



ALOPECIA AREATA SCHOOL GUIDE

*TOOLS FOR STUDENTS, PARENTS, AND TEACHERS
FOR SUCCESS IN THE CLASSROOM*



Alopecia Areata School Guide

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Section 1: Introduction

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Dear Parents, Teachers and School Faculty,

It is a mission of the National Alopecia Areata Foundation to ensure that families and schools have access to the resources they need to help promote alopecia areata awareness in the classroom. It is our responsibility to provide this information to you as it will enrich the curriculum and serve as an aid in giving students with alopecia areata, or other special needs, a positive and nurturing school experience.

In the classroom when teachers are planning their curriculum, meeting the special needs of children can be challenging, particularly when resources are not readily available. The purpose of the Alopecia Areata School Guide is to provide useful information to help both teachers and parents. It offers ideas about lesson plans and books to read, as well as feedback and insight from other teachers and parents.

As you're planning, it is important to consider the level of openness and maturity of the students. Challenges for a child with alopecia areata do vary, so take into account what particular struggles they face. It is also important to let the child lead at a comfortable pace. It often helps to implement discussions about alopecia areata, or self-esteem and differences, into the classrooms of students both younger and older than the child with alopecia areata; with a year more maturity and sensitivity, the older students will serve as advocates to their younger classmate, and the younger students will use their innocence to ask important and poignant questions regarding alopecia areata. All the students will learn a valuable lesson in humanity.

Once again, we hope you use this valuable aid when planning the curriculum for a class with a student who has special needs, whether alopecia areata or something else. We invite you to contact us with your personal experiences, or to request more insight regarding alopecia areata awareness in the classroom, including our seven-minute DVD available for showing to family, friends, school personnel, and peers.

Sincerely,

The NAAF Team

Things to Know about Raising a Child with Alopecia Areata

Parenting Strategies

My son has alopecia universalis. He had no hair for nearly six years before he turned 15 years old. Before that, he had mild, patchy alopecia areata.

During the first few years, we spent time seeing doctors, trying to figure out what the condition was and whether they could do something to make it better. My son had cortisone shots when he had the patches, which made the hair grow back, but then other patches developed. He used anthralin after his hair fell out; it made his scalp sensitive but didn't cause his hair to grow in the time that he used it.

So there it was. He had no hair. The first few months were very difficult for him. He tried to wear a hairpiece, but he didn't look like his old self and found it uncomfortable, so he wore it only once at a family wedding.

At school, kids teased him. The school principal once wanted him to take off his hat to show respect at a funeral, but fortunately someone spoke up for him and said that wasn't necessary.

Over the years while my son lost his hair, I watched him gain self-confidence. He appeared in the local newspaper and on television as a spokesperson for people with alopecia areata. I'm so proud of him. He has come a long way in dealing with not having hair.

I believe it's important for parents to feel that their child is okay just the way he or she is, with hair or without hair. Children's opinions of themselves are shaped by how they think their parents feel about them. If parents even hint that their child is damaged or is not quite the way he or she should be, the child will adopt these same feelings.

Everyone is unique, different from others in some way. To feel that everything will be okay (or better) if only the hair grows back sets up a possibility for long-term disappointment. If the hair grows back, it's wonderful, but it might fall out again. To count on something so unpredictable for self-esteem can be damaging.

I suggest finding (or starting) a local NAAF support group and attending with your child. Our night out together every other month has been a special time for me and my son (we drive one hour each way to these meetings). It has been meaningful to him to meet other people with alopecia areata, mostly adults, but also children, carrying on normal lives.

At our support group we have met quite a number of people with alopecia areata who have inspired us with their courage and humor in facing their condition, getting the best of it rather than letting it get the best of them.

Coping Strategies

Pediatric dermatologist, Dr. Nancy Easterly, suggests the following tips to help children deal with alopecia areata:

- Tell your child that it's okay to feel bad, to cry. But, after that, they need to move on and do what makes them most comfortable.
- Explain: "Maybe you have no hair, but we all have things to cope with in life. Other kids have other problems. It may be a little harder for you because everyone can see your problem, but it will help you to be a stronger adult. It will make you a better person, because you'll understand how other people feel when they have things that go wrong."
- If it is difficult for you to say these things to your child, don't be ashamed to seek counseling to help your child cope.
- Children with alopecia areata need to realize exactly what's going on in simple terms. Parents may think they're sparing the child by not discussing the problem, but in fact, they're probably creating much greater apprehension by avoiding open discussion.
- Teachers and parents need to remind other children that teasing is inappropriate, and they need to educate the children about alopecia areata.

(See section 2B on bullying.)

Classroom Strategies

When children return to school, and during the year, there's a lot of playing, yelling and running around, and lots of exciting new things to learn. A child who has alopecia areata may not join in the general excitement. What can you do to support the child who has little hair, who must face the daunting challenge of coping with what awaits them at school? Use this guide and the available DVD to help school administrators, teachers, and other students understand alopecia areata is important.



Tiny Ones

Little ones who are in day care or preschool, and many who are in kindergarten, really aren't affected by having or not having hair. At this age they adjust readily to whatever is going on. Hair is insignificant. The significance of not having hair, however, resides in their parents and other adults.

As parents, you're faced with dealing with other adults who make remarks, as well as your own feelings of pity, sorrow, guilt, and/or embarrassment that you take on for your child.

How you approach alopecia areata in your family will make a very big difference, especially as you work with teachers or preschool staff because they tend to adopt a similar approach in the classroom. A brief explanation to your child's caretaker or preschool will be very helpful along with this guide.

Kindergartners & Early Primary Students

Kindergartners and 1st and 2nd graders face comments from peers, who are usually just curious. Talking to both the principal and the teachers will ease curiosity, and soon no one will notice whether or not your child has hair.

A parent can't ignore a child's pain, but to buy into it will lay the foundation for the child to use their disease to escape future situations he or she doesn't want to handle or face.

Older Children and Teens

Beginning in the third grade, children become very aware of their appearance and they begin to judge themselves.

This reaches an extreme in the teen years when every hair has to be in place, the clothes have to be just right, etc. These are the painful years during which a child either develops strength of character or refuses to rise to the challenge.

There are many positive ways to provide support to children at this age:

- Consult the child often about how he or she would like to handle the problem. A child almost always has some idea about what would solve the problem. If possible, follow through with their desires. If not, it's important to explain why their solution won't work and then help them seek alternatives.
- Encourage the child to take up activities in which they can excel. From sports to science, your child will be able to find something he or she enjoys.
- Encourage your child to receive support from class members, teachers, coaches, etc.
- Continue to love and accept the child and talk with them about what they are thinking and feeling about themselves. Your efforts will eventually pay off!

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Self-Esteem & Students

Tips for Parents and Teachers

The school year can pose a particular problem for children who have alopecia areata. It is a time of life when school-age children and adolescents are especially sensitive about their appearance.

An individual's school experience can have a profound effect on the socialization process. Since most children are unfamiliar with alopecia areata, many are uncomfortable with interactions. Teachers can help the child with alopecia areata to cope and can help peers to be sensitive and understanding.

How you feel about yourself is, in part, a reflection of how you think others view you. As children grow and develop a greater sense of who they are, it is important that acceptance and integration exist for them. There are various factors that shape and affect self-esteem:

- **The respect, acceptance and concern of significant others.** “Significant others” change from family members for the very young child, to teachers for the school-age child, to peers for the adolescent. Giving others the opportunity to ask questions and to voice their concerns develops empathy, understanding and ultimately, acceptance.
- **A history of successes.** By encouraging recognition of the positives, children can form a basis in reality for self-esteem. Children can be “steered” towards experiences that are likely to be successful, in order to enhance a positive feeling of self-worth.
- **Values and aspirations.** The more successes we have, the higher our aspirations and expectancies of what we can achieve. People who have overcome their physical limitations can provide positive role models. Encourage the child's expression of thoughts, feelings and dreams.
- **Problem solving.** Teaching problem solving skills increases the likelihood that a child will feel a sense of control over life. Difficult situations can be viewed as learning experiences, rather than as a devaluation of self.

