

---

Patients Organizations and Industry Donors:  
**BUILDING SUSTAINABLE RELATIONSHIP**

EMSP ANNUAL CONGRESS, BRUSSELS MAY 12/13, 2011

Jean-François GRENIER, M.D.  
PharmExpand SPRL

# It Can and Does Work

- All these companies support EMSP regularly, even though it is not your purpose to help them sell their drugs...
- Nothing matters to decent people in the industry more than making sure patients get the best possible treatment
- Because in today's environment, industry has not only a moral but legal and financial obligations to demonstrate that their drugs are promoted and used appropriately:
  - Right patients
  - Right way



Source: François Meurgey, OUKELOS SPRL

# What Partnership Should NOT Look Like...



Source: *TheGloss.com* & *Scientific American*

# What Do Pharma Companies Want?

---

- They want to understand patients' perspective on the disease
- They want to help patients improve the quality of their dialogue with physicians, particularly highly-trained specialists
- They want to recruit patients in their clinical trials
- They want reimbursement for their latest product
- They want to maximize compliance to treatment
- Of course, they want to sell their products!

*Source: François Meurgey, OUKELOS SPRL*

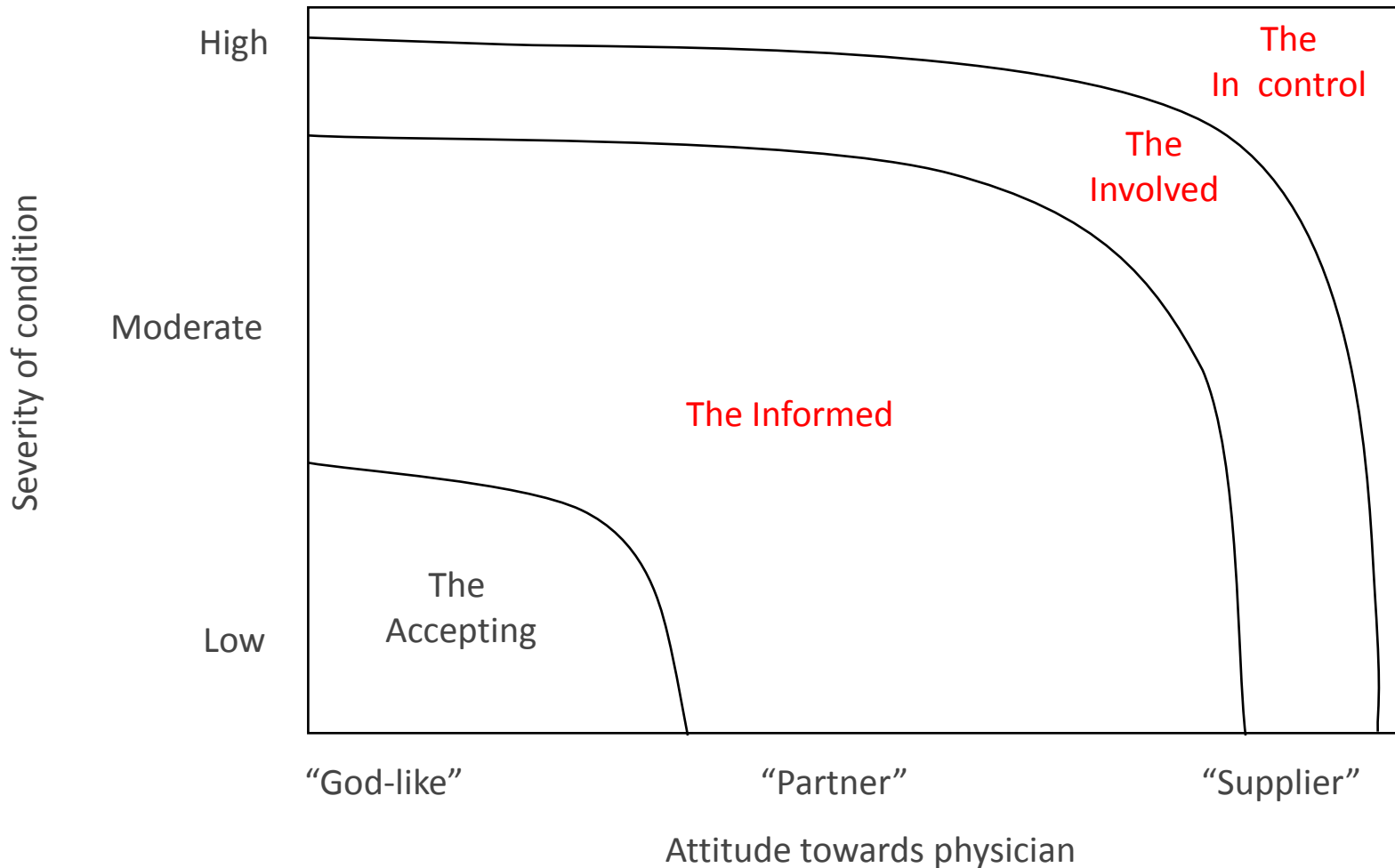
---

# The Patient Is No Longer Passive...



Source: *British Medical Journal* 1999; 319(18 September): 762.

