

# NEW HORIZONS GIST

SEPTEMBER 5 – 7, 2018 – VIENNA, AUSTRIA



## GISTERS in Japan



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## NPO法人GISTERS

- **2002 年** It opened an information exchange site about GIST and sarcoma on the Internet
- **2003 年** Signature activities seeking early approval of Gleevec (former caretaker Odashima Kazuhisa)  
Submit's signature total number of 62,064 people) to the Minister of Health, Labor and Welfare addressed (left)



- **2006 年** Participated in the 1st Relay for Life Japan in Tsukuba  
Formed the Team GISTERS (pictured right)

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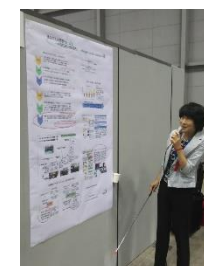
- **2007 年** Signature activities seeking early approval of Sutent (Total number of signatures: 134,739) to the Minister of Health, Labor and Welfare.



- **2008 年** It opened a patient participatory web site "GISTERS.net". (Social media)

- **2010 年** Start the holding of "patient study sessions" co-sponsored by the GIST Study Group.

- **2011 年** Begin participating in the "Patient-Advocate-program" of the "Japan Society of Cancer Therapy", "Japan Society of Clinical Oncology."



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2010 年 Life Fest 2010

Participation in the LifeFest became a major stimulus

## 活動内容 4

### 海外患者会との連携



GIST に関する情報収集を行ううえで、多くの第 1 相治験が行われているアメリカなどの、海外患者団体から得られる情報は非常に有益です。

「GISTERS.net」はアメリカの患者団体「Life Raft Group」等と連携し「Global GIST Network」の一翼を担っています。



昨年 2010 年は分子標的薬「イマチニブ」が誕生して 10 年目、Life Raft Group は盛大なイベントで祝いました。このイベント「Life Fest2010」では、この 10 年 GIST 治療に貢献した研究者、医師が表彰を受けましたが、日本の GIST 研究会はアメリカでもその功績が認められ殿堂入りとなりました。

「Life Fest2010」では、3 日間に渡りセミナー・ワークショップが開かれました。



#### Changes to Our Workshop

Presenters: Alice Bellizzi in New at 2:00 p.m. in Halland 1  
LAST 100: David Joseph in New at 4:00 p.m. in Halland 1 & 2

Liberty (L&S)	California (L&S)	Atlanta (L)
2:00 p.m. Molecular Basis of Resistance to Imatinib Crista Suter	2:00 p.m. New to Old Shengping	2:00 p.m. Nutrition Alice Bellizzi
3:00 p.m. Optimal Use of Imatinib Haruhiko I. Saito	3:00 p.m. 10th History of GIST (part 1) UK: No longer here	3:00 p.m. Lidocaine Shengping & Maria Tsimoy
4:00 p.m. Management of Recurrent Disease David Joseph	4:00 p.m. GIST 100 David Joseph	4:00 p.m. Cooperating with a multidisciplinary team David Joseph



GSITERS.net からは Life Raft Group が毎月発行しているニュースレターへ、日本の状況などのレポートを提供する一方、国内から海外、海外から国内の病院・施設へアクセスしたい患者の窓口となったり、海外患者団体の紹介を行うこともあります。

From the presentation poster at the Japan Cancer Therapy Association in 2011

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- **2013 年** Corporation the GISTERS.net "Non-Profit-Organization GISTERS" founded.
- Request for early approval of Stivarga, Request for expansion of doctor-initiated clinical trial, Request for implementation of patient support program, submitted to Ministry of Health, Labor and Welfare, National Cancer Research Center, Bayer Pharmaceutical.



- **2015 年** Study Group on Rare Cancer Medicine and Support Members Ministry of Health, Labor and Welfare.
- **2017 年** Opened "WorkPlace for GISTERS" social media dedicated to GIST enlightenment / awareness activities.

