
just when you think it's okay

Posted by amberlynSH - 2006/06/19 14:18

UGH.... normally wouldn't put this out there, but my support system is out of town for the week....

starting about 4 years ago my son began losing his hair... well actually the first time happened when he was 8 months old, but at the time no one realized why it happened... when it happened the 2nd time, we found out that he has a genetic flaw that tells his immune system that his hair is 'bad' and his immune system attacks his hair, causing it to fall out in large patches.... before he has lost his hair, his eyebrows, his eyelashes, even the babyfuzz on his arms... we did 2 years of steroid treatments... that would be steroid shots to his scalp... and got all his hair to grow back...

well in the past month, the bald patches began showing up again... no one knows what causes it... there is no 'cure' for it... we can do things to make the hair regrow, but we can't do anything to stop the cycle from happening... it's looking like he is on a 4 year cycle for this... this is the 3rd time it's happened to him, but harder this time because of his age... he just turned 12... shaving his head doesn't really work because basically, he's so white he glows in the dark... we shaved his head once and he looked like a very sick cancer kid which only made his feelings worse... so now we do the steroid treatments because they do work in making his hair grow back.... but it's so hard on him physically to go thru the treatments.... he had 75 shots to his scalp this morning... and now for the rest of the day he can't go outside into the sun... over the next 3 - 4 days, he will be moody, emotional, more so than the average 12 year old boy will be... his eating will be sporadic at best, but he will gradually become 'puffy' from the steroids...

as a mom, it's so hard to allow a dr to do something that you know is physically hurting him during the treatments... and the fears over what steroids could be doing to his body at this age... I have guilt feelings of what if these steroids are killing his chances of having children before he can even decide for himself if he wants them.... the shots are a low dose, but who really knows what damage steroids can do over a long period of time... they are still coming out with the dangers.... but the alternative is to let him have gaping bald spots that cause teasing by other kids.... they have 'outlawed' wearing baseball caps in school, we have gotten permission before for him to wear one in elementary school, but in jr high, it would only draw more attention to him.... so it's a horrible catch 22.... do something to help him that might in the end hurt him... or make him suffer thru endless teasing over something he has no control over... it's beyond just a difficult thing to decide for him... when he is asked what he thinks is best, he wants to suffer thru the treatments.... which are every two weeks now... we started treatments last week and had one today... the next one is 2 weeks from now... our hope is to have enough hair grown back by the time school starts again.... *crossing our fingers*

Re:just when you think it's okay

Posted by KPW1956 - 2006/06/19 14:34

Wow... You son is a brave and courageous young man to sit through 75 injections of steroids into the scalp...

The first thing I thought of was alopecia... but maybe this is something different.. Does it have a name and can you research it? Maybe there are other treatment options available.

What sort of doctor do you have to go to... A dermatologist?

Wasn't too long ago...that it was in vogue for the kids to have the Michael Jordan look.... But maybe because he is so young..it just won't carry...yet! The school might be able to use it as an opportunity to educate the other kids.. Teaching them to be sensitive to others.. and that you can look a little different and still be perfectly normal...or sometimes the opposite is true.. They can look perfectly normal and have behavioral handicaps..

I can't imagine having someone stick my scalp 75 times! That sounds torturous! My hearts out to you.. and him!

Re:just when you think it's okay

Posted by amberlynSH - 2006/06/19 14:45

it's called areta alopecia (sp) or childhood baldness.... we can either let it run it's course, which we did when he was a baby without realizing what he had... he was 8 months old when his hair fell out and almost 3 before it came back... his nickname as a baby was 'kojak'... he was 7 when it happened again, and now he's 12...he sees a dermatologist for it... we started with steroid creams applied twice a day to the spots followed by another cream to keep it from burning his scalp.... then the dr moved us onto the shots because the cream wasn't doing enough to regrow the hair... the shots do work, just takes time and a lot of the shots... they do use the smallest needle available, but it's still a needle....

unfortunately he just doesn't have the right look for going bald... and when the peach fuzz begins to grow in after shaving, he still has obvious spots where there is no hair... the bald spots are smooth like a babies bottom, no hair at all until the steriods start it growing, then it comes in pure white before turning brown....

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Re:just when you think it\'s okay

Posted by allthetime - 2006/06/19 17:58

Amberlyn, my heart goes out to you and your family. Indeed, what a courageous young man!!!

