

Bringing Psoriasis into the Light



Recognition of the public health impact of psoriasis by the World Health Organization will be a vital step in improving the treatment and quality of life for the many millions of sufferers around the world. That was the conclusion of an expert panel discussion held on the 9th of May in Geneva.

The four speakers at the event, hosted by the International Federation of Pharmaceutical Manufacturers and Associations (IFPMA), included representatives of sufferers, medical professionals, researchers and the pharmaceutical industry. The panel agreed that if as expected the WHO adopts the proposed resolution to, amongst other initiatives, develop a global report on psoriasis then existing gaps in reporting on and the understanding of the illness might begin to close.

More than 125 million people worldwide suffer from psoriasis, a non-contagious disease of the immune system that appears as patches of red, thickened and itchy skin that can also bleed. Because it presents on the surface of the body, many people living with the disease suffer rejection and discrimination, and it often exacts a heavy psychological price. Less well known is the strong correlation between psoriasis and other illnesses, "comorbidities" so-called, including cardiovascular disease, diabetes, stroke, liver disease and psoriatic arthritis.

Dr Mahira Hamdy El Sayed, *Professor of Dermatology and Venereology, Ain Shams University*, provided an overview of the impact of psoriasis on individuals and society, its correlation with other illnesses and drew on her experience trying to combat the illness and the stigma that surrounds it in Egypt and the Middle East.

Dr El Sayed began by sketching out key characteristics of the disease and its incidence: 1 to 3 percent of the population suffers from psoriasis; it can present as a lesion to the size of a fingernail to covering most of the patient's body; and there is a high correlation between the illness and cardiovascular disease.

Apart from the physical manifestations of the condition Dr El Sayed went on to describe the emotional impact a psoriasis patient is likely to bear. To quote her: "a psoriasis patient is (usually) a very unhappy patient". The psychosocial burden is very high and there is a significant impact on the quality of life of sufferers: they are subject to anxiety and depression; are more likely to withdraw from society; and they report higher levels of suicidal thoughts. Patients can have a much lower quality of life than people with other non-communicable diseases such as diabetes.

Furthermore, there is a strong correlation between the disease and lifestyle choices that are likely to exacerbate it. Psoriasis patients are much more likely than the general population to smoke, have problems with alcohol and have issues with obesity.

