THE WINSTON CHURCHILL MEMORIAL TRUST
OF AUSTRALIA

FELLOWSHIP REPORT

Report by:

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2009 Jack Brockhoff Foundation Winston Churchill Memorial Trust Fellow

The Jack Brockhoff Foundation Churchill Fellowship was awarded to gather data related to established children's programs catering for members of households significantly affected by either chronic illness or trauma in a parent. The evaluation of existing global service, particularly based in the USA, will be undertaken with a view to improving local Victorian and National services to families significantly affected by the changes that chronic illness and trauma in a parent brings.

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Dr Cynthia A Holland
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STUDY INTRODUCTION

Talking with children about loss and major change is no easy matter. As parent and caring adults we all like to protect our children from sadness and trauma. Parents unashamedly confess that they too cannot face the trauma and separation that diagnosis of serious illness brings.

A cancer diagnosis is more than one person’s illness. The news affects entire families, turning lives and households upside down. Treatments, extended hospital stays and sometimes death places extraordinary stress on patients’ partners, parents and siblings... and especially their children.

The My Kite Will Fly program was introduced to educate children about a parent’s diagnosis and to enhance a child’s understanding about what cancer is and how it is treated. It is important too to prepare frightened parents in the support they can so aptly give their children along the course that cancer as a life threatening illness often takes.

The current Fellow is indebted to the Jack Brockhoff Foundation for the award of the 2009 Jack Brockhoff Churchill Fellowship. The Travel scholarship allowed her to overview global data from established international familial and children's programs in the USA, and to explore IT and other programs geared to aid children in their understanding of what happens when a loved one is ill without or without the added guided supervision of trained health professionals.

In Australia current figures for proportions of adults having children under 18 or numbers of children per adult are very limited. Based on proportions similar to those in the USA (i.e. 24% of adults over 20 with cancer diagnosis have children under 18 and these adults have an average of 1.9 children each), the following figures have been produced in Australia.¹

In 2006 (latest actual incidence figures) there were 103,640 cancers diagnosed in Australians aged over 20 years,² and based on US figures for numbers of children in the dependent years to 18 years living or in contact with parental invasive cancers, we can estimate that figures will reach more than 47,000 Australian children under 18 years.

Using the AIHW incidence projections,³ together with comparable estimates for 2010 of 116,000 new cancers diagnosed in Australian adults in 2010, there will be 52,000 children under 18 years living with or in contact with a parent who has been diagnosed with cancer. For this group of 52,000 children, such an event permanently changes family dynamics, evoking many fears, doubts and questions about their future and that of their parents.

¹ Email communication from Vicky Thursfield, Cancer Control Information Manager, Cancer Epidemiology Centre, Cancer Council of Victoria, Carlton VIC 3053 received by the Fellow on 11 May 2010.
³ See fn 3 (AIHW, Annual Report 2008-2009)
EXECUTIVE SUMMARY:

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The 2009 Jack Brockhoff Foundation Churchill Fellowship awarded to gather data for members of households significantly affected by either chronic illness or trauma in a parent, took the Fellow to the east coast of America (USA), Boston, New York City and Washington DC in search of newly tested and improved IT and hospital based services. The Travel program established the current My Kite Will Fly (MKWF) as having state of the art pioneering excellence in cancer care for patients and supportive carers. There are no programs which replace the currently developing MKWF or which outdate the unique attributes of our current IT program. The MKWF program achieved an excellent international response, and now back in Australia, with careful strategic planning, final stage clinical testing and multi-disciplinary collaboration, the opportunity to change the face of family communication during parental cancer treatments is real and possible.

The RWH Executive has been asked to show leadership in supporting this project for women living with cancer in compliance with the already established RWH Strategic Plan 2006-2010. We now have a fully reviewed MKWF Project Plan with Recommendations for implementation. An online and hard copy Manual and Guidelines for Practice will be introduced to best guide Oncology medical, social work and allied health practitioners working in and around the Parkville Cancer Precinct and across other metropolitan treatment venues. The program will be formalised via a Colloquia at the Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne in early 2011. Clinical research continues at Royal Women’s Hospital (RWH) and Peter MacCallum Cancer Centre (PMCC) focused on mothers living with breast, gynae and melanoma diagnoses. This will expand to incorporate fathers living with prostate, lung and brain malignancies.

The Fellow will commence the Victorian ExperienceBank Leadership Training program during 2010 with the aim of skill building the MKWF as a charitable recipient of philanthropic community support. The Fellow will coordinate public policy advocacy with consumers, practitioners and policy-makers across state, national and globally affiliated bodies including the Clinical Oncology Society of Australia (COSA), Oncology Social Work Australia (OSWA), American Oncology Social Work (AOSW), the Victorian and national Women's Barrister Associations (WBA). The current Fellow has been invited in 2010 as Guest Speaker at the Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting. As the largest gathering of cancer health professionals in the Southern Hemisphere, COSA 2010 will highlight the Fellow’s recent work involving cancer parents as patients and their children as supportive carers. The Fellow has also been welcomed as speaker at the forthcoming international 2010 Changing Health Conference, Dublin, Ireland for her work on the Churchill Fellowship.

The following were valued colleagues in their respective specialities of Oncology practice and research during the Fellow’s travels: Dr Carolyn Messner, Director of Education & Training at CancerCare New York, and James R Zabora Sc D, Dean, National Catholic School of Social Service, Washington DC offered much lived experience and Oncology wisdom. Paediatrics Professor Maria Trozzi at Boston University Medical Centre, Boston offered the way forward to collaborative international on-line work during 2010-2012. Jay Warren, Training Coordinator at Beth Israel Deaconess Medical Centre, Boston contributed very memorable knowledge and practice wisdom; and Hester Hill Schnipper LICSW Chief Clinical Social wonderful MKWF related advice and consultancy to project planning. Most importantly, the 2009 Jack Brockhoff Foundation offered the current Fellow pioneering opportunity to introduce formative multi-disciplinary Oncology training for students, practitioners and young families working in parental cancers, a program which, like the words of Churchill following the victory at El Alamein on 10 November 1942: "...is not at the end...But perhaps, ...at the end of the beginning."
STUDY BACKGROUND

EVIDENCE GATHERED FROM RESEARCH AND CLINICAL PRACTICE

Our society avoids too much discussion of unpleasant emotion 'when something terrible happens'⁴ and there is much work to be done. The implementation of effective professional practice guidelines and hands-on-resources for children and adults was early identified by the author as a complex task that must be specifically tailored to selected fields of trauma.

A review of available literature clearly identifies four areas of need for investigators in this field of enquiry. The *My Kite Won’t Fly* study⁵ identified that:

- There were few resources available for mothers and children to deal with issues related to cancer, particularly to do with parental communication with their children in the event of a terminal illness
- There have been few resources to effectively deal with children’s feelings of distress and sadness in response to broader areas of parental chronic illness with particular attention to the specific developmental and gender based needs of children (approximately 3-12 years)
- There is minimal assistance from health professionals in assisting parents in their discussions with children about diagnosis, treatments and afterwards into palliative care and/or survivorship.

PREVIOUS RESEARCH ACROSS THE GLOBE

Across the globe, research over the past 30 years clearly shows that effective management of childhood grief in children during the developmental years and during parental chronic illness in a parent is critical to parental coping and to children’s normal developmental advancement.⁶ During the course of cancer interventions—surgery, usually followed by chemotherapy and or other affiliated treatments including radiotherapy and/or hormonal interventions—all members of a family are significantly affected.⁷ In such families the usual pattern of research findings reveals that removal of a parent from their established and usual role heralds major family distress, particularly for young dependent children.⁸ Parental

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⁴ M Heegaard (1991) *When something terrible happens children can learn to cope with grief*, Woodlands Press, Minneapolis, Min, USA
⁵ My Kite Won’t Fly was a program developed by Principal Investigator Cynthia Holland as part of Ph D investigations (1991-2006). Key findings are presented in C Holland (2006) Gynaecological Malignancy Unpub dissertation; The University of Melbourne, Melbourne.
roles change significantly during treatments. For a mother-child relationship, disruption to usual roles can seriously sever trusted links and affect developmental milestones. When simple activities such as taking children to school, meals, cuddles, homework and reading together are affected, fears of remaining ‘well’ into the future come alive.9 As disease progresses, family adjustment issues can become major, such that anticipated loss of a parent is reinforced by longer hospital stays and distanced emotional non-communications.10

This largely under-researched area of households living with parental cancers needs attention. The current Fellow earlier undertook comprehensive research into the needs of mothers diagnosed with gynaecological malignancy. In her ongoing clinical and post-doctoral work with families since that time she now prioritizes the development of an appropriate resource template useful for quality care of families where a parent has been faced with diagnosis of chronic illness and/or cancer. This tool would be used in routine multi-disciplinary treatment of patients and their young dependent families so that experiential work with patient families can be achieved on a comprehensive scale and made available at a later time globally.11

FEW COMPREHENSIVE HANDS ON RESOURCES FOR FAMILIES AND CHILDREN

There has been minimal professional resource development to better assist parents living with a cancer diagnosis in their discussions with children about diagnosis, treatments and afterwards into palliative care and/or survivorship. Nor have there been tried and tested experiential resources to effectively deal with children's feelings of distress and sadness when living with parental chronic illness. While researchers indicate ongoing interest in work inclusive of art and play therapies with children facing emotional trauma ‘when something terrible happens’, there is certainly no resolved use of programs with children during active disease threat and or other life traumas similar in profound threat.12

Turner and others published a series of articles (2007-2009) which highlight the need for a brief resource tool for parents and children when a parent is faced with accelerated malignancy, a tool which extends well beyond mental health consultations reliant on somewhat traditional psychological clinical counseling and intervention strategies.13 Turner indicates that "Although some resources have been

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11 C Holland (2006) PhD thesis."Gynaecological Malignancy" Unpub dissertation, The University of Melbourne, Melbourne. Holland undertook work with children of mothers diagnosed with gynaecological malignancy aged between 3 and 13 years in study investigations undertaken following routine discharges from hospital during active treatments and later palliative care. She continues post-doctoral research at The Royal Women's Hospital Parkville and Peter MacCallum Cancer Centre East Melbourne with dependent families living with parental cancers treated at both centres and funded by the Victorian Cancer Agency (2009-2010).


developed to assist parents with advanced cancer, it appears that these are not widely disseminated. In a later 2008 paper offers valuable academic and clinical advice, particularly for Oncology health clinicians, still a hands-on resource kit was missing.. Turner et al state: Parents with advanced cancer commonly express anxiety about the impact of the disease on their children, yet health professionals often feel unable to respond constructively because of lack of training, or concern that discussion about such difficult issues will compound parental distress.

Turner et al most recently offered an English language based educational intervention comprising a self-directed learning manual, supported by a day-long communication skills training workshop.

THE ESTABLISHED ROLE OF ART THERAPY IN IT RESOURCE DEVELOPMENT

The art therapy method is well established as a simple non-threatening way for parents, children and therapists to interact on fears, concerns and issues arising during the course of parental treatments for cancer related illness. Art therapy has an established function as a reliable method of detecting states of emotion in children and of informally naming and collating emotional responses across a broad range of developmental ages. The process allows a child to symbolically express feelings of sadness, fear, anger and anxiety and generates a guided tour to better coping when cancer is diagnosed in parents with dependent children.

The current Fellow initially adapted evolving child art therapy programs from the early work of Heegaard (1991) and Trozzi (1991-8) where art in crisis programs were being trialled to deal with children's experiences of loss, and or family dysfunction caused by a parent's illness related absence from the daily household. These programs were designed to deal with the important time points registered by children as periods of acute isolation, crisis, trauma and family dysfunction when a parent remains in hospital for unexpected periods due to chemotherapy protocols and associated unwellness due to disease progression.

REFINING A DEFINITIVE TOOLBOX OF CHILD BASED RESOURCES

At this stage there remains no definitive toolbox of child- based resources which rely on the language of children accounting for developmental and gender variations through the dependent years, nothing in the expressive arts, and nothing particularly staggered through the course of cancer treatments and recovery, diagnosis through to palliative care. There is no current literature which documents detailed guidelines or lesson plans for life management across genders where a parent has cancer and their families, particularly young dependent children are left caring for them.

