MEPs AGAINST CANCER MEETING

SKIN CANCER REGISTRIES IN EUROPE: FROM KNOWLEDGE TO ACTION

20 JUNE 2018, 10:00-12:00
EUROPEAN PARLIAMENT, ROOM A1H-1

HOSTED BY MEP CHARLES TANNOCK (UK, ECR)

ORGANISED BY:
ECL Association of European Cancer Leagues
EURO MELANOMA
EUROPEAN SOCIETY OF SKIN CANCER PREVENTION EUROSKIN
EADV
European Dermatology Forum

INTRODUCTION

Dr. **Charles Tannock,** MEP and Vice President of the MAC Group, welcomed speakers and other participants at the European Parliament. MEP Tannock, as skin cancer survivor himself, expressed the importance of knowledge of the risks of long term damage from sun exposure. It is important to have the necessary cancer data to further research, to support policy makers' decisions, and monitor whether public health initiatives are working.

Introductory note was followed by a presentation from Dr. **Wendy Yared**, Director of the Association of European Cancer Leagues (ECL), who introduced the work and upcoming events of the MEPs Against Cancer (MAC Group).

EXPERT PRESENTATIONS

WHY REGISTRATION IS INDISPENSABLE FOR SKIN CANCER CONTROL

Dr. ANA-MARIA FORSEA, EUROMELANOMA

Dr. **Ana-Maria Forsea** shared personal experience from her post-doctoral research when she faced a problem of the lack of quality cancer data. Improved data collection could have many beneficiaries ranging from researchers to physicians, patient advocates and policy makers. Dr. Ana-Maria Forsea in her presentation emphasised disparities within Europe, with Southern and Eastern Europe lacking good cancer registry system and at the same time suffering of late cancer detection and high mortality. Dr. Ana-Maria Forsea concluded: “Only what can be measured can be improved”

MEASURING THE IMPACT OF MELANOMA SKIN CANCERS

MARIA STELLA DE SABATA, FONDO ANGLESIO MORONI PER L'ONCOLOGIA

Maria Stella de Sabata presened results of a study analysing melanoma trends in Europe. During the years of 1995 - 2012 incidence of melanoma had been rising both in men and women despite mortality rates not having an increasing trend. Maria Stella de Sabata also concluded that currently the burden of melanoma skin cancer is widely measured, however non-melanoma skin cancer was lacking behind. Ms. De Sabata concluded that evaluation of where population-based measurements could be implemented is needed.

NON-MELANOMA SKIN CANCER DATA: A CHALLENGE FOR THE EUROPEAN CANCER REGISTRIES AND THE GROWING ECIS

ELISABETH VAN EYCKEN, EUROPEAN NETWORK OF CANCER REGISTRIES

Elisabeth van Eycken gave some background on the European Network of Cancer Registries (ENCR) which was founded in 1990, and was hosted and supported by the Joint Research Centre (JRC) since 2012. Ms. Eycken's presentation identified 4 challenges for registration of non-melanoma skin cancer, namely:

1. Completeness: All cases should be registered, with complete dataset for each case

2. Data validity: Data should be accurate and precise
3. Comparability: Data should be standardised to be comparable
4. Timeliness: Data should be current

Elisabeth van Eycken concluded that it is necessary to (i) include non-melanoma skin cancer in population-based cancer registries; (ii) explore availability of data; and (iii) collect and assess quality data.

ABSENCE OF NON-MELANOMA SKIN CANCER REGISTRY

Dr. SWEN MALTE JOHN, EADV

Dr. Swen Malte John shared data from Germany where projections indicated 4% increase for non-melanoma skin cancer incidence every year. However, he stressed the fact that non-melanoma skin cancers were not reported in many European countries. Dr. Swen Malte John added that skin cancer was among the most expensive cancers to treat. Moreover, skin cancer was identified as one of the most common occupational disease (e.g. 3rd most common occupational disease in Germany).

THE GDPR IMPLICATIONS ON CANCER REGISTRIES

MALVIKA VYAS, EUROPEAN SOCIETY FOR MEDICAL ONCOLOGY, ESMO

Malvika Vyas introduced European Society of Medical Oncology (ESMO) and its work related to General Data Protection Regulation (GDPR). The new regulation covers not only information and communication technology sector, but also other areas including clinical research and data registries. Ms. Vyas stressed the importance to ensure that population-based registries could operate on a no-consent policy, as registries could only be complete if all patients give consent. Current legislation and the Guidelines on Consent do not effectively explain how population-based registries may operate within a no-consent policy. Such lack of clarity may lead to a fragmented interpretation and possibly impede the functioning of the registries and leaves room for disparities on the Member State level.

DISCUSSION

It was agreed that cancer data was important for researchers, policymakers, other stakeholders and ultimately benefited general public. The discussion suggested various actions that could be done on the Member State or the EU level to improve standardised data collection for cancer registries.

MEPs **José Inácio Faria** and **Charles Tannock** expressed concerns regarding difficulties to act on the European level as health belonged to each Member State's national competency. Nevertheless, MEPs could be active in advocating for improvements on the national level and MEP José Inácio Faria shared experience from Portugal where he has noted reluctance and lack of interest from national government to improve the cancer registry system.

Speakers expressed their positive experience with EU projects that generally encouraged collaboration in health field, and suggested similar approach when it came to skin cancer registries. It was agreed that general public should be more involved and educated in order to put pressure on national governments.