To investigate models of care in well-established Long Term Follow Up (LTFU) & Survivorship Programs in leading international Blood & Marrow Transplant (BMT) Centres.

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Signed Gemma Dyer Dated 8th April 2013
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1. Executive Summary

Allogeneic Blood and Marrow Transplant (BMT) is used to treat a broad range of malignant and non-malignant conditions in adults and children. Over the past three decades advances in transplant techniques have resulted in an increase in both the number of people undergoing the procedure, as well as an increase in patients surviving long term following the procedure. While this is clearly desirable, it does not come without a cost. Increasingly the long term and late effects of BMT are being recognised in these survivors, such that Long Term Follow Up (LTFU) is now widely recommended. Internationally, survivorship and LTFU have long been embedded into BMT programs. In contrast, few Australian BMT centres have established BMT LTFU services for survivors of BMT. In late 2010 the Agency for Clinical Innovation, BMT Network, began work on a state-wide BMT LTFU Project to develop a coordinated program for BMT survivors in NSW.

The purpose of this fellowship was to investigate formal approaches to BMT LTFU. Between January 2013 and February 2013 I visited seven hospitals and attended the American Society of Blood and Marrow Transplantation (ASBMT) Conference. The sites included:

- New York Presbyterian Hospital, New York
- Philadelphia Children’s Hospital, Philadelphia
- Abramson Cancer Centre, Philadelphia
- MD Anderson Cancer Centre, Houston
- Fred Hutchinson Cancer Research Centre, Seattle Cancer Care Alliance, Seattle
- Children’s Hospital LA, Los Angeles, California
- City of Hope, Duarte, California

Fellowship Objectives:
The objectives of the fellowship were as follows:

- Gain an understanding of models of care for LTFU and Survivorship programs in leading international BMT Centres.
- Develop further knowledge regarding protocols and guidelines in BMT Long Term Follow-Up and Survivorship care.
- Attend established BMT LTFU and Survivorship clinics to gain a first-hand experience of their functioning.
- Increase knowledge of management of chronic graft versus host disease.
- Meet with and work alongside advanced practice nurses/nurse practitioners involved in management of LTFU and survivorship care in BMT.
- Develop an increased awareness of APN/NP models of care.
- Gain insights into different models of education regarding BMT for patients, carers and clinicians (pre, peri & acute post & long term).
- Increase knowledge regarding data collection & management of long-term survivor events and outcomes.

Key Learnings:

- All BMT units have established processes for LTFU
- All BMT units have dedicated LTFU Nursing support
- The LTFU roles performed by Advanced Practices Nurses (APNs)/Nurse Practitioners (NPs) vary but include: screening, diagnostics and early detection (physical and psychological), cGvHD assessment and management, and pharmacological and non-pharmacological interventions.
- Nurse-led LTFU clinics are either run solely by NPs/APNs or collaboratively with BMT Physician/s
- All LTFU clinics have administrative support e.g. for scheduling appointments – so LTFU Nurses only perform clinical functions.
- All BMT clinics provide patients with treatment summaries/care plans (which nurses extract from patient records).
- All BMT clinics provide surveillance for recurrence and screen for new cancers.
- All BMT clinics provide care co-ordination with primary care physicians and primary oncologists.
- All BMT clinics provide health promotion education and symptom management.
- All BMT clinics have psychology or social work involvement for psychosocial assessment and care.
- All BMT units collect data on post-BMT outcomes as part of the LFTU clinics.
- Many BMT units provide Post-BMT LTFU education sessions for patients and LTFU/Survivorship education materials for patients is made readily available
- Many BMT units provide patients with an electronic health record which can be accessed anytime via the hospital website by the patient or the patients GP.
- Transition is a challenge for all of the BMT services and is managed differently across different services. Some BMT units have established transition programs – which are largely nurse-led.
2. Introduction

Allogeneic Blood and Marrow Transplantation (BMT) is a procedure in which stem cells, derived from either bone marrow, blood or cord blood are collected from a donor and given to a patient following chemo- radiotherapy. Depending on tissue type matching the donor stem cells can be a provided by a sibling, an unrelated person, cord blood or a haplo-identical relative (parent or child).

Currently in NSW there are 15 BMT units performing autologous transplant and five BMT units performing allogeneic BMT.

Consistent with international trends, in NSW the number of BMT procedures being performed is increasing each year, with many of those who undergo BMT expected to survive long-term. It is estimated that there are approximately 2000 survivors of allogeneic BMT living in Sydney and rural/regional NSW.

While improvement is survival is clearly desirable, many of those who survive BMT will experience ongoing adverse effects of transplant. BMT is associated with a range of late toxicities resulting from the patient’s underlying conditioning, the effects of conditioning chemo-radiotherapy and immunosuppressive therapy and the immunological complications of allogeneic transplant (1). These late effects of BMT may occur at any time post-BMT, with some more prevalent in the first few months-years post-BMT and others only emerging many years after BMT. The effects of these toxicities are profound – being the major cause of mortality after the first two years post-BMT and the major determinant of quality of life.

