

## BOOK REVIEW

# Myotonic Dystrophy – The Facts

By Peter Harper, 1 pp. Oxford University Press, 2002

*European Journal of Human Genetics* (2003) 11, 552. doi:10.1038/sj.ejhg.5201019

This book is a real gem. It has been written by the world authority on myotonic dystrophy, as the blurb correctly indicates, and the author has succeeded in making a very informative book for patients with the disease and those closely related to them.

There are 11 chapters of which six contain medical information about the disease in general, the presentation and diagnostic approach, the course of the disease, other manifestations than muscle weakness and stiffness, infants and children with the disease, and genetic risks and testing. There is a chapter on the state of the art in research, followed by two very practical chapters on support and information, and management. The penultimate chapter looks into the future with regard to prevention and cure, in which the author clearly explains why it takes so long to bring a drug on the market which has proven to be successful in animal models. He even touches upon the sensitive subject of research on animals. There are three appendices, including information about support groups and organisations, anaesthetic considerations on myotonic dystrophy drawn up during a workshop of the European

Neuromuscular Centre, and a printed example of the 'myotonic dystrophy care card' to be obtained through the internet. Finally, there is a list of books and articles for further reading.

It goes without saying that the book has been written by a doctor, and a very knowledgeable one. The tone is authoritative, but not paternalistic, and open without being jovial.

The booklet, which is very reasonably priced and of which the royalties from sales will be donated for further research on myotonic dystrophy and other muscle diseases, is a must for every patient with myotonic dystrophy. The publishers are to be applauded for this wonderful initiative to provide patients with the necessary and up-to-date knowledge about their disease which will not only help them cope with the disease, but also empower them by taking an active role in managing the disease.

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