

PRESS RELEASE

For Immediate Release

From: Association of HPV Vaccine Injured Daughters (AHVID)

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Association of HPV Vaccine Injured Daughters responds to EMA conclusion that HPV vaccines do not cause POTS or CRPS

The European Medicines Agency has today released the Pharmacovigilance Risk Assessment Committee's conclusion of their review of HPV vaccines in relation to two serious neurological conditions, Postural Orthostatic Tachycardia Syndrome (POTS) and Complex Region Pain Syndrome (CRPS). The PRAC assessment concluded that the available evidence does not support that CRPS and POTS are caused by HPV vaccines.

The UK Association of HPV Vaccine Injured Girls (AHVID) are extremely disappointed by the committee's findings and are concerned by the lack of transparency and opportunity to scrutinise the evidence considered by the PRAC before the Committee for Medicinal Products for Human Use (CHPM) adopts the committee's findings.

Freda Birrell, Chair of AHVID said.

"Groups across Europe representing families of girls suffering new health conditions following HPV vaccination will naturally be very disappointed with this investigation and we are particularly concerned that the evidence considered by the PRAC will not be made available for scrutiny until after CHMP has reviewed the PRAC Assessment and adopted the decision. We have even been denied a request to know which experts submitted evidence. This shroud of secrecy is very concerning – something is leaving these girls seriously ill! We are however, very encouraged by the recent award of research funding from the Danish health authorities to a Danish team of doctors, to research adverse reactions to the HPV vaccination, and we await the results of that research with anticipation, particularly in light of recent reports from Denmark estimating 1 in 400 girls are suffering serious adverse reactions to the HPV vaccination."

AHVID recently conducted a survey of members for information to submit to the EMA review. The findings from nearly 100 members highlighted massive under-reporting of adverse reactions by health professionals, a failure of health professionals to recognise and acknowledge adverse reactions and the difficulties experienced getting a POTS diagnosis, with most girls waiting for more than two years. Shockingly, the survey also

found over 90% of respondents were initially told by their doctors that their symptoms were psychological.

The PRAC appear to have based their decision on their statement that the available estimates suggest natural rates of both POTS and CRPS to be around 150 girls per million in the age range of 10 to 19. AHVID are unable to comment on this statement because the request for copies of evidence and reports considered by the Committee have been refused until the Review is finalised, but the group remain convinced the HPV vaccination is resulting in girls developing serious autoimmune and neurological conditions, including POTS and CRPS.

The PRAC makes reference to an overlap of CRPS and POTS symptoms with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis and the 'large published study that showed no link between HPV vaccine and CFS', which the Committee considered particularly relevant. The study '*Bivalent HPV vaccine and the risk of fatigue syndromes in girls in the UK*' was undertaken and authored by MHRA scientists, it was looking only at the Cervarix vaccine, used data from the CRPD database which is collected for clinical management, not research, was open to confounding and selection bias and was at the mercy of the accuracy of GPs inputting accurate diagnostic codes. The study would also have been unlikely to have picked out cases of POTS or CRPS and would certainly have missed the many girls with POTS who were initially misdiagnosed with anxiety or psychological conditions.

AHVID will continue to support families with girls suffering new health conditions following HPV vaccination and will continue to fight for better treatment for the affected girls, more transparency and full information about the risks of this vaccination to be made available to parents prior to consent. Their aim is also to ensure the MHRA are held to account and made to follow up all reports of serious adverse reactions, which currently does not happen.

For further information about AHVID contact: Freda Birrell (chair) at jeanfreda8@btinternet.com or tel: 07752 945545

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Notes to Editor

1. AHVID recently conducted a member questionnaire and, so far, has received almost 100 responses. Information for the first 94 responses had been already shared with the EMA. Many of the questionnaire responses leave **no doubt whatsoever in our opinion that these vaccines have at least contributed to the girls' side effects.**

AHVID has found that in the first 94 questionnaire submissions:

- Yellow Cards have only been submitted by 13 doctors whilst the girls had been seen by a total of approximately 858 doctors. There were also 7 doctors who refused to raise Yellow Cards.
- 15 of these had reactions after the 1st and/or 2nd dose. They continued to have the 2nd and 3rd doses because the serious side effects were not perceived to be adverse reactions to the vaccine. They had all been told that the vaccine is safe and side-effects are only mild and short term.
- 27 girls had reactions on the same day as the vaccine, some of them within minutes. A further 22 had reactions within 7 days of vaccination and a further 16 within 30 days. This cannot be a coincidence.
- 66 girls with previously regular periods developed severe problems, many of them serious. 20 girls with irregular periods developed new problems, many of them serious. At least 4 girls have been diagnosed with polycystic ovaries.
- 53 girls were found to have vitamin and mineral deficiencies with 33 of these being for vitamin D.
- 24 have confirmed POTS diagnosis, some took 6 and a half years from vaccination to be diagnosed
- 37 have not been diagnosed with POTS but have an average of 16 typical POTS symptoms. Some had 33 typical POTS symptoms. 19 were refused POTS assessments.
- 8 have confirmed diagnosis of CRPS.
- 76 have not been diagnosed with CRPS but have an average of 5 typical CRPS symptoms. 14 were refused CRPS assessments.

2. Danish reports highlighting estimates of 1 in 400 girls suffering serious adverse reactions

<https://www.youtube.com/watch?v=IZCAFjLasf0>