



IFPA

GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE

Speaking up for psoriatic disease in Europe

JULY 2022



United – Now Act petition

The petition demands global action on five action points:

- **Change** the perception of psoriatic disease
- **Ensure** equal access to medicines
- **Stop** stigma
- **Advance** holistic care
- **Prepare** the health workforce

Sign the petition

Ensure your voice is heard at the United Nations High-Level Meeting on Non-Communicable Diseases 2025.



Contents

Introduction

Call to action	2
Foreword.....	3
Psoriatic disease explained	4

Burden

Psoriatic disease affects millions of people in Europe	7
Psoriatic disease is associated with multiple other conditions	8

Impact

Every aspect of a person’s life	10
---------------------------------------	----

Management and care

Addressing unmet medical needs	18
--------------------------------------	----

It’s time

Better health and well-being for people with psoriatic disease in Europe	23
IFPA – our vision	24
Contributors and editorial board	25

References	26
-------------------------	-----------

Call to action

In 2014, the 194 Member States of the World Health Organization (WHO) voted unanimously to approve the World Health Assembly Resolution on Psoriasis (WHA67.9). In doing so, they recognized psoriatic disease as a serious non-communicable disease (NCD) and committed to increasing their efforts to fight the stigma and unnecessary exclusion suffered by people living with psoriatic disease.

And yet, eight years later, improvement is still needed in numerous critical areas: awareness about psoriatic disease, support, equality of access and effective treatment.

This briefing book is part of a suite of actions from IFPA, the international federation of psoriatic disease associations, to progress critical conversations around the unmet needs of people living with and affected by psoriatic disease in Europe. The briefing book presents an overview of the region’s individual and societal burden of psoriatic disease. It offers evidence-based insights for thought leaders to draw on when discussing future priorities and changing the agenda for better care and support for Europeans living with psoriatic disease.

The Resolution on Psoriasis and the recent World Psoriasis Day 2021 United – Now Act petition are key milestones on the journey towards improved health and well-being for everyone living with psoriatic disease in Europe. We can make a difference by taking each step together, united.

IFPA has facilitated the development of this briefing book.

Foreword

It has been eight years since the Member States of the World Health Organization recognized psoriatic disease as a serious non-communicable disease and acknowledged that too many people needlessly suffer from it. At the time, global health leaders called governments and stakeholders to action to raise awareness, fight prejudice and exclusion and improve care. However, while much has been achieved, too many people living with psoriatic disease continue to face barriers that can be overcome.

In Europe, which has the highest prevalence of psoriatic disease globally, people living with the disease should have affordable, equitable access to healthcare. Psoriatic disease should not prevent someone from using public spaces or facilities, having a successful career or experiencing rich and rewarding social relations.

And yet, for many of the 6.4 million people living with psoriatic disease in Europe, the condition is a burden that is often carried alone or by families buckling under the financial pressure of additional healthcare costs and reduced earning potential. Many people living with psoriatic disease face unnecessary physical pain, disability or poor mental health because their condition was not diagnosed correctly or in a timely manner. Many people with psoriatic disease experience prejudice, stigma and exclusion because not enough has been done to create awareness and education about the disease among the general population. These are things we can change: we can raise awareness, we can give support and we can ensure that everyone living with psoriatic disease in Europe has access to effective, affordable treatment.

Now is the time for health leaders, governments, psoriatic associations, the private sector and people living with psoriatic disease to join forces and address the question of how this can be achieved.

Now is the time to properly consider how psoriatic disease affects mental health and quality of life. Now is the time to improve access to care for everyone with the disease. Now is the time to invest in a capable and adequate health workforce. Now is the time to consider how digital technology can support these goals. And now is the time to put people at the centre of the conversation about psoriatic disease.

Now is the time to speak up for people with psoriatic disease.

Psoriatic disease affects millions of people in Europe. Europe has the highest prevalence of psoriatic disease globally, with an estimated 6.4 million people living with psoriasis.

Psoriatic disease significantly impacts many aspects of an individual's life, including their physical, emotional, social, and economic well-being.

Psoriatic disease is associated with a substantial economic burden for individuals, healthcare systems and society.

Many people living with psoriatic disease often experience unmet medical needs, including being untreated or undertreated.

Introduction

Psoriatic disease explained



About **one-third of people with psoriasis will develop psoriatic arthritis**⁴



What causes it?

The causes of psoriatic disease are not known, but researchers believe that genetic and environmental factors play a role in the development of the disease.² Common triggers for the initial onset of the disease and subsequent flare-ups include stress, skin trauma (cuts, scrapes or tattoos), dry skin, certain medications, climate, alcohol consumption, smoking or infections.

What is psoriatic disease?

The term psoriatic disease covers all types of psoriasis and psoriatic arthritis. It is a systemic condition that affects the entire body, but the effects can be seen most notably on the skin and/or joints.

Psoriatic disease is:

Chronic: Psoriatic disease cannot be cured, and the disease can periodically relapse.

Noncommunicable: Psoriatic disease is not contagious.

Painful: Chronic inflammation leads to pain, especially joint and back pain.

Disfiguring: Psoriatic disease can cause permanent disfigurement, especially in its severe forms.

Disabling: Chronic joint inflammation can lead to permanent disability if left untreated or treated inadequately.

Inflammatory: Psoriatic disease is an immune-mediated disease. Abnormal activity of the immune cells results in an extreme inflammatory response affecting healthy body tissue. Chronic inflammation can cause damage to multiple body sites.

Not all cases of psoriatic disease look the same and there are many manifestations, including:

Plaque psoriasis is the most common form of the skin manifestation of psoriatic disease. It is characterized by inflamed and flaky plaques on the skin.

Guttate psoriasis, which typically presents as small round spots that are raised and sometimes scaly. About 8% of people living with psoriasis develop guttate psoriasis.

Inverse psoriasis, which typically presents where the skin folds. Up to 30% of people living with psoriasis develop inverse psoriasis.

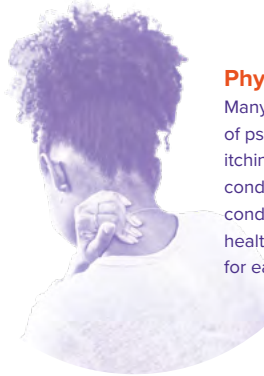
Pustular psoriasis, which typically presents as an acute, subacute or chronic pustular eruption and affects about 3% of people living with psoriasis. There are several different types of pustular psoriasis.

Erythrodermic psoriasis, typically cutaneous erythema and scale involving most or all of the body surface area, which is life-threatening and affects approximately 2% of people living with psoriasis.

Psoriatic arthritis affects about one-third of people with psoriasis¹, but it is possible to have psoriatic arthritis without psoriasis.

How does it affect a person?

Psoriatic disease has many consequences, including:



Physical

Many people find it challenging to live with the symptoms of psoriatic disease, which can include chronic pain, itching, burning and fatigue. The comorbidities (additional conditions an individual might have in addition to a primary condition) of psoriatic disease also significantly impact health and well-being. Finding the best treatment regime for each individual can be a long and complicated process.

Emotional
The stigma and prejudice often experienced by people living with psoriatic disease inflict a heavy emotional toll. Depression and anxiety are prevalent among people living with the disease.



Social

Living with psoriatic disease can have a significant impact on relationships with family, friends, partners, co-workers or fellow students. Many people with psoriatic disease report feeling unsupported. Persistent myths about psoriatic disease include the untrue notions that people with the disease are 'unclean', that they 'caused their psoriasis' or that the disease is contagious.

Economic
There are substantial costs associated with psoriatic disease. The medication can be costly or not covered by insurance providers. Absenteeism and presenteeism are higher in people with psoriatic disease compared with the general population. The presence of comorbidities increases the costs. All of this may contribute to economic challenges.



How is it diagnosed?

There are no specific diagnostic tests for psoriatic disease. A diagnosis is usually made based on a physical exam, imaging (x-rays and MRIs) and blood tests to rule out the possibility of conditions that present in similar ways.

How is it treated?

Psoriatic disease is treated with topical medication, non-steroidal anti-inflammatory drugs, light therapy, disease-modifying anti-rheumatic drugs and biologics. If psoriatic disease – particularly psoriatic arthritis – is not treated effectively early on, it can result in structural damage.³

“When you become a father for the first time, you’ve planned a life where you’d be this sporty, active dad.

Suddenly, I was back on crutches, crying doing nappy changes because my knees were so sore.”



Joel Nelson, UK

Living with psoriatic disease

I'm Joel Nelson, an IFPA psoriatic disease ambassador based in Norwich, UK. My story with psoriatic disease started at quite a young age. I was diagnosed around 12, and although I had symptoms around 10, the signs of some psoriatic element were always there. Fast forward until I was in my mid-20s, and then I had my first real psoriasis outbreak, and it came out of nowhere. The trigger was probably stress, as it is for many people.

At such a young age, it became the norm that there were periods where I was in wheelchairs, periods where I was on crutches and periods where I was okay.

The big change came in 2019 after a period of remission – we decided to start a family with the consultation of my doctors. My treatment was changed when my little boy arrived, and that caused an almighty flare. The flare lasted for about a year and a half non-stop. I was left in permanent pain, which was quite hard to process. When you become a father for the first time, you’ve planned a life where you’d be this sporty, active dad. Suddenly, I was back on crutches, crying doing nappy changes because my knees were so sore on the floor or having to learn to carry him up and down the stairs on my backside.