The long-term and late complications of BMT can impact upon every organ system and include:
- Cardiac failure and ‘accelerated’ cardiovascular disease (2)
- Diabetes, hypothyroidism and endocrine dysfunction (3)
- Infertility(4)
- Growth failure (5)
- Chronic lung disease and respiratory failure(6)
- Kidney failure(7)
- Liver dysfunction(8)
- Osteoporosis, arthritis and bone fractures(9)
- Chronic graft versus host disease (10)
- Immunodeficiency and infection(11)
- Secondary malignancies including leukaemia and ‘solid’ cancers including skin, brain, thyroid, gynaecological and breast cancer (12, 13)
- Cataracts and other ocular issues(14)
- Dental problems (15)
- Sexual dysfunction (1, 16)
- Depression and anxiety (17)

The collective impact of these complications cannot be overstated - with BMT survivors experiencing a 30% lower life expectancy than a matched population cohort (18). These complications also have a significant impact upon the quality of life of BMT survivors – with data indicating higher levels of unemployment, divorce and relationship difficulties, financial hardship and social isolation (19-21).
Increasing recognition of the needs of survivors of BMT has led international transplant organisations and networks (such as the Centre for International Blood and Marrow Transplantation (CIBMTR), the European group for Blood and Marrow Transplantation (EBMT) and the American Society of Haematology (ASH)), consumer and patient advocacy groups and individual BMT units to call for the creation of comprehensive, multidisciplinary long-term care services for BMT survivors. ‘Survivorship’ is also now a major part of the National Cancer Institute (NCI), a major focus of ASH, a recognised issue for the Cancer Council, the Leukaemia Foundation and the Myeloma Foundation, and the focus of Working Groups within the EBMT and CIBMTR and many BMT units worldwide, particularly in the United States and Europe, are reforming their institutional structures and processes to more appropriately address the needs of survivors.

At the current time in NSW there is no coordinated follow-up of adult patients, no standardised data collection regarding late effects of BMT and no successful transition program to enable the successful movement of BMT survivors between paediatric and adult centres and from BMT units to community health services.

3. Fellowship Itinerary

i. New York Presbytarian Hospital, New York, New York

a) BMT Program

People I met with:
- Mrs R Hawkes, RN, MSN, CPNP
  Paediatric BMT Nurse Practitioner
- Dr James Garvin, MD, PhD
  PaediatricHaematology-Oncology/BMT Physician
- Ms Danielle Dietzen, RN, MSN, CPNP
  Outpatient BMT Nurse Practitioner

Key Activities
- Meeting with Ria Hawkes and given overview of the hospital, BMT service and a hospital tour
- Attended Grand Rounds Presentation
- Attended the BMT outpatient Clinic with Dr James Garvin and Danielle Dietzen

Summary
The BMT Program operates within the PaediatricHaematology/Oncology/Stem Cell Transplantation Division at New York-Presbyterian Morgan Stanley Children's Hospital. The Multidisciplinary team consists of physicians, nurses, nurse practitioners, pain specialists, complementary medicine practitioners, psychologists, social workers, and child life specialists. Outpatient services are provided at the Herbert Irving Child and Adolescent Centre, and inpatient care at New York-Presbyterian Morgan Stanley Children's Hospital.

The Centre began performing allogeneic blood and marrow transplantation in 1997 and in the 24 month period between Jan 2009 – Dec 2010 reported 66 BMTs (average of ~33/year). Current 1 year survival rate is 71%. There are 5 Paediatric BMT consultants, a BMT Fellow and two BMT Nurse Practitioners. One of Nurse Practitioner deals with co-ordinating the transplants and is involved in patient care and education from diagnosis through to discharge following transplantation. The second Nurse Practitioner functions in the outpatient clinic and assumes care for the patient upon discharge. Patients are shared between this Nurse Practitioner and the BMT Fellow and overseen by the attending BMT consultant.

There is no set pathway for BMT patients in long term follow up as recovery is highly variable. In general the patients are followed by the attending together with the Nurse Practitioner/BMT Fellow until well and then either
b) The Centre for Survivor Wellness

**People I met with:**
- A/Prof Jennifer Levine, MD, MSW
  Medical Director, Assistant Professor of Clinical Paediatrics
- Ms Alison Fernbach, RN, MSN, CPNP
  Paediatric Nurse Practitioner

**Key Activities**
- Meet with A/Prof Jennifer Levine and Alison Fernbach regarding the Centre for Survivor Wellness and given an overview of the program
- Shadowed Alison Fernbach, CPNP while attending Survivorship Program Clinic
- Met Centre for Survivor Wellness Team

**Summary**
The Centre for Survivor Wellness has been operating since 2006 and sees approximately 150 patients per year. The clinic runs 4 days per week. It is located at Columbia Presbyterian, in New York and receives referrals from the hospital's oncology and BMT departments.

The team is multidisciplinary and includes an oncologist, nurse practitioner, neuropsychologist, social worker, nutritionist, exercise physiologist and patient co-ordinator.

Patients are referred to the service between 2-5 years after cancer treatment. The Nurse Practitioner sees all patients under the age of 21 years independently. All patients over 21yo are reviewed by Dr Levine. The Children's Oncology Group (COG) Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers are used to develop treatment summaries which outline the potential risks for long term complications as well as recommendations for lifelong follow up. This summary is given to the patient.

Specific functions of the centre are:
- Monitor and manage late effects of therapy
- Addressing psychosocial needs of survivors
- Educating survivors about their cancer and treatment
- Promoting wellness through education and healthy living
- Encouraging participation in survivorship research studies
- Offering programs for survivors including internships, exercise classes and group forums.

Particular attention is paid to the needs of adolescent and young adult survivors, including issues of education, job training, fertility, and a healthy lifestyle.

