

NEW HORIZONS GIST

SEPTEMBER 5 – 7, 2018 – VIENNA, AUSTRIA



**The NEW HORIZONS GIST Patient Advocacy Roundtable:
Improving access to treatment and quality of care
through global exchange**



Conference Report

NEW HORIZONS GIST Steering Committee

David JOSEPHY (The Life Raft Group, CA)	djosephy@uoguelph.ca
Vicky OSSIO (Alianza GIST, Bolivia)	vossiop@gmail.com
Ginger SAWYER (GIST Support International, US)	grsawyer@icloud.com
Norman SCHERZER (The Life Raft Group, US)	nscherzer@liferaftgroup.org
Piga Fernandez (The Life Raft Group, Fundación GIST Chile)	pfernandez@liferaftgroup.org
Markus WARTENBERG (Das Lebenshaus, DE / SPAEN, EU)	markus.wartenberg@daswissenshaus.de
Martin WETTSTEIN (GIST Gruppe Schweiz, CH)	m.wettstein@wp-ing.ch

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Michi GEISSLER (Sarcoma Patients EuroNet, SPAEN, EU)	michaela.geissler@sarcoma-patients.eu
Kathrin SCHUSTER (Sarcoma Patients EuroNet, SPAEN, EU)	kathrin.schuster@sarcoma-patients.eu
Tanja ULLERSBERGER (Das Lebenshaus, DE / SPAEN, EU)	tanja.ullersberger@gmx.de

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NEW HORIZONS GIST 2018

Participants in total	43
GIST Patient Advocates	31
Invited GIST Experts and Speakers	9
Guests from the Healthcare Industry	3
GIST-Patient Advocates	31
Countries	18
Organisations	19
(+ Alianza GIST + Sarcoma Patients EuroNet)	

1. Acknowledgement

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The idea, conception, planning, preparation, realization, management and the summary of the NEW HORIZONS GIST 2018 Conference are the responsibilities of the Steering Committee and Sarcoma Patients EuroNet (SPAEN) without any influence from the sponsors/funders.

We are looking forward to continuing these open and transparent partnerships with the healthcare industry towards achieving our goal of collaboration among independent GIST patient organizations on an international level.

We also would like to thank our friends/colleagues from the medical GIST-Expert Community. Thank you very much for agreeing to speak at NEW HORIZONS GIST 2018 in Austria. We very much appreciate that you are taking time out of your very busy schedules to come to NEW HORIZONS. We are very grateful for the valuable, trustful and long-term partnership between leading medical GIST experts worldwide and the Global GIST patient advocacy community.

2. Introduction

For several years now NEW HORIZONS GIST is the most important global annual conference for GIST patient advocates. The 2018 New Horizons GIST conference was held at the Trend Hotel Astoria in Vienna, Austria from September 5-7, 2018. It was again very well attended with over 40 participants: 31 GIST patient advocates of 19 different organizations from 18 countries, 9 medical experts and 3 representatives from the pharmaceutical industry. Once again, this conference was a great event for patients from the global GIST patient community to come together, to interact with top GIST experts, to have access to state-of-the-art medical and scientific information and to exchange best practice in patient advocacy among each other. The 2018 conference was a balanced symbiosis of medical content, advocacy topics and capacity building sessions.

The 2018 conference was chaired and planned by a steering committee and Sarcoma Patients EuroNet e.V./Assoc.

- Piga Fernandez, Alianza GIST (Chile)
- David Josephy, Life Raft Group (Canada)
- Vicky Ossio, Alianza GIST (Bolivia)
- Ginger Sawyer, GIST Support International (USA)
- Norman Scherzer, The Life Raft Group (USA)
- Markus Wartenberg, Das Lebenshaus (Germany)
- Martin Wettstein, Swiss GIST Group (Switzerland)



Amy Bruno-Lindner, GIST Support Austria and David Josephy, Life Raft Group Canada officially opened the 2018 NEW HORIZONS conference in Vienna with a very warm welcome thanking all participants – patient advocates, medical experts, industry representatives – who travelled long ways to join this important meeting in September 2018.



GIST 1: Challenges and open questions in GIST treatment from the patient perspective

- **Localized disease and adjuvant therapy:**
Norman Scherzer, US
- **Metastatic disease:**
David Josephy, CAN
- **Progressive disease:**
Markus Wartenberg, DE
- **Wild Type-/ Pediatric GIST:**
Jayne Bressington, UK

Written by Kathrin Schuster

What are the most pressing challenges and open questions in GIST from a patients' perspective? This was answered by Norman Scherzer, David Josephy, Markus Wartenberg and Jayne Bressington during the opening session of the NEW HORIZONS GIST conference 2018.

The current and most important challenges in GIST (David Josephy):

- Insufficient research capacity
- Doctors and oncologists who still have not heard of GIST
- Misdiagnosis; faulty pathology; lack of mutational testing
- Patients unable to access diagnosis, treatment
- Many countries that still have no support group
- Uncertain funding for patient support groups (and for New Horizons GIST)

Most of all, GIST patients face the challenge of survival!

Norman Scherzer defined the following questions as the most important in localized and adjuvant treatment in GIST:

- How long should patients be on adjuvant treatment?
- What dosage should patients be on? Does it matter based on mutational type?
- Does risk status matter with adjuvant treatment?
- Side Effects: Differ when first starting treatment vs. later – how can they be managed?
- What are the global access issues for adjuvant? Costs?
- Brand vs. generic imatinib for adjuvant treatment



What questions need to be answered in metastatic disease? (David Josephy)

- Can we (finally) push the need for mutational testing of all new GISTs?
- Will one of the new drugs - if and when approved - be better than imatinib in first-line treatment?
- When imatinib resistance develops, would it be better to continue imatinib and add a new drug, instead of stopping imatinib and switching to another drug?
- The long-term side effects of TKIs, including imatinib:
 - What can we learn from other diseases (esp. CML) that are treated with TKIs?
 - Can a useful animal model of side effects be developed?
- Is a more aggressive approach to residual stable lesions appropriate, given that so few options are available for effective control of progressive GIST?



In case of a confirmed progression, it is important to define the type of progression and the appropriate next steps. However, the following questions need to be addressed (Markus Wartenberg):

- Who are the patients benefitting from Imatinib as long-term patients? What are the main factors for long-term responses?
- When are we able to measure an upcoming progression (much earlier) by blood test as a standard procedure?
- How can we prevent or delay resistance?
- Does it make sense to change a therapy before resistance arises?
- How can we improve education for doctors and patients to use the three approved therapies as effectively as possible?
- What is the next generation of effective GIST-therapies?



Wild-type / Paediatric GIST are extremely rare. Jayne Bressington names the most important challenges in this GIST subtype:

- Ultra-rare cancer - not well known
- Small patient numbers – no big pharma attention
- Lack of infrastructure to support research
- Lack of funding to support research
- Lack of dedicated researchers
- Lack of awareness amongst medical community AND general public
- Doctors focusing on this disease do it as one small element of their work rather than full time. Everything takes longer than it would do if it had a dedicated team
- Not all GIST patients have mutational testing
- Mutational testing rarely tests beyond KIT/PDGFR α e.g. SDH deficiency testing



GIST 2: The role of pathology in the diagnosis of GIST: Morphology- Diagnostic pitfalls – Mutational analysis

Dr. Bernadette Liegl-Atzwanger, pathologist, Graz AT

Written by David Josephy

Dr. Liegl-Atzwanger is a Pathologist at the Medical University of Graz, Austria. She did her medical training in Graz. In 2006, she received a scholarship to train in GIST at Harvard Medical School, with Chris Fletcher and Jon Fletcher. Her research fellowship was on resistance mechanisms in GIST. She did lab research with Jon Fletcher and also went regularly to the clinical “sign-out” with Chris Fletcher. She also interacted with Katie Janeway on pediatric GIST. When she went back to Austria, she found that no mutational analysis was being done. It was hard work to get this started but now the facilities are in place.

Dr. Liegl-Atzwanger’s presentation was detailed and meticulous. Some highlights and excerpts are given below.

