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"Education on the Move"

A Project Promoting
Alopecia Areata Awareness
In the
Elementary School Classroom



National Alopecia Areata Foundation
14 Mitchell Blvd.
San Rafael, CA 94903

www.naaf.org

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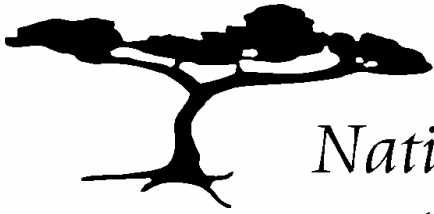
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Section 1

*** Introduction ***

- A. Introductory Letter to Parents, Teachers and School Faculty
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National Alopecia Areata Foundation

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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 that they need to help promote alopecia areata awareness in the classroom. It is our responsibility to provide this information to you as it will help enrich the curriculum of your school 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. When challenges are presented, it can be discouraging when resources are not readily available. The purpose of the *School Packet* is to provide useful information to help both teachers and parents, as it offers ideas about lesson plans, 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. You can 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, I hope you use this valuable aid when planning your curriculum for a class with a student who has special needs, alopecia areata or other. I invite you to contact me with your personal experiences, or to request more insight into what it is you bring into your classroom and into a child's future.

Sincerely,

Lisa Butler
Director of Support, Public & Government Affairs
National Alopecia Areata Foundation
lisa@naaf.org

Things to Know About Raising a Child with Alopecia Areata

To Help Cope

Pediatric dermatologist Nancy Easterly suggests some tips on helping children deal with alopecia areata:

- Tell your child that it's OK 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 go wrong."
- If it is difficult for you to say these things to your child, don't be ashamed to seek counseling in helping 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 educate the children about alopecia areata.

On Being a Parent

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. He 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 and 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 hair piece. He didn't look like his old self and found it uncomfortable; 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 it wasn't necessary.

Over the years while he lost his hair, I watched him gain self-confidence. He appeared in the local newspaper and on TV as a spokesperson for people with alopecia areata. I'm so proud of him. He came 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, hair or no 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 one another in some way. To feel that everything would be okay (or better) if only the hair would grow back sets up a possibility for long-term disappointment. If the hair grows back, it's wonderful, but you never know if it might fall out again. To count on something so unpredictable for self-esteem could be damaging.

I suggest finding (or starting) a local support group and attending with your child. Our night out together every other month was a special time for us (we drove 1 hour each way). It was meaningful to him to meet other people with alopecia areata, mostly adults, but also children, carrying on normal lives.

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



Children & School

When children return to school, 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?

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 the parents and other adults.

As parents, you're faced 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 the family will make a very big difference, especially for teacher's because they tend to adopt similar approaches in the classroom. A brief explanation to the child's care-taker would also be very helpful.

Kindergartners & Early Primary

Kindergartners and first and second 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 extreme in teen years when every hair has to be in place, the clothes have to be just right, etc., all just to make a merely acceptable human being. 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:

- Always *consult* the child 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 and help the child seek alternatives.
- *Encourage* the child to take up activities in which they can excel. From sports to science fairs, your child will be able to find something he or she enjoys.
- *Encourage* your child to receive support from class members, teachers, coaches, etc.
- *Keep loving, accepting, and talking and listening* to how a child is thinking and feeling about him or herself. Your efforts will eventually pay off!

Section 2

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Self-Esteem & Students

Self-Esteem and 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

Encourage Youngsters to Combat Teasing With Witty Remarks

Reprinted from the Baltimore Sun

Statement from reader: Don't advise kids who are being teased in school to ignore it. It wrecks a kid's self esteem. Kids used to call me ugly and stupid. It isn't until now, after almost 2 ½ years of therapy, that I'm beginning to get my self-esteem back.

Our professor in child psychology says kids should be taught to stand up for themselves, and come up with clever retorts for the teasers. I wish I'd known that when I was 13! If I had won a few of those teasing bouts, I would have kept a much higher opinion of myself.

