

# PRESS RELEASE



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## **RARE DISEASES POSE MEDICO-LEGAL RISK, SAYS MDDUS**

The diagnosis and referral of rare diseases pose a significant medico-legal risk for all doctors, warns MDDUS.

Dr John Holden, a senior medical adviser at the UK-wide medical defence organisation says: "Although individual rare diseases are by definition uncommon, many doctors will regularly encounter patients with a variety of rare diseases.

"In order to minimise the risk of overlooking a rare diagnosis it is important to assess patients carefully by means of a full history, an examination and by providing or arranging advice, investigations or treatment and by referring to a specialist when the doctor considers that this would be in the patient's best interests."

The difficulty in diagnosing rare conditions was highlighted recently when Sir Liam Donaldson, Chief Medical Officer of England, published his 2009 Annual Report.

Among five "key areas of public health" he addressed the dilemma faced by NHS patients suffering from rare conditions. A disease is classed as 'rare' when it affects fewer than five in every 10,000 people. But given that there are more than 6,000 rare diseases, it means that one person in every 17 will present with a rare disease – around 3 million people in England.

According to the report, two in five people with a rare disease have reported difficulty in getting a correct diagnosis and accessing the right services and support for themselves and their families. Recent figures revealed that inefficiencies in treating people with a rare disease are estimated to cost the NHS over £9million every year.

MDDUS advises that to avoid potential difficulties in all patient consultations doctors should follow GMC guidance which stresses the importance of recognising and working within your competence, respecting a patient's right to seek a second opinion and seeking the advice of colleagues when appropriate.

Dr Holden emphasises: "Clear contemporaneous records should also be kept of all discussions and actions relating to a patient's care.

"Primarily this will aid the care of the patient, and enhance the transfer of information between health professionals, especially if a patient moves away and registers with another GP.

"Good records are also invaluable should a complaint or claim arise as the result of a delay in diagnosis."

Ends

For further information contact Colin Calder on 0141 616 2677 or 07850 510881.

**Note to editors**

MDDUS (Medical and Dental Defence Union of Scotland) is a medical defence organisation providing access to professional indemnity and expert medicolegal advice for doctors, dentists and other healthcare professionals throughout the UK.

For further information on MDDUS go to [www.mddus.com](http://www.mddus.com).