New Horizons GIST

Dedicated in Memory of Anita Scherzer (1941-2016)

2017 CONFERENCE REPORT

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Contents

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At the request of the Steering Committee, New Horizons GIST received grants from these three companies. This funding is not related to any objectives or the content of the 2017 conference in New Jersey, USA.

The idea, conception, planning, preparation, management and summary of the New Horizons GIST 2017 conference are the responsibilities of the Steering Committee and GIST patient community without any influence from the sponsors.

We would like to thank our colleagues from the GIST expert community who travelled to speak at our conference. We are grateful for their time and insight during the discussions at the conference.

We would lastly like to thank the other external speakers who attended the meeting to provide valuable insight on real world data and treatment access.

Introduction

Traditionally, New Horizons GIST has brought together global GIST delegates to take part in a large annual conference with the aim of discussing critical information about GIST that impacts the global GIST patient and medical communities. Every year, participants have the opportunity to interact with leading GIST experts, learn about new medical and scientific information concerning GIST, exchange best practices and discuss advocacy issues.

This year, 31 participants from 15 countries attended the 2017 convocation. Our focus was on how disease advocacy organizations can utilize real-world evidence from patient health data. Our vision was to leverage shared health data to support advocacy, research, and advances in the treatment of diseases. New Horizons GIST 2017 provided the forum and the impetus to work toward the goal of improved treatment options and increased survival rates for those living with GIST around the world.

The 2017 conference was chaired and planned by a steering committee and the Life Raft Group.

David Josephy, GIST Sarcoma Life Raft Group (Canada)
Piga Fernandez, Alianza GIST (Chile)
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Norman Scherzer, The Life Raft Group (USA).

** (Markus Wartenberg is missing from this photo. In his place,* ***Gerard van Oortmerssen*** *represented SPAEN)*

Feedback from the Global GIST Community

Presentation of Survey Results

Norman Scherzer and Michelle Durborow
The Life Raft Group

Written by Michelle Durborow

The work of every GIST patient advocate around the globe is one that has developed over time, usually inspired by their own needs as a patient as well as by those of their families, and fueled by the desire to help others. Global Patient Advocates often face the most challenging issues in the GIST care continuum in their respective countries and become experts in navigating the changing and challenging healthcare landscape. Their insights, journeys, lessons learned and successes become best practices that are celebrated as a group at New Horizons, a global network of patient advocates.

At New Horizons, we believe in the value of the relationships formed between patient organizations. We work together to develop a deeper understanding of patient needs, and to integrate that insight into the collective vision and mission of the group, resulting in a culture we all share. We create partnerships that are essential to our work of supporting patients and their caregivers on their GIST journey to improved survival and quality of life.

In May 2017, global representatives were asked to participate in a pre-conference survey to collect and analyze data to achieve two things. First, to help shape the agenda for the meeting. Second, to identify the gaps and key priority areas which these advocates believe need to be addressed so that their constituents can benefit from the collective effort of the New Horizons group.

The survey had 7 major topics from which forty-four questions were developed.

The topics include:

1 Priority Issues

Representatives were asked about priority topics that they would like the group to focus on in this year's meeting and beyond. Of the ten issues presented, Research and Scientific Updates, Access to GIST Specialists, Access to Clinical Trials and Supporting Patients' Needs ranked the highest in terms of prioritization.

2 Mutational Testing

Feedback and comments were gathered regarding the state of mutational testing or Gene Mutation Screening for GIST in their respective countries, including barriers to its adoption as the standard of care. It was reported that mutational testing is not considered a standard of care in the majority of the countries represented by the survey participants. Doctor's decision is the foremost reason why patients' tumors get tested or why they do not get tested. The cost of testing and the lack of healthcare coverage for testing were identified as significant barriers to increasing mutational testing.

3 Imatinib Plasma/Trough Level Testing

This topic explored whether this test is performed in the representative's country and whether the cost is covered by health systems. Challenges for getting the test were identified. Participants' insights revealed that the lack of awareness about imatinib plasma level testing and physicians not recommending the test make up forty-five percent of the identified barriers for patients to get the test.

4 Access to GIST Specialists

The number of specialists in the representative's country and the accessibility to these specialists were evaluated, along with programs that patient advocates have in place to improve access. According to feedback from participants, patients find GIST specialists primarily through patient group organizations such as those to which they belong. Travel distance to get to the specialist is a primary concern as well as fear of offending current physician.

5 Oral Therapy: Access and Reimbursement

Accessibility and reimbursability of treatment and cost to the patients are integral to GIST management. Insights about these issues were gathered including other factors that affect treatment, such as access to clinical trials, off-label treatments, and patient assistance programs. Accessibility and reimbursability of sunitinib as a second line treatment and regorafenib as a third line treatment present challenges in both developed and developing countries. Patient assistance programs are limited, especially for both sunitinib and regorafenib. Based on the survey results, GIST patients do not have easy access to clinical trials.

6 Supporting Patient Needs

Patients have varying needs and priorities in different countries. What are their primary sources of information about GIST and symptom management? What are the things that they care about in the management of their disease? Is medical compliance or treatment adherence a significant issue? The survey collected feedback on patients' experiences as best represented by the participant. The aim was to uncover any opportunities for enhancements and improvements in information flow and program development. Participants representing the patient's voice indicated that Survival, Access to Expert Care and Disease Management and Access to Treatment are the 3 most important issues that patients care about in the management of GIST.

7 Impacting Policy

Advocating for better health policies that will benefit GIST patients is integral to the work of every patient advocate. They are now more influential than ever in shaping guidelines and policies for better care and access to necessary treatment. Participants provided insight on the various advocacy activities they perform and the collaborations they develop with other patient organizations to advance their advocacy goals. They also commented on the role of patient-reported data in developing guidelines for clinical practice in their country. Influencing health policy is an effective path to change, and the survey conveyed that there are patient groups currently doing so which can serve as models for other patient groups.

Highlights of the results were presented at the New Horizons' conference in Wayne, New Jersey on October 2, 2017, by United States delegates Michelle Durborow, Senior Director of Scientific Operations and Norman Scherzer, Executive Director, from the Life Raft Group. Results of further analysis of the survey will be published soon.

TO VIEW MORE OF THE SURVEY HIGHLIGHTS, PLEASE VISIT:
liferaftgroup.org/new-horizons-2017/

Emerging Therapies and Ongoing Trials in Advanced

Dr. Suzanne George
Co-Clinical Director, Center for Sarcoma and Bone Oncology, Dana Farber Cancer Institute

Written by Ginger Sawyer

Dr. George's talk was about two drugs that are currently in clinical trials, specifically BLU-285 and DCC-2618. These two compounds are now in development, and Phase III international trials of these compounds for patients with advanced GIST will soon be launched. Her presentation provided some background to the data that supports the development of the trials as well as to increase awareness of what is coming.