I was lucky. When I got older, I did start sticking up for myself. Some people never do. Encourage kids to respect themselves, or they'll become a population of doormats.

Answer from Elizabeth: Great advice. Clever retorts are much more effective than an angry or hurt response. It's not always so easy to do, but with practice, and coaching from sympathetic adults, every child can learn some kind of defense like this. Parents and teachers should be on the lookout for students who need this kind of help.

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

Adapted from Teacher Talk, Indiana University

- 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

Sample Lesson Plans

Lesson #1

Feeling Flashbacks

By: Bonnie Custer

St. Agatha School, Portland, OR.

Grade Level 1-8

Overview: Here's a lesson that's good for visual, auditory, and kinesthetic learners. This lesson uses a cooperative learning structure called *Mill and Mingle* to help students share and express their feelings and to help build a sense of community.

Objective: To share and express feelings
To build a sense of community in the classroom

Materials: Flash cards of different feelings
Tape recorder, or record player, and music appropriate for grade level
Space to move around freely
Paper and pencil (or a journal)

Activities and Procedures: *Mill and Mingle:* While music plays students circulate through the classroom. When the teacher stops the music, the students form pairs by turning to the person closest to them. The teacher calls out a feeling (showing the students a flash card, a cue for the visual learner) and the pair shares with each other a time when they have felt that feeling. The music starts and the students mill and mingle again. The process is repeated several times.

Possible feelings: Happy, angry, embarrassed, lazy, scared, frustrated, shocked, loved, proud, important, curious, pleased, bored, disappointed, upset, joyful, sad, surprised, terrific, alienated, ashamed, worried.

Note: It is very important that the teacher select what feelings are to be shared and to discuss and model them in the classroom prior to beginning the lesson.

Tying it all together: Ask the students to identify similarities and differences in the feelings that they shared.

Journaling: Ask the students to write down either on a piece of paper, or in their journals, about their experience of sharing feelings.

Lesson #2

Who I Am Collage

By: Linda Bauck

Wallowa Elementary School, OR

Grade Level 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 finding out 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 X 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 down who they think each collage belongs to.

Tying it all together: Each collage will be identified by its owner who will then be allowed to explain what the symbols stand for. Students love this activity. They also like for the collages to be displayed for a couple of weeks and from time to time they will make comments about things they should have included or 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 into your child/students 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 the teachers and told them the new plan. That way, he would not get into trouble. What a difference! None of the teachers called attention to John because of it, and he wears a hat 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 it work. They discussed it as a group at their staff meeting so everyone was “on the same page.”

Deb Clark
Ann Arbor, MI Support Group Member

Idea #2

Hat Pass *

“Before my daughter began wearing her wig, she wore hats. After getting special permission from the school she was made a “hat pass” pin that she wore to school everyday. 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.”

Diane Padgett
Helping Hearts Through Hands Member

Idea #3

Home Video

“Last year my daughter made a 3 minute video in which she told about alopecia areata and then went on to take her wig off and tell them how it was made and how she cared for it. Most importantly, she told them 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. Jenna made the video 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 daughters self confidence sky-rocketed!”

Diane Padgett
Helping Hearts Through Hands Member

* Refer to section 3C for information regarding wearing hats in school

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 asked if she could have show & tell about her alopecia. 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 video was very helpful). On show & tell day, our family came to the school and helped Caitlin with her presentation in front of thirty children. The children watched the video and then we talked about alopecia areata and how it makes Caitlin feel. The children asked some very good questions and Caitlin 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.”

Shannon LaRose
Helping Hearts Through Hands Member

Idea #5

Alopecia Areata: Why My Hair Falls Out Presentation

“We showed the video 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 did it with the assistance of the school nurse, principal, and the school counselor. This was a good idea because they felt that my presence may prevent the children from speaking their minds.”

Elba Mendez
Boston Support Group Leader



School-Wide Awareness Projects & 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.”

Carl Rostock, Teacher
Barrett Elementary Center
Cresco, PA.

