Newsletter: Data Connection

CIBMTR Clinical Research Associates Mentoring Committee

Friday, September 12, 2008

Mark your calendars for the 2009 BMT Tandem Meeting. It will be held at the Tampa Convention Center in Tampa, Florida. This is a combined annual meeting of the ASBMT and CIBMTR and it provides a comprehensive update on blood and marrow transplantation, laboratory research and patient care for clinicians, investigator and allied health professionals.

Clinical Research Coordinators - February 10-12
(Recommended for all Clinical Coordinators New and Experienced)
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- The BMT Tandem Meeting - February 11-15

  Meeting Registration (Early Registration Deadline: October 8, 2008)
  Hotel Reservation (Guaranteed Reservation Deadline: January 7, 2009)
  Abstract Submission (Submission Deadline: October 8, 2008)
  Scientific Agenda · CIBMTR Working Committees

Related Conferences and Programs
The BMT Tandem Meetings includes these related conferences, sessions and workshops:

  · FACT Workshops for Applicant Preparation and Inspector Training – February 10
  · Clinical Research Professionals – February 10-12
  · BMT Center Administrators – February 11-12
  · Pediatric BMT – February 12
  · BMT Pharmacists – February 13-14
  · Transplant Nursing – February 13-15
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• Meeting Registration
  The deadline for Early Registration, offering the best rates, is October 9. The registration fee includes five days of scientific sessions, CME fee, meeting materials, a welcome reception and breakfast, luncheon and dinner symposia.

Hotel Reservation
  Hotel reservations are first come, first served. Remember that February is a very popular vacation month in Tampa. The hotels closest to the Tampa Convention Center will fill up fast. The deadline for guaranteed reservations is January 7.

Abstracts
  Abstract submission is open through October 8. Sixty-six abstracts will be selected
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- Mailing List Signup

  External Links
  - CIBMTR
  - EBMT
  - Stemsoft
  - NMDP
  - BMT-infonet
  - CTCAE(3.0)
  - HIPAA
  - HLA Typing
  - On-Line Medical Dictionary
  - Social Security Death Index
  - Chemotherapy Acronyms
  - NCI Clinical Trials
  - Internet Drug Index
  - Estimated Creatinine Clearance
  - BSA Calculator
  - Day Calculator
  - Medical Calculator
  - National Association of Medical Examiners
  - National Center for Health Statistics
  - Basic Hematology
MENTORS

• **Hanne Baekgaard Laursen (chair)(Denmark)**
  E-mail: rh07604@rh.dk
  Transplant types: Allogeneic
  Age: All
  Disease: All allogeneic related
  Type of SCT: Marrow, PBSC, Cord blood
  Expertise: Leukemia’s
  Registries: CIBMTR, NMDP, EBMT, Different European donor registries

• **Denise Bellman (USA)**
  E-Mail: denise.bellman@cchmc.org
  Transplant types: Allo and Auto
  Age: Pediatric (0-25 years)
  Disease: All
  Type of SCT: Marrow, PBSC, Cord blood
  Expertise: Immune Disease, Neuroblastomas, Solid Tumors, Inherited disorders, Metabolic diseases, All anemias

• **Karen Manion, (USA)**
  E-Mail: karen.manion@northside.com
  Transplant types: Allo and Auto
  Age: Adults.
  Disease: All leukemias, NHL/HD, MM, Amyloidosis, MDS, SAA
  Type of SCT: Marrow, PBSC, Cord blood
  Expertise: All
  Registries: CIBMTR, NMDP
MENTORS
(continued)

• Gevel Jackson, CCRP (USA)
  E-Mail: GEVEL.JACKSON@childrens.com
  Transplant types: Allo and Auto
  Age: Pediatric (0-21 years)
  Disease: All leukemias, MDS, NHL, HD, Sickle Cell, Aplastic Fanconi, SAA, Hurler's Syndrome, FEL,
  Neuroblastoma, Rhabdomyosarcoma, Ewings, Wilms, WAS, Medulloblastoma, Germ Cell Tumor,
  Germinoma, Thallassemia Major, Pineoblastoma, Chediak-Higashi Syndrome, SCID
  Type of SCT: Marrow, PBSC, Cord blood
  Expertise: Leukemias, NBL, Unrelated, WAS
  Registries: CIBMTR, NMDP, PBMT