“It’s not so easy to diagnose a GIST. OK, perhaps it’s easy at Harvard, where they see them almost every day; but it’s not so easy if you only see a GIST once a year. These rare tumours have to be sent to experts.”

The pathology work starts with morphology - both gross and microscopic. Expertise is required to do the biopsy sample cutting, slicing, and slide preparation. It is best to prepare additional slides for research studies, but this is a matter of cost.

Immunohistochemistry (IHC) staining is key, to rule out differential diagnoses. The pathologist needs to be familiar with the properties of the antibodies she is using - some are reliable; others, less so. KIT and DOG1 antibodies are reliable, but results with the PDGFRA antibody are not as good. KIT and DOG1 antibodies stain the GIST cells, but false negative or false positive results are possible, so the pathologist needs to do additional IHC stains for differential diagnosis - to rule out all other possible tumours.

Dr. Liegl-Atzwanger discussed the subtle details of differential diagnosis of GIST. A spindle-cell GIST needs to be distinguished from possible leiomyoma, leiomyosarcoma, or desmoid tumours.

KIT-positive mast cells may be seen in non-GIST tumours. The pathologist must follow an algorithm for accurate differential diagnosis.

Wild-type GISTs (mainly pediatric and young adult cases) show a distinctive epithelioid morphology. An SDH stain will be negative in SDH-deficient GISTs.

She described, as an example of the difficulties of diagnosis, a case of a metastasis from a malignant melanoma which was, at first, misdiagnosed as a GIST: many of these metastases are KIT-positive.

Some GISTs have an unusual “pleiomorphic” morphology. GISTs with mutations in RB1 and P53 have unusual morphology and poor prognosis.

KIT-negative GIST comprises about 5% of cases.

She discussed risk classification, an important task of the pathologist. It is essential to define the size of the field for counting mitoses: this should be 5 mm², which is not necessarily the same as 25 high-powered fields - it depends on the microscope used (small-field vs wide-field).

She noted that GIST mutational analysis is not reimbursed in Austria, so she uses her research funding to cover the cost.

She discussed the problem of mutational heterogeneity even in a single metastasis and between metastases of a single patient. She noted that metastases sometimes lose KIT expression.

Dr. Liegl-Atzwanger summarized the characteristics of SDHB-deficient GIST:

- epithelioid morphology
- positive KIT and DOG1 expression by IHC
- the dogma is that these tumours do not have KIT or PDGFRA mutations, but that may be incorrect; she has seen a case with both an SDHA mutation and a KIT mutation
- for SDHB-deficient GIST, risk stratification according to the Miettinen criteria does not work
- lymph node metastases are common
- the disease is usually clinically indolent even when metastatic
- these GISTs usually do not respond to imatinib

A question was posed to the speaker: “How do we know that these SDHB-deficient GISTs are not actually a totally different disease?” Answer: “That’s a good point. This is a matter of discussion. You could call them a different tumour type, but with KIT and DOG1 expression.”

Dr. Liegl-Atzwanger discussed the present situation for mutational analysis at her hospital. “We decided at Graz not to do sequential testing – i.e., first test for KIT exon 11, exon 9, and then, if those are negative, go further. Instead, we decided to set up a next-generation sequencing (NGS) panel for GIST, including all of the known KIT mutations, PDGFRA mutations, BRAF, RAS, NF1, SDH expression, and even further mutations such as P53, RB1, etc.”



The NGS panel was presented:

gene	chr	transcript	covered regions
KIT	4	NM_000222	exons 8,9,11,12,13,17,18
PDGFRA	4	NM_006206	hotspots
PDGFRB	5	NM_002609	exons 13,14,17,18
K-RAS	12	NM_004985	hotspots
N-RAS	1	NM_002524	hotspots
H-Ras	11	NM_005343	hotspots
BRAF	7	NM_004333	hotspots
SDHA	5	NM_004168	full coding sequence
SDHB	1	NM_003000	full coding sequence
SDHC	1	NM_003001	full coding sequence
SDHD	11	NM_003002	full coding sequence
NF1	17	NM_001042492	full coding sequence
P16	9	NM_000077	full coding sequence
TP53	17	NM_000546	full coding sequence
RB1	13	NM_000321	full coding sequence

Ion Torrent Ampliseq technology is used, with 248 amplicons

Dr. Liegl-Atzwanger explained that “Sometimes people think, we do NGS, and then everything is straightforward”, but this technique too has its limitations. As an example, she noted limitations of NGS for detecting large insertions/deletions. So, in all KIT-negative GISTs, we additionally test KIT exon 11 by Sanger sequencing. One KIT exon 11 duplication (15 amino acids, 45 nucleotides) was not detected by NGS but was evident by Sanger sequencing.

The NGS panel costs us, in Graz, about Euro 1,700, and this is “because we do not make any money; we are an academic department. If you have a private practice, and need to make money, it might cost Euro 5,000 ... as opposed to a few hundred only, for Sanger sequencing. It’s a big difference.”

A question from the audience: “How often do you misdiagnose GIST?” Answer: I hope, never! But in the literature, you see that 1-3% are missed. With good antibodies/IHC, everybody should be able to get the right answer. And if you are not sure, you really should send the samples to an expert pathologist. I see about 500 STS per year, but I send at least ten cases every year to Chris Fletcher for consultation. (We have no trouble sending paraffin blocks to the USA by FedEx).

GIST 3: Rare and very rare subtypes in GIST: Where are we currently with “Non KIT-/PDGFRA- / Wild Type-/Paediatric-GIST”?

Dr. Venkata Ramesh Bulusu, oncologist, Cambridge UK

Written by Jayne Bressington

Dr Bulusu presented an update on the rare and very rare subtypes in GIST commonly known as “Non-KIT/PDGFRA Wild Type Paediatric-GIST” and began his talk with some background about his direct involvement with this group of patients.

He was very keen to emphasise that this is a very heterogeneous group made up of very different types of cancer ranging SDH deficient and NF1 related GIST or cancers where the oncogenic driver is not yet known. He impressed upon the audience the urgent need to find an oncogenic driver and a druggable target for these types of GIST which collectively represent c. 15% of the total GIST population.

Background

Dr Bulusu first attended the NIH Paediatric and Wild-type GIST clinic at the NIH in Bethesda, USA further to meeting Jayne Bressington, mother of a newly diagnosed SDH deficient GIST patient in the UK who had attended the clinic in 2010. Inspired, it was agreed that a clinic was needed in the UK.

The PAWS-GIST Clinic is a consortium of clinicians including oncologists, pathologists, surgeons, tissue banking specialists, specialist radiologists, SDH researchers, endocrinology specialists and GIST patient advocates working very closely together. A key element is the Clinic website: The www.pawsgistclinic.org website contains lots of information and is unique in that it offers patients the opportunity to register their interest in attending the clinic directly with the clinic and not just via their local clinician.



The PAWS-GIST clinics started in 2014 once a pre-agreed target of £40,000 had been reached. To-date, there have been 13 PAWS-GIST Clinics, each reviewing around 6-8 patients and with a male female ratio of 1:2. The median age of attendees is 38 years and patients ages at diagnosis have ranged from 9-74 years. There have also been some attendees for whom further more detailed investigations have found mutations in KIT EXON's 8 & 11 and at the last clinic in PDGFRA EXON 14, results which standard mutational testing has not found.



A very important aspect of the PAWS-GIST clinic is the welcome meal held the evening before the clinic. This is a rare opportunity for patients and their families to meet others in an informal setting. It is an icebreaker and a gentle lead in to the clinic which happens on the following day. Feedback from patients is very positive about this opportunity to meet fellow patients.



When compared to the reports from the NIH clinic in the USA, the cross section of patients attending the PAWS-GIST clinics is much the same and from the outset the focus for the PAWS-GIST clinic has always been the best available treatment plan for patients, research and collaboration.

This focus has stimulated work over the past eight years to create a supportive infrastructure in the UK such as The National GIST tissue Bank and The National GIST Registry. Widespread networking has also enabled connections with researchers to gain a better understanding of the biology and targets.

Throughout the past eight years there has been active engagement with pharma companies, researchers and specialists regionally, nationally and internationally.

