

A Report by the Psoriasis Association  
and LEO Pharma

# WAKE UP TO PSORIASIS

GIVE NOTHING  
TO PSORIASIS

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GIVE NOTHING  
TO PSORIASIS

*Give Nothing To Psoriasis* is a disease awareness campaign developed by LEO Pharma. The *Wake Up to Psoriasis* report was developed from a collaboration between the Psoriasis Association and LEO Pharma, as part of the *Give Nothing to Psoriasis* campaign. LEO Pharma has provided core funding, editorial input and undertaken survey-based research to support the development of the report.

# Welcome



The Psoriasis Association is proud to have worked alongside LEO Pharma to develop the *Wake Up to Psoriasis* report. For more than 50 years, the Psoriasis Association has been supporting people with psoriasis in the UK. Despite our heritage, we were shocked by some of the experiences that were uncovered through this research. We urge people affected by psoriasis to seek help from their healthcare professionals.

Psoriasis can impact significantly on quality of sleep, which can lead to a decline in work productivity, daily activities and quality of life. Through this report, we want people with psoriasis to realise they are not alone in their experiences of sleep loss and itch. We also want the general public to improve their understanding of the condition.

We want people living with psoriasis to be empowered to openly discuss their condition with family and friends, and to re-engage with healthcare professionals for holistic support. We urge healthcare professionals to look beyond the physical aspects of psoriasis and consider other patient-reported outcome measures to define treatment success.

With this report, and all the work of the Psoriasis Association, we are committed to supporting people affected by psoriasis and furthering education and awareness of the condition in the UK.

## **Helen McAteer**

Chief Executive Officer, Psoriasis Association



As a foundation-owned company, LEO Pharma recognise the important role of working closely with advocacy groups to support patients. Therefore, we are delighted to have partnered with the Psoriasis Association to develop the *Wake Up to Psoriasis* report.

When we first launched the *Give Nothing to Psoriasis* campaign, it was designed to empower and encourage patients to take control of their condition, and to stop living with restrictions. This campaign highlighted that many people living with psoriasis in the UK feel forced to give up significant aspects of their life, from careers through to their social life and hobbies.

I regularly travel for work, often experiencing jet lag and I'm a parent to three children so I'm used to functioning on limited sleep. However, I cannot imagine a life with the sleep deprivation experienced by many of the people who took part in this initiative. It brings into sharp relief the importance of our mission at LEO Pharma.

Through the *Wake Up to Psoriasis* report, we wanted to focus on identifying what people with psoriasis may be losing because of their condition – such as sleep and mental wellbeing. Psoriasis can impact people in many aspects of their lives, both physically and psychologically, and it is important to recognise and address the need for regular holistic and long-term support.

LEO Pharma keeps patients at the heart of everything it does. We are committed to constantly improving the education of healthcare professionals to extend what is possible for people with psoriasis. With the findings of this report, we are urging people to *Wake Up to Psoriasis* and make a positive change.

## **Geraldine Murphy**

Vice-President Cluster Europe North, Australia & New Zealand, LEO Pharma



# Executive summary

## Do you need to *Wake Up to Psoriasis?*

Psoriasis is a life-long condition for which there is no cure. Far from being 'just a skin condition', psoriasis is associated with a number of serious health conditions, both physical and psychological.<sup>1</sup> These wider health implications are often referred to as 'co-morbidities'.

The *Wake Up to Psoriasis* report shines a light on the detrimental effect of psoriasis on daily life, overall wellbeing and participation in wider society. The purpose of this report is to encourage people living with psoriasis and those around them to realise the true impact of the condition and to seek the regular, holistic long-term care they need from healthcare professionals.

The *Wake Up to Psoriasis* report identified two major under-recognised areas, that people living with psoriasis experience: disturbed sleep and the prevalence of itch. Losing sleep can not only impact physical health, but it can heavily influence a person's outlook on life, motivation and emotions.<sup>2</sup> In addition, the *Wake Up to Psoriasis* report identified a disconnect between people living with psoriasis and their engagement with healthcare professionals.

Through the publication of these findings, the Psoriasis Association and LEO Pharma want to encourage people in the UK to increase their awareness and understanding of psoriasis. The aim of the report is for everyone to recognise that psoriasis goes beyond the skin. People with psoriasis should be empowered to speak to their healthcare professional proactively, openly and honestly for support on the management of their physical and emotional symptoms and achieving a restful night's sleep.