These ideas may be used as a starting point by parents and teachers inside the classroom and in the community. Most important is that the focus be creative and interactive. Remember that each child is an individual.

Adapted and reprinted with permission from AboutFace, Toronto, Ontario, Canada



Improving Self-Esteem

Self-esteem is important in and out of the classroom. Teachers and parents can support self-esteem by remembering some of the following:

- Always accentuate the positive
- Give children the opportunity to tell you 10 things they like about themselves
- Avoid criticism
- Always remember that self-esteem is about how much children feel valued, appreciated, accepted, loved and having a good sense of self worth
- Understand that as parents and teachers, you play one of the biggest roles in how good or bad a child can feel about themselves; avoid criticism; influence from a parent or teacher can make and break a child's sense of self-esteem; don't abuse it
- Expectations must always be realistic
- See the learning in errors or mistakes

Self-esteem is an important component to almost everything children do. Not only will it help with academic performance, it supports social skills and makes it easier for children to have and keep friends. Relationships with peers and teachers are usually more positive with a healthy dose of self-esteem. Children are also better equipped to cope with mistakes, disappointment and failure; they are more likely to stick with challenging tasks and complete learning activities. Self-esteem is needed life-long and we need to remember the important role we play to enhance or damage a child's self-esteem.

Adapted from About.com



Strategies for Teachers to Use to Help Raise Student Self-Esteem

- Use student names
- Have conversations with every student
- Provide multiple ways for students to be successful in your class
- Display student work
- Give each student a responsibility in the classroom
- Provide opportunities for student work to be judged by external audiences
- Take time to point out positive aspects of your students' work
- Never criticize a student's question
- Take time to help struggling students understand the material
- Try to get to know about the student's life outside of school
- Ask students about their other activities (ex. "How was the soccer game, Natalie?")
- Help students turn failure into positive learning experience
- Encourage students to take risks
- Provide opportunities for students to make their own decisions about certain aspects of your class
- Provide opportunities for students to work with each other
- Don't make assumptions about student behavior
- Allow students to suffer the consequences of their behavior-don't be overprotective
- Allow students to explore options in different situations
- Celebrate your student's achievements, no matter how small

Adapted from Teacher Talk, Indiana University

Facts about Bullying

Facts for Families about Bullying

Bullying is a common experience for many children and adolescents. Surveys indicate that as many as half of all children are bullied at some time during their school years, and at least 10 percent are bullied on a regular basis.

Bullying behavior can be physical or verbal. Boys tend to use physical intimidation or threats, regardless of the gender of their victims. Bullying by girls is more often verbal, usually with another girl as the target. Recently, bullying has also occurred in online chat rooms and through e-mail.

If you suspect your child may be the victim of bullying ask him or her to tell you what's going on. You can help by providing lots of opportunities to talk in an open and honest way.

It's also important to respond in a positive and accepting manner. Let your child know it's not his or her fault, and that he or she did the right thing by telling you. Other specific suggestions include the following:

- Ask your child what he or she thinks should be done. What's already been tried? What worked and what didn't?
- Seek help from your child's teacher or the school guidance counselor. Most bullying occurs on playgrounds, in lunchrooms, and bathrooms, on school buses or in unsupervised halls. Ask the school administrators to find out about programs that other schools and communities have used to help combat bullying, such as peer mediation, conflict resolution, anger management training, and increased adult supervision.
- Don't encourage your child to fight back. Instead, suggest that he or she try walking away to avoid the bully, or seeking help from a teacher, coach, or other adult.
- Help your child practice what to say to the bully so he or she will be prepared the next time.
- Help your child practice being assertive. The simple act of insisting that the bully leave him alone may have a surprising effect. Explain to your child that the bully's true goal is to get a response.
- Encourage your child to travel with friends to and from school, during shopping trips, or on other outings. Bullies are less likely to pick on a child in a group.

If your child becomes withdrawn, depressed or reluctant to go to school, or if you see a decline in school performance, additional consultation or intervention may be required. A child and adolescent psychiatrist or other mental health professional can help your child and family along with the school develop a strategy to deal with the bullying. Seeking professional assistance earlier can lessen the risk of lasting emotional consequences for your child.



Facts for Kids about Bullying

What to Do If You Are Bullied

So you're being bullied, huh? That can feel pretty awful. But no matter how bad it makes you feel sometimes, you should know you're not alone. That's right, there are plenty of kids all over the world who go through the same things you do every day. And even though you may feel helpless sometimes, there are many things you and others can do to help stop the bullying. Give these tips a try:

Always tell an adult. It's hard to talk about serious things with adults sometimes, but they can help put a stop to bullying. Tell an adult that you trust and can talk to—your parents, your teacher, your school counselor, your coach, or your neighbor.

Stay in a group. Kids who bully like to pick on kids who are by themselves a lot; it's easier and they're more likely to get away with their bad behavior. If you spend more time with other kids, you will not be an easy target and you will have others around to help you if you get into a difficult situation!

If it feels safe, try to stand up to the person who is bullying you. If the person who is bullying you thinks you won't do anything about it, they are more likely to keep picking on you. This doesn't mean you should fight back or bully them back. Instead, tell the person bullying you that you don't like it and that they should stop! Keep it simple. You might just say, "Cut it out, Miranda!" and then walk away. If possible, try to talk to them in a calm voice. Kids who bully often like to see that they can make you upset.

If you are being bullied online, don't reply. Replying may actually make the bullying worse. Instead, be sure to tell a family member or another adult you trust. If possible, block any more communications from this person. (It might be a good idea only to accept messages from people you know.) Save evidence of the bullying. If you get a nasty email, print it out or save it so that you can show it to an adult.

What NOT to Do If You Are Bullied

Don't think it's your fault. Nobody deserves to be bullied!

Don't fight back or bully back. This probably won't make things any better and it might get you into big trouble. Besides, you should try to act better than the person who bullies you.

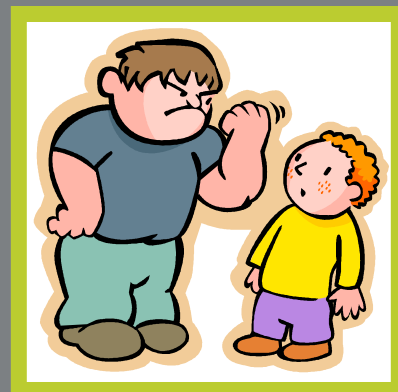
Don't keep it to yourself and just hope the bullying will go away. It's normal to want to try to ignore bullying and hope that it will stop—or hope that the person will start to pick on someone else. But often bullying won't stop until adults and other kids get involved. So be sure to report the bullying.

Don't skip school or avoid clubs or sports because you're afraid of being bullied. Missing out on school or activities that you enjoy isn't the answer. You have a right to be there!

Don't think that you're a tattletale if you tell an adult that you've been bullied. Telling is NOT tattling! It's the right thing to do.

Don't hurt yourself. Some kids who are bullied get so sad and depressed that they may try to hurt themselves because they think there is nothing else they can do. This definitely isn't the answer. Talk with an adult immediately and tell them how you are feeling. They can help stop the bullying.

Source: *United States Department of Health & Human Services, www.stopbullyingnow.hrsa.gov*



Sample Lesson Plans

Lesson 1

Continuum

Grade Levels 1-8

Overview: This lesson is interactive and helps students share and learn about each other, building a sense of community in the classroom.

Objective:

- To share and learn about one another
- To build a sense of community in the classroom

Materials: Space to move around freely

Activities and Procedures: The ideal group size is about 6 to 10 people. If you have more people, divide them into two or more groups.

Pick a theme and have the group arrange themselves in order creating a continuum. Give them enough time to sort themselves before moving to the next continuum. Always remember that the purpose is to get them talking and learning things about each other. The goal is not to create as many continuums as possible. Start with something simple like age or height. Then move on to more interesting topics like location of birth from East to West. Or try some of these ideas:

- According to the rainbow, by their favorite color
- Months of the year by birthday
- Time they woke up this morning
- The number of hours since they last watched TV
- The number of books they read this month

Create your own ideas based on the reason the group has gotten together.