Dr. George explained why she believes that there is a need for more therapies for GIST. While Imatinib is an excellent inhibitor of KIT exon 11, and to some extent of exon 9, it is a relatively narrow spectrum TKI. It is truly revolutionary in the primary and adjuvant setting, but it is not uncommon that resistance develops and it is a challenge that needs to be overcome. Sunitinib, which is the standard second-line TKI, targets a broader spectrum, treating exon 11, exons 9, 13 and 14 effectively. But it leaves out some of the other mutations, such as exon 17 and 18. The challenges for sunitinib are persistence of resistance and toxicity issues. Regorafenib is the third-line broad-spectrum TKI used in countries that have access to it. It showed effectivity on mutations such as exons 17 and 18, where sunitinib does not. Toxicity issues can be limiting.

It was pointed out during the presentation that while research has made significant progress from where it was before the development of these TKIs, there remains much to be done. On average, the duration of the effectiveness of each these therapies becomes shorter as the patient progresses through the different lines of therapy, so disease control is a challenge, and varies from patient to patient. Some of the challenges may be related to drug exposure, or from not taking the appropriate dosage because of toxicity. This is particularly true for second- and third-line therapies that present other challenges, such as hypertension, hand-foot skin reaction and diarrhea.

Dr. George then focused on the BLU-285 and DCC-2618 trials and discussed the data previously presented at ASCO and ESMO.

BLU-285 was developed as a very potent inhibitor of PDGFRa mutations that are structurally similar to exons 17 and 18. The study was a standard dose-escalation study to determine the maximum tolerated dosage as well as efficacy. It is being conducted in two parts, one for D842V mutations and the other for unresectable GISTs with previous multiple therapies. Data on D842V mutations showed evidence of extremely significant reduction in tumor size that had not been at all responsive to treatments. The data also showed important clinical activity, improvement and stability for those patients who had been

Both BLU-285 and DCC-2618 have demonstrated encouraging activity in advanced GIST, particularly in PDGFRa D842V and resistant KIT mutations.

pre-treated with Imatinib and other TKIs suggesting good activity for the KIT-mutant population as well. There is also significant progression-free survival of those patients who are continuing on BLU-285. In addition, most patients report only slight to moderate side effects, which are manageable, and these are not as problematic as those experienced with other medications.

Focusing then on DCC-2618, while the backgrounds of this compound is very similar to that of BLU-285, Dr. George pointed out that DCC-2618 works at a different location in the KIT protein than typical kinase inhibitors. Instead of targeting the ATP binding pocket like most kinase inhibitors, DCC-2618 binds to the switch pocket. DCC-2618 is a pan-kit and pan-PDGFRA inhibitor which targets a wide variety of mutations.

The study is not only using the standard FDG PET scans, CT scans but it does include plasma cell-free DNA (cfDNA) via liquid biopsies to evaluate response. The cfDNA evaluation data indicated marked reduction in the mutation allele frequency (measure of mutation taking place in the gene) indicating activity. But this requires further study comparing the DNA in the tumor with the DNA in the plasma at the time of treatment, as there may be more mutations that show up in the plasma than in a single tumor biopsy.

In the phase I trial, doses from 40 to 400 mg either once or twice per day were tested. The dose selected for expansion phase was 150 mg per day. Preliminary results of the study are promising, with significant progression-free survival over three months and six months. The most common side effects were; lipase increase, fatigue, anemia, decreased appetite and diarrhea.

Both BLU-285 and DCC-2618 have demonstrated encouraging activity in advanced GIST, particularly in PDGFRa D842V and resistant KIT mutations.

Dr. George also disclosed that both Blueprint Medicines and Deciphera had provided research funding to DFCI. She also serves on the scientific advisory boards of both pharmaceutical companies.

Dr. Bill Tap
Memorial Sloan Kettering Cancer Center

Written by Ginger Sawyer

Dr. Tap welcomed the New Horizon attendees by encouraging further cooperation between physicians and advocacy groups in their efforts to assist patients. He encouraged understanding of the history with GIST in moving forward. He reminded everyone that GIST is a rare cancer, once believed to be leiomyosarcoma. Traditional chemotherapy and radiation were not successful treatments, and mortality was high. Dr. Tap pointed out that GIST tumors are not smooth muscle tumors; they are actually tumors of the interstitial cells of Cajal, the

"It is frustrating that trials are becoming so specific that it limits the population of patients that can participate, but at the same time, patients are getting more options in the process," said Tap.

nerve layers that lay between the layers of cells in our GI tract that move food through the gut. These cells rely on KIT to mature from stem cells to progenitor cells to mature interstitial cells of Cajal. Studies conducted in Japan on the over-activity of KIT led to two major international trials that tested the efficacy of imatinib. Patients' survival rates increased significantly, and 45% of the patients had shrinkage of at least 30% in their tumors.

However, as imatinib is not curative, the majority of patients will develop secondary mutations. Sunitinib became the second-line drug, and it was a better binding drug. It works better on exon 13 and 14 mutations because of the binding pocket, but not as well in exons 17 and 18. This information has led researchers to be more interested in specific treatments for specific mutations, and there may be multiple mutations in a patient's tumor. It may be possible to suppress certain mutations, but others will start to grow. The challenge is to develop drugs to treat or prevent secondary mutations.

The medical community have been waiting for new drugs like BLU-285 and DCC-2618, and it is an exciting time because now patients can be offered more treatments.

Dr. Tap then discussed other options. The first is PLX3397+PLX9486. PLX3397 is actually a stronger KIT inhibitor than Gleevec. It also hits the Colony-Stimulating Factor 1 Receptor. Research shows that PLX3397 hits primary mutations in exons 8, 9 and 11, as well as resistant mutations in exons 13 and 14. PLX9486 also hits exons 8, 9, 11, but it hits exons 17 and 18 as well. The question is whether, by combining the drugs, the spectrum of primary mutations and resistant mutations are covered? There is a Phase I trial of the combined drugs, as well as a trial of testing PLX3386 with Sunitinib. In this way the efficacy of one over the other, as well as the toxicity of the drugs can be tested. This study is at a much earlier stage than BLU-285 and DCC-2618.

He expressed a bit of frustration that trials were becoming so specific that it limited the population of patients that could participate. But he also said that patients are getting more options in the process.

Dr. Tap then focused on the immune macro-environment and discussed about three important studies dealing with macrophages 1 and 2. It is particularly important to use macrophage 2 to enhance the efficacy of Imatinib. Dr. Tap does not believe that the checkpoint inhibitors alone can be successful; rather, they have to be combined with TKIs. This might be more effective if patients are given these treatments rather than taking them through all the various available treatments.

Dr. Tap presented Dr. Ping Chi's study of ETV1, a lineage survival factor that cooperates with KIT/MAPK signaling in GIST, as among the most important new studies. ETV1 is highly expressed in GISTs and is

required for the growth and proliferation of GIST cells. Dr. Tap described that it is like a marriage of KIT and ETV1, and both have to be dealt with. Dr. Tap then explained that with the inhibition of the MAP kinase and KIT signaling, ETV1 is synergistically destabilized and GIST tumor growth is suppressed. A MEK-162 combined with Imatinib trial is being developed for patients with newly diagnosed disease. He suggested new patients need to come from the local community centers, where they only get Imatinib, to the trial centers, where they could get the combination.

