

# Bullying

In our image-driven world, living with a rare disorder of the skin can present many challenging social situations. People who are uninformed about how ichthyosis can present itself may jump to negative conclusions, and in turn express negativity toward those affected. If you or your child has been a subject of teasing, taunting, or bullying, learning the most successful practices for coping with, preventing, or even transforming these negative comments or perceptions, is the best solution.

## STRATEGIES FOR DEALING WITH RUDE BEHAVIOR & BULLYING:

**Educate Them** - Sometimes explaining your or your child's condition is the best way to handle all the questions, stares, and negativity. FIRST can provide you with convenient awareness cards briefly explaining the genetic condition of ichthyosis and that it is not contagious. These cards can be very useful for public activities such as dining out or traveling. You can also distribute to someone who has made an offensive or rude comment or simply give to friends, family, or your community. (Text on the awareness card pictured to the right).

Contact [info@firstskinfoundation.org](mailto:info@firstskinfoundation.org) to place your request for information and/or some awareness cards.

**Build Your Inner Confidence** – Participating in activities that make you, or your child, feel confident and accepted will build resilience toward rudeness. Turning to games, physical activities, hobbies, personal interests – anything you enjoy – is not only enjoyable but can support an emotionally strong outlook in tough situations. Knowing that you have unique skills, strengths, and interests, and sharing those interests with others, will ensure that you are perceived as the multi-dimensional person that you are, and not solely defined by your skin disease. There will always be people who try and put others down. Self-esteem is the best defense.

**Good Loyal Friends** - Surround yourself with those who offer unconditional support, and realize that the positive can always outweigh the negative, if you make a conscious effort to surround yourself with positive people and activities. Focus on friendships and connections that will lift you up! FIRST events and Facebook groups are a great way to find the support you need. (Links to groups below).

**Self Advocacy** – If you are starting a new job, joining a new club, or moving to a new neighborhood, consider informing the community about your or your child's skin disorder. If it is a school-aged child, take time to visit the school and speak with the teachers. It is important to let your child be as involved as much or little as they wish. Perhaps a "show & tell" of special supplies like cooling vests, creams, or water bottles, and/or a Q&A regarding the disorder itself. Play the FIRST video for the classroom. FIRST's *Guide for Teachers and School Personnel* is a great resource to give to teachers of school-aged children and school administrators. (To order a copy of the *Guide for Teachers and School Personnel*, contact [info@firstskinfoundation.org](mailto:info@firstskinfoundation.org).)

Informing onlookers and peers will eliminate the whispers and stares, and you may even find an unexpected source of support and friendship. Also, it is easier for school-aged children to understand and accept differences when their parents are informed and can explain it to them. Think about sending a letter home from school to parents. Other parents can help in the process of accepting diversity and differences.

**The Whole You** – Be sure that when explaining the various aspects of you or your child's skin condition, you also introduce the other unique aspects of your personality and your life. If you

I was born with a rare skin disease called **ichthyosis**. My skin does not function normally due to a genetic mutation that I inherited at birth. **Ichthyosis** is not contagious, a bad sunburn or the result of poor bathing habits. It is my personal goal to educate the public so others with **ichthyosis** are not subjected to stares, teasing or misconception. If you would like more information about **ichthyosis** or want to support research to find a cure, contact the Foundation for **Ichthyosis & Related Skin Types** at (800) 545-3286 or visit their website at [www.firstskinfoundation.org](http://www.firstskinfoundation.org)

play an instrument...let them know. If you have a knack for baking or dancing or writing – tell them about it. You'll be surprised at how quickly people will connect with your other interests, and how soon your identity is based on the “whole you,” rather than your skin condition.

**Be Direct** – If you or your child is being singled out and bullied, or even before the situation occurs, be direct with your child about his or her differences. Let him or her know that together, you can decide how to inform people of his/her disorder, but that he/she will likely need to be proactive about his/her condition throughout his/her lifetime. Give the child examples of other types of “self-care” required with other lifelong disabilities, so as to avoid the feelings of being “the only one.” If there is person with diabetes in his/her class or neighborhood, explain how this child or adult needs to always be prepared with special food or insulin and will likely always be questioned about his/her disorder from peers. Or if there is someone within the community with another rare or genetic disorder, inform your child how daily life is for that particular person as well. For them, day-to-day challenges may be very similar. Along with the creams, cooling vests, and other necessary healthcare supplies, he or she should anticipate questions about his/her condition, and learn to accept that people will always be curious. Once this is accepted, it will become a part of his or her everyday routine, and not seem so disruptive.

