

**CALL FOR REINSTATEMENT OF 'LAST RESORT'  
LIFE-EXTENDING CANCER DRUG TO CANCER DRUG FUND LIST**

Many patients with a rare form of stomach cancer are set to lose invaluable time with their families after the decision to withdraw the only drug available to them from the Cancer Drug Fund (CDF) list.

**The drug regorafenib (Stivarga®)** was approved last year as third line treatment for patients with advanced Gastrointestinal Stromal Tumour (GIST). GIST is a rare type of cancer (a sarcoma) found in the digestive system, most often in the wall of the stomach. Regorafenib is used to treat GIST cancer that has become unresponsive to the existing drugs imatinib and sunitinib. **It has proved very successful in this situation, stopping the disease growing or causing significant shrinkage.** It also seems better tolerated than standard second line treatment in many patients.

One rare form of GIST which particularly occurs in younger patients, called “Wild-type” GIST, is very difficult to treat, but responds very well to regorafenib. The loss of this treatment option for these patients will be particularly difficult.

The withdrawal of this drug from the Fund means that patients whose GIST cancer is inoperable or has spread widely and is not being contained by the 1st and 2nd line treatments licensed in the UK will have no other treatment available options, and will die sooner than might have been the case when their cancer grows out of control.

Clinicians and charities working on the disease are now **calling on the decision to be reconsidered, and for regorafenib to be reinstated on the CDF list.**

There is currently no cure for inoperable GIST, but targeted drugs like regorafenib enable a patient to live for considerably longer, providing both time with their families and for research into other solutions to continue.

**Professor Ian Judson**, Head of the Sarcoma Unit at The Royal Marsden Hospital and Chair of the GIST Support UK Medical Advisory Board, says: ***"The Cancer Drugs Fund was initially set up to give access to drugs deemed not to be cost-effective by NICE, which has not appraised regorafenib for cost-effectiveness in this setting. The CDF press release says that they will not remove drugs from the list that are the only drug available for a given disease. However, regorafenib is the only treatment for GIST that is resistant to imatinib and sunitinib."***

***Here are some other reactions from people affected by this decision:***

*"GIST is a rare cancer, and while the number of patients affected by these decisions is relatively small compared for example to breast cancer, for those affected by this decision, it is a bitter blow. Withdrawing regorafenib when it represents the only available third line treatment is cruel in the extreme."*

*"From a psychological point of view, there are many patients on second line treatment, knowing that this will only work for a limited length of time, and despite a cancer diagnosis, they have had some comfort in the knowledge that if their cancer progresses there is another drug that can be used to slow it down and stabilise it. By removing the option of regorafenib, this option is gone and the future becomes a total nightmare".*

*"A significant number of GIST patients have had several years of good quality of life while using Regorafenib and still have, continuing to work and contribute to society."*

*"Taking away this lifeline for GIST patients on the pretext of funding better drugs just doesn't make sense - this drug is a real benefit now. There are currently no alternatives and will not be for years as there isn't anything else in the pipeline. It has shown particular benefit in Wild-type GIST cancer patients and is the drug that has been our hope for the future."*

*"The decision to remove this drug is wrong, and has been made on what we believe is an incorrect basis. The CDF panel indicated that they would have approved it had it not also been licensed for colorectal cancer. This is spurious logic, irrelevant to GIST patients who need access to this life-prolonging agent and flies in the face of common sense."*

Regorafenib must be reinstated to the CDF for GIST patients - time is what we need, in the hope that a new effective, curative treatment will be found, and regorafenib is the drug that gives us extra time.

- ends -

**For further information, please contact Jayne Bressington at:  
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*The following people are willing to be interviewed in support of this Press Release:*



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