



INTERNATIONAL PSORIASIS NETWORK FOUNDING MEETING

November 18, 2005 - Paris - France

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Foreword

Following the European Congress on Psoriasis Paris 2004, many participants have been very interested by the existence of Psoriasis National Clubs like in Italy.

Such clubs are based on collaborations between hospitals based dermatologists and dermatologists working in private practice and willing to join their efforts to perform clinical and therapeutic studies.

This kind of association seems of major importance now with the development of biological treatment and the need to study large cohort of patients.

Moreover, the quick development of very strong patients' associations in many countries offers a very good opportunity of collaborations between the national psoriasis club and the national associations of patients to work together for better care.

In this perspective, a short meeting was held in Paris in between the countries willing to develop such national psoriasis clubs and willing to connect this club in a friendship international network. 11 countries were able to send a representative and 9 additional countries have expressed a strong interest but were unable to come for different personal reasons. The President of the EUROpean associations for PSORiasis patients (EUROPSO), Michèle Corvest was kind enough to participate in the meeting.

This meeting has been organized with MCI, the communications and events management group in charge of the organization of the European Congress on Psoriasis 2004 and of the International Congress on Psoriasis 2007.

List of participants

>> Dermatologists

Prof. Hervé BACHELEZ, France
Prof. Luca BIANCHI, Italy
Prof. Michel de la BRASSINE, Belgium
Prof. Menno A. De RIE, Netherlands
Prof. Nejib DOSS, Tunisia
Prof. Louis DUBERTRET, France
Prof. Janos Laszlo HUNYADI, Hungary
Prof. Seija-Liisa KARVONEN, Finland
Prof. Andreas KATSAMBAS, Greece
Prof. Bardur SIGURGEIRSSON, Iceland
Prof. Jon STEINSSON, Iceland
Prof. Georg STINGL, Austria
Prof. Slavo URBANCEK, Slovakia

>> EUROPSO

Mrs Michèle CORVEST, France

>> MCI /Organization of the International Congress on Psoriasis 2007

Mr. Philippe FOURNIER, France
Mrs Emmanuelle VIAU, France

Countries willing to join the international network and unable to attend the founding meeting

>> China

>> Croatia

>> Germany

>> Ireland

>> Japan

Creation in 1985 of a society composed of 16 (one from each region) dermatologists or GP specialized in dermatology / 2 meetings a year / projects: epidemiology, quality of life, therapeutic guidelines, etc.)

>> Korea

Creation in 1966 of the Korean Society for Psoriasis / ready to chair one of the next meeting

>> Norway

>> Spain

Creation of a club 2 months ago.

>> United Kingdom

Next contacts

>> Algeria

>> Argentina

>> **Brazil**

>> **Canada**

>> **Czech Republic**
Prof. Petr Arenberger

>> **Denmark**

>> **Morocco**

>> **Sweden**

>> **Switzerland**

>> **USA**

What's going on?

>> **In Austria**
Prof. Georg Stingl

- 95 % of patients are treated in hospital because GP usually do not prescribe/initiate systemic treatment
- Collaborations with patients organizations are developing since biological treatment is available
- 1 psoriasis working group in the national Society of dermatology, this group could lead to creation of a larger club (subjects/activities of the existing group: make guidelines, organize meeting to educate patients, standardize treatments/methods)

>> **In Belgium**
Prof. Michel de la Brassine

- 2 patients associations
- 1 club of 6 dermatologists: 2 dermatologists from private practice, 2 young dermatologists, the Pdt and the V-Pdt of the national society of dermatology
- Fundings thanks to the industry through a foundation who supports research and network
- A letter has been sent to involve Belgium dermatologists (650)

>> **In Finland**
Prof. Seija-Liisa Karvonen

- 200 dermatologists
- Good network organization
- Very active patients associations
- Very active scientists
- 1 survey/common register on systemic treatment with follow-up of patients for daily practice in progress

>> **In France**
Prof. Hervé Bachelez and Prof. Louis Dubertret

- An association: managed by a scientific committee of 16 dermatologists, a support from pharmaceutical companies, an official recognition from the French Society of Dermatology in progress
- A survey was sent to about 3600 dermatologists with 2 questions
 1. Do you want participate in a meeting on psoriasis?
 2. Do you want to participate in clinical research studies?

