



# Complex Child E-Magazine

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## Teens and Mitochondrial Disease

by Heather “Kass” McNair

Years back, when all three of my children received a diagnosis of Mitochondrial disease, there was a real shift in our philosophy of life. We learned to focus on the day at hand, and not allow ourselves much time contemplating the future. It was always there, but then, as now, I was just going to be happy if we got them to adolescence. We would deal with the issues and associated joys when we got there. I am happy to say we are THERE, and actually have been for a few years, and it has indeed presented with new challenges and joys, but also a perspective I had not anticipated.



Madison, Chance, and Abigail in 1999

## **Preparing for the Teen Years Medically**

We'd been warned/cautioned/prepared--the right word is dependent on my state of mind on any given day--that puberty can be rough for Mito kids. With so much changing in their bodies, the stress was capable of bringing on new issues, exacerbating old ones, and simply being more than their bodies could tolerate. The beauty (if you will) of having our diagnosis when the kids were younger meant we had plenty of time to prepare for this stage. We could at least be proactive to get them through this time as unscathed as possible.

Putting together a good team of doctors and health care professionals before the teen years is critical. You need people who not only work well with you, but who start working well with the kids as they begin to mature and want or need to be a part of the decision-making process. While not on the same level as transitioning them to the adult medical world, there is a transition that takes place as they become teens. In some cases, the medical folks you've been dealing with are capable of making that transition with you; however, in some cases a real shift needs to take place in order to address a teen's needs. You may need to transition to an adolescent pediatrician if one is available, and make some changes with therapy as they age out of the expertise of most pediatric therapists. It's not only okay to make these changes, but it can make a world of difference in a teen's care by doing so.

Being proactive in their care can make a world of difference. I feel the need to clarify here that there IS a difference between being "proactive" and "aggressive" in my mind. Proactive care involves the anticipation of possible problems before they start and treating earlier than later. I personally do not subscribe to being "aggressive" in their care, for fear of being too quick to do something that could, and probably will, cause other problems down the road. But being on top of all the body systems and not hesitating to treat as needed can and does make a difference in our experience. It does mean lots of medical appointments, and sometimes more testing, but at other times it means we go ahead and treat without knowing the full extent of the issue. Ideally, your medical team takes the same approach and it can make the difference between having to wait for more problems to occur before treating, or an expedited course to testing as needed. Being able to preempt more problems that could arise from allowing their bodies to be stressed can make a real difference.

## **Self-Esteem**

Health issues are complicated and difficult to treat at times, but it's something that tends to be pretty black or white when it comes to treatment. Self-esteem in these kids can be a greater challenge because there simply is no single "treatment." It's trial and error in the biggest way, as it is for every child. The challenges these kids face--that they are "different"--can be daunting. Honestly, until this last year, I could not say for sure that the choices we have made were the right ones or not, and they still may not be. The glimpses into this aspect of their lives are so far looking positive though, and I am

incredibly grateful and really kind of amazed that we managed to get them this far with their self-esteem intact.

Accepting their differences, and even celebrating or finding the positive in them, has had the most significant impact. Our attitude has always been that their differences are what adds to the wonderful people they are. We have chosen not to dwell on the negative aspects of any of their challenges, and it appears to have made a real difference in how the kids see themselves and their differences. They are not ashamed of themselves or their differences, and this garners a completely different response from others than it would if they hid their differences or acted ashamed of them. It's difficult, if not impossible, to make fun of someone who is clearly not embarrassed by his differences.

They also clearly do not feel sorry for themselves, and again, this provokes a very different response from others than if the kids acted sad or pitiful about their unique issues. It's difficult to feel sorry for someone who so clearly does not feel sorry for himself. We started teaching this perspective early on, and while I was concerned that the teen years would change how the kids have dealt with it, I am happy to say that the positive attitude has continued. They do not see themselves as victims of this disease, and while they are not always positive about it all, they do have the strong foundation that this disease does NOT define them. They define themselves in many, many other ways.

