Dear Parents,

Many people have heard the story of our daughter Alexandra “Alex” Scott who was only four when she held her first lemonade stand to raise money to find cures for kids, like her, with cancer. Fewer people know that Alex is one of four kids in our family. Although Alex was the one in treatment, her three brothers – Patrick, Eddie and Joey – also experienced the effects of being part of a family affected by childhood cancer. We know that it has not always been easy for them dealing with the uncertainty, fear and worry that come along with a sibling’s cancer diagnosis, but their experience has also shaped them into the young men we are so proud of today. As we continue Alex’s legacy through Alex’s Lemonade Stand Foundation, Patrick, Eddie and Joey are strong supporters and have been with us every step of the way.

Having grown up with siblings ourselves, we know the integral role they play in our lives, whether in good times or difficult times. There is nothing quite like the sibling bond, and the unique support and sense of normalcy that a brother or sister can give to a child in treatment. We are honored to be able to give siblings the support that they too need through SuperSibs!

Best regards,

Liz and Jay Scott
Parents of Patrick, Alex, Eddie and Joey

Welcome to SuperSibs!

Here at Alex’s Lemonade Stand Foundation, we know that childhood cancer affects the whole family, not only the child who receives the diagnosis. Brothers and sisters of cancer patients often face fear, anxiety, changes in daily routines, worry, grief and even jealousy as their family is thrown into the emotional turmoil of managing a child’s cancer treatment.

SuperSibs, a program of Alex’s Lemonade Stand Foundation, is dedicated to comforting, encouraging, and empowering siblings during their family’s battle against childhood cancer, so these children and teens can face the future with courage and hope.

What to Expect from SuperSibs!

SuperSibs is free and provides comfort and care mailings to children ages 4-18 who live in the United States and have (or had) a sibling with cancer. Participating children receive support mailings from SuperSibs over a two-year period.

Each child and teen receives ongoing age-appropriate, evidence-based, personalized materials to reassure them that they’re not alone or overlooked, that the mix of feelings they may be experiencing is OK and that support is available to help them manage through and beyond this period.

Here’s what you and your child (or children) can expect from SuperSibs:

• This introductory Parent Toolkit and periodic parent e-newsletters
• 6 sibling comfort and care mailings per year, containing age-appropriate support resources and fun activities to help siblings manage through this turbulent time. Each mailing validates the child’s feelings, provides insight and encouragement to reach out for support, and offers recognition of the child’s uniqueness and importance in the family.
• Online resources at SuperSibs.org

When a mailing arrives, take the opportunity to use it as a conversation-starter with your child to talk about their feelings and remind them they are important to you. Ask what they received from SuperSibs or read the newsletter together.

To change your address, suspend SuperSibs services, or get in touch for any other reason, contact us at SuperSibs@AlexsLemonade.org or (866) 333-1213.
### Parent Voices

Everyone who has a child diagnosed with cancer finds their own individual ways to cope, and different strategies will work for different people, but we asked some parents who have been through this experience the question: What would you want others who have recently received a cancer diagnosis to know about the journey that lies ahead?

“When a child is diagnosed with cancer— it changes everything— including the lives of their siblings. Jilly, her brother and two sisters lifted each other like nothing else could! It was amazing to watch the love and bond they shared during our darkest days.”

-Jen Miller
Indianapolis, IN

“When our younger daughter was fighting cancer, it was hard on her and for us, but in the midst of this fight our older daughter faced her own lonely battle. We had to try extra hard so she didn’t feel less loved since we spent so much time at the hospital without her.”

-Dash Wallowillai
Georgetown, TX

“It is not enough to simply say that a child’s cancer diagnosis affects the entire family. It changes an entire family. Siblings separated from one another, as well as from parents, is simply unfair.”

“When his brother, Declan, was in treatment, SuperSibs sent Brendan his own gifts that I believe will continue to mean more and more to him as he grows older and works through the grief of losing his big brother to cancer.”

-Megan Roberts
Downingtown, PA

“Over time the impact of the focus on Payton played a role in her sister Jordyn’s personality. She tried harder to be noticed by us, she even wanted a scar like her sister and did her best to gain attention at every opportunity. As a result, Jordyn was and is both incredibly independent and at the same time incredibly dependent on our love and attention.”

