NEW HORIZONS GIST

Upgrading NEW HORIZONS GIST to a
Web-based Global GIST Patient
Information, Education and Collaboration Platform…

Outline (1st DRAFT) for New Horizons GIST Conference

15th to 17th of May 2015 in Miami
The History of “NEW HORIZONS”

An annual international “face to face” conference

NEW HORIZONS CML & GIST:

- Since 2003: Initiated and funded by Novartis Oncology
- Program developed by a “Steering Committee CML & GIST”
- Locations: Diessenhofen (CH), Milano, Dublin, Budapest, Baveno (IT), Bad Nauheim (DE), Lisabon, Vösendorf/Vienna, Amsterdam
- New Horizons = developed to a brand in the GIST-World

Common decision in 2011: To separate CML & GIST and to run NH GIST as a “patient owned” multi-funded conference…

- 2012 Paris (Estelle, Markus, et al)
- 2013 Miami (Diana, Sara, Norman et al)
- 2014 Zürich (Martin, Helga, Markus et al)
- 2015 Miami (Diana, Sara, Norman et al)
GIST-Patient Groups around the Globe

North America
South America
Europe

Canada
USA (2)
Argentina
Bolivia
Brazil
Chile
Colombia
Guatemala
Mexico
Venezuela
Cuba
Domin. Republic

Austria
Belgium
Bulgaria
Finland
France
Germany
Hungary
Italy
Netherlands
Norway
Macedonia
Poland
Romania
Spain
(Sweden)
Switzerland
United Kingdom
Ukraine

Israel
Kenya
India
(China)

Informal Network/Website:

GIST-Support:
Conference Funding NH GIST went down since 2012:
Today = 150,000 USD / appr. 130,000,-- EUR (Novartis, Pfizer, Bayer)
In the meantime: It’s challenging to run a global meeting with this budget
Planning, organizing and running means a lot of time/work/engagement
Thought: Is this time/budget used effective/well – by bringing 40 people together?
The profile of “NH GIST” so far - was very much based on
Information – Education – Sharing Best Practice – Networking
The profile of “NH GIST” – was less adequate to produce outcome or solve problems
But after 15 years of GIST: We still have a lot of unmet medical needs!
The Global GIST-Community has
- common/global interests/challenges/topics
- individual/regional interests/challenges/topics – LatAm, East-EU, HTA
Initial Situation (2)

- Very few activities, initiatives, projects – between the different conferences. Mainly inside the two regional networks: Alianza GIST and SPAEN >>> Sustainability???
- Alianza GIST & SPAEN are running their own regional-intl. conferences (Alianza GIST, linked to NH GIST – SPAEN Annual Conf. 19th to 21st of Nov. 2015)
- We still have many regions/countries in the world - without GIST Patient Support/Advocacy Groups - with inadequate basic information about GIST (Middle East, Africa, Asia, Australia…)
- Technology: More and better solutions/services are available to run virtual meetings/collaborations – such as “Webinars”, etc.
- There are initiatives – e.g. Bayer Global GIST Task Force (KOLs) – to invest money into intl. “patient information” >>> But this should be a common task of the intl. “GIST Patient Community” not of the KOLs…
Initial Situation (3)

Instead of moving forward like this and to wait until

- less or no funding is available for these types of “face to face conferences”

and/or

- others (KOLs, Industry) are working on intl. patient information:

Is there a better - more efficient and effective approach
to inform our patients globally and
to collaborate more effective on an international level?
Strategic Approach

- Web-based Global GIST Patient Information, Education and Collaboration Platform…

Diagram:

- Patients, Carer
- Information/Education
- Patient Groups
- Generating Insights/Data from the Community
- Global GIST Platform
- Virtual Education, Exchange, Collaboration
- Other Stakeholders
- Goal-Oriented Collaboration “GIST-Advocacy In Action”
- Experts, Industry

Working Title: New Horizons ePatient Campus GIST
NEW HORIZONS ePatient Campus GIST: Two Main Sections

A) **External** Section of the Global Platform: GIST PATIENTS & CARERS

B) **Internal** Section of the Global Platform: GIST PATIENT ADVOCATES

Ideally: Applicable via Computer, Tablet, Smartphone
Section A: External = Open Web-Platform

A) External Section of the Global Platform: GIST PATIENTS & CARERS

ePatient Campus GIST stands for: ePatient, Education, Empowerment
- Prio. 1: GIST Patients & Carers
- Prio. 2: Other interested stakeholders
- Multilingual > 15 Languages
- Lay language – patient friendly – non scientific
- Interesting aspect > opportunity:
  * Providing information – but also
  * Collecting information/insights/data
Section A: Potential Content/Services