This clinic has made the decision not to transition patients to an adult centre as there is no appropriate service available at this time to do this.

ii. Children’s Hospital of Philadelphia, Philadelphia, Pennsylvania

a) BMT Program

**People I met with**
- Prof Nancy Bunin, MD
Medical Director, Stem Cell Transplantation
- Dr David Barrett, MD, PhD
  Paediatric BMT Physician
- Mrs Ellen Levy, RN, MSN, CRNP
  Paediatric Nurse Practitioner

Key Activities
- Shadowing Ellen Levy in the BMT outpatient clinic
- Attending medical reviews of patients with Prof Nancy Bunin and Dr David Barrett.
- Reviewed BMT patient resources

Summary
The Paediatric Blood and Marrow Transplantation Program at The Children’s Hospital of Philadelphia is one of the oldest paediatric BMT programs in the country. The multidisciplinary team consists of BMT physicians, radiation oncologists, nurse practitioners, a search coordinator, a social worker, nutritionists and child life specialists.

The Centre began performing allogeneic blood and marrow transplantation in 1976 and in the 24 month period between Jan 2009 – Dec 2010 reported 110 BMTs (average of ~55/year). Current 1 year survival rate is 74%.

There are 6 Paediatric BMT consultants, 4 BMT Nurse Practitioners, and 1 transplant search co-ordinator. Two of the Nurse Practitioners work in the inpatient setting and two in the outpatient setting. Patients are reviewed separately by both the Nurse Practitioner and the attending BMT consultant. An immunologist and dentist also attend the BMT outpatient clinics monthly.

Once patients are well and off immunosuppression they are referred to the CHOP Cancer Survivorship Program. This is generally 2 years post BMT.

b) Cancer Survivorship Program

People I met with
- A/Prof Jill Ginsberg, MD
  Medical Director
- Mrs Wendy Hobbie, RN, MSN, CPNP, FAAN
  Associate Director

Key Activities
- Meeting with Wendy Hobbie and given overview of the hospital, the Cancer Survivorship Program and the evolution of Nurse Practitioners in the US as well as a hospital tour.
- Attended a Nurse Practitioner Masters Lecture “Difficult Discussions in Paediatric Palliative and End of Life Care”
- Shadowed Wendy Hobbie while attending the Cancer Survivorship Program Clinic.

Summary
This survivorship program has been operating since 1983 and sees approximately 500 patients per year. The primary Cancer Survivorship Program team consists of: a medical director/oncologist, a Nurse Practitioner and 3 x Registered Nurses. Patients are reviewed by the oncologist or the Nurse Practitioner. The RNs time is dedicated to extracting information from the medical records and arranging appropriate tests/follow-up according to the COG guidelines as well as oversee all the research studies from recruitment to IRB review board submission. The clinic is run two days per week. A nutritionist and clinical psychologist also attend the clinic and form part of the core team. Patients must be at least five years from diagnosis (or last evidence of disease) and two years after having completed all therapy.

Benefits of the survivorship program are:
- Comprehensive evaluation and physical exam focusing on potential and actual late effects of disease and treatment
- Patient/Family education and anticipatory guidance regarding potential late effects
- Accessibility to a dedicated Clinical Psychologist with experience in addressing issues specific to long-term survivors of childhood cancer
- Accessibility to ongoing studies, and ability to participate
- Accessibility to cohort of sub-specialists identified by the survivorship team, who have close collaboration of practice for specific known or potential late effects of therapy
- Collaboration with the survivorship team within the same CHOP system

It is expected that all survivors will have at least a one-time visit for complete evaluation and given recommendations regarding life-long follow-up – available for single consultation or regular visits.

Once a month the clinic is also attended by many sub-specialists including an endocrinologist, a pulmonologist, and a cardiologist, and a Registered Dietician. This is the clinic that the majority of BMT survivors are scheduled to attend. Patients are transitioned out of the Survivorship Program at approximately age 22. Their ongoing care is stratified according to therapy received. Patients with a very low risk of late effects are transitioned to their Primary Care Provider with recommendations for lifelong follow up.

If however, the patient received complex treatment, such as a BMT, their risks of late effects are much higher and they are therefore transitioned into the Living Well After Childhood Cancer Program at the Abramson Cancer Centre (detailed below).

Interestingly this clinic also co-ordinates the fertility sparing options for cancer patients as it was identified that it was during long term follow, when attending the Cancer Survivorship Program that patients and families would have questions regarding fertility and future options.

iii. Abramson Cancer Centre, Philadelphia, Pennsylvania

a) LIVESTRONG Cancer Survivor Centre

People I met with
- Mrs Carrie Stricker, PhD, CRNP
  Director of Clinical Programs, LIVESTRONG Survivorship Centre of Excellence
  Oncology Nurse Practitioner

Key Activities
- Shadowed Carrie Stricker, Nurse Practitioner in her Breast Cancer Survivorship Clinic.
- Reviewed resources available for Cancer survivors.

Summary
The LIVESTRONG Cancer Survivor Centre opened in 2001 and is a clinical, research, and education effort focused on early intervention and prevention of disease following cancer treatment. The program, also known as the Living Well After Cancer (LWAC) provides care and research opportunities to all cancer survivors treated at Penn and within the Penn Cancer Network hospital.

In the Breast Cancer Survivorship Clinic within the LWAC Program, patients are reviewed by the Breast Cancer Survivorship Nurse Practitioner and provided with a summary of the treatment received as well as an individualised plan for follow-up care.
Emphasis is placed on:

- Potential long-term or late side effects of cancer treatment, the symptoms and treatment.
- Recommendations for cancer screening for disease recurrence or a new cancer.
- Psychosocial effects, including relationships and sexuality.
- Planning follow-up visits.
- Social and economic concerns

b) Living Well After Childhood Cancer (LWACC) Program

People I met with
- Mrs Donna Pucci, MHK
  Program Co-ordinator

Key Activities
- Meet with Donna and given an overview of the LWACC Program and Clinic tour
- Reviewed patients resources

Summary
The Living Well After Childhood Cancer (LWACC) Program, established with a grant from the Lance Armstrong Foundation (LAF), is a collaborative effort between Penn and CHOP. The program assumes care for adult survivors of childhood cancer and holds a clinic once a week for Adolescent and Young Adult (AYA) patients.

