EDITORIAL

Reasons to welcome this new journal

Ian Hann

The launch of another new journal would often elicit a groan from the medical fraternity but one dedicated to the care of people with haemophilia is very much to be welcomed.

There is now a somewhat belated recognition that the management of such persons should always be through a multidisciplinary approach, whereby every member of the team is of equal value by dint of the specific expertise that they contribute, whether it be medical, nursing, physiotherapy, administrative, data management and those managing other resources.

This is no longer an era of medically driven empires encouraging hospital and centre dependence, but one in which families are empowered to manage their care at home and in the community, thus enhancing their quality of life. Evidence-based care is now being shared through haemophilia networks, both physical (hospitals working together in a cooperative manner) and virtual (such as Haemnet, the on-line platform that allows those in allied health care who care for people with bleeding disorders to share experience as needed). Just one example of the importance that we attributed to the team effort was the appointment of one of the first nurse consultants in this area, which can be a predominantly nurse-led service.

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My hope for this journal is that it will encourage research by all members of the multidisciplinary team. There will, I hope, be recognition that there should be no distinction between medical, nursing or any other types of research. Rather, there is just one type of research going back to Galileo, Newton and others with the same ethical and scientific stringencies applied.

Clearly the greatest challenges for contemporary haemophilia care in the developed world now concern the inhibitors of coagulation and managing severe platelet disorders, as well as the legacy issues of blood borne viral infection and joint disease. Besides that, the need to address the fact that around 80% of the world has little or no access to treatment is of paramount importance. It is to be hoped that this Journal, by taking an international allied health view, will prove to be of real benefit in describing international haemophilia care. Indeed, a start has been made in this issue with the paper by Forsyth and Khatun [1].

What else would I wish for and what else would be the desirable outcomes? Nearly a quarter of a century ago I was told that gene therapy was just around the corner. Like many great advances there have been many stops and starts and unforeseen hurdles along the way. However, many of the most worrying issues are at last being resolved and it is no longer a pipe dream. The big pharmaceutical companies have applied large amounts of R&D expenditure to the area of treatments but most has been used up on ever more marginal gains in preventing the ever diminishing risk of transfusion-transmitted infections. We need to have better therapies for those afflicted in this way in the past. Longer acting and more logistically feasible therapies are certainly not a pipe dream, and neither is the impact of good qualitative research to assess the benefits of these treatment enhancements.

Finally, what about governance issues and audit? Here I would like to throw out a challenge to the editors of and contributors to this Journal. More than 40 years ago the great pioneering Inga-Marie Nilsson [2] showed in Sweden that it was possible to stop persons with haemophilia from bleeding. My own group at Great Ormond Street Hospital in the UK extended this and showed that that was possible even in those with established joint disease [2]. Would it not now be wonderful to pioneer a process whereby children, without inhibitors, who had more than one spontaneous bleed per year were consigned to history along with procedures such as joint aspiration, radioactive synovectomy, and the need for protective clothing? I contend that this aspiration is eminently achievable and one from which I have never seen a need to resile.

Professor Ian Hann, formerly Professor of Paediatric Haematology and Oncology and Associate Medical Director at Great Ormond Street Hospital

References

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