Patients Organizations and Industry Donors:

BUILDING SUSTAINABLE RELATIONSHIP

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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…

“Sorry Doctor, but again I have to disagree.”

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
Patient-Centric Value Chain

- Involve patient associations in clinical trial recruitment
- Build patient-friendly protocol design and define patient-relevant clinical endpoints
- Understand disease patient experience to better characterize unmet needs
- Explore patient-centric distribution models
- Involve patients in strategic discussions of price setting and market access approaches
- Set up and train a dedicated reimbursement counseling staff
- Develop tools to enrich physician/patient dialogue
- Create virtual patient communities to facilitate experience-sharing
- Train “Disease Champions” in a therapeutic domain in order to improve quality of care and compliance

Medical Affairs
Research
Development
Marketing & Distribution
Manufacturing & Distribution
Market Access
Patients
PharmExpanding
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: firategrest – 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