Burden

Psoriatic disease affects millions of people in Europe

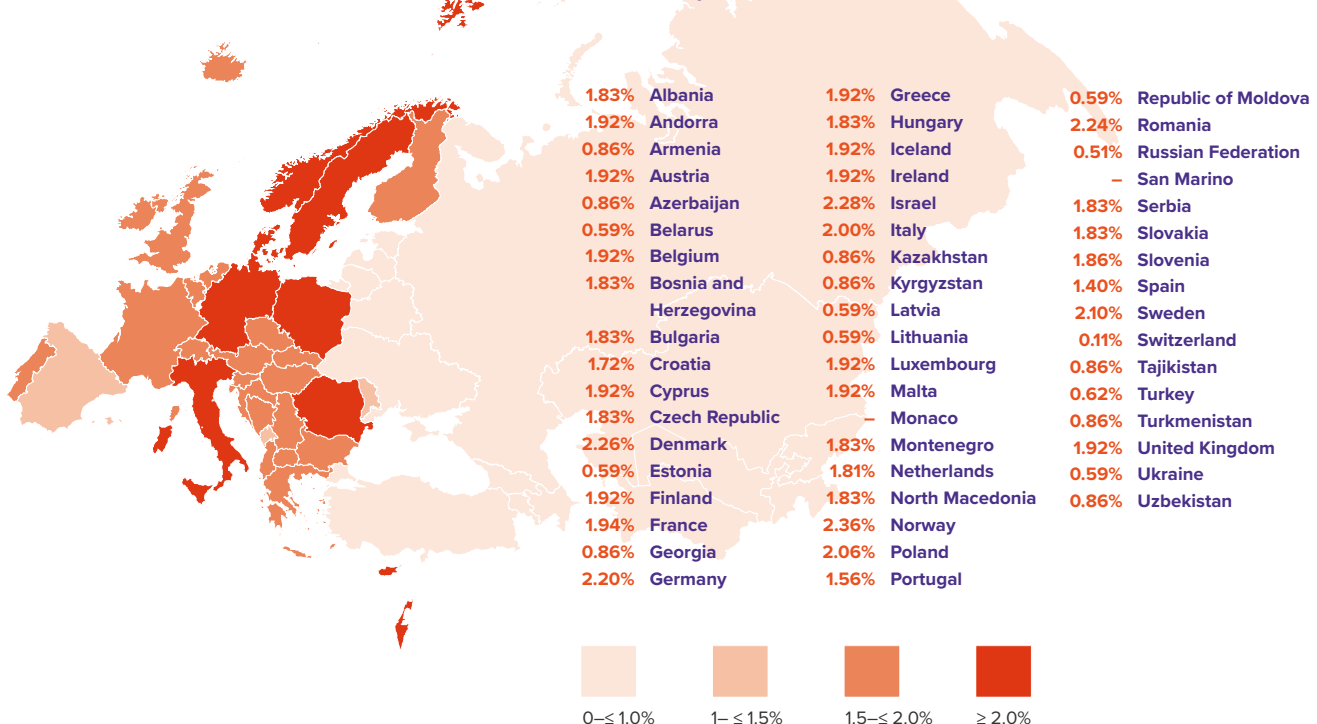
Psoriatic disease affects millions of people worldwide. Until recently, it was believed that more than 125 million people were living with psoriasis, but that was an extrapolation of 2% of the global population. Subsequent studies have shown that the prevalence is lower. The Global Psoriasis Atlas, the leading epidemiological resource on psoriasis globally, estimates that approximately 60 million people live with psoriasis worldwide.⁴ Large systematic reviews have shown that the prevalence of psoriasis varies from less than 0.1%

in some countries to maybe 4 or 5% in Northern Europe.⁴ Europe has the highest prevalence of psoriatic disease globally, with an estimated 6.4 million people living with psoriasis in the region.^{4,6}

However, considerable geographical gaps exist regarding prevalence data for psoriasis.⁴ These gaps grow larger when those living with psoriatic arthritis are considered – only one in five countries has epidemiological data on psoriatic disease.⁴

~ **6.4m**
people
are estimated to be
living with psoriatic
disease in Europe.⁴

Percentage of adults estimated to be living with psoriasis in countries across Europe⁴

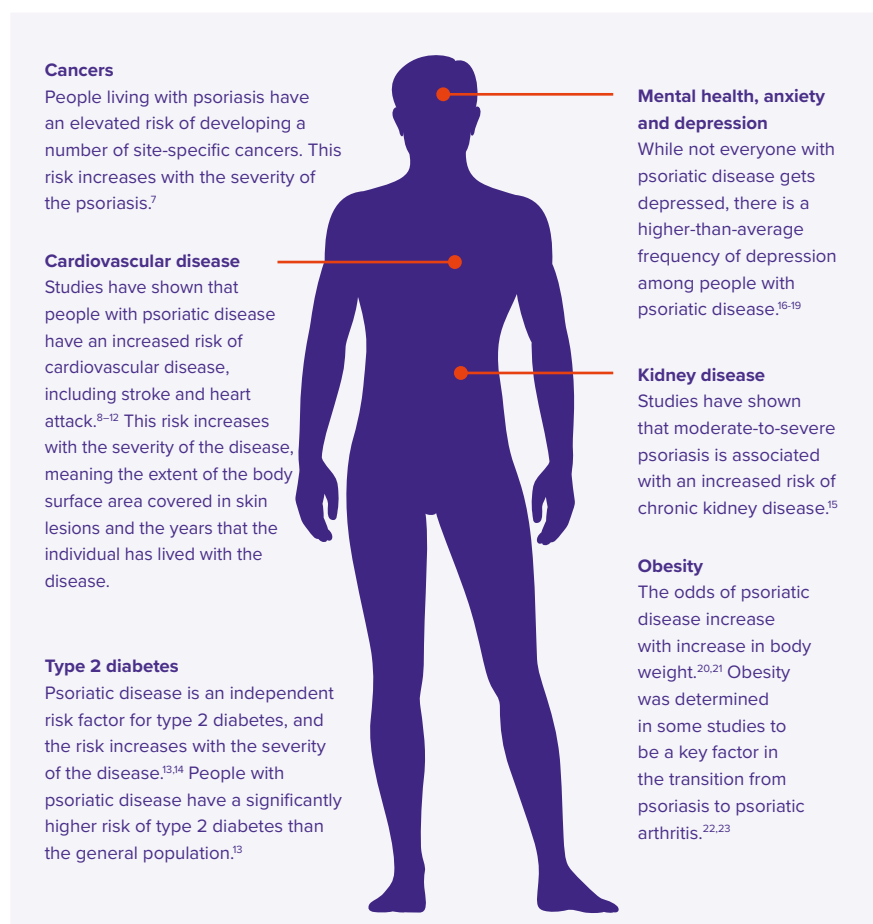


Higher prevalence rates have been reported in countries at higher latitudes, such as Northern Europe



Psoriatic disease is associated with multiple other conditions

In medicine, the term ‘comorbidity’ describes any additional conditions an individual might have in addition to a primary condition. Psoriatic disease is associated with numerous comorbid conditions, including several NCDs. These conditions – on their own and with psoriatic disease – harm an individual’s health and well-being and drive up healthcare costs.



Why understanding prevalence matters

Geographical differences in the prevalence of psoriatic disease could be due to climate, genetic background or immune system exposure to a toxin or foreign substance (antigen) caused by a pathogen or an environmental factor.²⁴ Higher prevalence rates have been reported in regions at higher latitudes, such as Northern Europe. In contrast, lower rates have been observed in African and Asian countries closer to the equator.²⁴

Understanding the epidemiology of psoriatic disease, including its causes, distribution pattern and impact, can help shape policy approaches, thereby ensuring appropriate prioritization and allocation of healthcare resources.

Did you know? Climate treatment is among the treatment options for people with moderate to severe psoriasis. For someone living with psoriasis in a cold, dark Nordic country, a stay in a place with natural sunlight and access to salty ocean water might be just what the doctor ordered.²⁵

Ingvar, Iceland

Living with psoriatic disease

I was 24 years old when I found out that I had psoriasis. It didn't affect me much because it was in such a small area and was just annoying. However, it escalated soon after that. It affected my personal and professional life as one must adapt according to the severity of psoriasis. People at my workplace kept looking at me, and I withdrew. However, I asked myself why I should feel bad because I have psoriasis. I then started approaching people and asking them if they had any questions. I stopped swimming because I was fed up with the way people looked at me and I didn't feel comfortable.

In Iceland, you generally are diagnosed quickly, and access to care is good. Your network is always your best guide. My advice to others is to try and surround yourself with people that can give you support and always be positive.



“With psoriasis, you’ll have moments in your life where you feel depressed and low on energy and stamina. Surround yourself with friends... and always be positive.”



Patricia, France

Physical and emotional impact

My name is Patricia, I come from France and I'm 60 years old. I was diagnosed with psoriasis when I was 16. My psoriasis covered all of my body. I'd never heard of that word before until I was diagnosed with the disease. I was a teenager, so it's always tough to talk about, even today, but the condition ruined my life. I wasn't able to wear what I wanted, I wasn't able to go to the beach and I spent most of my time hidden.

At the airport, I was waiting for my flight and I was stigmatized in front of everyone. I was so devastated and wanted to run away. I was saved when I went to the spa resort, and they organized a meeting with the French Psoriasis Association. I realized I wasn't alone. They helped me so much. Since then, I don't feel alone and I try to help explain to everyone that psoriasis is not contagious and that treatments exist. I've devoted my life to my organization. Despite the awareness campaigns, millions of French people still don't know what psoriasis is.

“Psoriasis ruined my life, I couldn't wear what I wanted and I spent most of my time hidden... I was so devastated....”