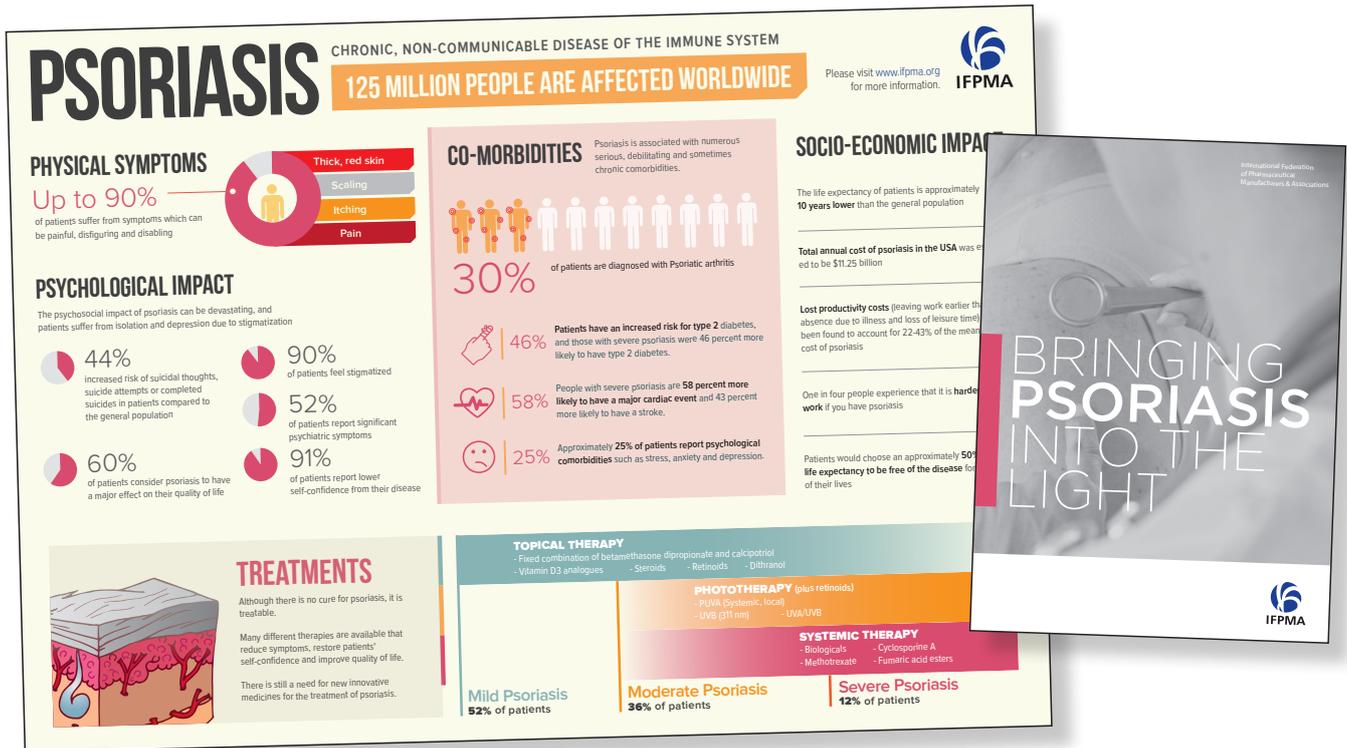
While progressively more effective treatments have been available to doctors in recent decades psoriasis remains a chronic condition that has to be managed. Dr El Sayed told the forum "You only treat the patient, you don't treat the disease. So every patient is different from another one". Her approach differs depending on the patient's economic status, the presence of comorbidities and even their attitude to the illness.

With regard to Egypt and managing psoriasis with limited resources, Dr El Sayed talked about the difficulties of funding her clinic without government support. She has access to some of the latest therapies but new generation drugs are often too expensive to employ.

She also presented her own plan for a national strategy by firstly making the case for a registry of psoriasis sufferers so that basic questions about the number of sufferers and the types of illness they have can be answered.

Psoriasis is not contagious but awareness is

Dr El Sayed



Also needed is an awareness campaign for health care providers and doctors, more specialized referral centers, more research on comorbidities, clinical studies on the impact on children and Hepatitis C sufferers and more collaboration with international experts.

Dr El Sayed concluded that early intervention is effective in reducing the impact of a disease that "usually does not take lives, but it does ruin them".

The Patients are waiting

Dr Kim D Kjølner, Senior Vice President of Global Development, LEO Pharma, described how the pharmaceutical industry is collaborating with patients to improve treatment for psoriasis sufferers.

LEO Pharma is a Danish foundation owned pharmaceutical company. Dr Kjølner described how psoriasis patients in Denmark have been logged in a registry system since 1977 and have had the course of their disease and treatment followed. Using this resource and others researchers have calculated that people with psoriasis die, on average, 4 years younger than the general population. Partly this is due to the suicidal pressures that Dr El Sayed introduced, and partly the prevalence of other diseases linked to psoriasis, known as comorbidities.

The awareness of these comorbidities amongst doctors is inadequate; the chances of having your blood pressure taken and your lipids measured if you present with psoriasis to a GP is practically zero despite the increased likelihood that you will suffer from cardiovascular disease. The elevation in risk is, in fact, twofold - a doubling. Exactly the same elevation of risk you find with diabetes.

Currently, research on treatment for psoriasis is divided into topical and systemic therapies. In general, clinical trials show that topical treatments work quickly and efficiently. However in practice, unless patients are consulted, the drugs are not always well designed for use. Dr Kjølner related the experience of inviting a patient into their R & D department to explain how they use one of their topical applications and found that it was essentially too viscous to easily apply.