Dr. Tap concluded that there are and will continue to be many potential treatments. Some of the promising proposals have failed for lack of funding, but there are many that continue with great promise.

Circulating Tumor DNA in GIST and its Implications for Treatment

Dr. Ciara Kelly
Assistant Attending Physician, Sarcoma Medical Oncology Service, Memorial Sloan Kettering Cancer Center

Written by David Josephy

Recent research has shown that many solid tumors, including GIST, may "shed" DNA (genetic material) into the bloodstream. This DNA can, at least in some cases, be recovered and analyzed. We refer to this DNA as "ctDNA" (circulating tumor DNA). Normal cells can also shed DNA into the bloodstream. So, more generally, we refer to "cfDNA": cell-free DNA. ctDNA is a component of cfDNA, but the presence of non-tumor cfDNA can interfere with the detection of ctDNA.

cfDNA in general, and ctDNA in particular, is present in only very small amounts in the blood. Of course, blood also contains many cells, such as white blood cells, and these carry a full "load" of DNA in their chromosomes. So, it is a challenge to separate out the small amount of ctDNA from the large amount of normal DNA - both non-tumor cfDNA and cellular DNA.

ctDNA may be recovered from the blood or from other fluids, such as cerebrospinal fluid (CSF) or even urine.

Even though the quantity of ctDNA is small, it can be detected by highly sensitive methods based on PCR (polymerase chain reaction) amplification and it can be sequenced.

ctDNA can be used as a "biomarker" of the presence of tumor cells in the body. Complementing surgical biopsy, the detection and analysis of ctDNA can provide information about the tumor non-invasively. For this reason, ctDNA analysis is often referred to as a "liquid biopsy".

To use this tool reliably, it is very important to distinguish ctDNA from non-tumor cfDNA. One requirement for achieving this is to collect (and sequence) a normal (reference) DNA sample from the patient. It is of particular interest to detect and identify sequence differences between the ctDNA and the patient's normal ("germline") DNA, because these differences may include important tumor (somatic) mutations, such as the kit gene mutations that drive many GISTs.

The science of cfDNA is new but it is developing rapidly. The FDA approvals of ctDNA tests for lung cancer (2013) and for EGFR mutations in non-small-cell lung cancer NSCLC (2016) show that ctDNA is moving into the mainstream of medical technology.

ctDNA in GIST

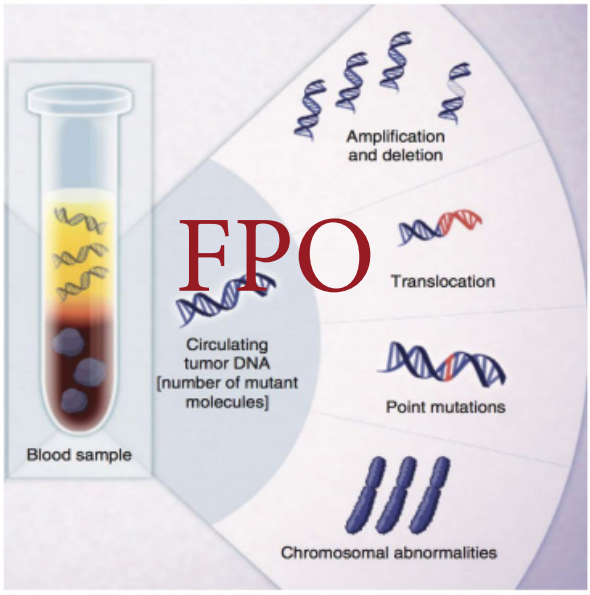
The use of ctDNA in GIST is also developing quickly. ctDNA analysis is being used in the ongoing Deciphera GIST clinical trial, for example (presentations at CTOS 2017).

Here are some potential applications of ctDNA in GIST.

Molecular Classification: Just as is done with a solid biopsy sample, ctDNA could be used to identify the mutational driver of a GIST, e.g., a KIT exon 11 mutation.

Therapeutic Selection: Knowing the mutational type could guide selection of therapy, just as for a solid biopsy. GISTs can become resistant to imatinib (or other drugs), due to secondary acquired mutations. If these mutations can be detected via ctDNA, the information could guide the selection of second- or later-line drugs, because each agent has a distinct pattern of effectiveness against specific secondary mutations.

Downstream Analysis



Downstream Analysis of ctDNA Facilitates Sequencing and Detection of the Tumor's Genomic Landscape

Haber, Cancer Disc 2014

However, all of these prospects depend on the validation of ctDNA as a reliable biomarker in GIST, and this has not yet been achieved. Validation research is needed and is ongoing.

For example, we need to measure concordance: when a specific patient's GIST is studied by both the traditional solid biopsy and by ctDNA, do we get the same results? Dr. Kelly stated that for the detection of primary KIT mutations, there is relatively good concordance rate (>80%), but for secondary KIT mutations (TKI resistance), the concordance is, as yet, poor. This does not necessarily mean that the ctDNA results are wrong: perhaps the standard solid biopsy is missing some secondary mutations. Suppose a TKI resistance mutation has arisen in one lesion, but the solid biopsy sample was taken from a different one; the solid biopsy might miss the mutation. ctDNA may provide a more comprehensive sample of what is happening in all of the GIST lesions.

Another promising application of ctDNA is in monitoring a patient's response to therapy. We know that more than one approach has been used to evaluate response based on radiology images (CT, MRI, PET scans), such as the RECIST criteria and the Choi criteria. Sometimes, a doctor will conclude that a GIST has progressed, based on radiology, but a doctor with more experience with GIST would not agree. Perhaps ctDA can provide a more reliable evaluation. If so, ctDNA could be applied to evaluate, for example, the effectiveness of adjuvant imatinib (picking up evidence of GIST even when radiology does not). Prospective studies have shown that the levels of mutational burden, as detected by ctDNA,

in GIST correlate with tumor volume and response to treatment. So, ctDNA analysis might be able to detect recurrence earlier than imaging does.

Dr. Kelly stressed that all of these goals will require thorough validation studies.

She also listed some "Unanswered Questions" regarding ctDNA in GIST

QUESTION

ctDNA reflects the shedding of DNA into the circulation by tumor cells - presumably as a result of tumor cells dying and rupturing. But what clinical factors determine the extent of tumor shedding?

ANSWER

This is not known.

QUESTION

How does the site of the GIST (e.g. stomach vs bowel) affect the shedding of ctDNA and its detection? Do some drug treatments reduce tumor shedding more than others?

ANSWER

Answers are needed if ctDNA analysis is going to be used reliably.