Impact

Every aspect of a person's life

A flare-up of psoriatic disease can mean that it is too painful to wear shoes. Or carry a child. Or leave home. Or even sleep. Psoriatic disease does not just affect skin or joints. It can leave a mark on every aspect of a person's life and significantly impact their physical, emotional, social and economic well-being.^{26,27}

Pain and discomfort: Inflammation can cause pain. Psoriasis plaques can become dry, cracked and itchy²⁸. Skin pain and discomfort – and the related sleep disturbance – are associated with poorer health-related quality of life.²⁹ Stiff, swollen and painful joints coupled with fatigue can be among the most apparent signs and symptoms of psoriatic arthritis.³⁰

Depression and anxiety: Living with psoriatic disease increases the risk of depression^{31,32}. The risk of depressive symptoms grows with low levels of perceived social support and high levels of stigmatization.³³ Recent evidence shows that systemic inflammation increases the risk of developing anxiety and depression. Research in Poland revealed that 13% of people with psoriasis had moderate depressive symptoms.³³ In France, a study of people with psoriatic arthritis found that 44% had anxiety and 29% had depression.³⁴

Stigma and social isolation: A notable proportion of people living with psoriasis in Europe have experienced discrimination due to stigma around the disease.³⁵ Stigma is fuelled by persistent myths that the disease is contagious, 'unclean' or the fault of the person living with the disease.³⁶

A survey of public perceptions in Germany found that 69% of people find psoriasis disgusting and 59% do not want to touch those who have the disease.³⁷ Not surprisingly, many people with psoriatic disease report feeling unsupported.^{36,38}

Economic hardship: Living with psoriatic disease can affect a person's ability to work and their employment prospects. Absenteeism, which can affect earning potential, is higher in people with psoriatic disease than in the general population.⁴ In addition to the possibility of reduced income, people with psoriatic disease often have significant costs related to medication (expensive or not covered by insurance), doctors' appointments and hospitalization. The presence of comorbidities increases these costs.³⁶

69%
of people find
psoriasis disgusting³⁷

59%
of people do not want
to touch people who
have psoriasis³⁷

The risk of depressive symptoms grows with low levels of perceived social support and high levels of stigmatization.³³



Stigma and discrimination are rife across Europe

The 2018 Clear about Psoriasis survey shows that a **high percentage** of people living with psoriatic disease in Europe **have experienced discrimination or humiliation**.³²

94% Finland	84% Turkey
91% Czech Republic	82% Germany
89% Norway	81% France
87% Austria	79% Portugal
86% Hungary	79% Sweden
84% Belgium	78% Ireland
84% Bulgaria	78% UK
84% Israel	76% Netherlands
84% Italy	71% Romania
84% Switzerland	

Uncovering people's perceptions

In 2014, as part of the Resolution on Psoriasis, the WHO requested that Member States introduce public measures to reduce stigmatization. Acting on the call, the National Conference on Health Care in Psoriasis, in collaboration with the regional German Psoriasis Networks (PsoNet), launched an initiative to better understand the stigmatization of people with psoriasis and other chronic visible skin diseases.³³

76%

of respondents agree that most people feel sorry for people who have psoriasis.

70%

think that most people avoid people with skin diseases.

65%

believe that most people think psoriasis is contagious.



34%
of women decided
to have a **smaller
family** (or no children)
because of their
condition

23%
of women felt worried
that their **job was at
risk**

57%
reported a moderate
or **low level of support**
from healthcare
professionals



Psoriatic disease in women

While everyone living with psoriatic disease is affected by the condition, the impact and associated risk factors are not uniformly distributed. Women of childbearing age are often disproportionately affected.³⁹

A multinational survey across 11 European countries that evaluated women between the ages of 18 and 45 revealed the following:⁴⁰

Family planning. 34% of women decided to have a smaller family (or no children) because of their condition; this was significantly higher among women with both skin and joint symptoms of psoriatic disease than among those with only one of the symptoms.

Psychological impact. Approximately one-third of women reported feeling pessimistic about the future. When asked about a typical day living with their condition, 78% said they experienced negative emotions. The majority of women (97%) reported negative emotions during disease flares.

Career. Due to their diagnosis, approximately 23% of women felt worried that their job was at risk, 21% felt discriminated against at work and 18% perceived that they earned less than colleagues doing the same job. 21% of women reported not having their desired career and stated that their condition was a major limiting factor.

Patient support. More than half of all women (57%) reported a moderate or low level of support from healthcare professionals (HCPs). The majority (55%) of those who were pregnant or had given birth in the previous five years reported a medium or low level of support from the HCPs managing their condition during pregnancy.

Treatment. Women of childbearing age need effective treatment at all stages of their lives, including pregnancy and breastfeeding. Many therapies are not approved for use during pregnancy and breastfeeding.⁴¹



Psoriatic disease impacts families

Living with psoriatic disease not only negatively impacts the individual, it also affects the person's family and their quality of life – even in the presence of mild disease.⁴² In cases where the individual experiences more severe symptoms and the knock-on effect causes their general well-being to deteriorate, family members are likewise affected more acutely.⁴³

Health and self-care. The impact on family health and self-care is widely reported. Participants with children with psoriatic disease interviewed for a study reported sleep disruption that resulted in fatigue, difficulty concentrating and impaired ability to manage personal care.⁴⁴

Emotional well-being. The family's emotional well-being was the most affected domain. Many families experience considerable stress directly related to their loved one's psoriasis, treatment, medical concerns and overall well-being, and sadness and frustration over the disease. Most participants had feelings of depression and anxiety that they considered directly related to their family member's condition.⁴⁴

Family and social function. Finances were a concern, as was the time it took to treat psoriasis and travel for appointments. Parents of children with psoriasis said that the child's condition had a substantial impact on relationships with family and friends, including their significant other. Many parents felt the need to raise awareness about their child's disease. The burden on the family included applying medications, using specific products, taking time away from their other children and being unable to leave the child in the care of others.⁴⁴

Many families experience considerable stress directly related to their loved one's psoriatic disease and its treatment

Underlying burdens of psoriatic disease

In the UK:

69%
of people with psoriasis are **not able to carry out work or hobbies, with 37% feeling humiliation.**⁴⁹

97%
of people with psoriasis and psoriatic arthritis are **affected emotionally, with 83% stating it impacts their family life.**⁵⁰



A heavy emotional toll

Living with a condition that is visible on the skin takes a heavy toll on a person's mental health as they struggle to cope with persistent feelings of poor self-image, low self-esteem and reduced well-being.⁴⁵ More than half of the people (56%) diagnosed with psoriatic disease living in Portugal responding to a survey said they deal with their disease daily.⁴⁶ The psychological impact of psoriatic disease, including feelings of stigmatization and depression, can also substantially affect a person's daily life.¹⁶

People living with psoriatic disease are frequently stigmatized and excluded from everyday social environments, including schools, workplaces and swimming pools. Stigmatization and other social difficulties may exacerbate negative emotions, false and irrational thoughts, unfavourable self-perceptions (such as reduced self-esteem and negative body image) and negative behavioural patterns (excessive social avoidance, for example).⁴⁷

The perception of stigma leads to a higher risk for psychiatric comorbidities such as anxiety and depression. Stigma should routinely be screened for in dermatological care.⁴⁸

Emotional triggers and physical impact

There is growing recognition that psoriatic disease has significant psychological ramifications. However, the relationship between psoriatic disease and emotional well-being is complex and multifaceted.⁵¹ Treatment of psoriatic disease after its initial onset may help relieve or resolve the symptoms of the disease. However, the disease can return periodically and unpredictably.⁵¹ The very prospect of a recurrence – called a flare – can cause stress and anxiety. For example, planning

Measuring the impact of psoriatic arthritis on people's lives

When it comes to understanding a disease and the effectiveness of treatments for managing it, the perspectives of the people living with it are indispensable. How do they experience symptoms, health-related quality of life, treatments and their own health status? The answers to these questions inform not only other patients and clinicians but also policymakers.

Research partners from 12 European countries have developed a tool based on the patient's perspective that can be used to assess the impact of psoriatic arthritis on people's lives.²⁶ The tool will help capture more complete data across several domains that may be valuable in clinical practice and trial settings.

vacations, weddings or even projects at work is difficult when faced with the lingering and ever-present possibility of a flare.

The physical symptoms of the disease – such as joint pain and skin itch – are both physically and emotionally stressful and can lead to sleep deprivation, fatigue and adverse effects on mental health.⁵¹

Psoriatic disease negatively impacts a person's quality of life – even more so than other types of chronic disease. On average, higher psychological and physical strain levels were identified in people with psoriatic disease than in those with chronic diseases such as diabetes, rheumatism, heart disease or even cancer.⁵²



Psoriasis impacts people's wellbeing

10 key insights from the World Psoriasis Happiness Report 2018⁵³

Approximately 80,000 people with psoriasis took part in a global survey conducted by the Health and Happiness Foundation that explored different aspects of living with the disease. A total of 10 key insights related to wellbeing emerged through an analysis of the responses:

Psoriasis puts a **cost on society**

Investing in happiness for people living with psoriasis can improve millions of lives and save societies billions of dollars

Unemployment (especially when permanent) is detrimental to happiness

People living with psoriasis often report struggling with **poor mental health**

People with **unhealthy lifestyles** are unhappier

Good sleep is a strong predictor of happiness

Loneliness is a risk factor for people living with psoriasis

Patient satisfaction is not an **indicator of happiness**

Substantial costs for individuals, healthcare systems and society

The economic burden of psoriatic disease is hefty for individuals, healthcare service providers and society.^{54,55} A person living with psoriatic disease incurs higher healthcare costs than someone without the disease, and the costs increase with the disease severity.^{56,57} Due to hospitalization and systemic therapies, psoriatic disease is often regarded as a costly disease⁵⁸. Evidence from several European countries shows that the healthcare costs associated with psoriasis are comparable with those of other costly conditions such as pancreatic cancer, prostate cancer and asthma.⁵⁹ However, there is a significant shortage of studies about the cost of psoriasis in Europe, and much of the available data are dated.

