Panel Discussion  
Long-Term Follow Up

Each panelist will share the strategy their center has in conducting long-term follow-up of recipients after receiving a hematopoietic stem cell transplant. The audience should be prepared to actively participate in a discussion with the panel. Bring your questions and thoughts to this interactive session.

Moderator

- Sharon Ewer CIBMTR, Minneapolis

Panelists

- Rachel Lawrence  Shands Hospital at the University of Florida  
- Jodie Mendelsohn  Fred Hutchinson Cancer Research Center  
- Cheryl Raffel  Medical College of Wisconsin/Froedtert Hospital

Rachel Lawrence, RN  
Shands at the University of Florida, 10118

Experience

- Started nursing career in 1991 in General Pediatrics  
- 1996 worked in Pediatric Hem/Onc  
- 2002 worked in BMTU  
- 2003 became Data Manager for BMTU

Transplant Information

- Our program was established in 1981 making it the oldest in Florida  
- The program has performed over 2000 blood and marrow transplants and is one of the largest in the south east  
- Shands performs 120-150 transplants per year including pediatric, adult, cord blood, and allogeneic transplants  
- Accredited by the Foundation for the Accreditation of Cellular Therapy (FACT)

Responsibilities

- Follow up with patients post-transplant for continuity of care as well as research  
- Communicate health related data with CIBMTR/NMDP to be inputted in to the SCTOD.  
- Provide feedback to providers as well as patients regarding care
Data Management Tools

- Follow up phone calls
- StemSoft
- Internal workflow diagrams
- Timelines
  - Master BMTU Patient Index in Excel
- Social Security Index
  - www.ssgi.rootsweb.ancestry.com/cgi-bin-ssdi.cgi
- Google
  - www.google.com

Jodie Mendelsohn, BSN
Fred Hutchinson Cancer Research Center, 10117

Experience

- I have approximately 10 years experience working in research.
- I have been at my current position as a data coordinator at FHCRC for 3 years.

Job Responsibilities

- My job responsibilities include filling out the TED, Baseline, and 3+ year post-transplant follow-up forms. Under the old NMDP agreement, we completed approximately 1,000 forms annually for patients who were 3+ years post-transplant.

Transplants

- Fred Hutchinson Cancer Research Center performs approximately 450 transplants a year on both pediatric and adult patients at the University of Washington Medical Center, Seattle Children’s Hospital, and the Seattle Cancer Care Alliance.
  - Auto – Approximately 37%
  - Allogenic, Related – Approximately 27%
  - Allogenic, Unrelated – Approximately 37%
Follow up at FHCRC

- All patients are referred back to their referring physician after discharge from the Center.

- For the follow-up forms, we receive our data from our Long Term Follow Up team. The LTFU team sends out annual questionnaires to approximately 4,500 patients and their physicians and requests updated outside medical records. Patients and their physicians receive free telephone consultation for life regarding post-transplant issues. Patients may return to the SCCA for follow-up care and consultation, if necessary. Patients may also be involved in additional post-transplant research activities. Questionnaires, phone notes, e-mail, and medical records received either by medical or research staff are scanned into an electronic file that is accessible by research staff.

Cheryl Raffel, RHIA, CTR
Center # 10128 – Medical College of Wisconsin/Froedtert Hospital

Education

- Bachelor of Science, Health Information Administration

Certifications

- RHIA – 1987 – Registered Health Information Administrator
- CTR – 1991 – Certified Tumor Registrar (Cancer Registry field)

Experience

- 4 years working in CIBMTR forms completion (2004-08)
- 18 years working in Cancer Registry (1987-2004)

Transplant Information

- Adult Only
- Autologous and Allogeneic (both related and unrelated)
- Number of Transplants per year – average of 95 per year over the last 5 years, but increasing (87 in 2004, 118 in 2008)
Responsibilities

- Our facility completes CIBMTR research forms for all transplant patients and has staff that work exclusively on CIBMTR forms. We maintain an internal patient spreadsheet as well as a patient database, both of which include all transplant patients from 1982 to the present. The spreadsheet helps track due dates of CIBMTR forms and the database collects transplant therapy and post-transplant data.

