



Bulgarian National Association of People suffering from Chronic Myeloid Leukemia

Greatest Success Initiatives for the period 2010-2011



Помислихте ли за себе си днес?

ENSURED STATE REIMBURSEMENT FOR SECOND LINE TREATMENT WITH II GENERATION TIROSINE KINASE INHIBITORS FOR A NUMBER OF PATIENTS WHO'S THERAPY WITH IMATINIB FAILED

Situation

In the beginning of 2010 Bulgarian Ministry of Health was planning to reimburse II generation Tiro sine Kinase Inhibitors for limited number of patients (~10), who's therapy with Imatinib was not successful

Mid January a rumor spread out, that because of the lack of resources, The Ministry of Health will reimburse only one of the II generation Tiro sine Kinase Inhibitors because of it's broader indication in second line treatment

There was real danger, that the CML patients and their treating physicians will be left without an important alternative for second line treatment and will have to use only the one reimbursed II generation TKI

How to improve it?

To ensure that Bulgarian Ministry of Health reimburses both II generation TKIs, in order there to be medication alternative for second line treatment for the doctors and patients

What have we done?

We started a correspondence with the Bulgarian Academic Hematology Society and asked them for their official opinion regarding the equality of the both available II generation Tiro sine Kinase Inhibitors

After receiving the experts opinion that both II generation Tiro sine Kinase Inhibitors are different and each of them has it's advantages and disadvantages (especially regarding their safety profile), we asked the Bulgarian Academic Hematology Society to send official opinion to the Ministry of Health regarding this matter and to defend the right or individualized choice for the doctors and their patients.

The Outcome

After receiving an experts opinion from Bulgarian Academic Hematology Society and letter from our CML Group the Bulgarian Ministry of Health decided that both available II generation TKIs should be reimbursed

Since May 2010 we have more than 25 patients on 100% state reimbursed second line treatment with nilotinib or dasatinib after failure of imatinib.

IMPROVED QUALITY OF CONTENT, ACCESSIBILITY AND INTERACTIVENESS OF OUR INTERNET SITE (WWW.HML-BG.COM)

Situation

In April 2010 during our group's Annual Meeting we gathered opinions from our members regarding what can we improve in order our website to be more useful to them

Major points were:

All the uploaded information on the site has to be consulted with expert in hematology for medical correctness

The site should be easily accessible by key words like Leukemia, CML etc. in the net

The site should be more interactive (not passive)

What have we done?

We involved young expert hematologist as a consultant of all site contents medical trust-worthiness

We changed the domain name of the site and registered it in all searching programs with some key words like CML, Leukemia, Patient organization etc.

We opened an interactive forum within the site and involved the expert hematologist as forum administrator.

The Outcome

We improved the quality and trust-worthiness of the information on the site

The site is now much easier accessible

The site is more interactive and much more visited than before

ESTABLISHED EDUCATIONAL PROJECT "DID YOU TOOK CARE OF YOURSELF TODAY" FOR CONTINUOUS SUPPORT FOR PATIENTS WITH CML REGARDING THEIR NEEDS OF ADHERENCE TO THERAPY AND DISEASE KNOWLEDGE

Situation

Despite our efforts to improve the reach of our organization to all CML patients in Bulgaria, in April 2010 on our Annual Meeting we realized that the members are only 1/6 of all patients with this disease.

Another major problem identified was, that the hematologists and hematology nurses are very busy with their everyday bureaucratic duties and cannot spare enough time for patients disease education and explanation of the importance of adherence to treatment

There were several reports on patient non adherence cases that ended fatally

How to improve it?

To drive the implementation of an Adherence and Disease knowledge Educational program that will constantly reach all patients with CML in Bulgaria

What have we done?

We started a Project called "Did You Took Care of Yourself Today", that consisted of preparation of gimmicks with the slogan of the program and the internet site of our organization

We started to distribute this gimmicks with the support of the hospital pharmacies to all patients with CML

The first gimmick was a calendar for the year 2011, the second one a mug and now we will start distributing the third one, that is a small pad with a pen in the colors of the project logo

The Outcome

The visits in our site improved significantly after the start of the Project

We have all gimmicks distributed, which means, at least passively, we have reached all CML patients in Bulgaria

ESTABLISHED "SUPPORT GREEN PHONE LINE" FOR CML PATIENTS FROM ALL OVER BULGARIA

Situation

Despite the improved Web site of our organization there are still patients that are not familiar with the modern technology and prefer to use more conventional ways of communication (phone)

How to improve it?

To cover the need of the patients relying on old fashioned way of finding information over the phone

What have we done?

We started a Project called "Green Phone Line for CML Patients", that consists of leasing of a specific phone line and hiring on part time of an experienced hematology nurse to answer questions of CML patients from all over Bulgaria

When the questions are outside the competence scope of the nurse, she collaborates with the expert hematologist that consults our internet site and delivers the answer within few days

The Outcome

The project started recently, but we already have some questions answered with good feedback regarding the service from CML patients