

Leprosy and the Pain of Autism

by Thomas A. McKean – 06/20/08

Sometimes when we set out to do something, we somehow end up doing something else instead.

Case in point, my past decade. I have lived here, nestled warmly in the Blue Ridge Mountains the past eight years or so. When I first arrived, I immediately delighted in immersing myself in the mountain culture and set about doing something I have since learned may not be possible.

I wanted to know who (or what) God really is. Or if He/She/It even “is” at all.

God may be simply a matter of individual perception. There are many different beliefs and faiths in the world. None of us knows for certain which, if any, of these beliefs is true until after we die. By then it is too late.

But I personally do believe that buried somewhere in all of these beliefs (or perhaps beyond them) is the truth.

It is that elusive truth I have been searching for.

I have studied under the best of the best. Dale Sides, Danielle Speranza, Travis Witt, and JoAnn McFatter, to name but a few. I can even call these people my friends.

Yet even now, eight years later, I still have not found the truth I seek.

But what I *have* found is a much deeper awareness and understanding of who Col. Thomas A. McKean really is and what he is all about.

If I were to write *Soon Will Come the Light* today, it would be much different and much larger. I know more of who I am and that has led me to being more comfortable with who I am.

I have had many successes in the advocacy of autism. But those successes are hard to enjoy (or sometimes to even remember) because, to me, they hide in the shadow of my many failures. I believe, perhaps incorrectly, that I need redemption in the field of autism. That I need to make up for the many mistakes I have made, despite the successes.

The only way I can think to gain that redemption is to go back to what led to the successes, to go back to my origins in advocacy and do what I did best. Do what created that awareness that was not there before.

That is sort of what this article is about. I want to write about something that has not been written about much by others with autism.

I want to write about the pain of autism.

I have written about this once or twice before in passing, and it somehow became fodder for the autism blogosphere. There have been many theories posted on the net about where the pain comes from, usually written by people who have never met me and do not know me at all outside of the writing. Sometimes they make me angry. But I have decided that it may be better just to laugh at them and move on.

As I have searched for Spiritual truth, I have also searched on the side for the truth about where my chronic pain is coming from. Recently I had the idea that maybe one way to search for the truth about constant pain was to research the constant *lack* of pain in others. So it made sense to me to begin by reading a bit about the work of Dr. Paul Brand.

Dr. Brand was a missionary who did some amazing work with leprosy in India back in the 50's. He discovered the cause (sort of), found scientific proof against the many myths and misconceptions that surrounded leprosy, and improved the lives of countless people who had the disease.

If I could do even a fraction for autism of what Paul Brand did for leprosy, I would die a happy man.

Like autism, leprosy is a most unique and fascinating disorder. It creates in its victims and complete and total lack of pain. For many years it was believed that leprosy "ate" the bones of the fingers and toes, because the bones would shrink and disappear over time for no apparent reason. Dr. Brand discovered that it was not the Leprosy itself, but rather it was rats eating the fingers and toes while the people slept. Since there was no tactile feedback whatsoever, they never felt it, never woke up, and the rats had a feast in the mud huts of India.

Templeton would have been in Heaven.

Once they started giving male Siamese cats to people with leprosy, the cats chased the rats away and the incidence of losing fingers and toes went way down.

Blindness was another problem with leprosy. It was, perhaps, one of the most tragic. Once you lose your sense of touch, you have only your eyes to guide to guide you. If you lose those, you're certainly going to have some problems navigating the world.

As with the other problems, it was assumed that leprosy just somehow caused blindness. No one knew how, just as there are so many unknowns about autism. No one really bothered to try to figure it out. They just went on believing that it was the nature of the disorder to cause blindness.

Dr. Brand discovered the cause of the blindness was once again related to the lack of pain. Because people with Leprosy felt no pain, they never bothered to blink their eyes. The eyes became dirty and dried out, and eventually they went blind.

This problem was far more difficult to solve. He tried telling people to blink their eyes. They wouldn't do it. They just never felt the need. He tried nagging them and warning them of impending blindness, but the words fell upon deaf ears.

Eventually he came up with the idea to perform a surgery that linked the blinking eyes to movement of the jaw. So every time someone spoke or ate or chewed gum, the eyes would blink.

This surgery is still in use today in parts of India, and has saved the eyesight of many people.