So, where are we currently with NON-KIT NON-PDGFRA WILD type GISTs?

Dr Bulusu confirmed that the standard first-, second- and third-line GIST treatments; Imatinib, Sunitinib and Regorafenib are still the standard recognised treatment pathway for Non-KIT Non-PDGFRA WILD-type GIST patients whose GIST is unresectable, although it is commonly agreed that Imatinib does not have any impact. (N.B. there are anecdotal examples of the odd response but it is unclear whether this is in actual fact the natural history of disease).

He explained that Sunitinib and Regorafenib inhibit VEGF and can help to stabilise disease and in some cases show minor responses. He also stressed the importance of being mindful of the toxicities related to these multikinase inhibitors. In real terms there is not much experience of using these second- and third-line drugs for long periods of time and wild-type GIST patients tend to be on them for much longer than mutated GIST patients. He flagged the need for close management with longer term use of these drugs.

Where do we go from here? Clinical trials and Research

Finding clinical trials for Non-PDGFRA WILD type GIST patients is not an everyday occurrence but there have been some early phase studies using drugs such as Linsitinib, an oral IGF1R inhibitor which was tested on 20 patients and where minor and FDG PET metabolic responses were seen in 35% of patients and at 9 months 45% had some clinical benefit. Another trial of a drug called Vandetanib, an oral multi kinase inhibitor inhibiting VEGFR2, EGFR, RET dependent signals had tolerability issues and did not result in objective responses so has now been discounted for WILD type GIST.

Dr Bulusu also flagged a selection of "All comers" studies i.e. all types of GISTs included, which are currently ongoing and which could include Non-PDGFRA WILD type GIST patients and which he is watching with interest:

- DCC-2618 vs placebo: Phase III randomised study in Metastatic GISTs
 - ClinicalTrials.gov Identifier: NCT03353753 • Multi centre, multinational • DCC 2618 is switch pocket kinase inhibitor • 3 prior lines of Rx • 2:1 randomisation • Cross over at progression on placebo • Ongoing
- Famitinib in GISTs: Chinese Ph II study • ClinicalTrials.gov Identifier: NCT02336724 • Imatinib resistant/intolerant GIST pts • All types of GISTs • Famitinib is a c-Kit, VEGFR2, PDGFR, VEGFR3, Flt1 and Flt3 multi kinase inhibitor • 25 mg once daily • NO results yet
- Immunotherapy in GISTs • ClinicalTrials.gov Identifier: NCT02880020 • UCLA Jonsson Comprehensive cancer centre • Nivolumab with or without Ipilimumab • WILD type GIST pts are not excluded • Post imatinib 2nd line • PD-L1 and other immuno biomarkers • Ongoing
- Immunotherapy in GISTs • ClinicalTrials.gov Identifier: NCT03291054 • Columbia university USA • PD-1 Inhibitor Pembrolizumab with IDO inhibitor Epacadostat • Unresectable or metastatic GIST • NO mention of mutational status • Up to 4 prior treatments allowed • Ongoing

What he is specifically interested in is trials for specific GIST subtypes and the exciting and recent development for example of the SDH Deficient GIST Consortium which was convened at LifeFest Miami July 2018 and which is now pulling together the specialists from the UK, USA and elsewhere in the world to focus on finding treatments and a cure for SDH deficient GIST.



SDH Deficient GISTs predominantly affect female patients and present as gastric, epithelioid multifocal tumours. A high percentage of these patients present with metastatic disease at diagnosis and there are several sub categories of SDH deficient GIST.

- Germline SDH subunit mutation
- SDHC promoter hypermethylation
- Hypermethylation of DNA

He described how SDH is a tumour suppressor and a key part of the Krebs cycle and that if deficient in a pseudohypoxic environment that tumours can then grow.

He then went on to describe two trials that are specifically concentrating on SDH deficient GISTs and a selection of other trials that are relevant to Non-PDGFR WILD type GIST patients.

Phase II Study of Guadecitabine in SDH deficient GISTs, Pheo, Paragangliomas

- ClinicalTrials.gov Identifier: NCT03165721
- John Glod NIH Bethesda
- Guadecitabine (SGI-110) – DNA methyl transferase inhibitor (demethylation)
- This drug is administered subcutaneously twice daily by injection 45 mg/m for 5 days per 28 days
- It is a Pro drug activated in the liver and there is a strong rationale for its use in SDH deficient GIST patients
- This trial opened in 2017 but has only recruited 3 patients so far from the whole of America and desperately needs more patients to apply. It is only open at the NIH in America and red tape is currently preventing it being opened outside of the NIH. Dr Bulusu has been trying to find a way to extend the trial so that it can open in parallel in the UK.

Temozolomide in SDH Def GISTs

- ClinicalTrials.gov Identifier: NCT03556384
- Jason Sicklick UCLA San Diego
- Temozolomide is a DNA Alkylating agent (Chemo) used to treat Brain tumours (GBM)
- It is administered orally 85mg/m² for 21/28 days for up to 6 months
- This trial has just opened

Glutaminase Inhibitor CB 839

- ClinicalTrials.gov Identifier: NCT02071862
- Cancer cells are dependent upon glutamine • The enzyme glutaminase, which converts glutamine to glutamate, has been identified as a critical choke point in the utilization of glutamine by cancer cells.
- CB-839 is a potent, selective, reversible and orally bioavailable inhibitor of human glutaminase
- Glutaminase is an oral compound and this trial is open at multiple centres in the USA. There are some concerns regarding toxicities

Tropomyosin Related Kinase (TRK) Fusion GISTs

There are rare occasions (c. 1%) where GISTs have an NTRK fusion. Translocation of Neurotrophic Tropomyosin Related Kinase NTRK1, 2 & 3 genes lead to a fusion protein with TRK and a partner (remember CML). Twenty different tumours have so far have been shown to have TRK fusion protein and later in the conference a Dutch oncologist mentioned that she had had one WILD type GIST patient with such a fusion. It was recommended that those GISTs that are often referred to

as quadruple negative i.e. WILD-type for KIT, BRAF, SDH & BRAF should be tested for NTRK fusion as there are some effective treatments for NTRK fusion GIST.

Larotrectinib is a drug which is being trialled in patients with NTRK gene fusion.

ID	Name	Location	Status	Date
NCT02576431	Larotrectinib (LOXO 101)	Phase II	Open	2017
NCT03165721	Guadecitabine (SGI-110)	Phase II	Open	2017
NCT03556384	Temozolomide	Phase II	Open	2017
NCT02071862	CB-839	Phase II	Open	2017
NCT03109301	Selumetinib	Phase II	Open	2017

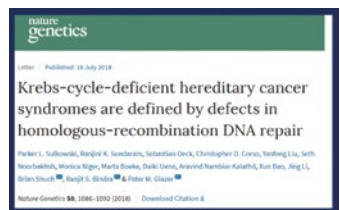
Dr Bulusu then posed the question - Any other bright ideas??

He went on to explain his interest in accessing BET and PARP inhibitors for SDH deficient GIST patients further to research papers that indicate a good rationale for using them.

BET Inhibitors



PARP Inhibitors



He flagged that there is a trial open for NF1 GIST patients assessing the MEK 1 & 2 inhibitor Selumetinib but that despite having opened in 2017 as yet no patients have been recruited.

- ClinicalTrials.gov Identifier: NCT03109301
- NIH NCI Dr Brigitte Widemann
- Selumetinib 50 mg continuous dosing

To conclude Dr Bulusu mentioned a couple of other studies that have potential for Non-KIT/PDGFR WILD type Paediatric-GIST patients one of which is being undertaken by Dr Ruth Casey who is attached to the PAWS-GIST clinic in the UK and another related to PARP inhibition.

For patients diagnosed with a subtype of GIST he recommends that they should always:

- Seek a specialist multi-disciplinary opinion – regional, national or even international
- Make sure it really is a rare subtype of GIST – insist on mutational testing
- Engage with your national patient advocacy group
- Explore what can be done and what needs to be done – with your specialist and your advocates
- Enrol onto clinical trials if they are available.

He highlighted the challenges affecting ongoing early phase studies in rarer subtypes of GISTs. One of the main challenges being that recruitment timelines are too slow!

