

Editorial

This edition of *Pharmaceuticals Policy and Law* provides an international overview of the challenges facing patients affected by rare plasma related disorders which include over 200 life-long and life-threatening conditions such as Alpha-1 Antitrypsin Deficiency, C1 inhibitor deficiency, Guillain-Barré syndrome, Haemophilia, Idiopathic Thrombocytopenic Purpura and Primary Immunodeficiencies.

Whilst many rare diseases cannot be diagnosed or appropriately treated, most rare plasma related disorders can be. Many of them are treatable with therapies derived from human plasma, but unacceptable diagnosis rates or misdiagnosis for some plasma disorders often means that treatment begin late, or not at all.

The rarity of some of these disorders means that information on treatment options, symptoms, diagnosis and access to treatment is not optimal and that unnecessary associated healthcare costs are incurred due to a higher rate of hospitalisation, increased number of missed days of school and work and increased infection rates.

Fortunately, in the European Union, rare diseases are rightly seen as a growing public health priority. Both the European Commission and several EU Council Presidencies have held Rare Diseases as a priority area in healthcare policy; the recently published European Commission proposals being the latest positive and significant step which will need to be supported and implemented by EU Member States.

An increasing number of EU supported actions on rare plasma disorders have also been observed recently. The European Consensus conference on primary immunodeficiencies in 2006, a seminar entitled 'Haemophilia: awareness and disparities of care' held at the European Parliament during the same year or more recently in 2008 a policy event on rare plasma disorders held by two Members of the European Parliament are a few examples that testify to the growing concerns and therefore interest into these issues.

Through the articles featured in this edition of *Pharmaceuticals Policy and Law*, the contributing leading specialists and key stakeholders have highlighted the priorities pertaining to this community and attempted to identify the solutions and the necessary actions that need to be put into place to ensure patients affected by rare plasma related disorders receive appropriate treatment in a timely manner and most importantly can lead normal, happy and productive lives. The political, regulatory and legislative framework are explored as well.

It is hoped that the book will be valuable to any person wishing to understand better the priorities of patients affected by rare plasma related disorders and will contribute to a better awareness of these important public health issues.

Pharmaceutical Policy and Law wishes to thank very vividly all authors that have made this monograph possible and specially the European Commissioner for Health, Ms. Vassiliou, that has highlighted European developments and actions in the field of rare diseases, and specifically on rare plasma-related disorders, during the last decade, in the Foreword to this volume.

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Editor