Example #2

“We recently held a fundraiser sponsored by the Eastwood PTO. We have two students and one staff member that has 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 classrooms, and the classroom that raised the most money would get 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 \$1700. 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.”

Eastwood PTO and Students, Families, and Staff
Eastwood Elementary
Newcastle, IN

Example #3

“When Carmen first began losing her hair she talked to her class at school and showed the video. 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 she was still experiencing teasing from other students in the school. The school administration at North Saanich Middle School has been fabulous and particularly Carmen’s teacher. After a few bad episodes at school it was decided that the education program needed to be spread throughout the entire school.

Mrs. Jones 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, Carmen 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, Mrs. Jones would shave her head in support of Carmen 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, Mrs. Jones's head was shaved with Carmen getting the first cut with the razor!

Since this event, Carmen 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.”

Trisha Rogers, Mother
North Saanich Middle School
Sidney, Canada

Example #4

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

Helen Clemetson, Principal
Harvey-Swanson Elementary
Ortonville, MI

Example #5

“My daughter and her friend decided to make angels similar to the ones sold at last year’s conference in Norfolk and sell them at their school’s Christmas store. The girls chose NAAF as the foundation to donate all the money they earned. The two girls (and both Moms!) ended up making 80 angel pins and Christmas ornaments to sell at the St. Simon Christmas Store. The pins were a big success to say the least. A few more of Alysse’s friends came to her after the event and said they wanted to donate their profits as well. Also, other friends at St. Simon’s will be donating their profits to NAAF directly.”

Steve and Amy Ploussard, Parents
St. Simon Elementary School
Los Altos, CA



Recommended Reading

Books to Promote *Self Esteem* and *Understanding* in the Classroom

Princess Alopecia

Author: Yaacov Peterseil, Avi Katz, Illustrator

Pitsopany Press, 1999

ISBN # 0943706262 (Hardback)

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 the 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.

The Princess Who Lost Her Hair: An Akamba Legend

Author: Tololwa M. Mollel, Charles Reasoner (Illustrator)

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, 2000 Gold Triangle Awards***

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.

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.

A Button in Her Ear

Author: Ada B. Litchfield, Eleanor Mill (Illustrator)

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.

Where the Sidewalk Ends

Author: Shel Silverstein

HarperCollins, 1974

ISBN# 0065256672

Lionel Learns What Matters Most

Author: Julie Merberg

Roundtable Press, Inc. 2003

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.

Sassafras

Author: Audrey Penn, Ruth E. Harper (Illustrator)

Child Welfare League of America, 1993

ISBN# 0878685855

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

Feeling Sad

Author: Joy Berry, Maggie Smith (Illustrator)

Scholastic Inc., 1996

ISBN# 0590623877

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

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.

Rosie...the Imperfect Angel

Author: Sandra Lee Peckinpah, Trisha Moore (Illustrator)

Scholars Press, 1991

ISBN# 0962708060X

In classic fairy tale tradition, Rosey, 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, Rosey triumphs and assumes her own unique place in a family in the Land Called Below. Addresses challenges children with birth defects or traumatic injuries experience; foretells a happy ending.

Just Like Everybody Else

Author: Jim Pierson

The Standard Publishing Company

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!

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.

Young Adults and Adults

Herman

Author: Lars Saabye Christensen

White Pine Press

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 teaches everyone something about friendship, courage, acceptance, and love."

Alopecia Areata: Understanding and Coping with Hair Loss

Author: Wendy Thompson & Jerry Shapiro

ISBN# n/a

This is a helpful book about alopecia areata. It is informative and helpful in understanding the disease. It is easy to read. This book lends friendly advice about dealing with the many physical and psychological details of alopecia areata. Treatments are discussed as well as purchasing wigs and hats.

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

Author: Michelle Roehm & Marianne Monson-Burton

ISBN# 1885223870

Boys Know it All is a book where boys speak their piece about what it is to be a boy. Boys, ages 6-16, 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

Author: Michelle Roehm & Marci Doane

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 mother and daughter to read together.

