

The logo for EUROPSO, featuring the text "EUR:O:PSO" in white, with a dotted circle around the letter "O".

EUR:O:PSO

# II YOUTH ROUND TABLE

*OF YOUNG PEOPLE WITH PSORIASIS AND/OR PSORIATIC  
ARTHRITIS*

**13th-15th March 2015**

**Barcelona, Spain**

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# OUTCOMES OF THE II YOUTH ROUND TABLE – EUROPSO

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## *INTRO*

The II Youth Round table took place in Barcelona 13-15 March 2015 and it was hosted by EUROPSO.

The II Youth Round Table (YRT) gathered 13 young representatives with Psoriasis and/or Psoriatic Arthritis from 8 countries of which 7 countries are members of EUROPSO (Croatia, Slovenia, Spain, Germany, Finland, Norway and Sweden). This year YRT was also joined by a representative from Serbia as a guest (Serbia is a future member of EUROPSO).

II YRT was also joined by representatives of “Mas che ideas fundacion” with whom EUROPSO established cooperation for future projects, a representative of Myeloma Patient Europe (Chairman), and specialists and representatives of pharmaceutical companies.

## *GOALS*

There were several goals to achieve by organizing II YRT:

- To give an opportunity to young representatives to meet face to face to discuss important subjects and to develop ideas,
- to provide education for young representatives,
- to create a video manifesto,
- to create a document manifesto – Psoriasis and psoriatic Arthritis Youth European Manifesto (PAYEM).

## *CONCEPT*

The concept of the YRT was as follows:

1. Educational part – consisted of three conferences lead by specialists for Psoriasis and Psoriatic Arthritis
  2. Workshops – three workshops with the goal to discuss important topics and to summarize results of the workshops for creating video and document manifestos (PAYEM)
  3. Filming of video manifesto
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# 1. DEVELOPMENT OF THE II YRT AND HIGHLIGHTS

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The opening of the YRT started with a welcome on behalf of EUOPSO presented by Ms. Celia Marin (EUOPSO Board member), Ms. Inka Marinic (Secretary of EUOPSO) and Mr. Ottfrid Hilmann (EUOPSO Board member).

Ms. Inka Marinic presented the work of EUOPSO and future projects, and together with Ms. Celia Marin briefly presented what the goal and the concept of II YRT are

Mr. Alfonso Aguaron, Chairman of Myeloma Patients Europe took the role of moderator of the YRT and gave an overview of the concept of the workshops which would follow after the specialist presentations in the educational part.

After the overview of the tasks for young participants Mr. Alfonso Aguaron introduced the speakers of the educational part.

## ***THE EDUCATIONAL PART***

The education of the young representatives started with the three sessions/conferences respectively held by physicians

### **CONFERENCE 1 Dermatology: “Psoriasis treatments in young patients. New developments and future expectations”**

**Dr. Lluís Puig, MD. PhD.**

Director, Department of Dermatology Santa Creu i Sant Pau Hospital

Professor, Universitat Autònoma de Barcelona

### **HIGHLIGHTS: key messages**

Dr. Puig singled out metabolic syndrome/co- morbidities in psoriasis. He also pointed out that GP’s are not aware of the importance of the metabolic syndrome in Psoriasis. Awareness of that should be raised among GP’s. Excess weight is an important issue and people with psoriasis should pay attention to that (also they need to be educated about BMI). Psoriasis is not only a skin condition!

Dr. Puig also explained the mechanism of immunological reactions in people with psoriasis and treatment options.

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One of the most important messages to young participant was – “You need to lobby to politicians to allocate the money for the best treatment. Lobbying requires knowledge.”

## **CONFERENCE 2 Rheumatology: Psoriatic arthritis: Joint clinic dermatology – rheumatology**

### **Dr. Anna López Ferrer**

Dermatologist Santa Creu i Sant Pau Hospital

Psoriasis Unit and joint clinic with psoriatic arthritis

### **HIGHLIGHTS: key messages**

“Psoriatic arthritis has a progressive course. Late diagnosis and treatment can lead to physical disability.”

