

Serving Siblings of Children with Cancer

SuperSibs!

Powered by: Alex's Lemonade Stand Foundation



PARENT TOOLKIT

Welcome to SuperSibs!

Alex's Lemonade Stand Foundation (ALSF) understands that childhood cancer affects the whole family, not only the child who receives the diagnosis. Siblings often face changes to daily routines, and experience emotions such as fear, anxiety, grief, and even jealousy.

When a family is thrown into the emotional turmoil of managing a child's cancer treatment, our goal is to provide siblings with courage and hope for the future.

What to Expect from SuperSibs

- **Age-appropriate Comfort and Care mailings to siblings throughout the year**
- **Special mailings if a patient's status changes**
- **Support and guidance for parents**
- **Resources for extended family, friends, and school professionals**
- **Access to other support programs and opportunities**

Dear Parents,

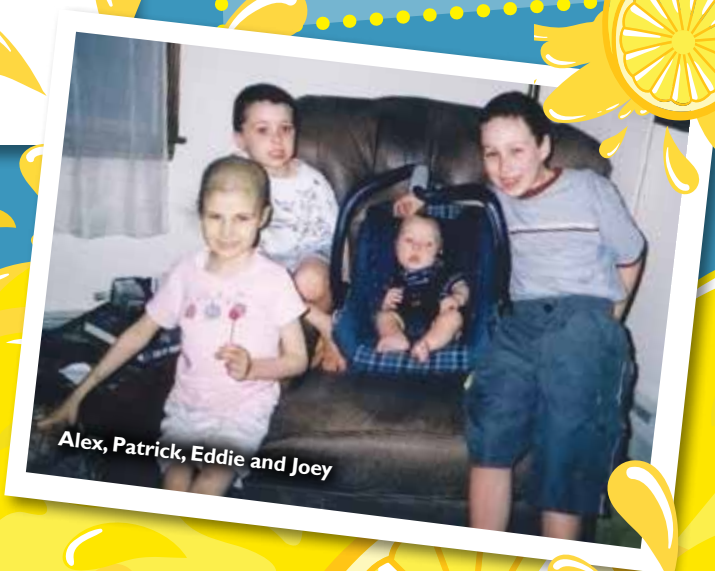
Many people have heard the story of our daughter Alexandra "Alex" Scott who was only 4 when she held her first lemonade stand to raise money to find cures for kids, like her, with cancer. Fewer people know that Alex is one of four kids in our family. Although Alex was the one in treatment, her three brothers—Patrick, Eddie, and Joey—also experienced the impact 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 comes 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



Alex, Patrick, Eddie and Joey

Comfort and Care Program

This program is specially designed for children ages 4-18 in the United States who have a sibling battling cancer currently or in the past. Over a two-year period, SuperSibs receive mailings that are age-appropriate, evidence-based, vetted by psychosocial support professionals, and designed to provide coping skills and encouragement.

Here's what you and your SuperSib can expect:

- Up to 8 mailings per sibling each year
 - Holiday and seasonal postcards with activities
 - Two workbooks each year with fun games and exercises to validate feelings, develop healthy coping skills, provide encouragement, and recognize each SuperSib's importance in their family
 - Birthday and milestone cards
 - Graduation plaque and card at the completion of the program
- Quarterly parent e-newsletters
- Online worksheets and archive of past mailings at **SuperSibs.org**



SuperSib Jacob L. with Playbook

“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 W.

“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 R.

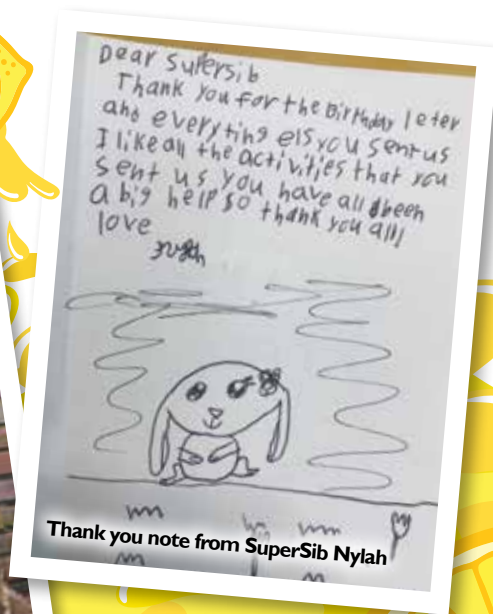
“When his brother, Declan, was in treatment, SuperSibs sent Brendan his own gifts that I believe will continue to mean more and more to him as he grows older and works through the grief of losing his big brother to cancer.”

