A patient’s perspective on drug regulation

SIR, If this letter achieves publication in your esteemed journal it will be a rarity, possibly unique, as it is written not by a rheumatologist or even a medical practitioner but a patient (male, age 62).

To have access to your publication I obviously have medical connections, my brothers are consultants, one a consultant rheumatologist and my father was a GP. My brother thought that I may wish to contribute to the debate represented by the articles; ‘To do no harm’ [1], ‘To do no good’ [2] and your editorial of 22 May 2006, ‘A patient-centred approach to drug regulation’ [3]. As a patient whose well-being is completely dependent on a prescribed anti-inflammatory drug, I am in complete agreement with the sentiments expressed in this editorial.

The ‘day that I grew old’, to lift a line from Simon and Garfunkel, was the first of January 2003, a readily remembered date. The prequel to my physical breakdown was a Christmas Ski Trip during which I had been taking diclofenac as a prophylactic against my knees swelling. On this occasion this treatment was completely successful and I stopped taking diclofenac as soon as the skiing holiday finished. A family party in Norfolk included a New Year’s Day walk on a beach. During this walk I effectively seized up and was rescued by car. The next 6 weeks was a nightmare or, to put it another way, I was suffering from ‘chronic dull ache and stiffness’. My condition persisted until a correct diagnosis was made by a consultant rheumatologist.

Initially I visited my GP complaining of back pain and was treated with painkillers and a booklet on back pain. This treatment was completely ineffective. Because neither I nor the GP realized that the anti-inflammatory had been maintaining hip joint mobility. Without this mobility my walking range was reduced, by pain, to ~50 m.

As a semi-retired teacher I was unable to take on any supply work. Life was painful, bleak and non-productive. Has drug therapy in the form of diclofenac 75 mg SR capsules benefited my condition? To illustrate I will run through my last week’s diary:

Wednesday 11, shared a friend’s Ginetta at a Brands Hatch track day.
Thursday 12, recreational walk from Holme to Thornham and back (Norfolk, 6 miles).
Friday 13, shared another friend’s Caterham at Cadwell Park.
Sunday 15, raced in the Monoposto Championship at Silverstone (class win).
Tuesday 16, accepted seven day’s work at a local Grammar School.
Wednesday 17, recreational walk in Cheedale, Derbyshire (6 miles).

An exceptional week but then so was the week that my wife and I spent skiing at Saas Fee, a month ago. As a finale, to a week were I skied between 3 and 5 h a day, I completed the Weltcupberg race run on the Plattgen with its 700 m vertical drop in 3 min 45 s.

The therapeutic effects of maintaining an active lifestyle should not be underestimated.

The simple message is that thanks to a daily intake of 75 or 150 mg of diclofenac, dependent on the day’s activity, I can maintain an active and productive lifestyle. I know that diclofenac has side-effects. As a trained biologist, I expect all drugs to have side-effects and for the side-effects to vary in severity throughout a population. I also believe that as an adult I am able to make an informed choice and that I am capable of assessing risk based on available information. In other words I feel fully able to discuss a benefit/risk ratio with regards to diclofenac. Without any special knowledge or research I would anticipate that all NSAIDs have similar side-effects. Those that have been withdrawn may have more severe side-effects than those currently available but the same legal arguments apply to all.

Thus, one can anticipate that those living in a world that can suggest drugs are risk free will advance similar arguments against all NSAIDs. The whole family of drugs and the benefits that they bring could be at risk. Binymin and Phillips [1] may find that ‘Doubling the risk of myocardial infarction and stroke to control chronic dull ache and stiffness due to arthritis …’ plays well with accountants and lawyers but to a patient the withdrawal of a valued and successful drug can reduce the patient from a contented, productive individual to a miserable burden on family and friends. It must be regretted that we live in a system where lawyers and accountants determine which drugs are useful, where a doctors professional opinion is little valued and the patient’s voice seldom heard.

The author has declared no conflict of interest.

P. HUSTON

Rheumatology 2007;46:1618–1619
doi:10.1093/rheumatology/kem196
Advance Access publication 17 August 2007

Muscular dystrophy mimicking refractory idiopathic inflammatory myositis: a trio of cases

SIR, A diagnosis of idiopathic inflammatory myositis (IIM) is usually considered when a patient presents with muscle weakness. Histological diagnosis with a muscle biopsy remains the gold standard test for IIM. The most common diagnostic criteria used for IIM are the Bohan and Peter criteria [1]. We report on three patients who presented with an initial diagnosis of polymyositis (PM), which was subsequently revised on repeat muscle biopsy.

