



European Cancer  
Patient Coalition

# Unveiling the Hidden Faces of NMSC: The Patient Journey

Apostolidis, ECPC President

Non-Melanoma Skin Cancer:  
Europe's Hidden Occupational Disease

13<sup>th</sup> of June 2019  
European Parliament, Brussels



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# Outline

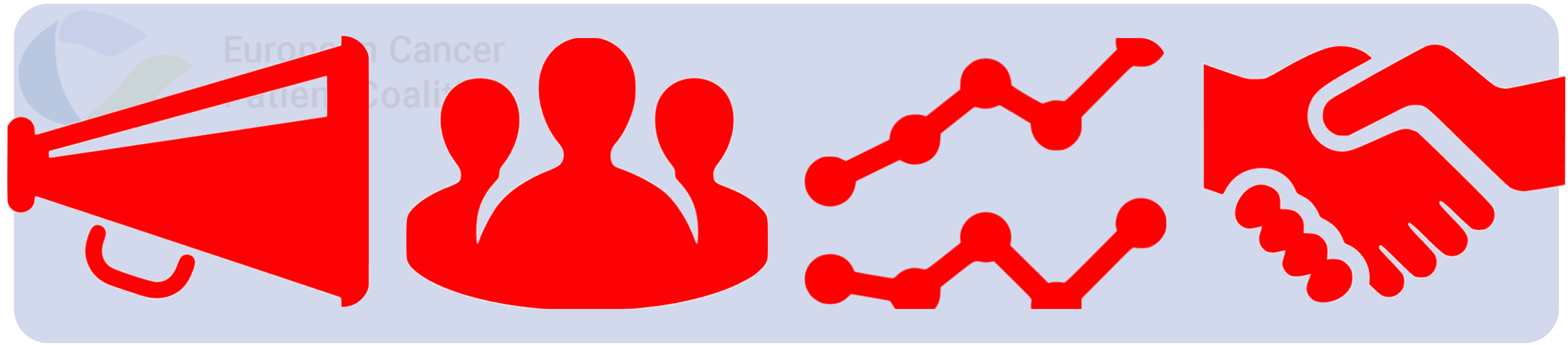
About ECPC  
Hidden faces of NMSC  
Building Awareness  
An NMSC patient  
Awareness  
Legislative framework  
NMSC Awareness best practice



## European Cancer Patient Coalition

- **Representing 448 cancer patient organizations in 47 countries**
- **Run and governed by patients**
- **Representing all cancers** – common and rare
- **Promoting timely, evidence based, sustainable access** to appropriate prevention, screening, early diagnosis, treatment & care for all cancer patients
- **Aiming at reducing disparity** and inequity across the EU
- Encouraging the **advance of cancer research & innovation**
- Increasing cancer patients' **influence** over European health and **research policy**