This program also allows collaborative research between ACC and CHOP.

Donna attends the CHOP Cancer Survivor Program at the patients last clinic visit in order to establish rapport prior to their transition to the AYA clinic.

iv. MD Anderson Cancer Centre, Houston, Texas

a) Stem Cell Transplantation and Cellular Therapy Allogeneic Survivorship Clinic

People I met with
- Ms Karen Stolar, RN, MS, FNP-BC, AOCN
  Survivorship Nurse Practitioner, Stem Cell Transplantation and Cellular Therapy
- Mrs Nerissa Sunga, RN, MS, FNP-BC, AOCN
  BMT Nurse Practitioner

Key Activities
- Meet with Karen Stolar and given an overview of the service as well as a hospital tour
- Shadowed Karen Stolar and Nerissa Sunga in the BMT Survivorship Clinic
- Reviewed resources available for BMT survivors.

Summary
MD Anderson Cancer Centre began transplanting in 1990 and is now one of the largest BMT centres in the world. In 2012 more than 800 BMTs were performed. It has 27 transplant physicians and over 200 BMT nursing staff. The BMT unit has 76 beds.

The Stem Cell Transplantation and Cellular Therapy Allogeneic Survivorship Clinic was developed in 2006 by Karen Stolar and conducts approximately 400 patient visits per year. BMT patients are first referred to the clinic at a Day + 80 for a ‘graduation class’. This class runs for 90 minutes and is individualised for patients. Patients receive extensive education on treatment effects and health promotion. They are then seen in the clinic 6 monthly for 2 years and then yearly. This clinic run concurrently with the patients BMT physicians clinic who’s primary focus is disease
surveillance and acute treatment issues. Patients receive a treatment summary and follow up care plan to share with their local Haematologist and general practitioner.

b) Childhood Cancer Survivors Clinic

**People I met with**

- Prof Joanne Ater, MD  
  Paediatric Oncologist
- Mrs Angela Yarbrough, RN, MSN, FNP-BC  
  Family Nurse Practitioner, Paediatrics
- Mrs Sung Kim, RN, MSN, FNP-BC  
  Nurse Practitioner, Paediatric Haematology and Oncology

**Key Activities**

- Attended weekly Paediatric haematology-oncology ward round
- Attended Grand Round Presentation (Paediatrics)
- Shadowed Angela Yarbrough in the Childhood Cancer Survivors Clinic
- Shadowed Dr Ater during medical review of LTFU patients
- Reviewed resources available for patients

**Summary**

The Childhood Cancer Survivors Clinic reviews patients on a yearly basis and provides individualised monitoring and treatment to minimize the impact of therapy received. Patients are able to self-refer into the program provided they were diagnosed prior to age 18 years of age and who have been out of treatment and cancer-free for at least three years.

Patients receive:

- Complete physical examinations
- Blood work and X-rays
- Regular cancer screening
- Summarized reports to your primary care physician
- Referral to medical specialists
- Genetic counselling

This clinic has made the decision not to transition patients to an adult centre as there is no appropriate service available at this time to do this.

v. Fred Hutchinson Cancer Research Centre/Seattle Cancer Care Alliance, Seattle, Washington

a) Blood and Marrow Transplant Service

**People I met with**

- Rosemary Ford, RN, BSN, OCN  
  Nurse Manager, Transplant Clinic
- Kerry McMillen, MS, RD, CSO  
  Registered Dietician, Stem Cell Transplant
- Mrs Shelley Moore, MEd  
  Staff Education Program Manager
- Lenise Taylor, RN, MN, AOCS  
  Hematologic Malignancies Clinical Nurse Specialist
**Key Activities**

- Met with Rosemary Ford and given an overview of the BMT service and history of BMT at the centre.
- Met with Kerry McMillen and discussed dietetic input into BMT care and reviewed patient resources.
- Met with Shelly Moore and Lenise Taylor and attended the ‘Nursing Management of the Blood and Marrow Transplant Patient’, two day course.

**Summary**

Fred Hutchinson Cancer Research Centre/Seattle Cancer Care Alliance is birthplace of BMT. The first transplant in the world was performed here in 1959 under the direction of Dr E D Thomas. In 2012 over 550 BMTs were performed.

**b) Transitional Transplant Clinic (TTC)**

**People I met with**
- Dow Dunbar, PA
  Physician Assistant
- Joanne Quinn, RN
  Clinical Nurse

**Key Activities**
- Met with Dow Dunbar and given a clinic tour and overview of the TTC
- Shadowed Dow Dunbar and Joanne Quinn in the TTC clinic reviewing patients

**Summary**

The TTC is an newly formed clinic (Sept 2012) which primarily deals with patients with the following indications; GvHD not well controlled requiring frequent visits; new diagnosis of late acute or chronic GvHD to help with management; GvHD flare, patient not responding to 1st line therapy; recent diagnosis of COP or BO requiring close monitoring; ARF or haemolytic uremic syndrome and other treatment-related toxicities; severe steroid-related myopathy requiring intensive physical therapy and that requires accelerated steroid taper; patients re-admitted (after Day+120) and discharged from the hospital for management or transplant related complications (not relapse) for initial evaluation to determine if they need close monitoring in the TTC clinic; Haemorrhagic cystitis requiring treatment and frequent monitoring; patients referred for consult from LTFU telephonic nurse management – for triage to most appropriate treatment or protocol.