How to Raise Your Self-Esteem

Author: Nathaniel Branden

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 self-wallowing in 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

ISBN: 0446526762

This is a very funny and poignant book about Linda Richman's life. She describes her life, which has had many ups and downs. A lot of Linda's life experiences have been sad, but, like life, there are 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

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 their life. He encourages people to take an inventory of life and then 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 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

Author: Pamela Espeland & Elizabeth Verdick

ISBN # n/a

This is a book that helps children face life challenges, containing 365 days of daily 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 Chose

Author: Wayne Dyer

ISBN: 066109224

Dr. Wayne Dyer has a compassionate and understandable 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

Bradley Trevor Grieve

ISBN: 0740704818

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 gives you the human condition as seen through the eyes of animals.

The Seat of the Soul

Author: Gary Zukav

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 to allow 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 others behavior even when they seem like “mean” or “bad” people.

When Bad Things Happen to Good People

Author: Harold S. Duschner

ISBN: 038063926

This book was written to help people who have lost faith and hope to learn to cope and accept the life challenges being offered. It’s a helpful tool to direct people who are really searching for peace. A reader commented, “Everyone at sometime 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 to refer to anyone who has suffered a loss.

Baldy Top-An English Christmas Story

Author: Pat WynneJones

ISBN: 0840796293

It is Christmas. The goblins under the oak tree are hurrying to finish the toys for Father Christmas to deliver, but in the rush one rag doll is left with no hair. As Father Christmas speeds toward the village, Baldytop is jolted out of the sleigh and left alone in a snowdrift. Will she ever find a friend? The smiling star of the night sky, a hungry squirrel, some chattering magpies, and even the friendly hare only leave her feeling more forlorn. But then a very special visitor comes by, and Christmas promises to be a happy one after all.

Because of Anya

Author: Margaret Peterson Haddix

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 US.

Alopecia Areata

Author: Janey Levy

ISBN: 1404206930

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

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.

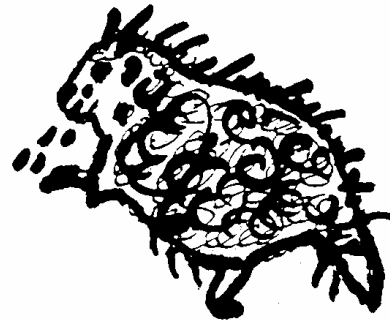
When her father came to her with the coat he had made, Celinda's eyes were very red from crying. Celinda and her mother had gone to several doctors to find out the reason why her quills had fallen out. At first, none of the doctors could give them an answer, but when they saw Dr. Oliver Owl, he said 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 went down to Crawdad Pond to look at her reflection in the water. When she looked down into the pond, she was disappointed to see that the reflection did not look very much like a porcupine. Celinda sat down on the bank and cried. She was sad and scared and wished she had never been born.



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.

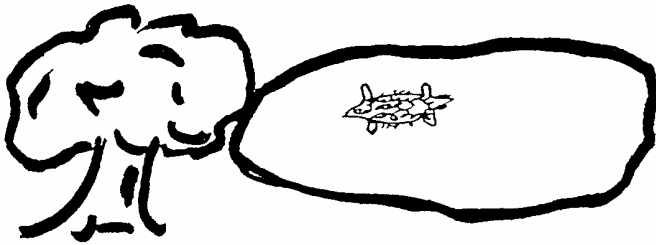
"Why are you wearing that awful coat?" asked Topper as he looked closely at Celinda. Celinda said nothing because the tears were running down her cheeks and her throat felt like she had eaten barbed wire.

"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.

