

THE ← NEXT STEP

Crossing the
Bridge to
Survivorship

Noah, age 9,
4-year Osteosarcoma survivor



THE NEXT STEP

Crossing the Bridge to Survivorship

An Educational Guide for Childhood Cancer Survivors and their Families

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Medical Disclaimer

No Medical Advice Given

The purpose of this survivorship guide is to provide comprehensive information on life after cancer to childhood cancer survivors and their families. It includes information assimilated from various secondary sources, including the Children's Oncology Group Survivorship Guidelines, standard medical and professional texts, and other pertinent publications and online resources. It covers information on different childhood cancers, standard treatment with chemotherapeutic agents, surgery and radiation, and late effects of treatment, as well as survivor advocacy and healthy living.

None of the information contained in this guide is or is intended to be medical treatment or advice. These guidelines should not be used as a substitute for professional medical attention and are strictly intended for personal use. For information about your personal medical care needs, you are encouraged to consult with your primary care physician or healthcare provider. Though every effort was made to ensure that the information included is correct, complete, and up to date, it is subject to change without notice in the event that corrections are necessary.

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Dedication

This guide is dedicated to childhood cancer survivors and their families across the globe who have faced some of life's biggest challenges and hurdles, but have crossed the bridge towards a brighter tomorrow. It is from these survivors that the world truly learns the meaning of the words courage, determination, and hope.

Kory, age 11 (right),
7-year Leukemia (ALL/BMT)
survivor, with his brother, Keri





www.tracyskids.org



IN THE EARLY 1990S, THROUGH THE COMBINED FORESIGHT of the Lombardi Comprehensive Cancer Center at Georgetown University and the Prevent Cancer Foundation, the Art Therapy Program and **Tracy's Kids** were born, ensuring that the psychological and emotional needs of children with cancer became a priority in their total care.

Tracy's Kids is dedicated to ensuring that each child and their family members are emotionally equipped to face long-term illness. Though never straying from its roots at Lombardi, in recent years **Tracy's Kids** has grown and become established in other hospital and clinic settings. By the end of 2008, it will be in four centers in the Washington Metropolitan area.

We extend our deepest gratitude to **Tracy's Kids** and the Prevent Cancer Foundation for their dedication to children with cancer. Once again, they have demonstrated their foresight as a funding partner in the publication of this manual, a personalized approach to cancer survivorship for Lombardi's patients and their families for the time in their lives when they are cancer free.

Aziza Shad, MD

Director, Cancer Survivorship Program
Lombardi Comprehensive Cancer Center

FORWARD

THANKS TO DECADES OF RESEARCH AND MEDICAL advances about which doctors and parents only dared to dream, over seventy percent of the children diagnosed with cancer will not only beat the disease, but also live the overwhelming majority of their lives cancer free.

Dr. Aziza Shad is a compassionate physician who has dedicated her life to ensuring that children who have completed their cancer treatments live active, fulfilling lives. The information contained in this book is a bridge to their future. It is so simply written and easy to understand that it makes the steps to staying healthy sound like common sense.

By following the advice set out in this book, young adults will be better able to ensure that having been sick does not define who they are or limit the opportunities that life has to offer them.

Matt Gerson

Executive Vice President
Public Policy and Government Relations
Universal Music Group

Matt Gerson wrote this forward on his fiftieth birthday—forty years after being diagnosed with rhabdomyosarcoma. Mr. Gerson is Vice Chairman of the Prevent Cancer Foundation and a founder of Tracy's Kids, a program for pediatric cancer patients that addresses the emotional stress and trauma caused by cancer and its treatment [www.tracyskids.org].

PREFACE

“CURE IS NOT ENOUGH!” THESE WERE THE WORDS Dr Giulio D'Angio used in May 1974 to describe the importance of prevention and long term follow-up for childhood cancer survivors at the American Cancer Society's Conference on Childhood Cancer in Dallas, Texas. This statement has been my motivation in establishing the Childhood Cancer Survivorship Program at Lombardi and now the publication of this personal guide for childhood cancer survivors.

Almost 80% of all children and adolescents diagnosed with cancer are long term survivors, and the majority are considered cured. This success has largely been due to the use of more intensive therapy using a combination of different chemotherapeutic agents, surgery, and radiation. However, no treatment is without cost! As childhood cancer survivors become adolescents and young adults, some of them are at risk of developing complications related to the very treatment that saved their lives. No longer can pediatric oncologists walk away from the responsibility of monitoring these survivors for late effects of treatment, most of which appear years after completion of treatment, and range from physical to educational to psychological issues.