The need for effective professional practice guidelines and a manual of illness adapted interventions for children and parents living with cancer, from diagnosis

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14 See fn 13 (Turner et al 2007).
through to palliative care (or if they be fortunate, disease survival) is widely recognized as a current gap which needs immediate rectification. What is also needed still too is appropriate educational guidance for clinicians devised to assist oncology staff to better understand the emotional impact of parental advanced cancer, encompassing information about specific reactions of children, including strategies to help children and families cope [and providing] clinically relevant information and evidence-based recommendations to guide supportive care.

THE MY KITE WILL FLY PROGRAM

Inspired by long-term research into child and family trauma when a parent with children in the dependent years is diagnosed with life threatening illness, the writer explored the ongoing use of Art in crisis as a tool to prevent denial, alienation or repressed patterns that occur when children are overwhelmed by feelings they can neither understand nor express. The writer too explored the promotion of healthy coping skills in children 'when something terrible happens’ to disrupt usual family functioning based on the established view that patterns and reactions formed by children in the early years if allowed to continue unhampered, disrupt and surface during adulthood years to disrupt and destroy usual healthy adaptation and adjustment (Heegaard, 1991).

The program arose from concerns registered by parents who were newly diagnosed with cancer, not only for one’s own health, but also for their children. Parents often asked themselves and the writer, "How will I be able to care for my children while I am going through all this?” The author then established the My Kite Will Fly Program as a continuous project evolving as the needs of the population became more defined and imperative. In summary My Kite was and remains a working clinical response built upon and responsive to the needs of this patient population and their families.

The My Kite Will Fly program became a formal post-doctoral project in late 2006 aiming to continue educating children about a parent’s diagnosis and to enhance a child’s understanding about what cancer is and how it is treated. It was sensitively geared for children in their exploration and understanding of what happens when a loved one is diagnosed with cancer through the transformative tools of online art therapy and guided supervision by health professionals.

Through a tool box of art therapy aids designed for the My Kite Will Fly program, the significant change and losses that parental illness imposes can be replaced by coping strategies enhancing good health, personal confidence and strength as support systems grow. As it stood the program acknowledged the inadequacy of existing support groups and resource centers in their attempts to address the many persisting overwhelming emotions that persist for individual family members, the

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20 See fn 11 (Holland 2006). Holland conducted a My Kite Won't Fly Program between 1995 and 2006, up to the time the PH D was submitted. The program conducted art therapy and associated therapeutic work with children of mothers diagnosed with gynaecological malignancy aged between 3 and 13 years following routine discharges from hospital during active treatments and later palliative care. Holland is currently continuing post-doctoral research comprising multi-hospital investigations at The Royal Women’s Hospital Parkville and Peter MacCallum Cancer Centre East Melbourne with dependent families living with parental cancers treated at both centres and funded by the Victorian Cancer Agency (2009-2010). Programs since 2006 are conducted under the program head- My Kite Will Fly Program.
incompleteness of current treatment resources in their attention to the needs of children during parental illness and chronic episodes of life trauma.

THE CURRENT WEBSITE TOOLBOX

The current My Kite Will Fly website built from an initial Sitemap comprising seven areas that children registered as important for them during parental illness underpinned focus group discussions undertaken with US professionals. The 7 step Sitemap was made up of the following categories:

1. My feelings
2. Special people in my life
3. Special places
4. At diagnosis
5. During treatments
6. When mum is very ill
7. Special memories

FELLOWSHIP OBJECTIVES

The Jack Brockhoff Foundation Churchill Fellowship was awarded to gather data related to established children’s programs catering for members of households significantly affected by either chronic illness or trauma in a parent. The evaluation of US based achievements was then undertaken on the writer’s return to significantly improve local Victorian and National services to families affected oftentimes traumatically, by the changes that chronic illness in a parent brings.

PRACTICE BASED ASSUMPTIONS

The writer undertook this Fellowship in the basis of the following practice based assumptions:

1. That promotion of healthy coping skills in children is important because previously patterns formed during earlier life traumas often continue serially into adulthood without check (Heegaard, 1991);  

2. Through a tool box of art therapy aids designed for the My Kite Will Fly program, health professionals have been provided with a unique opportunity to see into the minds and psycho-social exchanges of families and children enduring the path of traumatic illness in a parent;

3. The My Kite Will Fly program as it currently stands, offers early but invaluable insight into the significant change and losses that parental illness imposes on a young dependent family;

4. Because we know that children understand illness and death differently and uniquely as they develop, with timely and skilled professional - child involvement a range of excellent treatment options including coping strategies for children, can be designed within the parameters of the My Kite Will Fly program aimed at enhancing good health, maximal personal confidence and strength in parents, families and children;

5. Generating an accompanying *Manual and Guidelines* for effective multi-disciplinary clinical practice for Oncology and other staffs involved in therapeutic and information resources from diagnosis through to terminal disease, then appropriate commemorative programming for managing children and bereavement is a critical next step.

**TRAVEL METHODOLOGY**

**THE CHURCHILL AGENDA: VISITS TO THE US EAST COAST**

The Fellow attended Centers of Excellence in the USA over a seven week period. Institutions were situated along the east coast of America, namely Boston, New York, Washington and Miami.

The key purpose for undertaking the Churchill Fellowship on the east coast of the USA was to re-visit firsthand the many and varied data sources identified over the years in hospitals and affiliated communities in similar fields of patient-family care. Visits to each of the chosen international Centers of Excellence offered much opportunity to consult with global leaders in the field as well as reflective time to consider the many challenges facing a practice researcher trying to implement research evidence in the Australian setting.

Most members of teams at all key institutions visited were interviewed and their programs surveyed and evaluated in the clinical setting. The current MKWF program was also tested and applied to patient-family scenarios in US clinical settings with US experts. This offered much exchange of key practice issues, evaluation of key strengths and weaknesses across service regimes and a very useful improvement based mentorship for all institutions involved.

I have divided visits undertaken on the Churchill Travelling Fellowship Program into sub-themes describing major lessons learnt by the Scholar on her travels. These conceptual categories form the foundation on which key themes have been structured and presented. The Fellow is more than happy to additionally review each centre individually visited at any time but as it stands has included highlighted features of each setting within the *Institutions Visited* section of this report.

The challenge is to take hold of the growing momentum established from interest shared with our international peers in the area and take the opportunity generated to market widespread changes in beliefs, thinking and clinical practice underpinning those caring for children in clinical facilities and households wherein a parent is ill.

The Churchill Fellowship offered the Fellow significant opportunity to evaluate and form a template for a best practice model of multi-disciplinary intervention applicable to Australian Oncology health care settings. It did this by giving her opportunity to begin by observing current models of multidisciplinary work globally and then to refine a new comprehensive care package for parents, children and multi-disciplinary teams following diagnosis of terminal parental illness.

This process has proved to be very worthwhile work. Once the initial web based task agenda was reviewed by key staff at all sites visited, the next step was to revue and collate all suggestions made into a new IT based product for further trial and distribution. One key evaluative focus was to review all areas where the Australian *My Kite Program* offers innovative thinking, and separately, across comparative work settings, lags behind our international peer group and needs to do better.
KEY QUESTIONS
At these international Centers of Excellence the writer sought to answer the following key questions:-

- What are the identified needs of children whose parents have cancer and or other life altering family trauma?
- What are the historical and previous intervention strategies implemented to address these needs?
- What is the work being embarked on under MKWF to help better address these needs, including web-based supports?
- What do international Centers of Excellence tell us about intervention strategies which best diagnose and treat?

GENERAL COMMENTS AND IMPORTANT FELLOWSHIP THEMES
The study tour undertaken provides a way forward to address the burden imposed on parents trying to live with the strains that managing cancer imposes on their daily living. Up to 100 organizations and individual advocates, networks, practicing health professionals making extraordinary commitments in the field were visited and interviewed in the context of their practice setting. Out of all of this a clear pathway for better understanding current gaps and services, available tools and resources has been achieved. Research shows increased mortality is often caused by a lack of resources and knowledge in cancer awareness, screening, prevention, treatment and care.

With much global acknowledgment for the significant impact being made on children’s lives once a parent has been diagnosed with cancer, the nature of the impact on children- and well into childhood if overlooked – is the critical focus of this Fellowship. Together we will continue to refine our international grassroots attention to this issue as we move from individual research isolation to collaborative experiential programs for children and their parents. The MKWF team will work forward to focus on developing international partnerships, cancer advocacy, research and programs and data collection.

MAJOR RECURRENT THEMES:
Major themes identified during the course of travelling as the 2009 Jack Brockhoff Foundation Winston Churchill Memorial Trust Fellow fell into three key areas:

1. Those related directly to the building of the My Kite Will Fly program-information content for children and families; IT project development

2. Those programs indirectly related to the building of the MKWF project, but related to the welfare of families struggling on a daily basis with traumas imposed by disruption of the family household when a parent has cancer. These include psycho-legal, economic and other services to families

3. Academic investigation of all areas pertaining to the conceptual development of the MKWF program. These areas include knowledge related to running and building probono charitable programs; leadership training; socio-legal policy development
A comprehensive detailed exploration of all sites visited is listed as Appendix B.

1. **MY KITE WILL FLY LINKED RESOURCES**

**THEME 1: THOSE RELATED DIRECTLY TO THE BUILDING OF THE MY KITE WILL FLY PROGRAM including information content for children and families; IT project development**

The toolbox of critical resources necessary for children and families struggling with life threatening disease in a parent, more broadly, when something terrible happens within their primary household, and more particularly, when mum is diagnosed with cancer remains currently limited.

Everything in many ways has been done before, but nothing conclusively as an accepted template for treatment of children in the dependent years (as a general guide, 3-12 years approximately, leaving aside infancy and toddlerhood at this moment).

Most US east coast hospital facilities link, as is the case in Australia to a range of hand-on resources including storybook, information and sometimes an on-line website made available to a sick parent guiding the welfare of young children living in the household.\(^{23}\) These resources include art therapy materials and sometimes expressive arts kits designed to aid children offer in-person counselling and expressive group workshops. Sometimes families were referred out to specialist psycho-therapeutic counsellors for short-term grief therapy. Attention to specialist intense grief therapy is not currently prioritized in Australia.\(^ {24}\)

Comprehensive methodology for children is however lacking. While we cannot prescribe too carefully exactly how and what to say to children when a parent is diagnosed, undergoing treatments or entering a palliative care phase, we can formulate basic areas of information which needs to be covered, a basic range of expressive emotions which need to be checked given that children are rendered vulnerable with heightened distress should these go unnoticed, and demographic supports which must be in place for children to survive safely through this period of their daily living.

**WEBSITE DEVELOPMENTS**

The website we have created is an on-line specialty service aimed at offering a clear path of support through the course of the illness, enhancing communication between all on-line participants, enabling unhealthy causal thinking to be identified and treated (i.e. ‘Mum’s cancer is my fault- I was fighting with my brother that day’).

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\(^{23}\) For example- Dana Farber Kidspacks include the children’s book- P Ganz & T Scofield. Life Isn’t Always A Day At The Beach: A Book for all children whose lives are affected by Cancer, Nebraska: High Five Pub, 1996. See also Fn 4 for another reputed and very useful book (Heegaard 1991). Both books act as a workbook for children aged from about 5 years. Both books highlight feelings that arise for children ‘when a parent has cancer’ – happy sad, angry feelings; listing of child wishes for change and hope for recovery; supports at home, school and into the future. With a stated grief focus, Heegaard further identifies good and terrible things that have happened, and commemorative memories. Many agencies visited publish consistent but brief materials geared to educating parents as to how best to guide their children through the ‘cancer in the family’ experience. Written guides such as Helping Children When a Family Member Has Cancer by RCanoza, CancerCare NY, 2010 are adult level information based, For children the on-line site at http://www.cancercare.org/get_help/special_progs/cc_for_kids.php offers in person and on-line social work counseling, practical help, and age appropriate cancer information.

\(^{24}\) Examples of excellent specialists with whom the Fellow consulted about children and grief included Stephanie Smith, MA, MSW Lecturer in Psychiatry, Harvard Medical School; Supervisor, Adult and Child Psychiatry at Cambridge Hospital, Cambridge, MA and Boston Psycho-analytic Society and Institute, 15 Commonwealth Ave, Boston, MA www.bostonpsychoanalytic.org ; see also Louis D Brown Peace Institute, 1452 Dorchester Avenue, Dorchester, MA.
Children will have a baseline program to complete, with illness extensions based on demographic data which varies specifically at diagnosis, during treatment path, and according to site and family specific palliative needs.