He believes in an ideal world that personalised medicine, where drugs are tailored to the patient, is the answer but concedes that this is difficult to achieve in rare cancers. So, he urged Patient advocacy groups + Oncologists + Researchers + Pharma to drive this together.



GIST 4: New GIST treatment options ahead? Short profiles of three potential new agents/treatments: Avapritinib (BLU 285) – Crenolanib – DCC-2618

Prof. Dr. Patrick Schöffski, oncologist, Leuven BEL

Written by Ginger Sawyer

Prof. Patrick Schöffski, head of the Department of General Medical Oncology at the University Hospitals, Leuven, Belgium, detailed for New Horizons attendees specific new options for GIST patients.

Prof. Schöffski explained that 1/3 of GIST patients on adjuvant therapies will relapse on Imatinib within five years, and the progression-free survival (PFS) time for Imatinib is 20.4 months. On Sunitinib, the time of PFS is reduced to 5.7 months; and on Regorafenib, it is 4.8 months. He did note that the data is somewhat dated and he believes that more can be achieved.

While there has been nothing new in the past five years, many patients continue to be in desperate need of a drug. Research waned and we were victims of our own success when 70-80% of our patients benefitted from currently available drugs.

It was becoming impossible to show a new trial as effective as current drugs that are also easy to tolerate. Patients were lost for clinical trials, as it became more and more difficult to recruit first-line patients any more. It was only after a patient had failed drugs 1, 2 and 3 that they became available. Meantime, the pharmaceutical companies' interest in developing trials was decreasing, particularly when it was more expensive to run a trial than what would be a reasonable return on investment.

GIST patients need secondary resistance drugs, as do so-called wild-type patients. There is a small population of PDGFRA D842V mutant patients (one of five gastric GISTs) for which nothing has been working. Of them, 23% are high risk, and 30% relapse within five years of surgery. Many of these patients are still fit and are demanding a new drug because they can't take the old ones.

Hope for many of these patients lies in three drugs that are currently in trials:

Avapritinib (BLU 285) – Its agents target various exon 11 and 17 mutations. It is a clean compound that hits specific targets with fewer adverse events and less toxicity. It is currently in two relevant clinical trials.

The first is called "Navigator" and it is a phase II trial. Reports are that 2/3 of the patients benefit and 17% have partial responses. It extends PFS to a point that it's "too good to be true, but it's true" that all are responding and deriving benefits. There are some issues with cognitive effects (mood changes and personality changes); however those negative effects stop with dose reduction. Most of the other effects are similar as the TKIs. Only 20 slots are left, and they are reserved for patients who had only Imatinib before (not second or third line drugs).

The second is called "Voyager," and it is designed to test Avapritinib against Regorafenib. It is a huge, multi-site trial in both the United States and Europe. Patients may have taken Imatinib and Sunitinib, but they may not have taken Regorafenib.

Deciphera has DCC-2618 in trial, and it may be that its name will be Repritinib. It is a kinase switch inhibitor for exons 9 and 11, with secondary mutations 13, 14 and 17.

In the Phase I trial, no slots for GIST are left. The results are promising, as a majority of the patients have measurable shrinkage and control of the tumor is maintained.

The "Invictus" trial is a phase III trial that accepts patients who have previously taken 3 or more agents. One-third of the patients receive placebo, but there is crossover at progression. The trial has been recently modified to include patients who have only taken three agents (not four or more). Virtually all patients will need a new biopsy.

Another trial is also planned, similar to the Blueprint trial that will compare DCC-2618 to Sunitinib, but the dates and locations have yet to be determined.

AROG has also completed a Phase I trial on this TKI that may benefit 842V mutations. It is called Crenolanib. The main side effect is nausea and liver issues. Since the drug is to be taken 3 times a day, vomiting dosages becomes an issue. Patients may have had any of the other previous therapies; however, they should not have had any significant liver issues.

Prof. Schöffski concluded by saying that these three drugs could be very promising for many patients. In addition that are 22 or more other trials that have yet to report any findings.



Real World Evidence (R.W.E.) in Rare Cancers such as GIST: The Problem - The Solution - History - Future

Norman Scherzer, LRG, USA & Denisse Montoya, LRG, USA

Written by Norman Scherzer and Denisse Montoya

RWE utilizes observational data to determine the perceived benefit of treatments to increase survival and improve quality of life for cancer patients. The rich diversity of data collected from patients will yield more precise, better targeted, and therefore, more effective health care. RWD and the resultant RWE is being utilized to enhance and complement traditional research by providing a broader picture of the patient's GIST journey. The power of data was truly shown during this meeting, but the real question was "How can we transform that data into something more powerful?" The answer is simple – collaboration. The importance of collaboration in the GIST community is crucial due to the rarity of this cancer. Unifying and collaborating with the scientific community, advocacy groups, and patients/caregivers will lead to a faster cure.

More subtypes of GIST are being discovered (such as SDH-Deficient GIST). Currently there is a lack of effective treatment for such subtypes. It is important to collaborate in order to strengthen and advance research for effective treatments for patients from subtypes that have been unresponsive to the current standard treatments. The Life Raft Group and a roster of leading GIST experts have created the Pediatric & SDH-Deficient GIST Consortium. The objective of the Consortium is to identify at least one effective treatment within three years through initiation of new clinical trials for the Pediatric and SDH-Deficient GIST population.

Adjuvant treatment and metastatic disease were among other topics discussed, as well as new treatments for GIST. For years only three lines of drug treatments were known to be effective. However, with the advance of scientific investigations and clinical trials, more options are available for patients that failed the three standard treatment lines. Leading GIST experts who attended this conference were able to show many case studies of adults with advanced GIST who took a clinical trial drug that showed very promising outcomes. Such findings fill health-care practitioners, patients, and caregivers with hope and optimism for the future of GIST treatments.

What's new in the international GIST patient community?

Interesting projects, developments, updates

- **Updates on the LRG registry;**
Denisse Montoya, LRG, US
- **Salud con Datos;**
Rodrigo Salas, Alianza GIST, MEX
- **Fighting GIST and sarcomas together in one new organization German Sarcoma Foundation;**
Markus Wartenberg, Das Lebenshaus, DE
- **Status of data projects in the Netherlands Patient Platform Sarcoma;**
Gerard v. Oortmerssen,
Patientenplatform Sarcomen, NL
- **Challenges in India;**
Viji Venkatesh, The Max Foundation &
Nikhil Guhagarkar, Friends of Max, India
- **GISTERS in Japan;**
Yoshihiro Takanashi , GISTERS, Japan

Written by Piga Fernandez



Updates on the LRG registry

Denisse Montoya, The Life Raft Group, USA

- Updates on the LRG registry – Denisse Montoya – The Life Raft Group
- Actually with: 1800 patients, 778 tissues and the participation of 68 countries
- An observational study that contains 450 data fields
- Provides Real World Data
- Bridges the gap between the clinical reality and the patient world
- Benefits:
 - Describes the natural history of disease
 - Studies clinical and treatments' effectiveness
 - Evaluates specific patient outcomes
 - Increases international collaborations
 - Accelerates research development
 - Improves patient-physician communication