Dr. Kelly discussed the health economics issues of ctDNA in GIST. In the short term, there will be additional costs for the laboratory analysis, but longer-term, there could be cost savings: reduced need for invasive tissue biopsies and better selection of therapies for patients requiring adjuvant therapy. Dr. Kelly stated that the routine collection of ctDNA samples in prospective clinical trials in GIST is necessary to advance this technology forward.

Dr. Kelly and colleagues are conducting a study of ctDNA in GIST at MSKCC, and will be testing > 200 samples.

Reference on ctDNA in GIST: Bannon AE, Klug LR, Corless CL, and Heinrich MC, Using molecular diagnostic testing to personalize the treatment of patients with gastrointestinal stromal tumors, Expert Rev. Mol. Diagn. 17: 445-457, 2017.

Innovative Approaches to Prolong Survival: Case Studies

CASE STUDY PRESENTATIONS

Dr. Ciara Kelly – Localized Disease
Dr. William Tap – Metastatic Disease
Dr. Suzanne George – SDH-Deficient GIST

Written by David Josephy

Each of the doctors presented a case study of a GIST patient, with the cases spanning a wide variety of situations. These presentations illustrated the difficult clinical decisions that arise in GIST management, and we were all once again impressed by the importance of having an expert team of experienced doctors managing a GIST case. These cases will be briefly summarized here.

Dr. Kelly described a patient in whom a rectal mass, 5 x 4 cm, was detected by CT scan in 2015. A biopsy was performed and IHC pathology showed CD117+ DOG1+ (diagnostic for GIST) and 3 mitoses per HPF. Tumor debulking was needed before surgery could be performed, i.e. neoadjuvant imatinib therapy was administered. The patient entered the phase II clinical trial of a MEK inhibitor + imatinib. Side effects included rash and edema; these side effects stabilized and the regimen was tolerated well. PET scans showed that the treatment was very effective. Surgery was done in 2017 and a specimen of the tumor showed no mitotic activity. The patient continues to be disease-free after 6 months. The case illustrates the need to balance carefully the use of drugs and surgery.

Contrasting with the favourable outcome described by Dr. Kelly, Dr. Tap presented a case that illustrates the complexities of dealing with an aggressive and changing presentation of GIST. The patient

was first diagnosed with a duodenal GIST and liver metastases. Gleevec, 400 mg daily, was started, as is standard practice. Radical surgery was done, including partial hepatectomy and duodenal resection, and, following surgery, there was no evidence of disease (NED). The patient continued on Gleevec, but after one year, new liver disease was observed. The dose was raised to 600 mg and the patient was stable for another year, but then new liver lesions again appeared. Next, the dose was raised to 800 mg; but eventually new lesions appeared, including in bone - and an inoperable mass in the spine. Dr. Tap used radiation therapy on the spinal lesion and the patient started on Sutent. The patient continued on Sutent for some years, but then further liver progression was seen. A biopsy indicated an exon 13 resistance mutation and also a mutation in

the PTEN gene. A series of further drug interventions were tried: regorafenib, and sirolimus, and then the patient enrolled in a clinical trial of pexidartinib + pembrolizumab. The therapy was not tolerated and the patient left the trial. Brain lesions arose. Now the patient is in the Blueprint drug trial. As Dr. Tap put it, "GIST patients do well ... until they *don't* do well." Once drug resistance arises, management becomes more and more difficult.

Dr. Suzanne George described a wild-type GIST case. In 2006, a middle-aged woman developed GI bleeding and anemia, and a stomach mass proved to be GIST. She started imatinib therapy and underwent surgery (partial gastrectomy). The GIST showed 4 mitoses per 50 hpf and, unusually, lymph node involvement. Genetic testing showed that the tumor was "wild-type": no mutation was found in either KIT or PDGFRA genes. The patient was shifted onto sunitinib.

At the time, the role of SDH (succinate dehydrogenase enzyme and genes) in many wild-type GISTs was not yet known. We now know that SDH-deficient GIST dominates among cases in persons under age 30, and 80% of "wild-type" patients who show SDH mutations in the tumor also have a germline SDHB mutation. Indeed, the patient had a family history of GIST and was found to have a germline SDHA mutation. It was judged that the possible side-effects of TKI therapy outweighed potential benefit in this case. She has been off TKI therapy for 3 years. Dr. George explained that SDH-deficient GIST can be very indolent.

This case illustrates the rapid progress that is being made in understanding the biology of "wild-type" GIST, but this progress has not yet paid off in the development of new and effective therapies targeted at wild-type GIST.

Utilization of Real World Evidence among Different Stakeholders

MODERATOR:
Norman Scherzer
Executive Director, The Life Raft Group

Written by Sara Rothschild

This panel discussion was an important centerpiece to the meeting as it laid out the framework for the importance of capturing real world data and harnessing it to make it impactful.

Norman Scherzer began the session with a discussion of the meaning or interpretation of real world data/ evidence. He outlined that it is important for the management of cancer care as well as for decision making that is not derived from randomized clinical trials.

He provided background on how the landscape has changed for the treatment of GIST in that oral drugs have replaced IV drugs and patients are living longer on these oral agents. We now know that there are many more cancer sub-types, especially within rarer cancers that are few in number. More patients are being treated by less experienced local oncologists than GIST experts at centers of excellence. We rely on patients to take oral drugs, and we struggle to keep pace with long-term side effect management.

In contrast, cancer research structures and cancer research culture are stagnant. Traditional randomized clinical trials do not provide the evidence we need. Data evidence sharing is hinged on a post-publication structure that delays access to information. Clinical trial failures are unreported. Individual researcher competition remains a reality as opposed to collaboration. Compounding all of this, pharmaceutical competition is contingent on market priorities rather than what is required for cancer patient survival such as a combination of drugs.

Considering all of these factors, real world data is needed and must meet the following criteria: it has to be accurate, timely, reflect the patient perspective, go across the continuum of patient care from initial diagnosis to end of life and across institutional barriers; it has to be accessible, portable, support clinical trial recruitment, and be a source of economic data.

PATIENT PERSPECTIVE:

Rodrigo Salas

President, Fundacion GIST Mexico

The Role of a Patient Registry in Drug Access and Coverage in Mexico

Rodrigo Salas spoke about what patient groups can do in Latin America to ensure that there is enough information to make good decisions about treatments for patients.

As background to his situation in Mexico, Rodrigo Salas pointed out that the government has not allocated resources to create a national cancer registry. This information is important, as we need to evaluate how patients are doing.

In 2016, Salud con Datos was created to address the need for real world data to help inform health decisions. Patient organizations gathered with clinicians to identify what information is needed, why it is needed, and how it gets collected.

Within a year, databases were built comprising 390 patients in the Mexican patient registry. Soon there will be 250 patients in the Chilean registry and 250 in the Argentinian registry. Patient organizations have dedicated staff time for following up on patients, and have shared this information with clinicians for curation and publication. This led to two posters which were presented at the ESMO and ASCO conferences in 2017.