**Be Kind, Even When You Don't Want To** – Letting yourself get angry is only hurting you. Anger won't change perceptions and it will usually escalate an already upsetting situation. Smiling and telling the offender it would be good for him or her to learn more about rare disorders may be the best approach. If your child is being teased or stared at while you are present, he or she will take the cue from you as to how to react. Keeping calm and carrying on with your day will let him/her know that he/she should not let these situations affect the rest of his or her day, or life.

**Patience is Key** – As difficult as it may be to accept, sometimes people are just afraid of the unknown. It may take a little while for the whole community to become informed of the disorder, and the special circumstances it may present. Once they have a chance to get to know you or your child – beneath the surface – you will feel more and more comfortable just being yourself, and less concerned with what others may do or say.

**Words of Encouragement** – Simply put, sometimes you or your child just needs a reassuring hug. He or she is special, and needs to be reminded of how unique he/she is. Being there for your child and letting him or her know how grateful you are for him/her, may sometimes be all he/she needs when he/she is feeling isolated or singled out. It's the same for adults. Be sure to tap into your circle of true friends and family when you've experienced a bit of ignorance and need a little extra support.

**Report to Authorities** – All teasing and bullying derives from a negative outlook on the surrounding environment. Sometimes the perceptions of others can successfully be shifted from ignorance to awareness—negative to positive—and sometimes they cannot. If the teasing continues to persist even after you have consciously taken steps to resolve the situation, be sure to report the account to authorities or school administrators. In these cases, some people may be just cruel for the sake of being cruel, and may be unreachable. It's likely you are not the only victim of these types of bullies.

## **BULLYING RESOURCES FOR PARENTS, TEACHERS, STUDENTS:**

**The National Crime Prevention Council (NCPC)** – According to the NCPC website, “bullying can be a gateway behavior, teaching the perpetrator that threats and aggression are acceptable even in adulthood.” The NCPC has a page dedicated to bullying with great information and a variety of resources for parents, teachers, and students. Visit their website at <http://www.ncpc.org/topics/bullying>.

**The Pacer Center** is a parent center for families of children and young adults with disabilities. Along with the National Coalition for Parent Involvement in Education, the NEA, and the National PTA, the PACER Center sponsors bullying prevention month.

Founded in 2006, PACER's National Bullying Prevention Center actively leads social change to prevent childhood bullying, so that all youth are safe and supported in their schools, communities and online. PACER provides innovative resources for students, parents, educators, and others, and recognizes bullying as a serious community issue that impacts education, physical and emotional health, and the safety and well-being of students.

### How does PACER's National Bullying Prevention Center help?

1. Promotes a shared conversation and response to bullying in which everyone works together responsibly and collaboratively to create safe environments for students
2. Inspires entire communities to get involved with social change and promoting kindness, acceptance, and inclusion
3. Offers classroom activities, toolkits, and lesson plans for educators
4. Provides informative guides for parents to understand the dynamics of bullying, help their children through bullying situations, and learn how to communicate with school staff
5. Educates students with age-appropriate resources and information to manage bullying situations, be supportive of their peers, and take action to prevent bullying in their school, community, and online
6. Creates school-wide opportunities to address bullying, including National Bullying Prevention Month in October and Unity Day, initiatives both founded by PACER's National Bullying Prevention Center <https://www.pacer.org/bullying/>

WEB MD Bullying Resources: A comprehensive view of why bullying happens and what can be done about it.

**StopBullying.gov** is designed to help parents identify *what is bullying, who is at risk, how to prevent it and respond to it*, and also, *how to get help*. Visit their website at [www.stopbullying.gov/](http://www.stopbullying.gov/) for ideas to help your child deal with this issue. Of particular interest to FIRST members is the link at the bottom of the page with information about 'Bullying and Youth with Disabilities and Special Health Needs.' There is a wonderful tip sheet on this page with information about what you can do to help your child.

**Mr. John Halligan**, who lost his son **Ryan** as a result of bullying, travels the country hosting seminars about bullying, how to recognize it, and most importantly how to learn the signs that your child is being bullied. Visit his website [www.ryanpatrickhalligan.org](http://www.ryanpatrickhalligan.org) for detailed information about the presentation and also for a schedule of Mr. Halligan's appearances across the country.

## BOOKS FOR INDIVIDUALS, PARENTS, TEACHERS, STUDENTS:



**Still Dancing** by Gabrielle. Gabrielle Ford suffered bullies' torments for years while facing a devastating illness. One special love (her dog) pulled her out of her depression and isolation. Through strength and determination, she became a nationally-known motivational speaker featured on the Today Show and Animal Planet.

**Wonder** by R. J. Palacio. August (Auggie) Pullman was born with a facial deformity that prevented him from going to a mainstream school—until now. He's about to start 5th grade at Beecher Prep, and if you've ever been the new kid then you know how hard that can be. The thing is Auggie's just an ordinary kid, with an extraordinary face. But can he convince his new classmates that he's just like them, despite appearances.

