

Pediatric Cancer Survivorship

Life After Cancer Treatment

written and edited by

Martin Casella, Roger Holzberg, Adele Sender



“Cancer is rare and unexpected in the young, creating unique emotional and medical challenges. This Learn Guide offers an accessible first step in the journey. You will find reliable informations and experienced peer patient veterans to help light the way. You are not alone.”

– Nicolette Chun, Genetic Oncology Counsellor, Stanford Hospital Cancer Center

Reimagine Well Learn Guide:

Pediatric Cancer Survivorship

Life After Cancer Treatment

Martin Casella
Roger Holzberg
Adele Sender

"When it comes to cancer treatment and Survivorship, all of your knowledge becomes our knowledge - this is how we encourage and empower one another."

— Lilibeth Torno, M.D.

"Be patient with yourself and your progress. Remember: changing behavior takes time."

— Jocelyn Harrison, MPH, RD

This Pediatric Cancer Survivorship Learn Guide is designed to help patients and their families overcome the fear and anxiety of a cancer diagnosis, and to educate them as they transition through healing, wellbeing, and Survivorship. Our goal is to provide concise, evidence-based, easily understood resources to be used throughout the entire cancer journey.

The eBook version of this guide is interactive and will serve to empower both patients and caregivers navigating the entire patient journey. It will also provide a (private and safe) support community where families can learn from others who have already been there.

Team Reimagine Well

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NOTE:

Both Parts 1 and 2 of this Learn Guide are designed to go hand in hand.

As you use Part 1 of this Pediatric Cancer Survivorship Guide to educate yourself - and get coached on how to become an empowered patient - you may want to create your online patient or caregiver Support Community, which can be accessed at <http://www.reimaginewellcommunity.com/reimaginewell>. The details on how to best use the Support Community are found in Part 2 of this Learn Guide.

One final note on using this guide: Words highlighted in italics are words for which you might need a definition. There is a definition of the italics word in the back of the Learn Guide, in the section marked Glossary.

WELCOME

Three messages for Pediatric Cancer Survivors, their families, and caregivers.

From Leonard Sender, M.D., Co-Founder of Reimagine Well.

"Information can lead to knowledge. Knowledge is power. You have to become empowered to learn, then ask the right questions and get the information you need. The best way to get the type of treatment that is right for you, that will lead to the type of outcome we want for you, is to become fully engaged in the process."



The following messages are from Lilibeth Torno, M.D., and Jenee Areeckal, MSW, LCSW. Both are experts in the medical field of Pediatric Cancer and Survivorship.

*"It's very important to help educate patients (and their caregivers) how to become strong survivors.
It is possible to survive and thrive after cancer!"*

— Jenee Areeckal, MSW, LCSW

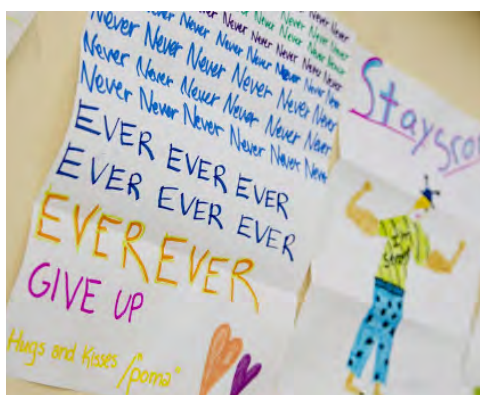
*"You can help other people. **When you're a survivor, share your story!**
This is how we learn from each other."*

— Lilibeth Torno, M.D.

Carry a copy of this Learn Guide, whether a hard copy or an eBook, with you to all meetings with your Health Team and Healthcare Professionals, and use it as a guide to get all of your post-treatment questions answered.

*"I totally agree that keeping positive and never giving up hope is paramount."
— Parent Of A 10-Year-Old With Neuroblastoma*

*"We should always be willing to share our stories with the newly diagnosed, and to be a calming influence...
we are living proof the disease can be stopped and cured."
— 14-Year-Old With Osteogenic Sarcoma*



*"What an amazing opportunity to build a community and connect with people who can relate to what it feels
like when you're told your young child has cancer... in the end, the experience of being more transparent
with my fears was cathartic and healing."
— Parent Of A 6-Year-Old With Wilms Tumor*

CONTRIBUTING EXPERTS



Leonard Sender, M.D.

Dr. Leonard “Lennie” Sender is currently the Medical Director of the Hyundai Cancer Institute at CHOC Children’s Hospital and co-director of the Chan Soon-Shiong Institute for Medicine (CSSIFM).

