Prescrire International Editorial

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An example to us all

Many patient advocacy groups exist. Few of them are independent financially.

Even rarer are patient groups that strive to use the painful experiences of their members to provoke active debate on risk prevention and compensation for serious harm suffered by patients and bring these issues into the political arena.

Amalyste, a French non-profit group that represents patients with Lyell syndrome (also known as toxic epidermal necrolysis) and Stevens-Johnson syndrome, is one such group (see pages 220-223 of this issue). These two syndromes are serious cutaneous drug reactions, a few words in a patient information leaflet, often buried in a long and varied list of potential adverse effects, but to the patients affected and still alive to tell the tale, they represent a great deal of pain and suffering.

Amalyste's commitment and dignified actions demand our attention as healthcare professionals. These syndromes are no longer just two rare serious adverse effects, but a reality for all affected patients.

These patients and Amalyste encourage us to stop, reflect and rethink our approach to potentially harmful drugs. Is it really worth prescribing or dispensing a drug that includes either of these two syndromes among its known adverse effects? Have the patients to whom we have prescribed, recommended, dispensed or administered any of these drugs been informed of this risk?

The actions of the patient group Amalyste remind us that even when a serious adverse effect is rare or even very rare, it is important to inform patients that such a risk exists. And to give them the option of taking part in the decision, with full knowledge of the facts, about whether or not to take a risk, by weighing it against the expected benefits of treatment.

Chances are that patients will not view the risk in quite the same way as healthcare professionals.

Amalyste, a patient advocacy group, is striving to promote greater public awareness about two potentially life-threatening syndromes, mentioned in patient information leaflets, but above all, affecting real patients. Their actions are aimed at ensuring that society reflects on drug-related harms. Amalyste is an example to us all and has earned our respect.

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