

# UDC *Update*

Spring 2007

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## **HOW WELL DO YOU KNOW THE UNIVERSAL DATA COLLECTION PROJECT (UDC)?**

Starting with this edition, the UDC Update will be featuring a quiz to see how well you know the UDC. The quiz will hopefully be a fun and informative way to share interesting questions and their answers that come up in the day to day world of working with the UDC data. We hope you will find this helpful. The answers are on the bottom of the page, so you can print this page and use it as a handy reference.

### **True or False**

1. The Mortality Form is to be completed upon death for every patient who was ever enrolled in the UDC.
2. If a patient at another Hemophilia Treatment Center (HTC) transfers to your center, in order to participate in the UDC, a Registration form must be completed even if the patient participated in the UDC at his/her old center.
3. On the Annual Visit form, question 9 should contain the inhibitor titer measured during the current visit.
4. In the Ranges of Motion section of the Annual Visit form, the Target Joint box should be checked for any joint that was ever designated a target joint by the patient's physician.
5. When measuring the head circumference of a child younger than 2 years of age, the goal is to measure the head at the spot where it has the largest circumference.

### **ANSWERS TO UDC QUIZ:**

1. **False.** A Mortality form should be completed upon death for every patient eligible for the UDC, regardless of whether or not the patient ever participated in the UDC.
2. **True.** A new Registration form is required so that a new CDC ID can be assigned. On the form, question 5 (HTC Status) should be checked "Transfer Patient".
3. **False.** The value that should be entered in question 9 is the highest inhibitor titer measured during or since the *last* UDC visit. The reason for this is that we do not want the form to be delayed until you have received the titer measured during the current visit. If no inhibitor titer was measured at the last UDC visit or since the visit, leave the value blank and check the box next to "not done".
4. **False.** The Target Joint box should be checked *only* when a joint has had recurrent bleeding on 4 or more occasions during the last 6 months. Therefore, in the UDC a target joint is not always a target joint.
5. **True.** Measure the head circumference by placing the flexible measuring tape just above the eyebrows and ears and around the back of the head where it slopes up prominently from the neck.



# UDC Update

## WE HAVE A NEW NAME!

As of November 2006, the name of our division has officially changed from the National Center of Birth Defects and Developmental Disabilities (NCBDDD)/Division of Hereditary Blood Disorders to the NCBDDD/Division of Blood Disorders (DBD). This change was made to better reflect the populations that we currently serve such as people with thrombosis with no known gene defect, and also so that our division could expand to include blood disorders not necessarily associated with inherited conditions. We look forward to the opportunities this expansion will provide.

## UDC DATA PRESENTED AT THE AMERICAN SOCIETY OF HEMATOLOGY (ASH)

A poster on behalf of the UDC investigators titled "Using Geographical Information Systems (GIS) To Examine Associations Between Characteristics of Males With Hemophilia and Geographic Distance to Hemophilia Treatment Centers (HTCs)" was presented by Dr. Ann McClellan, an Oakridge Institute for Science and Education (ORISE) fellow in the DBD, at the 48<sup>th</sup> Annual Meeting of the American Society of Hematology. The meeting was held in Orlando, Florida, December 9–12, 2006. Since 2004, Dr. McClellan has worked with GIS software to better understand how the distance participants have to travel to their HTC affects their care. Her abstract found that the average distance participants had to travel to an HTC was 68 miles. Her analysis also indicated that, among those who lived within 90 miles of an HTC, those over 25 years of age and using prophylaxis were more likely to live closer to an HTC. She conversely found that white participants and those utilizing a Health Maintenance Organization were more likely to live farther away from an HTC than their counterparts. She concluded that applying this type of analysis to information in the UDC may help to efficiently allocate resources and to direct programmatic activities. In addition, such information could be of critical importance during emergencies such as natural disasters and factor shortages. A Powerpoint presentation that includes national and regional GIS maps of patients with hemophilia enrolled in the UDC is available on the Web at the following address: <http://www.cdc.gov/ncbddd/hbd/surveillance.htm>.

## WE'VE MOVED

In August 2006, the DBD moved from our offices in Executive Park to Corporate Square, both part of the extended CDC campus in Atlanta. Our new physical address is:

Corporate Square Building 12, 3<sup>rd</sup> floor  
Corporate Square Boulevard  
Atlanta, GA 30329

Our mailing address remains the same, however:

1600 Clifton Road  
Mailstop E-64  
Atlanta, GA 30333

Our new main telephone number is 404-718-8600.  
Our new fax number is 404-718-8650.