We as dermatologists should screen all patients with psoriasis in order to detect psoriatic arthritis as soon as possible. Dr. Ferrer presented clinical manifestations of PsA types and treatment.

According to GRAPPA recommendations Psoriatic Arthritis has to be treated depending on different types and severity.

Joint clinic:

Dr. Ferrer asked participants what they think about a Joint clinic where dermatologists, rheumatologists and psychologists would work together. All participants agreed that it would be more than necessary to work that way.

Examples of Joint clinics were presented. It was pointed out that people with Psoriasis and psoriatic Arthritis do not usually mention to dermatologists whether they have joint problems because dermatologists are more focused on skin problems and vice versa. Therefore multidisciplinary cooperation is the best way to treat people with Psoriasis and Psoriatic Arthritis. It is also very important for patients to have access to nurses – Dr. Ferrer explained.

After the presentation of the Joint clinic, Inka Marinic asked Dr. Ferrera about this model of Joint clinic – is that something specialists during congresses discuss among themselves, what are the possibilities of the development of such clinics as a standard in treatment in other European countries?

Dr. Puig joined the discussion and pointed out that there is usually one rheumatologist per three dermatologists (so the number of specialists is not in balance). Rheumatologists are usually more specialized for Rheumatoid arthritis and not all dermatologists are specialized for Psoriasis. Psoriatic

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arthritis requires the interest of a specialist for that particular field and it is very complicated because it requires also cooperation with other specialists like dermatologists.

Mr. Alfonso Aguaron mentioned that almost all patient associations lobbying for multidisciplinary approach.

### **CONFERENCE 3 Psychology: The psychological effects of psoriasis/psoriatic arthritis on a young patient. Support elements and help tips.**

#### **Dr. Sandra Ros**

Psychologist, Department of Dermatology Santa Creu i Sant Pau Hospital

Spanish Group of Dermatology and Psychiatry Member

#### **HIGHLIGHTS: key messages**

Dr. Ros presented the work of psychologist in multidisciplinary team of Dermatology Department.

Psoriasis as visible disease is tremendous burden for people, especially young. She stresses out importance of working on self-esteem and way of accepting disease, coping mechanism, importance of group work and support. As it is known that Psoriasis is one of the diseases surrounded with stigma, myths, prejudice, discrimination she sent a message to participants that change need to come from the inside of each individual rather than expecting that society will change first.

It is important to keep inform society about nature of Psoriasis in order to break stigma, discrimination etc. Awareness is important. But even more important is to encourage people with Psoriasis to continuously working on fighting depression, fear of judging and rejecting, and empowering self esteem.

Lively discussion started after Dr. Ros presentation. One of the questions was – How to break stigma and discrimination? Dr. Ros, as mentioned above advised participants to keep working through associations on education of society. She also mentioned cultural issues. People/society usually feels fear toward unknown. The more awareness actions lead to less stigma and discrimination. She encouraged participants to keep fighting through awareness campaigns.

Second very important questions was discussed with dr. Ros – How to explain to employers on job interview visible/active Psoriasis? Again lively discussion started. Dr. Ros advised young participants that during job interview they can for expl. say to employer “You probably see that I have a skin condition but we can speak more about that later”. She said there is “no manual” how to handle situation on job

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interview. It is important to take into account that each person-employer is different and each job applicant is different. During job interview focus must be on skills! As previously mentioned – skin condition can be acknowledged shortly but it mustn't be focus of the interview. More detailed information about Psoriasis could be discussed after job/skills interview. Therefore she stress out once again that work on self-esteem is essential.

Dr. Puig advised participants that they need to think about career planning. Per expl. if hands are affected with Psoriasis and or/ Psoriatic Arthritis maybe it is better not to choose manual work like hairdressing etc. It is not necessarily discrimination but it is very same like each person healthy or not healthy need to choose a job according to skills and physical capabilities (per. exp. some healthy person can be short by height for some jobs or activities).

## **WORKSHOPS**

Each workshop was allocated 45 minutes of time which makes in total 135 minutes of group work and brainstorming. Also, each of the three workshops was divided into two parts.