Salud Con Datos

Rodrigo Salas, Alianza GIST, Fundación GIST México

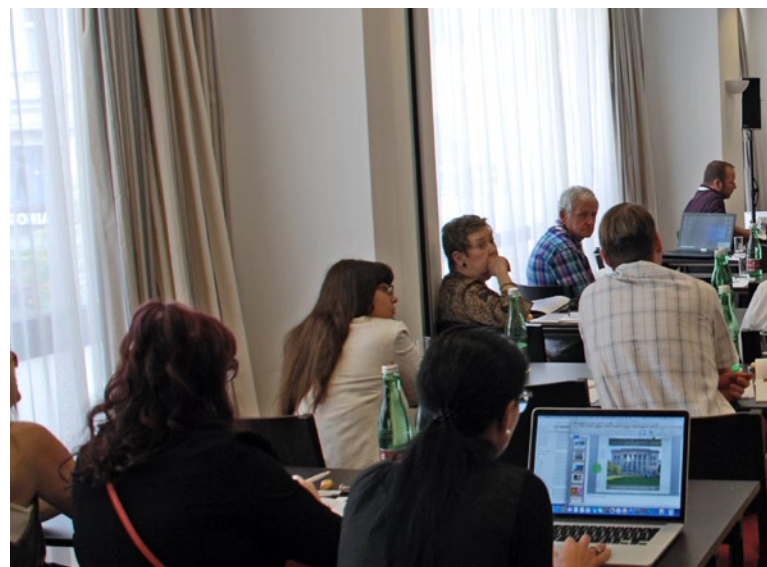
- Collaborative project between Argentina, Chile, México and The Life Raft Group
- Goals:
 - Identify GIST patients in Latin America
 - Obtain a centralized GIST Registry in Latin America
 - Gather access, demographic and socio-economic data for cancer patients in Latin America
 - Close information gap by understanding needs of GIST patients in LatAm countries and translating data to health authorities, medical professionals, and patients via surveys, publications and presentations
- Objectives:
 - Empowering participants to utilize data-driven evidence to help them make the case for health policies that will improve health outcomes
 - Establishing the credibility of evidence through peer-reviewed publications and poster presentations
 - Identifying and advocating for greater use of tools (such as patient reported outcomes) which capture the patient perspective in research
 - Developing a policy toolkit for members to encourage health authorities to put in place a regulatory policy environment that encourages clinical research and innovation in Latin America
- Anticipated Outcomes:
 - An increase in the number of patients entered into patient registries in Latin American countries
 - Collaboration with academia to publish articles on patient-reported outcomes
 - Presentation of posters and publications at international conferences
 - Create a network to conduct clinical trials in Latin America



Fighting GIST and Sarcomas together in one new organization

Markus Wartenberg, Das Lebenshaus / German Sarcoma Foundation, Germany

- FUTURE MODEL:
 - Kidney Cancer – will remain in “Das Lebenshaus Kidney Cancer” For Kidney Cancer Patients. No changes in the association. Future strategy: More voluntary work / teamwork - less pharma funding
 - GIST / Sarcomas are moving from Das Lebenshaus to: “German Sarcoma Foundation” for GIST and sarcoma patients. Using synergies, will work in a common future with the German Sarcoma-/GIST-experts in a new, joint and “non-profit” organization.
- MISSION
 - Innovative research, high-quality diagnosis and treatment by multidisciplinary sarcoma expert teams and patient-oriented support are crucial factors for better prognosis of sarcoma patients. Patients and experts are fighting together against sarcomas in six fields of action:
 - Research and Study
 - Support/Supply Structures
 - Diagnostic & Treatment
 - Knowledge Transfer
 - Patient-Support Experience
 - GIST
 - Soft Tissue Sarcomas (STS)
 - Bone Sarcomas / Bone Cancer
 - Desmoids
 - Sarcoma Awareness





Status of the Data Project in The Netherlands

Gerard v. Oortmerssen, Patientenplatform Sarcomen, The Netherlands

- Update on new developments of the Dutch Text Mining Project
- Background information: In online fora, patients share information, get advice from experienced fellow patients and support each other emotionally. These discussions are a rich source of information about personal medical information as well as experienced quality of life. The collective knowledge contained in these discussion fora can be of much additional value both to patients and medical professionals and researchers. Gerard uses state-of-the-art methods from artificial intelligence, natural language processing and data mining to find the "gold nuggets" hidden in the discussions.
- The project has been ongoing since 2015 with a focus on GIST. Gerard introduced some new interesting developments:
 - extending scope to ALL sarcomas
 - concentration of treatment in expert centers, creation of networks
 - value assessment, dialogue between specialists and patients
 - Patient Forum Miner project
- New project CHyMER (Clinical Hypothesis Minder from Experience Repositories): Analyzing unstructured, informal discussions with structured data
 - Get a hypothesis from a forum discussion, formulate questions and ask on the internet to generate more data to combine with information from informal discussions



Challenges in India

Viji Venkatesh, The Max Foundation and Nikhil Guhagarkar, Friends of Max, India

- Continuous meetings have empowered patients enabling them to take a more active role in their care and therefore improve their quality of life.
 - Specific meetings for GIST patients since 2012 in Kochi Hyderabad, Bangalore, Delhi and Kolkata
 - Meetings that enable patients to interact with physicians
 - Provide informational materials in regional languages, conduct GIST focused sessions
 - Therapy workshops which serve as a platform for patients and caregivers to participate and open up and empathize with one another and build friendships
 - Drama
 - Quiz sessions
 - Art Therapy
 - Testimonial sharing sessions
 - Yoga
 - Compliance workshop
 - Contribute to GIST Awareness Days
- Friends of Max and GIST Awareness Day

Projects:

- Chai for cancer: "Raise a cup for health" - Fundraising project
- Newsletter
- PAN INDIA GIST MEETINGS
- Patient meetings with The Max Foundation – "Max Access Solution"
- Contribute with activities for GIST Awareness Days





GISTERS in Japan

Yoshihiro Takanashi, GISTERS Japan

Patient support organization working since 2002 in access for GIST treatments. Legally constituted in 2013.

Main pillars of action:

- Provide information to the patient and provide a place for learning: "WorkPlace for GISTERS"
- Support for activities by region: 8 areas, 10 groups
- Website management
- Policy recommendations to national and local governments
- Advocacy: Seeking approval for Imatinib, Sunitinib and Regorafenib; as well as for clinical trials in Japan
- Participate and collaborate with GIST Awareness Day and Life Fest



Plenary bursts

(short presentations) and panel discussion: "How to cope with a life-threatening disease such as GIST?"

Dr. Elisabeth Andritsch, Psychotherapist, Graz, AT Panelists: Kai Pilgermann, DE, Nikhil Guhagarkar, IND

Written by Amy Bruno-Lindner

Ms Andritsch introduced Psycho-Oncology as a growing area of oncology focusing on the psychological, social, and emotional impact of cancer on patients and caregivers. The psychosocial dimension refers to the psychological response of patients to cancer at all stages of the disease, as well as that of their families and their caregivers.

Ms Andritsch emphasized that the emotional trauma of having a cancer diagnosis and undergoing treatment can be as potentially harmful for the patient as the disease itself. Cancer is perceived as an existential threat which affects all areas of the life of patients and their families. Patients especially experience fear and anxiety concerning recurrence and progression of disease. However, despite the fact that at least 50% of cancer patients suffer from stress-related symptoms or distress, not all patients have access to psycho-oncological care.

Psycho-social Interventions are intended to prevent or reduce the distress and psychosocial morbidity associated with cancer, to improve patients' skills in coping with the demands of treatment and the uncertainty of the disease, and to improve their quality of life. For patients in the initial phase of the disease, the aim is to facilitate the gradual regaining of control, self-efficacy and perspective. For patients in the palliative care situation, psycho-social support can help maintain hope and meaning, improve quality of life, and promote acceptance.

Ms Andritsch offered practical coping suggestions for patients: When dealing with negative thoughts, it can be helpful to learn to recognize those thoughts, keep track of when they occur, and consider how unrealistic or unhelpful they are. Negative thoughts tend to consist of "I should...." and "I must...." statements, and are often over-generalizations. It may help to 1.) STOP: Use strong emotions as a signal that you are facing a problem; 2.) EXAMINE: Become a detective and examine what triggered your feelings; and 3.) THINK: "What is going through my mind?". Further suggestions include keeping a happiness diary, in which good things that happened that day are recorded. Each patient has a different way of coping, and patients are encouraged to reflect on their own uniqueness and strengths, and to consider how



these can be of use in coping. Ms Andritsch pointed out that patients can remain the captain or the leader of their own life. Two quotes from the well-known Viennese psychiatrist and Holocaust survivor Viktor Frankl provide inspiration:

"When we are no longer able to change a situation, we are challenged to change ourselves..."

"Those who have a 'why' to live, can bear with almost any 'how'."

