



New IFPA project released:

First of a kind documentary project follows people living with psoriasis to see the effects of the disease on their lives over time

Stockholm, Thursday October 29th, World Psoriasis Day, 2009: The International Federation of Psoriasis Associations (IFPA) today launches the *Under the Spotlight* project, designed to illuminate the impact that psoriasis has on individual lives, over time. A number of people living with psoriasis have agreed to allow cameras into their lives, to create a unique documentary project, to see how the disease affects them and impacts the course of their lives, socially, in relationships and particularly at work.

Today, the first of a series of documentary programmes is made available, featuring six people living in the Nordics region of Germany, Sweden and Denmark. This documentary, along with other shorter films about the contributors can be viewed on www.underthespotlight.com. The project is the first of its kind and is intended to create a community of people living with psoriasis around the world, where support and reassurance can be gained through shared experience. IFPA intends to broaden the reach of the project by World Psoriasis Day 2010, when other countries will join the project, and to continue to extend its reach over the next five years.

Meanwhile, the biggest ever international survey of people living with psoriasis has shown that the disease can cause significant and permanent damage to lives, with more than a third (37%) of the respondents stating that they will never be same person again, even if their psoriasis symptoms are cleared¹.

Professor Uwe Gieler, a Psycho-Dermatologist from the University Clinic for Psychosomatics and Psychotherapy, in Giessen, Germany has been involved in the development of the *Under the Spotlight* project. 'There has never been any doubt that psoriasis is a devastating disease, but the recent survey results begin to paint a picture of how psoriasis can damage somebody's life potential, perhaps because of a profound psychological impact or because they have felt unable to follow their chosen path in life. This produces a 'gap' between somebody's natural life trajectory and the trajectory they ultimately follow, and that is a very sad situation, not rarely followed by depression and stigmatization feelings.'

22 year old Benjamin, from Aarhus, in Denmark, is one among several people featured in the documentary who has had to abandon his first choice of career. He was unable to work as an electrician because of practical problems with his skin, and is now studying to be an engineer. He anticipates a time when he may also need to leave engineering because of the appearance of his disease. He says, 'I'm worried because in my new career I will have to look representable, I can't look like a monster. I don't know how people will react. I'll have to take a job which is more suitable for my illness. I also have to worry about stress at work, as my psoriasis is affected by that.'

Lars Ettarp is President of IFPA. 'People still believe that psoriasis is simply a disease of the skin. But everybody who lives with this disease knows that there is a great deal going on under the surface that may be invisible to the world around them. It's time we try to understand the full implications of living with psoriasis, and to provide comfort to people who may otherwise feel they are alone in struggling to cope. It's appropriate that we are launching the Under the Spotlight project today, on World Psoriasis Day, to mark our determination to understand and support people living with psoriasis.'

The Under the Spotlight documentary and website

Under the Spotlight is an International IFPA project supported by Abbott, comprising a series of documentary films and a related website www.underthespotlight.com. The project is envisioned as a series of documentaries, where the same people are followed year after year, and each year additional IFPA member groups will join the project. The first documentary launched today, features people with psoriasis from Denmark, Sweden and Germany.

International Federation of Psoriasis Associations (IFPA)

IFPA is the global representative of 125 million people with psoriasis advocating for and responding to increased research in psoriasis, psoriatic arthritis and related diseases. IFPA is a non-profit organization that is made up of psoriasis patient associations from around the world. The majority of national psoriasis associations around the world are members of IFPA. IFPA conducts programs that bring together psoriasis patient associations, healthcare professionals and the health care industry. Their signature activities include World Psoriasis Day and the World Psoriasis and Psoriasis Arthritis Conferences. IFPA's long-term goal is to change the way the World Health Organization consider psoriasis, bringing needed recognition to the disease and support for psoriasis patients worldwide, especially to the most vulnerable populations and those without access to healthcare and treatment. www.ifpa-pso.org

World Psoriasis Day

October 29 is officially declared World Psoriasis Day. An annual day specially dedicated to people with psoriasis and/or psoriatic arthritis. Conceived by patients for patients, World Psoriasis Day is a global event, owned and presented by IFPA, that gives an international voice to the 125 million people around the world who suffers from psoriasis. World Psoriasis Day aims to raise the profile of a condition which needs to be taken more seriously and give people with psoriasis the attention and consideration they deserve. Each year, WPD has a different theme. In 2009 it is 'Psoriasis is a real disability that deserves attention.' www.worldpsoriasisday.com.

WPD is an awareness concept owned and managed by IFPA, to help them achieve the vision of a world without human suffering from psoriasis, and the mission, to be the unifying global voice of all psoriasis associations, supporting, strengthening and promoting their cause at an international level.

Psoriasis Uncovered survey

Psoriasis Uncovered is an international survey initiated by Abbott that aims to retrieve patient perspectives on the nature and quality of life impact of psoriasis. The Psoriasis Uncovered survey has been conducted in 17 countries, which of most are IFPA Members, via electronic survey modules such as www.psoriasisuncovered.com. Additional countries will be launching the survey in the near future. Results from >11,000 people are currently available. More detail on the results is available on request.

Interviews available with: IFPA, healthcare professionals involved in the development of the project, patient associations in participating countries, and contributors to the programme. B-roll also available.

For further information please contact: Annika Rastas, Director of IFPA Secretariat, +46 8 556 109 14, e-mail: ifpa@pso.se. Visit www.underthespotlight.com to browse the library of patient stories.

References

1. Psoriasis Uncovered, patient survey, findings report, Abbott, October 2009.