- Megan R.

Each mailing is an opportunity to check in with your child. Ask what they received from SuperSibs or read the newsletter together. Talk about the activities, their feelings, and remind them how important they are to you!



SuperSibs Brendan and Tommy, with photo of Hero Declan



Thank you note from SuperSib Nylah

SuperSibs at School

For children, school isn't just where they receive their education. It's also the center of their social universe. After a diagnosis, the school community can provide much needed support and stability for siblings. Extra support for siblings in the classroom can decrease their feelings of isolation, guilt, fear, or being misunderstood.

Some other ways teachers and school officials can be of help include:

- Siblings often face teasing or harassment because of what their hero is going through. It is important to be mindful of this even if the hero and SuperSib are not in the same school.
- School routine should remain the same as much as possible to ensure normalcy, but sometimes SuperSibs can benefit from decreased or modified academic assignments.
- Teachers and school administrators may pick up on SuperSibs' needs that can be addressed at home, so keep in communication with them.



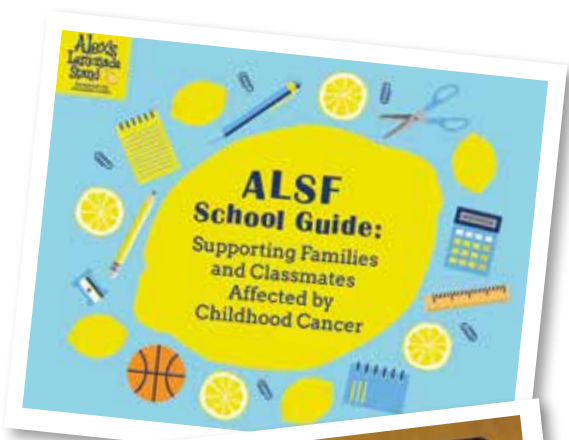
The ALSF's *School Guide: Supporting Families and Classmates Affected by Childhood Cancer* is a free resource designed to help families and school professionals address the unique needs of children diagnosed with cancer and their siblings in the classroom. **For more ways to support SuperSibs in the classroom, visit AlexsLemonade.org/School-Support. Available in print and for download.**

Support Through Changes

ALSF will send special SuperSibs mailings to siblings when there are changes in treatment status. When there are updates like completion of treatment, remission, or even relapse, please let us know so we can stay in touch.

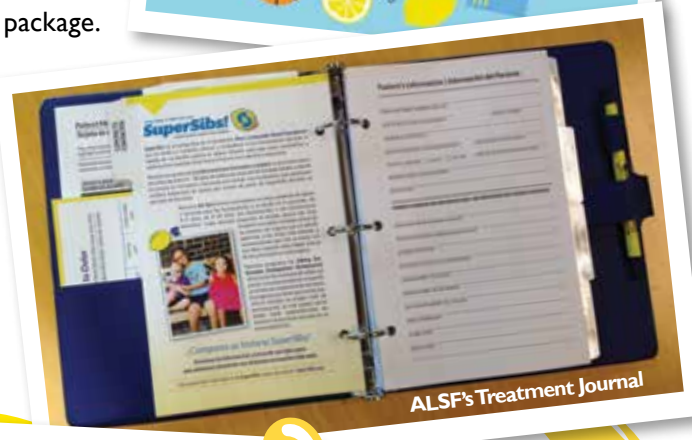
In the event their sibling passes away, we have specialized bereavement mailings for SuperSibs to enhance coping and acknowledge their grief. When we are notified of a patient's death, we will also send an accompanying parent package.

All updates can be made by calling (866) 333-1213 or emailing SuperSibs@AlexsLemonade.org.