Tying it all together: Try to choose continuums where being at either end is not about accomplishment. You might want to ask players on a new hockey team how many years they have played hockey, but not how many goals they scored last season. In a school classroom, you would not ask the kids to arrange themselves by how many "A" grades they got last year.

During this game, everyone should be having fun and learning something about the other people in their group.



Lesson 2

Who I Am Collage

Grade Levels K-6

Overview: It is surprising the range of knowledge and interests our students have, especially when we take the time to talk to them and learn. This activity gives students a chance to reflect on who they are and then to share that information in a fun way with their classmates.

Purpose: In order for students to build self-esteem they need to know who they are and what is important and unique about themselves personally. They also need to have a concrete way in a safe and supportive environment in which they can express what they feel about themselves. Students can become resident “experts” in the classroom. This lesson is one way of discovering what the range of knowledge is among a group of students.

Objective:

- Students will use an appropriate way to share facts about themselves.
- Students will become aware of the uniqueness of themselves and of others.
- Students will describe orally to a group of peers who they are.
- Students will find pictures or phrases to symbolize concepts of their personalities.

Resources:

- Magazines, 2 or 3 per student; include many areas of interest
- Construction paper, assorted colors
- Glue
- Scissors

Activities: Students will cut pictures or word phrases out of magazines that represent their personal interests and abilities. The pictures and words will be glued onto an 8 by 11 sheet of construction paper to form a collage. The completed collages will be displayed and numbered. Without discussion students will be given time to write who they think created each collage.

Tying it all together: Each collage will be identified by its creator who will then be allowed to explain it. Students love this activity. They also like the collages to be displayed for a couple of weeks. From time to time they will make comments about things they should have included or things that should have been included on a fellow student’s collage. Students love to find out about each other. They also love when a teacher creates a collage too!



Ideas from Other Parents

Included in this section are great ideas from parents of children with alopecia areata. These ideas are “tried and true.” They have been made extremely general so they can be readily adapted to fit any curriculum.

Idea 1

Talk to School Faculty in Advance about Wearing Hats

“One of the teachers suggested that my son be allowed to wear a hat all day in school. The administrator agreed, so I called all of the teachers and told them of the new plan. That way, my son would not get into trouble. What a difference! None of the teachers called attention to my son because of the hats, and he wears one every day. He has two or three hats he likes and wears them on different days. His friends think it is very cool! He is much more comfortable! Note: Talking to all his teachers and the school administration was the key to making this work. They discussed it as a group at their staff meeting so everyone was “on the same page.”

Idea 2

Get a Hat Pass

“Before my daughter began wearing her wig, she wore hats. After getting special permission from the school she was given a “hat pass” pin that she wore to school every day. If anyone questioned her about wearing a hat and breaking the rules she would show them her hat pass, no words had to be spoken. No adults questioned the hat pass.”

Idea 3

Create a Home DVD

“Last year my daughter made a three minute DVD in which she told her classmates about alopecia areata, and she then went on to take her wig off and talk about how it was made and how she cared for it. Most importantly, she told her classmates that she was a normal person and wanted to be treated that way. She encouraged her classmates to ask her questions if they wanted. She said she would rather tell them the right information than have people guessing. My daughter made the DVD in the privacy of our home so she didn't feel nervous and she appeared very confident. She said she probably could not have done it any other way. The principal heard about it and played it for the whole school as part of their morning news program. My daughter's self confidence sky-rocketed!

Idea 4

Show & Tell

“My daughter had mentioned to us that some children in her class were questioning her about her bald spots. There was some teasing from students. She decided to tell her teacher about her condition and ask if she could have Show & Tell about her alopecia areata. We prepared a poster on the positive and negative things about alopecia areata using her own words, and she drew a self-portrait of herself. I also prepared a letter to give to the parents of the children in her classroom to let them know what the Show & Tell was about. (The example that came with the NAAF DVD was very helpful). On Show & Tell day, our family went to the school and helped Caitlin with her presentation in front of thirty children. The children watched the DVD and then we talked about alopecia areata and how it makes my daughter feel. The children asked some very good questions and my daughter was a STAR that day! It is so true that when children understand something, they are less likely to tease another child. The posters that we made that day still hang in the classroom.”

Idea 5

Present the NAAF DVD:

Alopecia Areata: Why My Hair Falls Out

“We showed this DVD to all the children in my daughter's school. She was given the choice as to whether I would be present or not. She chose for me NOT to be there, and instead did it with the assistance of the school nurse, the principal, and the school counselor. This was a good idea because they felt that my presence might prevent the children from speaking their minds.”

School-wide Awareness Projects and Fundraisers

Example 1: “Funds were raised by selling daffodils to students and staff. The daffodils were grown from our own class garden. This is our fourth annual Daffodil Drive to benefit the National Alopecia Areata Foundation.”

Example 2: “We recently held a fundraiser sponsored by the Eastwood PTO. We have two students and one staff member who have alopecia areata. The staff member and one of the students are mother and son. When one student was diagnosed we realized that there was not enough awareness of this disease. It was then that we decided to hold a fundraiser to increase awareness. We issued a challenge to the students of Eastwood and their families. This challenge was to raise \$500 in a two-week period. We asked the students to bring in their loose change in sealed envelopes or baggies with their teacher’s name on it. We kept track of the amount of money coming in by classroom, and the classroom that raised the most money got a pizza party. The teachers kept track of each student who donated. But the grand prize for all the students, if they met the challenge, was the principal had agreed to dance at our Luau in a grass skirt. The students stepped up to the challenge and met it, they went past the \$500 goal and then received a check from a local business for \$500, and the Eastwood PTO kicked in the rest to make our total \$1,700. Our principal not only danced in a grass skirt, he also wore a coconut bra (over a t-shirt), which thrilled the students and their families. Each student who donated to the fundraiser received a helping hand certificate.”

Example 3: “Our school had a ‘Festival of Kindness’ recently and our students made hats so that NAAF could give them away to people who would enjoy them. We are a K-4th grade school with 565 students.”

Example 4: “Every year the seventh and eighth graders at my school put on a week-long musical performance and they designate one evening to be a benefit performance, with all proceeds going toward a special charitable organization. The cast and crew voted to support NAAF for the 2012 production. The cast and crew worked together for three months to put together the full-length, Broadway version of Beauty and the Beast. The performances were all spectacular, and at intermission several eighth-grade members of the cast presented the funds raised to representatives of NAAF.”

Example 5: “When my daughter first began losing her hair she talked to her class at school and showed the NAAF DVD, Alopecia Areata: Why My Hair Falls Out. We were very lucky that I work with someone whose daughter also had alopecia areata and thus had immediate access to all the NAAF information. Despite educating her own class this student was still experiencing teasing from other students in the school. The school administration at North Saanich Middle School has been fabulous, particularly my daughter’s teacher. After a few bad episodes at school, it was decided that the education program needed to be spread throughout the entire school.”

“My daughter’s teacher came up with the idea of explaining alopecia areata to the whole school and also conducting a fundraising event for NAAF. During the last week of May, my daughter went to every class in the school and gave an explanation of alopecia areata and answered questions. Students were asked to bring in a donation for NAAF at the end of the week. Those students who brought in a donation were allowed to wear any hat to school on the Friday following the event (hats are not normally allowed at school). The incentive to bring in donations was that if the school supported NAAF, my daughter’s teacher would shave her head in support of my daughter and NAAF. The class in the school that raised the most money would get to help shave her head. On June 4th, near the end of the school year, the teacher’s head was shaved with my daughter getting the first cut with the razor!”

“Since this event, my daughter now feels very comfortable at school and does not try to cover up her head. It is true that awareness is an amazing educational tool.”