In Europe, estimates of the total annual cost per person vary from 1,079 euros in Spain to 11,434 euros in Italy.^{60,61} This range can be attributed to differences in healthcare systems, variability in the pricing of medication and inconsistency in the methods used to ascertain costs.⁶²

A study that examined the costs of psoriatic disease in five European countries reported that the direct medical costs (medication, visits to healthcare professionals and hospitalization costs) were the most significant component of total expenditure (medical and non-medical) for both psoriasis and psoriatic arthritis.⁵⁶ In addition to the direct costs, psoriatic disease also drives indirect costs in the form of lost productivity, lost working days and restricted activity days.⁵⁶

The total annual costs per patient associated with managing and treating psoriasis and psoriatic arthritis in five European countries*⁵⁶

Germany, Spain, France, Italy and the UK

Psoriasis

**1,900 -
12,200 €**

per person[†]

Psoriatic arthritis

**10,900 -
16,000 €**

per person[‡]

*The total annual cost per person includes both direct costs (medical and non-medical) and indirect costs.⁵⁶

[†]Originally reported in US dollars (2,077–13,132 dollars per person).
[‡]10,924–17,050 dollars per person.

Out-of-pocket treatment costs can be problematic for individuals

High healthcare costs can be unavoidable for many people living with psoriatic disease.⁶⁴ While there is no cure for psoriatic disease, ointments, creams, moisturisers and other medications (sometimes in combination) can relieve the symptoms. But this relief can come with a high price tag, especially for someone with severe disease who pays 2.5 times as much.⁶⁵

Although most countries in Europe offer universal health coverage, many people still have to pay for various services out of their own pockets. In some countries, specialists are accessed via private healthcare providers, where services tend to be more expensive.⁴⁶ As such, many people find the cost of treating psoriatic disease unaffordable. Out-of-pocket payments can present a financial barrier to access – which means that those who cannot afford it do not get the services they need – or can result in financial hardship.

People with chronic conditions that require ongoing treatment and regular interaction with the healthcare system can rapidly accumulate debt due to out-of-pocket expenses. Studies have shown that the annual out-of-pocket expenses for people with psoriasis in the European Union vary from 480,67 euros to 797,00 euros.⁶⁵ This is mainly attributed to the use of dermatological products, including over-the-counter and alternative therapies.⁶⁵ For instance, more than 70% of people with plaque psoriasis registered with a national healthcare provider in Greece use a topical treatment. About 12.5% use the topical treatment together with a drug. In both cases, the individual must bear 25% of the cost.⁶⁶

New treatment options may result in more efficient and cost-effective care

A systematic review of the costs associated with treating psoriatic disease found that the costs increase with the treatment and management of more severe disease cases and with the use of biologics.⁵⁶ Biologics have been proven to provide reliable disease control with relatively few side effects and have greatly improved the quality of life of many people living with psoriatic disease.⁶⁷ However, biologics can be costly. The cost of these drugs is known to result in a high burden on healthcare budgets, which limits access to these novel therapies.⁶⁸

That said, biologic agents may promote more efficient management of severe psoriasis and more consistent control of symptoms.⁶⁵ A report from Germany noted that despite the high cost, the use of biologics had reduced the need for inpatient care, resulting in an overall reduction in costs per patient.⁶³ While it is clear that psoriatic disease carries a significant economic burden, further studies are required to establish a more accurate understanding of the weight of this burden.⁶⁹

Financial barriers may impact care

Portugal:⁴⁷

Most patients (62.9%) are scheduled for a **follow-up appointment** with a specialist dermatology physician.

51.9% of the 564 people surveyed claimed to attend a **private hospital or private clinic** for follow-up appointments.

25% said they had **difficulties accessing**

consultations, of which half mentioned that this difficulty was due to the **limited resources of the national health service, lack of specialists and difficulty in scheduling** appointments.

31% indicated that economic challenges such as **consultation costs and travel to appointments prevented** them from accessing consultations.

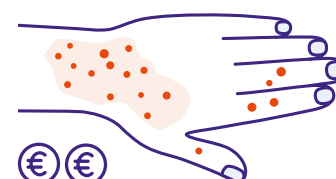
Disease severity and comorbidities are associated with higher healthcare costs

Routine analysis of the German health insurance database showed that comorbidities and disease severity drive healthcare and other indirect costs.⁶³

Annual economic burden per person, including indirect costs:



Less severe disease:
1,000 – 6,000 euros



Severe disease:
9,000 euros

Average cost:

per person:

5,543 euros
+ 2,400 euros
for comorbidities.



Addressing unmet medical needs

Poland: Only half of all people with psoriatic arthritis are detected

Despite recent improvements in detection in Poland, which is on a par with other European countries, it is estimated that one in two psoriatic arthritis cases remain undiagnosed.⁷⁶ In Europe, estimates of undiagnosed psoriatic arthritis among people with psoriasis vary between 10.9% and 29%.⁶

Denmark: Improved awareness equals improved diagnosis⁷²

In Denmark, healthcare professionals' improved awareness about psoriatic arthritis has markedly enhanced diagnosis. A recent study found that 21% of people with psoriatic arthritis received a diagnosis within three months of showing symptoms.

Psoriatic disease is a complex, multifactorial condition. A person's immune system becomes overactive and affects normal tissues in the body.⁷⁰ Psoriatic disease can worsen progressively, but its progression can be slowed with early diagnosis and treatment.

Because of the complexity of psoriatic disease, appropriate management can be demanding.⁵⁹ People living with psoriatic disease often experience considerable unmet medical needs. Many remain untreated or undertreated.⁵⁹ As such, there is a need for an improved understanding of the physical, psychological, social and economic impact of the disease and the barriers that people encounter in seeking treatment and management.⁵⁹

For people living with psoriatic disease, accessing appropriate care that is adequate and affordable can be challenging. Barriers to optimal care include insufficient knowledge about psoriatic disease among non-specialist healthcare professionals, high treatment costs combined with low reimbursement, and limited access to healthcare.^{34,36,51}

In the case of several other chronic diseases, disease management strategies – including educational programmes and digital technologies – have helped improve treatment outcomes. However, these strategies seem to be missing in the routine management of people living with psoriatic disease.³⁵

Access to early diagnosis and treatment

Early diagnosis of inflammatory rheumatic diseases, such as psoriatic arthritis, is essential to reduce the risk of irreversible structural damage and the deterioration of physical function and to improve long-term health outcomes.⁷ However, not only bodily function is at stake; undiagnosed or unmanaged psoriatic disease can also have negative psychosocial consequences.⁷¹ Delays in treating psoriatic arthritis may negatively impact mental health due to increased functional limitations restricting mobility coupled with discomfort and pain.⁷²

Therefore, early diagnosis, routine depression screening and suicidality monitoring are crucial to reducing future psychiatric morbidity and mortality in people with psoriatic disease. A lack of adequate screening tools can cause diagnostic delays and underdiagnosis, and this is exacerbated by weak referral systems or long waiting times for rheumatology specialists.^{73–75,36}

For example, in the UK, estimates indicate that 1.1 million people (or 1.7% of the population) are diagnosed with psoriasis.⁷³ The percentage grows to 2.78% when considering the estimated number of self-reported and undiagnosed cases.³⁶

Key takeaway

To improve early diagnosis and treatment, awareness of the importance of early detection and of the early signs of the disease is vital.

Mental health, stigma and quality of life

Psoriatic disease significantly impacts quality of life, negatively affecting mental health and relationships.⁷⁷ The psychosocial burden of the disease is well documented. In Europe, 12% of people living with psoriatic disease have been diagnosed with or have shown signs of depression.⁷⁸ Another study on the prevalence of comorbid depression among people with psoriasis found rates between 20% and 60%.²⁴ High levels of stigmatization, low levels of perceived social support, female gender and the length of time that a person has lived with psoriatic disease have all been associated with the severity of the depression.⁴⁷ Stigmatization, related to the fear of social rejection and deprivation of the basic need for belonging, emerged in one research article as the most potent predictor of depressive symptoms for people with psoriatic disease.⁴⁷

The World Psoriasis Happiness Report found that 30% of people with psoriasis are lonely, which is significantly higher than in the general population.⁵³ Psychological, mental or emotional pain – expressed as negative feelings of hurt, intense distress, emotional suffering, loneliness and shame, among others – affect how a person feels, thinks and interacts with the world around them.^{53,79} Thus, recurrent poor mental well-being can lead to a vicious cycle. Halting the cycle requires urgent recognition of the psychosocial and emotional load individuals with psoriatic disease carry so that steps may be taken to address issues as they arise.

In Europe, as in other regions, the psychosocial burden of psoriatic disease does not get the level of care and attention it requires. Psoriatic disease treatment guidelines do not address mental health concerns.⁵³

Key takeaway

There are no validated instruments available to determine the psychosocial burden of psoriatic disease.³⁶ To improve psoriatic disease care and the well-being of people living with it, ways to assess and address mental health problems must be developed and implemented in clinical practice.

Invest in mental health⁵²

COVID-19 brought into sharp focus mental health and well-being for everybody. People with chronic conditions, including psoriatic disease, were significantly affected by disruptions in healthcare services.

Goals and targets set by the World Health Organization's Comprehensive Mental Health Action Plan 2013–2030 for the inclusion of mental health services in health programs for NCDs and mental health training for primary care workers will improve psoriatic disease care. Preventing and diagnosing mental conditions in people with psoriatic disease must be a focus.

**Only
27%**
of patients reported
that their **healthcare
professional spoke
to them about their
mental health.**⁵³



The availability of specialist care differs vastly by country in Europe⁵²

Ireland:

15 

dermatologists*

Germany, France, Italy:

60-70   

dermatologists*

Greece:

100 

dermatologists*

* per 1 million inhabitants



Health workforce shortages

Recognizing and managing comorbidities is essential for the holistic care of psoriatic disease.⁸⁰ People with psoriatic disease are generally treated by their general practitioner (GP). If their symptoms are particularly severe or they do not respond well to treatment, their GP may refer them to a dermatologist. Although most dermatologists are familiar with the skin lesions, they may be less accustomed to musculoskeletal manifestations of psoriatic disease. Furthermore, they may lack the training necessary to provide psychological support for patients.⁸¹ GPs and dermatologists should be aware of the signs and symptoms of psoriatic disease and its comorbidities.