His primary research and clinical interests are in immuno-oncology. His belief that our innate protective immune system can be triggered to fight cancer keeps him at the cutting edge of molecular diagnostics and innovative clinical trials.

Lennie received his medical education in South Africa, his pediatric internship and residency at UC Irvine Medical Center, and his pediatric hematology/oncology subspecialty training at Children’s Hospital of Los Angeles. He served as chairman of Stupid Cancer, and is the founding member and chairman of SeventyK.org, an AYA cancer advocacy foundation.

He is a widely featured speaker on Immunotherapy, including at TEDMED 2018.

“I’m Leonard Sender. I’m the medical director of the Hyundai Cancer Institute at CHOC Children’s Hospital, and I’ve been involved with pediatric cancers, adolescents, and young adults for nearly 30 years. The first thing I want to say to a patient who has just completed their treatment is congratulations and, secondly, well done. What we need to talk about now is how we get you to your new normal, how we get you to adulthood, how we understand all the consequences of the therapy that you’ve been through, and how we make sure that you truly have wellbeing going forward.”



Jocelyn Harrison, MPH, RD

Jocelyn Harrison received her Master of Public Health from UCLA and completed a dietetic internship at the Los Angeles Veterans Hospital. She has developed nutrition programs and marketing for the USDA Dietary Guidelines for Americans, Choose Health LA, and the American Diabetes Association. In addition to nutritional and lifestyle advice, Jocelyn's Reimagine Well work includes literature reviews and helping with "immersive healing environment" patient benefit studies.

"My name is Jocelyn Harrison. The most important things you can do to fight cancer and prepare yourself after treatment are: eat a mostly plant-based diet, maintain a healthy weight, and be physically active. Although treatment can be overwhelming, you have a part to play in your own treatment. Be empowered, this is your journey."



Jenee Areeckal, MSW, LCSW

Jenee Areeckal is a clinical social worker at UCSF Benioff Children's Hospital. She is a three-time cancer survivor, and an amputee due to osteogenic sarcoma, who knows what it is like to live through and be treated for cancer as a teen and young adult. Today, she uses her story to inspire her patients and families both during and after treatment. She is proof that life after cancer can be wonderful and fulfilling.

"My name is Jenee Areeckal. I'm a pediatric oncology social worker. I am a three-time AYA cancer survivor. I had osteogenic sarcoma when I was 15, with two relapses, and had ovarian cancer at 38. I've been taking care of teens and young adults with cancer for about 10 years. It's been my life's passion to help them navigate through not only their treatment, but also post-cancer Survivorship."



Lilibeth Torno, M.D.

Dr. Lilibeth Torno is the Clinical Director of Outpatient Services and the CHOC ACTS (After the Cancer Treatment Survivorship) Program. She also leads the Ambulatory Care Services of The CHOC Cancer Institute and directs the CHOC Long-Term Follow-up Clinic for survivors of childhood cancer. The outpatient clinic provides comprehensive care of children undergoing chemotherapy, as well as those who have completed therapy.

She is board certified in pediatrics and pediatric hematology/oncology. Dr. Torno completed her fellowship training at Children's Hospital of Los Angeles. She completed her residency at CHOC. She attended medical school at University of Santo Tomas, Manila, Philippines.

"My name is Lilibeth Torno. I'm a cancer specialist, and I take care of childhood cancer survivors. I have worked at CHOC for approximately 17 years. The most important thing I would say to anyone who just finished therapy is congratulations. This is a major achievement in your cancer journey."

“The person who is most responsible for your Survivorship is YOU. You need to be the advocate and leader of your own care. It’s very important to educate yourself so you can become a strong survivor.”

– Jenee Areeckal, MSW, LCSW

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Leonard Sender, MD Dr. Leonard “Lennie” Sender is a pioneer in cancer care treatment, especially in adolescents and young adults. Lennie is Director of the Adolescent and Young Adult (AYA) Cancer Program at CHOC Children’s Hospital in Orange County, where he leads one of the nation’s largest programs considering the unique challenges faced by AYA cancer patients.



Lilibeth Torno, MD Dr. Lilibeth Torno is the Clinical Director, Outpatient Services and the CHOC ACTS (After the Cancer Treatment Survivorship Program). She also leads the Ambulatory Care Services of The CHOC Cancer Institute and directs the CHOC Long Term Follow-up Clinic for survivors of childhood cancer.



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