



**Dream Village**

Where Kids Build Better Tomorrows



The Grownup's Guide

# Today's the Day

Edition



100% of Proceeds from Today's the Day go to

  
Children's Cancer  
Research Fund®



# Introduction: Dream Village

At Dream Village, we divide our community into two basic groups: the children we want to entertain, educate, and inspire; and the grownups like you, who are our partners in making this journey possible for the kids you know and love.

For you, the dedicated grownup, we have created The Grownup's Guide: Today's the Day Edition. It's a guide for all grownups, not solely teachers, because we believe this guide can be used in any environment, from the classroom, to the community center, to the kitchen table.

Designed by Dream Village as an initial point of reference, the guide provides the kids in your life with a deeper understanding of the principles discussed in Today's the Day and on our website. It will help you answer questions that kids may raise when reading the book, and provides you with lessons and activities to pursue after exploring the book and website.

## Children's Cancer Research Fund

100% of the proceeds from Today's the Day go to Children's Cancer Research Fund. Visit <https://childrenscancer.org/> to learn more about the organization.

Have feedback on the Grownups Guide or anything relating to Dream Village?

- Send us an email: [suneet@dream-village.org](mailto:suneet@dream-village.org)
- Visit us on Facebook: <http://fb.me/welcometodreamvillage>



# Inspiration: Today's the Day

Today's the Day was inspired by three true stories, which we pulled together into one cohesive narrative to help bring their stories to light.

Juliet is an early reader of Dream Village and a friend of the community. She has been donating her hair since a very young age. Additionally, Juliet is a standout young woman at home, in her community, and at school. We chose to make Juliet a model for one of the characters in the book because of her experience with hair donation, but also because she is often called upon to befriend students at school who may or may not have a hard time adjusting, and who at times, may be victims of bullying. Juliet's love and friendship in the book are true and natural character traits for her, making her character in the book a reflection of the person she already authentically is.

Siona is based on the remarkable, powerful, and heartbreaking story of Siona, a young girl who fought High Risk T-Cell Leukemia before ultimately succumbing to the affliction. Siona, through family, is also a friend of the Dream Village community and it is the way she lived, the lessons she taught all of us, that served as the inspiration for the character of Siona in the book. Siona's favorite things (from spiders to butterflies) are strategically placed throughout the book to evoke her memory and to reflect her spirit. Similarly, the life lessons mentioned in the book are taken from the lessons her brother learned from his sister and how she lived her life. The following page is a blog post written by Siona's mom, Reshma, that outlines her journey.

The character of Siona is visualized by her older cousin sister, Saiya. Saiya is an equally amazing young woman with a tremendous spirit and energy. She first decided to grow her hair out so she could donate it to her cousin sister, Siona. This act of incredible empathy and generosity served as the core inspiration for the overall narrative of this story. Unfortunately, Siona passed away before Saiya was able to fully grow out and donate her hair. But Saiya has found a way to continue donating her hair in Siona's honor. And we could think of no better person to model the character of Siona after than her wonderful cousin, Saiya.

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# Inspiration: Siona's Story (Page 1 of 3)

When your children are born, as parents you have this feeling that everything is well with the world. You actually wonder what you ever did prior to having them and couldn't imagine your world without them in it.

As they grow, every now then, they get ill and for a moment you get that feeling in the pit of your stomach. The wave of relief when the doctor tells you it's nothing serious, puts you back in that 'all is well with the world' place.

On a hot summer day in 2008, I took the kids to their first swim lesson together. My son did well, but Siona, my daughter, cried through the whole lesson. It was very unusual for her to be clingy and cry so much. I made a note to ask the doctor about it later that day. I was taking Siona in for a checkup because she had been sleeping a lot and she had a low grade fever.

The doctor took a look and ordered blood work and said it was probably mono, but blood tests should confirm it. I went about my business thinking it would all be fine...the doctor said so.

The next morning, my husband woke me up early to say the doctor had called (at 5:30 a.m.) to say that we had to get Siona into Children's ER in Seattle. No explanation. They couldn't discuss it over the phone.

From that day onward life was never the same and would never be ever again. Siona was diagnosed with High Risk T-Cell Leukemia on June 26th 2008. We didn't go home that day. Siona was admitted to an overflowing cancer ward. I will always remember that first night...listening to the other children in the room crying in pain and being sick. The thought of Siona going through what those children were going through was unbearable.

Siona showed spunk from the very beginning. When the tech came in to draw blood for the tenth time that first day she had no more fingers left to poke, except one. She was mad, it was late and the tech couldn't get blood.

