Universal Data Collection Project

UDC Update

June 2002

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Online HTC Directory and UDC Reports Improved

The website containing the HTC directory and UDC summary reports, which has been available to the HTCs for several months at http://www.ncid.cdc.gov, has been significantly improved. Some original functions have been enhanced, and new functions have been added.

One new function in the directory is the ability to save your lists of facilities and staff as Microsoft Word files. In addition, an update program is now in place, which your regional coordinator can use to make changes to your HTC or staff information, including UDC contact roles. Please let your regional coordinator know about changes to this information so that he or she can keep the directory up to date and useful. **It is especially important to let your regional coordinator know about changes to your shipping address and fax number; our staff uses the online directory as our source for this information.**

The webpages with UDC summary reports have been expanded to include HTC-specific reports. The primary contact and UDC contact at each HTC have a user ID and password (sent by e-mail) that allow them to access these specific reports. The website also has a new report to help you schedule patient appointments. This report provides a list of your patients who are due for a UDC visit.

To find the site from http://www.ncid.cdc.gov, click on "Bleeding and Clotting Disorders Surveillance." You may want to add the site to your Bookmarks (Netscape) or Favorites (Explorer) for easier access.

We hope that you will find the online directory and summary reports to be as helpful as we do. Please let us know if you would like us to add other features or enhancements. We want the website to be as useful as possible. For questions about or suggestions for the online HTC directory or UDC summary reports, please contact Mike Soucie by e-mail at msoucie@cdc.gov or by phone at (404) 371-5278.

Shipping News

Notifying the serum bank before shipping

Sites are reminded that shipping regulations require them to notify the serum bank when a shipment of infectious substances is made. For security reasons, shipments that arrive without notification may be refused and returned to the sender. It is very important that the shipment notification form be completed fully, including the collection dates portion. Please help ensure that your specimens are processed correctly by conscientiously completing this form.

CDC Blood Safety

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Destroying FedEx air bills addressed to Meredith Oakley

Last autumn, we stopped using FedEx for your submissions of data forms to our office and began using project-specific, postage-paid US Postal Service envelopes instead. However, some of the older FedEx air bills (addressed to Meredith Oakley) are still around, and occasionally they end up attached to a FedEx shipment of blood specimens intended for Suzette Bartley at the serum bank (in Lawrenceville, GA). Shipments using the air bills addressed to Meredith cannot be delivered to the serum bank, and they become unclaimed freight.

Please help us prevent such "orphaned" shipments. Please check your UDC FedEx air bills and destroy any that are addressed to Meredith. When you ship your specimens, please use only the air bills that are addressed to Suzette.

Change to shipper's declaration and infectious substances label

On the current UDC shipper's declaration form and rectangular infectious substances label, the possible agents involved are listed as "HIV, hepatitis." However, some local FedEx offices require that the hepatitis viruses be listed individually on the shipper's declaration and on the package label. Therefore, we have altered the pre-printed shipper's declaration and rectangular infectious substances label to read "HIV, hepatitis A, hepatitis B, hepatitis C." We will soon be sending the new shipper's declaration and infectious substances label to each HTC. Please use both of these new versions together in place of the original versions.

Laboratory Testing News

Follow-up on unexpected lab results

We are processing the results of thousands of lab tests each year, and programs are in place to help identify discrepancies between test results and the historical information that you provide on the annual visit forms. However, occasionally you may receive serological test results that do not agree with a patient's health history. It is critical that you notify us of these discrepant results so that confirmatory testing can be performed on these specimens.

We are always willing to perform confirmatory testing on these specimens, even if those tests would not normally be performed under the UDC project testing algorithm. Sometimes a participant's serostatus cannot be resolved by additional testing of the original specimen, and a new blood draw is needed for certainty. We are eager to test these new specimens, and we ask that you send us a portion of the new specimen even if you are having repeat testing performed at your local lab. A new specimen will permit us to explore reasons for the discrepancy and additionally will ensure that a valid specimen for the participant will be stored in the serum bank. If you identify a discrepant result, please promptly contact Meredith Oakley by e-mail at mco6@cdc.gov or by phone at (404) 371-5277.

Routine Western Blot testing for HIV-1 discontinued for UDC project specimens

In the past, all positive EIA tests for HIV on UDC project specimens were followed by the Western Blot test to confirm whether the results were true or false. This procedure included specimens from UDC participants for whom multiple positive specimens have been submitted, as well as specimens from participants with no history of HIV infection.

Recently, however, some labs have experienced delays in receiving Western Blot test kits. To conserve resources, the CDC HIV lab is deferring Western Blot testing on specimens from UDC participants with a known history of HIV infection. **For the time being, the lab will perform Western Blot testing only on EIA-positive specimens from UDC participants with no history of HIV infection. For those specimens, Western Blot testing will be performed before the results are reported to the HTC.** This testing deferral applies only to UDC project participants because of the unique nature of repeated documented positive specimens from our participants.