However, a lack of adequate training of GPs and other HCPs has resulted in low awareness of psoriatic disease.³⁶ This lack of awareness is compounded by the short duration of medical consultations, making it difficult for HCPs to conduct thorough clinical examinations.⁸⁰⁻⁸² Even if symptoms are apparent, HCPs who lack specific knowledge about psoriatic disease may not recognize the seriousness of the condition.⁸⁰

In any event, referral to a rheumatologist or specialist is necessary for an accurate diagnosis of psoriatic disease or related comorbidity. Improving health service coverage and realizing a high standard of care for people with psoriatic disease depends on the availability, accessibility, acceptability and quality of health workers.³⁶ Without enough well-trained professionals, it is impossible to provide high-quality and universally accessible health services to meet the healthcare needs of people with psoriatic disease.

Even after a diagnosis of psoriatic disease, there are challenges associated with treating the condition. Psoriatic disease is often undertreated, despite the availability of effective therapies.⁸³ Primary care providers lack knowledge or experience in treating conditions visible on the skin.⁸³ For instance, there is inadequate education in medical schools in the UK and a lack of standardized mandatory training for GPs⁸⁴. On average, UK medical students receive no more than six days of training in dermatology in undergraduate training, even though one-quarter of GP appointments concern the skin.⁸⁴ A more able primary care workforce would reduce the pressure on secondary care.

Key takeaway

To improve the skills and capabilities of HCPs, education on psoriatic disease and its comorbidities should be included in undergraduate medical and nursing curricula and primary healthcare training.

Trained professionals will be empowered to increase early diagnoses and coordinate specialist care.



Digital transformation and telemedicine

Telemedicine and eHealth are increasingly being used by doctors and patients in managing people with psoriatic disease.⁸⁵ Modern technology is increasingly supporting healthcare at a distance and improving the accessibility of specialist consultations. Being a visually dependent specialism, dermatology is well suited for remote consultation, and the demand for teledermatology as a tool for monitoring and managing skin lesions is surging.⁸⁶

The COVID-19 pandemic compounded existing difficulties regarding diagnosing and managing psoriatic arthritis.⁸⁷ The use of eHealth helped close this gap in care by enabling faster, more targeted and more streamlined access to rheumatological care for people with psoriatic disease.⁸⁸ During the pandemic, telemedicine and remote consultations were leveraged to protect patients and healthcare workers from the risk of infection from COVID-19 by reducing the flow of patients through healthcare facilities.⁸⁹ However, there is no reason such an approach should end with the pandemic. Integrating digital health technologies into dermatological and rheumatological care could help empower people living with psoriatic disease.⁹⁰ Digital platforms already exist where people living with psoriatic disease can check their own symptoms.⁹¹

Bridging the digital gap in telemedicine

While eHealth can improve access to care, this is not always the case. Some people might not have the necessary digital skills or be comfortable using telemedicine. Furthermore, potential barriers exist regarding the quality of the digital connection and the patient's ability to show their healthcare professional certain body parts via the camera.⁸⁹

A study in Italy of people living with psoriasis found that almost half had a positive attitude towards telemedicine. The study suggests that providing individuals with training related to telecommunication technologies might increase their preference for this type of consultation.⁵⁵

In Germany, a disease management smartphone app was found to help achieve a long-term improvement in the mental health of people with psoriasis. However, this improvement was only noted in cases where the app was not frequently used. Further studies regarding the use of apps in dermatology are required.⁹³

Across Europe, the digital transformation has been embraced.

A survey in the United Kingdom found that:⁹¹

18%
thought that their
virtual consultation
was highly effective.

49%
felt that telemedicine
was as effective as an
in-clinic consultation.

48%
thought that virtual
consultation would
be beneficial post-
pandemic.



The European Alliance of Associations for Rheumatology (EULAR) recently published points to consider for developing, evaluating and implementing mobile health applications. In doing so, it hoped to provide guidance on some essential aspects of self-management for people living with rheumatic and musculoskeletal diseases.⁸⁷ Another project embracing digital technologies in rheumatology is the Joint Pain Assessment Scoring Tool (JPAST). Funded by the European Union, this tool combines eHealth with the analysis of validated biomarkers.^{88,92}

Key takeaway

Telemedicine and digital technologies for health (eHealth) provide opportunities for greater healthcare access by dermatologists and rheumatologists.

There are screening tools, assessments, guidelines and resources that can be applied to incorporate digital technologies into clinical care and optimised for people with psoriatic disease. Telemedicine can also contribute to training and education for patients and their providers.

Prof Dr. Peter van de Kerkhof

Dermatologist, The Netherlands



Awareness is critical to improving care and outcomes for people with psoriatic disease

Awareness of the importance of early diagnosis. Psoriatic disease is a chronic disease that can impact the whole body. It is also associated with many comorbidities, like cardiovascular disease. It can lead

to a shorter life expectancy of up to five years in people with moderate to severe forms of the disease. This is why early diagnosis is so important. Early diagnosis is essential for the biology and physiology of the disease and can make it easier to treat comorbidities.

What can be done? General practitioners need to be better at recognizing psoriasis and referring to specialists. Dermatologists need to be more aware of psoriatic arthritis and identify it earlier.

Awareness that psoriatic disease is beyond skin. Many people with psoriatic disease are treated with topical ointments and creams, and the start of systemic therapies is often postponed too long. The challenge is that dermatologists are, by origin, skin doctors and are inclined to adhere as long as possible to topical treatments and phototherapy compared with internal medicine specialists.

What can be done? We need to improve awareness among healthcare professionals and patients about different therapies, their profiles, and their advantages. For example, doctors and patients are often concerned about the side-effect profiles of some systemic therapies, but these can be managed. Cost is also a concern, but this should be considered in relation to the cost of managing comorbidities.

It's time to act

Better health and well-being for people with psoriatic disease in Europe

It is possible. Improved health outcomes and a better quality of life for everyone living with psoriatic disease are attainable. But first, we need to recognize that many people living with the disease have unmet needs. Then, we must ensure that the right policies are in place to bring about change and that the healthcare systems (and the professionals within those systems) have the knowledge, skills and resources to deliver on those policies.

Now is the time to recognize, prioritize and invest in psoriatic disease as a serious chronic NCD

Eight years have passed since the commitments made under the 2014 WHA Resolution on Psoriasis. Yet people with psoriatic disease continue to face stigma and discrimination and have many unmet needs – including inadequate access to medicines, early diagnosis and proper care.

Now is the time to realise the recommendations made under the 2014 WHA Resolution on Psoriasis.

Now is the time to develop policies that support people with psoriatic disease

People living with psoriatic disease in Europe continue to encounter many barriers to management and care, including a lack of diagnostic tools, low levels of knowledge about psoriatic disease among healthcare professionals, high treatment costs and limited access to healthcare.

Now is the time to develop supportive policies that can help address many of these barriers and ensure that people living with psoriatic disease have the care necessary to manage their disease, prevent disability or joint damage, clear skin symptoms, improve quality of life, and ensure mental and physical well-being.

Now is the time to ensure the right treatment at the right time with the right resources

People living with psoriatic disease and its associated comorbidities need lifelong access to comprehensive, multidisciplinary care. To make this possible, it is vital that we invest in a secure and sufficient, equitably distributed, adequately supported and well-performing health workforce. Such a workforce would be capable of supporting health goals and targets set by national governments and the international community.

Now is the time to invest in affordable treatment options, digital health solutions and an adequately skilled health workforce to improve the quality of care for people living with psoriatic disease.

Now is the time to put people living with the disease at the centre of decision-making

A people-centred approach to healthcare – as outlined by the WHO's global strategy on people-centred and integrated health services – will ensure that people living with psoriatic disease receive the treatment they need for improved health and better quality of life.

Now is the time to engage meaningfully with the organizations representing people living with psoriatic disease. Now is the time for people living with psoriatic disease to play a role in shaping the health policies that affect them.

Our vision



Founded in 1971, IFPA is the international federation of psoriatic disease associations. IFPA's members represent more than 60 million people living with psoriatic disease.

IFPA is the only global organization representing and uniting all people living with psoriatic disease – regardless of where they live, the type of psoriatic disease they have or how it impacts their lives.

Vision

A future where all people living with psoriatic disease enjoy good health and wellbeing, free from stigma and preventable disability and comorbidities.

Mission

Unite, strengthen and lead the global psoriatic disease community to improve the lives of all people affected by psoriatic disease.

Our members in Europe

REGIONAL: The European Psoriasis Organisation

BELGIUM WALLONIA: GIPSO asbl / Groupe d'Aide à l'Information et à la Recherche sur le Psoriasis, asbl (Support Group for Research and Information on Psoriasis)

BELGIUM FLANDERS: Psoriasis Liga Vlaanderen vzw (Flemish Psoriasis Association)

BULGARIA: Асоциация на хората с псориазис и псориаични усложнения (Association of people suffering from psoriasis and psoriatic disorders)

CROATIA: Društvo psorijatičara Hrvatske (Croatian Psoriasis Association)

CZECH REPUBLIC: SPAE / Spolek psoriatiků a atopických ekzematiků (Psoriatic and Atopic Eczema Association Czech Republic)

DENMARK: Psoriasisforeningen (Danish Psoriasis Association)

ESTONIA: EPSoL- Eesti Psoriaasiliit (Estonian Psoriasis Union)

FINLAND: Psoriasisliitto – Psoriasisförbundet ry (The Finnish Psoriasis Association)

FRANCE: Association France Psoriasis

GEORGIA: PSO Georgia

GEORGIA - GAPP: GAPP (Georgian Association of Psoriasis Patients)

GERMANY: Deutscher Psoriasis Bund e.V.