## Advocacy

Position papers  
Policy  
Awareness

## Capacity-Building

Working groups  
Education  
Annual Meeting

## Research

IMI PREFER  
IMI DO-IT  
FP7 eSMART  
DIADIC  
ELBA  
iPAAC – JARC  
PREDICT -LEGACy

## Partnerships

EAPM - EAU  
EORTC - OECI  
UICC - ESMO  
EMA/PCWP &  
ENCePP  
CDDF - WIN



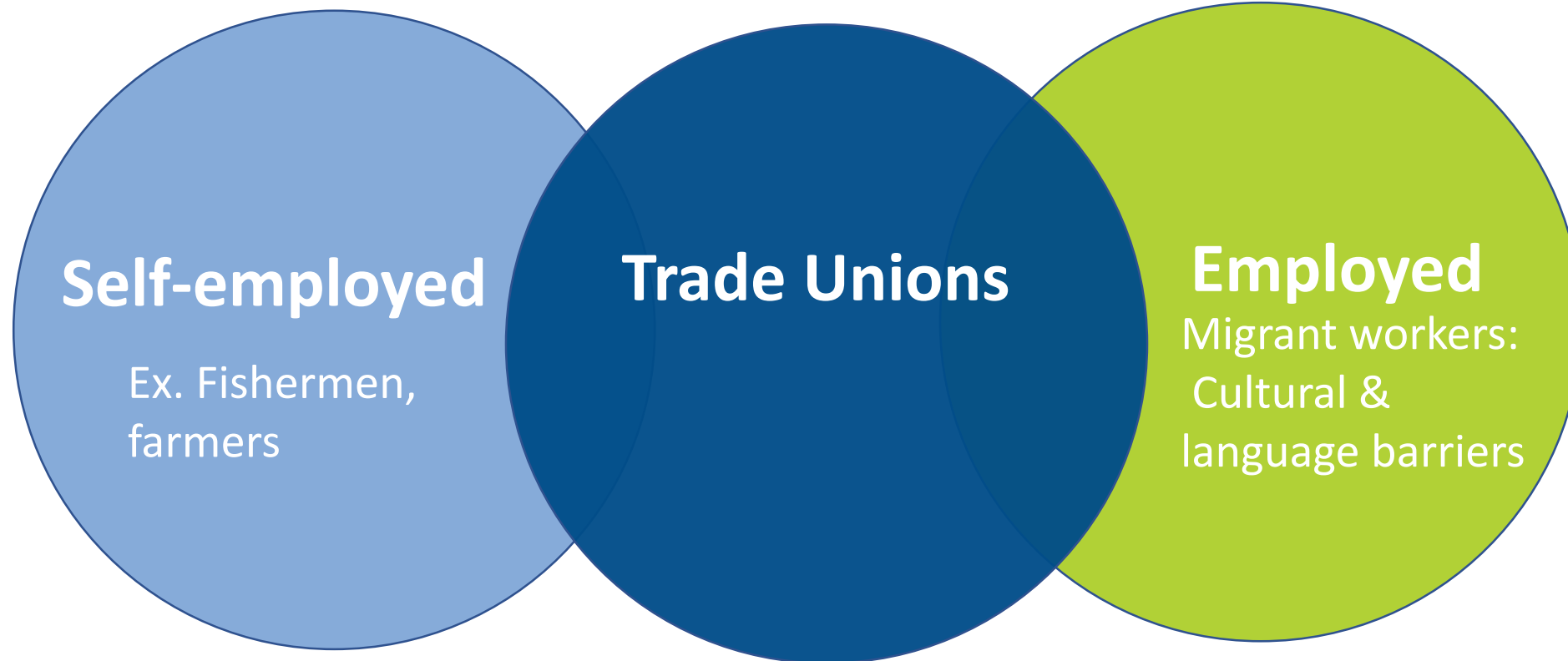
# Hidden Faces of NMSC

- EU: **14.5 million workers** spend 2/3 of working life outdoors: exposed to **2-3 times higher UVR** than indoor workers
- **80% of cases occur in people aged 60 and above** so the disease remains invisible until retirement age
- There is a general lack of **awareness** and **education** amongst those most at risk



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# Building Awareness





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## An NMSC Patient: Padraig Hurley



**“I never realized  
I would be one of those  
that ended up  
in the situation I am in”**



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# How do we approach this specific population?

Protection and screening not considered “manly” actions

**We need to change this perception!**

Patient advocacy groups, doctors and other HPs as well as employers should collaborate

**to promote skin cancer prevention  
and sun-safe working practices**

## OCCUPATIONAL SKIN CANCER:

AN OVERLOOKED EPIDEMIC FACING OUTDOOR WORKERS

### WHAT IS IT?



An occupational disease is any disease caused by exposure to **risk factors at work**.



Non-melanoma skin cancer (NMSC) is an occupational skin cancer that results from **excessive exposure** to the sun.



Occupational skin cancer has a disproportionate impact on people who **work outdoors** for **most of their working hours**.

### WHY IS IT IMPORTANT?



Today NMSC is by far **the most frequently diagnosed cancer** and its prevalence **continues to increase**.



After **five years** of outdoor work, the risk of developing NMSC can increase **as much as three times**.



In Europe alone, **15m outdoor workers** spend most of their working lives exposed to the sun, yet **few understand the risks**.

### WHAT CAN YOU DO?

On June 13th, we're launching the **first ever Global Non-Melanoma Skin Cancer Awareness Day** with the European Academy of Dermatology and Venereology (EADV).

Help us raise awareness by sharing our **Call-to-Action to End the Non-Melanoma Skin Cancer Epidemic**.

And use our hashtag **#FacingTheSun**

To learn more, visit:  
<http://bit.ly/NMSC-call-to-action>.





- **Recognition of NMSC as an occupational disease**
- **Standardised EU-wide registration of NMSC**
- **Tools to measure & quantify exposure to UVR**
- **Reporting of NMSC by health care professionals**
- **Promotion of NMSC prevention**
- **Address unmet needs of workers with persisting NMSC**



## Global Call to Action to End the Non-Melanoma Skin Cancer Epidemic in Outdoor Workers

April 26th, 2019

The seven co-hosting organizations<sup>1</sup> of the Multi-Stakeholder Summit on Occupational Skin Cancer – in cooperation with patient advocacy groups, workers unions, occupational safety and health professionals, social security representatives, dermatologists and oncologists – call for the implementation of a systematic approach to addressing the Non-Melanoma Skin Cancer Epidemic in view of the following:

Non-melanoma skin cancer (NMSC)<sup>2</sup> is by far the most frequently diagnosed cancer around the globe. It is also one of the most common occupational diseases in Europe and its prevalence continues to increase<sup>3</sup>. For instance, in Germany, it is the third most frequently reported occupational disease. In most countries, it is<sup>4</sup> also the most common occupational cancer. Despite this, victims remain overlooked while prevention efforts, screening and improved access to care are neglected.