In closing, Ms Andritsch emphasized the importance of recognizing and meeting the needs of family and other caregivers of people with cancer. She also pointed to the growing awareness that people affected by cancer should be involved in developing cancer services. Psycho-social care must be an essential requirement for quality of care, and patient support groups should work together with national associations of psycho-oncology in creating tools to help newly diagnosed patients cope with the disease. Following the presentation, the issues discussed by the audience included the importance of recognizing the emotional needs of caregivers and addressing these openly. Difficulties posed by mixed patient groups in advocacy settings were also discussed, and it was agreed that it can be a valuable experience for all when patients at different stages of the disease share their experiences with each other.

Nikhil began his brief remarks with a description of the shock he first felt when learning of his GIST diagnosis. He stressed that helpful techniques such as meditation and visualization, along with the strong support of his wife and family, have enabled him to cope with his diagnosis. A healer he consulted suggested that Nikhil forget the odds and try to live a normal life. Nikhil advises patients to take one day at a time and concentrate on their own well-being.

Kai told the audience that his GIST journey began with emergency surgery; he woke to the news that a tumor had been removed. He soon found the Lebenshaus and began attending regional patient group meetings. Kai stressed how helpful it is to talk about one's fears and anxieties with other patients who understand and can support each other. Kai has found that doing sports, especially running, can be a very successful coping strategy.





GIST 5: Following the Research Journey in GIST

- **Current and upcoming clinical trials / new treatments**
Prof. Dr. Sebastian Bauer, oncologist, Essen, DE
- **Current trends/developments in basic GIST-research**
Dr. Neeltje Steeghs, NL

Written by Norman Scherzer and Denisse Montoya

As time goes by, new discoveries are being made regarding GIST and the nature of the disease, as well as the development of GIST in patients. About 1/3 of the population has a micro-GIST that has a KIT mutation but do not develop into clinically relevant GIST. Which implies that it requires more than a KIT mutation for GIST to develop. A study performed in Cleveland Pathology Department crossed mice who had a germline mutation of KIT and a knockout of the CDK28. Results showed that mice that had a KIT mutation, did not develop an aggressive GIST. Only mice that had a homozygous knockout developed GIST. Which indicates having a KIT mutation is not the only inducer for causing GIST development.

Another trend in the GIST world is recurrence and the cause of recurrence among patients. A study was done to observe the reasoning on resistance. During this presentation a research study was shared in which it explained that if you take out every single metastasis lesion that you can get hold of and you study each lesion separately to observe every mutation it will help you identify if the progression was due to regular progression or a mechanical resistance by observing the different mutated genes on each cell. During this study, Retinoblastoma Gene (RB) and P53 were found in many GISTs cases. They were analyzed with the objective to observe if they were inducers of treatment resistance. Results showed that there was no correlation among the presence of RB and P53 genes and treatment resistance within the tested tissue. Binding sites mutations and secondary mutations are some of the known causes for resistance, therefore impacts the treatment response on patients. However, the main question as simple as it may sound is "what is the cause of resistance in GIST?" In theory a tumor that is no longer active would not be a candidate for resistance. However, the reality is that it can still develop resistance. Future development on GIST are focusing in understanding all the factors that lead to resistance among patients, including the appearance of secondary mutations.

From the early time of genomic testing, it is not common to see a secondary mutation being in a cell from the beginning of the disease, this makes us question if secondary mutations are pre-existing clones in a cell or is there some kind of low-level proliferation that allows the cells to create more mutations? The answer is not known; however, it is hypothesized that the secondary mutation is always there, but it is inactive at the beginning of the disease. The actual visibility of the secondary mutations is when the clone cells are big enough to be detected on a CT scan. The challenge that drug developers are facing is that tumors may have more than one mutation. Different techniques are being studied to observe which therapy drugs will be able to tackle certain mutations with the goal to identify the right binding site to prevent recurrence.

20 Years ago, c-KIT mutation in GIST was discovered, nowadays multiple different drugs have been discovered and thus they have increased the life expectancy of GIST patients dramatically. With many options available for different GIST patients, there is an important rule to follow in order to optimize treatment outcomes: "the right patient, the right drug, the right time, the right dose, and the right route".

Treatment with a NTRK inhibitor

As time progresses many more subtypes of GIST are being found. Patient that do not have a mutation on their KIT or PDGFRA gene should also be tested for NTRK gene fusions. Gene fusions are a hybrid (i.e., chimeric) gene formed from two normally separate genes. NTRK Gene Fusions are found in many rare cancers. A pooled analysis from three Larotrectinib clinical trial was performed to analyze the treatment efficacy among different tumor types. From the three different clinical trials, only three patients were diagnosed with GIST and had a NTRK mutation. All three patients showed a positive response. One of the three patients showed resistance after 1.5 years on medication.

Advanced or Metastatic PDGFRA D842V

Advanced or metastatic PDGFRA-D842V mutated GIST progress rapidly and do not respond to imatinib. Clinical trials are studying patients with this type of mutation. Crenolanib or Avapritinib (BLU 285) could potentially increase PFS and OS on patients with PDGFRA-D842V mutated GIST. Crenolanib is an orally bioavailable, highly potent, and specific inhibitor of FLT3, PDGFRA and PDGFRB receptors. During this study, Crenolanib showed 31% clinical benefit in patients with D842V mutated GIST out of 20 patients with GIST. A phase III study of Crenolanib in D842V GIST is currently ongoing in 6 US sites and 12 sites in Europe.



Another clinical trial drug for patients with PDGFRA-D842V is Avapritinib (BLU 285). Avapritinib has a broad activity against a spectrum of clinically relevant mutations and is a potent inhibitor of KIT and PDGFRA. In a Phase I Study of Avapritinib (BLU 285) 71% of PDGFRA-D842V patients presented benefit from the drug. Navigator Phase I trial 2L cohort still enrolling with more than 20 active sites in the US and 60 centers in Europe.

KIT resistance mutations

DCC-2618 has a worthwhile disease control rate of 77 % after 3+ lines (150 pts) in Phase I. A phase III study after 3 lines (vs placebo) is still ongoing and a phase III study in second line (vs sunitinib) are enrolling (soon) with many sites among the world.

For KIT resistance mutations, (BLU 285) in GIST showed that for patients with 3L+ KIT-driven GIST, 67% of patients showed tumor shrinkage.

In the other hand, masitinib: ABScience had to stop recruitment in all GIST masitinib studies in 2017 (first line, second line and adjuvant) by decision of the Health Authorities. EMA inspection showed deviations from the GCP in the conduct of the mastocytosis study and deviations related to the pharmacovigilance system.

Old Drugs

New drugs have increased the life expectancy of GIST patients dramatically. More new drugs are coming; however, we should not forget the merits of the 'old' drugs and keep optimizing their use.

Consider using therapeutic drug monitoring (TDM) to guide individual dosing to increase survival and decrease toxicity. It is important to understand that not all patients require the same amount of dosage. It is estimated that about 30% of patients are under-dosed causing a suboptimal efficacy. While about 15% of patients are overdosed causing unnecessary toxicity. Individualized dosing based on therapeutic drug monitoring is necessary to reach treatment optimization. In patient with low drug levels it decreases their progression free survival (PFS) to 11.3 months when compared to patients that received the right dosage which had a PFS of 30.6 months.

Assessment of Mutations in Tumors and in Circulating Tumor DNA (ctDNA)

Investigations on the use of ctDNA as early biomarker for resistance/ progression are ongoing. Tissues in our body tend to shed genetic material in our bloodstream. Circulating tumor DNA (ctDNA) is found in the bloodstream and refers to DNA that comes from cancerous cells and tumors. Therefore, it allows the analysis and detection of primary mutations in tumor tissue and ctDNA.

This technique is not a reliable solution to find the exact rate of recurrence. Therefore, this is a new technique in GIST that still needs some optimization, but yet will possibly bring many discoveries in different mutations. As an example, diagnosing the type of tumor using ctDNA can reduce the need for getting a sample of the tumor tissue by a tumor biopsy, which can be challenging when a tumor is difficult to access or too risky. Another potential way to use this technique is by being able to observe all the possible mutations that a patient has within one tumor, which can surely help optimize the patient's treatment.





