

NOTE: Below is an interview that Terri Waters did with Thomas. Please note that all text in blue ([like this](#)) is linked and can be clicked on.

Also be sure to read [this interview](#), done in 2001.

A Talk With Thomas A. McKean

(Interview by Terri Waters, 07/21/06)

Thomas A. McKean is an internationally known advocate for people with autism, currently living in Bedford, VA. He has served on the national board of *Autism Society of America*, he has written two books on autism, and he has appeared as a guest on the *Oprah Winfrey Show*. We sat down with Thomas recently to find out where he has been...and where he is going.

Welcome, Thomas, and thanks for doing this interview. Let's start with Oprah. What was that experience like?

A lot of people have asked me what Oprah herself was like, and I can't answer that question because I never met her.

I was approached by her producers after they saw an article about me in *Esquire Magazine*. (This was in the June, 2001 issue.) They wanted me to come on the show and tell them what it was like to have autism. Many people have asked me in the past what it is like to have autism, but all I can do to answer that is to ask them back what it is like to not have autism. Still, it isn't every day you are invited to do Oprah, so it wasn't exactly something I was prepared to turn down.

I wanted to go on the show and talk directly to Oprah. We were talking about this when that whole 9/11 thing happened. You'll recall the airlines were in a bit of a disarray after that.

Still, Oprah managed to get her producer and a cameraman out here to Bedford, and they interviewed me.

How long did the interview last?

A little over five and a half hours.

And what they showed on Oprah was...?

...was edited it a bit, yes.

Are you happy with what they did show of your interview?

For the most part, yes. This was hardly the first time I had been interviewed. I have done TV, newspapers, even had an NPR interview once. I'd have to say this is my favorite of all of them. They did a good job. I just wish they had put more of the interview on TV.

Do you think the interview made a difference for anyone?

Well, it definitely made a difference for *me*, anyway. I made over \$6000.00 in royalties in just one month after the show aired because people saw it and bought the book. Apparently everything they say about Oprah and book sales is absolutely true.

As for other people, I know that her producer was deeply affected by the interview. And I still to this day have tons of e-mail from people who saw it.

So yes, I think it may have made a difference. I am thankful for that.

About *Soon Will Come the Light*, I won't ask you what has been asked already, I have more specific questions.

First, is it true this book won a literary achievement award?

Sure enough. I had no idea that would happen when I wrote it. ASA presented me two awards just before the end of my first term. One was a literary award for the book, and the other was an award for service to the board and to the autism community.

Note that both of these awards fell apart soon after I received them. Despite many promises and reminders, they have yet to be replaced by ASA.

I'd like to ask you to comment on some individual passages.

I am tired of denying who I am. I will no longer do this. To myself or to the people I love. But before I can know, love, and accept who I am, and who I am growing into, I must find that person inside of me.

Indeed. I wrote this originally in a letter to my friend, Gwendolyn. This was also the reason for writing *Soon Will Come the Light*, so it seemed an appropriate quote to open the book.

Parents, please be careful in the way you raise your children. You never know when one of them may grow up to write a book about you.

That line has gotten many comments over the years. What people don't know is that it was the very last thing I added to the book before I sent it to the publisher. I wanted something "extra" to end the introduction I had written and that was all I could come up with.

The nurse who directed the band took us all out for pizza down the street to celebrate. We were happy. Looking back, the night had not been spectacular, yet those of us with a natural drive or need to make quality music had done so. And we were proud.

It was dark by the time we got back to the hospital. We were smiling and laughing and telling stories as we parked the van around back and walked into the back door. Our self esteem was up, which was a rare occurrence, and it seemed like we had been given a treasured memory that night. It seemed as though there was nothing that could possibly ruin that night, or take that memory away from us.

We walked in the door only to step into a thick trail of blood.

You never know what is going to happen hour to hour, even minute to minute, in a psychiatric facility.