This information has been beneficial in providing access to treatment, as the data was used to perform economic modelling that demonstrated to regulatory authorities that there is a cost savings with oral cancer drugs versus surgical management.

This project demonstrated the power of patient organizations in using real world rare cancer data to engage regulatory authorities in an effort to impact health coverage.

REGULATORY PERSPECTIVE:

Dr. Theresa M. Mullin

Director, Office of Strategic Programs, FDA Center for Drug Evaluation and Research

Patient-Focused Drug Development: Identifying and Building Needed Data Sources to Integrate Patients' Perspectives in Decision-Making

Theresa Mullin provided an overview of an FDA initiative focused on getting more patient voices and real evidence from patients into the regulatory process.

FDA has been talking with people living with certain diseases and asking them to share their perspectives. The FDA participated in 20 disease group meetings to hear from patients about the burden of disease. Questions were asked about symptoms and daily impacts as well as patient perspectives on current treatment approaches. All of these meetings led to the production of "Voice of the Patient" reports, detailing valuable patient perspectives as experts in their disease, as opposed to the perspectives we hear from medical experts in the field.

After the series of meetings, people wanted to know if those meetings changed the decision about a drug. The FDA stated that although the narratives are quite powerful, this input will not change the decision on the drug, but rather will inform development programs about the need to address burden of disease. This helps with the context and severity of a condition and degree of unmet need.

This leads to how we collect meaningful information in trials and ask questions such as "what's missing from the data collected?" or "What should companies address?". It also is important to review how to engage patients with the disease and what matters most to them. It is a matter of asking what

instrumentation should be used in trials to best measure impact and to consider how patient registries can help us understand how things perform in the delivery system.

POLICY PERSPECTIVE:

Dr. Carl Asche

Professor & Director, Center for Outcomes Research University of Illinois College of Medicine; Member of International Society for Pharmacoeconomics and Outcomes Research (ISPOR)

Evaluation of Health Care Interventions and Big Data: Review of Associated Data Issues

Dr. Carl Asche shared two important takeaways from his presentation: data access challenges such as data ownership, security issues and costs often serve as barriers to data access; and careful thought is required to fully realize the potential of 'Big Data' to draw accurate conclusions.

We need to consider that there are issues with data validation and linkage (i.e. lack of complete or linked information) and that some data pieces are missing from the researcher's arsenal, which limits researchers' assessment of certain interventions and public health outcomes. Additionally, data can be unavailable, biased, unmeasured and confounding.

Therefore, emerging partnerships between public and private organizations may improve researchers' abilities to access data. Currently, a successful project is underway through the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Working Group that makes various oncology databases available on their website.

With projects such as ISPOR and others, there are opportunities to accurately assess treatment effectiveness and outcome prediction as well as realize the potential of these data sources and draw accurate conclusions.

PHYSICIAN PERSPECTIVE:

Dr. Suzanne George

Co-Clinical Director, Center for Sarcoma and Bone Oncology, Dana Farber Cancer Institute

How Data Informs Clinical Guidelines

From a clinical perspective, Dr. George stated that we try to do the best we can balancing evidence by traditional means, considering the context of patients' priorities and goals, and then taking into consideration the constructs in which we work such as the payer system. The clinical trials world in oncology is moving fast and we are developing more data than we have had in a long time. We need to let data mature and take the time to be cautious in gathering a complete dataset. However, it comes back to a personalized approach to evidence-based decision making, priorities from the patient perspective, within the current system.

Historically, from a clinical trials regulatory perspective, the FDA audit can be quite complicated. We need to make sure the data is accurate for the submission process. It is important to have this dialogue, so we can hear the patient voice and be certain that what is truly important is captured and considered, which can help with clinical trial design and data element capture.

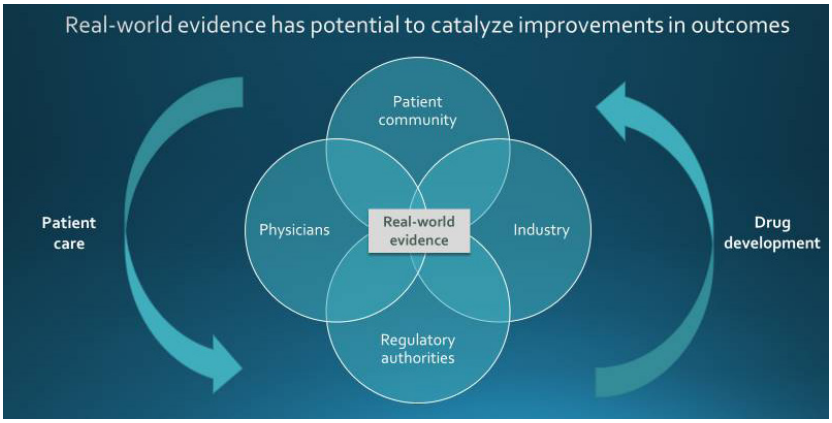
Conclusion

Each of these presentations brought a different perspective to the concept of real world data and highlighted the importance of continuing to reflect on why data is needed and what its purpose is in order to inform each direction of the work being carried out among different stakeholders in the healthcare system.

Collaborative Model to Understand the Patient Experience Analysis from a Data Project among a PAG, Academia and Pharma

Michelle Durborow
Senior Director of Scientific Operations,
The Life Raft Group

Written by Sara Rothschild



Real-world data (RWD) and real-world evidence (RWE) plays an increasing role in clinical drug development programs . In the United States, the 21st Century Cures Act, passed in 2016, highlights the use of these types of data to incorporate patient-reported outcomes (PROs) at earlier stages of development so that outcomes are meaningful to patients. The mandate places focus on using tools to capture these data in a reliable and quality way. The increasing role of RWE and RWD provides an opportunity to put the patient voice forward.

Real-world evidence is evidence from any and all sources of data that may contribute to more effective health care, including health care best tailored to the needs of individual patients.

– Network for Excellence in Health Innovation

Sources of real-world evidence include electronic health records, surveys, mobile health generated systems as well as patient registries. Real-world evidence has the potential to catalyze improvements in outcomes. As we improve patient care, the use of this evidence should translate into drug development.

The LRG Registry is a unique source of real-world evidence in that all of its data is contributed by patients or caregivers. Regularly reported medical updates pegged to the patient's scan frequency are sorted into 450 data fields which pair clinical information with mutational profiles gathered from our companion tissue bank in order to monitor the latest treatments for early indications of a response, and identify trends that can help our members reach tomorrow's cure.

This registry helps provide an understanding of GIST patient experience through real-world data.

A collaboration between Blueprint Medicines, Life Raft Group, and Sylvester Comprehensive Cancer Center was formed to analyze progress and remaining medical need in a GIST patient journey based on patient-reported real world experience.

