

# Recruiting patients and promoting GIST awareness in Italy



Presentation of  
A.I.G. Associazione Italiana GIST Onlus  
by Anna Costato

**May 13-15, 2011 New Horizons - Amsterdam**

# Motivation to start



# Background



- A.I.G. was started in 2006, all-volunteer group
- October 2006: launch of our website
- January 2008, officially founded as non profit organization
- May 2008: listserv/discussion forum started
- A.I.G. acknowledged as **rare disease patient advocacy group**
  - 1 - by the Rare Disease National Center run by Minister of Health
  - 2 - by the Regional Network Co-ordination center for Rare Disease of Lombardy

# Mission



- To supply **Information** and knowledge about GIST to Italian patients, overcoming language barriers. Relevant scientific news and useful information are translated into Italian by AIG volunteers
- To offer **support** to patients and caregivers
- To represent GIST **patient rights** with local and national health authorities
- To promote **research** on GIST with clinicians, pharma companies, hospitals
- To raise public awareness

# Target audience



GIST patients, caregivers and friends

Clinicians

Health institutions

Pharmaceutical companies

Other patients advocacy groups

Medias

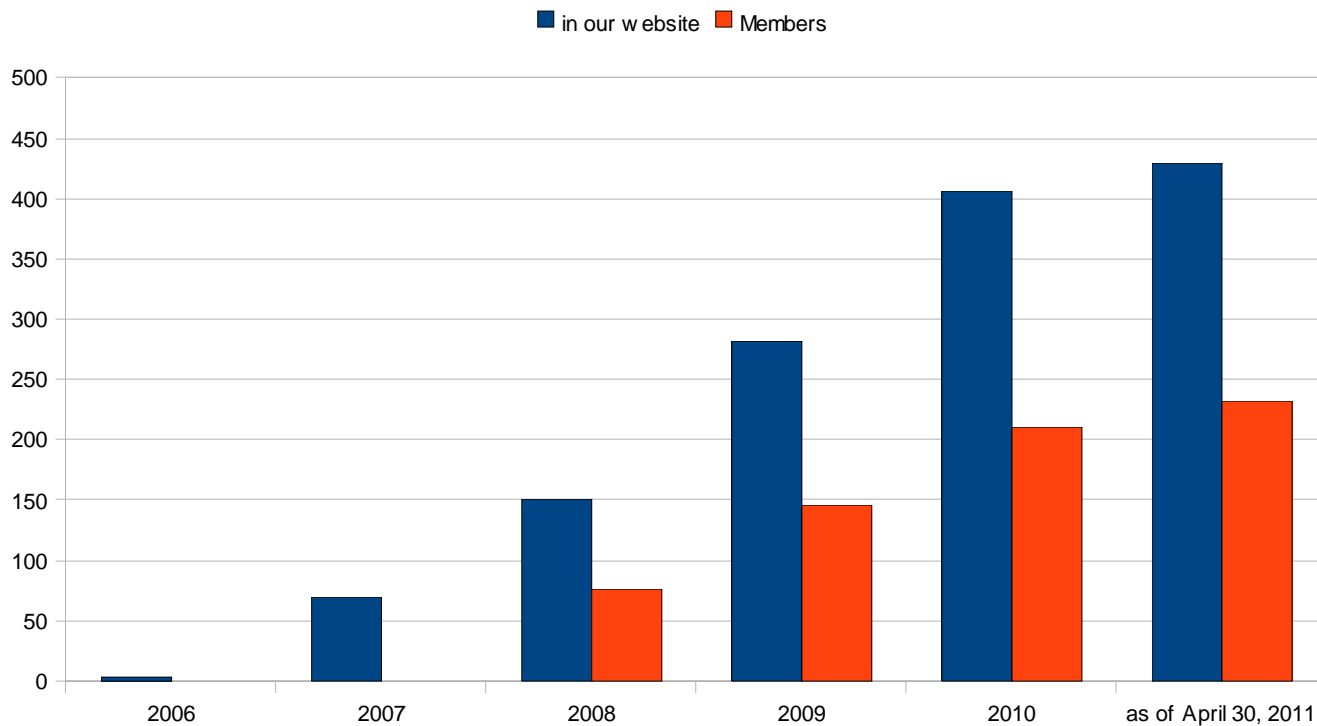
# How many are we?