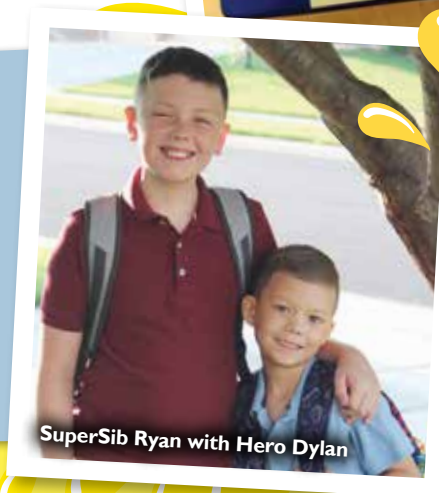
Treatment Journal

ALSF's Treatment Journal is a hand-held organizer designed to help keep track of appointments, labs, medications, nutrition, and many other details that come with managing a treatment schedule. **To order your free copy, visit AlexsLemonade.org/Treatment-Journal. The organizer is also available in Spanish translation.**



"I was worried about Dylan more than anything and how he was going to cope with this. I saw that ALSF has the SuperSib program and I really wanted to find something that would help him. As soon as we got out of the hospital I looked it up and got him enrolled in SuperSibs. It's helped him feel special and continue to provide amazing support and encouragement for Ryan."

- Jennifer E.



Share, Connect, Inspire

An important part of coping with any life-changing experience is finding the support and strength to keep moving forward. ALSF's Parent to Parent Network provides a great source of support by connecting caregivers who have had similar experiences. **To learn more, please visit AlexsLemonade.org/Parent-Parent-Network.**

Reading other's stories and sharing your own can be therapeutic, as well as provide encouragement and inspiration. **Visit AlexsLemonade.org/Stories.**

Another way to share your experience is by attending events or speaking in the community to raise awareness about childhood cancer and its impact on a family. SuperSib Ambassadors pick their own level of involvement as well as which events to attend. **More information at SuperSibs.org.**



SuperSib Monisha and Hero Ishani

Camps for Childhood Cancer Families

Going to camp can be a memorable childhood experience, but for SuperSibs it can have a deeper meaning. Specialized camps can provide a common ground for sharing and coping among peers.

Visit SuperSibs.org for a list of camps across the country that have specific programming for siblings and for the rest of the family.



SuperSib Maya with Hero Eden



Sibling Camper from Camp Okizu

Major R., SuperSib



Age: 7

Favorite Color: Blue

Favorite Activity: Drums, football, baseball and Nerf wars

Major is always happy, from the minute he wakes up in the morning until he goes to sleep at night! Major loves school and his friends. He is truly a great friend, constantly encouraging his buddies, giving them high fives and telling them "good job" on the playing field. Major's family describes him as the life of the party!

Major has handled his sister's diagnosis with such care and is eager to help Peyton in any way he can. He is always very concerned about her staying away from germs and is careful not to bump into her porch-a-corn. He is always very helpful. The fighter cells specialist explained to Major what leukemia was by calling the red and white blood cells fun names. The fighter cells were called ninja cells and the bad cells were called leukemia. Major was able to explain to his second grade class what leukemia is, how it is treated, and what his sister is going through in a way that he and other second graders can understand. He can still tell you all about leukemia and draw you a picture of what it looks like thanks to their child life specialist.

Peyton's child life specialist first told their family about the SuperSib program for Major because he is such an awesome little brother! SuperSibs sent Major a book and other treats specifically for him. He has never been jealous of the gifts Peyton has received since her diagnosis, but Major loved receiving the book about Jack who is also a sibling of a cancer patient. Major meets with his elementary school counselor once a week because Peyton spent several weeks in the hospital for high dose chemotherapy and that was difficult on him. Major brought HIS book to school for him to read to his counselor. She later shared how much that book helped her because she understood that siblings of cancer patients are so much more affected than a lot of people realize!

The best help for Major is to try to keep the family's routine the best they can. If his mom is at the hospital with Peyton and his dad is at work, then they try to make sure Major is picked up from school by someone he chooses that day. His parents want him to feel in control of decisions that involve him so he feels comfortable. His parents also talk to him about his sister's diagnosis whenever he asks. Which is very hard as a parent, and they try to their hardest to answer him honestly while protecting him from the realities of childhood cancer.

Major loves his big sister so much! She is his best friend and he loves spending time with her playing Nerf wars, riding bikes, and playing outside.

"I miss her when she is at the hospital for her treatments, but I know she is getting better every day and that makes my heart happy!"