The Late Effects Clinic was established five years ago as part of the general pediatric oncology program at Lombardi, and was initially staffed by just one pediatric oncologist. In addition to addressing specific issues related to late effects, we started putting together comprehensive 'Off-Therapy' summaries for all patients who finished treatment in our program, as it was evident that this was the most important piece of information we needed to provide patients and their primary care providers. As the clinic became established, our

patients' families came forward and started helping with funding of staff and research projects. To this end, I would like to say a heart-felt thank you to all our families that made it possible for us to succeed, especially the Lubins, Groves, and Ameys, all of whom continue to support the activities of this program.

In 2005, we were fortunate to receive a grant from the Hyundai Motor Corporation and Children's Cancer Foundation, which allowed us to bring in our nurse practitioner, Karen Hennessy, and to expand the clinic into a Cancer Survivorship Program. This funding has continued over the last three years and allowed us to grow as a program to provide better care for childhood cancer survivors, not just patients from Georgetown, but from the Greater Washington area and beyond. Today, in addition to an oncologist and a nurse practitioner, we have a social worker, an art therapist, and two psychologists, all of whom team together to address the physical, educational, emotional, and psychological issues that affect this population. Very soon, this team will expand to include an adult endocrinologist who will help us provide better care to young adults and enhance the on-going research in our program.

Over the years, our program has focused on health education and preventative care, provided guidance and support to survivors and their families, and promoted self advocacy. We have published research on behavioral risk factors in adolescent survivors of childhood cancer through the SHARE Program; produced a CD-ROM on solid tumors with a section on late effects in collaboration with the Degge Group, Inc.; and co-hosted the first 'Rise to Action' conference in 2006 for young adult survivors of childhood cancer with Children's Cause for Cancer Advocacy and Special Love Inc.

Thus, it was only natural that the next initiative of our program would be to produce a personalized guide for our patients as they embark on their survivorship journey. One could question the need for this guide in the face of several outstanding books and publications on survivorship currently available, especially the Children's Oncology Group Survivorship Guidelines. However, after hearing repeatedly from our patients and families regarding the need for a simple manual that could personalize their information; we decided to take on this project. 'The Next Step....Crossing the Bridge to Survivorship' is the culmination of these efforts by our team. It would not have been possible to accomplish this without a generous grant from 'Tracy's Kids' and the 'Prevent Cancer Foundation' who are well known for their dedication to children with cancer. They are our funding partners in the publication of this manual, and we thank them whole-heartedly for their foresight and support.

'The Next Step....Crossing the Bridge to Survivorship' will be personalized for all Lombardi patients and will include their 'Off-Therapy' summary, medical wallet cards, and a detailed letter to their primary care provider. In addition, the guide will include information on their cancer, its treatment, anticipated late effects, and plan for follow up. We have included information that emphasizes the importance of a healthy life style and prevention, and provided a list of resources available for cancer survivors today. We have made a concerted effort to present all this information in a simple, concise manner, still keeping it personal, through actual quotes and photographs of our survivors.

It is our hope that this personalized guide will be used by our patients as a resource for information on their treatment, follow up, and health care needs as they continue their journey through life after cancer. ■

Acknowledgements

I owe the growth and success of The Cancer Survivorship Program to so many people and organizations who have continued to support us through the years. I would like to take this opportunity to thank them on the following pages.



Ryan, age 13,
11-year Leukemia
(ALL/BMT) survivor



- Once again, I would like to thank **'Tracy's Kids'** and **Prevent Cancer Foundation** for providing the funds for us to publish this guide.
- No program can be successful unless there is support from the leadership of the institution. I would like to thank **Dr. David Nelson**, Chair, Department of Pediatrics, and one of the best advocates for childrens' health, for the vision, encouragement, and guidance that he has provided, every step along the way. I would also like to acknowledge the leadership of the **Lombardi Comprehensive Cancer Center** and thank them for all their support.
- Our patients and their families continue to remain the strongest supporters of our survivorship program, giving selflessly of time and resources. I would like to thank all of them, especially the **Ameys, Billings, Eichners, Groves, Lubins** and **Tomoffs** for their generosity.
- **The Children's Cancer Foundation**, a long-time supporter of our program, and **Hyundai Motor Corporation**, through their generous grants over the last three years, have given us the much needed funds to initiate valuable survivorship research. They were also the sponsors of the first 'Rise to Action' conference for young adult survivors of childhood cancer and their families in spring, 2006. We thank them for their continued support.
- The first 'Rise to Action' conference in Washington DC was a huge success, thanks to the collaborative efforts of **The Children's Cause for Cancer Advocacy** and **Special Love, Inc.** Together, we brought to the forefront important, yet often neglected issues that confront survivors in their daily lives. We have enjoyed our close relationship with both of these organizations, and look forward to hosting the second Rise to Action conference with them in April, 2008.