# Background & objectives

Psoriasis is a complex, serious, life-long, incurable immune-mediated condition.<sup>1</sup> Although the exact cause of psoriasis is unknown, the condition is characterised by the production of new cells occurring too quickly, resulting in the formation of red scaly patches on the skin.<sup>3</sup> Across the UK, up to 1.8 million people are affected by psoriasis.<sup>1</sup> Far from being 'just a skin condition', psoriasis is also associated with a number of co-morbidities including cardiovascular disease, psoriatic arthritis and some cancers.<sup>4,5</sup> While some people are familiar with the physical impact of psoriasis on the skin, there is less focus on the significant psychological impact that can negatively influence quality of life.<sup>6</sup> People living with psoriasis commonly report experiencing low self-esteem and anxiety, which in some cases can lead to depression.<sup>4</sup>

## About *Give Nothing to Psoriasis*

Launched by LEO Pharma in 2017, *Give Nothing to Psoriasis* is a disease awareness campaign with a difference. The objective of this campaign is to empower people living with psoriasis to take control of their condition. *Give Nothing to Psoriasis* is based on research that showed people with psoriasis often learn to cope with their condition by cutting out the parts of their life it affects. Too often, people with psoriasis underestimate how much of their lives they are cutting out. This can happen gradually, and often subconsciously, and as a result people end up giving up more parts of their life to help manage their condition.<sup>7</sup>

As part of the *Give Nothing to Psoriasis* campaign, the Psoriasis Association and LEO Pharma have commissioned the *Wake Up to Psoriasis* report to recognise the debilitating impact psoriasis can have on quality of life as a result of sleep loss and itch.



## WAKE UP TO PSORIASIS

### About the *Wake Up to Psoriasis* report

Taking a focus on sleep loss and wider health implications of psoriasis, the *Wake Up to Psoriasis* report is based on three pieces of social market research:



#### Qualitative research

Social market research involving 20 people living with psoriasis\*. Participants completed a daily diary for a period of two weeks



#### Quantitative research

Survey of 2,000 members of the public through an omnibus survey including 80 people with psoriasis\*



#### Quantitative research

Survey of 100 people living with psoriasis\*

In-depth insights into the impact sleep loss and itch can have on the quality of life of people living with psoriasis, and the misconceptions about the impact of psoriasis amongst the general public have been gained through this research. The aim of the report is to empower people living with psoriasis to speak to their healthcare professionals for support. The organisations also want to ensure that by highlighting the debilitating psychological impact, the UK general public will increase their awareness and understanding of the condition, and healthcare professionals will better understand the experiences of their psoriasis patients.

### About the partnership between the Psoriasis Association and LEO Pharma

The Psoriasis Association and LEO Pharma are proud to have been working in partnership for decades, building a strong relationship based on a shared vision to support people living with psoriasis in the UK. In addition to their collaboration to develop the *Wake Up to Psoriasis* report, they have worked together on numerous initiatives. They are continuing to work together to support people with psoriasis and healthcare professionals in the UK.



\* Participants are people with self-reported psoriasis



# Methodology

The *Wake Up to Psoriasis* report is based on social market research conducted in the UK in 2019. To ensure the report captured in-depth insights into the experiences of people living with psoriasis and the general public, the report focused on the following three key research streams.

## 01.

### Quantitative research of people living with psoriasis

An online survey of 100 respondents was conducted to reveal the impact of sleep loss on daily life. In the survey of people living with psoriasis, conducted in 2019, respondents were asked about their experience with psoriasis and the impact on their sleep and quality of life.

## 02.

### Quantitative research of the general public

The general public awareness survey of 2,006 UK respondents was designed to understand the potential stigma and disconnect between public perceptions of psoriasis and the realities of living with a chronic skin condition. In the survey, conducted in 2019, the general public were asked about their understanding of psoriasis, their attitudes and opinions on psoriasis, their personal experience of mental wellbeing and their sleeping patterns.

## 03.

### Qualitative research of people living with psoriasis

A two-week diary exercise of 20 respondents was designed to provide insights into the daily impact of the condition and to uncover the extent of sleep loss and impact of itch. The diary exercise asked respondents to describe and record their previous nights sleep, and the consequences of sleep loss on their daily activities. Respondents detailed whether their social plans and work were affected by their psoriasis, their feelings about their condition and what they thought could be done to mitigate the impact.

#### 01 Sample question from the quantitative research of people living with psoriasis

How often does psoriasis have a negative impact on your quality of life or general wellbeing?

- a) Every day
- b) Most days
- c) At least once a week
- d) Several times a month
- e) At least once a month
- f) Most months
- g) Once or twice a year
- h) Less frequently than once a year
- i) Not at all

#### 02 Sample question from the quantitative research of the general public survey

What do you know about psoriasis? Please tick below:

- a) I've never heard of it
- b) I've heard of it, but didn't know what it is
- c) I know about it, but don't know anyone with this condition
- d) I know someone with psoriasis – but not a close friend or family member
- e) I have a close friend or family member with psoriasis
- f) My spouse/ partner has psoriasis
- g) I have psoriasis

#### 03 Sample question from the qualitative research of people living with psoriasis

How did psoriasis affect your day today? Please describe in as much detail as possible any way in which psoriasis affected you. (E.g. impact of psoriasis on daily activities, what you wore, what you did etc.)