There were no interactive IT programs tracked by the Fellow on her global travels which offered new ways of approaching the area of practice that had not already been considered at home in Australia. Web and on-line checks undertaken at all sites visited however confirmed already developed and identified areas which must be retained and further developed in the My Kite Will Fly package. For example, children’s involvement in the learning package could benefit by the addition of a scripted story-line which they could write into by giving advice to the on-line characters as they go.

Programs of note are included in detail in Appendix B of this report. All tertiary cancer centers visited identified wonderful links to children’s programs, but nothing new or inspirational beyond the current awareness of the Fellow. The Good Grief program Boston led by accomplished Director A/Professor of Paediatrics Maria Trozzi was exceptional in its experience with familial grief and its application of the tried and tested four stage grief model initially developed by Sandra Sutherland–Fox.\textsuperscript{25} A/Professor Trozzi offered much consultancy and review of the potential My Kite program during the Fellow’s residency in Boston. Professor Trozzi has agreed to be part of the forward development of the program by initially contributing two scripted stories designed to engage children in an action plan for their own stories. One story will describe a young boy’s experience with his mum’s illness, with the outcome of her survival. In the other story, a young pre-adolescent girl builds a supportive parent-child relationship during parental palliative care. The Colorado based Children’s Treehouse program initially established a CLIMB group work training program for multi-disciplinary clinical practitioners across USA, and Life With Cancer in Fairfax, Virginia (both detailed Appendix B) built excellent individual and group programs for children and families living in households where a member has cancer. There is some attention to expressive therapies, and a keen focus on relationship building.

\textbf{WHY DEVELOP MKWF AS A SEPARATE AUSTRALIAN PROGRAM?}

My Kite Will Fly offers a unique on-line support for children. Because the My Kite Will Fly program heavily markets the use of the on-line medium as a primary benefit in learning to cope and confront cancer, it remains uniquely equipped as new style of support to children which mimics the ways children play and ultimately learn about the world around them.

There are several distinct advantages of delivering web based training with this population. While IT project development is a financial expenditure, computers are the way forward for our younger population and the primary means of preferred interpersonal communication for young community members. The MKWF concept remains innovative and new. Children can proceed through the training program at their own pace in their own time and place. Being designed to be interactive, with accompanying parental involvement and guided by professional clinicians, access is controllable, participation less intimidating and responses can be safely and carefully

\textsuperscript{25} Dr Sandra Sutherland Fox, creator of the Good Grief program initially developed a 4 step model for practice which Professor Maria Trozzi (2006; 2009) details in her current book, Talking with Children about Loss, Penguin: NY, 1st ed, 1999 and at http://www.bmc.org/pediatrics-goodgrief.htm
monitored.26 On-line there is great diversity in resources with hard copy access to geographical centers no longer a barrier.27

AGES OF DEVELOPMENTAL INVOLVEMENT ON-LINE
Most programs nationally and globally are geared primarily to children 5-6 years upwards. The current Fellow having dealt with very small children in families where a mum has been diagnosed with cancer over the years prefers not to exclude this group of very small children under 5 years from program developments.

There is nothing more frustrating for a small child to feel excluded from something they know is important.28 One child (7 years) stated: ‘They didn’t tell me until last because I was too small.’ For parents, clinical research results show that mum is most often worried about the unstated needs of her smaller children even though the young toddler group (12-24 months) tend to play alongside rather than with in a sharing collaborative way. Children of 3-5 years tend to learn to imitate familiar roles embellishing them in new ways, attaching new words to action and ideas, with imagination taking over play. It is critical at all times to include all children. Their perception of what they witness around them is important to assess. That they have options to be included is important.

2. MEDICAL-LEGAL PARTNERSHIPS FOR FAMILIES DURING PARENTAL ILLNESS

THEME 2 PROGRAMS INDIRECTLY RELATED TO THE BUILDING OF THE MKWF PROJECT, PSYCHO-LEGAL, ECONOMIC AND OTHER SERVICES TO FAMILIES
Theme 2 seeks to identify and review Programs indirectly related to the building of the MKWF project, but related to the welfare of families struggling on a daily basis with traumas imposed by disruption of the family household when a parent has cancer. These include psycho-legal, economic and other services to families

NYLAG was identified as a very impressive service centre providing free civil legal services to low income New Yorkers who would otherwise be unable to afford or receive legal assistance. NYLAG too serves the needs of approximately 3000 Oncology families annually when health related circumstances places families in desperate need of assistance. While there are many laws and government agencies designed to provide for an individual and a family’s basic needs, this does not always happen.

The National Center for Medico-Legal Partnerships situated at Boston Medical Center, in offering an inter-disciplinary approach to solving health issues seeks to recruit health issue trained lawyers to represent patients in relation to their housing, access to utilities, immigration, education, public benefits, education and family law. The service works to acknowledge the need for multi-disciplinary service aid to families and to safeguard children’s health and wellbeing by focusing on basic needs such as food, utilities and housing.

27 http://www.worldwidelearn.com/education-articles/benefits-of-online-learning.htm
Why clinical advocacy?
Each day doctors and health care staff bear witness to the inequities existing in our community in terms of youth and aged care, housing, education and overall social services undermining patient and family well being and quality of life. Although many clinicians lament the profound inequalities experienced by patients and families who are low income, only some recognise the need to advocate on their patients’ behalf for social change. Integrating advocacy into clinical practice enables clinicians to provide high-quality patient care while addressing social determinants of health.29

The current Fellow met with various members of the National Association of Social Workers in Washington DC, including Dr. Elizabeth Clark, Executive Director of the Association. In addition to promoting, developing, and protecting the practice of social work and social workers, NASW has a strong social justice and advocacy mission and has developed several impressive initiatives which both enhance the profession of social work and strengthen social work’s voice in public policy deliberations. Social workers in the US contribute directly on valuable Congressional debates and the work of Ms Asua Ofosu as Lobbyist and Senior Government Relations Associate for the National Association of Social Workers is more than noteworthy.

The professional relationship linking individual practice with policy implementation is a very strong one in the US. The integrating advocacy into clinical practice enables clinicians to provide high-quality patient care while addressing social determinants of health. There is a widely recognised capacity to recognise social need and to accordingly advocate on behalf of patients and their families for social change.

Capacity to advocate for social change through advocacy and the political arm of government was an inspiring feature of the Fellow’s trip to Washington DC. It is imperative that the MKWF program in Australia also maintains a strong commitment to improvements through policy change and national lobbying. To achieve comprehensive cancer care for all members of the household at all stages of diagnosis, treatment and through to end of life—over the entire continuum of cancer care, there is a need to work to remove any inhibiting obstacles in the way of constructive family communication during the path of parental cancers. Connecting research into how best to meet children’s needs during the experience of parental cancers to clinical practice must also link through to policy deliberations which inform policy makers and create a forum to examine current practice with young dependent children living in households where a parent has cancer.

3. CHARITABLE FUNDRAISING AND PRO BONO LEADERSHIP

Theme 3 seeks to review all programs pertaining to the conceptual development of the MKWF program. The Fellow had the privilege of attending various introductory sessions at the JFK School of Government, Harvard University, Cambridge, MA. This opened the way to

seeing need for the development of a strategic rigorous approach involving requisite charitable funds for IT and project development. There is a preliminary need also to gain experience in the development of leadership skills in project development. The Fellow will undertake the ExperienceBank program scheduled to run in metropolitan Melbourne through the later half of 2010.

CONCLUSIONS & RECOMMENDATIONS:
Conclusions and Recommendations for the following three key areas are detailed below:

1. Those related directly to the building of the My Kite Will Fly program-information content for children and families; IT project development

2. Those programs indirectly related to the building of the MKWF project, but related to the welfare of families struggling on a daily basis with traumas imposed by disruption of the family household when a parent has cancer. These include psycho-legal, economic and other services to families

3. Academic investigation of all areas pertaining to the conceptual development of the MKWF program. These areas include knowledge related to running and building pro bono charitable programs; leadership training; socio-legal policy development

1. MY KITE WILL FLY LINKED RESOURCES

THEME 1: THE BUILDING OF THE MY KITE WILL FLY PROGRAM
Theme 1: Those related directly to the building of the My Kite Will Fly program-information content for children and families; IT project development.

*My Kite Will Fly* IT program developments will specifically seek to address gaps identified in *My Kite Won’t Fly* clinical investigations, namely

- Parental communication- avoiding the concept of “silence as the family code” at diagnosis, during treatments and terminal illness;
- Resource gaps in available IT, including the building of appropriate commemorative programming for children, parents and families
- Specific developmental and gender based needs of children (approximately 3-12 years);
- Tabulation of a requisite skill set for staff working with patient parents and their young families.

The Fellow is fully committed to state of the art therapeutic program for oncology patients and their families. We now have a fully reviewed MKWF Project Plan. The recent global overview of the work of colleagues on the East coast of the USA, leads us to view our work thus far as very competent and competitive. Worldwide collegial benchmarking, portfolio building and therapeutic comparison with peers globally, lead us to believe that we now have a pro-active product which requires some refinement before final marketing. The thematic content is correct, the scripted storyline now underway and the technical building of this component shortly to commence.

As a word of caution amongst the optimism generated on the Fellow’s recent travels, there is no one way, no one person can enact a perfect system or template. Any new
diagnostic intervention tool needs to be specifically adapted to institutional and illness related treatment needs of a patient and his or her family. Careful strategic planning, appropriate resourcing, training and implementation by all staff in mind of requisite specialty skill development needs to co-exist within existing workplace culture and communication as a preliminary to successful implementation.

**A NEW MY KITE WILL FLY WEBSITE SITEMAP, CHILDREN’S GALLERY AND TALES FROM THE FIELD**

The website was built using an initial Sitemap to guide children, parents and families to key areas identified in past studies when something terrible happens. The website set out to encourage parent-child activities focused at each stage of illness-Diagnosis, Treatments and Post-treatment (largely parental palliative care) by means of programs designed to educate, advocate for and work directly with families to facilitate open communication with parents and children and to enable their meaningful and supportive inclusion when changes are occurring in the family.

Consequent to undertaking the travel component of The Jack Brockhoff Foundation Churchill Fellowship the Fellow will now lead a step by step expansion of the *My Kite Will Fly* program driven by competent implementation of multi-disciplinary patient and family centred care driven by appropriate staffing, space, equipment, and administrative support. Further protected research time, IT project development and ongoing data management together with call centre assistance is also essential.

Resource gaps identified during the Churchill trip will be addressed through a hard copy *Manual and Guidelines for Practice with families and children in Oncology* as a ‘best practice’ guide to health professionals attending training programs across affiliated educational sites.

There is an identified project priority on accessing support from the Fellow’s clinical and research base at The Royal Women’s Hospital. The Fellow seeks strategic prioritization of the project as an Executive priority of the hospital without or without seed funding for project development from the hospital. All reasonable endeavours will be made to approach philanthropic bodies so as to cover costs of building IT and associated business activities listed. Full development of IT is an expensive exercise but a critical next step.

**CLINICAL RESEARCH AND PROGRAM DEVELOPMENT**

Current gaps in clinical services for children and parents living in families where a mother has cancer are being attended to by post-doctoral research undertaken by the Fellow at The University of Melbourne Faculty of Medicine, Peter MacCallum Cancer Centre and The Royal Women’s Hospital. Parent patients and their young children are enrolled in the current post-doctoral study (clinical populations will be drawn from patients diagnosed with breast, ovarian and melanoma malignancies) with the Fellow as the Principal Investigator.

**2. MEDICAL-LEGAL PARTNERSHIPS FOR FAMILIES DURING PARENTAL ILLNESS**

30 The Principal Investigator undertook initial Ph D investigations (1991-2006) and post-doctoral studies in the field of children living with parental malignancy. Key findings are presented in C Holland (2006) Gynaecological Malignancy Unpub dissertation; The University of Melbourne, Melbourne.

31 See fn 4 (Heegaard 1991).
**Theme 2** Programs indirectly related to the building of the MKWF Project, including psycho-legal, economic and other services to families

Theme 2 identifies and reviews Programs indirectly related to the building of the MKWF project, but related to the welfare of families struggling on a daily basis with traumas imposed by disruption of the family household when a parent has cancer. These include psycho-legal, economic and other services to families.