The key project goals for this collaboration are to:

– Enhance understanding of real-world treatment of GIST patients

– Identify areas of collaboration to support patient empowerment

– Support Blueprint Medicines BLU-285 drug development program

Examples of data-posed topics include:

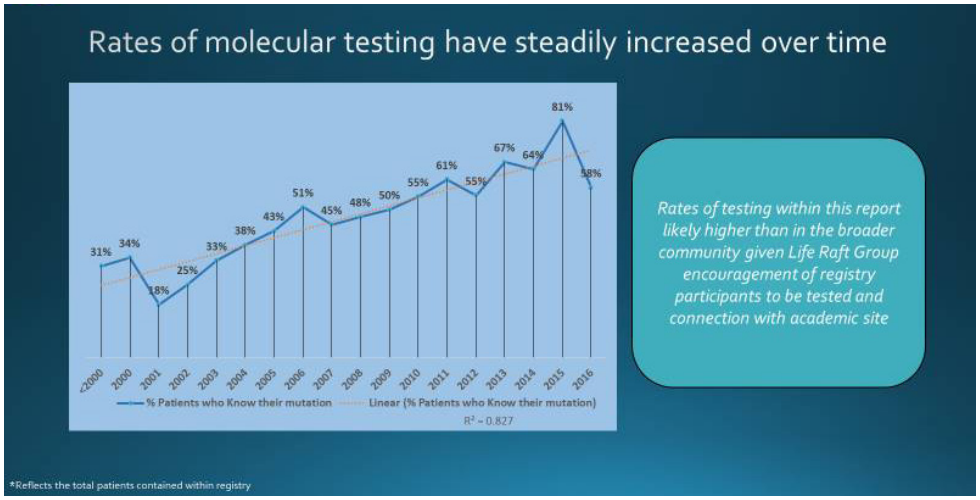
1. Have we improved in rates of mutational testing? Unfortunately, testing rate is still around ~15%; but the trend is higher in the LRG patient registry and the current rate at 75% is increasing over time. Over the years the LRG has been encouraging patients to receive mutational testing. Based off of our registry, it appears that as the years went on, a larger percentage of people received mutational testing. This means that GIST patients are more likely to receive mutational testing in 2017 than they would have in 2000.

2. Educational barriers remain with a significant portion of registry patients with unknown mutations. In the analysis, over 50% of patients who are alive (as of data cut off of April 2017) do not know their mutations.

3. Awareness of mutational status may positively impact overall survival. Those with known mutations have better overall survival than those with unknown mutations. A variety of factors confound this data: the LRG Patient Registry members are more proactive in their care, the LRG's GIST Collaborative Tissue Bank's initiative that encouraged testing and the availability of testing in other countries. Further analysis is currently being done to fully understand this data.

The registry is a powerful tool to enhance our understanding of the patient treatment journey. As patients have more access to treatments, their survival gets better, as there are more choices.

Real-world patient data highlights diversity of prescribed therapies following progression on the three GIST-approved drug therapies. It is important to understand what patients went through as they tried different medications at different lines of treatment. If we compared those medications with overall survival, there is a high medical need in the treatment of GIST in the post-imatinib setting.



Several additional areas have been identified for further analysis:

1. Delineate real-world treatment patterns
2. Determine key factors that impact GIST patients' quality of life
3. Understand the side effects and reasons for discontinuation

On a country level, an important takeaway is to gather enough evidence to be used to talk with payers. A patient who does not get to a patient organization or get mutational testing has a poorer outcome. Therefore, real-world evidence can help improve our advocacy efforts among different stakeholders in our countries.

Access to GIST Treatment in Low and Middle Income Countries: The Good, The Bad, and The Ugly

Pat Garcia-Gonzalez
Executive Director, The Max Foundation

Written by Piga Fernandez

The Max Foundation (TMF) has been in existence since 2001 as a third-party administrator of the Glivec International Patient Assistance Program (GIPAP), through which more than 11,000 patients have had access to Glivec.

TMF has expanded their programs, and are focused not only on CML and GIST, but on RCC and other rare cancers.

They are working on a new model called “CML Path to Care”, a patient-centered program that replaces the GIPAP program. In this new model they are working in collaboration with Novartis who funds it and donates the products.

To explain the situation of access to treatments in middle and low-income countries, Pat showed us the good, the bad and the ugly over the course of their work trying to achieve treatment access.

The good: The Max Foundation has established a humanitarian partnership with several pharmaceutical companies such as: Novartis, Pfizer, Otsuka, Takeda, Incyte, Pint, Bristol Myers Squibb and Ariad. Through this partnership with Novartis and Pfizer in several low and middle-income countries, GIST patients have been able to have access to Gleevec and Sutent.

The bad are the multiple obstacles that have to be surpassed in order to achieve their goals:

And finally, **the ugly** is the still very great number of countries where there is no infrastructure to treat GIST. The big challenge is how to contribute to the good, improve the bad and change the ugly.

“Providing lifesaving treatment to one patient does not save the life of one patient – it saves the lives of the dozens of small children and elderly family members who depend on that patient for their survival.” Dr. Damira Bayzakova, Kyrgystan

Patient Forums: Telling the Patient Story and its Impact on Healthcare

Gerard van Oortmerssen
Chairman of Board of Contactgroep GIST, Netherlands

Written by Gerard van Oortmerssen

On October 3, in the Best Practices session, the first presentation entitled “Patient Forums: Telling the Patient Story and its Impact on Healthcare” was given by Gerard van Oortmerssen, the chairman of the Patient Platform Sarcomas in the Netherlands and board member of SPAEN. Two years ago, the Dutch patient organization for GIST and sarcomas started a project to analyze the discussions of patients on the internet with the aim of retrieving information that might be of interest to both patients and medical professionals. The Internet has given us tremendous new possibilities to find information and to connect with other patients. Patients, in particular those with a rare disease, have a need to find similar patients in order to exchange information and experiences, as well as to support each other emotionally. GIST patients find each other on forums like the Life Raft Group’s listserv and GSI’s Facebook Group. These discussion platforms contain a wealth of information: personal disease histories, treatment, side effects of treatments, experienced quality of life, etc. Modern digital technology provides analysis methods using artificial intelligence, machine learning, natural language processing and data mining, which allows harvesting of interesting data from patient discussions. Gerard gave a few examples of practical results that have already been obtained using these methods:

- One of the GIST expert centers in the Netherlands had doubts about the best way to take a daily 800 mg dose of imatinib: the total dose once a day or 400 mg twice a day. Analysis of patient discussions revealed that most patients prefer to split the dose. Consequently the policy of the hospital was changed to advise patients to split the dose. Also, several patients reported that they took the drug with some dark chocolate in order to mitigate nausea. This is interesting information for doctors to suggest to their patients.

- Another application was to analyze which topics for research are of greatest concern to GIST patients. Important topics appeared to be possibilities for surgery of metastases, long term side effects of taking imatinib, extreme fatigue, interaction between medication and food. These results were used as input for the research agenda of an academic hospital.