A few of us had gotten together with a nurse and had made a bit of music together. We had the whole concert thing going, and we jammed to some Kenny Rogers and Eric Clapton and a few others. It was a great night.

We went out for pizza after and when we came back to the unit, there was, literally, blood everywhere.

So much for our great night.

One of the girls had gotten hold of a light bulb, had broken it, and had slit her wrists pretty deep. The good news is she did survive. I am sure the scars still have to be there.

Mozie was one incredible dog. She always knew what I was thinking or feeling, and she acted accordingly. She was the ultimate perfect personality in a dog for a child with autism. She had other unique qualities. For instance, if I took her for a walk in the park, she would actually climb up the ladder of the biggest slide, and then slide down. She would do this over and over. And the kids in the park really loved it. One fellow even went home to get his video camera to show his wife!

I can remember clearly the day I wrote this paragraph. I remember it because when I first wrote it, I had written "autistic kid" instead of "child

with autism." I changed it because I knew if the book was to be published, I had to be politically correct.

"Mozie" was short for "Mozambique" who was a wired hair terrier who followed me home one day. I walked in the house and my mother yelled at me, asking me where I got her. I told her she had followed me home, and we ended up keeping her.

Mom wanted me to name her "Clancy" because she was big on Irish names. I was feeling rebellious at the time and named her "Mozambique" because that was as far from anything Irish as I could think of.

And yes, she did do that trick with the slide. If she were alive today, I would take her on David Letterman's Stupid Pet Tricks, or submit a video to *America's Funniest Videos*.

TURNING EIGHTY

*There's a tapestry of time around you now.
You've made a legacy.
People you love surround you now,
love you in harmony.
You've watched your children grow,
now they have children of their own.
They're all here to see
you turn eighty.*

*You've seen the wars, they've come and gone.
The nation is fairly calm.
No more World War One or Two,
or Korea, or Vietnam.
You watched the death count rise,
it seemed to touch the skies.
Thank God it's history
as you turn eighty.*

*He was a special kind of man.
The kind you don't just come by.
You remember that day he took your hand
and the look he had in his eye.
You want him to be near,
but he just can't be here.
And we all miss his ministry
as you turn eighty.*

*The future seems like it's here today
and the past feels so very far away,
but that's the mystery
of turning eighty.*

*You now reflect on the days gone by.
You contemplate the days ahead.
Somehow, it all seems to make you smile
when you remember
what was done, what was said.
You've watched your grandchildren grow,
now they have children of their own.
And they hold you tenderly
as you turn eighty.*

I wrote this for my Grandmother when she turned eighty. These are the lyrics to a song and I recorded it in the studio and she had to go to everyone she knew so she could play it for them. She was so proud.

I am glad I was able to do that for her before she died.

Still, I wanted no part of the national board. It was not for me. Fly around the country? Sit in a room full of strangers all day? Voting on complex issues? No no no! What if I ... um ... made a mistake? What then? Was not worth the risk. I respectfully declined. I couldn't do it. I was just too scared. And I was not worthy of being on a national board. That was for really special and important people, not me.

Well, obviously something changed my mind. But I tell you true, never was I more frightened in my life than when that plane took off for Albuquerque and my first board meeting.

There was another conference going on. For the "[International Association of Gay Square Dancers Club](#)." This took me by surprise. Though after I spent a few more days in Albuquerque, I saw that it really should not have. (One thing that makes Albuquerque so wonderful is the cultural diversity.) I walked around the conference for a while, a couple guys came on to me, I saw some good square dancing, and my favorite part of the whole thing was buttons they were selling that said, "Dip me in chocolate and throw me to the lesbians!"

Yes, yes, it is all true. This was just hours after that first plane flight mentioned above. I walked over to the conference center from the hotel to look around and that is what I found. The ASA conference still had a day or two before it started, and there was this other conference going on in the meantime.

At first I didn't understand it. But then I realized that if the autism society had a right to do a conference there, then so did the gay square dancers.