(As an aside, I also learned while reading about leprosy that there are no muscles at all in the fingers. The movement of the fingers is done by tendons which are attached to muscles in the forearms. When you move your hand, you are using up to fifty different muscles all working together. Now I am sure some of you are thinking, *"You want proof that God exists, Thomas? Well, there it is!"* And yes, you are right. I suppose, at the end of the day, that I really don't have a problem with God or even with Jesus. My problem is with certain members of their fan club.)

In autism, we have somewhat of an opposite problem. Autism is kind of like Vegas. You shake the dice in your hand, blow on them, let cry with a "Baby needs a new pair of shoes!" and toss the dice out of your hand.

Then, good or bad, you accept how they land.

Autism is kind of like that. It affects everyone differently, and the experience of one person will not be the experience of the next. Some show one range of symptoms, some show another completely different set. So just because one person with autism displays a particular symptom, that does not mean the next person will.

For as long as I can remember, I have felt a constant, low intensity pain. It is with me always. It is never not there. I don't think there has been a day in my life that it has ever been not there.

Sometimes it is not so low intensity.

I have heard from parents I have worked with that some of them also believe their kids are affected in the same way. Consider the problems even early on. If you want your child to have an education (or, in the more extreme cases, if you want your child to benefit from ABA or some other form of therapy), the pain will get in the way. The energy they could be putting into an education or into learning life skills or socially appropriate behavior is instead being diverted to deal with the pain.

I was given an additional diagnosis of fibromyalgia in early 1997. I have always wondered whether this was a valid diagnosis, or whether it was just a way to explain and account for the pain I have always felt with the autism. Or, was I born with the fibro and the fibro and the autism are two completely different things?

Years before the fibro diagnosis, I was given another explanation by a doctor as to what was happening with me. I explained the pain was always there, but if I was hugging my friends, somehow it seemed to just disappear until I let go. Then it came back. I told him this had always confused me.

He told me he thought what had happened was that (due to the autism) my tactile and proprioceptive senses were under developed. So the “neuro-tactile feedback” would balance things out and temporarily eliminate the pain. He gave the example of a new born baby being wrapped in a blanket to acclimate to the environment outside of the womb. In my own case, he said, that acclimation never occurred, due to the under development of the tactile/proprioceptive.

Looking again at that paragraph, there is a part of me that thinks maybe the doctor needs his head checked. Yet there is another part of me that thinks maybe it makes sense. It would explain, perfectly, so many other things. The bottom line is there is still so much about autism that we just don't know. So, like all of you, I am also left without answers I am so desperate to have.

One benefit I definitely received from reading about leprosy was that I am doing some things right when it comes to managing my own pain, whatever the source.

For instance, I live alone. Granted people who live alone die sooner, but at the same time I have control over my life (with just a few notable exceptions, and I am working on those). Control has the psychological effect of reducing pain, or at the very least reducing the *perception* of pain. And just because I live alone for now doesn't mean that I will live alone always.

I have four Transcutaneous Electrical Nerve Stimulators on a shelf in my living room. They don't work for everyone, but they do work for me. (Sort of.) I have never used more than one at a time. Dr. Brand recalls an incident when he was suffering from back pain in the middle of the night. He put on a robe and went for a walk outside on a gravel road. He noticed the feel of the gravel against his feet had the same effect as a TENS would in blocking his pain, and it fit with the gate control theory TENS operates under. (Children with autism are somehow able to figure this out for themselves. Much of the self injurious and self abusive behavior we see in autism is nothing more than the kids using their own method of gate control to block their pain. More information on gate control can be found if you google "gate control theory" on the internet.)

I have friends in the community. Friends and support are very important when it comes to managing pain, autistic or otherwise.

I have learned that distraction is very good when it comes to pain management. I feel it a lot less if I am distracted or concentrating on something else. Once those distractions are over, I feel it again. The night time is never a good time for me.

I believe there is a physical component to the autism disorder. I believe there is a chronic pain in some children and adults with autism. They may not even be aware of it. It may be they think it is normal because it is all they have ever experienced. Traditional pain remedies are unlikely to help because the pain would be neurological.

What I am trying to say here is to be aware that if your child is having problems, this may be one of the causes. This, like all other symptoms, will not affect everyone with autism, but I do believe it affects more than we know about.

I want to give you answers. I want to write these articles every month and give you straight answers to your questions. But I don't have all the answers. Here, in this situation, I am really wishing I did. Not just for you, but also for me.

I am as in the dark as the rest of you are. I am working my way through the maze of autism just as you are.

If I ever find my way out of it, I will be sure to let you know how I found my way.