# Key findings

The *Wake Up to Psoriasis* research identified two areas where people living with psoriasis experienced a negative impact due to their condition, sleep loss and severity of itch.<sup>8,9</sup> In addition, a disconnect between people living with psoriasis and their engagement with healthcare professionals was identified, with many patients feeling unsupported by healthcare professionals, and others disengaging from the traditional healthcare system.<sup>9</sup>

## Sleep and itch

People with psoriasis often suffer more sleepless nights due to their condition, which can in turn make their psoriasis flare up, setting up a cycle of worsening symptoms leading to increased stress and more sleep problems.<sup>2,9</sup> Based on other existing research, this degree of long-term sleep deprivation can be associated with an increased risk of type 2 diabetes, hypertension, high cholesterol, obesity and metabolic syndrome.<sup>10</sup>

The *Wake Up to Psoriasis* report found that:

43%



Two out of five people (43%) with psoriasis reported difficulty sleeping in the past month, and one in ten was robbed of almost two weeks of sleep.<sup>9</sup>

73%



Seven out of ten (73%) people with psoriasis who reported sleep problems got less sleep than parents with three or more children.<sup>9,11</sup>

100%



100% of people with psoriasis who lost sleep due to psoriasis found itching uncomfortable.<sup>9</sup>

37%



37% of people with psoriasis who experienced sleep disruption are feeling despondent about their skin.<sup>9</sup> This can cause further anxieties and worries that may also keep them from sleeping.

Literature has shown strong links between sleep disruption and depression. Around 75% of people diagnosed with depression suffer insomnia, and insomnia is a risk factor for developing depression.<sup>12</sup>





**"Apart from the discomfort and pain that I felt all day, I have felt groggy and tired because of the lack of sleep. This has made me feel depressed, as I have had a few really good days up till now."**

Psoriasis patient diary response

**"Not being able to do things with my family makes me feel like a failure as a husband and a Dad. This can then play on my mind when I'm trying to sleep."**

Psoriasis patient diary response

**"I find in summer the heat and itchiness kind of team up on you at night."**

Psoriasis patient diary response



## Emotional wellbeing

Mental health problems can affect the way you think, feel and behave.<sup>13</sup> A mental health problem can feel just as bad, or worse, as any other physical illness – only you cannot see it.<sup>13</sup> Two thirds of people living with psoriasis believe the condition can impact their mental health.<sup>9</sup>

Studies have also found people living with psoriasis may experience alexithymia, which refers to difficulty in identifying and expressing emotions.<sup>14</sup> The prevalence of alexithymia amongst the psoriasis population is associated with numerous factors including higher levels of anxiety and depression, a higher risk of alcohol dependency and impairment of work productivity compared with patients without alexithymia.<sup>14</sup> As a result, it is important for healthcare professionals to recognise alexithymic patients with psoriasis in clinical practice, as they may experience a higher disease burden and may struggle to express their feelings.

The *Wake Up to Psoriasis* report found that:



The impact of psoriasis often goes beyond the physical discomfort of the condition. The effects of psoriasis on the skin cause people with the condition to experience embarrassment, loss of confidence and depression.<sup>9, 12</sup>



People with psoriasis may miss out on events that many people take for granted. The survey findings revealed 15% of people with psoriasis avoided clothes shopping on the high street, 13% avoid going to the gym and a further 11% have had their psoriasis impact the type of holiday they would take.<sup>9</sup>




53% of people with psoriasis find that the condition can make it more difficult to form close, intimate relationships.<sup>9</sup> These experiences are made worse by the stigma towards the condition amongst the general public, with 35% of people stating they would not like to have an intimate relationship with someone living with psoriasis.<sup>8</sup>



87% of people with psoriasis said stress makes their psoriasis worse, resulting in a vicious cycle and can contribute to a negative impact on the individual's quality of life.<sup>9</sup>

Living with psoriasis can affect many aspects of a person's life, from the ability to work and their emotional wellbeing, to romantic relationships and socialising with friends. However, people with the condition are not openly discussing the full impact with healthcare professionals.<sup>9</sup>



**"It's good to see my mate, I wish I felt like spending more time with him, but I ache, and I need to try and get moisturiser on my back. Had a nice day, seeing friends is so important to me. I'm alone so much I need human contact, so it was worth it. I will pay for it tomorrow though."**

Psoriasis patient diary response

**"I have been very agitated today and this in turn flares my skin. I tossed and turned, and my genital psoriasis was really burning. This in turn affects the intimacy between my husband and I, which has been a problem for a while."**

Psoriasis patient diary response

**"I feel unemployable due to the unpredictable nature of my condition."**

Psoriasis patient diary response



"I always find when I go to see any healthcare professional that I have to explain about my psoriasis, and I would just really like them to ask me how I'm feeling and how my psoriasis is today."