One of the few regrets I have in my life is that I did not take those men up on the offer to dance. It isn't every day you get to square dance with a bunch of gays. It would have been an experience I am sure I would have not soon forgotten.

I have heard many parents tell me that their kids with autism seem to have problems being potty trained. I would ask that these parents take into consideration the possibility of a pain factor. I had this problem growing up, and one of the main reasons was because it hurt like hell.

This was all I wrote on the subject and it has gotten a lot of comments. There are a lot of books out there about how to train children with autism, and there are a lot of people giving presentations on it at conferences.

Many of them are missing the big picture. This process is very sensory oriented and it is going to be affected by sensory dysfunction. If your child is having problems, one reason may be that it is literally painful to go.

The professionals of the autism field have responsibilities. For instance, if the child is diagnosed as having autism, the professional should inform the parents the child is autistic, rather than saying he is "developmentally delayed." Too many times I have heard the tragic story that the parents were unaware of the diagnosis, simply because the doctor was not straight with them. Some parents have speculated that maybe the doctor was trying to spare the feelings, but they would rather have gotten the truth. The truth does hurt, but at least it is the truth. And you have to begin somewhere.

Professionals are also obligated to keep to date with research and therapies. More than once, I have paid to see a professional and ended up paying to teach them things about autism they already should have known. If your doctor does not seem to know as much about autism as you do, perhaps it is time to see about finding a new doctor.

I stand by this statement. Doctors need to have a clue. Some do, but a lot don't. If you aren't comfortable taking your child to a specific doctor, you are well within your rights to find another.

If that isn't enough for you, then I personally give you permission to find another doctor.

My vision has problems, too. The color yellow is blinding. Looking at anything yellow is like looking directly into the sun, even if it is nowhere near as bright.

I have noticed in my travels that the problem some people with autism have with color is always either red, yellow, or blue. Anyone with even a grade school education knows these are the three primary colors.

This can't be a coincidence. I think it is fascinating, and worthy of further research.

I know you have written a sequel, and we will get to that. But have you written anything else along these lines?

Plenty. I have written several books over the past ten years. But I was never happy with them. Even today I am still trying to write something that is as good as *Soon Will Come the Light*. Somehow it just doesn't seem to be happening. But I'll get there one day.

I do have some chapters that I like. I am working on others and hopefully I can get another book out of it.

I was fortunate to be able to contribute a blurb on the back of your second book, *Light on the Horizon*. What happened with that book?

It never caught on. (And no, I don't think it was because of your blurb.)

Whereas *Soon Will Come the Light* was a great success, *Light on the Horizon* was just as great as a failure.

How do you feel about that?

The attitude I have decided to take with it is that I have had one success and one failure, and I have learned from both.

What caused it to fail?

I was very sick when I wrote it. I didn't even know that I was sick, that is how sick I was. The illness definitely shows up in the writing, or lack thereof. Add to that mistakes by the publisher and the printer, and you have a recipe for disaster.

Sometimes I hear from someone who has read it that it is a good book. I have to wonder what they were smoking.

What is the current status of that book?

Dead.

There are fifty to maybe (MAYBE) one hundred copies of it out there. I have another couple of hundred here at home in the closet. That's all the copies there are of it.

Because of its rarity, I will sometimes see a book seller advertise it on amazon for an ungodly high price. I think the highest I have seen is \$328.00 or so. This used to make me angry because I get no royalties from those sales, but then I realized that it was to my advantage.

What I do is list a book of my own, in brand new condition, with the option of a personalized autograph from the author. I put it up for half of whatever the other person is selling for.

Every now and again, someone will buy it. Even for over \$100.00! That always makes me feel good.

Looking at some excerpts from this book as well...

I love doing conferences. I feel that I am contributing something very important to society in a way that very few people can. The world is a better place now because of that involvement and many less children are in pain. That makes me feel good. Like I am doing something very worthwhile.