Follow-Up at Our Facility

- Includes all of the following:
  - Review patient charts from follow-up visits
  - Talk with our physicians regarding patients
  - Talk with clinical research study coordinators (for patients on research protocols)
  - Obtain record copies from other MD’s/facilities
  - Phone contact with other health care facilities
  - Contact the patient, both in writing and by phone
  - Check on-line resources (death index, phone directory, other)
Long-Term Follow-Up – Helpful Information

Release of Information

ROI Forms

- Can be completed by patient at time of signing transplant consent, for obtaining records (can specify for long-term follow-up)

ROI in Different States

- Different states will have varying release of information regulations and may make it difficult to obtain records across state lines.

Talk to Medical Record/Health Information Department Staff

- At some Clinic/MD Offices/other hospitals, ROI forms may be scanned into electronic charts, but sometimes hard copies may only be kept in the paper chart. ROI to a different physician/facility may not be recorded elsewhere and you may need to specifically ask them to check for a ROI form to find the patient’s new physician.

Other Ideas - Where Else to Look?

Call Cancer Registries

- Many hospitals (except very small or rural hospitals) have a Cancer Registry that collects much of the same information we do regarding the patient’s cancer diagnosis and also follows the patient till their death. A patient will be included in the hospital’s registry if they are either diagnosed at or have part or all of their cancer treatment at that hospital.

Research Study Follow-Up

- If patients are on a clinical research study, either at your facility or elsewhere, they will need to follow the patient as well and can also be a good source for information.

Checking Online Resources

- Look for obituaries in local newspapers of city where patient lives. Many newspapers have online obituaries, but some do not have free searches if it is too far past the death date. Also check the social security death index – though not all deceased patients are in the index (most are, but if no social security benefits are claimed they will not be entered). Some credit check sources can also be used to find the patient’s current address (ie. TransUnion, be aware that some searches are not free)
Helpful Tools

Form Letter

- Develop a form letter to send to patients asking for certain data items (ie. Work info, physician name, current address/phone) Can also create a form to send to physicians to complete with follow-up information.

List of Data Needed

- Have a list of information needed for each follow-up period (different information needed for the 6month-2year follow-up versus 3+ year follow-up). Use the list to help determine which records are needed when calling elsewhere.

Patient Tracking Spreadsheet

- How we do it…
  Each transplant patient is entered into an Excel spreadsheet. Patient information can be sorted or selected/grouped by any of the following items: name, UPN, CIBMTR ID number, disease, type of transplant (auto, allo, MUD), date of transplant, month that next form is due, specific CIBMTR form due (baseline, D100, 6month, yearly follow-up or TED follow-up)

Lost Cases

- Keep checking to find lost patients on a yearly basis. Patients may be lost for several years and then miraculously re-appear. Sometimes patients don’t go to their physician every year, especially those who are younger, healthier, lacking insurance or further out from transplant and doing well.

Deceased Cases

- Many times it is best to work on these as soon as possible after the patient is deceased. If there are questions regarding their death information, as time increases the physician may not remember all the details. It also becomes more difficult to obtain record copies if too much time has elapsed after the patient’s death.
Patient:

Source/Contact:

Phone:

FAX:

Calls ☐ Taken by or ☐ Placed by:

Date and Time of Call(s):  ____/____/____  ____/____/____  ____/____/____

Initial contact from voicemail? ☐ Yes ☐ No

Time spent on case: ☐ <5  ☐ ≥5  ☐ ≥10  ☐ ≥15  ☐ ≥20  ☐ ≥25  ☐ ≥30  ☐ ≥40  ☐ ≥50  ☐ ≥60  ☐ ≥75  ☐ ≥90

☐ DUAGE

☐ Pu/MD Demographic change  ☐ GVHD  ☐ Meds  ☐ Other Toxicity  ☐ Scheduling/Insur.  ☐ Other: __________

☐ Relapse (date of relapse: __________)

☐ New Malig. (date of new dx: __________)