GREECE: Epidermia

ICELAND: Samtök Psoriasis og Exemsjúklinga / SPOEX (Psoriasis and Eczema Association)

IRELAND: Irish Skin Foundation

ISRAEL: Israel Psoriasis Association

ITALY: APIAFCO Associazione Psoriasici Italiani Amici della Fondazione Corazza

MONTENEGRO: Association for helping people with rheumatic diseases Montenegro

NORWAY: PEF, Psoriasis- og eksemforbundet (The Psoriasis and Eczema Association of Norway)

THE NETHERLANDS: Psoriasispatiënten Nederland

PORTUGAL: PSOPortugal - Associação Portuguesa da Psoríase

RUSSIA: Interregional Charitable Public Organization "Skin and Allergic Diseases"

SERBIA: Udruzenje Pacijenti Protiv Psorijaze (Association of Patients Against Psoriasis)

SLOVAKIA: Spolocnost Psoriatikov a Atopikov SR (Slovak Psoriatics and Atopics Eczema Association)

SLOVENIA: Društvo Psoriatikov Slovenije (Psoriasis Association of Slovenia)

SPAIN: Acción Psoriasis (Psoriasis Action)

SWEDEN: Psoriasisförbundet (The Swedish Psoriasis Association)

SWITZERLAND: Schweizerische Psoriasis und Vitiligo Gesellschaft / SPVG (Swiss Psoriasis and Vitiligo Organisation)

TURKEY: Türkiye Sedef Hastalan Dayanisma Dernegi (Psoriasis patients solidarity association)

 National member organizations in Europe

Contributors and editorial board

Anette Meyer, Patient representative, German Psoriasis Association, Germany

Anette Meyer is a patient representative from the German Psoriasis Association (DPB). At the office in Hamburg, she is responsible for public relations, editing the DPB member magazine PSO Magazin and the information brochures on psoriatic disease. She has psoriasis herself. She finds it very exciting to prepare complicated medical issues in terms of language and content so that they can be easily understood by patients, their relatives, and other interested people. Anette's mission is to raise public awareness of psoriatic disease.

Hannele Kirveskoski, Advocacy Specialist, Finland

Hannele Kirveskoski is an advocacy expert responsible for monitoring the interests of people with psoriatic disease, for example, by giving statements and meeting with decision-makers. She is also involved in organizational planning by supporting psoriasis associations and their volunteers in the region of Southwest Finland. Hannele has a Master's Degree in political sciences and has previously been involved in student organizations in advocacy and educational roles.

Jaime Melancia, President of PSOPortugal, Portugal

Jaime Melancia is president of PSOPortugal, the Portuguese Association of Psoriasis. Jaime has held this volunteer position since 2016 and advocates tirelessly for the rights and causes of people living with psoriatic disease. On behalf of

PSOPortugal, he is a member of the governing bodies of the Portuguese National Federation of Chronic Diseases (FENDOC), Eupati-Portugal, and Health in Dialogue Platform. He is also a member of the Superior Council of the National Health Convention. Internationally, Jaime is a member of the Board of Europso and Chair of its Community Advisory Board. He is also a member of the GlobalSkin-Europe Advisory Committee.

Jamie has more than 30 years of experience in the information technology sector and a background in telecommunications and electronics engineering. Currently, he works as a marketing manager in a Portuguese company, implementing videoconferencing solutions. Previously he was a field engineer in wireline services for the oil industry.

Tina Koukopoulou, Treasurer of Epidermia, Greece

Tina Koukopoulou, is the treasurer of the Panhellenic Association of Patients with Psoriasis and Psoriatic Arthritis, Epidermia. She is also a substitute member of Europso and represents Epidermia in IFPA. Tina has psoriasis and psoriatic arthritis and knows first-hand what it is like to live with the condition. She has been actively advocating for people living with psoriatic disease since 2015. Tina is also a Clinical Trial Ambassador. Professionally, Tina works as a Surveyor Engineer with a Ph.D. in Cadastral Systems. She is currently living and working in Thessaloniki, Greece.

Paul Sutton, Director, Therapeutic Area Strategies Lead, International

Government Affairs, AbbVie, Canada

Paul Sutton is the Therapeutic Area Strategies Lead in the International Government Affairs organization at AbbVie. Paul has been with AbbVie since 2014, ultimately leading Government Affairs in the Canadian affiliate prior to joining the Global organization in 2020. Before joining AbbVie, Paul worked for many years in the Canadian policy and advocacy response to HIV and hepatitis C. Paul holds a Master's Degree in English Literature from York University in Toronto and a Master's Degree in Communication Studies from McGill University in Montreal.

Prof Dr. Peter CM van de Kerkhof, Dermatologist, The Netherlands

Prof Dr. Peter CM van de Kerkhof became a registered dermatologist in 1983. Between 1991 and 2018, he was the chairman of the Department of Dermatology of Radboud University. Prof van de Kerkhof has worked on understanding the pathogenesis of psoriasis by studying the transition between symptomless and clinically involved skin. He has also been a principal investigator in many clinical trials and participated in international collaborative groups to understand treatment selection in daily practice. He has published more than 800 papers in peer reviewed journals and gives presentations abroad on invitation.

Currently, he is a senior Professor of Radboud University and Chief medical officer of the International Psoriasis Council (IPC). Prof van de Kerkhof also provides consultancies for pharmaceutical companies and gives lectures and masterclasses abroad.