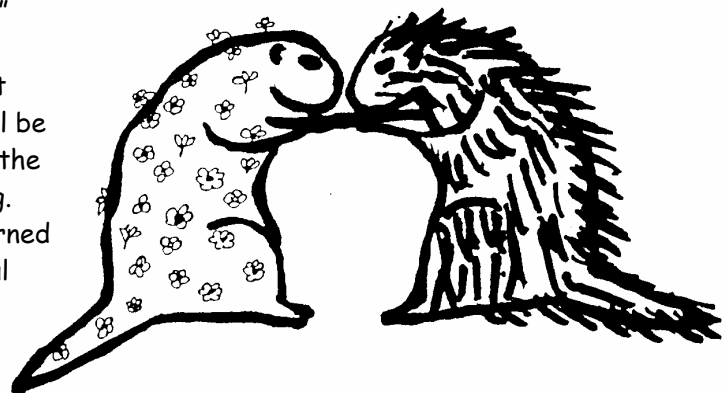
"Take off your coat," asked Topper once again and Celinda trusted him enough to take off her coat. Topper took the flowers and wrapped them around Celinda until she was covered with white roses and deep purple violets. To look at her, it was obvious that she did not have quills, but the coat of flowers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





NATIONAL ALOPECIA AREATA FOUNDATION

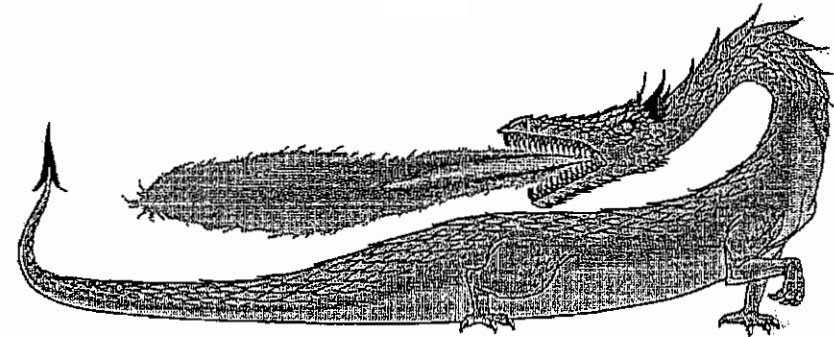
A Story for Sarah: A Children's Story

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 was covered with scales but unlike 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 Deparatus." 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 by 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 have my beautiful scales and I don't even look like I belong in the Land of the Drag-

Continued

A Story for Sarah

ons. I should just leave so you won't have to listen to Benny Bozo and Veronica Snobb any more," 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 some 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 Bozos and Snobbs in her life, but she was also sure 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 Scalopelia Departus stop her from meeting all those wonderful and very special dragons in the Land of the Dragons. Lance and Phyllis had helped her find the beauty inside which made her a very pretty dragon indeed. *This is an original story by Robert Schrader, Denver Support Group Leader, dedicated to eight year old Sarah Horstman who has alopecia areata.*

Section 3

*** Tools for Parents ***

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

Advice for Parents from Parents

Advice #1

Dear Parents,

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 (Betsy) contacted me and asked for help to educate her daughter's classmates, a group of 7th graders, about alopecia areata. NAAF had already provided her with the video, *Alopecia Areata: Why my hair Falls Out*. Sharing about her daughter's disease caused Betsy great emotional stress. As a parent of a child who has alopecia areata, I know the devastation she feels. I offered to come to Megan's school to be her advocate, and Betsy set up a meeting with the teacher, principal, and faculty to view the video. They decided that it would benefit Megan if her classmates also watched the video, and if someone could be present in the classroom to answer inquiring minds.

I had met Megan's parents at a support group meeting and understood what they wanted, but also found it important to know what Megan wanted. I felt it was also important to talk to Megan about what a difference talking to her classmates would make, as well as to talk to her about her fears, likes, and dislikes. I wanted to know Megan's thoughts and concerns, like was she 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?

Megan 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 Megan one favor (she had never met anyone with alopecia areata); I asked her if she would watch my daughter Olivia in the library and to read her books while I talked to her class. She agreed.

I learned that Megan 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 Olivia, she would see her as a normal kid, just like herself.

I explained to Megan that since Olivia 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. Megan had to understand this as well, as she faces an unpredictable journey.

