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a valutare l'opportunità di aggiornare l'allegato n. 1 del regolamento
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Senato. Approvata mozione malattie rare e presentata mozione per vittime sangue infetto

Parliamo di malattie rare, argomento di cui non si conosce mai abbastanza e per lo più è misterioso per la stragrande parte delle persone. QUANDO? - Intanto chiariamo quando una malattia è considerata ...

Diabete. Ne soffrono 4 milioni di italiani ma l'accesso alle terapie più innovative è limitato
a valutare l'opportunità di aggiornare l'allegato n. 1 del regolamento di cui al decreto del Ministro della sanità n. 279 del 2001, contenente l'elenco delle malattie rare, esentate dalla ...

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Condizione cronica, aumentata mortalità e disabilità gravi sono i principali problemi socio-sanitari che accomunano le malattie rare del sistema immunitario, la cui bassa frequenza le rende spesso poco note ai medici, con conseguenti difficoltà e ritardi diagnostici. Una recente indagine nazionale, relativa alla totalità delle malattie rare, ha rilevato che oltre il 50 per cento dei pazienti ha ricevuto una diagnosi più di un anno dopo l'insorgere dei sintomi e che il 18 per cento ha dovuto attendere anche dieci anni. Questo volume è dedicato nello specifico alle malattie rare a patogenesi immunologica: dopo un breve inquadramento generale, le singole patologie vengono discusse attraverso interviste ai maggiori esperti di queste malattie, ai Presidenti delle associazioni e a figure professionali coinvolte nel sostegno dei pazienti. La forma del “ domanda e risposta ” rende questo libro una guida agile, precisa e aggiornata ai problemi reali affrontati dalle

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persone affette da malattie rare immuno-mediate, dalle loro famiglie e dai caregivers. Pensato quindi in primo luogo per i pazienti, questo volume è rivolto anche alle associazioni di pazienti, ai medici di medicina generale e agli esperti del settore, in cerca di informazioni su ciò che si sta facendo e su ciò che ancora resta da fare nel campo delle malattie rare e del loro impatto sulla società.

Guidebook which aims to improve MPA management by providing a framework that links the goals and objectives of MPAs with indicators that measure management effectiveness. The framework and indicators were field-tested in 18 sites around the world, and results of these pilots were incorporated into the guidebook. Published as a result of a 4-year partnership of IUCN's World Commission on Protected Areas-Marine, World Wildlife Fund, and the NOAA National Ocean Service

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International Program Office.

The European Convention on Human Rights and European Union law provide an increasingly important framework for the protection of the rights of foreigners. European Union legislation relating to asylum, borders and immigration is developing fast. There is an impressive body of case law by the European Court of Human Rights relating in particular to Articles 3, 5, 8 and 13 of the ECHR. The Court of Justice of the European Union is increasingly asked to pronounce itself on the interpretation of European Union law provisions in this field. This handbook presents this European Union legislation and the body of case law by the two European courts in an accessible way. It is intended for legal practitioners, judges, prosecutors, immigration officials and nongovernmental organisations, in the EU and Council of Europe

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Member States.

Patient engagement should be envisaged as a key priority today to innovate healthcare services delivery and to make it more effective and sustainable. The experience of engagement is a key qualifier of the exchange between the demand (i.e. citizens/patients) and the supply process of healthcare services. To understand and detect the strategic levers that sustain a good quality of patients' engagement may thus allow not only to improve clinical outcomes, but also to increase patients' satisfaction and to reduce the organizational costs of the delivery of services. By assuming a relational marketing perspective, the book offers practical insights about the developmental process of

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patients' engagement, by suggesting concrete tools for assessing the levels of patients' engagement and strategies to sustain it. Crucial resources to implement these strategies are also the new technologies that should be (1) implemented according to precise guidelines and (2) designed according to a user-centered design process. Furthermore, the book describes possible fields of patients' engagement application by describing the best practices and experiences matured in different fields

This volume includes a number of papers written in English and published in the last fifteen years in which the Italian labour market faced many changes. The book not only provides the international readership with a frame of reference – in both conceptual and legal terms – that helps to appreciate the Italian Labour Law currently in

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force, but also represents a contribution to moving beyond the self-referential nature of the Italian debate on the reform of labour laws. As such, the book supplies the reform process of the Italian labour market with an international and comparative dimension which – in accordance with the programmatic approach of Marco Biagi – will also feed the debate at the national level.

Evidence Based Medicine provides a clear explanation of the central questions: how to ask answerable clinical questions; how to translate them into effective searches for the best evidence; how to critically appraise that evidence for its validity and importance; and how to integrate it with patients' values and preferences.

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This book will help the reader confused by a multiplicity of diseases responsible for similar symptoms in different patients. The chapters are noticeably sign-oriented rather than disease-oriented, each dealing with one of the four cardinal modalities of HRCT presentation. Each chapter is introduced by a list of diseases, immediately followed by a detailed description of each disease, and the chapters are illustrated with enlarged images giving rhythm to the written text.

o history of endocrinology can be written without reference N to Sir Humphry Davy Rolleston, whose monumental study of the subject appeared in 1936 under the modest subtitle: The Endocrine Organs in Health and Disease with an Historical Review. It was based on the author's Fitzpatrick Lectures at the Royal College of Physicians of

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London in 1933 and 1934. The lectureship, which dates from 1901, is devoted to the History of Medicine. Rolleston's work as regards scholarship and delivery cannot be surpassed and will remain the solid basis for any further study. It is of interest to note that Rolleston gave the Fitzpatrick Lectures when he was 71 years of age and had his book published when he was 74. By that time he had achieved most of his professional aims and all the honours a distinguished medical career can offer (see Section II). He perceived clearly that endocrinology was "an enormous subject in a most active stage of growth", which "recently has received most valuable help from organic chemists, who have devoted much time to the elucidation of the structure, isolation and synthesis of the hormones". He remarked that the knowledge of endocrinology was expanding with extreme rapidity, and it has been suggested that in this respect it would appear to be itself influenced by a

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growth hormone. He continued: "Before 1890 there were comparatively few publications dealing with the ductless glands, but in 1913, A.

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