**c) Allogeneic Paediatric Clinic**

**People I met with**
- Denise Plath, RN
  Clinic Nurse, Continuing Care Paediatrics

**Key Activities**
- Met with Denise Plath and given an overview of the paediatric service
- Shadowed Denise in a new BMT patient education and consent session

**d) Long Term Follow Up (LTFU) Program**

**People I met with**
- Dr Mary Flowers, MD
  Medical Director
- Judy Campbell, RN
  Clinical Nurse
- Jackie Saxon, RN
  Clinical Nurse
Anne Chafee, RN  
Clinical Nurse

**Key Activities**
- Met with Judy Campell, Jackie Saxon and Anne Chafee and given an overview of the service and reviewed patient resources
- Attended the Patients and Family discharge education class
- Attended the weekly case presentation meeting.

**e) Graft versus Host Disease Clinic**

**People I met with**
- Carina Moravec, RN, MSN, ARNP  
  Nurse Practitioner, Long Term Follow Up and Graft versus Host Disease Clinic

**Key Activities**
- Shadowed Carina Moravec in the Graft versus Host Disease Clinic
- Attended a case conference with a LTFU patient

**Summary**

The LTFU team consists of one attending physician, 2 primary providers, 2 Research/Clinical middle level practitioners and 3 team nurses. The LTFU office has 4 dedicated nurses and 3 patient co-ordinators who triage telephone calls and faxes and schedule patients to return to the centre for evaluation. The LTFU office receives request calls and faxes for consultations on LTFU patients under the care of their primary oncologist.

There are five types of clinics for BMT LTFU patients:

1). Comprehensive LTFU: For patients 1 year post BMT who return to SCCA for a comprehensive evaluation that includes H&P, GVHD evaluation, disease restaging, and evaluation of possible post-transplant toxicities. Patients return to Seattle for 5 days to complete all necessary tests and assessments.

2) Abbreviated LTFU: For patients whose insurance requires that they have their testing completed through their home town physician.

3) Chronic GvHD Clinic: Patients diagnosed with GvHD are reviewed in this clinic.

4) Post-transplant Departure Evaluations: For patients who are ready to be discharged back to their local haematologist/oncologist. Involves full assessment of treatment, response, GvHD, infections, disease and chimerism status.

5) Pre-Donor Lymphocyte Infusion (DLI) evaluation visit: For patients due to received DLIs.

**vi. Children's Hospital Los Angeles, Los Angeles, California**

**a) LIFE Cancer Survivorship and Transition Program**

**People I met with**
- Corissa Pacillas Smith, BA  
  Program Assistant
- Ms LislSchweer, BA, MSW, LCSW  
  Social Worker
- Mrs Ellie Rosenthal, RN, MSN, CRNP
Nurse Practitioner
- Mrs Kelly Fons, RN, MSN, CRNP
Nurse Practitioner
- Kasey Rangan, RN, MSN, CRNP
Nurse Practitioner
- Dr David Freyer, MS, DO
Director

Key Activities
- Met with Carissa Pacillas Smith and given an overview of the program and hospital tour
- Attended the Leukaemia and Soft Tissue Tumour Survivors Clinic and shadowed Ellie Rosenthal.
- Met with Ellie, Kelly Fons and Kasey Rangan discussed Nurse Practitioner roles within the LIFE Program
- Met with Lisl Schweer and discussed Social Work role in the LIFE Program
- Reviewed LIFE and other Cancer Survivorship patient resources
- Met with Dr Freyer regarding the program

Summary
The Long-term Information Follow-up and Evaluation (LIFE) Survivorship and Transition Program began in 1992. The clinical team consists of physician, three nurse practitioners, a social worker and a research psychologist. The clinics are held Monday to Friday with one morning per week dedicated to the LIFE Program Clinical Management Conference where all patients are discussed, issues raised, referrals actioned and potential research participants/studies identified.

At each clinic survivors are educated regarding the long-term risks of cancer treatment, how to stay well both physically and emotionally, personal relationships and intimacy, locating a primary health care provider, how to find and maintain health insurance, and planning for education and a career. The program also connects survivors to other valuable HOPE Program services (detailed below), as well as other useful community resources.

For the past year the LIFE Program has established a transition clinic in collaboration with a local adult cancer centre. Once a month, the staff from the LIFE program (Physician, one of the Nurse Practitioners and the Social Worker) host a LIFE Clinic in the adult centre together with the adult service physician, and nurse practitioner. This transition occurs when the survivors reach 22 years of age. After this review the survivors care is overseen by the adult unit.

b) BMT Program

People I met with
- Mr Amber Denbleyker, BA, NSW
  BMT Social Worker
- Dr Hisham Abdel-Azim, MD
  BMT Physician

Key Activities
- Met with Amber Denbleyker and given an overview of the BMT Outpatient Clinic
- Shadowed Dr Hisham Abdel-Azim during clinic consults

Summary
The BMT Program at CHLA began in 1983 and performs approximately 45-55 BMTs annually. The Long-term care of BMT patients is overseen by BMT Consultants and patients are followed up in this clinic for life.
c) Teen Impact Program

People I met with
- Mr Tavo Zavala, BS
  Program Administrator, Teen Impact

Key Activities
- Meet with Tavo Zavala and given an overview of the Teen Impact Program

Summary
Teen Impact is the group-based psychological, emotional and social support program at Children’s Hospital Los Angeles. Support group meetings are held once a fortnight, are facilitated by mental health professionals and trainees and are designed to provide pre-teens, teens and young adults that have or once had cancer or a blood disease with an opportunity to share their stories, form a peer-support network and learn to cope with their diagnosis in a positive way. The Teen Impact program also provides groups for parents and siblings of patients and survivors. Additionally, Teen Impact also runs a three-day retreat, art workshop, field trips, and music and cultural experiences. Approximately 300 childhood cancer survivors are involved in this program.

