

## **UDC Working Group Membership Guidelines**

### **UDC and the mission of CDC**

The mission of the Division of Hereditary Blood Disorders of the Centers for Disease Control and Prevention (CDC) is to prevent or reduce the complications of bleeding and clotting disorders. The Universal Data Collection (UDC) project was established in the hemophilia treatment centers as part of a cooperative agreement to provide comprehensive health management and prevention services by using multi-disciplinary teams of healthcare specialists, state-of-the-art clinical research programs, outreach and education programs, and blood safety monitoring and surveillance. In addition to monitoring the safety of treatment products in terms of infectious disease and inhibitors, UDC data are used to identify risk factors for complications and to monitor the effectiveness of interventions designed to reduce these complications. The UDC will also serve as the foundation for a national database for clinical research.

### **Working Group composition and purpose**

The UDC Working Group is comprised of 12 individuals who represent both consumers and providers of health care to the bleeding disorders community. Members include a consumer, physicians (adult and pediatric), nurses (one each from a small and a large treatment center), a social worker, a physical therapist, a data coordinator, and a regional coordinator. The Working Group assists CDC by evaluating the appropriateness and usefulness of data collected, by posing important clinical questions to be addressed using UDC data, and by participating in data dissemination efforts. In addition, working group members serve as a conduit between CDC and their colleagues to transmit ideas and suggestions about data uses from the field and to obtain feedback about the data collection process in hemophilia treatment centers (HTCs) and to help identify problems.

### **General requirements**

Candidates should have a good knowledge of data and should be involved in data collection for the UDC. Affiliations with other organizations such as the Medical and Scientific Advisory Council of the National Hemophilia Foundation, the Hemophilia and

Thrombosis Research Society, or with vocation-specific organizations such as the Social Work or Physical Therapy Working Groups of the National Hemophilia Foundation, while not required, are desirable as a means to facilitate coordination of UDC activities with those of other organizations.

Working group members are expected to participate in monthly hour-long conference calls and to attend two in-person meetings per year, usually held in Atlanta, Georgia. CDC will arrange travel and reimburse expenses for the in-person meetings. Working group members are also required to review and prioritize proposals from research investigators who wish to query the UDC data.

All members will serve at least a three year term which will provide time for members to develop an understanding of how the Working Group operates and to provide continuity for the Working Group. Rotation will be by self request or lottery. It is also possible that members who have not been able to make the commitment required of the project and committee membership may be requested to rotate off.

### **Recruitment procedures**

Requests for nominations will be published in the CDC newsletter and members will inform their peers of vacancies. In addition, regional coordinators will help with recruitment and will collect application materials from interested individuals in their region. Application materials consist of a letter or email to the regional coordinator that identifies the vacancy for which the applicant is applying and a paragraph or two about why the applicant would like to serve on the working group and information pertinent to their qualifications. A resume or CV is also requested.

Applications received by the regional coordinators will be forwarded to CDC staff and UDC members will review the qualifications of the applicants for the vacancy. The review will focus on identifying the candidates whose qualifications most closely match the criteria for the position as well as the current needs of the Working Group in terms of factors such as representation with other organizations, regional representation, pediatric vs. adult practitioner, special knowledge of target populations (e.g., women's issues), data knowledge, and research involvement. The list of qualified nominees will then be submitted to the regional coordinators and directors who will make the selection by vote.