I screamed at him to leave and Siona calmly gave him her only unbandaged finger – the middle one.

Appropriately, it symbolized my feelings to a tee. 'Take that cancer!'

Life puts many obstacles in our way and how we choose to deal with them makes us who we are.

Children don't even see these obstacles. They are usually experiencing everything for the first time, so to them, if it is new it must be normal...right? To Siona, every kid was doing the things she was.

Siona never cried about what was happening to her. She cried when she was in pain when it was at its worst.



# Inspiration: Siona's Story (Page 2 of 3)

Siona never cried about what was happening to her. She cried when she was in pain when it was at its worst.

She took the daily needles in the chest, feeding tubes shoved down her throat and the constant prodding and poking in stride. The long hospital days and long stays were accepted without question. She would look around in the waiting room and comment on another girl's cute shoes or notice a child crying and say, 'He/she is not happy today.' I could tell it would affect her. She was always smiling and wanted that for the other kids too. Her goal was to get out of the hospital as fast as she could, so she would opt out of the 'let's count to 10 before we rip this tape off your chest'. Honestly, there is no gentle way to take a needle out of your chest! She would say, 'Just do it! I want to go home and ride my scooter!'

The first year was the hardest. The chemo made Siona very sick and also shut down her adrenal system. She was on a feeding tube most of the first year. She was a sight! She would be running, riding her bike, and playing without a care – all with the tubes hanging out of her. Cancer wasn't going to slow her down. As she grew older, Siona started to notice that she wasn't getting to do the normal things other kids her age were doing. The first day of kindergarten and getting on the school bus she had always wanted to get on weren't going to happen for her. We would keep the windows shut so that she couldn't hear the kids outside. Once, and only once, did she say to me, 'Mama, I wish I was normal.'

Children with Leukemia go through a longer course of therapy. Girls go a total of 2 years, boys 3. After the first intense year, Siona went on maintenance therapy for the next year. She was doing well until March 26th of 2010 (ahhh the 26th again!). After a routine blood test the results showed some abnormalities. Siona had relapsed. It was like re-living the first time we found out, but worse.

With cancer you are bombarded with statistics. Your child's chances of survival are based on percentages. It's terrifying. Siona's chances weren't great this time around. The first time she had had an 85 % chance of surviving. Now? 5% if she was lucky. Siona needed a bone marrow transplant and donors for children of Asian descent are hard to match. Her brother, who had decided he was going to save her, wasn't a match for her. We found two blood cords that may have worked, but first we needed to get Siona into remission.

We went to St. Jude's in Memphis where they are 10 years ahead of all institutions in the search for a cure for childhood cancer. We found out that Siona actually had a rare subset of Leukemia called ETP Leukemia. It was newly discovered by doctors at St. Jude's. We were thrown back to the beginning...again. A whole new diagnosis for which chemo is useless. Siona should have had a transplant while she was in remission. We were devastated.



# Inspiration: Siona's Story (Page 3 of 3)

We brought Siona home because that is where she wanted to be. St Jude's had new treatments, but they were all experimental. No guarantees. Siona was all about 'Home'. She just wanted to be home with her brother and family.

Through Siona's illness she remained positive and would tell US everything was going to be okay. We would call her the 'wise one' because she would say things that a 4 or 5 year old would never say. She observed people closely and if she heard or saw that someone was hurt or down, she would try to cheer them up.

She once said to her brother who was sad to see grandparents go home, 'Just because they are gone doesn't mean that you won't see them again one day.' She was very practical girl in matters of the heart. Her fashion sense on the other hand was a different story. She was all about purple (a happy color in her mind), pink, and lots of bling!

She lived everyday to the fullest. At least to the point her body would let her. She loved holidays; Halloween, Diwali, and Christmas. She loved to be with family and sing, do her arts and crafts, dance in her princess dresses and heels, and to giggle with her cousins. She would look into the sky at butterflies and birds and wondered how it would feel to fly 'free' as she put it. She taught many of us so much about life. It was hard to think someone so young could be so mature and matter of fact.

She was so excited for Christmas 2010 to get here. We know she hung on for that reason. During her last week with us, she said her goodbyes in her way. She told me, 'Mama, I'm tired now.' She made calls to family and left messages in the middle of the night. She told me to 'Be calm Mama, be calm' right before the paramedics came to get her. The night before she passed she told her Dad, 'Daddy, I'm flying free!'