Example 6: “My daughter and her friend decided to make angels and sell them at their school’s Christmas store. The girls chose NAAF as the organization to receive all the money they earned. The two girls (and both Moms!) ended up making 80 angel pins and Christmas ornaments to sell at the school’s Christmas Store. The pins were a big success to say the least. A few more of my daughter’s friends came to her after the event and said they wanted to donate their profits as well. Also, other friends at her school will be donating their profits to NAAF directly.”

Recommended Reading

For Children

A Button in Her Ear

Author: Ada B. Litchfield; Illustrator: Eleanor Mill
Albert Whitman & Company, 1976
ISBN 0807509876

A little girl relates how her hearing deficiency is detected and corrected with use of a hearing aid. It's a universal lesson in difference and compassion.

Arnie and the New Kid

Author: Nancy Carlson
Puffin Books, 1990
ISBN 0140509453

When an accident requires Arnie to use crutches, he begins to understand the limits and possibilities of his new classmate, who has a wheelchair.

Different Just Like Me

Author: Lori Mitchell
Charlesbridge Publishing, 2001
ISBN: 1570914907

While preparing for a visit to her grandmother, a young girl notices that, like the flowers in Grandma's garden, people who are different from one another also share similarities and it is okay to like them all the same. There are games and a five day lesson plan available at www.differentjustlikeme.com/educatorsresources.html as a resource for educators who use this book in the classroom.

Elmer

Author: David McKee
Thomas Nelson Publishers, 1991
ISBN 0688091717

Elmer the elephant has bright colored patchwork all over. No wonder the other elephants laugh at him! If he were ordinary elephant color, the others might stop laughing. That would make Elmer feel better, wouldn't it? The surprising conclusion of David McKee's comical fable is a celebration of individuality and the power of laughter.

Feeling Sad

Author: Joy Berry; Illustrator: Maggie Smith
Scholastic, 1996
ISBN 0590623877

Through this interesting story Joy Berry explains how to handle even the toughest situations and emotions.

Just Like Everybody Else

Author: Jim Pierson
The Standard Publishing Company, 1993
ISBN 0874038421

Derek's teacher says a new girl with cerebral palsy is joining their class on Monday. Derek is worried. What will Amy be like? What will he say to her? How should he act? A Saturday outing with Granddaddy helps Derek understand that people with disabilities are really just like everybody else!

Lionel Learns What Matters Most

Author: Julie Merberg
Roundtable Press, 2003
ISBN B0050MM77M

Available only through the National Foundation for Ectodermal Dysplasias.

Inspired by children who are affected by ectodermal dysplasias, a genetic birth disorder, this story is about a cub who struggles with being different, and discovers that by being different he has many gifts to offer the world.

Little Cloud and Lady Wind

Author: Toni Morrison & Slade Morrison
Simon & Schuster Children's Publishing, 2010
ISBN 1416985239

Little Cloud drifts alone not wanting to blend into a group. Lady Wind teaches her she is part of everything.

Princess Alopecia

Author: Yaacov Peterseil; Illustrator: Avi Katz
Pitspopany Press, 1999
ISBN 0943706262 (hardback); 0943706254 (paperback)

Princess Alopecia is the first picture book aimed at young children with alopecia areata and their friends.

The story line, supported with colorful illustrations, details the physical development of alopecia areata and the emotional roller-coaster ride for Princess Alopecia. The book provides an excellent way to introduce and explain alopecia areata to young children and may encourage children to talk about their feelings and thoughts on hair loss.

Rosie . . . the Imperfect Angel

Author: Sandra Lee Peckinpah; Illustrator: Trisha Moore
Scholars Press, 1991
ISBN 0962708060X

In classic fairytale tradition, Rosie, the imperfect angel, tells of a little angel who suffers from the taunts of her angel peers and her own poor self-image. With loving guidance, Rosie triumphs and assumes her own unique place in a family in the Land Called Below. This book addresses the challenges for children with birth defects or traumatic injuries, and foretells a happy ending.

Sassafras

Author: Audrey Penn; Illustrator: Ruth E. Harper
Child Welfare League of America, 1993
ISBN 0878685855

When Chester the raccoon is reluctant to go to kindergarten for the first time, his mother teaches him a secret way to carry her love with him.

The Princess Who Lost Her Hair: An Akamba Legend

Author: Tololwa M. Mollel; Illustrator: Charles Reasoner
Troll Association, 1993
ISBN 081672816X

This story accurately reflects alopecia areata. The book is based on an East African legend about a princess who was very proud of her hair but lost it in a gust of wind. This book could be used as a spring board to discuss alopecia areata with young children. ***Winner of 2000 Gold Triangle Award***

The Paper Princess

Author: Elisa Kleven
E P Dutton, 1994
ISBN 0525452311

This is a classic lost-and-found story, but for children with alopecia areata it has an added dimension.

This is My Hair

Author: Todd Parr
Little, Brown & Company, 1999
ISBN 0316692360

This short story tells children that they need to feel good about themselves no matter how their hair looks. It's cute and colorful and good for the younger audience.

Where the Sidewalk Ends

Author: Shel Silverstein
HarperCollins, 1974
ISBN 0065256672

Shel Silverstein's masterful collection of poems and drawings is at once outrageously funny and profound.

For Young Adults and Adults**Alopecia Areata**

Author: Janey Levy
Rosen Publishing Group, 2006
ISBN 1404206930

This book provides information about the history and future of alopecia areata research.

Alopecia Areata: Understanding and Coping with Hair Loss

Author: Wendy Thompson & Jerry Shapiro
Johns Hopkins University Press, 1996
ISBN 0801853524, 9780801853524

This is a helpful book about alopecia areata. It is informative, guiding readers to better understanding the disease and it is easy to read. This book lends friendly advice about dealing with the many physical and psychological challenges of alopecia areata. Treatments are discussed as well as the process of purchasing wigs and hats.

Because of Anya

Author: Margaret Peterson Haddix
Simon & Schuster Books for Young Readers, 2004
ISBN 0689832982

In this heart-tugging story of friendship, renowned author Margaret Peterson Haddix introduces readers to a young girl with alopecia areata, a life-altering disease that affects millions of people in the United States.

Boys Know It All: Wise Thoughts and Wacky Ideas from Guys Just Like You

Authors: Michelle Roehm & Marianne Monson-Burton
Gareth Stevens Publishing, 1999
ISBN 1885223870

Boys Know It All is a book where boys speak their piece about what it is to be a boy. Boys ages 6 to 16 have written chapters offering helpful hints for tough situations, like talking to girls, surviving siblings, and growing up male in America. Boys and their parents can gain interesting insights into the minds of other young men. Some articles are all for fun, while others tackle more serious subjects.

Girls Know Best: Advice for Girls from Girls on Just About Everything

Authors: Michelle Roehm & Marci Doane
Turtleback Books, 1997
ISBN 0836824520

A young female reader remarks, "This was a great book, full of samples of different kinds of writing, and good advice on, as they say, just about everything. From babysitting to eating disorders, from the environment to depression, this is a wonderful can't-put-down book. Although this book does not specifically deal with alopecia areata, it does give advice on things that are hard to talk about, especially things in young women's lives. This is a good book for mothers and daughters to read together.

Herman

Author: Lars Saabye Christensen
White Pine Press, 1992
ISBN 1-877727-245

Herman is not that different from other 11-year-old boys, except that he's going bald! Presented with this dilemma, Herman uses his fertile imagination and a comical viewpoint on life to navigate through the rough seas commonly known as growing up, and in the process he teaches everyone something about friendship, courage, acceptance, and love.



How to Raise Your Self-Esteem

Author: Nathaniel Branden
Random House Digital, 1988
ISBN 0553266462

A reader writes, "Picking up this book was one of the most positive things I've ever done. You don't need to have problems or need therapy in order to benefit greatly from reading this book." This book will help you to have more self-esteem and confidence in yourself, in your career, in your relationships and in your dreams. This is not a book about wallowing in self-pity or blaming others for how you feel about yourself. Branden's message is simple and effective. With some simple exercises, he shows you how to achieve more self-esteem and have a happier mental attitude.

