Universal Data Collection (UDC) Project

TIMELINE

1998 - Enrollment reaches 1,400

DO THE 5

- UDC begins
- "Do the 5" campaign initiated by National Hemophilia Foundation (NHF)

1999 - Enrollment reaches 5,400

2000 - Enrollment reaches 8,300

2001 - Enrollment reaches 10,200

2002 - Enrollment reaches 12,300

12,300

- Normal range of motion study initiated
- Parvovirus B19 testing of specimens from children

2003 - Enrollment reaches 8,300 (including 39 babies)

- Data forms for children younger than 2 years old piloted (Baby UDC)
- Electronic data submission begins
- 2002 specimens tested for West Nile virus

2004 - Enrollment reaches 15,800 (including 110 babies)

- Baby UDC introduced
- UDC mapping projects initiated
- BMI identified as risk factor for joint disease

2005 - Enrollment reaches 17,600 (including 300 babies)

- Quality of life questionnaire introduced
- UDC Inhibitor Pilot Project begins
- Female UDC Working Group formed
- Labtracker adapted as national data collection tool
- Data summit held to discuss national database
- Research proposals from HTC investigators formally invited
- 2003 specimens tested for West Nile virus

2006 - Enrollment reaches 19,400 (including 524 babies)

- Coordinating Committee for the CDC Cooperative Studies in the Prevention of Bleeding Disorder Complications through Regional Hemophilia Treatment Centers formed
- American Thrombosis & Hemostasis Network (ATHN) established to provide stewardship of a secure national database to be housed at CDC

2007 - Enrollment reaches 20,900 (including 524 babies)

- Rare Bleeding Disorders Working Group formed
- Certificate of confidentiality obtained for UDC
- Baby sites added to UDC Inhibitor Pilot Project

2008 - Enrollment reaches 21,300 (including 760 babies)

21,300

- Female UDC data form piloted

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