I still feel the same way. I don't know how much credit I can take for things being different nowadays in the autism field, but I do know that I had at least some small part in it. Illness has gotten in the way of doing conferences as much as I would like and as much as I used to, but I am working on getting back out there again soon.

There are some out there who call those of us doing these things "professional autistics." The irony is that the person who has been saying that the most is now one of the most professional autistics out there.

I hope he has stopped his hypocritical ways...

I have been rallying since that conference for all speakers to get royalties on tapes they sell. Not just me, but every speaker. They deserve this (and so much more) but ASA refuses to accommodate. It is the speaker's thoughts and the speaker's voices on those tapes. The excuse I get for no royalties is that it is too difficult to keep track of how many of each are sold. Nothing is too difficult to keep track of so long as we have all these computers around.

The conference in question here is the 1993 international autism conference that was held in Toronto. I know speakers who have refused to sign a release to have their session taped, because they are not getting

royalties. I personally have never been quite this petty, and for those speakers who are (and they have a right to be if they want to), it hurts everyone. It is not unusual for some of the best talks to be the ones that go unrecorded. How does that help anyone?

Speakers deserve royalties. The people who are purchasing the tapes are usually the people who were just in that session. They want to hear it again, or share it with someone who wasn't there. Either way, that wouldn't be happening if the speaker wasn't good. Good speakers deserve compensation.

I'd like to see a fund set up to financially assist individuals with autism in attending national conferences.

This referred to ASA national conferences. I still feel this way. It was talked about briefly while I was on the board, but it never went anywhere.

The autistic population has much to contribute, probably more to contribute than anyone else at those conferences. They deserve to be there. They deserve a voice. God bless Julie Donnelly for giving them one, but what she does isn't enough.

Several people have asked me to elucidate on the cryptic message in my Foreword of Soon Will Come The Light about the terrorist threat and the FBI.

I suppose you would have to bring that up...?

Okay... Short version:

We had a situation in 1994 where a - shall we say - "disgruntled" person called me (me as a board member) and threatened to appear at our next conference with an AK-47 and kill as many members of ASA as he could.

We had to take this threat seriously to protect the membership. We called in the FBI (who came to my home) and we had our first (and to my knowledge still the only) incognito board meeting to discuss events.

When that guy was ranting at me, I went into my bedroom and hit the MEMO/REC button on my answering machine. This was before the days when the button beeped in your ear. he incriminated himself and the FBI nailed him.

The conference (held in Las Vegas) went down as planned with no incident.

Like most (if not all) people with autism, I have more than my share of loneliness. Friends are good at helping me deal with this issue. You learn through this sometimes who your friends really are and who just "say" they are your friends. All of us have come across people like that in our lives.

Sad but true. For a while there, everyone and their Great Aunt Petunia wanted to be my friend. They wanted me to do things for them, but they didn't want to do anything for me. It was a very painful thing. But through that pain, I learned how to choose my friends. Now it is something I am very good at doing.

I tend to hang out with the right kind of people these days. And I can say, now that it has been ten years since I have written this, that I am no longer the least bit lonely like I was back when I wrote that.

I believe that autism, as if it were not complicated enough, is further complicated by being a metamorphic disorder. What is true and right for a child one day may be false and wrong the next. A child may persevere on a certain item or issue for years and then wake up one morning and decide he wants nothing to do with it anymore, taking up a new, totally different perseveration. A child may be happy with certain foods for a period of time and then one day want none of them. This is metamorphic autism, more commonly referred to as "driving the parents crazy."

I am glad you brought this up. That is one of my most favorite passages in the book!

To be a truly effective speaker, you must leave time for a Q&A session. But you must also be prepared. You truly have no idea what those people out there in front of you are thinking while you are delivering your presentation. Because of this, it is not unlikely that you may be surprised at some of the questions asked. (Things like, "Excuse me, Thomas; when you urinate, do you...?") One good thing to do may be to look over your outline, try to anticipate questions, and then answer those questions as the final part of your presentation.

If you are wondering about the question, the answer is YES, it really happened.

