

The Association of CML Patients and Their Families "IZUMI"

"IZUMI" means spring in Japanese, from which water, the origin of life, spills forth to sustain life.

PUBLICATION~VOICES FROM PATIENTS

- I was encouraged after meeting with those who are fighting the same disease/heartened/I am not lonely...
- I was encouraged after knowing that they share the same feelings.
- There is something that can be understood only by those who are struggling with the same disease.
- I committed myself to positively cope with the disease.
- I was relieved with their various opinions.
- I learned about the disease, and corrected my misunderstandings.

A brochure for the CML patients and their families, which covers patients' stories, is in preparation.

QUESTIONNAIRE SURVEY FOR PATIENTS

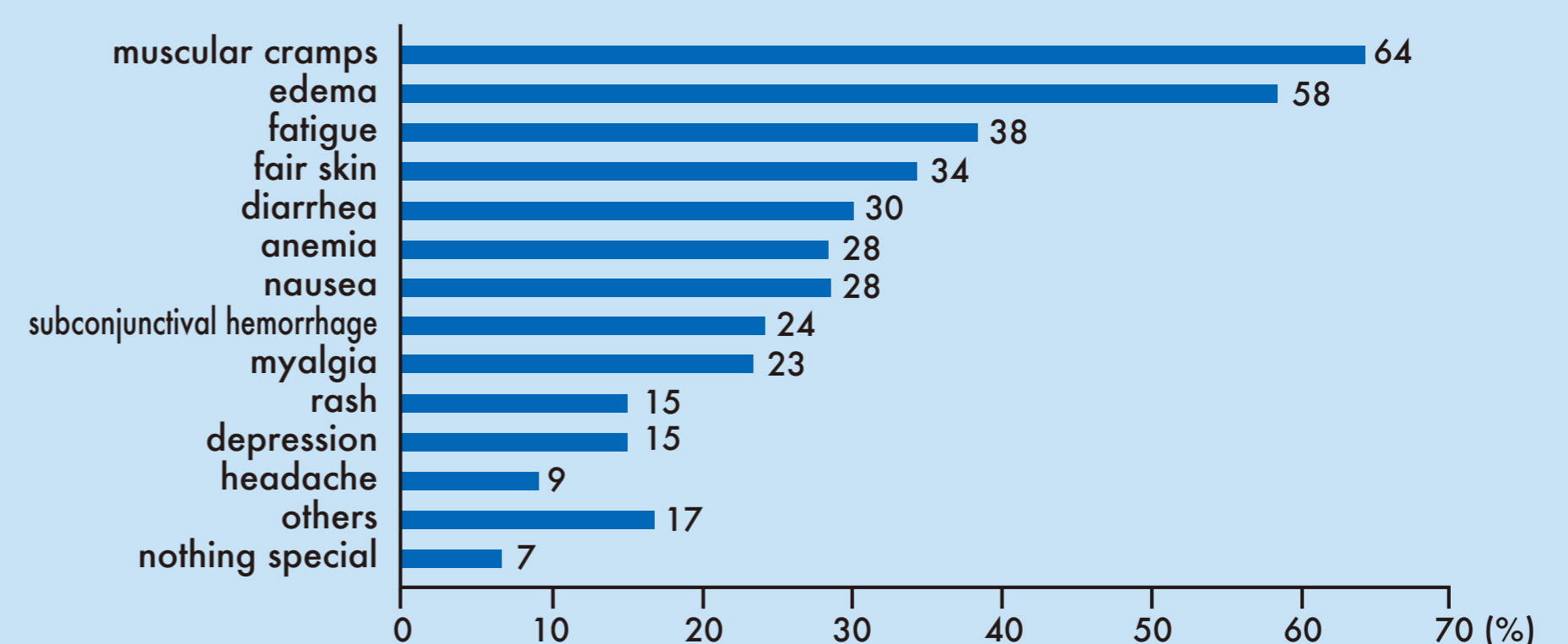
<Objectives>

To identify problems and concerns of patients and their families, and convey them to the medical professionals and pharmaceutical companies toward better and improved therapies.

<Questions>

- annoying symptoms, daily activities, social activities, daily life
- satisfaction level in the communication with medical professionals
- method to collect information, information needed
- examinations, anticipation and satisfactory level for the therapy

Annoying symptoms (n=120)



CML WORKSHOPS AND STUDY SESSIONS

2008 4 sessions: NAGOYA, OSAKA, TOKYO (twice)
2009 6 sessions: FUKUOKA, TOKYO (twice), OSAKA, NAGOYA, TOHOKU



TALK AT THE TRAINING WORKSHOP FOR COUNSELLORS

We gave a talk at the training workshop for those who work as counselors at the support centers of cancer hub hospitals, to deepen their understanding to the importance, issues and the tips to continue the activity of patient organizations.

BROADCASTING

IZUMI was introduced as a society, in which the CML patients mutually support each other, in a human documentary TV program. This program targets patients who are battling cancer and their families, and it focuses on the latest cancer therapies from a scientific viewpoint. (2009.2.11 broadcast on the national television network)



INTERNATIONAL EXCHANGE

We invited members of the Korean blood cancer association to a Forum in Japan. They exchanged opinions with the Japanese patients, which has led to the international collaboration.

IZUMI is a patients' association for chronic myeloid leukemia (CML), which aims to provide information regarding the disease and improved medical compliance. While most CML patients spend their regular daily lives on an oral medication therapy, they face serious concerns, such as side effects, costly medical expenses, and anxiety for the rest of their lives. Our motto is, "Sharing vitality with those who are in the same circumstances" via talking and supporting each other.

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Auspices: Novartis Pharma K.K., Bristol-Myers K.K., Wyeth K.K. **Constituency:** NPO Japan Clinical Research Support Unit

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<http://members.jcom.home.ne.jp/firstsight/izumi/>