# Patients Are Getting More Involved



Source: Harris Interactive 10,000 patient survey (Oct-99) and BCG analysis

# Pharma has (finally) recognized the importance of patients and their needs

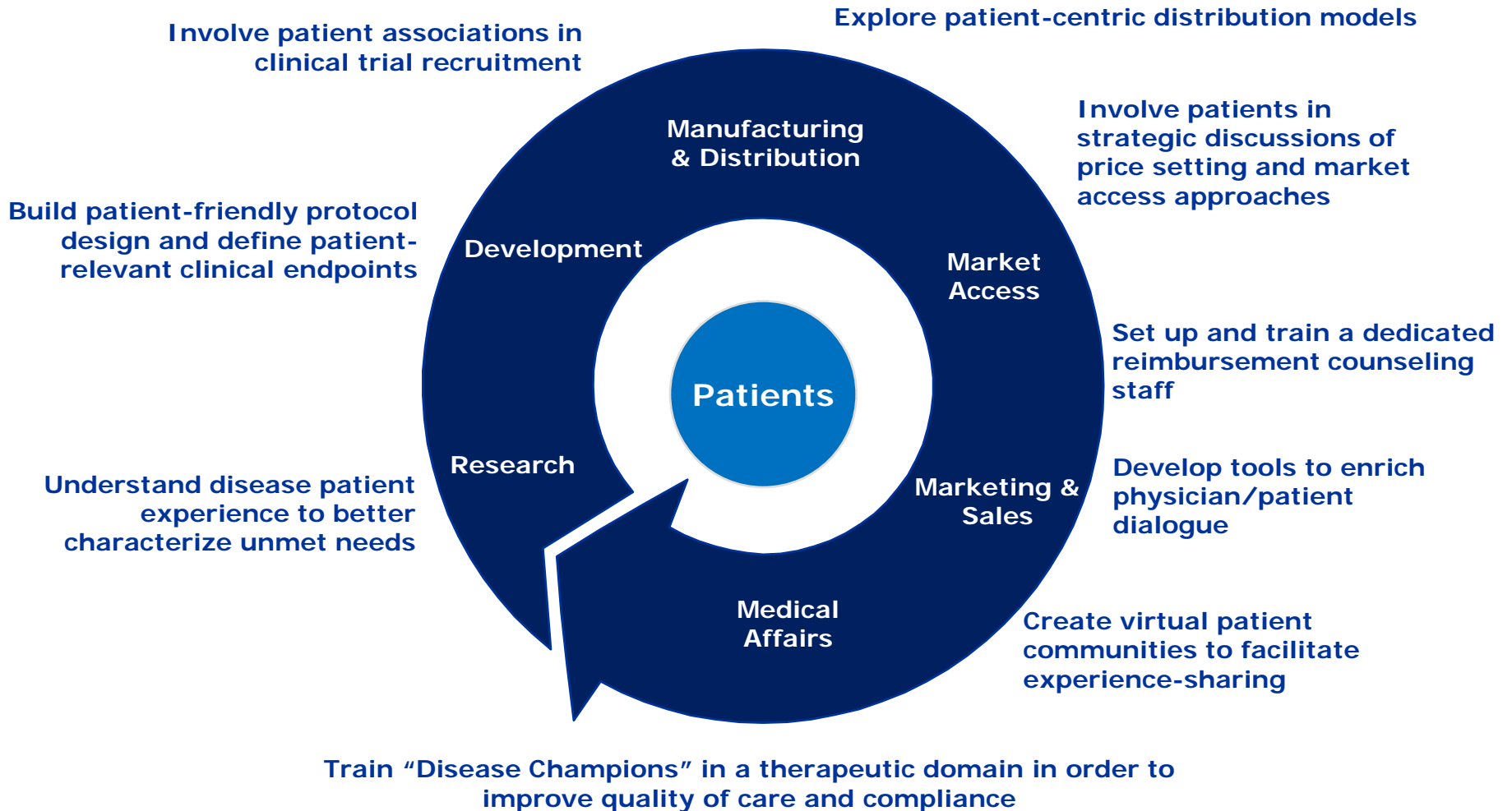
---

## Shift of Focus



Source: [healthcarepackaging.com](http://healthcarepackaging.com) & [forumed-santé-dz.org](http://forumed-santé-dz.org)

# Patient-Centric Value Chain





## Possible Initiatives by PharmaCo

---

- Establish standing Patient Advisory Board by disease
- Make patient insight a key component of Brand Plan
- Involve patients systematically in developing
  - Promotional materials (tone, language, images,...)
  - Market Research questionnaires
- Provide forum for NGOs to share best practices on patient support services
- Help patient support groups with admin/PR support
- Pilot “total care” solution for severe chronic disease
  - Nurse program
  - Smartphones and Online support (disease information, drug compliance, patient diary, physician finding, respite for caregivers, etc)