Right in front of everyone at the conference.

What was the rest of the question?

No comment.

Let's talk about your website, www.thomasamckean.com. We'll start with the non autism related stuff.

You wrote an [outline for a novel based on the "Secret of Isis" TV series of the 1970's](#). What possessed you to write for a show that many have forgotten?

I don't think many have forgotten it. Isis was not without its charm and many remember it fondly. They still [talk about the show on the web](#). Once I saw there was still an interest, I decided to write the Isis story I had always wanted to see.

What is unique about this story?

There are two things. First, I was always intrigued by one of the lines at the beginning of the show. Recall what the royal sorcerer said to Hatshepsut, which was, *"You and your descendents are endowed by the goddess Isis. ... You will soar as the falcons soars, run with the speed of gazelles, and command the elements of sky and earth."*

We saw Andrea do these things throughout the run of the series, of course. But if all of Hapshepsut's descendents are endowed by the goddess Isis, then what would happen if, say, Andrea had a twin sister who got her hands on the amulet?

Another thing I wanted to explore was the relationship between Andrea and Rick Mason. We really didn't see it on the surface, but underneath, it was clear that Rick was struggling. He obviously loved Isis, yet he also had feelings for Andrea. I would not be surprised if he sometimes lost sleep at night wondering how he could so love two separate women, not knowing they were the same person. I wanted to explore the ramifications of that a bit in the novel. It was never done in the series, and the Isis comic book was cancelled before they could get into it.

Will you ever actually write the complete novel?

Likely not. Isis is still licensed property, so there are legal issues there. If I could get around them, I would love to finish it. Right now it is just a fair use fan fiction novel outline.

It is likely to stay that way, sad to say. But for fans of the show, I'd like to think it would be a good read. It is almost like a lost episode, and it does bring back Cindy Lee, who left after the first season.

You also wrote a [screenplay based on "All in the Family" TV series](#). Talk about that a little bit.

That was completely different. I wrote that years ago. Sometime back in the late 80's or early 90's.

This was a show that tackled all of the tough issues, political and otherwise. I wanted to tackle the toughest political issue of all, that being abortion. I have seen people on both sides of this issue. I have seen them fight each other. I wondered what would happen if Archie and Michael had a difference of opinion, and where it would lead.

I think I managed to stay true to the flavor of the original series with this. It is so true to the characters that there are some people out there who have read this and have believed I wrote an actual script from the series.

But if that were true, I would have been less than 10 years old when I wrote it. And it would be much longer.

You have three stories based on the same premise in the [prose section](#) of your site.

Like many things, that is just a happy accident. Years ago I took a computer to a friend of mine in Illinois because he wanted to borrow it. He started messing with the word processor and typed out a sentence:

This is the beginning of the era of word processing as known by the people of the tree.

He was called away and his wife walked by and wrote some more, Then I finished it. If you [read the story](#), you will see that while it is entertaining, it is also poorly written. This is because it was rushed. But through the years, the general idea of "the people of the tree" remained with me and I wanted to explore it further.

My first attempt was to write a sci-fi/fantasy novel called, [From the Alexandra Chronicles](#). But I had no idea what the heck I was doing back then. I didn't outline the story and I dug a hole for myself that I couldn't get out of. I had to abandon the story.

Years later, Melanie and I [wrote a bed time story](#) for her daughter, Alesha. We had planned to write a series, but we separated before that ever happened. This is unfortunate because the series had possibilities. Even all these years later, I still consider this to be a good work of fiction and a great story for kids.

On your older site, which is no longer up, you posted that you were going to write a novel based on *Wonder Woman* and maybe another novel based on *Speed Racer*. Are you still planning this?

Yes and no. Wonder Woman has changed so much since the *Crisis on Infinite Earths* that I am not sure I know who she is anymore. This would make it very difficult to write for her.