GIST 6:

Let's act together as a GIST Tumor Board: Discussing long-term progressions despite complex disease situation and/or multiple progression

Prof. Dr. Thomas Brodowicz, Vienna AT
PD Dr. Peter Reichardt, Berlin DE

Written by Kathrin Schuster and Markus Wartenberg

What is it really like to be in the doctor's shoes? The audience of the New Horizons GIST meeting 2018 had the chance to explore this during the session on GIST case studies held by PD Dr. Peter Reichardt, Germany and Professor Dr. Thomas Brodowicz, Austria.

Dr. Reichardt started to take the audience through the steps that need to be taken when patients first present at the specialist with a suspected diagnosis of GIST. He emphasized that as a first step, diagnosis must be confirmed. Depending on the location of the (suspected) tumour, not all diagnostic measures need to be taken into account, e.g. swellings in the stomach should not be examined by CT or MRI, endoscopic ultrasound would be the preferred option.

However, only biopsy can definitely confirm a GIST. But is it needed in every case? No, said Dr. Reichardt. It depends on the location and whether or not the tumour can be removed without major mutilation or loss of function. However, if shrinkage of the tumour before surgery will improve outcomes of the operation, it is necessary to perform a biopsy. Dr. Reichardt stressed that mutational analysis of the biopsy is crucial – pre-operative (or any other) treatment should not be started without knowledge of the specific GIST mutation. Dr. Reichardt also underscores that (in contrast to previous reports) biopsy of GIST is not dangerous, especially when carried out through endoscopic measures.

Before a surgery is done – independently of any neo-adjuvant treatment – a CT scan for peritoneal and liver metastasis has to be performed.

After surgery and no evidence of metastasis, there is the option of adjuvant treatment with imatinib. But who should be treated, who shouldn't?

The following information about the tumour is essential for any further decisions:

- Size of the tumour
- Location of the tumour
- Mitotic rate
- Margins
- Rupture – yes or no?
- Mutational status

All six aspects need to be answered to do proper risk assessment. Dr. Reichardt suggested to make use of at least two different risk assessment systems to have a reliable result and to class patients into one of the two groups: high risk and low risk. High risk patients require treatment whereas low risk patients don't. For high-risk patients, (localized disease) Dr. Reichardt recommended a minimum of 3 years of adjuvant imatinib treatment. Whether or not a longer period of treatment is beneficial has yet to be proven. Again, knowledge of mutations is essential, as adjuvant treatment with imatinib does not make sense in wild-type or D842V-mutated GIST. Exon 9 mutated GIST would ideally start with 800mg/day imatinib, according to Dr. Reichardt.

Follow-up during adjuvant treatment should take place every 6 months, followed by every 3 months for 2 years after stopping treatment. After two years, follow-up can be performed every 6 months again.

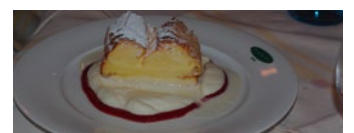
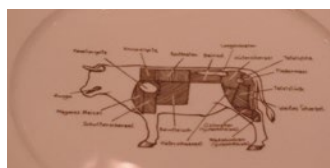
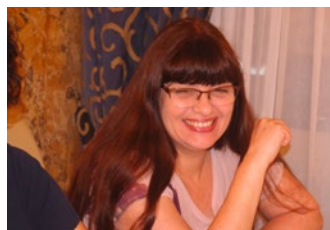
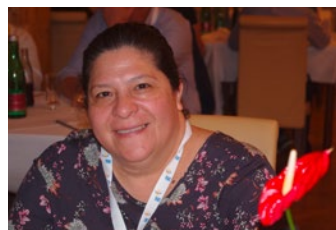
Professor Brodowicz took a closer look at patients with progression and metastasis. He pointed out that it is important to make the most of current therapies and not to switch too fast. In a case of slow progression, other therapeutical options such as surgery of metastasis or local interventions could be considered. If progressing lesions can be removed, it should be considered to continue imatinib and/or escalate the dose before switching to sunitinib.

Apart from surgery of metastasis, local interventions also include embolization: radio frequency ablation (RFA), coil embolization and chemoembolization. However, Prof. Brodowicz pointed out that chemoembolization is not an option for GIST patients as GISTs are insensitive to chemotherapy – therefore chemoembolization does not make sense.

Both experts agreed that the new drugs currently being tested in Phase III trials might completely change the treatment landscape in GIST. It offers more options, but will also become more complex and will raise new questions e.g. about optimal sequential treatments.



Participants and Impressions from the external dinner in Vienna



4. Conference Programme

NH GIST 2018 takes place in room Führich

ARRIVAL / REGISTRATION – WEDNESDAY September 5, 2018	
From 17:00	Arrival of all Participants / Registration / Conference Package
19:00	Get Together: “Small Austrian specialties” at the hotel (Restaurant “Großer Salon”) (Late arrivals can join any time!)

DAY 1 – THURSDAY September 6, 2018	
08:30	OFFICIAL START OF THE CONFERENCE Plenary Sessions – Room Führich
08:30 (30)	Opening, Welcome, Organizational Issues, Thanks to the Sponsors, etc. <i>Speakers: Amy Bruno-Lindner – on behalf of GIST-Support Austria</i> <i>David Josephy – on behalf of the NH GIST Steering Committee</i>
09:00 – 10:30 (90)	Session Chair: Martin Wettstein, CH GIST 1: Challenges and open questions in GIST treatment from the patient perspective (10 min each) Localized disease and adjuvant therapy: Norman Scherzer, US Metastatic disease: David Josephy, CAN Progressive disease: Markus Wartenberg, DE Wild Type-/ Pediatric GIST: Jayne Bressington, UK Joint discussion about challenges and “open questions” from the patient community
10:30 – 11:00	TEA / COFFEE BREAK (30 minutes)
11:00 – 11:45 (45)	Session Chair: David Josephy, CAN GIST 2: The role of pathology in the diagnosis of GIST: Morphology-Diagnostic pitfalls-Mutational analysis <i>Speaker: Dr. Bernadette Liegl-Atzwanger, pathologist, Graz AT</i>
11:45 – 12:30 (45)	Session Chair: Jayne Bressington, UK GIST 3: Rare and very rare subtypes in GIST: Where are we currently with “Non KIT-/PDGFRA- / Wild Type-/Pediatric-GIST”? <i>Speaker: Dr. Venkata Ramesh Bulusu, oncologist, Cambridge UK</i>
12:30 – 14:00	NETWORKING LUNCH (90 minutes) Restaurant “Großer Salon”

DAY 1 – THURSDAY September 6, 2018

<p>14:00 – 15:30 (90)</p>	<p>Session Chair: Ginger Sawyer, USA</p> <p>GIST 4: New GIST treatment options ahead? Short profiles of three potential new agents / treatments Avapritinib (BLU 285) – Crenolanib – DCC2618 <i>Speaker: Prof. Dr. Patrick Schöffski, oncologist, Leuven BEL</i></p> <p>An update on the MITIGATE project <i>Speaker: Arman Smakic, radiologist, Mannheim DE</i></p>
<p>15:30 – 16:00</p>	<p>TEA / COFFEE BREAK (30 minutes)</p>
<p>16:00 – 17:15 (75)</p>	<p>Session Chair: Norman Scherzer, USA</p> <p>Real World Evidence (R.W.E.) in Rare Cancers such as GIST: The Problem - The Solution - History - Future <i>Speaker: Norman Scherzer, LRG, USA & Denisse Montoya, LRG, USA</i></p>
<p>17:15 – 18:15 (60)</p>	<p>Session Chair: Piga Fernandez, CL</p> <p>What's new in the international GIST patient community? Interesting projects, developments, updates...</p> <p>6 short presentations:</p> <ul style="list-style-type: none"> ● Updates on the LRG registry <i>Speaker: Denisse Montoya, LRG, US</i> ● Salud con Datos <i>Speaker: Rodrigo Salas, Alianza GIST, MEX</i> ● Fighting GIST and sarcomas – together in one new organization <i>Speaker: Markus Wartenberg, German Sarcoma Foundation, DE</i> ● Status of data projects in the Netherlands <i>Speaker: Gerard v. Oortmerssen, Patient Platform Sarcoma, NL</i> ● Challenges in India <i>Viji Venkatesh Max Foundation & Nikhil Guhagarkar, Friends of Max, India</i> ● GISTERS in Japan <i>Yoshihiro Takanashi, GISTERS, Japan</i>
<p>18:15 – 19:15</p>	<p>BREAK BEFORE DINNER (60 minutes)</p>
<p>19:15</p>	<p>External Conference Dinner: Plachutta, Wollzeile 38, 1010 Wien</p> <p>Meeting point: Hotel lobby at 19:15 – restaurant is in walking distance from hotel</p>

