Announcement

The International Registry for the Hemolytic-Uremic Syndrome
An international registry for the hemolytic-uremic syndrome (HUS) is being established; its Secretariat will be located in Bergamo, Italy. The purpose of the Registry is investigational and its primary function will be to provide a facility for the storage of plasma samples and clinical data. Recent studies have indicated that the measurement of plasma factors involved in the synthesis of prostacyclin may yield important information concerning the pathogenesis of the HUS. More importantly, a large number of plasma samples in a centralized facility will provide an immediately available ‘bank’ of material for current and future research. Questions can be answered quickly and common samples can be used to compare the values obtained in different laboratories. The Registry will collate and communicate data in a manner that serves the best interests of all participants.

Data generated from a specific plasma sample will remain the primary property of the participant who provided the sample. Such data can be used in personal publications on the assumption that the Registry will receive acknowledgement for any special studies performed. The cumulative data will remain the property of the Registry, and any publications stemming from it will be specifically authored by ‘the International Registry for the Hemolytic-Uremic Syndrome’. Credits accompanying such publications will include the names of the writing committee and the names of the participants who provided the samples from which the cumulative data were generated. All participants with access to cumulative data will treat them as ‘privileged communications’ and under no circumstances will cumulative data be used as the basis for a personal publication.

The Secretariat of the Registry will be under the direction of Dr. Giuseppe Remuzzi who will, from time to time, communicate with participants on matters of general interest. The activities of the Registry will be open and the Secretariat welcomes suggestions from participants. We are confident that the Registry can attain its goal and serve as an example of the working relationship that can be achieved by an international community of scholars united by a common interest.

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