- 5 minutes – introduction of tasks
- 30 minutes for creating the video manifesto statements (PAYEM) – working on tasks 1, 2, and 3
- 10 minutes for Creating the document Psoriasis and Psoriatic arthritis Youth European Manifesto (PAYEM)

Young representatives were divided into 2 groups for more efficient work on the tasks.

All together – both groups were united for a group work dedicated to PAYEM.

### **WORKSHOP 1: "LIVING IN MY SKIN"**

#### **FIRST PART**

Young representatives had 3 tasks in this workshop. After a 5 min introduction they had 10 min for each task. The last 10 min of the total of 45 min was dedicated to PAYEM through a set of questions for a group sharing of experience, information and thoughts.

The first task was:

<p><b>w1. TASK 1.</b> When it comes to the term "LIVING IN MY SKIN", describe with maximum 3 sentences <b>or words HOW</b> is to live with psoriasis in:</p>
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- a) daily life/every day situations
  - b) social life
  - c) in relationship
  - d) during education
  - e) when looking for/applying to the job  
or planning your career

**HIGHLIGHTS: key messages**

- a) Limiting (don't want to show skin), need to talk to friends, scratching, make up, treatment, pain, everyday moisturizing the skin,
- b) rejection, people think it is contagious, hiding, left my social life in sport, team etc.; judgement, pain hard to explain to other people, limited in swimming because of people's reaction, people think psoriasis is dangerous
- c) Rejection, fear of losing a partner and not finding another, fear to open up, in the long term partner "pulls back" (withdraws)
- d) Exclusion, explanation, limited concentration, pain
- e) Discrimination, hiding skin, planning career (cannot apply for a certain job), problem with handshaking, how to present myself

**w1.TASK 2.** What DO YOU NEED TO DO **EXTRA** in compare to a healthy person in: Use maximum 3 sentences or words for each field

- a) daily life/every day situations
  - b) social life
  - c) in relationship
  - d) during education
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e) when looking for/applying to the job

or planning your career

**HIGHLIGHTS:** key messages

a) more time for body caring, caring about food, extra money for supplements, clothes cleaning, more time for applying cream, hospital visits

b) hospital visits, hiding, fighting against judging, choosing clothes

c) explanation and extra talks, explaining needs, more understanding for condition, difficulties to find partner

d) cleaning time, planning time and situations, fighting pain, extra time, losing time for treatment

e) time to prove, extra explaining, justifying visits to hospital, hiding, to be better than others, choose career in which psoriasis isn't an issue, prepare more for job interviews, takes more time to find a job than others

**W1.TASK 3.** What do you need from society **TO BE DIFFERENT TOWARD PEOPLE WITH PSORIASIS?**

Describe using 1-3 sentences or word/phrases

**HIGHLIGHTS:** key messages

treat us as normal whole persons, we are not a disease, education, understanding of the disease, break the stigma, break the discrimination, more money for treating psoriasis, inform schools so kids/people can be prepared, make other people look at you as a normal person, more time for specialists, interdisciplinary approach, more awareness that the disease is not contagious

## **SECOND PART OF THE WORKSHOP 1**

All participants were working together on answering the following questions:

1. Do GPs have sufficient knowledge about day to day care?

2. What is the impact on all aspects of life when GPs and other healthcare professionals do not choose the most effective treatment according to patient's condition and existing guidelines (respecting individual course of disease, education, career, and family life)?

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3. In your country: is there an established multidisciplinary approach and fast and effective cooperation between healthcare professionals (GPs, dermatologist, rheumatologist... etc...)?

**HIGHLIGHTS: key messages**

1. No. There is a need for more education about psoriasis among GPs. They don't have enough knowledge about complexity of disease. They don't have enough knowledge about co morbidities in psoriasis. They usually think it is only skin condition.

2. Impact is strong it affects all aspects of life and persons with Pso/ PsA can have limitations that can be avoided by choosing the right treatment at the right time.

3. Most of participants are not aware of such cooperation. They are usually led by one specialist. They need an interdisciplinary approach!

**WORKSHOP 2 "LIVING WITH MY JOINTS"**

Young representatives had 3 tasks in this workshop. After a 5 min introduction they had 10 min per task. The last 10 min of the total of 45 min were dedicated to PAYEM through a set of questions for group sharing of experience, information and thoughts.

