

Assessment of the quality of life and needs of a group of Polish patients with Philadelphia-negative myeloproliferative neoplasms (MPNs)

(a planned project to be implemented after the establishment of a patient organization, authors: Magdalena Roszkowska-Lwow - Wrocław Medical University, Monika i Cezary Orlikowscy - founders of the Polish patients' organization)

INTRODUCTION & AIMS

(a project to be implemented)

Philadelphia-negative myeloproliferative neoplasms (MPNs), essential thrombocytopenia (ET), polycythaemia vera (PV) and primary or prefibrotic myelofibrosis (PMF or PreMF), are a group of rare disorders of the bone marrow that cause an increase in the number of blood cells.

Most people who develop MPNs are over 60. Nevertheless, around 10-20% of MPNs could be diagnosed below 40 years old and according to recent data this number is increasing.

Even though MPNs is a cancerous disease, the system treats them (especially those with ET and PV) more like patients with a chronic disease. By observing Internet forums and talking to patients, we noticed the need to determine what the needs of this patient community in Poland (especially the younger group of patients) are and how we can help. The next step would be to perform the same survey among MPN patients in Europe (in collaboration with EHA-MPN work group).

METHODOLOGY

(a project to be implemented)

Target audience: Polish patients with a confirmed diagnosis of MPNs.

Time of conducting surveys: approximately 3 months online and in paper version.

Questionnaires used: FACIT-F fatigue scale (Functional Assessment of Chronic Illness therapy- Fatigue) and own survey.

Evaluation strategy: After receiving the survey results, we want to create a website that will meet the greatest needs of patients and then conduct the survey a year after the website was launched and compare the needs.

REFERENCES

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RESULTS

(a project to be implemented)

Our key expected results of a planned project are:

- examining the quality of MPN patients life in Poland
- understanding the level of patient care
- understanding the educational needs of a specific patient with MPNs

CONCLUSIONS

Currently, there is no operating organization in Poland that supports and integrates patients with MPN. Our goal is to create such an organization. This survey will help us to discover real needs of MPNs patients, including younger ones, in Poland.

Regardless of the project described here we have the pre-defined areas that we intend to develop in the newly created organization:

- developing reliable information about MPN in cooperation with doctors and pharmaceutical companies.
- collecting information (e.g. questionnaires) from a possibly wide group of patients with MPN in Poland about their experience, problems, expectations during treatment.
- creating a place for the exchange of information between patients and doctors.
- expressing patients' opinions on the availability of modern drugs and the problem of their reimbursement by the health care system in Poland.

We hope that our participation in the Warsaw MPN conference will be inspiration and a source of practical information from other MPN groups. In particular, we are interested in some aspects of running a organization like:

- who would allow us to use content from websites about the MPN disease?
- how do start a new group? Virtual or personal meetings?
- how can you influence national authorities to support new medical treatments?
- the methods of cooperations with doctors and pharmaceutical companies?

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