A) External Section of the Global Platform: GIST PATIENTS & CARERS

**GIST: Basic Information:**
- Disease-Diagnosis-Treatment-Follow up
- Available Treatment Guidelines/Charters
- Mutational Analysis
- Therapy- and Side Effect Management

**Understandable profiles and results of intl. available Clinical Trials**

**Future/upcoming topics – e.g. “Generics” or “Immuno-Oncology”**

**Important For The Community:**
Web-Platform > Analytics/Statistics

**Available in >15 languages**
Lay languages, patient friendly, non scientific

**GIST-Patient Support/Advocacy around the globe (overview and links to the national groups)**

**Intl. GIST-Patient initiatives/projects e.g. registries, PAWS-GIST, etc.**

**Email-registration for participating in patient surveys**

**Important For the Community:**
Generating insights/data…
### Section A: Potential 15 Intl. Languages

<table>
<thead>
<tr>
<th>Language</th>
<th>Native</th>
<th>General</th>
<th>Intl. Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>375</td>
<td>1500</td>
<td>5</td>
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<tr>
<td>Chinese</td>
<td>982</td>
<td>1100</td>
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</table>
NEW HORIZONS ePatient Campus GIST: Two Main Sections

A) External Section of the Global Platform: GIST PATIENTS & CARERS

B) Internal Section of the Global Platform: GIST PATIENT ADVOCATES
Section B: Internal = Password Protected User Area

ePatient Campus GIST stands for:

**eAdvocate, Exchange, Engagement**

- Prio.: GIST Patient Advocates
  - Leaders of national GIST-Patient Groups
- English
- Interesting aspect > opportunity:
  * Providing information
  * Sharing Best Practice – but also
  * Collecting information/insights
  * Collaborative projects
### Section B: Potential Sub-Sections/Content/Services

**B) Internal Section of the Global Platform:**

- **GIST PATIENT ADVOCATES**

  **Forum:** Virtual & real exchange/collaboration
  - Online-Forum: News, Exchange, Discussions
  - “GIST-Advocacy in Action”: Position Papers, Roundtables, Task Forces, Tool-Kits, etc.
  - Initiating Group-Surveys, etc.

  **Profiles:**
  GIST-Patient Groups (incl. Contact Details)

  **Monitor:** Treatment Monitor (Interact. Map)
  Access to GIST-Treatments (per country)

**Available in English Editable System >>> Groups**

- **Campus:**
  - Planned & Realized Webinars
  - Conferences/Meetings

- **Experts:**
  Leading GIST-Experts (short profiles)

- **Library:**
  Upload your Materials, Presentations

**Important For The Community:**

- Web-Platform > Analytics/Statistics
- Generating Insights/Data…
Supporting parts of the initiative…

Communication
Social Media

Web-Platform
10-FOR-I.O.
10 Languages

Communication
Classic Media
“GIST Advocacy in Action”

Following a “Strategic Planning Process” we need to work out:

- What are our open needs, challenges, “building sites”
- What are our objectives and how will we measure success?
- Do we have enough knowledge/experience to act – or do we need additional information, training, external support, etc.
- Do we need to collect additional information/data, etc.?
- What are the right tools/initiatives/campaigns – to tackle/to solve them?
  - On a global level?
  - On a regional level?
  - What is effective to do?
- Position Paper, Roundtable, Task Force, Exchange with Experts, Tool-Kits, etc.
- What are max. 2 – 4 feasible “projects” per year.
  - Instead of doing a lot of “hot air” – let’s get the right things done!!!
Some questions to consider…

- How to divide/handle the basic work – to set up the system?
- What are the “set-up” costs – what are annual “maintenance” costs?
- Legal issues – reg. where the system will be hosted/operated? (US Sunshine Act – Funders – Experts etc.?)
- How can we handle the enormous translation efforts? Costs? Reviews?
- Do we get a “long-term” commitment (3 – 5 years) from all Funders?
- Do we see additional Partners for the future?
- …
Our way forward...

1. Discussion / Brainstorming during NH GIST 2015 in Miami
   - Web-experienced volunteers for a small global “Project Team”?

2. Updating / Completing the concept incl. >>>
   - First draft for time line and budget plan

3. Presenting the concept to Industry/Funders and Global GIST Task Force (e.g. ideal start during ASCO)

4. Written proposal for Industry/Funders >>>
   - Funding Requests for 2016

5. Project Team >>> Autumn 2015: Working-Meeting for clear specifications and roles & responsibilities

6. Strategic Planning Process incl. to identify “unmet medical needs” – pot. common projects for “GIST-Advocacy in Action”
   - Action-Plan 2016 - 2018