There are many more possible applications which will be further explored in the future. Moreover, the development

and scientific underpinning of the method will continue to be pursued. Funding has been obtained for a PhD project at Leiden University, which will start soon and which will involve GIST and sarcoma specialists in addition to computer scientists and patients. The intention is to make the method available both to patients, who may thus find more valuable answers to their questions, and to researchers, who may benefit from the actual experience of patients and may find unexpected patterns in the patient information. Gerard also reported on another project in which the Dutch sarcoma group is involved, one which aims at increasing patient participation and shared decision making. A value assessment was carried out among sarcoma patients and sarcoma specialists at the Erasmus Medical Center in Rotterdam. It was found that patients and doctors share the same vision about the ideal treatment situation for sarcoma patients. The current situation, however, is experienced differently by doctors when compared to patients. This study will be repeated in other hospitals in the near future and will then be used to start a dialogue between patients and medical professionals in order to stimulate a change towards the desired situation. The projects Gerard presented demonstrate the potential we as patients have to actively contribute to research as well as to better health care.

Improving Patient Advocate-Patient Communication: Principles and Techniques

Amy Bruno-Lindner
Co-Founder, GIST Support Österreich, Austria

Written by Martin Wettstein

Amy's key message was expressed at the very end of her professionally presented speech:

"The blockbuster drug of the century is an engaged patient" (Leonard Kish).

This idea applies specifically to patients, relatives of patients and other supporters of our GIST community (and of course to any other patient with a rare disease). But what is an engaged patient and how does he or she become engaged?

Here is where the responsibility of patient advocates and advocate groups begins. A patient advocate possesses knowledge and he or she knows how to access sources of information. For Amy, advocacy

work equals communication; communication does not only occur between advocates and patients, but also between advocates and physicians, researchers, trial teams, regulators, pharma representatives, other advocacy groups, caregivers, etc.

In addition to providing information, a patient advocate also aims to express empathy and to foster empowerment. Examples of important communicative functions of a patient advocate are explaining medical/scientific concepts, providing information about side effects, helping patients to express fears and concerns, preparing patients for physician appointments, helping patients to take responsibility, and encouraging self-advocacy. Together with the audience, Amy identified communication challenges that advocates are faced with and the group discussed how we can overcome these challenges.

With a variety of key principles, Amy introduced some helpful hints:

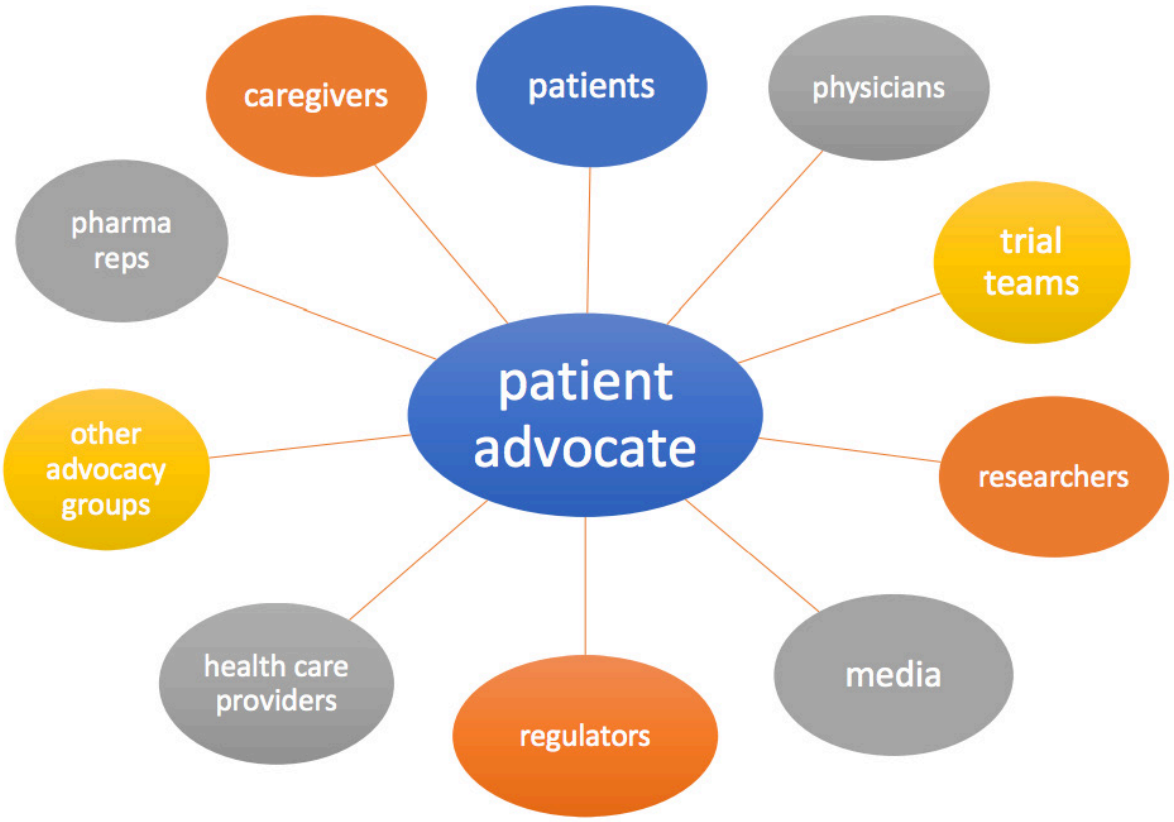
- Sharing information with the use of plain language, analogies and key messages.

- Expressing empathy with openness, mirroring, silence. Asking open-ended questions, practicing active listening.

- Fostering empowerment with action orientation, awareness of patient rights and encouragement: coaching patients to speak up and to take action.

"THE BLOCKBUSTER DRUG OF THE CENTURY IS THE ENGAGED PATIENT."

– Leonard Kish



Breakout Groups Developed and Developing Countries

Written by Sara Rothschild

Based on the report provided at the introduction of the meeting regarding survey results, we narrowed down the main topics that are important to address by global GIST advocates. We took those topics and assigned breakout groups for participants to strategize on how to address the obstacles, create solutions, and identify best practices. Breakout groups were divided into 'developed' and 'developing countries' categories.

Clinical Trials (Developed Countries)

The sentiment is that the clinical trial process is "broken" in that there are too many trials, especially clustered at the same medical centers, and they are not the right kind of trials. For some, patients may not participate because of fear of participation as well as a language barrier.

Solutions to address this need include, but are not limited to, the following: Focus on the geographic areas that have a need, start on an easier market such as Europe, set up virtual trials, and develop a business plan with each institution. Creative trial designs were discussed and an introductory wish list was created: 1. Treat resistant GIST, 2. Improve upfront treatment, and 3. Reduce time spent on therapy.

This discussion is the start of a longer dialogue in which advocates will continue to explore objectives to achieve the outcome of better clinical trials for this population.