It is imperative that the MKWF program maintain a strong commitment to comprehensive cancer care for all members of the household at all stages of diagnosis, treatment and through to end of life—over the entire continuum of cancer care. This work demands the removal of any inhibiting obstacles which add rather than remove family stress and prevent constructive communication during critical illness pathways.

It is imperative that correct referral of vulnerable families’ takes place so that sources of distress and vulnerability are carefully sourced. Clinicians must be given correct tools to integrate diagnostic advocacy into their practice by asking themselves what the real underlying discomfort/s experienced by each family might be. Clinicians need a practical method for eliciting a history of social circumstances that focuses on specific domains vital to family health and wellbeing and amenable to direct intervention.

MKWF sessions will need to correctly identify stressors which specifically inhibit familial coping and attack these as a preliminary to beginning any MKWF education. Clinicians will need to early identify:

- The range of named social determinants of health
- Correct screening of patient families for non-medical barriers to health/unmet needs including issues of income, housing/utilities, education, immigration legal status, personal and family stability, each of which have been shown to directly impact patient and family health
- Laws and systems governing these non-medical barriers
- Diagnose patients in consultation with a community legal referral service
- Correct treatment of patients with effective advocacy interventions

Providing children with a safe decent affordable home is like giving a vaccine. According to Dr Megan Sandel, ‘It keeps kids healthy’ (Megan Sandel 2008).  

It is imperative that the MKWF program in Australia maintains a strong commitment to remove any inhibiting obstacles in the way of constructive family communication during the path of parental cancers. Everything possible must be done to ensure that families can remain in their homes with adequate basic services and a place to live with security, dignity and effective protection against the elements. Everyone needs a place to call home and acting as an information broker, the Fellow will responsibly create processes to move research into practice, and correspondingly informing policy makers of the need for dialogues between researchers and key stakeholders.

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32 Dr. Megan Sandel contributed this statement in her role as the National Medical Director with the National Centre for Medical-Legal Partnership and assistant professor of Pediatrics at the Boston University School of Medicine, and a nationally recognized expert on housing and child health. As author of the text “There’s No Place Like Home”, a second report documenting how asthma, lead, injuries, homelessness, food insecurity, chronic disease and educational attainment were all affected by housing, Dr Sandel continues to advocate for social change so as to minimize medical crises in vulnerable families.

33 The Sixth Nelson Mandela Annual Lecture 2008 was delivered by Mrs Ellen Johnson Sirleaf, President of Liberia.
stakeholders involved in implementing service delivery to vulnerable families living with parental cancer. The Fellow will further develop papers and use print and electronic media and policy briefings to disseminate findings and recommendations catering for members of households significantly affected by cancer and its associated traumas in a parent.

Recommendations for implementation will be fully addressed under the following section where leadership by the Fellow is imperative to follow up in all related clinical and professional settings.

3. CHARITABLE FUNDRAISING AND PRO BONO LEADERSHIP

**Theme 3 Programs pertaining to MKWF conceptual development**

Theme 3 seeks to review all programs pertaining to the conceptual development of the MKWF program. These areas include knowledge related to running and building pro bono charitable programs; leadership training; socio-legal policy development

**At the Royal Women’s Hospital and Parkville Cancer Precinct**

There are clear plans for dissemination and implementation of Fellowship study findings at the Royal Women’s Hospital and Parkville Cancer Precinct. Various articles were published on intranet both within the hospital precinct and with the Department of Human Services during 2009. A celebratory Churchill @ The Women’s evening was held at RWH on 25 November 2009 when Mr Shane Ringin, President Churchill Fellows’ Association in Victoria, introduced the Winston Churchill Fellowship program to potential Victorian applicants. The RWH Staff Development Newsletter profiled the Fellowship during the week that Fellowship names were released during mid-2009 and the Public Affairs Department remains committed to gaining further media coverage on this important issue.

Regular updates on the information gained directly during the course of the Fellowship Travel Grant and with the further development of the program will be disseminated locally at the Royal Women’s Hospital, across and more broadly within the oncology social work and medical trainee programs conducted through The University of Melbourne post-graduate training programs; and other metropolitan Victorian universities. Various presentations to multi-disciplinary Oncology staffs including medical, nursing and social work have been fulfilled since the return of the Fellow from the USA both on the needs of families and children when a parent suffers chronic illness, global ‘best practice’ models for the delivery of services to this clinical population and the place that further development of the My Kite Will Fly program could have in delivering a global standard to patient-family care in Oncology.

The RWH Executive has been asked to show leadership in this area in terms of supporting this project as a priority area for the hospital as the program meets all key criteria under the RWH Strategic Plan 2006-2010. Project criteria specifically met include a contributory presence in optimising patient and family access to quality clinical services in Oncology; the opportunity to contribute to and overcome specific gaps in our clinical workforce expertise; the opportunity to encourage leadership in these particular areas of education and research so that services at state, national and global levels can be effectively enhanced. There is also the chance to realistically via evidence based practice, to enhance advocacy and policy roles drawing on consumer experience and our excellent research efforts.
An Advisory Group for management of the My Kite Will Fly Program was established once the Churchill Fellowship was received by the current Fellow last June 2009. Intra-hospital updates on progress with the Executive will continue to be communicated both inside RWH and through each of the hospitals participating in the development of the new Parkville Precinct as a centre of excellence for state of the art cancer treatments and innovative biomedical research. The RWH Director of Oncology Orla McNally and past Director of Oncology and Dysplasia Professor Michael Quinn have committed to supporting both clinical and research arms of the My Kite Will Fly Project; as well as to fundraising for IT Project Development.

Locally outside the Royal Women’s Hospital and Parkville Cancer Precinct

A request will be made to the Victorian Department of Human Services and various philanthropic charitable trusts for support seed funding for IT project development. There will also be assistance required to strategically plan the dissemination of resources related to and emerging from the project as it develops.

The current Fellow has been accepted to commence leadership training under the ExperienceBank Leadership program during June 2010. She will aim to:

- Strengthen clinical and research affiliations in the field of practice
- Strengthen leadership, management and relevant education skills
- Strengthen community development skills particularly the roles of legislative and community voice so as to better access and improving services for children
- Solidify initiatives in public policy so that health and support services for adults living with young dependent children can be enhanced. Objectives include developing a long range policy agenda so that community service professionals can better strategise and meet the needs of the young adult parent living with ongoing chronic illness and life threat.
- Increase resource and practice skill development, particularly on-line training
- Be mentored by senior persons with acknowledged leadership and fund management capacity

After completion of further leadership training, a Leadership Program facilitated by the Fellow will be introduced to train multi-disciplinary professionals working with young parent families as members of the Oncology health care team.

Multi-disciplinary training for Oncology related health clinicians will commence with a Colloquia format at the Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne in early 2011. A Strengths-Weaknesses-Opportunities-Threats (SWOT) model will be used to collate information with a view to developing a new service delivery model in Oncology. Final on-line and print versions of the procedural training manual titled Guidelines and Manual for Practice with families and children in Oncology will be made available at the beginning of 2011.

The manual will be later adapted for parents diagnosed with a broad range of cancers and serve professionals working across sites dealing with both fathers and mothers as patients. Expansion of the initial model and IT template so that...
appropriate programs may be extended beyond the initial design is the next project goal e.g. grandparents; the specialist needs of children of a mother or father diagnosed with brain malignancy and who early cease to recognise a child or family will be considered as a priority trauma.

The current Fellow will lay the groundwork to coordinate public policy advocacy in this field of health care practice by building comprehensive and targeted communication with consumers, practitioners and policy-makers. Part of the challenge of this response and commitment is being able to sustain these changes over time. Promotion of diverse fundraising strategies, a dedicated advocacy and policy development initiative, and creative solutions are demanding and difficult tasks. Established partnerships with various national bodies—Oncology Social Work Australia, American Oncology Social Work, Women’s Barrister Association at local, State, National and international centres are underway with the purpose of extending education and training clinical staff.

ACROSS THE STATE AND NATIONALLY ...
State and National conferences and workshops offer wonderful opportunity for dissemination of information, allowing effective communication of lessons learnt to others in the field. Professional communities to which the current Fellow belongs at State and National levels include the Clinical Oncology Society of Australia, Oncology Social Work Australia and the Victorian Oncology Social Workers Group; Members of the Victorian Women’s Barristers Association and Post-Graduate Training programs conducted from the Faculties of Medicine at both The University of Melbourne and Monash University Clayton, Victoria. Both universities have in recent weeks requested lectures to be held over the coming months on the current status of My Kite Will Fly Program and its affiliated research focus. Several University students have been enrolled to complete student placements involving MKWF program activities during the second half of 2010.

National and international conferences and workshops offer further opportunity for effective communication of MKWF program developments to clinicians across the globe. Over the next 12 months many and various opportunities have presented themselves for dissemination of information generated from the Fellow’s recent Churchill Fellowship Travels. The international multi-disciplinary health conference scheduled for July 2010 titled Changing Health in Dublin Ireland has accepted a paper generated by the Fellow for oral presentation and titled Development of manual & guidelines for working with parents as patients and their dependent children (3–12 years) as young carers.’ The 2010 Clinical Oncology Society of Australia and Oncology Social Work Australia National conferences to be held in Melbourne during November-December 2010 will also be the recipient of two similar papers.

At a later date for purposes of global communication and training, the Fellow plans to undertake further training in charitable pro bono fundraising at Harvard University in programs offered by the JFK School of Government.

APPENDIX A: TESTIMONIALS:
FAMILIES & THE MY KITE WILL FLY PROGRAM:

They didn’t tell me till last because I was too small. Cynthia worked with me and now I know.
Daniel, 7

Being a mum your attention goes towards the children and how they are going to cope [with my cancer diagnosis]. Cynthia and her work with My Kite Will Fly gets the children involved in what is going on. But not in an ‘in your face’ way...The program takes them away from the harshness...It takes their mind off it.
Barbara, mother of twins 5.

My Kite Will Fly provided resources for our family when we were too frightened to speak...with our children. Sometimes the children spend time alone with Cynthia; sometimes we are there. All round, the end product has been to feel close and share – I remember the proverb – a problem shared is a problem halved.

PROFESSIONAL COMMENTS:

Having a place to share experiences and questions with others, as well as learn how to cope, all from the comfort of home will greatly benefit cancer patients.


It was just wonderful to see and speak with you, Cynthia. Your work is remarkable ... I asked my class to look at the site and give feedback. They loved it!
Hester Lampert Hill, Senior Oncology Clinician, Beth Israel Deaconess Medical Centre and Harvard Medical School, Cambridge, MA.

As much as we’d like to, we can’t shield our children from loss. We can help our children bounce back – if only we know how. How children perceive and interpret illness-related events, what to do when children won’t talk about painful events and when to seek help...these are things that the My Kite Will Fly program can provide...into the future
Maria Trozzi Director, Good Grief Program, Boston Medical Center & Associate Professor Pediatrics, Boston University School of Medicine, Boston, MA.

Thank you again Cynthia. The feedback from staff is all positive and they embraced your use of art therapy via the web based tool. As a matter of fact, the nursing staff shared your website with a patient today. Thank you for the work you do.
Holly Dowling, RN, BSN, OCN, Clinical Nurse Educator, Ambulatory Hematology/ Oncology, BIDMC Harvard University Medical School, Boston, MA.

The MKWF project has the potential to not only significantly improve the outcomes for young children whose mothers have Gynaecological cancer but also should be able to be easily adapted to any acute or chronic disease situation.
Professor Michael Quinn MB ChB Glas. MGO Melb. MRCP (UK) MRCOG FRANZCOG FRCOG CGO

This project offers a space for children, even very young ones, to express and communicate their anxieties, which could, through the transformative power of expressive art, have a cascading therapeutic effect when families have to face serious illness or traumatic events.
A/Prof Frances Thomson Salo, LL.B. MCPP, Ph.D. Consultant Infant Mental Health University of Melbourne & RWH Centre for Women's Mental Health; Associate Researcher, Murdoch Children’s Research Institute; Teaching staff Medical Faculty; Senior Child Psychotherapist RCH.
APPENDIX B: INSTITUTIONS VISITED:

Visits have been listed sequentially according to the timeline during which the Churchill Fellowship was undertaken. A tabulated version of each site visit follows. It has been expanded to include new sites recommended once an appropriate next step visit was suggested by professional staff working on similar project sites in the US:

NEW YORK

CANCER CARE FOR FAMILIES AND INDIVIDUALS

CancerCare NY, Dr Carolyn Messner, Director of Education & Training 275 Seventh Avenue, NY 10001 Tel (212) 712-8400
Dr Carolyn Messner, Director of Education & Training 275 Seventh Avenue, NY 10001 Tel (212) 712-8400

Carolyn Messner, DSW, MSW, LCSW-R, BCD, has been an oncology social worker for 30 years. She is currently director of education and training for CancerCare, Professor at the Hunter College School of Social Work, and President of the Association of Oncology Social Work, a non-profit, international organization with more than a thousand members, practicing, providing clinical services to people with cancer and their families, since the 1970s. CancerCare works with healthcare professionals across the country as part of the interdisciplinary team with more than 60 years of experience in helping people with cancer and their families, commonly emotional and practical issues experienced by patients with cancer, cancer survivors, their families, and caregivers.