I'd Rather Laugh

Author: Linda Richman
Hachette Book Group, 2001
ISBN 0446526762

This is a very funny and poignant book about Linda Richman's life, which has had many ups and downs. A lot of Linda's life experiences have been sad, but, like life, there is good to outweigh the bad. She talks about coming out of the abyss of helplessness and describes the sometimes crazy and funny ways she found joy and happiness again.

Life Strategies: Doing What Works, Doing What Matters

Author: Phillip McGraw
Hyperion, 2001
ISBN 0786884592

Do you feel that you're capable of more than what you are actually accomplishing in your life? Dr. Phil is a no-nonsense writer. This is not a soft, feel good book. Dr. Phil challenges the reader to look at his or her life, taking an inventory of it, and then he guides them to make choices that will support a fully functioning life. His Life Laws and Life Strategies will help to eliminate negative and destructive thoughts and teaches you how to reach positive life goals. Dr. Phil's message is that people can take control of their lives.

Making Every Day Count: Daily Readings for Young People on Solving Problems, Setting Goals, and Feeling Good About Yourself

Authors: Pamela Espeland & Elizabeth Verdick
Free Spirit Publishing, 1998
ISBN 1575420473, 9781575420479

This is a book that helps young adults face life challenges. It contains 365 days of inspiration, affirmation and advice. It helps kids plan for the future and learn how to appreciate their unique qualities. Each entry includes a thought-provoking quotation, a brief essay, and a positive "I" statement that personalizes the entry.

Pulling Your Own Strings: Dynamic Techniques for Dealing with Other People and Living Your Life as You Choose

Author: Wayne Dyer
HarperCollins, 1991
ISBN 066109224

Dr. Wayne Dyer has a compassionate and understanding way of helping people. He shares how we can prevent ourselves from being victimized by others and begin to operate from a position of personal power. He teaches you how to free yourself from your own limiting beliefs and start recognizing your own personal power.

The Blue Day Book

Author: Bradley Trevor Grieve
Andrews McMeel Publishing, 2011
ISBN 1449414044, 9781449414047

This book is the perfect medium for taking your mind to a positive place no matter how bad you feel. The match between the pictures and thoughts are perfect on every page. This is a book for all ages. It will provide a refreshing pause, so you can regain perspective. This book shows you the human condition as seen through the eyes of animals.

The Seat of the Soul

Author: Gary Zukav
Simon and Schuster, 1999
ISBN 067169507

Gary Zukav talks about the spiritual (not religious) aspects of life. He describes personal responsibility and taking control of the way that you live and feel. This book helps a person to become a better person. One reader commented, "This is a book that allows you to grow . . . to understand life a little more . . . see it through more positive eyes . . . to see others with kindness and understand other's behavior even when they seem like "mean" or "bad" people.

When Bad Things Happen to Good People

Author: Harold S. Kushner
Random House Digital, 2001
ISBN 0805241930, 9780805241938

This book was written to help people who have lost faith and hope learn how to cope and accept the life challenges they are being offered. It's a tool to direct people who are really searching for peace. A reader commented, "Everyone at some time in their life is overwhelmed emotionally by a loss or other crisis . . . it will enable one to endure the unbearable and keep life in perspective." This book is good for anyone who has suffered a loss.

A Story for Sarah: A Children's Story



Once upon a time in an enchanted land very far away, where dragons lived and worked as we do today, there lived a little girl dragon by the name of Daphne Veriprettie. Like all the other dragons, Daphne's scales were the prettiest in the land. If even the smallest beam of light were to touch one of Daphne's scales, the scale would shimmer and sparkle in colors of blue, green and lavender. Daphne was the envy of all her classmates.

One morning when Daphne awoke, she noticed that a few of her beautiful scales lay lifeless and gray in her dragon bed. She had seen this happen before but there seemed to be more scales this time. Daphne looked very closely in the mirror but could not see where the scales had come from so she decided it was nothing important and went on to school. The next morning there were more gray lifeless scales and the next morning more and next even more.

Daphne went running to her mother because she would not find the spots, where once sparkling scales were, only soft pink appeared. Mrs. Veriprettie also became worried and said, "We must go see Doctor Fixit." Dr. Fixit was a well known Scalotologist in the Land of Dragons and Daphne felt better because Dr. Fixit had easily cured the small rash which had appeared on one of her delicate wings.

After checking the places where Daphne had lost her dragon scales, Dr. Fixit said, "Well, Daphne, you have what is called Scalopecia Departus." He also explained, "Scalopecia causes your scales to fall off for some unknown reason but will not harm you any other way. Unfortunately, the treatments we have to make your scales grow do not always work and you may continue to lose your scales after the treatments. If your scales come back," Dr. Fixit added with a sigh, "they will do so on their own." Daphne was sure her beautiful Dragon scales would not leave her forever so, with that thought, she went on with her happy dragon life.

But, as each day passed and turned into weeks, her dragon scales continued to disappear, to be replaced with the soft pink skin. Daphne became so unhappy that even her best friends, Phyllis Faithful and Lance Caring, could not cheer her up. After all, very few dragons in the Land of Dragons had ever heard of Scalopecia, let alone seen it. Daphne no longer wanted to go to dragon school or to be a part of dragon playtime. Even though Phyllis and Lance were always there, Daphne knew that Benny Bozo, the dragon school bully, and Veronica Snobb, a schoolmate who had always envied Daphne's scales, were making fun of her.

And then one day it happened. Benny and Veronica walked to the table where Daphne, Phyllis and Lance were sitting eating their lunch. Benny and Veronica began to call Daphne names, make fun of her soft pink skin and tease Phyllis and Lance for being with Daphne who they said, "didn't even look like she belonged in the Land of the Dragons." Both Phyllis and Lance tried to explain what had caused Daphne's scales to disappear, but Benny and Veronica would not listen, they just made fun. Daphne could take it no longer and burst into tears. It was then that Lance quietly stood and calmly said to Benny and Veronica, "you have done what you planned to do, made Daphne cry because of something which she cannot change. Maybe it's time for you to leave." To the surprise of all, Benny and Veronica walked away.

"Oh," sobbed Daphne, "why do you stay with me? I don't even have my beautiful scales and I don't even look like I belong in the Land of the Dragons. I should just leave so you won't have to listen to Benny Bozo and Veronica Snobb anymore," Daphne suggested. Lance and Phyllis looked at each other in surprise and Phyllis said, "Why, Daphne, we like you! Even when you had the most beautiful scales in the land, you liked everyone."

"Yes," added Lance, "your scales did not make you a beautiful dragon-it was you and what you have inside that made me want to be your friend.

Just because you don't have scales does not mean that you aren't an important dragon friend to me and no one but you will change that," Lance stated as he hugged Daphne. Daphne knew she was lucky because she had two very good dragon friends and wondered, "Why are there dragons like Benny and Veronica?"

As Daphne thought about Benny and Veronica, she began to realize that Benny was not very happy. His dragon parents didn't pay much attention to him and he didn't have many dragon friends. The friends Benny had seemed to be afraid of him more than being his friends. Maybe Benny could only feel better about himself by being more powerful than the other dragons and to do that, he had to bully them.

But what about Veronica who seemed to have everything? Maybe she didn't have everything or, maybe, wanted more. Veronica had always envied Daphne's scales and now that Daphne didn't have them, Veronica could make herself more important. Maybe, Veronica was very unhappy with her life because she thought a person's looks made them important! Daphne had learned from Lance and Phyllis that looks didn't make you important to the dragons, who really were true friends. Daphne hoped that Benny and Veronica would be able to learn that same day. Daphne began to feel better about herself. Oh, there were days when she dreamed of having her beautiful scales come back, but she also knew having good friends was more important. Daphne was a little afraid of when she grew older, when she wouldn't have Lance Caring and Phyllis Faithful close by her side. She knew there would be more Caring and Faithful friends to meet.