### **Self-Advocacy and Preparing to Make Their Own Medical Decisions**

I am blessed that my children have not had significant cognitive impairments from their Mitochondrial disease. However, with an essentially appropriate cognition comes a challenge, because teens definitely have an opinion about what's going on. They NEED to have an opinion and some input in how they are treated medically. They need to "own" their medical plans as much as we as parents do, or the uphill battle that would ensue could be devastating.

It is also an opportunity for them to begin the self-advocacy that they absolutely need to have as they enter into adulthood. It becomes imperative that they know what is happening with their bodies, what treatment options there are, and that when possible, they have some say in what course is taken. As Mom, and the one making most of the decisions all these years, it can be a challenge to start letting go. But it has become clear that it is also incredibly rewarding to see them taking on the responsibility and making sound decisions.

Early on I made the decision that the kids needed to know enough so there were no surprises. Even if I knew there would be some level of stress on their part, I needed to weigh each new thing and determine the best time to tell them. In the end they absolutely had to be able to trust me. As time has gone on, they have needed to be able to trust the doctors also, and this is something we continue to work on. There IS information that we choose not to share. If it's something negative that there is nothing we can do anything

about, it's not something they need to be burdened with. However, in most respects, the kids know a great deal about their bodies and how they are being treated.



Chance, Madison, and Abigail today

I have always said, “knowledge is power,” and it has been clearly shown in my children. While some of what they know is not pleasant and even scary, they clearly feel more powerful having the information. While this has been the case since early on, I have attempted to make sure they had the information that is age appropriate. In other words, they don't need to know everything, particularly if it would take away their hopes, but they need to have the general information. Being informed helps them have some control over the situation, and aids them in helping to make decisions about their care. At some point, these decisions will be all theirs, and I hope that the direction we have taken will allow them to be their own best advocates someday.

### **Transitioning and Legal Matters**

As much as the teenage years snuck up on me, the adult years are doing the same thing. My son just turned 17, and the reality that in one year he will be 18 has only recently started to dawn on me. As when they were little, mostly I am still holding onto the idea that I am just so pleased to have gotten him this far. The reality is that there are complications and issues that need to be dealt with to make this transition less stressful and hopefully as productive and comprehensive as possible. I have one year to make that happen, but I wish I had perhaps started thinking about it a little sooner.

I am still learning, so I don't have a lot of practical information on this topic to share yet, but some of the issues I am contemplating include the following:

- ❑ Medical access: What steps do we need to take so that we can continue to be a part of Chance's care as he moves into adulthood?
- ❑ Financial issues: What steps do we need to take to help him with finances until he is ready to deal with it on his own?
- ❑ Medicaid/SSI issues: What needs to take place as he transitions into adulthood, and how can we best help him to be a productive citizen while still maintaining his services?
- ❑ Medical transitioning: At what age will our many doctors need him to transition to the adult world? What assistance is available to make this happen as seamlessly as possible, and how do we best gather the information and contacts together that will help us make this transition?
- ❑ Education and Work: What programs are available to help with post-secondary education, as well as transitioning into the working world?

I have to admit that I am rather overwhelmed with all we need to accomplish in this next year, but at the same time I am thrilled to be finding out that there is a lot of help out there for both my son and me.

### **Friends and Friends with Mito**

Home-schooling has presented some challenges to regular social interaction, particularly with other kids their age. More though, their health has made the social end of things more complicated--doable, but complicated. Finding ways to allow them social time, whether in person, over the phone, or electronically, has made a world of difference in how well they mentally deal with their circumstances.

We have been blessed to have contact with other families with kids close to my children's ages, but the reality is that most of the families we know and spend time with have young children diagnosed with Mitochondrial disease. This presents a challenge, one I was not quite sure how to overcome. The kids NEEDED to not only hear about but also SEE other kids their ages dealing with similar issues. This became especially important when on three different occasions medical professionals made proclamations about "never seeing teenagers with Mito." I don't believe these were ill-intended statements--and may have even been compliments--but they brought to light how important it was to know other teenagers with Mito. It is critical for them to know they are not alone, as teenagers dealing with this disease and life in general.