A lack of reporting and accurate data on the disease burden has allowed this crisis to remain in the shadows. Outdoor workers in construction and farming industries, recreation and public services may be exposed to solar UV radiation (UVR) for more than 75% of their working hours. UVR is classified by WHO as a group 1 carcinogen. WHO threshold levels are exceeded by five times in many outdoor professions. It is estimated that the risk of developing skin cancer increases significantly – up to more than 100% - with five or more years of outdoor work. If not detected and prevented at an early stage, NMSC leads to a life-long chronicity with abundant newly forming lesions.

The economic costs of NMSC continue to increase, placing governments and healthcare systems under significant economic pressure and affecting the livelihoods of millions of workers around the world.

Despite this alarming reality, outdoor workers lack legislative protection to ensure adequate prevention measures, diagnosis and effective treatments for this occupational disease globally. For that reason, WHO and ILO are currently assessing the global disease burden of occupational skin cancer within the UN Sustainable Development Goals 2030 framework<sup>5</sup>.

<sup>1</sup>The seven co-hosting organizations are the European Academy of Dermatology and Venereology (EADV), the European Association of Dermato Oncology (EADO), the International League of Dermatological Societies (ILDS), the Association of European Cancer Leagues (ECL), the European Dermatology Forum (EDF), the International Commission on Occupational Health (ICOH), and the European Cancer Patient Coalition (EPCO).

<sup>2</sup>NMSC refers to a group of mostly skin-coloured cancers that slowly develop in the upper layers of the skin; the main clinical entities are basal cell carcinoma and squamous cell carcinoma/actinic keratosis. These tumors are also referred to as keratinocytic carcinomata.

<sup>3</sup>Didona D, Paolino G, Bottioni U, Cantisani C (2018) Non Melanoma Skin Cancer Pathogenesis Overview. *Biomedicines* 6(1):6.doi:10.3390/biomed6010006. Last accessed 17 January 2019.

<sup>4</sup>Jahn SM, Trakatelli M, Gehring R, Finlay K, Fionda C, Wittlich M, Augustin M, Hilpert G, Barroso Dias JM, Ulrich C, Pellacani G (2016) CONSENSUS REPORT: Recognizing non-melanoma skin cancer including actinic keratosis as an occupational disease - A Call to Action. *J Eur Acad Dermatol Venereol*. 2016; 30 (Suppl. 3):39-45. doi:10.1111/jdv.13608.

<sup>5</sup>Silva Paulo M, Adam B, Akagwu C, Akparibo I, Al-Rifaie RH, Bazrafshani S, Gobba F, Green AC, Ivanov I, Kezic S, Leppink S, Loney T, Modenese A, Pega F, Peters CE, Pötsch-Östlin A, Tankate T, Ujita Y, Wittlich M, Jahn SM (2019) WHO/ILO work-related burden of disease and injury: Protocol for systematic reviews of occupational exposure to solar ultraviolet radiation and of the effect of occupational exposure to solar ultraviolet radiation on melanoma and non-melanoma skin cancer. *Environment Int.* doi: 10.1016/j.envint.2018.09.039 [Epub ahead of print]



# New European Parliament mandate

- **Legislative framework** at EU, national and regional level **for adequate protection of outdoor workers** in accordance with the European Pillar of Social Rights
- Strengthen **legislation enforcement** to protect outdoor workers
- Facilitate accessibility to regular **screenings, earlier treatments, survivorship care**

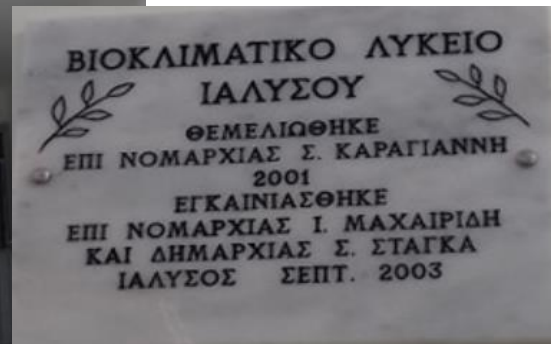


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## A NMSC awareness Best Practice from Greece

- **Problem:**  
Difficult to reach adult island population:  
Farmers, fishermen & construction workers
- **Solution:**
- AgaliaZO, cancer patient organization, reached the adult population through their children
- Seminars to high school children by physicians & patient advocates in early spring





## ΕΚΠΑΙΔΕΥΤΙΚΟ ΠΡΟΓΡΑΜΜΑ ΟΕΚΚ - ΑΓΚΑΛΙΑΣΩ

### ΓΥΜΝΑΣΙΑ ΚΑΙ ΛΥΚΕΙΑ ΠΕΙΡΑΙΑ 2018

*Καρκίνος του Δέρματος και Μελάνωμα*





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Thank you  
for your attention

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*Nothing about us without us*