Daphne had a full and maybe different life to look forward to. She was not going to let her Scalopecia Departus stop her from meeting all those wonderful and very special dragons in the Land of Dragons. Lance and Phyllis had helped her find the beauty inside which made her a very pretty dragon indeed.

Celinda's Dance

By Lesa Fichte

Celinda was very glad she was a porcupine. She was smart and fun and a very good swimmer. When Celinda walked down the path in the forest, she felt good about herself. Every day she played games with her friends and the bright sun made her long quills sparkle.

One sunny morning, Celinda got up for a new day of chasing butterflies and playing with frogs. It was already hot, but Celinda felt chilled so she walked out to the flat rock in the buttercup field and lay down to sun herself. Along the ivy path came Topper and Sassie as they were looking for Celinda to come and play with them.

"Celinda! Celinda!" they called out. Celinda stirred from her nap and hearing their voices replied, "Here I am – on the rock in the buttercup field."

Topper and Sassie ran over but, they stopped suddenly when they saw Celinda. At first their eyes grew wide and then they burst into laughter holding their sides as they rolled in the buttercups.

"What's so funny?" asked Celinda.

Topper stopped laughing long enough to shriek out, "Your quills are gone!" He and Sassie ran off through the fields shouting "Celinda lost her quills! Celinda's bald!"

Slowly, Celinda looked down at her body and saw bare patches on her skin where her beautiful quills used to be.

"I must be sick!" thought Celinda as she ran off in to the forest to find her mother and father.

When Celinda reached the forest, she found her mother hunting berries down by Blackrock Creek.

"Look, Mother!" Look at what has happened to me!" cried Celinda.

Celinda's mother looked at her and began to cry, wailing out songs of pain... "Why, oh, why? Why my beautiful Celinda? What did we do to deserve this? How can it be?"

When Celinda's father saw her, he was embarrassed and did not want others in the forest to see Celinda without her quills. He ran off to the crabapple grove to gather thorns and moss. For two days and two nights, Celinda's father worked to weave the moss and thorns into a coat Celinda could wear to cover her bare skin.

When her father came to her with the coat he had made, Celinda's eyes were very red from crying. Celinda and her mother had gone to several doctors to find out the reason why her quills had fallen out. At first, none of the doctors could give them an answer, but when they saw Dr. Oliver Owl, he said that Celinda had alopecia areata. As there was not yet any successful treatment, Dr. Owl advised them that the quills might grow back on their own or that they might never return. He also suggested they contact the National Alopecia Areata Foundation for information and the address of a local support group. There are also pen pals – others with alopecia areata who would write letters to Celinda and be her friend.

None of this made Celinda feel any better and she was very sad. Her mother felt guilty that she could not help Celinda and she tried to be strong for the both of them. She told Celinda that the quills did not really matter, as she was healthy and also a kind porcupine. "True beauty is on the inside," she said as she rocked Celinda in her arms.

Celinda looked at the coat her father made from moss and thorns. It had a little hood with openings for her ears and a little flap that covered her forehead. It was a nice coat and while it did not look like real quills, Celinda put it on because it was better than being bald.

Celinda's grandmother had told her to be brave and to believe in herself. As Celinda thought of those words she felt a bit better so she wiped her nose on a dandelion leaf and went down the path to find Topper and Sassie.

"Topper! Sassie!" Celinda called out. When she finally found them, they were eating blueberries near Widow Tanner's old barn.

"You sure look stupid!" snapped Topper when he saw Celinda in her coat. Sassie did not say anything, but backed away as Celinda came closer.

"What's the matter, Sassie?" asked Celinda. Sassie did not answer and ran away because she thought she might catch whatever made Celinda's quills fall out.

"Why are you wearing that awful coat?" asked Topper as he looked closely at Celinda. Celinda said nothing because the tears were running down her cheeks and her throat felt like she had eaten barbed wire.

"I'm sorry," said Topper. "Let's just forget about it and go play." Celinda nodded and followed Topper down the path. They laughed, chased butterflies, played tag and did all the things Celinda liked to do before she lost her quills.

Along the way to Crawdad Pond, Celinda and Topper met some of their friends. No one said anything to Celinda about her coat, but when she wasn't looking, some of them giggled and made jokes.

As it was very hot and Celinda loved to swim, everyone decided to take a dip in Crawdad Pond. The cool water felt wonderful to Celinda as she dove into the pond. When she climbed out onto the bank, Celinda didn't hear anything at first because there was water in her ears. As Celinda shook out the water, she heard the loud laughter. She turned around slowly and was horrified to see her coat floating in the pond.

Celinda quickly snatched her coat from the water and ran off into the forest. When she reached home and told her parents what happened, they decided they needed a fresh start away from all the porcupines who knew about Celinda's quills. They packed all their belongings that afternoon and moved to another valley where no one knew them.

Her father made Celinda a new coat and it was much better than the first one. No one could tell that it was not real unless they looked very closely or touched it as her father had mixed in a few of his own quills to make it look real.

Celinda went to school in the new valley, played in the band, took meals to sick friends and did everything she liked to do – except swimming. Whenever it was time to swim with her friends, Celinda would say that she heard her mother calling and scurried off.

After ten springs, Celinda's quills still had not grown back, and she wanted more than anything to go to the annual Chestnut Dance. Everyone had a date, but no one had asked Celinda so she decided to stay home and take care of old Myra Bear who was sick and needed someone to gather berries for her. Celinda found an old coffee can by the highway and she carried it off with her to put berries in, as Myra was very hungry. Celinda had already been in the blueberry patch for an hour when she looked up and saw someone watching her.

"Hello, Celinda," said the stranger.

"Who is it?" asked Celinda. "I can't see your face because the sun is in my eyes."

The figure moved slowly down the bank and before her stood the most handsome porcupine Celinda had ever seen.

"Don't you remember me?" asked the stranger. "Well... perhaps you don't. I wasn't very nice to you the last time I saw you."

The voice was very familiar to Celinda, as were the mischievous eyes. "Topper!" she cried as she suddenly recognized him. Celinda had missed him so much and wanted to hug him but was afraid because she did not want him to touch her coat.

"I've just moved to this valley," said Topper, "and I've been hoping to find you."

Celinda did not know what to say and she looked at the ground, rubbing the pebbles with her toes.

"The Chestnut Dance is tonight," said Topper. "Would you like to go with me?"

"I... I... ccccan't!" stammered Celinda. "I have to take care of Myra Bear."

"My mother will take care of Myra Bear tonight," offered Topper.

"I still can't go and you know why!" shouted Celinda and she ran down the path into the forest before Topper could stop her.

An hour before the dance, Celinda sat at the bottom of her favorite oak tree. "How can I go to the dance?" thought Celinda. "I'm so ugly Topper would never want to touch me... He's probably just feeling sorry for me." Up between the branches of the great oak the first star twinkled down on Celinda. She made a wish for long beautiful quills so she would look like everyone else.

The sound of footsteps woke her from her dream and when she opened her eyes, Topper was standing there. "It's time for the dance, Celinda."

"How can I go to the dance with this awful coat?" screamed Celinda. She tried to run away, but Topper stopped her and said "Take off your coat." Celinda stopped in her tracks. No one but her parents ever saw her without her coat.

"I like you, Celinda. Your coat doesn't matter because I like you – your laugh, your smile, the nice things you do for others... Take off your coat and come to the dance."

"Everyone will laugh and stare!" cried Celinda.

Topper was quiet for a moment and then he spoke – "Wait here and I'll be back in ten minutes. He ran off down the path before Celinda could say anything. Just as he had promised, Topper returned and he was carrying the most beautiful flowers Celinda had ever seen.

"Take off your coat," asked Topper once again and Celinda trusted him enough to take off her coat. Topper took the flowers and wrapped them around Celinda until she was covered with white roses and deep purple violets. To look at her, it was obvious that she did not have quills, but the coat of flowers was spectacular.

"You're beautiful no matter what you wear," said Topper tenderly as he kissed Celinda's cheek. Slowly, they walked out of the forest and down the hill to the Chestnut Dance.