Relevance to the My Kite Will Fly project: Amongst other services to New Yorkers living with their young children during chronic and serious cancer diagnoses, Cancer care specializes in talking with children appropriately during the course of parental cancer treatments. Children and teens affected by cancer have special needs and concerns and CancerCare has a special program called CancerCare for Kids® where kids 'draw their feelings' and participate in therapeutic recreational events that teach children and parents how to talk to each other about cancer. The Fellow carefully explored the information base and resources offered by the service, noting that current services do not include any experiential IT program such as My Kite offers.

RESEARCH PSYCHO-ONCOLOGY AND MEDICINE

Robin Hood, 826 Broadway, 9th floor New York, NY 10003 Tel (212) 227-6601
Michael M. Weinstein, Chief Program Officer, 826 Broadway, 9th fl, New York, NY, 10003 Tel: 212-844-3593, 227-6601

Since 1988, the Robin Hood Foundation has targeted poverty in New York City initiating projects where unmet community needs are identified. Because poverty is tabbed by the organization as more than a single problem, rather than a series of overlapping issues, supported programs in early childhood, youth, education, jobs and economic security were investigated by the Churchill Fellow as relevant to psycho-emotional stresses arising for patients and their young families during the course of disease management.
People can and do work their way out of poverty. Robin Hood’s job programs have helped thousands of people get jobs. But creating economic security for New York’s poor isn’t always about getting someone a job. They also support organizations that provide loans and grants to entrepreneurs, small business owners, and credit-worthy individuals experiencing temporary financial setbacks, help support poor working families gain access to public benefits and tax credits, offer one-on-one confidential counseling about public benefits, financial decisions, legal problems, jobs and family services. The children of these families are at high risk of child abuse and neglect and the Robin Hood Foundation makes the case that early-childhood interventions have deep impact, where intense and sustained. The early-childhood programs are grouped into two categories: parenting education and child early intervention. Parenting-education programs help parents help their children to develop on schedule. Child early intervention serves needy children directly by preventing or overcoming developmental delays.

**Relevance to the current project:** Research developments available through the RHF for young children needing early intervention during times of parental crisis and familial trauma offered well formulated intervention and procedural guidelines to the evolution of *My Kite Will Fly* services in Australia.

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**THE NEW YORK ACADEMY OF MEDICINE, 1216 FIFTH AVENUE, NEW YORK, NY 10029**

Tel (212)822-7237

Janice J Kaplan MLn, Director, Research and Librarian Services, NYAM;

Pat Volland, Director, Social Work Leadership Institute, Senior Vice President for Strategy and Business Development, New York Academy of Medicine;

Jeannine Melly, Associate Director, Social Work Leadership Institute, NYAM.

The New York Academy of Medicine seeks to advance the health of people in cities. As an independent organization since 1847, NYAM seeks to address the health challenges facing the world’s urban populations through multi-disciplinary approaches to policy leadership, education, community engagement and research.

One of the current priorities of the New York Academy of Medicine are in general terms, to strengthen systems that prevent disease and promote the public’s health by helping individuals and communities tackle avoidable aspects of illness, managing treatments, psycho-social, physical and other symptoms of illness, disability and death; and giving vulnerable communities equal opportunities for health recovery and growth.

The NYAM Library is particularly focused on multi-disciplinary qualitative and quantitative medical research. It is one of the largest medical libraries in the United States, with exclusive holdings of primary source materials relating to clinical medicine, disease, and public health in the United States.

**Relevance to the current project:** A comprehensive investigative resource for all clinical researchers. The Library is a meeting place for several exemplary multi-disciplinary research programs observed by the Fellow involving social workers in leadership roles on multi-disciplinary projects based in social medicine. Important to observe well formulated intervention and procedural guidelines so as to effectively guide program teaching and development as the *My Kite Will Fly* program unfolds.
LEGAL HEALTH MEDICINE

NYLAG New York Legal Assistance Group, 450 West 33rd St, 11 floor New York, NY 10001 Tel (212) 613-5000
Randye Retkin Esq. NYLAG New York Legal Assistance Group, NY 10001 Tel (212) 613-5000

Randye Retkin Esq. Director Legal Health met with me on my visit to NYLAG. The New York Legal Assistance Group has been in existence since 1990 providing free, quality civil legal services throughout the New York City metropolitan area to those unable to afford legal services. NYLAG provides direct representation and case consultation in all general law areas, namely government entitlements, health and medical benefits, wills, consumer protection, employment and discrimination matters. It also provides Legal Health services to New Yorkers with chronic and serious illness including cancer, asthma, and lupus through partnerships with the hospitals and community organizations serving this vulnerable population. Cancer Care is one such agency in legal partnership with NYLAG serving oncology families with children.

Relevance to the My Kite Will Fly project: Legal Health services to New Yorkers living with their families, often young children during chronic and serious illness including cancer.

BOSTON

DIAGNOSTIC AND TREATMENT BASED HOSPITAL CARE OF ADULT PATIENTS AND FAMILIES

Beth Israel Deaconess Medical Centre, 330 Brookline Ave, Boston, Massachusetts 02215 Tel (617) 632-0030
Annie Banks LISCW Palliative Care social worker and Bereavement specialist
Betsy Barnet LICSW Senior Clinical Social Worker, Obstetrics and Gynaecology
Hester Hill Schnipper LICSW Chief Clinical Social Worker, Consultant Haematology Oncology, Harvard Medical School and Beth Israel Deaconess Medical Center.
Jay Warren, BIDMC Training Coordinator

Beth Israel is a teaching hospital of Harvard Medical School. The hospital boasts a 621-bed general medical and surgical facility that had 38,255 admissions in 2007, performing 11,169 inpatient and 13,606 outpatient surgeries. Its emergency room had 54,028 visits in 2007. The hospital treats all major illnesses, particularly cancer in multi-Modality & multi-Disciplinary clinics using a Coordinated Approach to Comprehensive Patient Care. Treatment may involve radiation oncology, medical oncology, surgery, imaging, pathology, and primary care. Patients can also access a wealth of support services such as pain management, counselling, and coordinated palliative care to help ease the physical and emotional complications of grave disease.

Women receive comprehensive care in an environment dedicated to helping them manage the physical and emotional challenges associated with gynaecologic and breast cancers. Patients receive personalized care from oncologists who work in partnership with a pathologist and a radiation oncologist who have special expertise in each particular oncology specialty. Patients also receive support from social
workers dedicated to oncology and BIDMC's extensive network of cancer support resources. Routinely care for patients' children are handled by distribution of a Children’s Guide to parents and or carers titled ‘Talking to Children about Hospitalization.’

http://www.bidmc.org/PatientAndVisitorInformation/PreparingforYourVisit/ChildrensGuide.asp

BIDMC publishes the following helpful guide:

**Discussing Your Condition**

- Give your children age appropriate information about your medical illness and reason for hospitalization.
- Explain the plan and how it will affect their lives – Who will take care of them while you are in the hospital? How long will you be separated?

**Preparing for a Visit**

- If a child expresses interest in visiting the hospital, first ask the nurse if there are any restrictions to visitation on the unit.
- Prepare the child for what they will see including the machines, monitors, IV poles, bandages, sounds, smells, and the number of patients in a room. Also describe how their loved one will look including pallor, hair, all aspects of appearance, confusion or fatigue, whether the parent can talk or ambulate, if the parent is in pain, and what is helping with the pain.
- It can be helpful to take a photograph of the patient and the room to show the child prior to visiting. The child will need preparation to see a parent whose appearance is dramatically altered.

**The Visit**

- Bring an additional supportive adult to the visit who can keep the child occupied elsewhere in the hospital if the child tires of the hospital room, or if the child has a difficult time.
- Keep the visit brief. Let the child know the visit was meaningful to the parent, even if there was not a lot of interaction.
- If the child does not want to visit, explore their reasons – Fear of how parent will look, fear of the hospital setting? Fear of what might happen? Do not force the child if they do not want to go.
- If a child does not want to visit or if there are restrictions to visiting, consider alternatives such as phone calls, video, email, photo communication. For younger children, making drawings or writing a note and receiving feedback about how much the parent liked it often can feel gratifying to them.
- Visits should be postponed or avoided if the parent is temporarily agitated or unable to recognize the child. If the parent is terminally ill, you should make it possible for the child to go for a last visit. Encourage them to talk to their parent and /or hold their hand even if the parent is unconscious.
- After each visit, talk to the child about how they felt at the hospital – What surprised them? What made them afraid, if anything? This helps to plan for a next visit or for the parent’s return home from the hospital.

**Relevance of MKWF presentations:** As Churchill Fellow I gave several lectures for nursing, social work and medical staff at BIDMC interested in skill development with parents and children living with familial cancer in a parent. Case based discussion also occurred with a number of very experienced oncology social workers who work with patients and their families in Hematology/Oncology, Radiation Oncology, and
the in-patient services. Helected hospital staff also reviewed the MKWF program as it currently stands and prior to post-travel changes. A range of Oncology clinical practitioners agreed to trial The My Kite Will Fly program website with their patient families:

Annie Banks LISCW Palliative Care social worker and Bereavement specialist

Betsy Barnet LICSW Senior Clinical Social Worker, Obstetrics and Gynaecology

Hester Hill Schnipper LICSW Chief Clinical Social Worker, Consultant Haematology Oncology, Harvard Medical School and Beth Israel Deaconess Medical Center.

Hester Hill Schnipper, an experienced oncology social worker, breast cancer survivor and author of two books, After Breast Cancer: A Common Sense Guide to Life After Treatment (Bantam Books, NY, 2006) and Woman to Woman: A Handbook for Women Newly Diagnosed with Breast Cancer surveyed the current Kite website and made the following comments:

_It was just wonderful to see and speak with you, Cynthia. Your work is remarkable ... I asked my class to look at the site and give feedback. They loved it! (March 2010)_

Jay Warren, BIDMC Training Coordinator

Holly Dowling, RN, BSN, OCN, Clinical Nurse Educator, Ambulatory Hematology/Oncology, BIDMC Harvard University Medical School Training Hospital

_Thank you again Cynthia. The feedback from staff is all positive and they embraced your use of art therapy via the web based tool. As a matter of fact, the nursing staff shared your website with a patient today. Thank you for the work you do._

LOUIS D BROWN PEACE INSTITUTE, 1452 DORCHESTER AVENUE, DORCHESTER, MA 02122-1386, (617) 825-1917 WWW.LOUISDBROWNPEACEINSTITUTE.ORG

Lisa Fliegel, Art therapist, Louis D Brown Peace Institute Dorchester, MA 02122-1386, (617) 306 8317

On the recommendation and referral of therapeutic staff at Beth Israel Deaconess Medical Centre, the Fellow visited the Louis D Brown Institute. The Louis D Brown Institute arose from one mother’s grief experience with child-familial tragedy. In 1993, as a high school sophomore, Louis was shot and killed in his Dorchester, Massachusetts neighborhood- crossfire in local gangland warfare. His mother, Tina Chery responded to this tragedy by co-founding the Louis D Brown Peace Institute, and empowering families impacted by violence by providing crisis management and support to survivors of homicide. The Institute continues to address issues pertaining to families surviving the murder of a loved one, specifically youth homicide family survivors, ages 13-17, connecting them to each other in a peer support network that helps them explore grief and anger. The program helps these students transform their anger into positive energy to prevent violence and promote peace as a collaborative effort with the Harvard School of Public Health Division of Public Health Practice.