References

- Mease PJ, Gladman DD, Papp KA, et al. Prevalence of rheumatologist-diagnosed psoriatic arthritis in patients with psoriasis in European/North American dermatology clinics. *Journal of the American Academy of Dermatology*. 2013;69(5):729-735.
- Griffiths CEM, Armstrong AW, Gudjonsson JE, Barker J. Psoriasis. *Lancet (London, England)*. Apr 3 2021;397(10281):1301-1315. doi:10.1016/s0140-6736(20)32549-6.
- Gottlieb A, Merola JF. Psoriatic arthritis for dermatologists. *Journal of Dermatological Treatment*. 2020/10/02 2020;31(7):662-679. doi:10.1080/09546634.2019.1605142.
- Global Psoriasis Atlas. Psoriasis statistics: Prevalence. Accessed March, 2021. <https://www.globalpsoriasisatlas.org/en/statistics>.
- Laskowski M, Schöler L, Gustafsson H, Wennberg AM, Åberg M, Torén K. Cardiorespiratory fitness in late adolescence and long-term risk of psoriasis and psoriatic arthritis among Swedish men. *PLoS one*. 2021;16(1):e0243348. doi:10.1371/journal.pone.0243348.
- Damiani G, Bragazzi NL, Karimkhani Aksut C, et al. The Global, Regional, and National Burden of Psoriasis: Results and Insights From the Global Burden of Disease 2019 Study. *Front Med (Lausanne)*. 2021;8:743180. doi:10.3389/fmed.2021.743180.
- Trafford AM, Parisi R, Kontopantelis E, Griffiths CEM, Ashcroft DM. Association of Psoriasis With the Risk of Developing or Dying of Cancer: A Systematic Review and Meta-analysis. *JAMA dermatology*. Dec 1 2019;155(12):1390-1403. doi:10.1001/jamadermatol.2019.3056.
- Gelfand JM, Neimann AL, Shin DB, Wang X, Margolis DJ, Troxel AB. Risk of myocardial infarction in patients with psoriasis. *Jama*. Oct 11 2006;296(14):1735-41. doi:10.1001/jama.296.14.1735.
- Gelfand JM, Dommasch ED, Shin DB, et al. The risk of stroke in patients with psoriasis. *Journal of Investigative Dermatology*. 2009;129(10):2411-2418.
- Li L, Hagberg KW, Peng M, Shah K, Paris M, Jick S. Rates of Cardiovascular Disease and Major Adverse Cardiovascular Events in Patients With Psoriatic Arthritis Compared to Patients Without Psoriatic Arthritis. *J Clin Rheumatol*. Dec 2015;21(8):405-10. doi:10.1097/rhu.0000000000000306.
- Jafri K, Bartels CM, Shin D, Gelfand JM, Ogdie A. Incidence and Management of Cardiovascular Risk Factors in Psoriatic Arthritis and Rheumatoid Arthritis: A Population-Based Study. *Arthritis Care Res (Hoboken)*. Jan 2017;69(1):51-57. doi:10.1002/acr.23094.
- Mehra NN, Yu Y, Pinnelas R, et al. Attributable risk estimate of severe psoriasis on major cardiovascular events. *The American journal of medicine*. Aug 2011;124(8):775 e1-6. doi:10.1016/j.amjmed.2011.03.028.
- Charlton R, Green A, Shaddick G, et al. Risk of type 2 diabetes and cardiovascular disease in an incident cohort of people with psoriatic arthritis: a population-based cohort study. *Rheumatology (Oxford, England)*. Jan 1 2019;58(1):144-148. doi:10.1093/rheumatology/kez286.
- Azfar RS, Seminara NM, Shin DB, Troxel AB, Margolis DJ, Gelfand JM. Increased risk of diabetes mellitus and likelihood of receiving diabetes mellitus treatment in patients with psoriasis. *Archives of dermatology*. Sep 2012;148(9):995-1000. doi:10.1001/archdermatol.2012.1401.
- Wan J, Wang S, Haynes K, Denburg MR, Shin DB, Gelfand JM. Risk of moderate to advanced kidney disease in patients with psoriasis: population based cohort study. *Bmj*. Oct 15 2013;347:f5961. doi:10.1136/bmj.f5961.
- Bewley A, Ersser S, Hansen M, Ward CJUpPE, Prag, 27-30 september. Psychosocial and symptomatic burden of psoriasis for patients in Europe, the USA and Canada.
- Parisi R, Webb RT, Kleyn CE, et al. Psychiatric morbidity and suicidal behaviour in psoriasis: a primary care cohort study. *The British journal of dermatology*. Jan 2019;180(1):108-115. doi:10.1111/bjd.17004.
- Łakuta P, Marcinkiewicz K, Bergler-Czop B, Brzezińska-Wcisło L. The relationship between psoriasis and depression: A multiple mediation model. *Body Image*. 2016;19:126-132.
- Bavière W, Deprez X, Houvenagel E, et al. Association Between Comorbidities and Quality of Life in Psoriatic Arthritis: Results from a Multicentric Cross-sectional Study. *J Rheumatol*. Mar 2020;47(3):369-376. doi:10.3899/jrheum.181471.
- Ramírez J, Azuaga-Piñango AB, Celis R, Cañete JD. Update on Cardiovascular Risk and Obesity in Psoriatic Arthritis. *Frontiers in medicine*. 2021;8:742713-742713. doi:10.3389/fmed.2021.742713.
- Gottlieb AB, Wu JJ, Griffiths CE, et al. Clinical efficacy and safety of secukinumab in patients with psoriasis and comorbidities: pooled analysis of 4 phase 3 clinical trials. *Journal of Dermatological Treatment*. 2020:1-9.
- Budu-Aggrey A, Brumpton B, Tyrrell J, et al. Evidence of a causal relationship between body mass index and psoriasis: A mendelian randomization study. *PLoS medicine*. 2019;16(1):e1002739.
- Rodríguez-Cerdeira C, Cordeiro-Rodríguez M, Carnero-Gregorio M, et al. Biomarkers of inflammation in obesity-psoriatic patients. *Mediators of inflammation*. 2019;2019.
- Griffiths CEM, van der Walt JM, Ashcroft DM, et al. The global state of psoriasis disease epidemiology: a workshop report. *The British journal of dermatology*. Jul 2017;177(1):e4-e7. doi:10.1111/bjd.15610.
- Svensson S NT, Thorsteinsson T, Johansen T, Bäckman S, Hansen KF. *The impact of climate treatment on quality of life for psoriasis patients – How can we secure equal access now and in the future?* Accessed 28 March, 2022. https://psoriasis.dk/sites/psoriasis.dk/files/media/document/Nordic%20Whitepaper%20on%20Climate%20Treatment_NORDPSO_Psoriasisforeningen.pdf.
- Gossec L, de Wit M, Kiltz U, et al. A patient-derived and patient-reported outcome measure for assessing psoriatic arthritis: elaboration and preliminary validation of the Psoriatic Arthritis Impact of Disease (PsAID) questionnaire, a 13-country EULAR initiative. *Annals of the rheumatic diseases*. 2014;73(6):1012-1019.
- Pompili M, Innamorati M, Trovarelli S, et al. Suicide risk and psychiatric comorbidity in patients with psoriasis. *J Int Med Res*. Sep 2016;44(1 suppl):61-66. doi:10.1177/0300060515593253.
- Aldredge LM, Higham RC. Manifestations and management of difficult-to-treat psoriasis. *Journal of the Dermatology Nurses' Association*. 2018;10(4):189-197.
- Hedin CRH, Sonkoly E, Eberhardson M, Ståhle M. Inflammatory bowel disease and psoriasis: modernizing the multidisciplinary approach. *J Intern Med*. Aug 2021;290(2):257-278. doi:10.1111/joim.13282.
- Ogdie A, Coates LC, Gladman DD. Treatment guidelines in psoriatic arthritis. *Rheumatology (Oxford, England)*. 2020;59(Suppl 1):i37-i46. doi:10.1093/rheumatology/kez383.
- Global Psoriasis Atlas Phase II. *Annual Report April 2020 - March 2021*. 2021.
- Armstrong A, Jarvis S, Boehncke WH, et al. Patient perceptions of clear/almost clear skin in moderate to severe plaque psoriasis: results of the Clear About Psoriasis worldwide survey. *Journal of the European Academy of Dermatology and Venereology*. 2018;32(12):2200-2207.
- Sommer R, Topp J, Mrowietz U, Zander N, Augustin M. Perception and determinants of stigmatization of people with psoriasis in the German population. *Journal of the European Academy of Dermatology and Venereology : JEADV*. Dec 2020;34(12):2846-2855. doi:10.1111/jdv.16436.
- IFPMA. *Bringing Psoriasis into the light. International Federation of Pharmaceutical Manufacturers & Associations*. Accessed 25 March, 2022. <https://www.ifpma.org/resource-centre/bringing-psoriasis-into-the-light-2/>.
- Domogalla L, Beck A, Schulze-Hagen T, Herr R, Benecke J, Schmieder A. Impact of an eHealth Smartphone App on the Mental Health of Patients With Psoriasis: Prospective Randomized Controlled Intervention Study. *JMIR mHealth and uHealth*. 2021/10/25 2021;9(10):e28149. doi:10.2196/28149.
- World Health Organization. *Global Report on Psoriasis*. 2016. Accessed 25 March 2022.
- Schielein MC, Tizek L, Rotter M, Konstantinow A, Biedermann T, Zink A. Guideline-compliant prescription of biologicals and possible barriers in dermatological practices in Bavaria. *Journal of the European Academy of Dermatology and Venereology : JEADV*. Jun 2018;32(6):978-984. doi:10.1111/jdv.14811.
- Svedbom A, Dalén J, Mamolo C, Cappelleri JC, Petersson IF, Ståhle M. Treatment patterns with topicals, traditional systemics and biologics in psoriasis - a Swedish database analysis. *Journal of the European Academy of Dermatology and Venereology : JEADV*. Feb 2015;29(2):215-223. doi:10.1111/jdv.12494.
- Guillet C, Seeli C, Nina M, Maul LV, Maul J-T. The impact of gender and sex in psoriasis: What to be aware of when treating women with psoriasis. *International Journal of Women's Dermatology*. 2022;8(2):e010. doi:10.1097/jw9.000000000000010.
- McBride SR, Fargnoli MC, Fougere AC, et al. Impact of psoriatic disease on women aged 18 to 45: Results from a multinational survey across 11 European countries. *Int J Womens Dermatol*. Dec 2021;7(5Part B):697-707. doi:10.1016/j.ijwd.2021.08.011.
- Gottlieb AB, Ryan C, Murase JE. Clinical considerations for the management of psoriasis in women. *Int J Womens Dermatol*. Jul 2019;5(3):141-150. doi:10.1016/j.ijwd.2019.04.021.
- Solmaz D, Bakirci S, Kimyon G, et al. Impact of Having Family History of Psoriasis or Psoriatic Arthritis on Psoriatic Disease. *Arthritis Care Res (Hoboken)*. Jan 2020;72(1):63-68. doi:10.1002/acr.23836.
- Salman A, Yucelten AD, Sarac E, Saricam MH, Perdahli-Fis N. Impact of psoriasis in the quality of life of children, adolescents and their families: a cross-sectional study. *Anais brasileiros de dermatologia*. Nov/Dec 2018;93(6):819-823. doi:10.1590/abd1806-4841.20186981.
- Tollefson M, Finnie D, Schoch J, Eton D. Impact of childhood psoriasis on parents of affected children. *Journal of the American Academy*