Diagnostic Tests (Developed Countries)

One of the most common topics discussed over the years at New Horizons meetings, which has also been

confirmed by the international advocate survey, is the lack of mutational testing performed on patients. Participants from developed countries sat together to brainstorm solutions to this problem and came up with the following solutions: 1. the need to mandate mutational testing in clinical guidelines; 2. the need for buy-in from key opinion leaders; 3. the need for accredited pathology laboratories to perform the testing; 4. the need to identify obstacles to overcome the mandate; and 5. The need to highlight the consideration of cost implications which far outweigh the misuse of drugs.

Diagnostic Tests (Developing Countries)

Among the participants from the developing countries, it was clear that they felt strongly that mutational testing needs to be incorporated into government guidelines and that much advocacy is needed to make this happen. The following steps toward a solution were identified:

1. Identify companies developing liquid biopsy techniques
2. Identify foundations willing to donate money to support this testing
3. Develop a key opinion leader network
    - approach international pathology organizations
    - publish results
    - offer tissue bank to compare results
    - decide when is the best time to involve the government
    - in case of recurrence, try to retest pathology DNA testing

Supporting Patient Needs (Developing Countries)

A key foundation that needs to be incorporated in every GIST organization is patient support. Each country has a different culture or view on seeking psychosocial support. For some, there is a stigma attached to seeing a psychologist, and for others there are logistical barriers to overcome, such as the distance to seeing a specialist. Much depends on the stage of disease of the patient and how well they are feeling. The breakout group went around and shared what each organization does to support their patients' needs. A best practice that was highlighted was the use of a chat group on WhatsApp that allows patients to talk with one another.

Strategies identified to enhance patient support include: Allow patients/caregivers to talk while advocates just listen and provide answers to questions (use of "one-liner" information with statistics can be a tool); provide materials with positive messages (this can help to continue to engage them with the local organization); and share patient video testimonies (short clips that address topics of interest from chat forms such as side effects).

Conclusion

The meeting ended with a discussion about the future of the New Horizons GIST meeting. Everyone had the opportunity to speak regarding their preferences to meet again in 2018, dependent on funding. It was unanimous that advocates would like to meet again in 2018 at the next conference which will be held in Europe.

As we plan for the next meeting, we will continue to meet virtually to address the needs outlined in the global survey and to develop our strategies on how to accomplish our goals.

The New Horizons GIST Steering Committee would like to thank again the following sponsors for the 2017 meeting: Blueprint Medicines, Novartis Oncology and Pfizer Oncology.

New Horizons GIST is looking forward to a continued alliance with our global partners to improve the survival of GIST patients and enhance their well-being.

Agenda

Sunday October 1, 2017	
Time	**Presentation / Activity**
During the day	Arrival of all Participants
16:30 – 18:00	General Meeting of the Organizational Team
19:00	Meet in the Lobby of Crowne Plaza Fairfield at 18:45 Transportation to: Antik Greek Kitchen 335 Fairfield Road, Fairfield, NJ 07004

Conference Location: 155 US Highway 46, Wayne Plaza II, Suite 202, Wayne, NJ 07470

Monday October 2, 2017	
Time	**Presentation / Activity**
8:00	Meet in Lobby for Transportation to Conference Location
	Breakfast at Conference Location
8:30	Official Start of the Conference – Welcome, Purpose of the Conference, Thank you to Sponsors Sara Rothschild, Program Operations Senior Director - The Life Raft Group
08:45 – 09:15	Feedback from the Global GIST Community *Presentation of Survey Results* Norman Scherzer and Michelle Durborow - The Life Raft Group
	Emerging therapies and ongoing trials in advanced GIST
09:15 – 09:55	Part I Dr. William Tap, Memorial Sloan Kettering Cancer Center
09:55 – 10:30	Part II Dr. Suzanne George, Dana Farber Cancer Institute
10:30 – 10:45	**Break**
10:45 – 11:15	Circulating Tumor DNA in GIST and its Implications on Treatment Dr. Ciara Kelly, Memorial Sloan Kettering Cancer Center
	Innovative Approaches to Prolong Survival: Case Studies
11:15 – 12:30	Case Study Presentations Dr. Ciara Kelly – Localized Disease Dr. William Tap – Metastatic Disease Dr. Suzanne George – SDH-Deficient GIST
12:30 – 13:30	**Lunch**
13:30 – 15:00	Utilization of Real World Evidence among Different Stakeholders Moderator: Norman Scherzer, Executive Director, The Life Raft Group Patient: Rodrigo Salas, President, Fundacion GIST Mexico *The Role of a Patient Registry in Drug Access and Coverage in Mexico* Physician: Dr. Suzanne George, Co-Clinical Director, Center for Sarcoma and Bone Oncology, Dana Farber Cancer Institute *How Data Informs Clinical Guidelines* Regulatory: Dr. Theresa M. Mullin, Director, Office of Strategic Programs, FDA Center for Drug Evaluation and Research *Patient-Focused Drug Development: Identifying and Building Needed Data Sources to Integrate Patients' Perspectives in Decision-Making* Policy: Dr. Carl Asche, Professor & Director, Center for Outcomes Research University of Illinois College of Medicine; Member of International Society for Pharmacoeconomics and Outcomes Research (ISPOR) *Evaluation of Health Care Interventions and Big Data: Review of Associated Data Issues*

Monday October 2, 2017	
Time	**Presentation / Activity**
15:00 – 15:30	Break
15:30 – 16:00	Collaborative Model to Understand the Patient Experience *Analysis from a Data Project among a PAG, Academia and Pharma* Michelle Durborow, Senior Director of Scientific Operations, The Life Raft Group
	Best Practices
16:00 – 16:30	Access to GIST Treatment in Low and Middle Income Countries: The Good, The Bad, and The Ugly Pat Garcia-Gonzalez, Executive Director, The Max Foundation
19:00	Leave directly from LRG headquarters at 17:00 for Spirit Dinner Cruise on New York City's Hudson and East Rivers.

Tuesday October 3, 2017	
Time	**Presentation / Activity**
8:00	Meet in Lobby for Transportation to Conference Location
	Breakfast at Conference Location
	Best Practices (Continued from First Day)
08:30 – 09:00	Patient Forums: Telling the Patient Story and its Impact on Healthcare Gerard van Oortmerssen, Chairman of Board of Contactgroep GIST, Netherlands
09:00 – 09:30	Improving Patient Advocate-Patient Communication: Principles and Techniques Amy Bruno-Lindner, President, GIST Support Österreich, Austria
09:30 – 10:30	"Speed dating" Roundtables with Patient Advocates and Pharma Topics per table based on survey results 1. Obstacles 2. Possible Solutions 3. Best Practices
10:30 – 10:45	Break
10:45 – 11:45	Wrap Up Discussion
11:45 – 12:45	Future Direction of the Global GIST Patient Community
12:45 – 13:45	Lunch
14:00	General Meeting of the Organizational Team
Departures	

Participants

New Horizons GIST 2017 Meeting Participants

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