Source: François Meurgey, OUKELOS SPRL

---

# A few words on Partnership

---

## Partnership

- Is an arrangement where parties agree to cooperate to advance their mutual interests
- Can greatly benefit individuals, entities, and societies
- But can also greatly damage the partners
  - Conflict of interest
  - Ethical problematic



## Partnership: Basic Principles

---

- Mutual respect for the aims and integrity of each party
- Familiarise with each other's structures and key people
- Delineate clearly what you are not ready to do for each other, and agree on where your collaboration will stop
  - You will never promote, endorse or recommend their pharmaceutical product
  - Will not give or share your lists of members or patients

*Source: Relationship between the EMSP and the pharmaceutical industry – Code of conduct & François Meurgey, OUKELOS SPRL*

---

## Go for Long-Term Relationship

---

- Identify areas where you can both benefit from a sustained effort
- Have a candid discussion with your industry counterparts about **your** and **their** Short-Term and Long-Term objectives
- Compare and contrast your goals and identify very precisely areas of common interest and programs you can run together

*Source: François Meurgey, OUKELOS SPRL*

---

# You and the industry partner have many common interests

---

- The well-being of people with MS
- Understanding of MS and the need for treatment
- Development of new and more effective treatments
- Rigorous clinical trials of drugs
- Take-up of effective drugs
- Education of patients and families
- Education of physicians

*Source: Relationship between the EMSP and the pharmaceutical industry – Code of conduct*

---

# Starting on the Right Foot

---

- Arrange a face-to-face meeting once contact has been initiated
- Present:
  - your advocacy mission
  - your clear and transparent general objectives
  - your specific program objectives
- Explain how your group operates in terms of industry relationships
- Understand how the industry donor itself work

*Source: François Meurgey, OUKELOS SPRL*

---

# Preserving Your Reputation

---

- You cannot and should not under any circumstances compromise on your core values of:
  - Independence
  - Integrity
  - Transparency
- Know when to say “NO”
- Diversify your sources of funding so that you never become too dependent on one donor
- Consider that all your agreements are “public” even if they are written “in confidence”

*Source: François Meurgey, OUKELOS SPRL*

---

# Establishing Trust

- Behave in a business-like manner:
  - come prepared
  - keep your commitments
  - be discrete about your discussions
- Be honest and direct
- Don't avoid difficult discussions
- Keep and share minutes of your meetings
- Communicate regularly
- Don't hesitate to give positive and negative feedback to each other
- Establish written contracts detailing the support you will give each other (financial, personal, other commitments)



Source: François Meurgey, OUKELOS SPRL



# Written agreements between patient organisations and the pharmaceutical industry

---

- Name of the activity
- Names of partnering organisations
- Type of activity (unrestricted grant, specific meeting, publication, etc.)
- Objectives
- Agreed role of the pharmaceutical company and patient organisation
- Time-frame
- Amount of funding
- Description of significant indirect/non-financial support (donation of PR agency's time, free training courses, etc)
- Code(s) of practice that apply
- Signatures

*Source: EFPIA CODE OF PRACTICE ON RELATIONSHIPS BETWEEN THE PHARMACEUTICAL INDUSTRY AND PATIENT ORGANISATIONS*

---

# Practical Tips for Fund-Raising

---

- Approach companies well ahead of product launch in your country
- Identify and develop relations with Medical Affairs, Marketing and whenever possible with the General Manager
- Inquire about the donor's budget planning cycle
- Always contact pharma companies in Spring: when they develop their next year's budget
- If possible, agree on a multi-year program and obtain a multi-year commitment
- Create an League for MS in your country where all pharma companies are represented and engage in common projects
- Think creatively beyond pharma: medical devices, imaging companies, disability aids and devices...

*Source: François Meurgey, OUKELOS SPRL*

---

## Companies currently developing MS drugs

---

- Novartis: fingolimod (Gilenya®) oral, approved
- Teva/Active Biotech: laquinimod - oral, Ph. III
- Biogen-Idec: daclizumab (Zenapax®) – IV, Ph.III
- Genzyme: alemtuzumab (Campath®) IV, Ph.III
- Sanofi-aventis: teriflunomide, Ph. III
- Roche: rituximab (Rituxan/MabThera®) IV, Ph.II/III
- Opexa: cell therapy (Tovaxin®) sub-Q, Ph.IIb
- J&J/Centocor: CNTO 1275 – sub-Q, Ph.II
- Roche/Biogen: ocrelizumab – IV, Ph.II
- GSK: finategrast – oral, Ph.II
- GSK: ofatumumab (Arzerra®) Ph.I

## Facts of Pharma Life

---

*“In this world nothing can be said to be certain, except death and taxes.” Benjamin Franklin*

*“In the pharmaceutical world, nothing is certain, except **patent expiry** and taxes!”*

- Some of your sponsors will disappear, either because their drug:
  - has failed in clinical trials
  - Has been genericized
  
- You should be able to anticipate these things, and prepare for this eventuality

*Source: François Meurgey, OUKELOS SPRL*

---

# Sustainable Partnership: Goals achieved!

---



Source: *iStockPhoto.com*