“By keeping our doors open, our lines clear, and our support readily available, we are working to alleviate the survivors’ human instincts of retaliation and revenge.”
Co-founder Chery Brown developed the following Institute Goals and Objectives:

1. Schools: To develop programs and activities that teaches and instils the values of peace and enriches the lives of young people.

2. Families: To assist and empower survivors of homicide victims with tools that not only rebuild their lives but also their communities; through Education, Collaboration, and Policy Advocacy.

3. Community: To inform and educate the public about the causes and the consequences of violence on the individual, the family and the community, while transforming the community into an environment where young people are valued by adults and by their peers the for their peacemaking efforts.

**Differences and similarities- how a project of difference helps the MKWF project:** Community response to Grief and loss amongst its members can come as a very worthwhile learning exercise to outsiders. In hospital based care of mothers who fear leaving their children, there is time to plan 'to leave'- but with the painful realisation that much preliminary pain must be endured. Families of a lost adolescent attended the Louis D Brown Institute for communal involvement in shared art therapy and other therapeutic projects to commemorate their much loved young son or daughter (Sutherland-Fox 1982). The Fellow noted the great skills exercised by the co-founders in policy development, community leadership and advocacy used to initially build and later financially maintain this charitable organisation.

**GOOD GRIEF PROGRAM, BOSTON UNIVERSITY SCHOOL OF MEDICINE, BOSTON MEDICAL CENTRE, ONE BOSTON MEDICAL CENTER PLACE, BOSTON, MASSACHUSETTS 02118 TEL (617)414 4005**

Maria Trozzi, Associate Professor of Pediatrics, Boston University School of Medicine.

Tel (617) 921 4008; (617) 696 1875

For more than 20 years, the Good Grief Program has offered clinical, training and consultative services to families, educators and health providers and communities to help adults help children facing life’s speed bumps. Assoc Professor Trozzi has been at the forefront of this Program and before her, Dr Sandra Sutherland Fox, creator of the program. As Chief Social Worker at Judge Baker Children’s Centre Boston,Sandra developed a 4 step program which has been widely acclaimed since that time in services to children facing life trauma. Trozzi (2006; 2009) details the scope and purpose of the program in her current book, *Talking with Children about Loss*, Penguin: NY, 1st ed, 1999 and at [http://www.bmc.org/pediatrics-goodgrief.htm](http://www.bmc.org/pediatrics-goodgrief.htm): When children and families face any of life’s stressors, they can feel overwhelmed, whether it’s acute or on-going, due to illness, a disruption in the family, a death or a divorce, a difficult diagnosis or any of life’s speed bumps. Based on the premise that with crisis comes an opportunity to develop, strengthen and master coping skills, the mission of Good Grief is to train adult professionals, support families and scaffold children so that they gather resilience in the face of loss.

**Relevance of the Good Grief Program:** Our purpose of building a best practice state of the art program for Victoria and across Australia for families affected by the changes that parental chronic illness and trauma brings, is clearly linked to the work of US based Trozzi Good Grief program. A search through relevant and available

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existing research and practice based clinical services in the USA was undertaken with A/Professor Maria Trozzi who devoted much time and attention to the investigative process I had begun.

**BRAZELTON TOUCHPOINTS CENTRE** 1295 BOYLSTON STREET, BOSTON, MASSACHUSETTS 02215-3407 Tel (617) 355-4959
J Kevin Nugent, Director Brazelton Institute, The Children’s Hospital and Harvard University, Boston;

Ann C Stadtler MSN CPNP, Director, Site Development and Staff Support

Kim Alcyne, Project, Training and Conference Management team

T. Berry Brazelton, M.D. Professor of Pediatrics Emeritus at Harvard Medical School has been for many years a world-renowned authority on pediatrics, child development and parent-child relationships. He initially established the Brazelton Touchpoints Center at Harvard University, Cambridge, Boston, MA serving 80 communities across the country and the Brazelton Institute, umbrella for 14 international centers and trainers. As the author of over 40 books on pediatrics and child development, including the best-selling 2006 Infants and Mothers and Touchpoints: Your Child’s Emotional and Behavioral Development Perseus Books, Cambridge, MA. T Berry Brazelton MD has been a fundamental partner with the Good Grief Program since its inception with Dr Sandra Sutherland-Fox at Judge Baker’s Children’s Hospital, Boston and its more recent Directorship with AP Maria Trozzi. His LIFETIME television series ran for twelve years across America and correspondingly won two Emmy Awards. Dr Brazelton is now over 90 years old and still works part-time in pediatrics aided by Joshua Sparrow MD, current Director of Touchpoints.

**Relevance to the My Kite Will Fly project:** Touchpoints particularly specializes in comprehensive medical, emotional and behaviorally developmental services to parents and children aged between birth and 3 years. The program has particular relevance to families living with young children under 3 years and who are enduring chronic and serious illness including cancer.

**DANA FARBER CANCER INSTITUTE, 44 BINNEY ST, BOSTON, MASSACHUSETTS 02115-6084 Tel (617)632 5603**
Michael K Hubner LICSW, Director of Social Work & Program Manager, Oncology Care Coordination, Dana Farber & Brigham Women’s Cancer Center

Nancy Borstelmann, MPH LICSW, Director of Patient and Family Support Services, Department of Care Coordination, Dana Farber & Brigham Women’s Cancer Center

Nathaniel R Lamkin MS LICSW, Social Work Manager, Department of Care Coordination, Dana Farber & Brigham Women’s Cancer Center

Annette Quinn MSW LCSW, Clinical Social Worker, Department of Care Coordination, Dana Farber & Brigham Women’s Cancer Center

Tammy Weitzman LICSW, Clinical Social Worker, Bone Marrow Transplant Program, Department of Care Coordination, Dana Farber & Brigham Women’s Cancer Center

**DANA FARBER RUNS A SPECIFIC FAMILY CONNECTIONS PROGRAM, SITED AT [www.dfcio.org/family connections Program](http://www.dfcio.org/family connections Program) with Ms Jessiaha Adamopoulos as Program Coordinator, Tel**
The Program aims to cater for parents, grandparents, other family members and carers who are involved in caring for children affected by parental cancers.

The Program's mission is to identify and respond to the needs of parents and children through supporting, supplementing, and empowering parent and child coping as a family. Resources and relevant information are listed to help families manage the impact of cancer on their lives. Three key program components observed were:

1. **The Kidpack Program**

The backpacks are tailored to specific age groups: preschool, school age, and teens. Each pack contains age-appropriate materials—small comfort toy, pencils, educational stories, encourage expression, learning and creativity guided by a third party helper of the child or parent’s choosing.

**BackPacks**
- Special packs are created for preschool children under 4 years old.
- School-age packs for children ages 4-7, include (among other materials):
  - Workbook and storybook for children whose lives are affected by cancer
  - Small stuffed animal
- School-age packs for children ages 8-12 include (among other materials):
  - Small stuffed animal
  - Creative art materials
  - Recommended booklist

**Teen Packs**
- Teenage packs for those ages 13 and older, packs Include (among other materials):
  - Age-appropriate information on their own reactions, questions, and needs when a parent has cancer
  - A mood magnet set
  - A journal designed for both sketching and writing

**Parent Information Binders**
- Information specific to talking with children about cancer in the family, coping as a parent with cancer and adjusting as a family
- Suggestions for activities
- Cancer centre, community and other resources
- A booklist, with brief descriptions, that also includes videos and Web sites

**Bereavement Support**

A bereavement packet of supportive information and resources is available for surviving parents/partners/caregivers, with a focus on the special challenges of parenting and children. These packets are available through an oncology social worker from the Department of Care Coordination or by request in the Eleanor and Maxwell Blum Patient and Family Resource Center.

**Relevance to the My Kite Will Fly project**: The Family Connections program provides information and resources to adult patients and their children. The aim is to provide support and information during each phase of cancer care. The resources including Kid Packs, Parent Binders and Grief materials are provided free of charge to parents with cancer and their children and aiming to provide age appropriate
information and guidance to patients and families coping with cancer whilst attending the Dana Farber/Brigham and Women’s Cancer Centers. Because important legislative change has been tabled to improve the cancer experience under current health care legislative reforms, including a landmark federal Cancer bill to modernize research and improve access to quality comprehensive care for patients, families and carers, Dana Farber/Brigham and Women’s Cancer Center have mobilized a clear ongoing priority on addressing service gaps and better resourcing patient family need. All such developments are of particular relevance to the current Fellow and the compass of My Kite Will Fly project. There is currently no on-line program designed by those working with the changes imposed by parental illness and which offers tailored individual work with families. Online developments offered by the MKWF project have been offered for trial at DFCI Boston. All materials collected were engaging but not necessarily child centred.

An external agency relied on by Dana Farber Social Work staff is important to reference at this point. In information sessions provided to social work staff at the Institute, a critical question continued to be raised- How is the MKWF program different from the one we use- The Children’s Treehouse? The Fellow then set about investigating and understanding the following children’s program so as to provide an informed response to team members.

THE CHILDREN’S TREEHOUSE FOUNDATION 50 SOUTH STEELE STREET, SUITE #430, DENVER, COLORADO 80209 TEL: 303-322-1202
One of the notable programs highlighted by Dana Farber Cancer Institute was the Children’s Treehouse Foundation originally founded in Denver, Colorado and online at www.childrenstreehousefdn.org.

The Children’s Treehouse Foundation, was founded in January of 2001 in Denver, Colorado, by Peter van Dernoot whose wife had been diagnosed with terminal lung cancer when their children were 11 and 15, and died at the age of forty-five in 1980. The Foundation prides itself in providing hospital-based, cancer-focused, psychosocial intervention training and in-person programming to parents, children and professionals dedicated to improving the emotional health of children who have a parent with cancer. The Foundation seeks to provide special CLIMB workshops for professionals working with children of parents with cancer; and pays special attention to groupwork by providing direct practice family support, professional training and tailored counselling programs for children affected by parental cancers. The three program arms are: 1. Family support based group programs; 2. A children’s program called CLIMB® - Children’s Lives Include Moments of Bravery- geared to helping children identify and normalise their feelings, including anxiety and anger; and to communicate more effectively with parents; 3. A professional development program- geared to professional training for Social Workers, Nurses, Clergy, Psychologists, Child Life Specialists, and Oncology support personnel such as art and music therapists interested in launching a psychosocial intervention, group-support program for children of parents with cancer, at their own hospital or cancer center.

Features common to the CLIMB program and MKWF:
• Kids completing the program know other kids facing the same situation are working on these programs too. The children learn of others they can call upon for support – maybe by on-line chats or telephone connections.
• The working environment provides a safe environment in which kids can learn about cancer, ask questions of professionals, and gain reassurances. Online
programs are electronically and by phone check in connected to the clinical team, groups have walk in exchange and telephone connection.

- Commonly children undertaking either site or groups are encouraged to learn new coping skills to handle their fears, improve self-confidence and self-esteem.
- In both, children vent their feelings about their parent’s cancer and how it affects them, while enjoying playful, learning activities, offering new sources of fun, allowing them to still be a child.
- Conversation between the parent and the child is a priority facilitated through both mediums aiming for strengthened trust and reassurance to the child of the parent’s ongoing, unconditional love.

**Lessons learnt through the MKWF program Australia:** My Kite Will Fly offers a unique on-line support for children which is both unique and offers distinct advantages in this field of family geared communication and learning. There were no interactive IT programs tracked by the Fellow on her global travels which offered new ways of approaching the area of practice that had not already been considered at home in Australia. All programs of note are included in this Appendix.

While IT project development is a financial expenditure, computers are the way forward for our younger population and the primary means of preferred interpersonal communication for young community members. There is nothing more frustrating for a small child to feel excluded from something they know is important. Most programs nationally and globally are geared primarily to children 5-6 years upwards.

It is critical at all times to include all children. Their perception of what they witness around them is important to assess. That they have options to be included is important. The current Fellow having dealt with very small children in families where a mum has been diagnosed with cancer over the years prefers not to exclude this group of very small children under 5 years from program developments.

Children can proceed through the training program at their own pace in their own time and place, with accompanying parental involvement and guided by professional clinicians to monitor responses through safe and caring IT monitoring methods. On-line there is great diversity in accessible resources with hard copy access at institutions attended no longer being a necessary prerequisite.