☐ Death  ☐ Labs  ☐ Pt activities/risks  ☐ Specimen issues  ☐ Other: __________

WEIGHT: __________ kg / lb

SKIN(% BS involved): ☐ <20  ☐ ≥20 –50  ☐ ≥50 –75  ☐ >75%

HAIR/NAILS:

EYES:

ORAL:

RESP:

GUESOPHAGUS:

GU/ SEXUALITY:

JOINTS (contracture,pain)/ EXTREMITIES:

MUSCLE / NEURO:

CURRENT MEDICATIONS

☐ PDN  ☐ TMP/SMZ

☐ CSP  ☐ PCN-

☐ FK506  ☐ ACV / GCV

☐ MMF  ☐ ITRA/ FLUCO

☐ RAPA  ☐ THAL

☐ IFN

DATES

HCT (Hg)/ Plat

WBC / ANC

EOS/LYMPH

BLASTS

ALK PHOS

AST / ALT

BILI (total) / LDH

CREATININE

CSP / FK506 level

Reviewed w/ ___________________________ on:  ____/____/____

3/1/02

TREATMENT PLAN REVIEWED WITH ATTENDING

Additional time spent on case by LTFU support staff (if applicable): ______ minutes
Please complete this form for <<p_name_notitle>> for the period since <<date of last form>>.

**Performance/Play Score at this Visit***
- Karnofsky
- Lansky __________ %

**Chronic GVHD**
- None or Not applicable
  - Date of diagnosis: __/__/__
  - Platelet count at diagnosis: __x10^9/L
  - Karnofsky/Lansky Score at cGVHD diagnosis: __ __ __ %

**Maximum extent of Chronic GVHD during this period***:
- None
- Limited
- Extensive
- Unknown

**Complications**
- Skin or hair
- Finger/toenails
- Eyes
- Lungs
- Mouth
- GI
- Liver
- GU
- Musculoskeletal
- Other: __________________________

**Severity of Chronic GVHD**
- Mild
- Moderate
- Severe

**Treatment of Chronic GVHD**
- Off systemic immunosuppression
- On systemic immunosuppression as of date of this visit

**Current medications/treatments for chronic GVHD (or attach list):**

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**Assessment of Pre-Transplant Malignant Disease**

**Current Disease Status**
- N/A – not tx’d for a malignant disease
- Remission
- Relapse/disease progression
- Unknown/ not evaluated

**Current Disease Evaluation**
- Molecular testing done (PCR: BCR/ABL, Ph1, etc.)
  - Date: __/__/__
  - Disease detected? Yes No Unk
  - Results are considered to be relapse or progression
- Cytogenetic/FISH testing done
  - Date: __/__/__
  - Disease detected? Yes No Unk
  - Results are considered to be relapse or progression

**New Malignancy**
- None
- Clonal cytogenetic abnormality without leukemia*
- Myelodysplasia or MDS
- Other malignant disease

**Other Disorders**
- Adrenal insufficiency
- Avascular necrosis
- Bronchiolitis obliterans
- Cataracts
- Congestive heart failure (EF < 40%)
- Cryptogenic organizing pneumonia (COP)
- Diabetes/hyperglycemia
- DVT not due to catheter
- HRT for gonadal dysfunction/infertility
- Iron overload, treated
- ITP
- Joint replacement
- Growth hormone deficiency/disturbance
- Hemorrhagic cystitis (requiring medical intervention)
- Hypothyroidism
- Interstitial pneumonitis/ ARDS
- Myocardial infarction
- Liver toxicity (non-infectious)
- Osteoporosis
- Pancreatitis
- HUS/TTP or similar syndrome
- Pulmonary hemorrhage
- Renal failure (requiring dialysis)
- Stroke/seizure
- Other: __________________________

**Infectious Diseases**
- None
- Mycobacteria
- Invasive mold
- Muco-cutaneous yeast
- Pneumocystis carinii
- Systemic candidiasis
- Hepatitis A B C
- Pneumonia
- HHV6
- HIV
- Bacteremia
- Nocardia
- Human metapneumovirus
- Other: __________________________

**Other**
- Pregnancy in patient or partner
- Organ transplant, specify: __________________________

**Date patient was seen:** __/__/__

**Date Completed:** __/__/__

*See definitions on back of this form