

## I beg to differ

C. David Naylor, Dean of Medicine at the University of Toronto, declares that the university and the Hospital for Sick Children (HSC) have “moved on” from the scandal surrounding the clinical trials of deferiprone at those institutions.<sup>1</sup> But, as other articles in the same issue clarify,<sup>2-4</sup> several central issues remain unresolved.

Naylor relates that “[i]ncalculable amounts of time and money have now been spent on ... a dispute about a single drug that has, at best, uneven efficacy and uncertain toxicity.” Indeed, over several years, HSC’s administration authorized the spending of large amounts of public money on a series of expensive proceedings against me that relied on unfounded allegations by two senior professors in the Faculty of Medicine.<sup>5</sup> The allegations were abundantly contradicted in documents available to these professors and to HSC at the time, and have now been dismissed by independent inquiries that declared my actions “commendable.”<sup>6,7</sup>

Also using public money, university staff and professors made public unfounded allegations of research misconduct against me at an academic board meeting, in the University of Toronto Bulletin,<sup>8</sup> in the press and, for a period of 18 months, on a university hospital Web site. These allegations have now, finally, been discarded by Dean Naylor himself. However, despite repeated requests to do so, the university has not repealed, in similar venues, the announcements that disgraced and defamed me publicly. Nor has the Dean or any member of the hospital administration addressed the conduct of the senior professors who advanced demonstrably incorrect testimony against me.

Subsequent to our taking a stand for patient safety and academic freedom, my colleagues and I have, for nearly 6 years, been subjected to unfair treatment by the university and hospital administrations.

We have spent our personal money in defending these rights and principles, in the face of “incalculable amounts” of public money spent by others.

Naylor states that deferiprone “has, at best, uneven efficacy and uncertain toxicity.” It is interesting that an observation that the university once termed controversial is now stated as fact. It was by taking this now-acceptable view of the efficacy and safety of deferiprone<sup>9</sup> that I became the target of repeated threats of legal action by the drug’s manufacturer, Apotex Inc., and was sued by the company for \$10 million in a statement filed in Ontario Superior Court on June 19, 2000, an action still before the court.

Naylor next takes issue with clinical research in the hemoglobin disorders and suggests that genetic therapy is the future direction for the treatment of thalassemia: all this fuss, he claims, has focused on a “primitive” and “palliative” measure: iron chelation therapy. In fact, iron chelation therapy has been life-saving for my adult patients, allowing them extensions of life to age 40 and older, education opportunities, employment and health, including fertility — all of which would have been unknown to such patients 2 decades ago. Genetic therapy is not a clinical option, nor will it be for many years — not even for the richest thalassemia patients in the most advanced academic centres worldwide.

In the meantime, despite its “uneven efficacy and uncertain toxicity,” deferiprone is being administered to many patients with thalassemia in many parts of the world, in place of the effective, safe, somewhat onerous standard therapy with deferoxamine. In promoting deferiprone, Apotex has used the scientific opinions of the same senior professor who was the leading source of the unfounded allegations used by HSC as the basis for its actions against me.<sup>10</sup>

All of us, including the Canadian public, will be pleased to “move on”

once the central issues of disclosure of risks, academic freedom, due process, professional accountability, and redress for harm done have been resolved at their source.

**Nancy Olivieri**

Professor, Pediatrics and Medicine  
University of Toronto  
Toronto, Ont.

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## [The author responds:]

Nancy F. Olivieri’s unfortunate letter speaks little to broad principles for the future, and mostly to a search for personal redress and vindication as she defines it. She ignores the University’s progress in implementing