**INDIVIDUAL PSYCHO-MEDICAL SERVICES TO ADULT PATIENTS AND FAMILIES WITH ONCOLOGY &/OR CHRONIC ILLNESS**

Strategic Outreach to Individuals and Families 1105 Massachusetts Ave, 3F Cambridge, MA 02138 Tel: (617) 492-0280

Kenneth Reich Ed D Clinical Psychologist and Psychoanalyst, Individual and Family Therapies

SOFARUSA STRATEGIC OUTREACH TO FAMILIES OF ALL RESERVISTS 1619 MASSACHUSETTS AVE, CAMBRIDGE, MA 02138 TEL: (617) 492-0280

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38 http://www.worldwidelearn.com/education-articles/benefits-of-online-learning.htm
Jaine Darwin Psych D & Kenneth Reich Ed D, Co-Directors SOFARUSA- Strategic Outreach to Families of all Reservists. The site publishes an excellent Web based Provider Guide for families and servicemen www.sofarusa.org. Jaine Darwin and Kenneth Reich, the Co-Founders of the Massachusetts based SOFAR: Strategic Outreach to Families of All Reservists (www.sofarusa.org), directed a program that provides pro bono mental health services to extended family members of National Guard and Other Military Reservists who are serving or have returned from service in the Wars in Afghanistan (Operating Enduring Freedom) and Iraq (Operation Iraqi Freedom).

Relevance to the My Kite Will Fly project: The project was undertaken and funded as an exercise in social entrepreneurship. It serves families (children, partners and carers) of return servicemen, oftentimes damaged by prolonged exposure to war and associated traumas. There are many parallels in the building of the current program and the need for appropriate leadership through critical developmental periods.

LEADERSHIP AND LEGAL SERVICES FOR ADULT PATIENTS AND FAMILIES FACING LIFE CHALLENGE

HARVARD UNIVERSITY, LAW SCHOOL, 1563 MASSACHUSETTS AVENUE, CAMBRIDGE, MA 02138-2996, TEL: (617) 495-1000

Professor Robert Mnookin, Samuel Williston Professor of Law Harvard Law School; Chair of Executive Committee, Program on Negotiation, Tel: (617) 495 9200

Harvard University is threaded with memorabilia about Churchill’s remarkable contribution to our world. According to Henry Kissinger, the 56th Secretary of State of the United States from 1973 to 1977, ‘Our age finds it difficult to come to grips with Churchill. The political leaders with whom we are familiar usually aspire to be superstars rather than heroes. The distinction is crucial. Superstars strive for approbation; heroes walk alone. Superstars crave consensus; heroes define themselves by the judgment of a future they see it as their task to bring about. Superstars seek success in a technique for eliciting support; heroes pursue success as the outgrowth of their inner values.’...Winston Churchill was a hero ...with something more, something titanic that moved him to attack obstacles with a focus borne of desperation and ambition ...but with his indomitable will, this force was summoned in the greatest of all his battles- for mastery over himself.

Churchill visited Harvard University on September 6 1943, over three years after John F. Kennedy had graduated cum laude with a degree in international affairs, and

39 For a complete chronological coverage of Churchill globally and in the US, see Chartwell Booksellers (55 East 52nd St in the arcade of the Park Avenue Building between Park and Madison Avenues New York City) Tel: (212) 308 0643
40 Comment taken from the accomplished works of Henry Kissinger was himself an accomplished Harvard graduate after having been raised in Germany as a German-Jew (1923- ). Harvard University over the centuries has played a formulative role in the evolution of US politics. Henry Kissinger received his A.M. and Ph.D. degrees at Harvard University in 1952 and 1954, respectively. After time in England and invaluable other political pursuits, as a Rhodes Scholar, he was eventually hired by Harvard President Abbott Lawrence Lowell, and he was to remain at Harvard for the next 41 years, during which time he served as National Security Advisor and later concurrently as Secretary of State in the administrations of Presidents Richard Nixon and Gerald Ford. Kissinger remained at Harvard as a member of the faculty in the Department of Government and at the Center for International Affairs, he was Director of the Harvard Defense Studies Program and International Seminar Program between 1951 and 1971 (Taken from S Brody. Jewish Heroes & Heroines of America : 150 True Stories of American Jewish Heroism, Hollywood, FL: Lifetime Books, 1996).
with his first book published: *Why England Slept*. 43 On receipt of an Honorary degree received from President of Harvard University, James B Conant, Churchill spoke of the necessity for global unity and the need for academic wisdom in order to preserve humanity- "The empires of the future are the empires of the mind." 44 In meetings held with Conant, a leading member of the Manhattan Nuclear Project during the same visit, Churchill and Conant contemplated the deployment of weapons of mass destruction in WW2, issues underpinning their use and control during the same period. These issues been a major focus of international relations policy ever since.

Professor Robert Mnookin, the Samuel Williston Professor of Law at Harvard, Chair of the Program on Negotiation at Harvard Law School, and Director of the Harvard Negotiation Research Project offered great expansive inspiration to the work the current Fellow has set out to do. Several works published by Professor Mnookin- most recently, *Bargaining with the Devil: When to Negotiate, When to Fight* 45 published during my Fellowship visit offered much inspirational mentorship to the work I am trying to formulate. Part 2, Chapter 5 of his book *Bargaining with the Devil* was titled *Winston Churchill: May 1940- Should Churchill Negotiate?* and offered a wonderful chapter summarizing Churchill’s critical intuitive decision making and inspired strength – "a white glow, overpowering, sublime which ran through our island end to end" 46 while sandwiched between the Good-Evil dichotomy that he detected Hitler (That Man 47) offered. Professor Mnookin’s earlier books were titled *Beyond Winning* (with S Pepper and A Tulumello)48 and *Dividing the Child* (with E Maccoby)49

As the Jack Brockhoff Foundation Churchill Fellowship had been awarded to the current Fellow to gather data related to established children’s programs catering for members of households significantly affected by either chronic illness or trauma in a parent, the evaluation of existing global services was undertaken with a view to improving services to families significantly affected by the changes that chronic illness and associated family trauma brings. Some of the principles pertaining to the process of divorce outlined in *Dividing the Child* paralleled the current MKWF areas of investigation- "there are four distinct areas of relationships ... that need to be transformed- the intimate social and psychological- between the parents- the previous single economic household- spouses redefinition of parental roles because of new arrangements are required for the children- and the documentation required to register changes in new relationship between the parents and children." 50

**Relevance to the MKWF project:** Professor Mnookin educated the current Churchill Fellow that ‘something terrible happens’ is a concept well studied before and that


44 Acceptance Speech in his review to cadets on the steps of Memorial Church, Harvard University, September 6 1943.


negotiating one’s way through changes imposed require calculated intuitive skill drawn from a capacity to show leadership drawn from life courage, intuitive experience, academic humility and genuine will to succeed in achieving a ‘best case outcome’ from the facts and circumstances presented for problem resolution.

FUNDRAISING FOR PRO BONO CHARITABLE PROGRAM DEVELOPMENT

Harvard University, John F Kennedy School of Government, 79 John F Kennedy St, Cambridge, Massachusetts 02138 Tel (617) 496 0484 (Public Leadership) or 496 5675 (Hauser Nonprofit Organizations)
Dean Williams Lecturer in Public Policy, Centre for Public Leadership, JFK School of Government Tel: (617) 496 8506

Aviva Luz Argote, Executive Director, The Hauser Center for Nonprofit Organizations (617) 495 1115

Over the last 70 years, the Kennedy School has become the global leader in educating and empowering legislators, nonprofit executives, social entrepreneurs, advocates from every corner of the globe to create positive social change through innovative research:

Nothing is more stirring than the recognition of great public purpose. Every age is marked by innovation and daring- by the ability to meet unprecedented problems with intelligent solutions. JFK March 2, 1962.

The Harvard Kennedy School offers unique opportunity to advance the public interest and ask what we can do to solve them using a multidisciplinary approach. United by a common desire to make the world a better place, it takes leadership from John F. Kennedy’s famous call to service: “Ask not what your country can do for you — ask what you can do for your country”

The JFK School of Government aims to negotiate and achieve the highest standards of analysis and integrity available for public leadership particularly selected for investigation by the student drawing from their own case settings.

School of Government and Leadership

Dean Williams Lecturer in Public Policy, Centre for Public Leadership, JFK School of Government

Dean Williams Faculty Chair of Leadership in Public Policy at Harvard Kennedy School directs the bi-annual program Leadership for the 21st Century: Chaos, Conflict and Courage. The program confronts issues such as creating and claiming value, understanding the relationship between leadership and authority, exercising influence, and managing the individual and institutional dynamics of change. This year it will be conducted during the week of October 17, 2010 - October 22, 2010 Application Deadline: September 3, 2010 Program Fee: $6,450 for the October 2010 session; Program Fee includes: tuition, housing, curricular materials, and most meals.

Hauser Center for Non-Profit Organisations

Aviva Luz Argote, Executive Director, The Hauser Center for Nonprofit Organizations

The Hauser Center for Non-Profit Organizations at Harvard University seeks to accelerate critical thinking about the role and leadership of non-profit and non-governmental organizations through research, education and practice. As a university wide center, the Hauser school follows a range of disciplines, intellectual approaches and interests. Conversant with domestic, foreign and transnational issues the Center actively explores questions of advocacy, leadership, service delivery, performance management and the distinctive contributions of nonprofit organizations to solving complex social problems. Of the five domains of practice undertaken at the Center- Humanitarian aid in developing countries; Nonprofit organizations in China; Arts and Culture in arts institutions; Justice and Human Rights particularly involving global criminal justice reform; and Philanthropy-maximizing social impact and the unique contributions possible through community foundations.

The Hauser Center is a resource for leaders of nonprofits who want to align their organization with the latest research findings and exemplary practices- from financial strategy to accountability and governance. The Center connects leaders of nonprofits to scholarly researchers offering inspirational solutions to their particular project scenario through workshops, conferences, interactive websites, publications and structured project planning exercises.

Relevance of schools of thought at Harvard University to the evolution of the My Kite Will Fly program

The MKWF project is now at the beginning of a new phase. It has great potential for expansion and development. The concept underpinning the program is an excellent one and there is no current experiential site where children and families can explore the traumas and hardships that parental illness brings to a previously functional independent household. The program now needs to be more fully funded. The expansion of IT is a costly exercise; the testing of phased clinical trials at each new step of IT development is an important and responsible next step to take. There is a need for effective leadership planning and resource management.

The Harvard School of Government and the Hauser Center offer excellent nonprofit guidance and leadership mentorship.

Raising The Bar For Health- National Centre for Medical and Legal Partnerships Boston Medical Center, 88 East Newton St, Vose 5, Boston, Massachusetts 02118 Tel: (617)414 3658
Ellen Lawton Esq. Executive Director
Katlyn Marple Esq. National Program Director
Johanna Flacks, Senior Staff Attorney

American Bar Association Center for Pro Bono Support- a Project jointly aided by the Standing Committee on Pro Bono and Public Service, ABA Health Law Section, ABA AIDS Coordinating Committee, and the ABA Center on Children and the Law. Tel: (312) 988 5805
It cannot be disputed that our health is greatly affected by our social circumstances. While there are many laws and government agencies designed to provide for an individual and a family’s basic needs, this does not always happen. Oftentimes inconsistent program implementation coupled with excessive bureaucratic administration often results in loss of services to patient families, and sometimes unlawful denial of benefits and services, adding to what could have been preventable health outcomes.

Increasingly doctors and lawyers are working together to address the multiple social and other issues that affect the health and well-being of vulnerable populations resident in our community. The National Center for Medico-Legal Partnerships is situated at Boston Medical Center, offering an inter-disciplinary approach to solving health issues anchored in psycho-social and economic circumstances. Today there are over 80 partnerships providing medico-legal assistance to patients in hospitals and health care clinics across the United States. Lawyers represent patients on a number of issues including housing, access to utilities, immigration, education, public benefits, education and family law. This innovative service works to safeguard children’s health and wellbeing through legal advocacy services which focus on basic needs such as food, utilities and housing.

**Why clinical advocacy?**
The horror of being told one has cancer carries much anxiety and existential concern. To be told “You have cancer” is listed as ‘the three most frightening words most people will ever hear...They set in motion a world of confusion, worry and doubt. Will I be able to handle the treatment? How will I balance my care with the needs of my family? How will this affect my job? Will I live?’ 52 are questions flashing through our minds at lightning speed, worrying all of us terribly.

