CAC Corner: Disabilities Affected by Attitude | CPD

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Well we are half way through May, and so far it has been a stressful, hectic month. But having said that, there are also special things happening this month. My daughter, Kirstin, just graduated from the University of Alabama with her master’s degree. Not bad considering when she was born, the doctors did not think she would live. Kirstin has a rare genetic skin condition called Ichthyosis. May is National Ichthyosis Awareness Month. My daughter is living proof that many disabilities, while serious, are often more affected by attitude than anything else. When people have told her she cannot do something, she asks “why?” Things she has been able to do include acting, fencing and teaching. Here is a recent posting she put up on her blog.

When I was younger, I did not really like to participate in sports. Running often left me overheated, football was a series of painful scrapes, and horseback riding rubbed the insides of my thighs raw. I had always dreamed of fencing—even with my physical limitations. There was something in the perceived elegance of sword fighting that I could not resist. And, let’s be honest, being able to use a sword was just plain awesome. In junior high, I met a boy who was part of the local fencing club. He convinced me to drop past and see what a typical evening was like. I agreed to come past that Saturday, which just happened to be the day after the fifth Harry Potter book was released. So, I hauled myself, my best friend Kylie, and Harry Potter and the Order of the Phoenix to the fencing club that Saturday morning. I fell even more in love with the sport than ever. Eventually, my parents agreed to let me give fencing a try. When I showed up for my first lesson, the coach—a brilliant woman named Julie—took one look at me and frowned. “Are you sure you want to do this?” she asked. I assured her that I would know if I was pushing myself too far and that I would be fine. I was lying through my teeth, of course, but I did not care. I had to give it a try. The first lesson was pretty basic: How to move like a fencer. Amy, one of the few women in the club, showed me the strange, squatting stance used throughout the fencing world. I sank down into it, and she was confused. Rather than standing flat on my feet, I was perched up on the balls of my feet—more like a ballet dancer than a fencer. She ordered me to be flat-footed, but it turned out to be a hopeless struggle. My skin has always made it difficult for me to even walk flat-footed, so I will often just walk up on my toes. This phenomenon is relatively common among people with EHK. Some even call it the velociraptor gait. My strange fencing stance earned a lot of comment from the other fencers, and I even earned the name “Jackrabbit” for the way I would bounce around on my toes. This challenge was the friction. When a fencer would hit me with the tip of their weapon, sometimes it would create enough friction that my skin would simply slough off. My skin does this instead of bruising, kind of as a deflective mechanism. More often than not, I wouldn’t even notice how many hits had peeled off my skin until the end of the night when I took my jacket off. Sometimes, after a particularly brutal bout, my arms would be a series of cuts—sometimes even my legs and chest falling victim to the same treatment. Competitions proved even more exciting, though, since the fencers I came against were not aware of my skin’s peculiarities. During a team match, one fencer hit my arm with particular vigor (by accident). I shook it off and the match resumed. For some reason, the other fencer was incredibly distracted, and I easily won the match. When I went to unhook my weapon, though, I looked down at my arm. The entire sleeve was soaked with blood. My coach and teammates rushed over to me, asking if I was
alright or needed a doctor. Carefully, I stripped off my jacket and looked at the five inch gash running up my arm. "It's fine," I said. "Just a scratch." Without looking back, I walked into the bathroom, washed off my arm and the jacket, and returned to the match. Every time I went up to fence that day, my opponents treated me like I was made of glass. Ultimately, fencing was one of the best and worst decisions I made, growing up. When I finished my three-year fencing career, I was in peak physical condition and could fit into size 6 clothing. I had loved the challenge of it, but ... after a time I had realized it was taking up too much of my life. Forty to sixty hours a week of fencing was preventing me from working on my schoolwork like I needed to, especially since I was entering my final year of high school and wanted to get into college. And, realistically, it was taking a toll on my health. The fencing equipment would need frequent cleaning, otherwise I would catch a staph infection or some other illness. If someone came to the club sick, I was the first person to catch whatever they had. Taking on sports when you have a disability really is a fantastic challenge. If you ever look at a sport and say "I wish I could do that" I would suggest trying it. You never know what might happen or whose mind you might change.