



# Creating dialogue and engaging patients organisations in research: the INSERM case

## Patients organisations and research

The patients organisations are more and more interested in research:

- They have an expertise of “disease experience”
- They participate actively to clinical trials, survey, data bases and biological samples collections etc.
- They are active in the diffusion of recent scientific information
- They financially sustain research projects
- They organize large public communication events

Since the emblematic actions of AIDS associations and the muscular dystrophy association, the trend to become partner of the research institutions is strongly claimed by a great number of patients associations, in a great diversity of diseases and handicaps.

## Participation and dialogue with INSERM

As the main research institute dedicated to research for health in France (350 laboratories, 15000 researchers and coll), Inserm has entered into dialogue with patients organisations, being convinced that

*“the research for the benefit of sick persons can progress only on the condition that we work with them”*

## How to create dialogue?

### 3 Pillars

1. Strategic committee with the patients organisations (GRAM) (composed with 8 associations, 4 researchers and 5 administrative heads) linked directly to Inserm Director  
→ makes recommendations, sets priorities and follows the actions
2. A *liaison* office with patients associations : “open door” for the associations, in charge of coordination
3. An annual meeting with the patients organisation

## Principles

the GRAM elaborated some principles and requirements from which Inserm draws its inspiration in order to develop its opening policy:

- recognition of legitimacy and of specific competences of associations
- encouragement to lead partnership operations
- transparency of actions

Even if all patients associations are not interested in research, those that are interested are privileged interlocutors for Inserm without size or financial requirement.

## Actions

### 4 big projects

- Associations integration into scientific strategic committees
- Upstream participation in clinical research
- Capacity building
- Information - communication

## What has been achieved so far...

38 associations are members of the strategic committees of 8 national research programs (cardiovascular, nephrology, endocrinology and reproduction etc.)

College of reviewers for the clinical protocols to assess quality and pertinence of the information given to the patients:  
General call to all associations, 69 candidates, training

Training programs on “how to read a protocol”, “how to search for biomedical information on the web”, “how to organise a scientific survey”, “how to build a data base”:  
11 sessions with 158 participants in 2006,  
3 sessions with 50 participants in 2007

Data basis documented for the implication of the associations in research : 317 French patients, disabled people and families associations and 77 European federations (<http://www.cipast.org>)

An information platform at <http://www.associations.inserm.fr>

Participation of Inserm to European projects: Cipast and Capoira (capacity building for patient organisations in research activities - )