February 1999 Vol. 2, No. I

Newsletter for the Universal Data Collection Project

In this issue

- HIV reporting
- CDC support
- PPTs
- Shipment fax forms
- PT - ROM
- Helpful hints
- Analysis

CDC
Centers for Disease Control and Prevention

We're bringing in the new year with the 3rd edition of the "UDC Updates" newsletter, designed to provide a forum for information exchange among participating centers. First things first—there are 18 new participating centers, bringing our grand total to 73 centers!

WELCOME NEW CENTERS!

In this issue you'll find information on CDC support, HIV and Hepatitis reporting, PPT tubes, physical therapy notes, and statistical updates. Also visit our new website for previous issues at www.cdc.gov/ncidod/dastlr/hematology

Don't Panic....Help is Close By

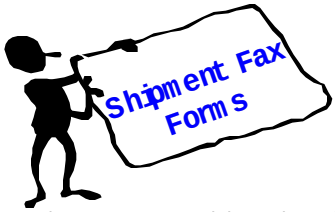
We want to make your UDC experience painless and productive. Don't let the steam build under your hats–we're here to help solve any problem. We are always happy to get your input, whether positive or not so positive. Your problem maybe shared by other centers and your input can help pinpoint difficulties. While certain problems cannot be changed, others may be flexible. Please continue to share your UDC experiences and let us help you get through the rough spots. Contact your Regional Coordinator, or for immediate problems, call us directly at (404) 639-4026.

Plasma Preparation Tubes

HTCs are now responsible for acquiring plasma preparation tubes (PPTs). Initial supply kits for newly participating centers will continue to contain a starter box of 100 PPT (enough for 50 patients). However, CDC will not supply additional tubes once this initial box has been used or has expired. Check your institution's laboratory or central supply to see whether PPT are stocked or if they are willing to obtain these tubes for you. You may order PPTs directly from certain distributors. Be aware, these tubes are not widely marketed. Contact your Regional Coordinator for more information.

HIV Reporting

As many of you realize, HIV reporting continues to be delayed. Currently, results are reported from the lab approximately one month after specimens are received. However, the testing lab has made progress towards implementing a more efficient reporting mechanism and expects these delays to be eased when the new reporting system is in place. Meanwhile, we appreciate your patience and suggest that you inform patients that their results will not be immediately available.



Please remember to fax a "Shipment Fax Form" to the serum bank on the day blood specimens are shipped. **This is not just a courtesy, but is required by the IATA regulations under which these specimens are shipped**. The serum bank uses the information contained on the forms to prepare log-in sheets for each specimen and to track missing shipments. Since a fax travels faster than FedEx, this form could be faxed either before or after the specimens are turned over for shipping. However, should any changes to the shipment occur after the fax is sent, a corrected notification form must be faxed. Otherwise you are likely to get a phone call to clarify the discrepancy. This also applies if a package is not shipped on the day planned because it is refused by FedEx, returned to your site, or just not picked up. When you have knowledge of these events, notify the serum bank that the package has been delayed and when it is scheduled to be reshipped.

Physical Therapy

Recent Range Of Motion Guide and Video

Range of motion (ROM) measurements are a vital component of the UDC data set, providing a tool by which to gauge the extent of joint disease related to bleeding disorders. To ensure both completeness and accuracy when measuring ROM, UDC contacts should make sure that the person performing the measurements at their center has a copy of the **recent** Range of Motion Guide and new video describing how to accurately measure ranges of motion according to the UDC study protocol. For example, a goniometer with single degree measurements is required and measurements should be recorded to the nearest degree. The recent ROM Guide was included in your green Procedures Manual (Appendix H) and is NOT the guide sent in early 1997. Please note that the covers are nearly identical, however, page one of the recent guide states "revised October 8, 1997". Also, the example of the Data Collection Form in the recent guide should match the current Data Collection Form found in the Data Form Masters (fourth page of the Annual Form).

When the Physical Therapist is Not Available

All centers should have either an alternate physical therapist or a non-physical therapist trained to perform the ROM measurements on site when the primary therapist is unavailable to collect data for UDC.

ROM Measurements on Mild Patients

The issue of joint disease in patients with mild bleeding disorders continues to be hotly debated. With a lack of scientific data to substantiate the argument, documenting range of motion among patients with mild bleeding disorders provides important and unique data with regard to joint disease among these persons. Preliminary UDC data shows persons with mild bleeding disorders DO experience some joint complications. Thorough and accurate range of motion measurements taken on many patients with mild bleeding disorders will be required to resolve this controversial issue.

Data Forms

Writing Notes on Data Forms

It's OK to write notes for your own use on the data forms, however, please take care to avoid making them in a location or manner such that they may be confused with data. This is especially important in the boxes for recording range of motion endpoints. Often, these markings make it difficult to interpret the measurements that are written and they can be incorrectly entered in our database. For example, shorthand for "secondary to" can easily be confused with "2 degrees" when seen out of context during data entry.

Completing Data Forms

Please be sure to completely and accurately fill in all required information on UDC data forms. Two common oversights are the "Form Completed by"

and the "Date Form Completed" boxes in the General Information section of the data forms. The computer does not allow **any** information on the form to be entered if these items are blank.

