

Item 6.2 Psoriasis and World Psoriasis Day

Background

Prepared at the request of a Member State, the Secretariat's report ([EB133/5](#)) describes the global burden of psoriasis and outlines effective strategies within health and social sectors to address psoriasis. The Board is invited to note the report.

The report summarises the clinical features of psoriasis, including arthritis and other co-morbidities; epidemiology; aetiology (quite unclear); impact on quality of life; diagnosis and management; and health service policy implications. The report ends with a number of broad principles which might guide national health policy.

The report was accompanied by

- Draft resolution EB133/CONF/REV./1 'World Psoriasis Day'
- EB 133/CONF/2/ADD.1 dealing with the financial and administrative implications of the proposed resolution.

Neither of the Conf papers were posted on the EB133 web page.

EB consideration

The EB commenced its consideration focusing on the Secretariat's report. It then proceeded to consider the resolution.

Cuba, DPRK, Chad (on behalf of AFRO MSs), Argentina, Mexico, Indonesia, Japan, Libya, Suriname all spoke to underline the importance of psoriasis, variously commending the Secretariat for its report or supporting the draft resolution.

Cuba, Mexico, Indonesia and Japan all emphasised the need for more research into treatments and models of service delivery. Cuba and Japan emphasised the need for decent health systems.

The Democratic People's Republic of Korea and Libya both spoke about the stigma associated with psoriasis, the risk of discrimination and the need for public education. Argentina, Mexico and Japan also spoke about the need to raise awareness.

Suriname expressed caution about the financial implications for the Secretariat of the resolution as tabled.

After the member states had spoken IAPO (the International Association of Patient Organisations) and the IFPMA (International Federation of Pharmaceutical Manufacturers and Associations) both made statements to the Board.

The IAPO representative identified as a psoriasis sufferer and public affairs director of the Psoriasis Association¹. She presented psoriasis as an autoimmune disease and emphasised the stigma and discrimination that sufferers experience.

1. The [Psoriasis Association \(UK\)](#) is in part [supported](#) by grants from AbbVie, Dermal Laboratories Ltd, Forest Laboratories Ltd, Galderma (UK) Ltd, LEO Pharma, MSD and T&R Derma.

The IFPMA representative emphasised the disease burden associated with arthritis and other co-morbidities. He also emphasised the problem of stigma and discrimination.

At this point the Chair opened discussion on the draft resolution included in EB133/CONF/REV./1 'World Psoriasis Day'.

Panama spoke to their draft resolution. Panama emphasised stigma and discrimination and the importance of awareness raising. Panama explained that civil society had established World Psoriasis Day² and that it should be officially recognised. This would send out a clear message that the MS attach great importance to these issues at national, regional and global levels. Panama urged MSs to get behind this effort and help to improve the care of these people. Panama thanked its co-sponsors including Sudan and Switzerland. Monaco and Nigeria also spoke in support of the resolution.

At this point the Chair noted the provision in the draft resolution for a new section on the WHO web site to raise public awareness of psoriasis and its risk factors and to improve understanding.

Malaysia expressed concern about the proposed World Psoriasis Day. There are already eight official 'days' or 'weeks', all associated with diseases with high morbidity and mortality. Malaysia suggested that perhaps a threshold and criteria be set for allocating World Health Days. Malaysia acknowledged the suffering of folk with psoriasis but worried about the burden of extra World Health Days.

Panama explained that 29th October is already celebrated in many countries as World Psoriasis Day, 'sponsored by psoriasis patients' and has been for 10 yrs. The resolution seeks WHO support for this work in terms of raising awareness; seeks to recognise and support the work of civil society. This is not about official world health days; the purpose is not to overload the organisation.

South Africa then intervened suggesting that perhaps the resolution should be entitled something other than 'World Psoriasis Day'. The Chair suggested changing the title of the resolution to simply 'Psoriasis' but Panama urged that the resolution remain entitled 'World psoriasis day' as this day is already organised. Panama assured the EB that there would be no financial implications.

Finally the Chair reviewed the amendments and the resolution ([EB133.R2](#)) was adopted as amended – still entitled World Psoriasis Day.

PHM Comment

Psoriasis is a common and sometimes debilitating disease and in some cases may be associated with discrimination. There may be benefits (to sufferers) of awareness raising activities, including access to information and reduced stigma. There is always a need for more research.

². [World Psoriasis Day](#) is sponsored by the [International Federation of Psoriasis Associations](#) which claims member associations in 49 countries. The IFPA is supported by Pfizer, Novartis, Lilly, Leo, Celgene and Abbvie. 22 of the 42 member associations with active websites (13 June 2013) acknowledge drug company support on their websites (including Abbvie, Leo, Janssen, Pfizer, Abbott, Ducray, La Roche-Posay, Pierre Fabrie Dermatologie, Janssen-Cilag). It seems likely that most of the others also receive such support, in many cases through the IFPA.

However, it seems likely that the appearance of this item and resolution on the EB agenda has been driven at least in part by the International Federation of Psoriasis Associations which is funded by drug companies working with IAPO (the International Association of Patients' Organisations) which is also funded by drug companies. The IFPA appears to be the main sponsor of World Psoriasis Day. It is reasonable to speculate that the involvement of drug companies in supporting the IFPA (and its member associations) and their support for World Psoriasis Day is in some degree a marketing strategy directed to expanding the global market for psoriasis treatments.

The amount of funding provided to psoriasis associations and the IFPA is not trivial. The only website which actually indicates the size of the sponsorships is the USA which has one donor of >\$1m and several providing six figure donations.

There was no reference during the EB debate to the possibility that World Psoriasis Day serves two separate functions: first, awareness raising for the benefit of sufferers and second, expanding the market for drug company products. There was no discussion of the criteria which might be involved in evaluating the benefits to psoriasis sufferers of WHO giving its name in support of World Psoriasis Day, weighed against the reputational risks to WHO of supporting a drug company marketing strategy.

It is ironic (to say the least) that this item was on the same agenda as the item about WHO's involvement with non-state actors. In fact several of the countries who spoke about managing conflicts of interest in the debate over WHO's relations with NSAs (including Panama, Argentina and Monaco) actually supported this resolution without reference to any conflict of interest.

In PHM's statement to the EB under the NSA agenda item we said:

Defining 'primary and secondary interests' is beside the point. There is always a swirl of different purposes in the motivation of NSA. What is critical is that WHO officials and delegates enter into relationships with NSAs with a realistic understanding of these swirling purposes.

Transparency is a pre-requisite for accountability but is irrelevant if there are no effective accountability mechanisms in place. Managerial accountability is important but not sufficient. There is also a need for whistle blowers, including CSOs, to bring public attention to potential failures in integrity.

*Accreditation of NGOs to participate in governing body meetings should be based on a fixed term relationship, with periodic renewal, rather than being restricted to particular meetings. **As a condition for granting accreditation WHO should require sufficient information to understand the range of purposes that the NGO might be seeking to advance through its accreditation status. Such information should be publicly available.***

Note that the IFPA is not an NGO in working relations with WHO; it is a member of IAPO which is an accredited NGO. In this case the Secretariat should have had a clear understanding of the extent of drug company funding provided to IAPO and IFPA and should have ensured that this information was made available to the EB before opening the resolution for consideration.

It would also be materially relevant to know the provenance of the resolution and the pathways involved in getting this item on to the EB agenda. The passion with which Panama and certain other countries spoke on behalf the resolution was noteworthy. When the Chair suggested that the resolution should be simply titled 'Psoriasis' Panama spoke urgently (and successfully) in support of maintaining it as 'World Psoriasis Day'.