d) The HOPE Program

People I met with
- Mrs Kathy Ruccione, MPH, RN, FAAN
  Co-Director, HOPE Program Founder & LIFE Cancer Survivorship and Transition Program

Key Activities
- Met with Kathy Ruccione and discussed Cancer Survivorship and the HOPE Program

Summary
The HOPE Program consists of the HOPE Resource Centre, the School Transition and Re-entry (STAR) Program, Teen Impact, The LIFE Program, HOPE Psychology and Neurocognitive Service, HOPE Health Outcomes Research and Celebrate Life. Kathy founded the program over 30 years ago.

The HOPE Resource Centre provides free information, services, referrals, and innovative technology resources for health education to cancer and blood disease patients and families and staff.

The STAR Program helps young people continue regular school and learning experiences, and assists parents in obtaining special school help whenever needed.
Teen Impact is discussed above.

The LIFE Program is discussed above.

HOPE Psychology and Neurocognitive Services provide psychological support for children and families experiencing difficulties in coping with life threatening illness, and assistance when illness or treatment has impacted the ability to learn.

HOPE Health Outcomes Research develops and evaluates new approaches to supportive care and health services to improve quality of life.

Celebrate Life is the hospital’s annual one-day signature event at Paramount Pictures studios for patients and families which focuses on survivorship, health and wellness.
vii. City of Hope, Duarte, California
   a) Childhood Cancer Survivorship Program

People I met with
- Mrs Wendy Landier, PhD, RN, CPNP  
  Clinical Director
- Mrs Karla Wilson, RN, MSN, FNPC  
  Nurse Practitioner

Key Activities
- Meet with Wendy Landier and Karla Wilson and given an overview of the service and hospital and tour
- Reviewed resources available for patients
- Meet with Karla Wilson separately and Survivorship service further discussed

Summary
The Childhood Cancer Survivorship Program provides specialized follow-up care for patients who have completed treatment for a cancer that was diagnosed before they were 22 years old. Survivors must be at least two years since completion of all cancer therapy, at least five years since diagnosis and in remission. Survivors are reviewed annually in the clinic by a physician or nurse practitioner, a dietician, and a psychologist or social worker. Survivors must have a primary health care provider as the program does not provide routine medical care.

Survivors receive:
- A personalized record of cancer treatment and recommendations for ongoing health monitoring.
- Information about methods to prevent new health problems and to stay as healthy as possible
- An emphasis on healthy lifestyle practices
- Referrals to specialists, and for additional resources and services, if needed
- Communication with primary healthcare provider and treatment team

The program is part of the research program at City of Hope so all information from the clinic review is collected and analysed for research purposes.

viii. American Society of Blood and Marrow Transplantation Conference

American Society of Blood and Marrow Transplantation (ASBMT) is an international professional membership association of physicians, investigators and other healthcare professionals promoting blood and marrow transplantation and cellular therapy research, education, scholarly publication and clinical standards. The conference, also known as BMT Tandem Meetings are a combined effort of ASBMT and the CITBMTR. The conference hosts several Meetings or Conferences simultaneously. These include the scientific meeting, the paediatric BMT meeting, the BMT CTN Co-ordinators/Investigators Meeting, Clinical Research Professionals/Data Management Conference, the BMT Centre Administrators Conference, the BMT Pharmacists Conference, the Transplant Nursing Conference, the BMT Clinical Education Conference, the BMT Medical Directors Conference and the CIBMTR Working Committee Meetings.

This year the conference was attended by 2,800 health professionals. I attended a mix of Nursing, BMT Centre Administrators, Clinic Education and scientific presentations/lectures, concentrating on sessions addressing late effects and quality of Life of BMT survivors.
Sessions Attended

Wednesdays, 13th February, 2013
BMT Tandem Poster Session I

Thursday, 14th February 2013
BMT 101 Lecture for Advanced Practice Professionals – NPs, Pas, Fellows and Junior Faculty

BMT Centre Administrators Conference
- How Programs and Health Plans are Using Data to Improve Program Performance
- Beyond Electronic Data Capture (EDC) to Data Sharing: Update of ASBMT/CIBMTR/NMDP IT Programs
- How is Your Transplant Program Preparing for the Future – HCT 2020
- Networking for Quality: Benchmarking with Peers for Programs Excellence
- Coding and Reimbursement Update: Improving Revenue Cycle for BMT: A Collaborative Network Approach
- Transition to Long Term Follow Up
- What Every BMT Administrator May Want to Know About Staffing Models

Friday, 15th February 2013
Transplant Nursing Conference
- Choosing a Donor
- Oral Complications
- Young Adult and Adolescent Patients: Care Issues for All Nurses
- Hot Topics

WBMT Luncheon Session: Legacy of E Donnell Thomas – 1,000,000 Transplants
- E Donnell Thomas: From Cooperstown to Global, Fredrick Applebaum, MD
- Challenges to Future Growth: The Transplant Centre Perspective – North America, Richard Champlin, MD
- Challenges to Future Growth: The Transplant Perspective – Central/South America, Carmem Sales-Bonfim, MD
- Challenges to Future Growth: The Transplant Perspective – Asia-Pacific, Alok Srivastava, MD
- Challenges to Future Growth: The Donor Registry Perspective, Dennis Confer, MD
- Challenges to Future Growth: The WHO Perspective, Luc Noel, MD
- Improving Research Collaborations to Move Forward, Jane Apperley, MD