While biological therapies present some of the most promising approaches for systemic treatment, the search for tablet form has proved very difficult. However, success in this quest is likely in the next two or three years and this will be significant for people with serious cases of the illness, Dr Kjølner said.

Experience has shown that a significant barrier to the successful application of therapies is the myths and uncertainties that surround the disease. Pharmaceutical companies have an important role in better explaining psoriasis and its treatment to patients, their families, health professionals and broader society.

At the level of public policy, understanding

of psoriasis is severely hampered by a lack of data. Pointing to the example of the Diabetes Atlas which over the period of its 6 editions has totally transformed the global conversation around diabetes, Dr Kjølner said Psoriasis "needs to get onto the agenda..." and added "...the patients are waiting".

Psoriasis is not just a skin disease

Mr Steve O'Dell, CEO, International Psoriasis Council, gave the forum the perspective of global dermatology researchers and professionals in promoting understanding of and best practice in treating psoriasis and related illnesses.

To understand the full impact of the disease, including its prevalence and burden, the International Psoriasis Council (IPC) has formed a global partnership with The International Federation of Psoriasis Associations (IFPA) and the International League of Dermatological Societies (ILDS) to execute a Global Atlas on psoriasis. Given that prevalence and incidence data drives public health decisions, such a document is going to be vital. It's also worth noting that the pharmaceutical industry uses this kind of information to direct decisions on research. Existing gaps in understanding are enormous. For instance, the current figure of 1 to 3 percent of the population as sufferers

of psoriasis is really guess work; studies have shown rates ranging between 0.1 and 12 percent. Further, there is some evidence from the last 30 years that there is an increasing trend in the incidence of psoriasis, but again, without better data it's difficult to know whether this is due to better reporting or an actual increase in the number of sufferers.

Modelled on the Diabetes Atlas the report aims to build an evidence base that all interested groups can take advantage of. It will enable them to advocate for appropriate treatment, to improve access to care, to bolster recognition of the burden of disease of psoriasis, to encourage more research and the collection of data which will ultimately lead to better use of limited resources.

Apart from the Psoriasis Atlas project the IPC has just finished a major genetic study to understand the chromosomal foundations of psoriasis and comorbidities, the results of which will be available later this year. Also, the IPC coordinates a number of working groups taking a comparative look at treatments and has recently launched a new multi-billion dollar initiative called the Psoriasis Stratification to Optimize Relevant Therapy (PSORT) in the United Kingdom.

When you live with this disease you will do practically anything to get help, because you don't live a full, normal life.

Ms Barbra Bohannon, *Head of Operations and Strategic Communications, International Federation of Psoriasis Associations (IFPA)*, provided case examples including sharing her own experience as a sufferer.

To highlight the stigma that surrounds the disease, Ms Bohannon related the personal histories of two sufferers. One, a friend in a country where there is little understanding of the disease, was not diagnosed for twenty years and even then had access to only basic treatments. Topical applications were needed every day but she was unable to reach parts of her back. Her family feared that the psoriasis was contagious and refused to help her. Ultimately a daughter agreed to apply the lotions but only if she could wear rubber gloves.

Another sufferer she knows has to wrap his entire body in plastic film before dressing, as clothes tear at the lesions. He is in excruciating pain every day of his life.

"Anyone can get this disease: it doesn't matter if you are male or female, it doesn't matter what nationality you have, what ethnological group you belong to, it doesn't matter what your income is or your standing in society. You can get psoriasis.", Ms Bohannon said.

Her organization, the IFPA hears regular reports of people being arrested and threatened with deportations, of people being refused entry on to flights. They hear from many people who know longer wish to live as the disease has ruined their lives.

Ms Bohannon shared her own experience, explaining that she suffers from psoriasis and

severe psoriatic arthritis, a commonly related condition. Like many with the disease she also has what she described as a "package" of other conditions such as frequent respiratory inflammation, hypertension, and recurrent eye inflammation.