She is free to fly high in the sky now. Free from pain. We miss her terribly. The house is too quiet without her loud voice and happy chatter and singing. How do you learn to be an only child if all you can remember is having a sibling? How do you parent an only child when all you remember is parenting two? We are all re-learning how to live life without Siona. As she said, 'Just because she is gone doesn't mean we won't see her again one day.'

After Siona passed away, her brother sat down with his Dad to write down everything he had learned from his little sister. He learned the most from his sister. Her lessons to him became Siona's Life Lessons for us. He tries to live everyday with as much zest and enthusiasm as she did. She would be proud. We have included 'Siona's Life Lessons below. They keep us strong and focused...living everyday with the way she would want us to – with purpose, making a difference.



# Children's Cancer Research Fund

100% of the proceeds from Today's the Day will be donated to Children's Cancer Research Fund. Children's Cancer Research Fund is a national nonprofit, and thanks to donors and partners around the country, has contributed \$150 million to research, education and awareness and quality-of-life programs for childhood cancer families.

Children's Cancer Research Fund believes kids deserve safer, less toxic treatments, and is committed to funding groundbreaking research and services that enhance healing and care.

## Important Reference Materials from Children's Cancer Research Fund

- Host a Fundraiser - Every day 43 kids will be diagnosed with cancer. When you fundraise with Children's Cancer Research Fund, you're helping support the brightest and boldest minds whose groundbreaking research is saving children's lives. Learn more here: [http://support.childrenscancer.org/site/PageServer?pagename=Fundraise\\_Your\\_Way\\_Home#](http://support.childrenscancer.org/site/PageServer?pagename=Fundraise_Your_Way_Home#)
- Join an Existing Fundraiser - There are individually sponsored events around the United States. Get started by joining one that interests you; whether you bring your energy to an existing event or use that to inspire hosting your own your voice and your contribution are invaluable. Learn more here: [http://support.childrenscancer.org/site/PageServer/?pagename=Fundraise\\_Your\\_Way\\_Search](http://support.childrenscancer.org/site/PageServer/?pagename=Fundraise_Your_Way_Search)
- Learn more by visiting Children's Cancer Research Fund online for ways to donate, volunteer, and much more: <https://childrenscancer.org/>



# References: Today's the Day

Dream Village has compiled the following resources to help you better facilitate discussion around the topics raised in Today's the Day, and to better equip you to answer the discussion questions that follow.

## Hair Donation Reference Materials:

- Chicago Tribune: <http://www.chicagotribune.com/redeye/culture/redeye-comparing-pantene-beautiful-lengths-wigs-for-kids-and-locks-of-love-20160120-story.html>
- Snopes FACT CHECK: <https://www.snopes.com/fact-check/wig-doubt/>

## School Bullying Reference Materials:

- Stop Bullying Facts and Background Information: <https://www.stopbullying.gov/media/facts/index.html>
- 11 Facts About Bullying from DoSomething.org: <https://www.dosomething.org/us/facts/11-facts-about-bullying>
- Facts About School Bullying and Bullying Behavior: <http://www.bullyingstatistics.org/content/school-bullying.html>

## School Attendance and Absenteeism:

- 10 Facts About School Attendance: <http://www.attendanceworks.org/chronic-absence/the-problem/10-facts-about-school-attendance/>
- Brookings Report - Chronic Absenteeism: An old problem in search of new answers: <https://www.brookings.edu/research/chronic-absenteeism-an-old-problem-in-search-of-new-answers/>
- Georgetown University Health Policy Institute - School Attendance and Health Care: Why Chronic Absenteeism Isn't Just About Truancy: <https://ccf.georgetown.edu/2015/09/29/school-attendance-health-care-chronic-why-absenteeism-reasons-truancy/>



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Dream Village has compiled the following resources to help you better facilitate discussion around the topics raised in Today's the Day, and to better equip you to answer the discussion questions that follow.

## Hair Donation Resources:

- Wigs For Kids: <https://www.wigsforkids.org/donate-your-hair/>
- Locks of Love: <http://www.locksoflove.org/get-involved/>

## School Bullying Resources:

- How to Prevent School Bullying: <https://www.stopbullying.gov/prevention/index.html>
- Webisodes and Kid Videos on Bullying: <https://www.stopbullying.gov/kids/webisodes/index.html>
- Bystander vs Upstander: <http://www.upstand.org/>
- Helplines: <http://bethechangen.org/contact-and-helplines.html>

## School Attendance and Absenteeism Resources:

- Helping parents build a habit of good attendance; <http://www.attendanceworks.org/resources/handouts-for-families/>
- School Attendance Improvement Strategies: <https://www.cde.ca.gov/ls/ai/cw/attendstrategy.asp>