When they arrived at the dance everyone grew quiet and watched as Celinda and Topper began to dance. She didn't look like the other porcupines, and for the first time, Celinda didn't care. Celinda felt beautiful as she and Topper danced in the light of the moon. While they were dancing she thought about her life...

"It's hard being different and not having quills. I have to be strong and remember that there are things more important than quills. I need to like myself and believe in myself the way Topper likes me and believes in me. I promise I'll never stop doing the things I like to do just because I don't have quills."

Celinda knew tomorrow would not be easy, but she decided she was going swimming – without quills, without her coat, and even without Topper's flowers. Tomorrow would be a very special day.



Section 3: Tools for Parents

- A. Advice for Parents from Parents
- B. Sample Letters from Parents to Other Parents
- C. Do You Need to Construct a 504 Plan?

Advice for Parents from Parents

Advice 1

It is an important part of my life to reach out to children who have alopecia areata and offer my support by helping their schools better understand how alopecia areata affects a child emotionally, socially, and academically.

Recently, a mother contacted me and asked for help to educate her daughter's classmates, a group of seventh graders, about alopecia areata. NAAF had already provided her with the DVD, *Alopecia Areata: Why My hair Falls Out*. Sharing about her daughter's disease caused the mother great emotional stress. As a parent of a child who has alopecia areata, I know the devastation she feels. I offered to go to the child's school to be her advocate, and the mother set up a meeting with the teacher, principal, and faculty to view the DVD. They decided that it would benefit the child if her classmates also watched the DVD, and if someone could be present in the classroom to answer inquiries.

I had met the child's parents at a support group meeting and understood what they wanted, but I also felt it was important to know what the child wanted. I felt it was important to talk to the child about what a difference talking to her classmates might make, as well as to understand her fears, likes, and dislikes. I wanted to know the child's thoughts and concerns, and determine if she was ready to share her condition. Would she feel more comfortable out of the class while I discussed alopecia areata with them? Did she want her mom to be there?

The child told me that she didn't want her mom to be there, that she wanted to do this on her own. I agreed to talk with her mom and to explain her daughter's feelings. I did ask the child one favor (she had never met anyone with alopecia areata); I asked her if she would watch my daughter in the library and read her books while I talked to her class. She agreed.

I learned that the child was afraid of meeting a little girl that was totally bald. She feared that she might have to face total hair loss someday too. Nevertheless, I knew that once she met my daughter, she would see her as a normal kid, just like herself.

I explained to the child that since my daughter was so young, I could introduce her to the class as an example of what a child who has alopecia universalis looks like so that they could better understand how the disease can progress. Each person with alopecia areata has to face the possibility of their condition progressing to alopecia totalis or alopecia universalis. The child had to understand this as well, as she faces an unpredictable journey.

Before we had left the house that morning, the mother called me and said, "My daughter wants me there!" I said that was wonderful. After all, she was taking a huge step in her life. The child was scared, not so much about sharing her alopecia areata, but about meeting my daughter and facing the possibility of losing all her hair. I was concerned for the child. For a moment I wondered if meeting my daughter might be harmful for her? But I knew that once she met my daughter she would be okay. This was one more step the child had to take on her journey.

I took along a display board on which I hung photos of people with alopecia areata (of all ages), some NAAF brochures, and copies of the story "Celinda's Dance" by Lesa Fichte and is great for teachers to read in the classroom.

Upon arriving at the school, I met with the principal, and then I met the child for the first time. She was shy and scared. The mother arranged to bring my daughter back to the child soon after my daughter met the students.

We took my daughter right into the classroom. I introduced her (she was wearing a hat) and said I was there to talk to them about a condition that my daughter has (she then removed her hat) - alopecia areata. The expressions on the students' faces were a mixture of curiosity and sadness, and some of them even looked speechless. I said, "Most of you may think my daughter has cancer, or has had chemotherapy treatments, but this is not true. My daughter is perfectly healthy and normal and she is full of life. She just doesn't have hair on her head, eyelashes, eyebrows, or anywhere on her body. We are very blessed my daughter has alopecia areata." My daughter then left to play with the other child with alopecia areata.

I then told the students one of their classmates also had alopecia areata and I was going to play a DVD about it. After the DVD, I talked to the kids about how to pronounce ALOPECIA AREATA, and I distributed one of the NAAF brochures.

I said, "Today, everyone in this room will become educated on this condition. You will probably know more than half of the doctors in the city. At the end of this day, I would like you to go home and share this with your parents, family and friends. Your parents are going to be really impressed that you know something that they didn't. If you or your parents have any questions, please call your school, NAAF, or you can call me." (I made sure to include my number on the back of the brochure).

I didn't know what type of response to expect from this group of kids. I think I jumped the gun thinking these 12-year-olds were not going to talk to me or ask questions. I was WRONG!

As I talked, I passed around the photo board and explained that you can develop alopecia areata at any age. "It doesn't matter if you're male or female, if your skin is light or dark. Your classmate developed alopecia areata at age 12 and my daughter developed it at age one." I explained that their classmate "could lose all her hair, but then could re-grow her hair too. No one knows. However, what is most important is the way you treat a person that has alopecia areata."

I then asked, "Does anyone have allergies in the classroom?" And I noted, "You cannot catch an allergy from someone. Alopecia areata is not contagious so you cannot catch it from your classmate or my daughter. Your classmate's immune system is responding to her hair like it is an allergy. Her body is saying NO and will not let the hair grow on her scalp; it makes it go to sleep.

"How do you get it? Research is trying to find out. Nobody knows exactly what triggers the body to reject hair growth. Researchers are trying to find the reason for this. They are also trying to find an acceptable treatment and ultimately the cure. Until then, we must educate the public about it.

"Your classmate can do anything you do! She likes to swim, skate, and hang out at the mall, and when she is much older...go out on dates, get married, and have children. She is just like you. And can do the same things you do.

"Does anyone know how your classmate might be feeling? Sad, depressed—not well. It is hard for her right now; she is scared that she is going to lose all of her hair, and her self-confidence has dropped. She is embarrassed, angry, scared, sad, and yes, sometimes she feels depressed. It is tough for her right now. Can you put yourself in her place for a moment and feel how she might be feeling?

"Do you think your classmate wants you to feel sorry for her? Does she want your pity? NO. Your classmate does not want this. She wants you to treat her just like any other student. You can help her by just treating her normally, and by being a caring friend.

"If you see someone that does not know about your classmate's condition and is giving her a hard time, staring, pointing or poking fun, you can stand up for her in a very nice and informative way, explaining the situation to that person. You will be 'Promoting Awareness'. Your classmate would appreciate you helping her by sharing her condition with others."

The class came up with some great ideas to help their classmate feel comfortable with her condition. The boys were all ready to shave their heads! One student suggested having a scarf or hat day in honor of their classmate! The BEST IDEA OF ALL was that they wanted to educate the other classes in the school about alopecia areata. They could be the ones teaching the other students.

Kids together can make a huge difference if they understand and are educated. They have great thoughts and ideas and are very willing to help if they understand. They proved it that day in honor of their classmate and their friend.

I feel that it is important to be honest and up front about your child's alopecia areata from the very beginning. The longer you wait, the harder it becomes. If you get in there and educate others about this condition, it will become easier for your child to accept his/her condition and enjoy life the way a child should.

You can make a difference for a child who is out there suffering at school. The reward is priceless, knowing you improved the life of a child.

Advice 2

We have been supporters of the NAAF for several years; however, we have only recently realized the benefits of belonging to such a wonderful organization.

The first part of the year I contacted the office and asked for information for my son who had a social studies project entitled, "Bald is Beautiful." We were in a crunch for time so I offered to pay for having the information mailed overnight. The very next afternoon I received a package filled with information and two DVDs. This information was very helpful in preparing for this project.

We have also realized what a wonderful group of people belong to the NAAF. As we began to work on my son's project we thought it would be neat to include a collage showing pictures of people with alopecia areata. We went through all of our old NAAF Newsletters and used any addresses (pen pals, contributors, etc.) to mail letters requesting a picture. In all, we mailed 85 letters and within a ten-day period we received 40 responses! We never dreamed that so many people would be willing to help.