## WELCOME TO OUR NEW DIVISION DIRECTOR!

In June 2006, Roshni Kulkarni, MD became the new director of DBD. She comes to us from the Michigan State University (MSU) Comprehensive Center on Bleeding and Clotting Disorders in Lansing, Michigan where she was the director for pediatrics. Roshni has been working in pediatric hematology/oncology since 1977 and has held the positions of professor of hematology and oncology and director of pediatric and adolescent hematology and oncology in the College of Human Medicine at MSU. Since arriving at the division she has been busy getting acquainted with the staff and all the responsibilities associated with her new role. She is very excited about the opportunities for growth and development of existing and new programs in our division and looks forward to steering the vision for our future. We welcome her and are very glad she has decided to lead our division into our next phase of growth.

## NEW FACES IN THE DIVISION

In December 2005, Chris Parker joined the Division of Hereditary Blood Disorders (DHBD) (since renamed DBD) to serve as the acting Deputy Director. Since joining the division, he has provided management and administrative oversight for division operations. Prior to coming to DBD, he worked in the National Center for Birth Defect and Developmental Disabilities, Office of the Director as a senior public health analyst on the Program Development Team. Chris has a PhD in health science from Touro University and holds graduate degrees from Emory University (MPH) and Louisiana State University (MPA). He completed his undergraduate work at the University of Mississippi in respiratory therapy.

## UDC Update

Rodney Presley joined DBD in December 2006 as a behavioral scientist. He has a PhD from the University of Georgia in educational psychology with an emphasis in research methodology and evaluation. Rodney has also worked with the Georgia Department of Education, as well as with the Mercer Medical School's Family Practice Residency Program. In addition, he supervised the Behavioral Risk Factor Surveillance Survey site at the Fred Hutchinson Cancer Research center in Seattle, Washington, and has directed Medicare quality improvement programs and done program evaluation work in Seattle and Atlanta. At DBD, he will be working with the UDC group to expand and improve the UDC as needed. Rodney also wishes to serve as a CDC resource for investigators in the blood disorders community who want to work with UDC data.

Dhelia (Dee) Williamson joined DBD in November 2006 as an epidemiologist. She holds a doctoral degree in Epidemiology from the University of North Carolina at Chapel Hill and has received advanced degrees in preventive medicine and political science from Ohio State University. Dee's work experience includes environmental health, sexually transmitted diseases, AIDS surveillance, and occupational health. Her research focus has been on examining the role of environmental exposures and genetic susceptibility in individuals with multiple sclerosis. At DBD, she is currently working on thalassemia and sickle cell disease.

Chengbin Wang is originally from China, where he received an MD in preventive medicine and an MS in toxicology. After working 2 years with the CDC in Beijing, China, his interest in public health led him to further his education by obtaining a PhD in epidemiology from the University of Alabama at Birmingham. In November 2006, he accepted an epidemiologist position in DBD to further develop his skills in public health.

Phillip Kucab is a medical student who is doing a 1 year fellowship at CDC and will be working primarily on seroconversion discrepancy reporting. He received his undergraduate degree from the University of Michigan where he studied Cellular and Molecular Biology. He finished his first year of medical school at Georgetown University in Washington, DC this past year. Phil is very active within the hemophilia community on both the national and local level.

### LABORATORY UPDATE

The DBD laboratory is now performing U.S. Food and Drug Administration-approved confirmatory tests for hepatitis C (RIBA) and HIV (Western Blot) instead of sending specimens to an outside laboratory.

### LAB FORMS NOW E-READY!

The Laboratory Form is ready to go electronic! With a simple upgrade, those of you with Lab Tracker can now transmit your Laboratory Forms electronically. If you do so, you no longer need to include a green hard copy of the form with your blood specimens when you

send them to the serum bank. However, it will now be *critical* that you include the collection date for each specimen on the shipment notification form that you fax to the serum bank. Specimens without a collection date cannot be imported into the database and tests cannot be ordered for them, so a missing collection date will result in testing delays. Lab Tracker has been modified to include the collection date on the label with the bar code. In addition to the Lab Form, the most recent version of Lab Tracker also contains the updated Annual Visit form dated 10/2005.

### UDC WORKING GROUP MEETING UPDATE

On June 12<sup>th</sup> and 13<sup>th</sup>, 2006, the UDC Working Group met in Atlanta. The purpose of the meeting was to allow the group members an opportunity to review the progress of enrollment and the data being collected in the UDC project, offer advice on possible additions to data collection activities, and provide feedback to CDC about the progress of UDC efforts in the group members' institutions or regions. Presentations were given on the latest UDC enrollment, the preliminary normal range of motion project data, the joint infection study, and findings from the Quality of Life forms received to date. Progress reports on the inhibitor pilot project and Lab Tracker were also presented. In addition, the members discussed revisions to the UDC Adult and Baby Registration, and Annual Visit forms. Group members also discussed the procedure for selecting new working group members, and picked a slate of possible data coordinator candidates to join the working group; this slate will be sent out to regional coordinators for a vote. Finally Mike Soucie, PhD and Barbara Konkle, MD were chosen to serve as co-chairs for the group.