Finally Ms Bohannon outlined a brief history of the disease on the global health agenda. In 2009 the IFPA and other groups began agitating for greater recognition of Psoriasis as a serious non communicable disease (NCD) within the WHO. Panama stepped into the process and championed the cause within the WHO with the ultimate result that a resolution recognizing the impact and need for further information is put before the World Health Assembly in May of 2014.

Q & A

Many representatives from the diplomatic community in Geneva attended the event and were able to contribute their understanding of the issue and profess their support for the WHO resolution.

Q: Francis Ngantcha, the Cameroon Mission to the United Nations: How long before we know the causes (of psoriasis), how close are we?

A: Steve O'Dell: We have no idea how close we are. There is a lot of research going on to determine what those causes might be... but it is a complex disease and certainly not just one disease.

Q: Do General Practitioners have a good understanding of diagnosis and treatment of psoriasis and associated illnesses?

A: Steve O'Dell: Dermatology is probably about a week of a General Practitioners training...the diagnosis of psoriasis is not always easy and the reluctance to refer right away to a dermatologist is of concern.... It continues to be an area where we need more education. I would say that we have moved the needle quite a bit in the last 14 years, since therapies have become much more effective but we still have a long way to go.

Q: What is the economic impact of psoriasis?

A: Barbra Bohannon: "... people tend to look very much toward the cost of treatment and don't necessarily consider the time consuming aspects to it. One woman (she knew) has to travel 300 km one direction, three times a week

for phototherapy... there's no way you can travel that much and have a full-time job. Also absenteeism rates from work and school are very high... you have to look at the full picture, it's not just about the cost of treatments...it's also about the cost to society...

Also responding **Kim Kjoller:** this is why the resolution is so important. When we present the menu of new treatments being taken forward there is a tendency on always to be focusing on the direct medical costs... the cost to society is completely overlooked and even the massive costs to the individual not being able to take control of the disease is (not accounted for).

Luis Espinosa, Ecuador Mission to the United Nations made a statement outlining the work Ecuador and Panama have put into developing the resolution by the World Health Organization. In his view "there is consensus, it's just a matter of approval during the World Health Assembly". When pressed by the moderator of the event Mr Espinosa said he was 95 percent certain the ratification of the resolution would go ahead.

Dhulfiqar Aal-Yasiri, Iraq Permanent Mission to the UN offered a personal observation. At university he had a friend with psoriasis and people, including himself, were avoiding physical proximity with this person. It was only after seeing a discussion on Iraqi TV that he and others realized the disease is not contagious. Mr Aal-Yasiri added that he "wanted to thank those supporting the WHO resolution. It is a great first step to move this issue one step forward in this journey."

Contributors



Pete Forster
Broadcast journalist

Pete Forster is an experienced broadcast journalist. His most recent role was as senior editor of news and programs

for World Radio Switzerland, a public service broadcaster and part of the Swiss Broadcasting Corporation.



Barbra Bohannan
Head of Operations and Strategic Communications International Federation of Psoriasis Associations (IFPA)

IFPA, the International Federation of Psoriasis

Associations, is a global NGO comprised of 50 national psoriasis patient associations, holding Special Consultative Status with UN ECOSOC, full member of IAPO (International Alliance of Patients' Organizations). The IFPA Secretariat is based in Stockholm, Sweden.

Ms Bohannan is responsible for the daily and strategic operations and communications of IFPA, to ensure that all activities are aligned with the overall mission and goals for the organization and to further its development globally.

Secretary of the Scientific Executive Committee for the 4th World Psoriasis & Psoriatic Arthritis Conference 2015.

The World Psoriasis & Psoriatic Arthritis Conferences are scientific multi-disciplinary meetings held every three years, with the aim of providing an international platform for the sharing of scientific information and best practice for dermatologists, rheumatologists, general practitioners and allied health professionals, primarily active within psoriasis and psoriatic arthritis.