**The Bully, the Bullied, and the Bystander** by Barbara Coloroso. It's the deadliest combination going: bullies who terrorize, bullied kids who are afraid to tell, bystanders who watch, and adults who see the incidents as a normal part of childhood. All it takes to understand that this is a recipe for tragedy is a glance at headlines across the country. In *The Bully, the Bullied, and the Bystander*, which includes a new section on cyberbullying, one of the world's most trusted parenting educators gives parents, caregivers, educators and kids—the tools to break the cycle of violence.

**Bullied** by Carrie Goldman. Written by the mother of a bullied first grader, and popular blogger, this inspiring true story triggered an outpouring of support from online communities around the world. *Bullied* is a guide to the crucial lessons and actionable guidance about how to stop bullying before it starts. It is a book born from Goldman's post about the ridicule her daughter suffered for bringing a *Star Wars* thermos to school—a story that went viral on Facebook and Twitter before exploding everywhere, from CNN.com and Yahoo.com to sites all around the world.

## Children's Books K-2

**Giraffs Can't Dance** by Giles Andreae. Gerald the Giraffe feels sad when all of the other animals tease him about his dance moves. But he comes to know that when he dances to his own beat, his dancing is pretty special!

**Stand Tall, Molly Lou Melon** by Patty Lovell. A whimsical journey of transformation of perspective – turning faults into marvelous talents, on every page. *Stand Tall, Molly Lou Melon* leaves readers with the feeling that anything can be accomplished if you are the best person you can be and make the most of your gifts.

**One** by Kathryn Otoshi. Blue is a quiet color. Red is a hothead who likes to pick on Blue. Yellow, Orange, Green, and Purple don't like what they see, but what can they do? When no one speaks up, things get out of hand — until One comes along and shows all the colors how to stand up, stand together, and count. As budding young readers learn about numbers, counting, and primary and secondary colors, they also learn about accepting each other's differences and how it sometimes just takes one voice to make everyone count.

**Chrysanthemum** by Kevin Henkes. She was a perfect baby, and she had a perfect name. Chrysanthemum. When she was old enough to appreciate it, Chrysanthemum loved her name. And then she started school. "I'm named after my grandmother," said Victoria. "You're named after a flower." Chrysanthemum wilted. Life at school didn't improve. In fact, it got worse until students were introduced to their music teacher, Mrs. Twinkle. And suddenly, Chrysanthemum blossomed....

More children's books to assist in explaining disabilities and building self-esteem:  
<http://www.friendshipcircle.org/blog/2011/11/10/explaining-special-needs-to-your-child-15-great-children%E2%80%99s-books/>

## SUPPORTIVE BLOGS & SOCIAL MEDIA CHANNELS FOR FAMILIES & INDIVIDUALS AFFECTED BY ICHTHYOSIS:

Reading about others within the ichthyosis community is a great source of information and support. Among other helpful topics, many of the bloggers and Facebook groups listed below share real-life experiences regarding overcoming adversity and everyday challenges, particularly in social situations.

**FIRST Facebook Groups:** [FIRST Facebook Group for Adults](#), [FIRST Facebook Group for Parents](#)

[www.blessedbybrenna.com](http://www.blessedbybrenna.com): Daily journal of real life experiences, challenges, and lessons learned, written by the mother of a two-year-old girl with Harlequin Ichthyosis.

<http://globalgenes.org/blog>: Human interest, news and educational blogs from a wide range of rare disease communities.

<http://carlyfindlay.blogspot.com>: A candid, and thought-provoking chronicle of life with a rare skin disorder written by a young Australian woman with Netherton Syndrome. She has dedicated her life to advocacy for differences in appearance.

[Centre for Appearance Research](#): Research and resources regarding the psychological affects of differences in adults and children.

*This information is provided as a service to patients and parents of patients who have ichthyosis. It is not intended to supplement appropriate medical care, but instead to complement that care with guidance in practical issues facing patients and parents. Neither FIRST, its Board of Directors, Medical & Scientific Advisory Board, Board of Medical Editors, nor Foundation staff and officials endorse any treatments or products reported here. All issues pertaining to the care of patients with ichthyosis should be discussed with a dermatologist experienced in the treatment of their skin disorder.*



Foundation for  
Ichthyosis & Related  
Skin Types

PO Box 1067, Lansdale, PA 19446-0687

Phone: 800-545-3286

Website: [www.firstskinfoundation.org](http://www.firstskinfoundation.org)

Email: [info@firstskinfoundation.org](mailto:info@firstskinfoundation.org)

***Improve lives and seek cures for those affected by ichthyosis and related skin types.***

*January 2021*