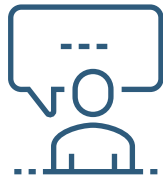
Psoriasis patient diary response

## Interaction with healthcare professionals

Based on existing research, people with psoriasis perceive GPs to be lacking in confidence when assessing and managing their conditions.<sup>15</sup> The *Wake Up to Psoriasis* report identified a disconnect, and disengagement, between people living with psoriasis and their healthcare professionals. The survey also revealed over a third of the UK general public have never heard of psoriasis or don't know what it is, along with patients who feel they lack adequate knowledge and understanding of the condition.<sup>8,9</sup>

The *Wake Up to Psoriasis* report found that:

40%



40% of people living with psoriasis do not tell their doctor the full impact that psoriasis has on their life.<sup>9</sup>

76%



76% of people with psoriasis don't regularly see their doctor in connection with their condition.<sup>9</sup>

47%



47% of people with psoriasis wished that their healthcare professional would offer more support.<sup>9</sup>

14%



14% of people with psoriasis have had a healthcare professional suggest that psoriasis is 'only a skin condition' or not important.<sup>9</sup>

29%



Only 29% of people with psoriasis have been asked by their doctor about the impact of psoriasis on their life.<sup>9</sup>

34%



34% of people with psoriasis have used their GP or doctor to find out more information about psoriasis in the past 12 months.<sup>9</sup>





# Conclusions

Through the *Wake Up to Psoriasis* report, the Psoriasis Association and LEO Pharma have identified a clear need for the support and care of people with psoriasis to look beyond the physical impact. Psoriasis is a common, lifelong, incurable condition that can greatly impact those living with it, both physically and psychologically.<sup>1,3</sup>

## Beyond the skin

The report highlights that people living with psoriasis are having their sleep and emotional wellbeing impacted by the condition. However, this is not well known by the general public, with over a third of UK adults having never heard of psoriasis or not knowing what it is.<sup>8</sup> The link between sleep and mood has been observed by other researchers, with people struggling with sleep disturbance experiencing greater levels of depression and anxiety than those who do not experience sleep loss.<sup>16</sup>

Sleepless nights can cause more than just a lack of focus or a bad mood.<sup>10</sup> Research has shown decreased sleep quality is associated with wider health implications, such as increased risk of obesity, heart disease and diabetes.<sup>10</sup>

There is also a disconnect between the reality that people living with psoriasis are faced with, and the understanding of the general public, which can lead to the stigmatisation of people with psoriasis.<sup>8,9</sup> This stigmatisation can further harm emotional wellbeing, leading to low self-esteem and anxiety, which may contribute to sleep loss.<sup>12,17</sup>

## Seeking support

Further to this, people living with psoriasis are feeling disengaged with their healthcare professionals, due to either a perceived lack of support or a reluctance to seek out support from healthcare professionals to address the full impact of the condition. People with psoriasis can find themselves unable to communicate with healthcare professionals about the true impact of their psoriasis on their sleeping patterns and emotional wellbeing. However, GPs may have received little dermatology training and education as the provision of dermatology training has historically been poor with no compulsory requirement within undergraduate or postgraduate curricula.<sup>18,19</sup>

In addition, psoriasis assessment tools, such as the Dermatology Life Quality Index (DLQI), are used to measure the severity of psoriasis and its impact on an individual's daily activities.<sup>20</sup> However, existing studies have revealed that these tools may not take into account all aspects of a person's daily life, such as itch and sleep quality.<sup>19</sup>

As well as supporting patients, the Psoriasis Association and LEO Pharma are committed to providing, and championing the need for, dermatology education to improve communication between patients and healthcare professionals. The findings of the *Wake Up to Psoriasis* report highlight that greater focus is required to effectively manage under recognised sleep disturbances for people living with psoriasis to improve overall quality of life.

## Looking ahead

Through the *Wake Up to Psoriasis* report, and the *Give Nothing to Psoriasis* campaign, the Psoriasis Association and LEO Pharma are calling on people living with psoriasis, their family, friends, colleagues and healthcare professionals across the UK to recognise that psoriasis is more than just a skin condition. Given the complex needs for people living with psoriasis, we encourage those individuals to speak to their healthcare professional to seek regular, holistic, long-term support for the impact the condition has on their quality of life and daily activities.

Through this report, the Psoriasis Association and LEO Pharma urge people to:

***Wake Up to Psoriasis***  
**Take action**  
**Engage with healthcare professionals**





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