Number of Patients and Caregivers (as of end April 2011):

450 are signed-in our website

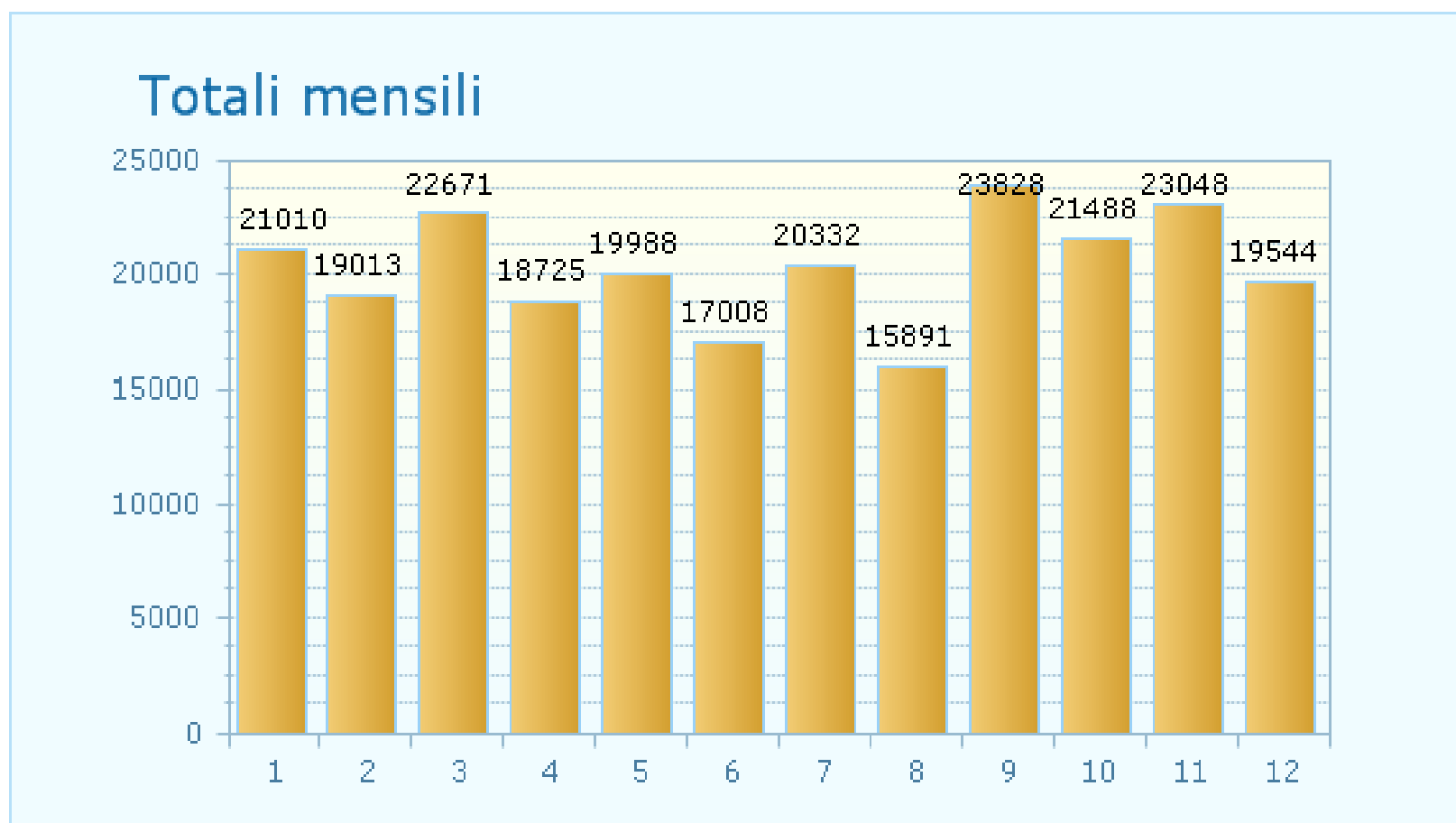
230 are Full Members



# Visits to our website



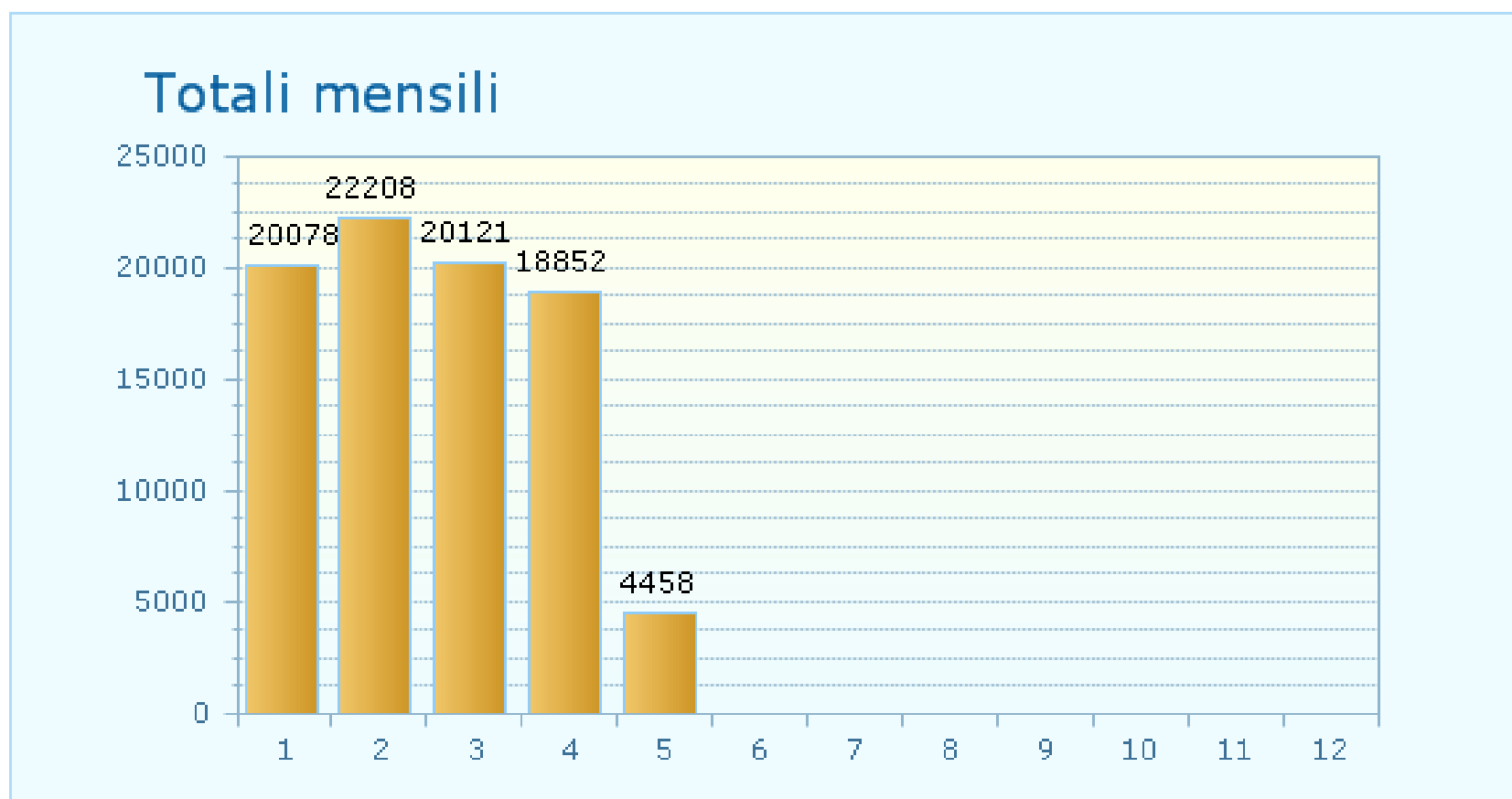
## Monthly Page Views in 2010



# Visits to our website



...in 2011, as of May 5





# Ordinary activity



4 national annual patient meetings in Milan

6 local meetings in 2010 (5 in 2011)

48 monthly newsletters

5 teleconferences among patients and Gist experts

Interviews with oncologists, surgeons and pathologists

Participation in several medical workshops on GIST to make AIG known to the medical community all over Italy

# Some achievements



**Summer 2008:** Promotion of a Laboratory for Imatinib plasma level test for GIST patients at Istituto Nazionale dei Tumori, Milan (lab activity started on January 2010).