Case 1 is a 23-year-old female presenting with fatigue and proximal muscle weakness. Anti-nuclear antibodies (ANA) were absent and creatinine kinase (CK) level was 11 297 IU/l. A muscle biopsy showed small basophilic muscle fibres infiltrated with macrophages and lymphocytes, necrotic fibres and increased connective tissue. She was treated for PM with steroids and multiple immunosuppressives (azathioprine, methotrexate, cyclosporine A, cyclophosphamide, plasma exchange) for 7 yrs with limited success. A second muscle biopsy again suggested an IIM. The development of calf hypertrophy led to a third muscle biopsy...

1 Binymin KA, Phillips K. To do no harm. Rheumatology 2007;46:368–70.

Rheumatology 2007;46:1618–1619
doi:10.1093/rheumatology/kem218

A patient’s perspective on drug regulation

SIR, If this letter achieves publication in your esteemed journal it will be a rarity, possibly unique, as it is written not by a rheumatologist or even a medical practitioner but a patient (male, age 62).

To have access to your publication I obviously have medical connections, my brothers are consultants, one a consultant rheumatologist and my father was a GP. My brother thought that I may wish to contribute to the debate represented by the articles; ‘To do no harm’ [1], ‘To do no good’ [2] and your editorial of 22 May 2006, ‘A patient-centred approach to drug regulation’ [3]. As a patient whose well-being is completely dependent on a prescribed anti-inflammatory drug, I am in complete agreement with the sentiments expressed in this editorial.

The ‘day that I grew old’, to lift a line from Simon and Garfunkel, was the first of January 2003, a readily remembered date. The prequel to my physical breakdown was a Christmas Ski Trip during which I had been taking diclofenac as a prophylactic against my knees swelling. On this occasion this treatment was completely successful and I stopped taking diclofenac as soon as the skiing holiday finished. A family party in Norfolk included a New Year’s Day walk on a beach. During this walk I effectively seized up and was rescued by car. The next 6 weeks was a nightmare or, to put it another way, I was suffering from ‘chronic dull ache and stiffness’. My condition persisted until a correct diagnosis was made by a consultant rheumatologist.

Initially I visited my GP complaining of back pain and was treated with painkillers and a booklet on back pain. This treatment was completely ineffective. Because neither I nor the GP realized that the anti-inflammatory had been maintaining hip joint mobility. Without this mobility my walking range was reduced, by pain, to ~50 m.

As a semi-retired teacher I was unable to take on any supply work. Life was painful, bleak and non-productive. Has drug therapy in the form of diclofenac 75 mg SR capsules benefited my condition? To illustrate I will run through my last week’s diary:

Wednesday 11, shared a friend’s Ginetta at a Brands Hatch track day.
Thursday 12, recreational walk from Holme to Thornham and back (Norfolk, 6 miles).
Friday 13, shared another friend’s Caterham at Cadwell Park.
Sunday 15, raced in the Monoposto Championship at Silverstone (class win).
Tuesday 16, accepted seven day’s work at a local Grammar School.
Wednesday 18, recreational walk in Cheedale, Derbyshire (6 miles).

An exceptional week but then so was the week that my wife and I spent skiing at Saas Fee, a month ago. As a finale, to a week were I skied between 3 and 5 h a day, I completed the Weltcupberg race run on the Plattgen with its 700 m vertical drop in 3 min 45 s.

The therapeutic effects of maintaining an active lifestyle should not be underestimated.

The simple message is that thanks to a daily intake of 75 or 150 mg of diclofenac, dependent on the day’s activity, I can maintain an active and productive lifestyle. I know that diclofenac has side-effects. As a trained biologist, I expect all drugs to have side-effects and for the side-effects to vary in severity throughout a population. I also believe that as an adult I am able to make an informed choice and that I am capable of assessing risk based on available information. In other words I feel fully able to discuss a benefit/risk ratio with regards to diclofenac. Without any special knowledge or research I would anticipate that all NSAIDs have similar side-effects. Those that have been withdrawn may have more severe side-effects than those currently available but the same legal arguments apply to all.

Thus, one can anticipate that those living in a world that can suggest drugs are risk free will advance similar arguments against all NSAIDs. The whole family of drugs and the benefits that they bring could be at risk. Binymin and Phillips [1] may find that ‘Doubling the risk of myocardial infarction and stroke to control chronic dull ache and stiffness due to arthritis …’ plays well with accountants and lawyers but to a patient the withdrawal of a valued and successful drug can reduce the patient from a contented, productive individual to a miserable burden on family and friends. It must be regretted that we live in a system where lawyers and accountants determine which drugs are useful, where a doctors professional opinion is little valued and the patient’s voice seldom heard.

The author has declared no conflict of interest.

P. HUSTON

57 Eastwood Road, Boston, Lincolnshire, PE21 0PL, UK
Accepted 11 June 2007
Correspondence to: Mr P. J. Huston.
E-mail: herbyhustonbuzz@aol.com

Rheumatology 2007;46:1618–1619
doi:10.1093/rheumatology/kem218