Sometimes when kids (or adults, for that matter) just accept these occurances and kind of go with the flow and are still able to keep their confidence, then others will take note and be encouraging instead of discouraging. I don't know if that made any sense! A dear friend of mine had leukemia when we were in our teens. She tried the wigs and stuff for a while but just hated them. She decided to just go without any head covering to see how it felt. She walked around bald with a big, beautiful smile on her face and - Wow! She had more dates than the rest of us combined. People were drawn to her for her honesty and spirit of acceptance, I think. I don't know how your son would feel about that, but it might be less stressful than trying to cover it up. Just the fact that it would definitely grow back would be an encouragement!

I don't know how you feel about alternative health treatments, but I recommend homeopathy and chiropractic to everyone who will listen to me. They have both saved my life by improving the quality of it immensely. It probably wouldn't help with the cycle he's in right now, but it could possibly prevent the next one. God Bless.

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Re:just when you think it\'s okay

Posted by patacake - 2006/06/19 17:59

It might be helpful if you can get him into a peer support group to help toughen him up for his teen years. If he gets too much teasing, his teachers, etc. can be prepared and go to bat for him. If he's a little guy, he may just have to learn to "roll with the punches." Maybe he could develop a better sense of humor-- many comedians compensated with humor while growing up. Also, help him find something he can be good at-- where hair doesn't matter-- something like swimming, self-defense, boy scouts etc.

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Re:just when you think it\'s okay

Posted by grizzlys4 - 2006/06/20 01:16

Your family is my thoughts and prayers, amberlyn. It is so hard as mothers to watch our children go thru such difficulties. Although we don't have the same medical issue, I can understand what it's like to have a child that's affected by something. Please know that you do have support and encouragement here. God Bless.

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Re:just when you think it\'s okay

Posted by amberlynSH - 2006/06/20 16:27

thank you to those that are truely kind in their hearts and said supportive things....

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Re:just when you think it\'s okay

Posted by piper - 2006/06/21 17:33

Just a concerned, SINCERE thought amberlyn.
I do know how scary the steriods are.

It is exactly that, Prednisone, that caused the circulation of blood in my bones to cease, causing them to rot away. This was started in 1986. I am still dealing with it 20 years later.
No matter what you feel for me, personally, please take this as a truly caring note.

This is not to scare you, but to let you know, that they are finally admitting to this side effect these days. The main thing to realize is that it is LOW dose, that your son is on, much safer than high dose, any day. I wouldn't wish him harm in any way.

(I was on 90 mgs for 4 months, then 4 more months to trickle down 10 mgs a week.....so the bad stuff is usually when it's long term, MAJOR amts. not the lower dosages.)

If I were you, however, no matter what the doctors say, I'd *demand* the doctor does a 'bone scan' now, so you can determine if his bones will be affected.

I really hate to put any fear out, for your child, but did want to stress to you the importance of low dose/high dose, and the NEED for a total body *bone scan* for comparative studies as he ages.

I will pray for him, you and the rest of the family, on my list, now. :)

MaryBeth

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Re:just when you think it\'s okay

Posted by Debby - 2006/06/21 17:54

It looks as if you have received some great advice here. I would add that while it appears that you have obtained substantial medical advice, it may be wise to get a second opinion for your son if possible.

I recently was able to become a patient of an outstanding research physician in my area. I saw him speak at a seminar and took note of his knowledge and sensitivity. He received his PhD and MD at the same time. I am told that is a good thing. He is in the top in his field and I had to devote much time and effort to get an appointment. It was worth it.

As I waited in the lobby, several patients told me that this doctor saved their life. They said he was a miracle worker they described in detail how the cutting edge treatments he had prescribed how made dramatic changes in their health.

During the first consult we discussed my issues and he printed out 2 medical articles that addressed my particular condition for me to read and consider. He had written one of the articles and conducted the clinical trial on it. I am so relieved. There are so many new developments for so many ailments. I now have faith that I can be helped. I shudder to think of my fate had I not found this man and this knowlegde.

The course of treatment you are doing may be all that is available, however, I would try to make certain of that.

Perhaps the doctors can refer you and your son to a support group for other children with this condition. Sometimes it helps to know that you are not alone and that other folks are going through similar feelings.

I think it means so much that you are aware of the impact that this may have on a 12 year old boy. I do wish you the best.

