From Camp Discovery to the Clinic: Five Lessons about Children with Skin Disease

Children with severe skin disease just want to be kids. You can help by seeing life through their eyes at each office visit.

By Alanna Bree, MD

It may be the way the moonlight reflects off of the lake or the way the cool night air rustles through the trees. Or, maybe it is the sound of giggles from the cabins after lights out that makes Camp Discovery so magical. Whatever the reason, the experience at Camp Discovery is truly life-changing.

As a volunteer on the medical staff for the past several years, not only have I administered medications, applied dressings, and evaluated scrapes and bug bites, I have also had the privilege of getting to know the children who attend Camp Discovery. Although each child is very different, they all have one thing in common: a severe skin condition that alters their lives.

Along with the memories of fishing, tubing, boating, horseback riding, singing, dancing, and playing games, I also left camp with new insight and understanding of how to deal with children who are severely affected by their skin disorder. Below, I’d like to share some lessons I have learned at Camp Discovery over the years, which have enhanced my care of children with severe skin disease.

Lesson 1: A child with a skin disorder is not defined by that disorder.
Your patients with unusual or severe skin disease are not defined by their skin disorder. They are children and adolescents who face the same things you faced as a child. They are growing up, learning to deal with others, and developing their sense of self. They certainly did not need my help. It was amazing to watch her handle the needle as she punctured her blisters using her disfigured scarred hands. In fact, she has taught me many of the dressing techniques that I still use for my patients with EB. She also gave me insight into how she deals with her disease on a daily basis, which I share with my patients as well.

Lesson 2: Doctors don’t always know best.
These children deal with their skin disorder by maintaining a positive attitude and by being patient with others. Many of them are advocates for their disorders and are happy to share their insights with those who want to learn more. It is not easy to be obviously different in a world that values our outward beauty, but these children do it everyday. Nearly all who attend Camp Discovery learn to cope with their differences, and most face each day with a smile and determination that is inspiring. As dermatologists, we owe it to these children to be their advocates as well.

Lesson 3: Patience and a positive attitude will get you far.
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Lesson 4: Be a good listener and friend.
Children with skin disorders are simply children, and they want someone to listen when they have a problem or concern. Sometimes all they need is a shoulder to lean on or a willing ear to listen. The children at Camp Discovery accept one another with open arms. They are not judgmental or cruel as are...
so many others they have encountered. They put aside their differences and provide an environment of acceptance and friendship, which is so important to these children.

Take the extra time during your visit with these patients to ask them how they are doing, how their lives are going, and what they are looking forward to in the future. Not only will this help you get to know your patient, it will also enhance the child's overall treatment.

**Lesson 5: Don't underestimate the power of touch.**

These children and adolescents endure the daily stares of others. They are different, and they know it. They see the expressions on people's faces when they first meet them. They live life in skin that is not beautiful by society's standards. For some of these disorders we have treatments; for others we lack effective interventions. But there is one treatment that is effective in all of these patients—your touch. By placing your hand on the arm of your patient, you say more than by giving a long awkward discussion on the etiology of their disorder. You instantly show your acceptance of that patient, and it helps to momentarily erase the differences that they feel everyday.

**Discover Your Place**

Maybe it is not the moonlight or the wind or even the late night giggles that make Camp Discovery so magical, but rather the brave and courageous children who we have the privilege to care for in our practices each and every day.

You, too, can participate. Consider sending one of your patients to Camp Discovery, donating your time as a volunteer on the medical staff, or making a monetary contribution to the American Academy of Dermatology who graciously funds this experience for these children. To learn more about Camp Discovery, visit www.aad.org or call (847) 330-0230.

**New in Your Practice**

**Lousy Foam.** A new foam-based lice treatment with a reported 96 percent efficacy rate is on the horizon for your pediatric patients, Foamix recently announced following the results of Phase II/III data. Consisting of 1% permethrin and two proprietary enhancers, PerFoam is an alcohol-free, non-irritating, drip-free foam that effectively killed head lice in 96.4 percent of 56 children and completely destroyed lice eggs in 60 percent of the children after one 10-minute treatment. Neither scalp nor eye irritation occurred.

**No Fun in the Sun.** Pediatric melanoma appears to be on the rise, with the rate increasing 2.9 percent each year from 1973 to 2001, says a recent study in Journal of Clinical Oncology (23:4735). The five-year survival rate for children with melanoma was 93.5 percent, notes the study; but unfavorable prognostic factors include male sex, older age, advanced disease, location of primary other than extremities or torso, earlier year of diagnosis, and previous cancer. The study notes that risk factors include being white, being female, increasing age, and environmental UV radiation.