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- Four pillars of activity

1. Provide information to the patient and provide a place for learning
2. Support for activities by region
3. Website management
4. Policy recommendations to national and local governments

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## GISTERS.net

One by one main page

Usage situation

Phase 1, March 2008 -

Number of users: 720

Phase 2 2015. February ~

Number of users 312

(2018. As of July 13)

Object:

GIST · Sarcoma patients and families

Usage Fee: Free

Pageview 900 / day

Member diary  
All other members  
can see

Comment on diary

Attach photos to comments

2018年08月30日 14:32  
**2: ミルヒ一**  
つっちー 昨日の説明会は50を超えるチームの申し込みがあるみたいですよ！人数が多すぎたんですけど、つっちーの言葉が紹介されてたよ。  
今度カンサースピーカーで小学生に話すからばくっていい？

2018年08月30日 15:13  
**3: つっちー**  
ミルヒ一さん  
大人数の前で紹介って恥ずかしい(笑)  
もちろんバクリOKよん  
多分、全国のRFLの会議ん時のプレゼン時の言葉かな？  
プリントアウトしてる資料を持っていくから、どれでも好きな言葉を持ってけ〜(^^)

2018年08月30日 16:52  
**4: ミルヒ一**  
ありがとー  
メモしらんかったから助かります

2018年08月30日 18:58  
**5: kim**  
鉤子からルミナリエで思いを空に飛ばしておきます。  
みーんなでRFLを味わってください☆

2018年08月30日 20:32  
**6: えちらい**  
つっちー  
今度は開くほうに回るよ〜。  
えちらい、ホスト側ですが、手足痛くて戦力になりません(笑)。皆さん、九州GISTERSのサポートよろしくです。

2018年08月31日 02:14  
**7: 雪**  
お世話になります。  
初めての福岡リレボ!!!  
楽しみだぁ♪♪♪  
よろしくお願ひします (まろ)

2018年08月31日 15:47  
**8: ビートルジョン**  
ミルヒ一さん  
RFL福岡の成功を祈ります。

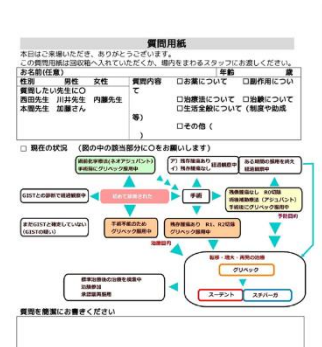
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## Workplace for GISTERS



Discussion board of each region  
8 areas  
10 groups



File sharing function  
Group chat function



Usage situation  
Opening 2017.11 ~  
Number of users: 72

Object  
NPO corporation GISTERS full members

Dues  
¥ 3.000 (year)

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## 2017・2018年度 GISTERS MAP

- ・ イベント等への参加地・開催地  
（リレーフォーライフ・定期的な交流会・親睦会）★
- ・ 定期的なセミナー・患者会の開催地 ★



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GIST AwarenessDay Seminar Tokyo 2018 in National Cancer Research Center Tsukiji Campus 166 participants



Dr. Toshiro Nishida



Dr. Youichi Naito



Dr. Yoshitaka Honma



Dr. Akira Kawai



Ns. Yoko kato

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The screenshot shows the National Cancer Institute (NCI) website. At the top, the NCI logo and name are displayed. Below the navigation bar, the page title is 'Clinical Trials Using HSP90alpha/beta Inhibitor TAS-116'. The main content area includes a description of clinical trials, a link to NCI's basic information about clinical trials, and a section titled 'A Study of TAS-116 in Patients With Solid Tumors'. The sidebar on the left contains various navigation options related to cancer treatment and clinical trials.

**NIH NATIONAL CANCER INSTITUTE**

1-800-4-CANCER Live Chat Publications Dictionary

ABOUT CANCER CANCER TYPES RESEARCH GRANTS & TRAINING NEWS & EVENTS ABOUT NCI search

Home > About Cancer > Cancer Treatment > Clinical Trials Information

**CANCER TREATMENT**

- Types of Cancer Treatment +
- Side Effects
- Clinical Trials Information
  - Find NCI-Supported Clinical Trials +
  - What Are Clinical Trials? +
  - Paying for Clinical Trials +
  - Patient Safety +
  - Deciding to Take Part in a Trial
  - Questions to Ask about Treatment Clinical Trials
  - Selected NCI-Supported Trials
- A to Z List of Cancer Drugs +
- Complementary & Alternative Medicine (CAM) +

## Clinical Trials Using HSP90alpha/beta Inhibitor TAS-116

Clinical trials are research studies that involve people. The clinical trials on this list are studying HSP90alpha/beta Inhibitor TAS-116. All trials on the list are supported by NCI.