-Brian Riggs
Mickleton, NJ

### Tips for Parents: How to Talk to Siblings About Cancer

It can be gut-wrenching to think about explaining cancer to your children, yet whether they are young children or teens, it’s important for them to receive age-appropriate information. Children who are not given the facts will often invent terrible scenarios in their imaginations. Honest, open, ongoing conversation with your children or teens will help reduce unnecessary stress, guilt and anxiety and build trust.

Your hospital’s pediatric oncology social worker, psychologist, child life specialist or nurse may have more suggestions and resources to guide you.

**For Young Children (2-5)**

For this age group, keep explanations very simple. Here are some suggestions for what to say:

To explain leukemia: “Sammy’s blood is very sick. The doctors are going to give him medicine to help his blood get better. Sometimes he will take it at the hospital and sometimes at home. The doctors are going to do everything they can to make his blood get better.”

Solid tumor: “Stephanie has a bump on the inside of her head. The doctors want to make that bump go away, so they might try to take the bump out, or they might give her some special medicine to make it shrink.”

**For School Age Children (6-10)**

For this age group, focus on giving information and asking questions to start a conversation. Here are some suggestions for what to say:

Leukemia: “Sammy has cancer. Have you ever heard that word before? There are different kinds, and Sammy’s kind is called leukemia. That means that the cancer is in his blood. The doctors are going to give Sammy a very strong medicine called chemotherapy. It’s called ‘chemo’ for short. The chemo will help make the leukemia go away.” (Reiterating): “The doctors and nurses are going to do everything they can to make the leukemia go away.”

Solid tumor: “Sometimes the cells inside the body start to do strange things and the doctors don’t know why. The cells might start to be in a weird shape or they might clump together into tumors. The doctors found a tumor in Stephanie’s brain. The tumor was pushing on the part of her brain that helps her walk and run and that’s why she was having trouble with her balance. The doctors don’t want the tumor to stay in her brain so they are going to try to take it out with surgery. She’ll be sleeping the whole time and won’t feel anything.”

**For Tweens and Teens (11-18)**

Start with the basics and elaborate, depending on how much information they want to hear. Some want a lot of information, some want to read about it themselves, and some want to know only what they need to know.

Suggested questions for conversation:

- What do you know about cancer?
- Do you think cancer is contagious? (No, it’s not “catchy”)
- Do you think cancer is caused by something someone did? (It’s not!)
- How is your life different now?
- What is the biggest change in your life?
- What additional things do you have to do at home now?
- What do you want/need from us, your parents?
- What do you want/need from your friends?
- What do you want/need from school?
- How do you know you are loved?”
How to Help a Child or Teen During a Sibling’s Cancer Treatment

Here are some tips to support your SuperSib:

• Siblings often say they are “OK” when asked how they are doing, but they may be feeling jealousy, anger, fear, guilt, uncertainty, loneliness, grief and other feelings. Remember they are managing their own unique cancer journey and experiencing the “roller coaster” too.

• Siblings are often asked for medical updates by family and friends. Encourage loved ones to ask you (or a designated point person) instead — or create a website (carepages.com and caringbridge.org are popular, easy and free) so siblings don’t feel caught in the middle. Write about and post photos of each of your children.

• Encourage everyone (medical professionals, friends and neighbors) to greet and introduce siblings by their own names (not as “patient’s brother or sister”).

• Siblings deserve the opportunity to be heard and receive help with the emotional impact of a cancer diagnosis on the family. Seeing a good therapist (a “feelings doctor”), child life specialist or pediatric oncology social worker can be healing for your SuperSib (and you, too).

• It’s OK for your children to see that you are experiencing a variety of emotions. Sometimes you may even cry together. Your children will learn from your example that all feelings are valid.

• One on one, ask your children how they are doing. Then, just listen. Your children and teens have a life outside cancer, with their own hopes, dreams, disappointments and successes.

• Sometimes older siblings are thrust into the “third parent” role. Beware of loading too many adult responsibilities onto a child or teen. Reach out to friends, neighbors and extended family to take on some of the extra chores such as grocery shopping, laundry, carpooling, etc. Be prepared by making a list so you’ll know what to say when people ask, “What can we do?”

• Remind your kids that it is OK to laugh and have fun, even while a sibling is undergoing cancer treatments. Funny movies and joke books can be a great bonding experience and a stress-relieving release for everyone.