### Take a look at the UDC Working Group!



Members of the UDC Working Group attending the June 2006 meeting—from the left: Tom Abshire, MD; Randy Curtis, MBA; Nigel Key, MD; Brenda Nielsen, RN MSN; John Drake, RN MSN; Nancy Duffy, RN; Barbara Konkle, MD; Claire Phillip, MD; Mike Soucie, PhD; Angela Forsyth, MSPT; and Roshni Kulkarni, MD.

# UDC Update

## WELCOME TO THE NEW MEMBERS OF THE UDC WORKING GROUP

Pam Bryant, program administrator for the Emory/Children's Healthcare of Atlanta Hemophilia Program Office in Atlanta, has been elected to the newly added data coordinator representative position on the UDC working group. Pam has worked at Emory since the hemophilia program was started there in 1985. In addition to her many years working with UDC data, her qualifications include overseeing pilot testing for Lab Tracker and B-testing the electronic submission of UDC data from Lab Tracker at Emory.

Drs. Joan Gill, Director of the Comprehensive Bleeding Center at the Blood Center of Wisconsin in Milwaukee, Wisconsin, and Brian Wicklund, Pediatric Director of the Kansas City Regional Hemophilia Center at Children's Mercy Hospital in Kansas City, Missouri, were elected to serve on the UDC Working Group to represent pediatric hematology. Drs. Gill and Wicklund will replace outgoing members Drs. Thomas Abshire and Roshni Kulkarni. Dr. Michael Recht, Director of the Phoenix Children's Hospital Hemophilia Center was elected as an alternate member.

Dr. Craig Kessler, Director of the HTC at Georgetown University Hospital, Lombardi Cancer Center in Washington, DC, and chair of the Medical and Scientific Advisory Council of the National Hemophilia Foundation (NHF) was appointed to the working group as a liaison.

We thank the outgoing members for their hard work and dedication and contribution to the UDC project. We welcome the new members and look forward to working with them in the coming years.

## NEW VACANCY ON THE UDC WORKING GROUP

The Working Group for the Universal Data Collection (UDC) project is seeking a consumer representative.

The consumer representative would be responsible for:

Representing the consumer perspective in the multidisciplinary working group.

Participating in one conference call per month, two in-person meetings per year, and various other projects throughout the year.

The following is a list of the qualifications for the ideal consumer representative:

- Is a consumer at a federally funded Hemophilia Treatment Center (HTC) that participates in UDC, and has himself/herself participated in UDC.
- Has knowledge of and interest in UDC data collection.
- Has experience in data management.
- Has research experience.
- Has an awareness of efforts to develop national research databases.

Interested candidates should submit a letter or email through their HTC by May 1, 2007 that includes a paragraph or two describing their qualifications and their interest in UDC or other issues of importance to the bleeding disorders community. A current resume or curriculum vitae should also be attached, along with a statement of any possible conflicts of interest.

For more information about the UDC Working Group please see the "UDC Working Group Membership Guidelines" posted at: <http://www.cdc.gov/ncbddd/hbd/surveillance.htm>

## Data Entry Corner

### Quality of Life Forms

An important reminder regarding the Quality of Life (QOL) forms: please don't forget to write the CDC ID number and date of visit on the QOL form before giving it to the patient. To maintain confidentiality, the patient completes the form and immediately seals it in an envelope. If there is no identification on the form, the data for that patient are potentially lost. Thanks again for your cooperation on this issue!

### Validation Errors

We continue to appreciate all your efforts to help ensure that the UDC database is current. Presently, we are catching up on the corrections on the validation reports for 2006. At this time, we are asking that anyone who has outstanding validation reports from 2006 or before to please fax them in (404-718-8650 or 404-718-8640) as soon as possible. As a reminder, we will send the centers with outstanding validation errors requests for corrections until your data are current.

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## UDC STAFF

Roshni Kulkarni, MD, Division Director

Sally Owens, RN, Health Scientist

Mike Soucie, PhD, Epidemiologist

Meredith Oakley, DVM, MPH, UDC Project Coordinator

Nina Larsen, MSPH, UDC Associate Project Coordinator

Rodney Presley, PhD, Behavioral Scientist

Evet Palmer, Data Entry

Ashaki Brockington, Data Entry

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