Saturday, 16th February 2013
BMT Clinical Education Conference (for NPs, PAs, Fellows and Junior Faculty)
- Bone Marrow Transplant for Non-Malignant Disorders, Parinda Mehta, MD
- Advanced in the Management of GVHD, Daniel Courier, MD
- Relapse, A John Barrett, MD
- Acute Leukaemia – Diagnosis and Treatment, Edwin Alyea, MD
- Late Complications after Transplant: Diagnosis and Treatment, Carina Moravec, MD
- The Impact of Exercise on Haematopoietic Stem Cell Transplant Patients, Randi Hoffman, RN, PhD (c), CNP

Meet the Professor Session 5: How to get your paper published
John M Goldman, DM

Oral Abstracts – Session J – Late Effects/Quality of Life and Immune Reconstitution
- A population based cohort study of second malignancies and late mortality in children treated by allogeneic stem cell transplantation for haematological malignancies, Adam Nelson, MD
4. Conclusions

This fellowship has provided important insights into the issues of survivorship and long term follow up following BMT. The opportunity to visit many of the major North American BMT Centres enabled a vision of how things could be done differently and how Australian health care could be bought into line with international best practice. All centres differed in size (treatment numbers), patient population (paediatric, AYA and adult), institutional structure and length of time established. However, all programs comprised the core elements of survivorship in some form.

- **All BMT units have established processes for LTFU**
  LTFU is embedded within units as a distinct phase of the patient journey and patients attend specific LTFU clinics. Although time-points for referral to LTFU differed between institutions, in each centre there was a clear delineation between patients who are in the acute BMT period and those who require LTFU.

- **All BMT units have dedicated LTFU Nursing support**
  All LTFU and Survivorship programs were nurse-led.

- **The LTFU roles performed by Advanced Practices Nurses (APNs)/Nurse Practitioners (NPs) vary but include:** screening, diagnostics and early detection (physical and psychological), cGVHD assessment and management, and prescription of pharmacological and non-pharmacological interventions.

- **Nurse-led LTFU clinics are either run solely by NPs/APNs or collaboratively with BMT Physician/s**

- **All LTFU clinics have administrative support e.g. for scheduling appointments – so LTFU Nurses only perform clinical functions.**
  The LTFU care of BMT patients is complex with survivors requiring numerous test and assessments on a yearly basis. Often co-ordinating these test is the most time consuming part of LTFU, particularly if the patient is travelling from a rural area/interstate and requires that test be performed on one day or on consecutive days. All services in the US have removed this burden from nursing staff allowing LTFU nurses/NPs to focus on providing clinical care and health promotion education.

- **All BMT clinics provide patient with treatment summaries/care plans (which nurses extract from the patient record).**
  Treatment Summaries have long been a part of the Survivorship movement in the US. They provide useful information regarding treatment history, complications and health risks for patients and primary care providers.

- **All BMT clinics provide surveillance for recurrence and screen for new cancers.**
The occurrence of secondary cancers in long-term BMT survivors is increasing in incidence, particularly for survivors of childhood BMT. This necessitates regular and vigilant screening including skin checks, mammography, Pap Smears, thyroid examination and so forth.

- **All BMT clinics provide care co-ordination with primary care physicians and primary oncologists.**
  Fragmentation of care is a universal issue for patients and health services. BMT Clinics need to co-ordinate and communicate openly with patient’s primary care providers to overcome this barrier. This is particularly important as more and more of the BMT survivors care will be overseen by their local provider in the long-term.

- **All BMT clinics provide health promotion education and symptom management.**
  BMT patients are at a higher risk of developing chronic health conditions compared to the general population. It is essential, therefore, that patients understand the risks of and contributors towards chronic illness, know how to avoid those risks they can avoid, and know how to mitigate chronic illnesses that they develop.

- **All BMT clinics have psychology or social work involvement for psychosocial assessment and care.**
  The psychosocial impacts of BMT are vast, including fear of recurrence, difficulties in being able to return to work and difficulties adjusting to “the new normal”. Psychosocial input is therefore an essential element of holistic LTFU care and its importance to quality of life cannot be overlooked.

- **All BMT units collect data on post-BMT outcomes as part of the LFTU clinics.**
  Collection of LTFU data is a vital part of improving the care of BMT patients as it allows assessment of experienced and unmet needs. All clinics collected this data systematically.

- **Many BMT units provide Post-BMT LTFU education sessions for patients and LTFU/Survivorship education materials for patients is made readily available**
  Many BMT units hold either one-on-one education sessions or group classes when patients are approximately day +90 post BMT. These sessions outline the road ahead for BMT patients. Most focus on the signs and symptoms of GvHD and how to decrease the risk of infection over the following months. They also provide patients with information about the chronic, long-term less imminent effects of BMT.

There is a wealth of education materials made available for cancer survivors and their carers. These are produced by both individual institutions and other organizations (BMTLink, National Marrow Donor Program etc).

- **Many BMT units provide patients with an electronic health record which can be accessed anytime via the hospital website by the patient or the patients GP.**
  Most institutions offer access to electronic records including clinic letters and results via the hospital website. The patient’s primary care provider can also access these results when reviewing the patient in their clinic.