- 700 positive answers: 200-300 have participated in the first surveys (180 for free, 300 paid)
- 2 ongoing surveys:
 1. A survey analysing the clustering method on 1480 patients
 2. A survey involving 1420 patients about their therapeutic needs (30% require systemic treatment, 10% eligible for biological treatment)
- Exchange with patients associations
- 3 scheduled research program:
 1. Build a medical report software for psoriasis
 2. Validate a psoriasis score already accepted by EMEA
 3. Develop a methodology to share the medical decision with the patients
- 2007: project with Serono to follow a cohort of 2000 patients

>> In Greece

Prof. Andreas Katsambas

- Meetings on psoriasis
- Marketing to mass media: to sensitive people to go to doctors
- Psoriasis units and outpatients clinics to unify
- A patient association to be set up

>> In Hungary

Prof. Janos Laszlo Hunyadi

- 3 universities involved in psoriasis
- 3 patients organization
- Connections to build in between different organizations
- 1 club for research to be created

>> In Iceland

Prof. Bardur Sigurgeirsson and Prof. Jon Steinsson

- 20 dermatologists
- A strong patients association
- An informal network of scientists who works on psoriasis
- Forum for guidelines on psoriasis and eczema about to begin

>> In Italy

Prof. Luca Bianchi

- 1st club created in Europe
- Psocare: a national project developed in every region to create specialized centers for psoriasis in Hospital and University Hospitals with the following goals: education, common guidelines, choice of systemic therapies, quality of life
- Strong patients association (Adipso)
- Next meeting: February 2006

>> In Netherlands

Prof. Menno A. De Rie

- 1 club to be set up
- 1 psoriasis patients organization

>> In Slovakia

Prof. Slavo Urbancek

- 1 group of 16 active members
- Activities/subjects of interest: quality of life, presentation of dermatology meeting, etc.

>> In Tunisia

Prof. Nejib Doss

- Many cases of psoriasis
- 1 club is being set up with connections with Algerian and Moroccan colleagues

>> EUROPSO

Mrs Michèle Corvest, President

- Can support creation of national association in countries willing to
- Go-between with the French psoriasis club (ARP) and the APLCP
- Member of IFPA, International Federation of Psoriasis Associations

What about a national psoriasis club?

Summary of the propositions around the table

>> Why such a club is needed?

- Involve practitioners in research: “patients is the base of research”
- Make clinical and therapeutical research
- Increase the quality of care
- Share experience and knowledge
- Give a different perspective to psoriasis (in relation to research network and association of patients)
- Strengthen connections in clinical and therapeutical research

>> What is a club?

- A working group of people interested in psoriasis (clinical and therapeutical research)
- Based on friendly relationships

>> Who can be part of a club?

- Dermatologists: practitioners from hospitals, private practice, etc. depending on the country
- It is opened to patients but they are not member

>> How is organized a club?

- Organization (formal/informal) of the group depends on the country: it can be a society (e.g.: in Japan, Korea, etc.), an association (e.g.: in Italy), etc...
- To get fundings, the club needs somehow to have an official/administrative existence or to be linked to an official entity

>> How to set up a club?

- On an informal basis:
 - Contact people interested in psoriasis by sending a questionnaire to every dermatologist
 - With the ones wishing to be involved, organize a national meeting (on the agenda: discussions about goals to reach and projects to be developed)
 - Once some actions have been launched and a kernel is built, the newborn club can ask for an official recognition from the national society of dermatology
- On a formal basis:
 - Contact the board of the national society of dermatology to create such a club

Why collaborations in between countries are important?

Summary of the propositions

>> Why collaborations are needed?