Each day doctors and health care staff bear witness to the inequities existing in our community in terms of youth and aged care, housing, education and overall social services undermining patient and family well being and quality of life. Although many clinicians lament the profound inequalities experienced by patients and families who are low income, only some recognise the need to advocate on their patients’ behalf for social change. Integrating advocacy into clinical practice enables clinicians to provide high-quality patient care while addressing social determinants of health.53

**Usefulness to the MKWF program:** Over the years we have amassed a wealth of knowledge about the management of cancers in our community. The impact of cancer on people’s and family living cannot be underestimated. Recent ACCV statistics for Victoria indicate in 2006 that one in three men and one in four women will have a cancer diagnosis during the course of their lives so a significant majority of our population will be affected either directly or within the family structure.54

The MKWF program maintains a strong commitment to comprehensive cancer care at all stages of diagnosis, treatment and through to end of life. For families then, the entire continuum of cancer care must gain significant attention. Identification and removal of as many of the obstacles as inhibit progress in comprehensive care of

52 Change: Collaborating to Conquer Cancer- Introduction pamphlet, 1776 Eye St NM, 9th floor, Washington DC www.c-changetogether.org
54 Canstat No 46, March 2009.
patient families is essential. The range of stresses affecting families and other family variables which impact on capacity to opening participate freely in communication tasks available through MKWF must therefore also be attended to.

WASHINGTON
At the time of the current Fellows’ trip to the US, the One Hundred Eleventh United States Congress was sitting in its capacity as the legislative branch of the United States federal government, composed of two chambers- the Senate and the House of Representatives. It began during the last two weeks of the George W. Bush administration, with the remainder spanning the first two years of the Barack Obama administration. The Congress is scheduled to last from January 3, 2009, until January 3, 2011, and began its first session on January 6, 2009.

The current Fellow had the privilege of being able to follow the proceedings of Congress closely and to review the path of Congressional legislative procedures for the short time she was there. Most time was spent consulting with various members of Congress, ranging from Legislative Legal Counsel drafting new legislation (at that time immigration based), to Congressional Liaison with Australian Embassy staff, and thirdly, the Communications Director at Black Caucus, a role which monitors the path of Presidential direction taken by President Obama.

THE LEGISLATIVE MECHANISM @ CONGRESS OF AMERICA
HART OFFICE BUILDING, SUITE SH-317 WASHINGTON DC 20510 TEL (202)224 5941
Darrell Doss Esq. Legislative Counsel Office of Mark Udall US Senator, Colorado 877-7-MUDALL

CONGRESSIONAL LIAISON, EMBASSY OF AUSTRALIA 1601 MASSACHUSETTS AVE, NW WASHINGTON DC 20036 TEL (202)797-3253
Jonathan Kolieb, Congressional Liaison Officer

COMMUNICATIONS DIRECTOR, CONGRESSIONAL BLACK CAUCUS
J.Jioni Palmer is current Communications Director at Congressional Black Caucus. He has been National Press Secretary at Media Matters for America, Press Secretary at U.S. House of Representatives, Committee on Ways and Means and Congressional Correspondent at Newsday.

POLICY AND LEGISLATIVE CHANGE
C-CHANGE- COLLABORATING TO CONQUER CANCER, 1776 EYE ST, NW 9TH FLOOR WASHINGTON DC 20006 TEL (202)756 1431
Tasha B Tilghman-Bryant MPA, Project Associate

NASW NATIONAL ASSOCIATION OF SOCIAL WORKERS, 750 FIRST ST NE, SUITE 700 WASHINGTON DC 20002-4241 TEL (202)408 8600
Karyn Walsh ACSW LCSW, Senior Policy Associate for End of Life and Bereavement Care

Stacy Collins MSW, Senior Practice Associate
Becky S Corbett ACSW, Chief Operating Officer
Asua Ofosu JD, Lobbyist/Senior Government Relations Associate

The current Fellow met with Dr. Elizabeth Clark, Executive Director of the National Association of Social Workers. Located in Washington, DC, the NASW is the largest membership organization of professional social workers in the world with nearly 150,000 members. In addition to promoting, developing, and protecting the practice of social work and social workers, NASW has a strong social justice and advocacy mission.

NASW has developed several initiatives to enhance the profession of social work, including the Social Work Policy Institute (SWPI) established as a think tank within the National Association of Social Workers Foundation (NASWF) in order to strengthen social work’s voice in public policy deliberations, inform policymakers through the collection and dissemination of information on social work effectiveness. It acts as a forum to examine current and future issues in health care and social service delivery. Social Work maintains high level social policy involvement, one that sparks dynamic and valuable debates on public policy and the role of social work in affecting social changes.

Ms. Asua Ofosu has been employed as Lobbyist and Senior Government Relations Associate for the National Association of Social Workers in Washington DC (NASW). As the NASW health lobbyist, Ms. Ofosu handles a variety of health issues ranging from health disparities, genetics, HIV/AIDS, aging, and women’s health and serves as the GR representative to the Social Work Reinvestment Initiative. While at ATS, Ms. Ofosu handled research and advocacy issues dealing with lung disease. Before ATS, Ms. Ofosu was the Legislative Manager in the Health Care Practice Group of Smith, Bucklin & Associates, Inc. Government Relations Department. In that capacity, she represented a variety of health care clients including the American Society of Nephrology, American Psychiatric Nurses Association and the Society for Maternal-Fetal Medicine.

**PSYCHO-SOCIAL RESEARCH ONCOLOGY & CHRONIC ILLNESS**

**The Catholic University of America, National School of Social Service, Washington DC 20064  Tel (202)319 5454**

James R Zabora Sc D, Dean, National Catholic School of Social Service

Karlynn BrintzenhofeSzoc, Ph D OSW-C, Post-doctoral Research Assistant, National Catholic School of Social Service

Professor James R. Zabora, Dean of the National Catholic School of Social Service and Professor of Social Work for the Catholic University of America, is an inspirational global researcher at the forefront of psycho-social Oncology research and clinical practice. His current role transcends a 20-year career at the Johns Hopkins University School of Medicine where he served as an Assistant Professor of Oncology in the School of Medicine with two secondary appointments as an Assistant Professor in the School of Public Health in Environmental Health Sciences & Health Policy and Management.

As a Johns Hopkins administrator, he served as one of the five Associate Directors in the Comprehensive Cancer Center with a special focus on community programs and research. In addition, he was the administrator of the Breast and Cervical Cancer Screening Program for low-income women living in Baltimore City. Currently, Dr.
Zabora maintains a Visiting Professorship at Johns Hopkins, and his research continues to focus on psychosocial screening, problem-solving education, and quality of life among cancer patients and their families.

Dr. Zabora is the Editor of the Journal of Psychosocial Oncology and the author of more than 60 papers and book chapters on cancer prevention, psychosocial screening, and community program development, quality of life, and problem-solving education. In March 2007 at the Annual Meeting of the American Psychosocial Oncology Society, Dr. Zabora received the Holland Distinguished Leadership Award based on his "outstanding contributions (in clinical practice, education, research and leadership) in the field of psychosocial oncology." It was a privilege to have Professor Zabora spend time with me reviewing the role of the My Kite Will Fly program in improving children’s services where a parent has cancer.

It was a privilege also to meet and clinical review the My Kite Will Fly program with Karlynn BrintzenhofeSzoc, Ph.D., OSW-C, LCSW-C Associate Professor, Director, Data Management and Outcomes Assessment and an accomplished multi-skilled clinician and researcher in the field of Psycho-Oncology and currently situated at The Catholic University of America. Her research interests have been in psychosocial impact of cancer on those diagnosed with the disease, chronic illness, instruments development, and program evaluation. Dr. BrintzenhofeSzoc teaches research courses in the MSW foundation year, practice evaluation in the MSW advanced year, and research methodology in the Doctoral program. Dr. BrintzenhofeSzoc is a member of the Board of Director of the South Atlantic Division of the American Cancer Society, is on the Board of the DC Pain Initiative and the Washington Partnership, Acting Chair of the American Cancer Society’s DC Government Relations Policy Committee, and is Past President of the Association of Oncology Social Work.

Results of clinical evaluation of the My Kite Will Fly program with staff of the Catholic University of America: As Associate Professor, and Director of Data Management and Outcomes Assessment particularly experienced in distress and vulnerability of patients living with cancer and their families, Karlynn BrintzenhofeSzoc, was a wonderful person to meet with and talk through clinical testing and trial development aspects pertaining to the My Kite Will Fly on-line program. Professor James R. Zabora, Dean and Professor of Social Work similarly offered an invaluable incentive to continuing work of parent and child distress during the course of cancer management. Associate Professor BrintzenhofeSzoc suggested further testing of our MKWF program using Social Service post-graduate students attending CUA once IT developments have furthered the project and implementation is imminent at the conclusion of 2010.

COMMUNITY CANCER RESEARCH & CARE AGENCIES

LIFE WITH CANCER INOVA CANCER SERVICES [COMMUNITY SUPPORTED INFORMATION, EDUCATION AND SUPPORT]
8411 PENNELL ST FAIRFAX VA 22031 TEL (703)776 8958
Gordon Hay, Director, Inova Cancer Services, Fairfax

Sabine Gnesdiloff MSW LCSW OSW-C Program Manager
Jean McCaw MA ATR-BC Art therapist
Jenny Eckert, LCSW, Children’s and Teens Program Manager
The mission of Life with Cancer is to enhance the quality of life of those affected by cancer by providing education, information and support free of charge, no matter where the patient family lives or receive treatment. The aim is to connect with a community of people who face many of the same challenges and while cancer affects everyone including family members and friends, it is often the case that children may be taking it the hardest feeling that “Nothing is the same anymore” or “It’s all my fault” or “He/she is so grumpy; I must have done something wrong.”

At Life with Cancer, children learn about cancer, meet others who have a loved one with cancer, and talk about the wide range of feelings and changes that cancer brings to their lives. Services are provided by highly experienced and caring professionals including social workers, nurses, an art therapist and volunteers who provide the help and support children and parents need. The Center provides various programs for children with cancer and their families, from diagnosis through the end of treatment and beyond, including dealing with late effects. These programs include:

- **Curious About Cancer**: Children ages 5-12 are invited to learn about cancer through discussion and activities to find way to manage the emotions and changes that come when someone in the family has cancer.
- **Teens Meet and Eat**: Teens ages 13-18 who have a family member with cancer meet monthly to eat, hang out and have a little fun with others who understand the concerns, changes and feelings teens may be experiencing.
- **Good Grief for Children**: Children ages 5-12 who have lost a loved one through cancer are invited to share their thoughts and feelings, and work through the grief process through discussion and art therapy.
- **Good Grief Dinner for Teens**: Teens ages 13-18 meet monthly for dinner to meet with other teens who have lost a love one to cancer, to learn about the grief process and share thoughts and feelings.

**Value to the MKWF program development**: The facility offers a rigorous and comprehensive set of services to patients and families of all ages. The maturity and skill base of all treating staff observed demonstrated the combined commitment and capacity for staff to offer genuine care and comfort to all attendees. Art therapy with children plays a big role in the language of coping at LWC, a model which the current Fellow gained much exchange and experiential support from.
REFERENCES AND OTHER READING:

Aoun Dr S. The Hardest Thing We Have Ever Done. Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People. Canberra: Palliative Care Australia; 2004.


Sutherland Fox Dr S. *Good Grief: Helping Groups of Children When a Friends Dies*. Boston: Judge Baker Children’s Centre; 1983.


Alice in Wonderland set out to cross the huge expanse offered by her very own life journey. She asked of the trusty Cheshire cat- ‘Would you tell me please which way I ought to go from here?’ ‘That depends a good deal on where you want to get to!’ said the cat. ‘I don’t much care where’ said Alice. ‘Then it doesn’t matter which way you go’ said the cat. ‘So long as I get somewhere’ Alice added as an explanation. ‘Oh you’re sure to do that’ said the cat, ‘if you only walk long enough.’

No one knows what they’ll do until they’re faced with it. Sometimes the unexpected happens.

There are those who battle long and hard, with a sense of life challenge in conquering what even becomes ‘the unconquerable.’ There are many noteworthy souls too, who with touch and care for others, help their children and families face towards the future, understanding what was real back there- will be again...