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	Austria	Israel
USA (2)	Belgium	Kenya
	Bulgaria	India
Argentina	Finland	(China)
Bolivia	France	
Brazil	Germany	
Chile	Hungary	
Colombia	Italy	
Guatemala	Netherlands	
Mexico	Norway	
Venezuela	Macedonia	
Cuba	Poland	
Domin. Republic	Romania	
	Spain	
	(Sweden)	
	Switzerland	
	United Kingdom	
	Ukraine	

Sarcoma Patients EuroNet

Alianza GIST

Informal Network/Website:

Global GIST Network
Crossing Borders to Unite Against GIST

GIST-Support:

The Max Foundation

Initial Situation (1)

- 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: <u>We still have a lot of unmet medical needs!</u>
- 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…
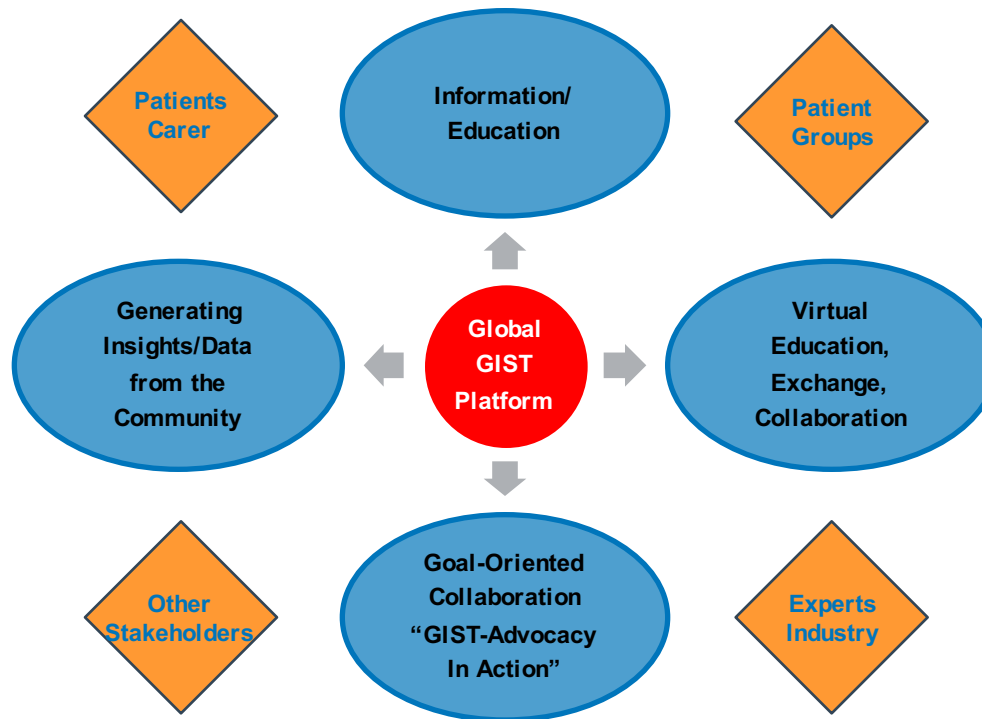
Initial Situation (3)

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
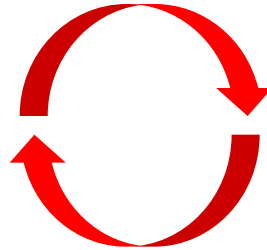**to collaborate more effective on an international level?**

Strategic Approach

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

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: Appicable 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 | Available in >15 languages Lay languages, patient friendly, non scientific |

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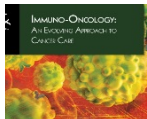- Therapy- and Side Effect Management

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

Understandable profiles and results of intl. available Clinical Trials

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

Future/upcoming topics – e.g. "Generics" or "Immuno-Oncology"

Email-registration for participating in patient surveys

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

Important For the Community: Generating insights/data…
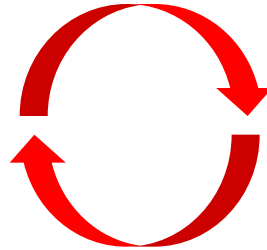
Section A: Potential 15 intl. languages

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

	Native:	General:	Intl. Meaning:
English	375	1500	5
Chinese	982	1100	3
Hindi	460	650	2
Spanish	330	420	4
French	79	370	4
Arabic	206	300	3
Russian	165	275	3
Portuguese	216	235	2
Bengali	215	233	1
German	105	185	3
Japanese	127	128	2
Korean	78	78	1
Italian	70	70	?
Dutch	25	25	?
Polish	46	46	?

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

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

Section B: Potential Sub-Sections/Content/Services

B) Internal Section of the Global Platform: GIST PATIENT ADVOCATES	Available in English Editable System >>> Groups
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.	**Campus:** - Planned & Realized Webinars - Conferences/Meetings
Profiles: GIST-Patient Groups (incl. Contact Details)	**Experts:** Leading GIST-Experts (short profiles)
Monitor: Treatment Monitor (Interact. Map) Access to GIST-Treatments (per country)	**Library:** Upload your Materials, Presentations
Important For The Community: Web-Platform > Analytics/Statistics	**Important For the Community:** 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