

< PUPS COHORT DESIGNATED FOR RESEARCH IN THE FRANCECOAG NETWORK: OBJECTIVES, DRAWING AND PRELIMINARY DATA.>

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< Since 1994, French health authorities financed 2 consecutive prospective projects, that resulted in a national cohort of hemophiliacs. The first project (Suivi thérapeutique National des Hémophiles - SNH), chiefly dedicated to surveying of treated hemophiliacs, has been continued by the FranceCoag Network since 2003. The current project, that combines epidemiological research and surveillance purposes, aims to acquire notably the largest record of hemophiliacs in French hemophilia centers.

The Previously untreated patients (Pups) Protocol was recently designated for specific research within the FranceCoag Network, through 2 main objectives concerning children with severe hemophilia: (1) to know better the risk factors for inhibitor development, including genetic features, and the therapeutic modalities in these patients, (2) to estimate feasibility, observance, tolerance and impact of standardized prophylaxis treatment regimen.

The Pups Sub-cohort is defined as the following: hemophilia A or B, anti-hemophilic factor <0.02 UI/ml, and fewer than 4 cumulative exposure days with factor VIII or IX. Patients that exhibited these characteristics upon entry in the previous cohorts joined retrospectively the Pups Sub-cohort. Thanks to the input of French centers, the number of children included in the national cohort as Pups has increased dramatically recently.

Nb of Pups per year	1991-95	1996-97	1998-99	2000-01	2002-03	Apr 2004
Year of birth	20	15	23	53	42	0
Year of enrollment	11	11	17	35	75	4

Among the 153 Pups registered at this time, 77 (50%) were less than one year old and 77 were not treated yet, at entry in Pups Sub-cohort. >