- **Dr. Judith Jones** and **Sharmila Kamani** of the **Degge Group, Inc.** have been long term research partners with us. We worked together on two collaborative projects which resulted in the production of two CD-ROMs; one for leukemia patients and the other for adolescents with solid tumors with a specific section on late effects, an extremely valuable educational tool for all childhood cancer survivors. This survivor guide has benefited from some of the material in the CD-ROMs and we would like to acknowledge it and thank them for their support and encouragement in the production of this publication.
- **The Children's Oncology Group Survivorship Guidelines** are a wonderful resource and contain a wealth of detailed information for survivors and caregivers. We have used some of that information from the Guidelines with permission, and would like to acknowledge it here.
- We would like to acknowledge "**Transition to Survivorship**", a publication of the **Dana Farber Cancer Institute**, Boston, MA and **Nancy Keene's** book '**Childhood Cancer Survivors**,' both of which served as valuable reference sources in the writing of this publication.
- This survivors' guide would not have been possible had it not been for the untiring efforts of my co-authors, **Karen Hennessy** and **Nabeel Arastu**, who put in long hours writing, researching, and simplifying the information we have put together. I would like to thank them whole-heartedly for their outstanding work.
- I would also like to extend my gratitude to **Tracy Council** and **Leslie Nelson** for their contributions to the design and resources section of the guide.

- Thank you to **Jeanne Wagner** of **Marcotte Wagner Communications**, who got personally involved in the production of this guide and brought it to life with all the colors of hope, as well as to **Allison Whitney**, Lombardi Director of Communications, for her guidance.
- It would be impossible to end without a big thank you to our own families who patiently allowed us the time to work on this project. I would like to thank my husband **Tahir**, and my children **Zain**, **Zaamin** and **Zeeshan** for their unwavering love and support over the years; and my parents, **Shirin and Rajabali Hussain**, for always believing in me and teaching me, that if you work hard enough, dreams do come true. I would also like to acknowledge the support and encouragement that I constantly received from my in-laws, **Fazal Bibi Shad** and the late **Iqbal Shad**.
- Karen would like to thank her four children, **Sean**, **Molly**, **Patrick**, and **Kira** with great big hugs for all of their patience while Mommy had to work; her parents, **Ted** and **Joan Montrella**, for their endless support and love since childhood, and for all of their kidsitting to help make this possible. She would also like to remember her late husband, **Jim Hennessy**, who always supported her work in oncology nursing, and who would have been so proud of this book.
- Nabeel would like to humbly thank his parents, **Hyder** and **Shamim**, for their endless patience and guidance. Many thanks also go to his dear sister, **Nermeen**, for her unrelenting encouragement and invaluable advice. Nabeel would especially like to keep in memory his **Grandmother Maryam** and **Uncle Zakir**, whose own personal struggles with cancer enlightened him to pursue a medical career.

■ Finally, a special thanks to our **survivors and families**. This survivors' guide has been written for the benefit of all our patients and their families. We tend to a unique population at Lombardi, an extremely involved and enthusiastic group of childhood survivors and a pro-active Parents Support Group. Every step along the way, they have been involved, by providing quotes for the guide, participating in picture shoots, approving the design and editing content of the manual for simplicity. They are the heart and soul of this publication and our program and I would like to thank each and every one of them personally for their support and encouragement. A special thank you to all the parents who helped in the editing of the content.

■ **Adnan, Asia, Cinzia, Danielle, Julio, Kara, Kory, Meghan, Noah, and Ryan**— this book is for you and all other childhood cancer survivors. The courage, determination, and strength that all of you have shown as you defeat cancer is evident on every page of this book. It has been a privilege taking care of you and I hope this guide will be a valuable resource for you as you continue your life journey. ■



Aziza Shad, MD

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