Although these results are being checked before being reported, an error may occur. So, if an HIV result that you did not expect is reported for one of your UDC participants, please contact us immediately so we can check for a clerical error. If you need additional information about this change to the UDC

project testing algorithm, please contact Meredith Oakley by e-mail at mco6@cdc.gov or by phone at (404) 371-5277.

UDC Working Group To Meet in Atlanta

On June 24 and 25, 2002, the UDC Working Group will meet with UDC staff at the offices of the Hematologic Diseases Branch of CDC in Atlanta, GA. The purpose of the meeting is to review the progress of enrollment in the UDC project, to review the data being collected as part of the project, to advise on possible additions to data collection activities (e.g., data collection on infants, as discussed in the "Eligibility for UDC Enrollment" article below), and to provide feedback to CDC about the progress of UDC efforts in the group members' institutions or regions. The Working Group also meets monthly via teleconference.

Current members of the UDC Working Group are

- Randall Curtis, MBA—Berkeley, CA
- Ann Forsberg, MA, MPH—Worcester, MA
- Angela Forsyth, MS, PT—Philadelphia, PA
- Sue Geraghty, RN, MBA—Aurora, CO
- Julie Hambleton, MD—San Francisco, CA
- W. Keith Hoots, MD—Houston, TX
- Heather Huszti, PhD—Orange, CA
- Robert Janco, MD—Nashville, TN
- Roshni Kulkarni, MD—East Lansing, MI
- Margaret Wagner, RN—Newark, DE
- Scott Ward, RPT, PhD—Salt Lake City, UT
- Gilbert C. White, II, MD—Chapel Hill, NC

From the Data Entry Desk

ROM measurements: negative or positive?

Properly recording joint range-of-motion measurements can be tricky. Some measurements are recorded using negative values, while others are recorded using positive values. As part of the UDC project, extension measurements are recorded as either negative numbers or zero, while hyperextension measurements are always recorded as positive values.

Extension measurements are taken for all patients on the hip, knee, and elbow. The normal starting position for these measurements is 0 degrees. Some patients may not be able to extend the hip, knee, or elbow to the starting position. In this case, the range to be recorded is the number of degrees from 0 to the position of the femur (for hip measurements), tibia (for knee measurements), or forearm (for elbow measurements); the range should be recorded as a **negative** number.

Some patients can extend the knee or elbow beyond 0 degrees, so-called hyperextension. The number of degrees beyond 0 that the patient's joint can move should be recorded in the hyperextension box as a **positive** number. In addition to recording the number of degrees of hyperextension in the hyperextension box, it is also necessary to enter a 0 in the extension box for that joint. This is a common omission, which results in a validation error.

If you are unsure about the proper way to take or record measurements, please consult pages 4 and 5 of the *UDC Joint Range of Motion Reference Guide* or consult the *UDC Joint Range of Motion* video.

Eligibility for UDC Enrollment

There have been some questions recently regarding patient eligibility for enrollment in the UDC project. Some patients are being overlooked because they are believed to be ineligible, while others are being enrolled without meeting enrollment criteria. A detailed list of eligibility requirements can be found on page 13 of the *Universal Data Collection HTC Procedures Manual* and is reproduced below:

Eligible

To participate in the UDC, patients must meet at least one of the following criteria:

1. Age 2 years or more with a bleeding disorder due to congenital deficiency or acquired inhibitors in which any of the coagulation proteins is missing, reduced, or defective and has a functional level of less than 50 percent. *(This criterion includes carriers, as long as their functional level is less than 50 percent.)*

2. Age 2 years or more with a diagnosis by a physician of von Willebrand disease.

Not Eligible

Individuals specifically excluded from participation in UDC include persons with any of the below:

1. An exclusive diagnosis of a platelet disorder. *(Glanzmann's thrombasthenia is an example of a platelet disorder.)*
2. Thrombophilia.
3. Coagulation protein deficiencies due to liver failure.

We are very pleased with your eagerness to enroll patients in UDC as early possible. However, under our current protocol, we cannot collect data on patients younger than 2 years old. While it may be tempting to enroll patients if you see them in clinic just before their second birthday, please resist the urge! For now, you must wait until these patients' next visit to register them in UDC.

It is our goal to enroll these young children in UDC in the near future. With substantial input from the UDC Working Group, we are developing a data collection form specially designed to gather information about infants. The form is near the final stages of design and will soon be pilot-tested for efficiency and ease of use.

Transferred Patients Require New Registration

Please be aware that you must complete a new registration form for any patient participating in the UDC project who transfers to your HTC from another center. Use the CINGA program to assign a new CDC ID to the participant.

UDC Staff in CDC's Hematologic Diseases Branch

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