Thankfully, Camp Korey added a Mitochondrial disease week to their camp schedule, and for the first time, the kids were able to spend a week with other kids their ages who were also dealing with Mitochondrial disease. I saw a group of kids walk away from camp with a renewed sense of hope and friends that they could REALLY talk to...kids that "got it." Of all the things we have done to facilitate the kids getting through adolescence, this one week made an impact greater than almost anything else. As we prepare to head back for our week this year, this time with my son as an assistant

counselor, I am excited to know they have this opportunity to experience all that camp is for them. I cannot emphasize enough how critical this has been to their well-being.

### **Talking about Parenthood, Sex and Genetics**

I sincerely thought I'd have until the kids were older before the need to discuss this aspect of our lives with them, specifically, the question of whether their children would have Mito also. We did all the usual "Birds and the Bees" talks at appropriate ages, but there was more to this story, and I knew at some point the questions would be asked. I was totally unprepared when the girls started asking the question at ages 10 and 11. They wanted to know if their children would also have Mito, and I needed to give them an answer that we could all live with.

I can now look back and say that the earlier I told them important information, the better they dealt with it. For example, we have told the kids since they were little that they would be able to get their permit to drive when they were 16 and driver's license when they turn 18. Perhaps unorthodox, but something my husband and I believe in wholeheartedly. While not thrilled knowing that other kids will get their licenses younger, we've not experienced the backlash that may have occurred had they not known this all along.

I approached the genetics of this disease in the same way. I sat down and explained the genetics to them, and while it hurt my heart a great deal to tell them their children would in fact have Mito also, it was information I felt they needed to know. As I sat watching my still little girls chew on this new piece of information, I was not sure what their response might be, but needed it to be THEIR response, not mine. In other words, I did not tell them they should not have children because of this. I just gave them the information as clearly as I possibly could and then allowed them to come to their own conclusions. In the end, at least for now, both feel strongly that they will adopt their children in the future, and talk about it with a great deal of pride and excitement. I realize there will be times when it will not be something they can so easily accept, and they may even change their minds at some point. But for now I know I have given them the best information available.

While my children are home-schooled, thus more insulated than most from the temptations of sex, it is still there and still has to be dealt with. In addition to the issue of the inheritance pattern we deal with, my daughter Madison is now on a medication that would have very serious consequences if she were to become pregnant. While not the most comfortable thing to talk about, the realities of the situation have to be impressed upon all of my children. It's not "just sex" for any children, but understanding the consequences of sex is even more important when it comes to our Mito kids, and we have to somehow convey that.

## Looking Back

Our lives have really never been, and never really will be, the ideal of other people's "normal," but it is OUR normal and it's a good place to be. It changes, and we have adjusted to "new normals" more times than I care to count. But with each one we are learning to make that adjustment a little quicker and with a little less grief. The kids watch me--they always have--and respond to new situations based on how they see me respond. Finding a place of peace and the ability to make these adjustments is a critical part of their care. Emotions and stress require energy, and it's just in too short of supply to use it without care.

This last year, for the first time, I have been able to look back at our lives and the decisions we have made, and breathe a small sigh of relief. While in the moment we were making choices, it was never clear we were making the right choices. But there is a great deal of relief when they reach an age when you are able to see more clearly how they are turning out and what impact the decisions you've made has had on them.

Living with Mitochondrial disease means that the future is very uncertain and unpredictable. I still subscribe to the philosophy that all we can do is take it one day at a time, make it the best day possible, and try to make tomorrow even better when we get there. Some days it's easier to follow this than others, but in the end, regrets are few and far between when you know you've done the best you can with the information you had on hand at the time.

Mito kids can and do make it to the teenage years. We are proof of that, and while there are challenges, there is an amazing amount of joy and excitement that comes with the teenage years, too!!!

*Heather "Kass" McNair is a stay-at-home-homeschooling-mom living in Dallas with her husband, Michael, and three adolescents: Chance (17), Madison (13) and Abigail (12). The kids were given a probable Mitochondrial disease diagnosis in 2001, and it was confirmed genetically by mtDNA in 2008. When time allows, she keeps family and friends posted on the kids at their CaringBridge site, [www.caringbridge.org/visit/mcnairs](http://www.caringbridge.org/visit/mcnairs)*