Epidermolysis Bullosa: Basic and Clinical Aspects

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Because skin blisters are the initial manifestation of epidermolysis bullosa (EB), patients invariably present to the dermatologist for diagnosis and treatment. However, EB is a systemic disease whose management requires input from clinicians in virtually all fields of medicine, including pediatri cians, surgeons, dentists, gastroenterologists, hematologists, otorhinolaryn gologists, dietitians, and physical therapists, to name a few. Because EB is a rare disease, few clinicians are familiar with it, and many recoil at the pros pect of caring for individuals covered with blisters caused by a disease they know little about. For patients, insult is thus added to injury and they feel abandoned, neglected, and frustrated. One way to remedy this deplorable situation is to provide clinicians with a compact source of information de tailing the principles of EB diagnosis and treatment. This text seeks to fulfill this role. From 1986-1991, The Rockefeller University Hospital has been the co ordinating center of the National EB Registry. Supported by The National Institutes of Health, this Registry consists of four university centers* commit ted to collecting clinical data concerning diagnosis, treatment, and epidemio logy on all American EB patients. As of April 1992, nearly 1,799 EB patients have enrolled nationwide. The Registry is now in its second five-year phase of operation.

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