NCI's [basic information about clinical trials](#) explains the types and phases of trials and how they are carried out. Clinical trials look at new ways to prevent, detect, or treat disease. You may want to think about taking part in a clinical trial. Talk to your doctor for help in deciding if one is right for you.

Trial 1 of 1

### A Study of TAS-116 in Patients With Solid Tumors

A First-in-Human (FIH) study of TAS-116 in patients with advanced solid tumors was first initiated in Japan in April 2014 and has been ongoing since then. The study consists of a dose escalation phase and a dose expansion phase. Three dosing regimens of TAS-116, once daily (QD), every other day (QOD) and 5 days on / 2 days off regimens in 21-day cycles, are being evaluated. This phase I study is also planned to enroll patients with advanced solid tumors in UK to confirm the MTD, safety, tolerability, and pharmacokinetics of TAS-116 in a Western patient population in the dose expansion phase. In addition, patients with HER2+ MBC, NSCLC harboring EGFR mutations or NSCLC harbouring ALK translocations will be further evaluated for safety, tolerability, and efficacy in 3 separate cohorts at recommended dose of TAS-116 on the 5 days on / 2 days off regimen.

**Location:** 5 locations

## TAS-116 HSP90 inhibitor

In Japan, the Phase III trial on GIST is started from October.

We are aiming for approval in 2020.

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## DCC-2618



deciphera

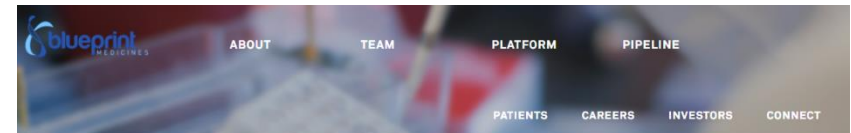
About Science Pipeline Patients Investors Careers Contact

Pipeline

### Development Status

Tumor Type	Target	Status	Retained Rights
GIST – 4th Line	KIT and PDGFR $\alpha$	<a href="#">Phase 3 Pivotal Trial – Ongoing</a>	Worldwide
GIST – 2nd Line	KIT and PDGFR $\alpha$	<a href="#">Phase 3 Pivotal Trial – Planned</a>	Worldwide
GIST, ASM, gliomas	KIT and PDGFR $\alpha$	<a href="#">Phase 1 Expansion – Ongoing</a>	Worldwide
Solid Tumors	KIT and PDGFR $\alpha$	<a href="#">Phase 1 Expansion – Ongoing</a>	Worldwide

## AVAPRITINIB



blueprint MEDICINES

ABOUT TEAM PLATFORM PIPELINE

PATIENTS CAREERS INVESTORS CONNECT

### BLUEPRINT MEDICINES PIPELINE

	RESEARCH	CLINICAL DEVELOPMENT	COMMERCIAL RIGHTS
+ AVAPRITINIB FOR UNRESECTABLE, TREATMENT-RESISTANT GASTROINTESTINAL STROMAL TUMORS (GIST)		PHASE 3	BLUEPRINT MEDICINES
+ AVAPRITINIB FOR ADVANCED SYSTEMIC MASTOCYTOSIS (SM)		PHASE 1	BLUEPRINT MEDICINES
+ BLU-554 FOR ADVANCED HEPATOCELLULAR CARCINOMA (HCC)		PHASE 1	BLUEPRINT MEDICINES
+ BLU-667 FOR RET MUTATIONS, FUSIONS, AND PREDICTED RESISTANT MUTANTS		PHASE 1	BLUEPRINT MEDICINES
+ BLU-782 FOR ALK2 MUTATIONS IN FIBRODYPLASIA OSSIFICANS PROGRESSIVA (FOP)		PRECLINICAL	BLUEPRINT MEDICINES
+ 3 UNDISCLOSED KINASE TARGETS		DISCOVERY	BLUEPRINT MEDICINES
+ IMMUNOKINASE TARGETS (IN COLLABORATION WITH ROCHE)		DISCOVERY	BLUEPRINT MEDICINES ROCHE

Regarding these two drugs, there are no plans for clinical trials in Japan. We somehow want to attract these two clinical trials in Japan.

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Chairman **Sumito Nishidate**  
Secondary chairman **Kimie Sakurai**  
Tokyo area member **Yoshihiro Takanashi** Guitar man

And friends



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thank you for your attention