Before we had left the house that morning, Betsy called me and said, "Megan wants me there!" I said that was wonderful. After all, she is taking a huge step in her life. Megan was scared, not so much about sharing her alopecia areata, but about meeting Olivia and facing the possibility of losing all her hair. I was concerned for Megan. Would meeting Olivia be harmful for her? I thought. No, I knew that once she met Olivia she would be okay. This was one more step Megan 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), NAAF Brochures, and made copies of the story, "Celinda's Dance" by Lesa Fichte (which is included in this packet and great for teachers to read in the classroom).

Upon arriving at St. Martin de Porres Catholic School, I met with the principal Ms. Chris Guthrie, and then I met Megan for the first time. She was shy and scared. Betsy arranged to bring Olivia back to Megan within a few minutes of Olivia meeting the students.

We took Olivia right into the classroom. I introduced her (she was wearing a hat) and said I was there today to talk to them about a condition that my daughter Olivia has (took off her hat), alopecia areata. The expressions on the student's faces were of curiosity and sadness, and some of them even looked speechless. I said "most of you may think Olivia has Cancer, or has had chemotherapy treatments, but this is not true. Olivia is perfectly healthy and normal and she is full of life. She just doesn't have hair on her head, her eyelashes, eyebrows or anywhere on her body. We are very blessed Olivia has alopecia areata." Olivia then went to play with her new friend, Megan.

"Today we are going to present to you a video about alopecia areata. Not only does Olivia have alopecia areata, but one of your classmates named Megan has it as well." After the video, I talked to the kids about how to pronounce ALOPECIA AREATA, and passed out one of the NAAF brochures.

"Today, everyone in this room will become educated on this condition. You will probably know more than half of the doctors in St. Louis. 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. Just like when Megan developed alopecia areata at age 12 and Olivia developed it at age one." I explained that "Megan could lose all her hair, but then Megan 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."

"Does anyone have allergies in the classroom? You can not catch an allergy from someone. Alopecia areata is not contagious so you can not catch it from Megan or Olivia. Megan's 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? There is research currently going on trying to find out the reason. Nobody knows exactly what triggers the body to reject hair growth. Researchers are trying to find the reason, an acceptable treatment and ultimately the cure. Until then, we must educate the public about it."

"Megan 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 Megan 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 feels depressed. It is tough for her right now. Can you put yourself in Megan's place for a moment and feel how she might be feeling?"

"Do you think Megan wants you to feel sorry for her? Does she want your pity? NO. Megan 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 Megan's condition 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." Megan would appreciate you helping her in sharing her condition with others." The class came up with some great ideas to help Megan feel comfortable with her condition. The boys were all ready to shave their heads! One student suggested scarf or hat day in honor of Megan! In addition, and 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 one of their classmates, their friend Megan.

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.

I'm helping to create a booklet for NAAF to distribute to parents about becoming a child's advocate. I'm interested in hearing about how you introduced alopecia areata to your child's school, and how they responded. It's important to hear stories from all age groups. I'm asking for your help in creating this great resource. If you would like, please send your child's story and photo to my address.

Thank you,
Jody

Jody Penn
6315 Sprucefield Drive
O'Fallon, MO 63366

(Adapted from N100)

Advice #2

Dear Parents,

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, Colton, 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 videos. 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 Colton'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. With a ten-day period we received 40 responses! We never dreamed that so many people would be willing to help.

Colton's project won 1st place at his school and the chance to compete at the regional fair held in 2000. At the regional fair Colton placed Honorable Mention. We are very proud of Colton, not only because he won, but because he has accepted his alopecia areata and now wants to help others to understand. Colton 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% of hair.

Thank you so much for all of your help!

Lynn & Cheri Johnson
9832 South Chase Circle
Shreveport, LA 71118

(Adapted from N101)

Advice #3

How Peter Ralph's Parents Prepared for the First Day of School

Peter and his parents, Tom & Tina, put a lot of thought into how they would present a personally sensitive subject to their child's school. They would like to share with you their formula for success as they embarked on an aggressive education campaign prior to the start of the school year.