My son's project won first place at his school and the chance to compete at the regional fair. At the regional fair my son received Honorable Mention. We are very proud of him, not only because he did well, but because he has accepted his alopecia areata and now wants to help others to understand. My son had most of his hair at the time of the fair. His hair comes and goes. One year before the fair he had less than 20 percent of his hair.

Thank you so much for all of your help!



Advice 3

My daughter was diagnosed with this condition in the summer of 2007. Her condition went from small-to-medium patches of hair falling out to full baldness in early 2010. Today, she has about 80 percent hair regrowth 2+ inches long in places. Originally thought to be connected to stress, her dermatologist concluded she has alopecia areata. She had a biopsy taken of her scalp, which came back inconclusive, yet her doctor confirmed the alopecia diagnosis after she went fully bald. We have tried various topical medications, but truly believe alopecia has a mind of its own and runs its course no matter how you try to resolve it.

Of course hair loss will affect a person. And how it affects someone depends on all types of sociological, emotional well-being, and physical factors. My daughter's feelings have ranged from embarrassment to sadness to anger to understanding to coping to silliness to acceptance of her condition. In the 2009–2010 school year she was fully bald, which was the hardest time in the three and a half years alopecia areata has affected her. Kids at school were starting to make fun of her and that really hurt her feelings. To deal with it all, each year we have taken proactive steps to deal with her alopecia. I have given presentations at her school to help staff and students understand her condition. In daily life, we've had people ask us if she has cancer . . . and we always respond with "Thank God, no . . . just a condition called alopecia areata which makes her hair fall out." We try to maintain an attitude of gratitude that what she has is not a grave health issue. This past spring, my daughter decided she wanted to try wearing a wig. But that only lasted about a month as it was too cumbersome for her active life (at school and outside of school). For a couple of weeks, she would wear it only on the days she didn't have gym class at school. Then, she finally said, "I'd rather just not wear it at all." My daughter has the sweetest disposition and actually handles it very well. She absolutely encourages me with her attitude and bravery.

Today, my daughter aspires to be a model . . . whether she has hair or not. She has never let alopecia areata keep her from her favorite sport: gymnastics. Her friends have stuck by her from her full head of hair to baldness . . . and back again. She has a great support system at home and at school and doesn't let alopecia areata affect her in a negative way, mostly. We are now part of a National Alopecia Areata Foundation Support Group here in Kansas City where she is the youngest member. She likes being connected with others who have this condition and knowing she can learn from them.

I wish you the best of luck in your project and educating people about alopecia areata!

Sample Letters from Parents to Other Parents

Example 1

Dear Families,

Our daughter was diagnosed with a condition called alopecia areata. Alopecia areata is an autoimmune condition that has no other ill effect besides hair loss. Although our daughter is a healthy, happy seven-year-old, she began losing her hair one year ago and is now completely bald. Her hair loss often causes others to think she is ill with cancer or leukemia.

Because of our daughter's appearance, we wanted to share our story with you in hopes of answering any outstanding questions. Our daughter chose to attend this year's Back to School Open House, in August, not wearing a hat on her head. She regularly attends school wearing nothing on her head. This is a change from last year as she had consistently covered her head while she was losing her hair. Her change in appearance has generated some questions and concern for her well-being. We feel so fortunate that both the parents and children of Basswood are genuinely concerned about her health.

What is alopecia areata? Alopecia areata is a poorly understood autoimmune disorder. Like hay fever, asthma, and eczema, Rose's condition, alopecia areata, has a genetic predisposition and no cure. You can't "catch" alopecia areata, it is not contagious. When asked, we describe her condition as "being allergic to her hair," which is a simplified, not a medically accurate, description. Currently, there is no effective treatment for alopecia areata.

Alopecia areata affects people of both sexes and all ages, but is most common in children. It is a disease experienced by over 5 million Americans. There is no pain or discomfort, and the overall health effect is benign. The course of alopecia areata is highly unpredictable; hair can spontaneously regrow even after years of extensive hair loss. It can (and often will) fall out again. Although alopecia areata is not medically disabling, it often is, as you can imagine, very challenging emotionally. The emotional pain can be overcome with one's own inner resources and the support of others.

Although our daughter is comfortable in her appearance and often attends school without anything on her head, we have asked for and received permission from the principal to allow our daughter to wear hats to school if she so desires. As the temperatures drop in Fall and continue to drop in Winter, she may wish to wear hats to school for warmth. She has also requested that we purchase a wig for her just in case she would like to wear "hair" to school in the future. We are in the process of obtaining a wig for her.

As a result of our daughter's condition, we have become members of the National Alopecia Areata Foundation (NAAF). This organization provides information and support to those affected by this condition. One of the goals of the organization is to educate the public on this condition. In addition to this letter we are enclosing a pamphlet provided by NAAF, which offers information about alopecia areata. If you wish to obtain more information about alopecia areata or NAAF, you may do so by visiting www.naaf.org.

In a world where we are encouraged to accept all individuals regardless of our differences, we hope that you have found this letter to be helpful in educating your children. We appreciate you taking the time to read our letter and hope that you will share this information with your family. We feel education is vital, especially for children, in understanding people's differences.

We feel fortunate to have been given the opportunity to share our story with you. We are grateful for the staff at our school, who have embraced our daughter and have made her transition through these changes more manageable. Thank you for your time. If you have any questions regarding our daughter's condition or NAAF, please feel free to let us know.

Example 2

Dear Teachers and Staff,

Our son is starting kindergarten this fall. He has been diagnosed with a disease called alopecia areata. Alopecia areata is a highly unpredictable, non-contagious, autoimmune disease resulting in the loss of hair on the scalp and elsewhere on the body. The disease affects approximately 2 percent of the population. The hair follicles remain alive, but in a hibernation-like state with the possibility of hair regrowth at any time. Those who develop their alopecia areata in childhood usually have a poorer prognosis; this early-onset form is usually chronic and lifelong. In recent research there has been verification that a patient's own T lymphocytes (a major class of white blood cells, which are a vital part of the immune system) attack the hair follicle and suppress hair growth.

In a physical sense, alopecia areata is not disabling; persons with it are usually in excellent physical health. In an emotional sense, it can be challenging, if not devastating, especially for those with extensive hair loss. My son has been lucky so far to have healthy self-esteem and to be accepted by friends without being ostracized. He does experience hurt feelings from stranger's remarks and comments. This is where we would like to ask for your help! Knowledge is power and if his schoolmates are aware of our son's story, we believe that the teasing and harassment will be kept to a minimum. We would appreciate any help you can give in the education of others about alopecia areata. We would also like to know of any teasing of our son so that we can help him deal with it.

Our son has already gone through all the treatments available and appropriate for him; there is no cure for alopecia areata. He currently is not on any treatment. He does wear a hat for both emotional comfort and protection from the elements. Please let our son decide for himself if he needs to wear his hat or not. Please feel free to contact us with any questions, suggestions or comments.

Thank you for your help and support.

Do You Need to Construct a 504 Plan?

What is Section 504?

Section 504 is part of the Rehabilitation Act of 1973. It is an anti-discrimination law that protects people with disabilities.

How Will It Help?

If a child qualifies under Section 504, he or she may receive services or accommodations in the general classroom that can enable the child to be successful in school.

Most schools currently prohibit the wearing of hats within the classroom and many have adopted a school wide “no-hat” policy. So you might want to apply for an exception to this policy through the US Equal Employment Opportunity Commission under the Individuals with Disabilities Act (IDEA).

Please Visit This Website for a List of Resources:

<http://teachers.henrico.k12.va.us/exed/ExEdHCPS/504PlanLinks.html>

Other Reference Sites:

<http://www2.ed.gov/policy/rights/guid/ocr/disability.html>

<http://www2.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html>

Contact Information:

The ADA Information Line: 800.514.0301

US Employment Opportunity Commission (ADA): 800.669.4000





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