- **Transition is a challenge for all of the BMT services and is managed differently across different services.**
  **Some BMT units have established transition programs – which are largely nurse-led.**
  Transition between paediatric and adult health services is always difficult. Paediatric patients, their families and the staff caring for them often form strong bonds over many years during treatment and LTFU. Consequently, adult health services, which are generally less well-resourced and require that patients are autonomous are seen as scary places for these vulnerable young adult BMT survivors. Adult health service providers are also sometimes reticent to take on the care of BMT survivors with complex health care needs. Centers that transition patients between paediatric and adult services often have in place processes for meeting the survivor at their last LTFU visit in the paediatric service. In this setting the LTFU nurse is generally the key health provider and contact person.
5. Recommendations

Recommendation 1
Identification of the needs of BMT survivors in NSW

There is a dearth of data regarding the outcomes and needs of BMT survivors in Australia. In an effort to gain a better understanding, the BMT Network in collaboration with the ACI has developed a multi-centre cross sectional survey for survivors of BMT. The survey asks for detailed information about the physical, psychosocial impacts and quality of life of allogeneic BMT survivors. This survey will assist in understanding the effect that transplant has had on survivors and the challenges or problems that they have faced since having the procedure. This is essential information which will help us in the design and delivery of appropriate LTFU services for NSW.

This survey is due to be carried out in 2013.

Recommendation 2
Establishment of Nurse-led BMT LTFU Programs

BMT is performed with curative intent and is a high cost procedure for the health service (approximately $115,000 for an adult and double that for a child). But while we have succeeded in improving survival rates following BMT, what we have not succeeded in is providing adequate long term care. This is clearly suboptimal and is also inconsistent with the NSW Governments 10 year plan (NSW2021) which aims to 1) to keep people healthy and out of hospital and 2) To provide world class clinical services with timely access and effective infrastructure. Importantly, there is an emerging political and clinical consensus that this gap in service delivery needs to be addressed.

While the paediatric hospitals in NSW (Children’s Hospital Westmead and Sydney Children’s Hospital) operate world class BMT LTFU programs, the adult transplant centers currently do not have capacity to provide long-term care. As a consequence BMT Clinicians in the paediatric centers are unable to transition the care of their adult survivors of childhood BMT to adult institutions, as there are simply no appropriate services available.

The increasing demand of BMT has also meant that BMT services and BMT physicians are largely focused on acutely unwell BMT patients and are unable to adequately oversee the long term chronic care of BMT survivors. This is a particular problem for rural BMT survivors who return to their home town to the care of a local specialist or GP who is also busy with the needs of other patients and who has little experience in the area of BMT LTFU.

This fellowship has allowed me to see how international institutions deliver world class LTFU care. It is clear that a coordinated BMT LTFU service which delivers preventative health care, focuses on wellness and reducing the burden of chronic disease in BMT survivors, and is delivered by specialist nurses, is most consistent with the NSW 2021 goals and with the delivery of optimal post-transplant care.

Recommendation 3
Development of educational material for NSW

While optimal post-BMT care will require the establishment of comprehensive LTFU/Survivorship clinics, there is also an urgent need for NSW specific BMT educational resources.

The NSW BMT LTFU Project Working Group of the ACI recently developed state-wide consensus guidelines for post-BMT care (“BMT Chronic Care: A Summary of Minimum Standards for BMT Follow-Up in NSW” document) and developed resources (factsheets) to guide non-BMT services treating survivors of BMT. Information sheets have also been developed for adult patients to introduce them to LTFU and for BMT recipients who are to transition from paediatric to adult healthcare services.
However much remains to be done. In 2006 the Institute of Medicine (IOM) recommended that all cancer survivors be provided with a comprehensive care summary and follow-up plan. While providing patients and families with a ‘Treatment Summary’ is standard practice in the paediatric centres, the same has not been instituted in adult BMT services in NSW. There is a pressing need to develop a BMT treatment summary for NSW adult survivors (which may be paper-based or part of an electronic medical record) and develop processes for using these to improve communication to patients and to their GPs. This type of treatment summary may also usefully serve as a resource to all health care providers involved in the BMT survivors care.

Education materials should also be developed to address the various health risks following BMT and the best ways that BMT survivors can stay healthy. In this regard it is noteworthy that the BMT Networks booklet - “Allogeneic BMT: A Patient Guide” does not cover aspects of long-term care. The development of a BMT Network LTFU guide would therefore provide an invaluable asset for patients and carers as well as health care professionals in NSW and beyond.

**Recommendation 4**

**Stakeholder engagement**

Development and/or implementation of any of the above recommendations need to be done in consultation with all relevant stakeholders including patients and carers. Interviews and/or focus groups should be conducted with BMT survivors, carers and advocacy groups, such as the Leukaemia Foundation, to inform strategic decisions regarding long-term care and increase the likelihood that policies and processes adopted for supporting BMT survivors have widespread support.

### 6. Communicating Fellowship Findings

The findings of this fellowship along with the recommendations will be communicated formally and informally through presentations at scientific and professional meetings and in academic and lay publications.

The following presentations and education sessions have been scheduled:

- March 2013 – BMT Network BMT LTFU Working Group
- April 2013 – Agency for Clinical Innovation Staff Meeting
- May – Dec 2013 (Date TBA) – NSW Allogeneic BMT center in-house education sessions
- June 2013 – Haematology Society of Australia and New Zealand (HSANZ) Nurses Group
- July 2013 – BMT Network ‘Introduction to BMT Nursing’ Study Day
- Sept 2013 – BMT Network Annual Scientific Forum
- Dec 2013 - BMT Network Senior Nurses Forum

The following publication is in preparation:


An abstract on BMT LTFU Care will also be submitted for this year Haematology Society of Australia and New Zealand (HSANZ) Annual Scientific meeting in October.

I will also seek opportunities to collaborate with and present to the ACI Rural Network to ensure rural and regional patients and families and health care professionals working in those areas also benefit from the results of this fellowship.
7. References


