (without identifiers). Your participation is voluntary, and you may stop completing the survey at any point.

Our goal is that results of this survey will lead to further research on the possible impact of TKI therapy on neurocognitive function. Most immediately, we hope that our study leads to tailoring of cognitive-behavioral therapy to counteract the cognitive effects of TKI treatment, using an approach that has been found to be effective in breast cancer survivors.

This study is being conducted by Dr. Anette Duensing in collaboration with Drs. Dana Bovbjerg and Robert Ferguson (Biobehavioral Oncology Program, UPMC Hillman Cancer Center, University of Pittsburgh School of Medicine) and Dr. Beth Snitz (Department of Neurology, University of Pittsburgh School of Medicine). Dr. Duensing may be reached at 412-623-5870, if you have any questions.

By clicking the “link to survey” below, you are agreeing to participate in this research study by completing the survey. You will find some general instructions on how to fill out the survey on the first screen.

Thank you very much for your time!