Information provided by: Carrie R., Major's Mom, 04/2016

KEEP IN TOUCH!

To change your address, update family information, suspend SuperSibs mailings, or get in touch for any other reason, contact us at SuperSibs@AlexsLemonade.org or (866) 333-1213.



Tips for Parents: How to Talk to Siblings About Cancer

Though it can be intimidating to think about explaining cancer to your other children, it's essential for them to receive honest, age-appropriate information. Without the facts, children often invent worst-case scenarios in their imaginations. Open, on-going conversations 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)

Keep explanations simple. Here are some suggestions:

- Leukemia: "Sammy's blood is sick. The doctors are going to give him special 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 it out, or they might give her some special medicine to make it shrink."
- Emphasize that they cannot catch cancer or cause it.
- Prepare them for physical changes like hair loss, bruising, and weight loss or gain.

For School Age Children (6-10)

Focus on giving information and asking questions to start a conversation. Here are some suggestions:

- Leukemia: "Sammy has cancer. Have you 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 strong medicine called chemotherapy. It's called 'chemo' for short. The chemo will help make the leukemia go away." Emphasize that 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 one in Stephanie's brain. The tumor was pushing on the part of her brain that help 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 will get medicine to help her sleep and not feel anything."
- This age group may think cancer is contagious, like a cold, so making the distinction is important.
- It's appropriate to prepare this age group for physical and emotional changes.

For Tweens and Teens (11-18)

Start with the basics and then elaborate, depending on how much information they want to hear. Every child will want different amounts of information, and some may want to read about it themselves.

Suggested questions for conversation:

- What do you know about cancer?
- Do you think you can catch cancer? (No, it's not contagious.)
- Do you think cancer is caused by something someone did? (It's not!)
- 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 that you are loved?



How to Help Your Child During Their Sibling's Cancer Treatment

Siblings tell us the one thing they crave most is more time with their parents. We know how hard that can be, so remember that even brief, special moments can make a difference! [Here are 10 ways to support your SuperSib:](#)

1. **Keep your SuperSib informed.** This fosters a bond of trust that promotes healthier adjustment to the changes occurring within the family.
2. **Have family and friends ask you (or a designated point person) for medical updates rather than asking your SuperSib.**
3. **Encourage medical professionals, friends, and neighbors to greet and introduce siblings by their own names (not as “patient’s brother or sister”).**
4. **If siblings are unable to visit the hospital, connect through video chat or send photos through text messages.**
5. **Remind your kids that it is OK to laugh and have fun, even while a sibling is undergoing cancer treatments.**
6. **Try to set aside brief, special times alone with your SuperSib to take a walk, get ice cream, or read a book together.**
7. **Connect your SuperSib with other siblings.** Your social worker may be able to help connect you to other families, support groups, and community resources.
8. **Older children often fall into a “third-parent” role during treatment.** Avoid overloading your SuperSib with too many responsibilities, and instead call on family, friends, and community members.
9. **Ask your children, one-on-one, how they are doing.** Then, just listen. They have a life outside of cancer with their own hopes, dreams, disappointments, and successes.
10. **April 10th is National Sibling Day.** Use this day to celebrate your SuperSib!

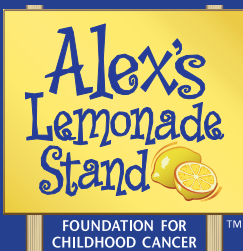
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About SuperSibs Powered by ALSF

Melanie Goldish founded SuperSibs in 2002 after noticing firsthand the impact of childhood cancer on siblings and recognizing the importance of giving them support and compassion too. Later, in 2014, SuperSibs became a part of Alex's Lemonade Stand Foundation (ALSF), a national nonprofit whose mission is to find cures for childhood cancer through funding innovative medical research and to support families throughout their journey.

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, Alex's Lemonade Stand Foundation, a registered 501(c)3 charity, has raised more than \$150 million toward fulfilling Alex's dream of finding a cure, funding over 800 pediatric cancer research projects nationally. In addition, ALSF provides support to families affected by childhood cancer through programs such as Travel For Care and SuperSibs. For more information on Alex's Lemonade Stand Foundation, visit [AlexsLemonade.org](#).

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[SuperSibs.org](#)