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Re:just when you think it\'s okay

Posted by amberlynSH - 2006/06/21 18:47

for the record, we saw 4 dermatologist before accepting that this was the best treatment... we also started with simply a steriod based cream and then moved onto the shots.... we even took him back to his former pediatrician in Houston, who sent us to a dermatologist there before accepting what the dr's in Georgia said... not saying GA drs are bad, but I wanted the opinion of the dr who took care of him longer than anyone else has.... I trusted her the most because of her good advice before.... we had the longest talk with her and her recommended dermatologist about our choices and it was agreed all around that while the hardest to go thru, this method is the best treatment for the problem... it has the best results.... which is regrowing the hair... that is all we can do for him, something to make his hair regrow....

since this is the 3rd cycle for this happening, we have already talked to a support group, which kiddo was not comfortable with....98% of the children there were cancer children with much more serious problems than kiddo, he did however get some good advice for dealing with the teasing about the hair loss... he also has had a counselor from the school district that he has talked to since we found out what he had and the effects of it... he has also spoken with a child counselor from our church about it.... he does have a very good support system around him, his friends do not tease him and stand up for him when he is teased.... he was able to return the favor by being a listening post to a friend who's mother was recently diagnosed with ovarian cancer.... i thought he would be over his head with such a subject, but he was very understanding and listened incredibly well and offered to call his church counselor for the other boy....

I have done massive amounts of research about areata alopecia to make sure I am as up to date as possible and am always asking questions about new treatments or other options and long term effects... his eating this week has been so so... he ate most of lunch today and was hungry for dinner when he left to spend the night at grandma's today, so that's a good sign... the moodiness is going strong tho.... that preteen tone along with an extra whiny to it... and after just 2 treatments we can see the start of white fuzz in 1 of the bald spots... when his hair grows back, it comes in pure white at first, then turns dark... he has not lost his eyebrows or eyelashes yet this time and we are hoping that he won't.... and for the record, we don't do shots to the eyebrows, he just has to go without them until they grow back on their own.... we (including kiddo) joke about how he won't have chest hair when he grows up most likely, but that's okay because it's considered 'hot' now to have a smooth manly chest.... he has a relatively good attitude 85% of the time about it.... emotionally, it's harder on me to put him thru it...physically it's very hard on him.... he has the most emotional issues with it when the treatments are being done.... that 'male' urge to not cry in front of women... his dr is female because *I* trust and feel more comfortable with female dr's... so we slow the pace of treatments down so that he can ask to stop for a moment so he doesn't cry.... what should take 45 minutes can take 2 hours when we go at his pace.... but that's what we do....

as the dr has said, when he's 20 if it happens again, he can decide to say screw it and deal with the comments or continue the treatments.... we have asked him many times if he would rather deal with the bald spots and no shots, because we would do that if he wanted... he says the shots.... not that he has final say, but we want to take his views into consideration... if he was totally anti shots, we would still consider it.... he has had a physical every 6 months during the shots to check his growth, weight, blood work ups, all that good fun stuff... coming from a tall family, he is already 5'11 (at age 12), so we can't clearly say the height and weight is steroid related... I have uncles that are 6'5" or taller on both sides of the family, his extra height could be just genetic family stuff.... his weight fluxuates during the treatments, but not by anything drastic....

honestly, my biggest fear from the steroids is sterilization.... it is a low dose and considered 'topical' because it goes on the skin surface and right below the skin, but it's still steroids... I can see the mood swings, eating habits, and puffy water weight gain, but can't see what is could be doing inside... so it's something I worry about often... not that I am all that anxious to be a grandma, but I don't want to take away his chances before he even is old enough to make that choice for himself...

Re:just when you think it's okay

Posted by KPW1956 - 2006/06/21 19:53

I applaud you for your diligence in being his most ardent advocate and supporter... As any good mother would. To me, it seems you have left no stone unturned... for this unusual malady...

I am sure the moodiness and steroids are interconnected but that hormonal thing teenagers go through... I like to call it 'angst'! can probably exacerbate it! I just hope that this is something that provides an extra measure of glue to your family.. Bond you a little more tightly.. It sounds like it is making him be a more sensitive guy too.. One day the ladies will love that! Then you'll be dealing with a whole new set of problems!

Glad to hear that he deals with it fairly well for the most part. Is there any sort of topical or local anesthetic they can use during the procedure? It might help make the procedure more bearable... I am sure there must be some reason they can't...maybe the drugs don't interact well or counteract one another...

Re:just when you think it's okay

Posted by mazzy - 2006/06/24 12:34

Amberlyn... I'm learning it pays to advertise. LOL

Sometimes just writing about a painful topic is helpful. I'm new at "cyber sharing," and have received comfort, and wisdom from the goils of the SOT site.

Amberlyn... your child is lucky to have a sensitive, caring mother.

Take care.

Mazzy

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