In addition, blood test results are not returned when the corresponding data forms are incomplete and have not passed the validation step of data entry. This includes incomplete range of motion data. We understand that physical therapists are not always available at every clinic and that this may be the reason ROM measurements are not taken. However, having an alternate therapist or trained non-therapist should eliminate this problem.

CDC Support for Notification System

The Centers for Disease Control and Prevention would like to express their support for the new Patient Notification System administered by the National Notification Center. Although the name might not sound familiar to you, information about the Patient Notification System has already been distributed by NHF. Persons with bleeding disorders who elect to enroll in this program will be directly notified of a withdrawal or recall of certain blood products. Patients can designate the type or brand of blood products they wish to be notified of and can also choose the mode of notification (express letter, phone, fax, or e-mail). Once enrolled, patients will receive a confirmation form by mail within two weeks to verify both their enrollment as well as the products they wish to be notified about and their contact information. If they do not receive this confirmation, then patients are requested to enroll again. All patients are strongly encouraged to sign up. They can do so by contacting the National Hemophilia Foundation at 1-800-42-HANDI to request an enrollment form.

Helpful Hints:

Hint #1: For those of you that have reached their wits end trying to peel the backing from the P-touch labels, you'll love this neat trick. Just cut a small piece off the corner of the label at a sharp angle, helping to separate the label from its backing, and peel!

Hint#2: Photocopying the multi-page Annual Visit form can be a challenge, so next time, tear the sheets apart along their perforated fold and go for it! Just remember to staple the forms back together in order.

Statistical Updates

As we begin the new year, the number of centers now participating in UDC is soaring. Check out the statistics below.

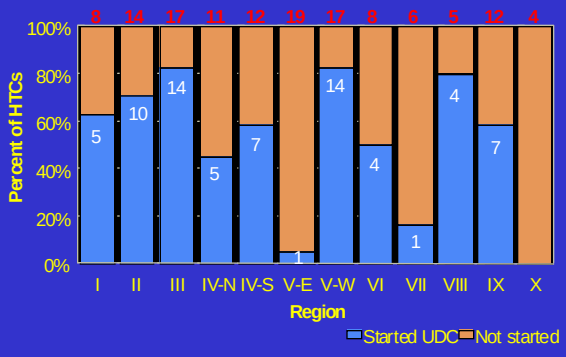


Fig. 1 As of January 31, 1999, UDC has began in 73 centers representing 9 regions. Each week more centers are joining. The numbers in white represent the participating number of centers in each region. Numbers in red represent the total number of federally-funded HTCs in each region.

UDC Patient Enrollment

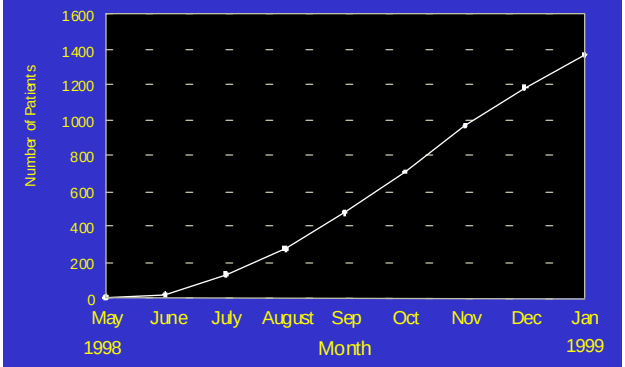


Fig. 2 The first patients were enrolled in UDC during May 1998. Since that time, the number of participants has steadily increased .

Distribution of Bleeding Disorders

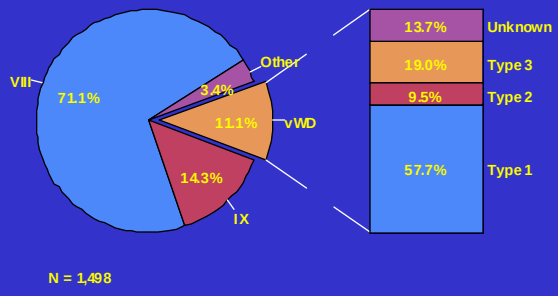


Fig. 3 The pie chart shows the distribution of bleeding disorders among the 1,498 participants between May 1st and December 31st. Approximately 71% of the participants had factor VIII deficiency, 14% had factor IX deficiency, and 11% had von Willebrand disease (vWD). Most of the participants with vWD had either type 1 or type 3 pattern.

UDC Updates provided by:

The Hematologic Diseases Branch
Centers for Disease Control & Prevention
1600 Clifton Road NE, MS-E64
Atlanta, Georgia 30333
(404) 639-3925

UDC Staff at CDC:

Bruce L. Evatt, M.D.	*Chief, Hematologic Diseases Branch*
Sally Crudder, R.N.	*Director, HTC Program*
Mike Soucie, Ph.D.	*Epidemiologist*
Lisa Richardson. M.D., M.P.H.	*Epidemiologist*
Meredith Oakley, D.V.M, M.P.H.	*UDC Project Coordinator*
Ayesha Khan, M.P.H.	*CJD Project Coordinator*
Beverly Roberts, B.S.	*Program Management Officer*