**w2. TASK 1.** When it comes to the term "LIVING WITH MY JOINTS" describe with maximum 3 sentences/words **HOW** is to live with psoriatic arthritis in:

- a) daily life/every day situations
- b) social life
- c) in relationship
- d) during education
- e) when looking for/applying to the job  
or planning your career

**HIGHLIGHTS: key messages**

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- a) get up, wearing clothes, mobility is reduced, special shoes are needed sometimes (expensive), problems with hands, extra time to soften my joints, strong impact on daily activities
  - b) Mobility problems when travelling, handshakes can be painful, family don't understand the changing symptoms, you might have to change your life
  - c) Physical contact can be limited, family doesn't understand the disease
  - d) Teachers and fellow students don't understand and therefore creating stigma "do your exercises in the closet", they don't believe you have limitations, they don't see the pain, pain can take control over you
  - e) You can be late for work, you don't know the future, cannot work certain jobs

**w2.TASK 2.** What DO YOU NEED TO DO **EXTRA** in compare to a healthy person in: Use maximum 3 sentences or words for each field:

- a) daily life/every day situations
- b) social life
- c) in relationship
- d) during education
- e) when looking for/applying to the job  
or planning your career

HIGHLIGHTS: key messages

- a) extra treatment which is time consuming, much more planning in life
  - b) It is hard to keep in touch due to time constraints, people ask you too much, making you more tired and reminding you of the disease, sometimes you are rejected
  - c) respect the extra effort to do things for others, what you do sometimes takes a very long time due to the disease but people are not aware of that effort
  - d) teachers treat you differently making you feel excluded
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e) You need to hide the disease. The employer may think you cannot do a good job.

**w2.TASK 3.** What do you need from society **TO BE DIFFERENT TOWARD PEOPLE WITH PSORIATIC ARTHRITIS?** Describe using 1-3 sentences or words/phrases

**HIGHLIGHTS: key messages**

respect, other people need to be more patient, flexibility at work, focus on qualities and the best job position regarding the disease, awareness is the key to change, people need to understand living with limitation, handrails where there are many stairs, urban planning, adopting laws and social needs.

**SECOND PART OF THE WORKSHOP 2**

All participants worked together in answering the following questions:

1. Do people with psoriasis have any type of help/support /educational program available in hospitals/medical centres for education and coping mechanism after receiving initial diagnosis – if not, how necessary is it to develop one?
2. Are you informed about what you as a patient should take care of and pay special attention to regarding the medication you are taking?
3. Does the specialist when making decisions about your therapy take into account your current needs regarding education, career, and family planning?

**HIGHLIGHTS: key messages**

1. There is a kind of support program in Norway. Some participants are not sure if there are any available support programs besides associations. Participants agree that it is essential that every major clinical hospital centre has an educational program.
  2. Participants agree that they are mostly informed about benefits but not about the special attention that some medication requires. They agree that Google should not be the primary source of information.
  3. For participants it is hard to make a general statement about this, but they agree that specialists are more focused on the medical part rather than on both the medical part and life circumstances.
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### **WORKSHOP 3 – “Psychological effects of a psoriasis/psoriatic arthritis on young patients”**

Task:

What would be different IN your life living with psoriasis and psoriatic arthritis IF each person in society when look at you RECOGNISE IN FIRST FEW SECONDS THAT YOU HAVE PSORIASIS AND IS COMPLETELY AWARE THAT IS NOT CONTAGIOUS DISEASE AND ACCEPT YOU WITHOUT ANY PREJUDICE OR DISCRIMINATION?

*(imagine how it would be if each person in society give you 3 extra seconds to look at you as a whole person, not only wondering in first 3 seconds – what kind of disease or condition you have)*

#### **HIGHLIGHTS: key messages**

No problems at work or school.

Less over-protection from family.

No pain due to discrimination.

More self-confidence, more independence.

People will empower me and not just say “pity, I am sorry”. People will focus on positive things.

No need to explain and speak about the disease all the time.