- First, they contacted NAAF for brochures and other material to better understand alopecia areata and the need for support.
- Then, they met privately to discuss the situation with the school principal and with Peter's teacher.
- Next, they sent a letter and a copy of Peter's speech to all the parents (a copy of the letter and of Peter's speech is included in this school packet).
- Then, they sent the same letter with a brief cover page from the principal to the school staff.
- The principal then held a meeting to explain the situation to the faculty and staff and to ask for their support.

With all preparations in place, Peter and her mother gave their presentation with poise and self-confidence.

Tom and Tina acknowledge that attending the NAAF conference in Denver was instrumental in sparking the plan to go forth boldly to educate the students and staff at Peter's school. In addition, a lot of material that NAAF distributes was used to write the informative letters that Tom and Tina sent.

Peter participated in the talent show at the Children's Conference Camp during the NAAF conference in Denver and did a repeat performance of her "Ice Cream Crazy" number for the school principal—his strong support made a world of difference. Tina tells us that Ashton has unbelievable stage presence for a six-year-old.

The results have been tremendous. Everywhere Peter goes in his school, all the children say, "Hi, Peter!" And now he is famous in his school—not for being the kid without hair, but for being the kid who is a natural on stage!

Tom, Tina, and Peter wish to thank NAAF for its support and are inspired to help other parents and children who are dealing with alopecia areata.

(Adapted from N96)

(continue)

Peter Ralph's Speech

Remember your first day in the first grade? Six-year-old Peter Ralph of Redondo Beach, California, will remember his first day for a long time; he had something important to tell all 200 students on opening day in 1999 at the Redondo Public School. Peter's initiative is a great example of how kids can take an active part in dealing with their alopecia areata.

Hi, my name is Peter, and this (Peter points) is my mom. I'm in the first grade here at RPS. In a lot of ways, I'm probably just like you. I like to go swimming (mom throws a swim suit to Peter), ride my bike (mom hands a helmet to Peter), and I'm learning to roller blade (mom gives Peter his roller blades). But there is one thing about me that I bet is different from you.

How many of you have hair? Raise your hands. Now, how many of you can take your hair off? Your hair is probably like my mom's—stuck on your head (tugs at mom's hair). But, I can take my hair off! That's because, about two years ago, something happened to me that doesn't happen to very many people. My hair fell out. We don't know why—I'm not sick or anything—my hair just fell out. But other than that, I'm just a normal kid. So, sometimes when you see me I'll be wearing my hair like this, and you just say, "Hi Peter!"

And sometimes I may be wearing no hair, just my hat (mom hands her the hat), and you just say, "Hi Peter!"

And sometimes, if I'm on the playground and it's really hot, you may see me with no hair, and no hat, and then you just say (Peter points to the audience), "Hi Peter!" But other than that, I'm just a normal kid. It's been nice talking to you!

(Adapted from N96)

Sample Letters from Parents

Example #1

To the parents of all students XYZ School,

You and your family are probably as excited as we are about the start of school. Our daughter will be attending _____ this year in the first grade. She is eager for school to start, and looking forward to renewing friendships and making new friends. As her parents, we share her enthusiasm, but we also feel very anxious about a unique situation with _____, and that's why we are writing to all the parents with children at _____.

As the result of alopecia areata, _____ has lost all of her hair, including her eyebrows and eyelashes (called alopecia universalis, described as the most severe form of alopecia areata). We would really appreciate it if you would take a few moments now to read this important letter and be sure to share this information with your family before school begins.

Although _____ has always been and continues to be quite healthy, she suddenly began losing her hair in _____. For over a year she has been completely without hair. She sometimes wears a wig, sometimes a ball cap, and sometimes she just goes "naked from the neck up," which can be visibly quite shocking, if you're not used to it.

Alopecia areata is a poorly understood autoimmune disorder—like hay fever, asthma and eczema—and, like those atopic conditions, there is a genetic predisposition and no cure. You can't "catch" alopecia areata; it is not contagious. When asked, _____ may describe her condition as "being allergic to her hair," which is a simplified if not a medically accurate description. Currently there is no effective treatment for alopecia areata (universalis).