4. Conference Programme

DAY 2 – FRIDAY September 7, 2018

<p>08:30 – 10:00 (90)</p>	<p>Session Chair: Amy Bruno-Lindner, AT</p> <p>Plenary bursts (short presentations) and panel discussion:</p> <p>“How to cope with a life-threatening disease such as GIST?”</p> <ul style="list-style-type: none"> ● The role of psycho-oncology? ● Personal coping strategies? ● How to address/handle this topic as a national patient organization? <p><i>Speakers: Dr. Elisabeth Andritsch, psycho-oncologist, Graz AT</i></p> <p><i>Panelists: Kai Pilgermann, DE, Nikhil Guhagarkar, IND</i></p>
<p>10:00 – 10:30</p>	<p>TEA / COFFEE BREAK (30 minutes)</p>
<p>10:30 – 12:00 (90)</p>	<p>Session Chair: Norman Scherzer, USA</p> <p>GIST 5: Following the Research Journey in GIST</p> <ul style="list-style-type: none"> ● Current & upcoming clinical trials / new treatments in GIST ● Current trends/developments in basic GIST-research <p><i>Speaker: Prof. Dr. Sebastian Bauer, oncologist, Essen DE</i></p> <p><i>Speaker: Dr. Neeltje Steeghs, NL</i></p>
<p>12:00 – 12:45</p>	<p>SHORT LUNCH (45 minutes) Restaurant “Großer Salon”</p>
<p>12:45 – 14:30 (105)</p>	<p>Session Chair: Markus Wartenberg, DE</p> <p>GIST 6: Let’s act together as a GIST Tumor Board:</p> <p>Discussing long-term progressions</p> <p>despite complex disease situation and/or multiple progression...</p> <p><i>Speaker: Prof. Dr. Thomas Brodowicz, oncologist, Vienna AT</i></p> <p><i>Speaker: PD Dr. Peter Reichardt, oncologist, Berlin DE</i></p>
<p>14:30 – 15:00 (30)</p>	<p>Exchange / Brainstorming / 1st Ideas:</p> <p>How to secure the sustainability of New Horizons GIST in the future?</p> <p>Moderator: Norman Scherzer & Markus Wartenberg</p>
<p>15:00</p>	<p>OFFICIAL END OF THE CONFERENCE</p>
	<p>Depending on individual departures: Travelling by train or shared taxis to the airport</p>

5. Invited GIST-Experts/Speakers



Elisabeth Andritsch

Medical University of Graz
Graz, Austria
Elisabeth.Andritsch@klinikum-graz.at



Sebastian Bauer

Westdeutsches Tumorzentrum, Sarkomzentrum,
Essen, Germany
sebastian.bauer@uk-essen.de



Thomas Brodowicz

Medical University Vienna
Vienna, Austria
thomas.brodowicz@meduniwien.ac.at



Venkata Ramesh Bulusu

Cambridge University Hospitals NHS Foundation Trust
Cambridge, UK
ramesh.bulusu@nhs.net



Bernadette Liegl-Atzwanger

Medical University Graz
Graz, Austria
bernadette.liegl-atzwanger@medunigraz.at



Peter Reichardt

Helios Klinikum Berlin-Buch
Berlin, Germany
peter.reichardt@helios-gesundheit.de



Patrick Schöffski

KU Leuven
Leuven, Belgium
patrick.schoffski@kuleuven.be



Arman Smakic

Universitätsmedizin Mannheim
Mannheim, Germany
Arman.Smakic@medma.uni-heidelberg.de



Neeltje Steeghs

Netherlands Cancer Institute
Amsterdam, Netherlands
n.steeghs@nki.nl

6. Participants

COUNTRY	NAME	GIST-ORG./-GROUP
Austria	Bruno-Lindner Amy	GIST-Support Austria
Austria	Bruno Martin	GIST-Support Austria
Bulgaria	Popova Yuliana	GIST Alliance for Patients-Bulgaria
Canada	Joseph David	The Life Raft Group Canada
Chile	Fernandez Piga	Alianza GIST / Fundación GIST Chile
Colombia	Becerra Jairo	Fundación GIST Colombia
Finland	Maaniittu Inga-Katriina	Association of Cancer Patients in Finland
Finland	Salo Tuula Sinikka	Association of Cancer Patients in Finland
Germany	Pilgermann Kai	Das Lebenshaus e.V. / Deu. Sarkom-Stiftung
Germany	Wartenberg Markus	SPAEN
Germany	Geissler Michi	SPAEN
Germany	Schuster Kathrin	SPAEN
Guatemala	Castillo de Armas	Asoc. de Pacientes con LMC ASOPALEU
Hungary	Kalo Silvia Zoltan	Gyogyulj Velunk Egyesulet
India	Guhagarkar Nikhil	The Friends of Max
India	Venkatesh Viji	The Max Foundation
Israel	Rachvasky Jaacov	Israeli GIST group
Japan	Takanashi Yoshihiro	GISTERS
Mexico	Salas Rodrigo	Fundacion GIST Mexico
Netherlands	van Oortmerssen Gerard	Patientenplatform Sarcomen
Netherlands	van Kampen Paul	Patientenplatform Sarcomen
Poland	Fonrobert Piotr	Polish GIST Patients Support Assoc.
Switzerland	Meier-Schnorf Helga	GIST-Gruppe Schweiz
Switzerland	Wettstein Martin	GIST-Gruppe Schweiz
UK	Falconer David	GIST Support UK
UK	Weldon Terry	PAWS-GIST
UK	Bressington Jayne	PAWS-GIST (SDH deficient GISTs)
USA	Sawyer Ginger	GIST-Support International
USA	Montoya Denisse	The Life Raft Group
USA	Scherzer Norman	The Life Raft Group

EMAIL-ADDRESS

amy.bruno-lindner@univie.ac.at

info@gist-bg.com

djosephy@uoguelph.ca

pfernandez@liferaftgroup.org

jairo.becerra@fundaciongistcolombia.org

runoilija65@gmail.com

kaipilgermann@yahoo.de

markus.wartenberg@sarcoma-patients.eu

michaela.geissler@sarcoma-patients.eu

kathrin.schuster@sarcoma-patients.eu

asopaleu@hotmail.com

zoltankalo@yahoo.com

gdental99@gmail.com

vvenkatesh@THEMAXFOUNDATION.ORG

yaacovrach@gmail.com

g-net@wish.nifty.jp

rodrigo.salas@fundaciongist.org

gerard.vanoortmerssen@gmail.com

haver043@hotmail.com

pfonrobert@gmail.com

helga.meier@bluewin.ch

m.wettstein@wp-ing.ch

david.falconer48@gmail.com

weldon.terry@gmail.com

jayneandkim@aol.com

grsawyer@icloud.com

dmontoya@liferaftgroup.org

nscherzer@liferaftgroup.org



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ESMO 2017: Resultados Prometedores Demostrados con DCC-2618 en GIST

Los pacientes con tumores del estroma gastrointestinal (GIST) mostraron respuestas prometedoras al DCC-2618, según los hallazgos de un ensayo clínico presentado en ESMO 2017, el Congreso Anual de la Sociedad Europea de Oncología Médica en Madrid, España.

2017 ASCO ANNUAL MEETING

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- Mejorar el conocimiento de los pacientes y los médicos.
- Permitir que los pacientes accedan a tratamientos y recursos adecuados.
- Apoyar a las organizaciones locales de apoyo al paciente, incluyendo la creación de otras nuevas.
- Fomentar la colaboración y coordinación con la comunidad médica.