• Offer ways for your child to get involved — sorting supplies, reading stories to their sibling with cancer, etc. A meaningful role helps them feel included and important.

• Help your SuperSib connect with other kids in a similar situation, either through a camp for siblings of kids with cancer (a list is available on our website, SuperSibs.org) or in your local community.

• If your hospital restricts sibling visits, it’s even more important to help each family member feel connected, comforted and loved.

Siblings and School

Visit SuperSibs.org for a print and email friendly version of this section to share with your child’s teachers.

Supporting the siblings of a child with cancer is a team effort. Support can come from parents or guardians, grandparents, extended family, neighbors or friends. Teachers are an important part of the team.

Many children spend more time with their teachers than anyone else during the day. Teachers who are aware of what is happening in a child or teen’s family life will be more able to help the sibling manage through difficult times and keep up with schoolwork and activities.

Sibling Reactions to a Brother or Sister’s Cancer

• Complaints of not feeling well
• Withdrawal
• Decline in academic performance
• Periods of extreme productivity (overachievement)
• Frequent absences or tardiness
• Difficulty concentrating
• Decreased attention span
• Anxiety
• Depression
• Anger

Interventions - How Teachers Can Help

• Err on the side of concern
• Provide as much positive feedback as possible
• View irritability as sadness rather than confrontation
• Encourage peer support
• Decrease or modify academic demands
• Assign ongoing parent contact person at school
• Encourage the child to write or draw about her feelings
• Let the student know you care

School is often the place where a sibling can get a break from their concerns and worries. Sometimes, giving the sibling space and not asking how the family or patient is coping is most helpful. Check in with the student to see what he or she prefers.

Siblings Share:
Things That Make Us Feel Better

• Having your friends treat you the way they always did
• Teachers asking how I’m doing
• School friends making and sending cards to the brothers and sisters
• Having everyone know
• Remembering that you can’t catch cancer
• Talking to someone special
• Cookies
• Recess

Special THANK YOU to the Sibling Program, Dana–Farber Boston Children’s Cancer and Blood Disorders Center, for sharing this resource with SuperSibs.
Share Your Story

Parents & Guardians
Share your voice and have your childhood cancer experience be counted. Register to join The Childhood Cancer Database Project (MyChildhoodCancer.org), created by Alex’s Lemonade Stand Foundation to better understand how childhood cancer affects families. The Project’s goal is to measure the personal and economic impact of childhood cancer and find ways to support families through the journey.
Visit MyChildhoodCancer.org to get started.

Sibling Ambassador Program
Our Ambassador Program provides the opportunity for childhood cancer families to speak at and/or attend events in their community. Siblings of kids with cancer can share their personal story, talk about their experience with SuperSibs or ALSF, and share how cancer effects the entire family – all with the purpose of raising awareness about childhood cancer.

For more information or to sign up for the Ambassador program, please visit: SuperSibs.org

*Please note siblings under the age of 18 will require a parent to complete the form.

Additional Resources
Check out our website, SuperSibs.org, for more resources:
• Sibling summer camps and program
• SuperSibs Activity Sheets (by age group)
• Sibling quotes and stories
• SuperSibs online signup and referral
• Teacher Tips, and lots more!

About SuperSibs Powered by ALSF
SuperSibs was founded in 2002 by Melanie Goldish, mom of a SuperSib, after seeing firsthand the unique journey siblings experience when a child is diagnosed with cancer. The program’s Comfort & Care mailings reached siblings far and wide and made a positive impact in their lives. In 2014, SuperSibs transitioned to become part of ALSF where it will complement an existing family resource program and continue to provide support to siblings affected by childhood cancer.

About Alex’s Lemonade Stand Foundation
Alex’s Lemonade Stand Foundation (ALSF) emerged from the front yard lemonade stand of cancer patient Alexandra “Alex” Scott (1996-2004). In 2000, 4-year-old Alex announced that she wanted to hold a lemonade stand to raise money to help find a cure for all children with cancer. Since Alex held that first stand, the Foundation bearing her name has evolved into a national fundraising movement, complete with thousands of supporters across the country carrying on her legacy of hope. To date, ALSF has funded hundreds of childhood cancer research projects across North America and developed resources for families of childhood cancer. For more information on Alex’s Lemonade Stand Foundation, visit AlexsLemonade.org.

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Serving Siblings of Children with Cancer
SuperSibs.org