Alopecia areata affects both sexes, and all ages, but is most common in children. There is no pain or discomfort, and the overall health effect is benign. Alopecia areata is a common disease experienced by over four million Americans. The course of alopecia areata is highly unpredictable; hair can spontaneously regrow even after years of extensive hair loss. It can (and often does) fall out again.

Although alopecia areata is not medically disabling, as you can imagine, it can be very challenging emotionally. The emotional pain can be overcome with one's own inner resources and the support of others. As you know, beginning around age six children are becoming much more concerned about how others view them, how they may differ from others, and whether others might be making fun of them. Since children at this age have become so aware of individual differences, they unfortunately can sometimes be disposed to poke fun at those who don't fit their definitions of "normal." One of the most frequent problems of teasing described by children with alopecia areata is having their wig or hat pulled off at school. Additionally, little girls wearing a cap are often mistaken for boys.

One of the reasons we have chosen _____ is because of the school's firm commitment to teaching and upholding high standards of individual respect and dignity. We hope you feel the same way, and share our commitment, and that _____ will not endure ostracism or suffer any shameful or humiliating experiences. We really need your assistance and are asking you to discuss _____'s situation with your child, and to point out and emphasize standards of behavior consistent with mutual respect and The Golden Rule.

Like all parents, we're eager to help make our child's school experience as positive and successful as possible. We hope you find this letter helpful in understanding her particular circumstance, and that it will help you talk with your child about it before school begins. We are aware that this will be a new and different situation for your child to grasp. Like any new behavior pattern, it may need reinforcement throughout the school year and we hope we can count on all the families at RPS to understand this.

If we can answer any further questions, please don't hesitate to call us. In advance, thank you for your help and support.

Sincerely,

Tom & Tina Ralph
Redondo Beach, CA

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 % of the population. The hair follicles remain alive, but in a hibernationlike state with the possibility of hair re-growth at any time. Those who develop their alopecia areata in childhood usually have a poorer prognosis; this early-onset form is usually chronic and life-long. 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 a 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 Travis' story, we believe that the teasing and harassment can 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 Travis so that we can help him deal with it.

Travis 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 Travis 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,

Jerry & Rhonda Hedger
Charlotte, NC

Do you Need to Construct a 504 Plan?

Unfortunately, most schools currently prohibit the wearing of hats within the classroom and many have adopted a school-wide “no-hat” policy. You may therefore consider applying for an exception through the US Equal Employment Opportunity Commission under the Individuals with Disabilities Act (IDEA). Here is a list of resources that will help with this process:

Reference Sites:

<http://www.chtu.org/504.html>

<http://idea.ed.gov>

Contact Information:

The Americans with Disabilities (ADA) Information Line: 800-514-0301

US Employment Opportunity Commission (EEOC) Information Line: 800-669-4000

Resources:

Council of Administrators of Special Education, Inc.(1991). Student access: A resource guide for educator, Section 504 of the Rehabilitation Act of 1973. Albuquerque, NM.

Council for Exceptional Children, Department of Public Policy. (1994). The rights of children with disabilities under ADA and Section 504: A comparison to IDEA. Reston, VA.

ERIC Clearinghouse on Disabilities and Gifted Education (1992). Legal foundations1: Section 504 of the Rehabilitation Act and the Americans with Disabilities Act. Reston, VA.

Morrissey, P. (1993). The educator’s guide to the ADA. Alexandria, VA: American Vocational Association.

National Association of State Directors of Special Education (June, 1992). The Americans with Disabilities Act: New Challenges and Opportunities for School Administrators. Liaison Bulletin, 18 (4).

US Equal Employment Opportunity Commissions & US Department of Justice, Civil Rights Division (1992). The Americans with Disabilities Act: Questions and Answers (EEOC Publication No. EEOC-BK-15). Washington, DC.

West, J. (1994). Washington State Department of Education (Sept. 1993). Meeting the Needs of all Students. Olympia, WA.