As Secretary of the Scientific Executive Committee, Barbra oversees the development and implementation of the scientific program and acts as liaison between the Scientific Executive Committee and the Organizing Committee.

Ms Bohannan has lived with both psoriasis and psoriatic arthritis since she was very young.



Mario Ottiglio
Director, Public Affairs & Global Health Policy IFPMA

Mario Ottiglio is Director at the IFPMA where he has been working since 2007 in positions of

increasing responsibility. Mario leads on global health policy, coordinates IFPMA Members' policy positions and conveys them to government and UN Specialized Agencies officials. Mario also heads IFPMA's public affairs and communications efforts, developing partnerships and promoting active dialogue with key stakeholders from governments, multilateral organizations, and civil society. Prior to joining the IFPMA, Mario worked as a consultant for both the private sector and governments. Mario holds an MA in Political Science from the Naples Eastern University and is an Italian national.



Steve O'Dell
CEO International Psoriasis Council (IPC)

Mr Steve O'Dell is Chief Executive Officer at the International Psoriasis Council (IPC). As head

of IPC, Mr O'Dell is responsible for developing and leading the IPC strategic plan to evolve and expand the organization reach with a focus toward addressing key issues within the scientific, educational and patient care areas. He will also work to enhance IPC's influence in the dermatology field through identifying and developing collaborative partnerships with scientific organizations, representatives from industry and academia, health care vendors, international and national nonprofit agencies and other public and private organizations.

Mr O'Dell's background includes more than 24 years as a leader in both for-profit and nonprofit healthcare companies. From 2008, until he joined the IPC in January 2014, he held the position of Owner and President of a home healthcare company he started in Erie, PA (USA). Prior to that venture, Mr O'Dell held various leadership positions in the medical research, biopharmaceutical, and medical education industry, beginning in 1990. His expertise includes in-depth knowledge and experience in regards to the process of clinical drug development and commercialization, with an emphasis on psoriasis, psoriatic arthritis and other immune mediated inflammatory disorders. Mr O'Dell holds a Bachelor of Arts degree in International Business and Economics and an Associates of Applied Science degree from The State University of New York.

Founded in 2004, The International Psoriasis Council (IPC) is dermatology led, voluntary, global nonprofit organization dedicated to innovation across the full spectrum of psoriasis through research, education and patient care. The mission of the IPC is to empower our network of global key opinion leaders to advance the knowledge of psoriasis and its associated comorbidities, thereby enhancing the care of patients worldwide.



Mahira Hamdy El Sayed
Professor of Dermatology and Venereology Ain Shams University

Professor Mahira Hamdy El Sayed is a Professor

of Dermatology and Venereology Ain Shams University Cairo Egypt and the administrative Medical director of the department.

She Graduated from Ain Shams University in Dec 1980 with honors, got her Master's Degree 1984 and her M.D degree 1989 as joint supervision between Ain Shams University and Glasgow University Scotland U.K

Prof. El Sayed published several national and international publications, also she has been a speaker in several national and international conferences.

She has special interest in Psoriasis. 3 years ago, she established a Psoriasis clinic that is running on weekly basis.



Kim D Kjoller
Senior Vice President of Global Development LEO Pharma

Dr Kim Domela Kjoller is Senior Vice President for Global Development

at LEO Pharma. He joined LEO Pharma in 2010, after holding executive positions at other pharmaceutical companies in Denmark.

He received his degree in medicine from Copenhagen University Medical School in 1994, after which he held a position in the Department of Plastic Surgery at Copenhagen University Hospital, before continuing on to the Danish Cancer Society and later to industry.

Dr Kjoller has authored and co-authored over 35 scientific publications, speaks regularly at scientific and industry meetings in Europe and the United States, and is a member of the Board of FADL, the union for Danish medical students.

For more information about IFPMA:
www.ifpma.org