- of *Dermatology*. 11/01 2016;76doi:10.1016/j.jaad.2016.09.014.
45. Padmavathi Nagarajan DMT. *Clinical Profile of Patients with Psoriasis and their Attitude Towards the Illness*. 2019.
 46. PSO Portugal. *PeSsOa Study: Clinical epidemiological profile and quality of life of patients with psoriasis in Portugal*. 2016.
 47. Kakuta P, Marcinkiewicz K, Bergler-Czop B, Brzezińska-Wcisło L. How does stigma affect people with psoriasis? *Advances in Dermatology and Allergology/Post-py Dermatologii i Alergologii*. 02/01 2017;34:36-41. doi:10.5114/pdia.2016.62286.
 48. Germain N, Augustin M, François C, et al. Stigma in visible skin diseases—a literature review and development of a conceptual model. *Journal of the European Academy of Dermatology and Venereology*. 2021;35(7):1493-1504.
 49. Sampogna F, Tabolli S, Abeni D. Living with psoriasis: prevalence of shame, anger, worry, and problems in daily activities and social life. *Acta dermato-venereologica*. May 2012;92(3):299-303. doi:10.2340/00015555-1273.
 50. Pariser D, Schenkel B, Carter C, Farahi K, Brown TM, Ellis CN. A multicenter, non-interventional study to evaluate patient-reported experiences of living with psoriasis. *The Journal of dermatological treatment*. 2016;27(1):19-26. doi:10.3109/09546634.2015.1044492.
 51. IFPA. *Inside Psoriatic Disease: Mental Health*. <https://ifpa-psy.com/resources-tools/inside-psoriatic-disease-mental-health>.
 52. Matthias Augustin MAR, Jobst Augustin. *Psoriasis Healthcare and Facts in Europe For decision makers and stakeholders*. 2018;European Healthcare facts volume 1.
 53. Health & Happiness Foundation. *The World Psoriasis Happiness Report*. 2017:1-108. Accessed May 2022. <https://psoriasis-happiness-report/static/documents/world-psoriasis-happiness-report-2018.pdf>.
 54. Mustonen A. Economic burden of psoriasis. University of Turku Doctoral Programme of Clinical Investigation; 2015.
 55. Kristensen LE, Jørgensen TS, Christensen R, et al. Societal costs and patients' experience of health inequities before and after diagnosis of psoriatic arthritis: a Danish cohort study. *Annals of the rheumatic diseases*. Sep 2017;76(9):1495-1501. doi:10.1136/annrheumdis-2016-210579.
 56. Burgos-Pol R, Martínez-Sesmero JM, Ventura-Cerdá JM, Elías I, Caloto MT, Casado M. The Cost of Psoriasis and Psoriatic Arthritis in 5 European Countries: A Systematic Review. *Actas dermo-sifilograficas*. Sep 2016;107(7):577-90. Coste de la psoriasis y artritis psoriásica en cinco países de Europa: una revisión sistemática. doi:10.1016/j.ad.2016.04.018.
 57. Yu AP, Tang J, Xie J, et al. Economic burden of psoriasis compared to the general population and stratified by disease severity. *Current Medical Research and Opinion*. 2009/10/01 2009;25(10):2429-2438. doi:10.1185/03007990903185557.
 58. Gianfredi V, Bricchi L, Casu G, Rongioletti F, Singnorelli. Review of literature in the field epidemiology of psoriasis in Italy.
 59. Feldman SR, Goffe B, Rice G, et al. The challenge of managing psoriasis: unmet medical needs and stakeholder perspectives. *American health & drug benefits*. 2016;9(9):504.
 60. Colombo G, Altomare G, Peris K, et al. Moderate and severe plaque psoriasis: cost-of-illness study in Italy. *Ther Clin Risk Manag*. Apr 2008;4(2):559-68. doi:10.2147/tcrm.s2740.
 61. Olivieri I, de Portu S, Salvarani C, et al. The psoriatic arthritis cost evaluation study: a cost-of-illness study on tumour necrosis factor inhibitors in psoriatic arthritis patients with inadequate response to conventional therapy. *Rheumatology (Oxford, England)*. Nov 2008;47(11):1664-70. doi:10.1093/rheumatology/ken320.
 62. Navarini AA, Laffitte E, Conrad C, et al. Estimation of cost-of-illness in patients with psoriasis in Switzerland. *Swiss Med Wkly*. Feb 6 2010;140(5-6):85-91. doi:smw-12756.
 63. Augustin M, Glaeske G, Schäfer I, Rustenbach SJ, Hoer A, Radtke MA. Processes of psoriasis health care in Germany—long-term analysis of data from the statutory health insurances. *Journal der Deutschen Dermatologischen Gesellschaft = Journal of the German Society of Dermatology : JDDG*. Sep 2012;10(9):648-55. doi:10.1111/j.1610-0387.2012.07893.x.
 64. Thomsen SF, Skov L, Dodge R, Hedegaard MS, Kjellberg J. Socioeconomic Costs and Health Inequalities from Psoriasis: A Cohort Study. *Dermatology (Basel, Switzerland)*. 2019;235(5):372-379. doi:10.1159/000499924.
 65. Obradors M, Figueras M, Paz S, Comellas M, Lizán L. Costs of psoriasis in Europe. A systematic review of the literature. *Value in Health*. 2014;17(7):A606.
 66. Souliotis K, Golna C, Kani C, Litsa P. Reducing patient copayment levels for topical and systemic treatments in plaque psoriasis as a case for evidence-based, sustainable pharmaceutical policy change in Greece. *Journal of Medical Economics*. 2016;19(11):1021-1026.
 67. Campanati A, Ganzetti G, Giuliodori K, Molinelli E, Offidani A. Biologic Therapy in Psoriasis: Safety Profile. *Curr Drug Saf*. 2016;11(1):4-11. doi:10.2174/157488631066615104115532.
 68. Putrik P, Ramiro S, Kvien TK, et al. Inequities in access to biologic and synthetic DMARDs across 46 European countries. *Annals of the rheumatic diseases*. Jan 2014;73(1):198-206. doi:10.1136/annrheumdis-2012-202603.
 69. Kharawala S, Golembesky AK, Bohn RL, Esser D. The clinical, humanistic, and economic burden of generalized pustular psoriasis: a structured review. *Expert review of clinical immunology*. Mar 2020;16(3):239-252. doi:10.1080/1744666x.2019.1708193.
 70. Carvalho AL, Hedrich CM. The Molecular Pathophysiology of Psoriatic Arthritis—The Complex Interplay Between Genetic Predisposition, Epigenetics Factors, and the Microbiome. *Front Mol Biosci*. 2021;8:662047. doi:10.3389/fmolb.2021.662047.
 71. Haugeberg G, Lund Nilssen TI, Kavanaugh A, Thomsen RS, Gulati AM, Hoff M. Physical and Psychosocial Burden of Psoriatic Arthritis: Longitudinal Data From a Population-Based Study in Norway. *Arthritis Care & Research*. 2021;73(1):138-145.
 72. Haroon M, Gallagher P, FitzGerald O. Diagnostic delay of more than 6 months contributes to poor radiographic and functional outcome in psoriatic arthritis. *Annals of the rheumatic diseases*. 2015;74(6):1045-1050.
 73. The University of Manchester. New figures show Psoriasis affects 11 million people in UK. <https://www.manchester.ac.uk/discover/news/new-figures-show-psoriasis-affects-around-11-million-people-in-uk/>.
 74. Sørensen J, Hetland ML. Diagnostic delay in patients with rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis: results from the Danish nationwide DANBIO registry. *Annals of the rheumatic diseases*. Mar 2015;74(3):e12. doi:10.1136/annrheumdis-2013-204867.
 75. Belinchón I, Salgado-Boquete L, López-Ferrer A, et al. Dermatologists' role in the early diagnosis of psoriatic arthritis: expert recommendations. *Actas Dermo-Sifilograficas (English Edition)*. 2020;111(10):835-846.
 76. Thustochowicz M, Wierzbza W, Marczak M, et al. Trends in psoriatic arthritis epidemiology in Poland. *Rheumatology international*. 2021/01/01 2021;41(1):139-145. doi:10.1007/s00296-020-04734-x.
 77. Armstrong A, Bohannon B, Mburu S, et al. Impact of Psoriatic Disease on Quality of Life: Interim Results of a Global Survey. *Dermatology and Therapy*. 2022/04/01 2022;12(4):1055-1064. doi:10.1007/s13555-022-00695-0.
 78. Puig L, van de Kerkhof PCM, Reich K, et al. A European subset analysis from the population-based Multinational Assessment of Psoriasis and Psoriatic Arthritis shows country-specific features: results from psoriasis patients in Spain. *Journal of the European Academy of Dermatology and Venereology : JEADV*. Jul 2017;31(7):1176-1182. doi:10.1111/jdv.14195
 79. González-Parra S, Daudén E. Psoriasis y depresión: el papel de la inflamación. *Actas dermo-sifilograficas*. 2019;110(1):12-19.
 80. Betteridge N, Boehncke WH, Bundy C, Gossec L, Gratacós J, Augustin M. Promoting patient-centred care in psoriatic arthritis: a multidisciplinary European perspective on improving the patient experience. *Journal of the European Academy of Dermatology and Venereology : JEADV*. Apr 2016;30(4):576-85. doi:10.1111/jdv.13306.
 81. Bagel J, Schwartzman S. Enthesitis and dactylitis in psoriatic disease: a guide for dermatologists. *American Journal of clinical dermatology*. 2018;19(6):839-852.
 82. Raharja A, Mahil SK, Barker JN. Psoriasis: a brief overview. *Clin Med (Lond)*. 2021;21(3):170-173. doi:10.7861/clinmed.2021-0257.
 83. Kumar S, Flood K, Golbari NM, Charrow AP, Porter ML, Kimball AB. Psoriasis: Knowledge, attitudes and perceptions among primary care providers. *Journal of the American Academy of Dermatology*. 2021;84(5):1421-1423. doi:10.1016/j.jaad.2020.05.151.
 84. Eedy D. Dermatology: a specialty in crisis. *Clin Med (Lond)*. 2015;15(6):509-510. doi:10.7861/clinmedicine.15-6-509.
 85. Havelin A, Hampton P. Telemedicine and e-Health in the Management of Psoriasis: Improving Patient Outcomes - A Narrative Review. *Psoriasis (Auckl)*. 2022;12:15-24. doi:10.2147/ptt.S323471.
 86. Pala P, Bergler-Czop BS, Gwizdź JM. Tele dermatology: idea, benefits and risks of modern age - a systematic review based on melanoma. *Postepy dermatologii i alergologii*. 2020;37(2):159-167. doi:10.5114/ada.2020.94834.
 87. Gottlieb AB, Wells AF, Merola JF. Telemedicine and psoriatic arthritis: best practices and considerations for dermatologists and rheumatologists. *Clinical Rheumatology*. 2022/05/01 2022;41(5):1271-1283. doi:10.1007/s10067-022-06077-3.
 88. Fagni F, Knitza J, Krusche M, Kleyer A, Tascilar K, Simon D. Digital Approaches for a Reliable Early Diagnosis of Psoriatic Arthritis: Mini Review. *Frontiers in Medicine*. 2021-August-11 2021;8doi:10.3389/fmed.2021.718922.
 89. Standing Committee of European Doctors (CPME). CPME Policy on Telemedicine. 2021:6.
 90. Giovannini I, Bosch P, Dejacq C, et al. The Digital Way to Intercept Psoriatic Arthritis. *Frontiers in Medicine*. 11/01 2021;8:792972. doi:10.3389/fmed.2021.792972.
 91. IFPA. *Telemedicine for Psoriatic Disease Care*. 2021:1-12. <https://ifpa-psy.com/resources-tools/telemedicine-for-psd>.
 92. Jethwa H, Brooke M, Parkinson A, Dures E, Gullick NJ. Patients' perspectives of telemedicine appointments for psoriatic arthritis during the COVID-19 pandemic: results of a patient-driven pilot survey. *BMC Rheumatology*. 2022/02/22 2022;6(1):13. doi:10.1186/s41927-021-00242-y.
 93. Marasca C, Annunziata MC, Camela E, et al. Tele dermatology and Inflammatory Skin Conditions during COVID-19 Era: New Perspectives and Applications. *J Clin Med*. Mar 10 2022;11(6)doi:10.3390/jcm11061511.