• Tammy Ural (USA)
  Email: tural@tulane.edu
  Type of Transplants: Allos & Autos
  Age: Adults
  Type of SCT: Marrow, PBSC
  Tulane University Medical
  Registries: CIBMTR, NMDP

• Cathy Fortney (USA)
  cforte1@hfhs.org
  Type of Transplants: allo, auto, URD, CB
  Age: Adults (about 50 transplants a year)
  Type of SCT: BM and HPC; URD and CB transplant center only
  Expertise: BMT lab, quality, data management, FACT prep, billing
  Registries: CIBMTR & NMDP
MENTORS (continued)

- **Joanne Chilton, CCRP (USA)**
  - E-Mail: chiltonj@upstate.edu
  - Transplant types: Allo and Auto
  - Age: Adults
  - Disease: All
  - Type of SCT: Marrow, PBSC
  - Expertise: Auto
  - Registries: CIBMTR, CALGB, pharmaceutical studies (incl. Regulatory documents)

- **Juanita Rogers (USA)**
  - E-Mail: jrogers@chla.usc.edu
  - Transplant types: Allo and Auto
  - Age: 0-21 years.
  - Disease: All diseases including, Pediatric solid tumors (neuroblastoma etc.), immune deficiencies and other genetic disorders.
  - Type of SCT: Marrow, PBSC, Cord blood
  - Expertise: Immune deficiencies and other genetic disorders.
  - Registries: CIBMTR, NMDP, New York Cord Blood Bank, St. Louis Cord Blood Bank, annual reports and accreditations including data outcome surveys, etc. to various insurance companies, contracts and case rates and any documentation that is required.
MENTORS (continued)

- **Joanne Sanders (New Zealand)**
  E-Mail: joanne.sanders@cdhb.govt.nz
  Transplant types: Allo and Auto
  Age: Adults
  Disease: All
  Type of SCT: Marrow, PBSC
  Expertise: AML, ALL, NHL, Myeloma
  Registries: CIBMTR, EBMT, ABMTRR, NZBMDR

- **Sahar Zadeh, BSc. (Canada)**
  Email: sahar.zadeh@uhn.on.ca
  Transplant type: Autologous
  Age: Adults
  Disease: NHL, HD, Myeloma, Amyloids, Germ cell
  Type of SCT: Bone marrow, PBSC, mixed
  Expertise: Lymphoma, Myeloma
  Registries: CIBMTR
Helping Hand Guide for Data Managers

• The Web site "Helping hand guide for data managers" lists the most commonly used abbreviations in BMT.

• A
  Abbreviation = Translation
  ABMTR = Autologous Blood and Marrow Transplant Registry
  ACC = Accession Number
  ACR = American College of Rheumatology
  Acyclovir (ACV) = used in relation to Herpes Simplex, Herpes Zoster and CMV
  AdEERS = Adverse Event Expedited Reporting System
  Adriamycin = Daunomycin
  AE = Adverse Event
  ALD = AdRenoleukodystrophy
  ALL = Acute Lymphoblastic Leukemia
  AML (ANLL) = Acute Myelogenous Leukemia
  Amphotericin = Fungizon
The Notice Board

• At this Web site Data Managers can place informal information, advertisements (e.g. wishing to get in contact with other DM or CRP, a roommate to lower the cost of IBMTR meetings, someone to do a research project with) or good advice (how to organize your work or how to make a good margarita).

• This part of the website is not used very often.
Organizing the work

• CRP and DM often face problems in relation to gathering the information needed to fill out the different forms. The intent of this Web site is to gather and convey tips and ideas to and from CRP and DM on how to solve such problems. If you have questions that you think others might help you solve or if you have tips or ideas that you think others might benefit from then please send an e-mail to Hanne: rh07604@rh.dk
Questions and Answers

• The most common questions asked when filling out CIBMTR forms will be published on this Web site. If you have a question in relation to CIBMTR forms that you would like answered, go to www.mentors.blogspot.com or use the link "Mentors" to find the e-mail address.
Audit and Accreditations - Tips and Ideas

• Data Managers and Clinical Research Professionals face different types of audits and accreditations (CIBMTR, NMDP, FACT) on a regularly basis. To help you accomplish such events, we have gathered personal experiences from DM´s and CRP´s to give you tips and ideas, you might find useful. This is based on personal experience, so errors or inconsistencies might occur. If you have an experience, tips or ideas, you would like to share, send an e-mail to: Hanne, e-mail address: rh07604@rh.dk.