- Learn from the experience of others: from how to create a psoriasis club to therapeutic strategy to how each country pushes research, etc...
- Share: common study and guidelines (although guidelines are based on data and studies and the way they are interpreted are very specific to the country)
- Clinical research on problem involving a small number of patients needs to be done on a transnational level
- Important for small countries

>> On which subjects?

- Surveys on specific treatments
- Follow-up of patients for daily practice
- Education
- Guidelines

>> Who will be in charge of the international secretariat/coordination?

- a permanent administrative structure is needed
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How to liven up the international network?

Summary of the propositions

>> A newsletter

- **Language?**
 - In English only
 - In English and in the native language of the physician who publishes information
- **Form?**
 - On line -and printed according to the fundings-
- **Periodicity?**
 - Between 2 to 4 times a year, probably 3
- **Contents?**
 - Define a common editorial line
 - How each country works on psoriasis (national interpretation of guidelines, clinical trials, information on new drugs -although many treatments are very expensive and not available in some countries-, research such as thesis which are not usually published, updated information on what's going on in national clubs)
 - Events
 - Information delivered by patients associations and interesting for them
- **Circulation?**
 - if printed, to the members of the national psoriasis clubs through their national scientific board

>> A website

- **Language?**
 - English
- **Contents?**

- The newsletter
- The email of participants
- Information for patients
- A forum according to the budget
- **Publishing and editing?**
 - In each country, one member of the club can update/publish directly the information on the website
- **Access?**
 - Full access: members of the club
 - Limited access: for non members
 - Incitements to join the club
- **Who will be in charge?**
 - A permanent secretariat with the help of web design firm

>> The international Congress on Psoriasis

- **Administrative organization**

Where will be held the next international congresses on psoriasis (2010, 2013, 2016, etc.)?

2 solutions have been discussed:

1. Moving from one country to another in order to involve further each national psoriasis club. the choice of the country would be done by secrete vote or according to his level of activity (the congress will take place in the country of the most active club)
2. Staying in Paris where the last congress was held

Solution voted: staying in the same country (Paris) for convenience's reasons

Who will get the presidency of the international congress on psoriasis (2010, 2013, 2016, etc.)?

Since the place stays the same, the general rule is that the presidency should rotate from one club to another.

France will keep the presidency for 2007 (400th anniversary of the foundation of Saint Louis Hospital).

How the money back of the international congress on psoriasis (2010, 2013, 2016, etc.) will be used?

3 solutions have been discussed:

1. The money back has to help the club in charge of the organization of the congress
2. The money back has to help the international secretariat
3. The money back has to help both the club in charge of the organization of the congress and the international secretariat

Solution voted: the money back will support international secretariat (70%) and national psoriasis club (30%)

- **Scientific committee for the 2007 international congress**

Who is part of the scientific committee?

2 solutions have been discussed

1. A limited scientific committee taking advice from each national psoriasis club
2. A large scientific committee with a representative of each national psoriasis club

Solution voted: a limited scientific committee -to be appointed soon- taking advice from each national psoriasis club

How the scientific programme will be prepared?

The organizing club will prepare a draft letter asking 2 to 3 propositions of subject/speaker to each representative of national club (or club to be). From the answers collected, a draft programme (general scheme) will be prepared, then sent to each representative of national club (or club to be). The final programme will be decided on April 6-7 2006 (April 6: 17.00-20.00/ April 7: 8.30-17.00)

***Reminder** : The International Congress on Psoriasis 2007 is a meeting mainly for practitioners. It focuses on clinical treatment with of course, a few talks on physiopathology.*

Organization of the International Congress on Psoriasis 2007

Solutions proposed by MCI / Ph. Fournier

>> Organization of the previous European Congress on Psoriasis 2004

- Previous European Congress on Psoriasis organized in 2004 by MCI
- 615 registrants: 94% Europe, 3% Asia, 3% America

>> Organization of the International Congress on Psoriasis 2007

- Same logo with different colors
- Different visual
- Website: www.pso2007.com
- Email address: pso2007@mci-group.com
- Location: palais des congrès
- Proposed agenda (cf. 2004 meeting)