Without these problems I might be less strange.

It would be easier to be ourselves.

Society would accept me.

I would stop bio medicines, because then it wouldn't matter.

Less stress and less worry, you can be yourself.

#### **SECOND PART OF THE WORKSHOP 3**

All participants were working together in answering following questions:

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1. Is it necessary to raise awareness about psoriasis at expl. Universities through student councils, .....maybe liaising with other diseases that carry the burden of stigma, myths, discrimination ?
  2. What would be most helpful for young people with psoriasis to improve the quality of life on a daily basis?
  3. What do you expect from decision makers (institutions)?

#### **HIGHLIGHTS: key messages**

1. Participants agree that that kind of awareness is essential. Without it they think it is not possible to change the perception of other students about psoriasis.
2. To learn how to cope with the prejudice of society, to reduce stigma and discrimination in society, to have an opportunity to show their full work potential, to have an interdisciplinary approach regarding treatment
3. To raise awareness about psoriasis on all levels of society, to help stimulate employers to employ people with psoriasis, to secure/allocate funds for the most effective treatment of people with psoriasis.

During the workshops young representatives discussed a lot about everyday situations at work, school, society.

Beside dealing with disease itself, treatment, prejudice, pain some very specific situations were discussed.

One which is worth to take attention to was handshaking when you meet somebody – to handshake or not if psoriasis is visible on the hands.

Second one is that one participant stated that he would stop taking biological treatment (bearing in mind that is serious type of medication) if society break a stigma toward people with psoriasis. He can accept himself with visible plaques and he is ready to bear every burden of everyday living with skin changes – but because society is not accepting him, he continues to takes treatment in hope that plaques will disappear.

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## SUMMARY FROM THE II YRT

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**Follow up of the workshops was group discussion about key messages from the education part and especially from the workshop.**

**The most used words were TIME and HIDDING.**

People with psoriasis need TIME for:

- skin care
- treatment
- hospital visits
- dealing with pain
- explaining people that psoriasis is not infection
- fighting prejudice, myth, stigma, discrimination, rejection etc.
- time for hiding plaques and skin pilling
- time for courage to handshake, make friendship,
- time for convincing employer that skills are not affected by appearance of the skin
- time for hiding in front of friends, acquaintance, strangers, people in the shopping mall, public transport, coworkers, teachers – in another words everyone accept family

**Some conclusions were:**

None of that would be necessary if society know that psoriasis is not contagious disease or problem of bad hygiene.

People with psoriasis wish to have a chance to be recognized as person – and not to be judged by appearance of the skin. **Few extra seconds would change their life if in those few seconds other people recognize psoriasis as non contagious disease. That would give them a chance to be recognized as whole person.**

We know phenomena called halo effect explains that in everyday contact we make impression about people in first few seconds. That specific first impression makes **overall impression about a person**. If we define in first few seconds somebody as attractive/unattractive/smart/not as smart/ nice/not very nice we will also conclude that particular person has all other favourable or unfavourable qualities.

People with psoriasis have visible damages on the skin. In general – majority of people in society believes that those damages/plaques are contagious and person **with psoriasis experience**

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**discrimination/prejudice/stigma** when applying for a job, on the beach, swimming pool, when trying to make a friendship or romantic relationship etc...

Those first few seconds are spend on analyzing the appearance of the skin and are NOT used even for superficial halo effect.

Although judgement about somebody via halo effect is not correct – because it takes much more time to really know the person, in everyday life via this superficial effect we choose which person we will ask to go out, try to know more about that person etc....

Therefore the idea of the video is to sent out the message that people with Pso/PsA need EXTRA 3 seconds to be under halo effect. They don't even have that superficial right to be "judged" in ANY OTHER DIRECTION BESIDE – contagious, stigma, discrimination – so they ask for a right of the extra 3 seconds to be recognised as person.

**Participants prepared a sentence to be sent out in awareness campaigns via video manifesto with a title "Give me my 3 seconds" or "Right for my 3 seconds".**

**Video manifesto was made.**

Awareness campaign for distributing the video will be discussed among EUROPSO Board members with support of participants of II Youth Round table.

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