**October 2008:** participation of AIG to an important press conference highlighted the need for GIST patients to be followed by experts. Several articles have appeared in medias since then

**November 2009:** RAI3 national television broadcasted a program on GIST, our group and interview with Dr. Paolo G. Casali

<http://www.youtube.com/watch?v=O7VyekHN7ao>

**From Feb. 2010,** 20 videos for Gist patients published on

<http://www.oncologytube.com/gistonline?pro=videos>

(more than 9000 views as of May 5, 2011)

# Projects



- (1) To obtain the **inclusion of GIST in the National and Regional Rare Disease Registers**, providing benefits to rare disease patients, such as
  - a) easier access to off label drug and compassionate use drugs**
  - b) Public fundings to research**
- (2) To obtain important changes in rules about use of **off label drugs in oncology** by **A.I.F.A. Italian Medicines Agency**  
Current laws: barriers for Gister, too strict and unfair
- (3) Fund-raising for research

# Networking is KEY



In order for **ideas** to become **facts**

we network with experts,  
pharma companies,  
other patient communities,  
medias

**and build strategic alliances**

# International partners



Mission: to encourage and support GIST patient resources worldwide and to facilitate information sharing, mutual support and advocacy.



**Sarcoma Patients EuroNet (SPAEN)**  
**Sarcoma, GIST and Desmoid Patient Advocacy Groups.**

Mission: information, support and advocacy to patient organisations across Europe.

# Partners in Italy



**Fondazione IRCCS Istituto Nazionale dei Tumori, Milan** (main cancer research and treatment center in Italy)



**RTR National Rare Tumors Network** (100+ facilities)



**ISG Italian Sarcoma Group** (300 clinicians)

**UNIAMO Rare Disease Italian Federation**  
(95 advocacy groups, 600 rare diseases)



# Example of profitable partnership



## Istituto Mario Negri in Milan



Most important pharma research institute in Italy. Non-profit organization on biomedical science.

In 2007 they wrote the first Gleevec and Sutent drug interaction guideline for Italian Gisters and their doctors.

MN manage telephone service on drug inteaction to public in general: great relationship established for info to Italian Gisters!

# Success factors



- Active leaders
- Medical knowledge and interest in research
- Knowledge of national health system, laws and rules
- Networking with the experts
- Networking with other patient groups
- Building strategic alliances with clinicians, researchers, pharma companies and other patient groups
- Participate in clinicians' meetings (visibility)
- Credibility and good reputation: good public image!
- Transparency in relationship with pharma & other donors



# Challenges



Group activity wholly based on voluntary commitment:

- a) small number of active members
- b) full time jobs and other personal engagements: limits
- c) lack of time

Group continuity at risk

Limited resources: donations and member fees

(at present no other pharma support, but Novartis)

Operating difficulties

Time consuming and strict law requirements for non-profit organizations

# Take home message



Strategic alliances are crucial:

**never work alone (neither as a group, nor individually)**

Networking, sharing experience and learning from one another is  
**the first key to success**

National and international partners can help you reach your goals

**Focus on important partners who can make a difference**

Be prepared to share and reciprocate

Be prepared for hard work

Don't get discouraged and be resourceful: many rely on you

Be creative

Your energies are not UNLIMITED: focus on what really matter

**Remember your message will reach more people than you think!**

# Last...



Whatever you do, there can always be someone who does not like what you do or how you do it.



**Don't get discouraged, the most like you!**

## Support among patients



.....and among patients, doctors, & researches

# Project Attribution



Anna Costato together with the Board of Directors of  
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