



Introduction of GIST Patients Support Activities in Japan

Sumito Nishidate, Kimie Sakurai, Rieko Hashimoto, Ayumu Hiratsuka

NPO GISTERS Japan 特定非営利活動法人GISTERS

SUMMARY

GISTERS, an NPO, is a Japanese patient organization that supports patients with GIST and soft tissue sarcoma and makes policy recommendations regarding pharmaceutical affairs.

Since we have members from all over Japan, we use our own social media to communicate with each other, and we focus on regional activities, holding meetings and seminars in each region.

It is said that there is not enough information about rare diseases in Japan, and GISTERS is working with various stakeholders to provide necessary information for GIST and sarcoma patients.

HIGHLIGHT IMPORTANT INFORMATION HERE

GISTERS Japan has continued to make requests to increase the number of GIST treatment options provided by public insurance. However, the "Drag Ross" situation continues, in which drugs approved in the U.S. and Europe do not enter Japan after 2020. Japan is also the only country where Pimipitespib, an HSP90 inhibitor that has not been developed in the US or Europe, has been approved. We are committed to creating an environment in which patients can receive the same treatment as in Europe and the U.S. and disseminating information about drugs developed in Japan that can benefit patients worldwide.

OBJECTIVES

1. Create an environment where patients from different regions can support each other.
2. Seminars and other events will be held in various locations.
3. Policy advocacy to bring needed treatments to patients who need them.
4. Continually learning information empowers our patients. We are here to help.

When you are surrounded by anxiety and sadness after being diagnosed with GIST, an unfamiliar "rare cancer," it is the real voices of patients walking ahead of you that can help you overcome these feelings. It is "convincing" evidence that they can still live and that there is hope.

By sharing their experiences, patients can give hope and encouragement to the patients and their families who will follow.

We want to spread such connections throughout Japan. That is one of the goals of GISTERS and the starting point of our activities. The person who consulted with us today is encouraging another person the next day. Such "connections" have grown into a network that we are proud of over the past 18 years. Each patient is an important mainstay of GISTERS, and their experiences are the foundation that supports GISTERS.

IMPLEMENTATION

• GIST Patient Seminar 2023⁴⁴ Figure 1.

Saturday, March 25, 2023, 13:00-16:00 Auditorium, NCC Hospital East

The topics of the presentations were drug therapy for GIST, consideration of surgical treatment at recurrence, and current development of new drugs. The lecturers were Dr. Saori Mishima, Dr. Naoto Gotoida, and Dr. Yoichi Naito

• Rare Cancer: Consultation Q&A with Everyone_GIST Webinar Figure 2.

Wednesday, July 19, 2023, 18:30-20:00, held online Co-hosted with NCC Rare Cancer Center

response to our questions, Dr. Toshiro Nishida, Dr. Yoichi Naito, and Dr. Hidekazu Hirano answered our questions.

They gave us answers and explanations in an easy-to-understand manner for the general public.

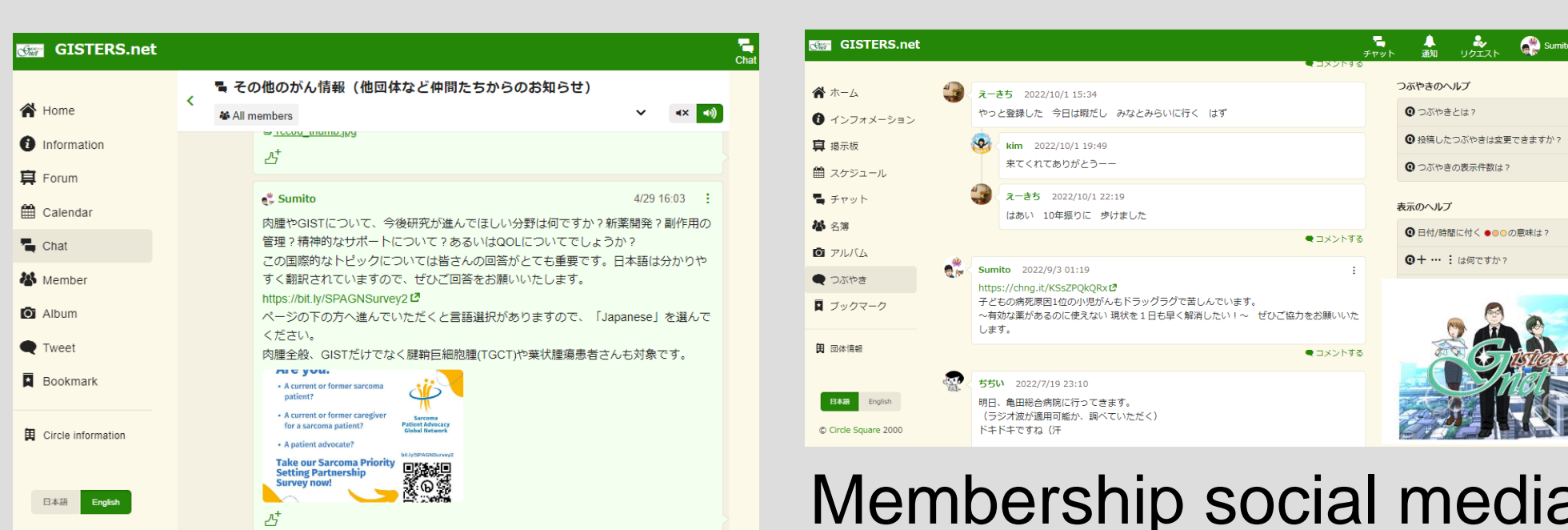
ACTIVITIES



GIST patient seminar co-hosted with NCC



Joining Charity Events



Membership social media



Public Discussion Board



Yokohama Fukuoka Seminars and social events around Japan



Sendai Sapporo, Okayama, Kumamoto, etc.



Figure 1. GIST Patient Seminar 2023



Figure 2. Consultation Q&A with Everyone_GIST Webinar

Collaboration in Japan

- **Rare Cancers Japan**
日本希少がん患者会ネットワーク
A coalition of 21 patient groups, including pediatric and head and neck cancer patient groups.



- **NCC Rare Cancer Center**
国立がん研究センター希少がんセンター
Central organization for rare cancer treatment and information in Japan.



NEXT STEPS

- Learning from US and European Patient Associations.
- Collaboration with Asian Patient Groups
- Development of Relationships with Emerging Biopharmaceutical Companies
- Dialogue with pharmaceutical companies based in Japan

CONTACT INFO

NPO GISTERS Japan

1. Web Site
Information page for GIST patients
<https://www.gisters.info/>
2. Mail : mail@gisters.info
3. Facebook
<https://www.facebook.com/npogisters>
4. twitter
https://twitter.com/NPO_GISTERS