My idea was to have Donna Troy catch a virus called *Amazon Fever* that was fatal only to the amazons of Themyscira, who Donna happened to be visiting at the time. Diana would then have to find a cure before an epidemic broke out. A lot of the novel would focus on the relationship between Diana and Donna. But again, both have changed so much that I don't think I could write it.

Speed Racer had 52 episodes and no changes since then. Of course there have been those two later Speed Racer series, but neither captured the charm or magic of the original, and I don't think most people consider them canon.

I want to explore what happens to Spritle when he grows up. When we left Speed the last time, he had figured out that Racer X was his brother. Has Rex returned to the Racer family? Is Pops still alive? Speed will be older, too. Is he still racing? What ever became of him and Trixie? Did Spritle join the racing circuit? What happened to Chim Chim?

Enquiring minds want to know.

Because Speed is licensed, like Isis, I will probably write another outline and let it go at that. But the outline should answer those questions. At least from one person's point of view.

I heard rumors that you once had a job writing childrens programming for television.

Again, yes and no.

Back when I was doing a lot of advocacy work in Wisconsin (I think it was around 1995 or 1996), I was approached by the director of a show that Chris Burke (From [Life Goes On](#)) was putting together, called, *Forever Friends*.

This was to be a half-hour childrens educational programming show that taught, among other things, tolerance for disability, something that is still desperately needed in today's society.

Since I was a writer with a disability, I was invited to write for the show. I wrote a rough draft of three scripts total. I meant to write more and to polish the ones I had.

But, like 85% of all programs pitched to the networks, the show was never picked up or accepted so it was cancelled before it even started.

That was the beginning and the end of my TV writing career.

Fortunately I was not the only writer at the time, so I don't have to take the blame for the show's demise.

Did you meet with Chris Burke?

Yes I did. A few times. We worked on the writing.

What's he like?

Very friendly and outgoing. Also incredibly smart. I was looking forward to hanging out with him some more, but it didn't work out.

On your site, you have an essay on [how to use a TENS unit](#). What was that about?

I wrote that because there is precious little information out there, even on the web, about what these things are and how to appropriately use them. I am, unfortunately, intimately familiar with chronic pain, as a lot of people are. TENS is not for everyone, and it certainly won't work for everyone. But it does work for a lot of people if they know what they are doing. Adjusting the dials incorrectly could be very painful, possibly dangerous.

I have three units total that I have collected over the years from the black market. I wanted to try them to see if they would help. But I knew that I had to know how to use them if I wanted any kind of possibility of relief, so I spent several months researching TENS.

The article is very, VERY basic, and doesn't even begin to cover the more technical aspects of the device. But it will give you some tips and some ideas to relieve your pain. If anyone reading this wants to know more or wants to discuss some deeper aspects, they can [e-mail me](#) and I will talk to them about it.

Does TENS help you?

Yes.

What is the source of your pain?

Fibromyalgia.

There seems to be a split pretty much down the middle. Half of people with fibro say TENS helps them, half say it doesn't. Maybe I am one of the lucky ones.

How did you get involved with the black market?

I acquired some contacts along the way in my advocacy travels. I don't like using them, and I do feel guilty about it sometimes, but it has been a blessing to me on occasion when I am looking for something that is hard to find or hard to get. (Though I do have to clarify that aside from getting the TENS, I have never done anything illegal with them.)

TENS units are not always easy to get. Federal law requires a prescription and doctors are not always so quick to write one. So you have to get a TENS by other means.

Like a lot of other people, I will do what I have to do to reduce the pain. No one could expect less of me.

Speaking of which. why did you write the "[Seven Things Thomas Wants to Tell You](#)" article?

The answer to that is in the article itself. I simply got tired of people not getting it. I know that autism is hard to understand, and that sometimes it may make Thomas hard to understand as well. But I have run across a lot of people who don't even try. That article was written for them.

I wasn't sure if I was even going to keep it up on the site because it is intensely personal. But, much to my surprise, that single, small article has gotten more of a response than anything else I have written outside of *Soon Will Come the Light*. I had no idea that so many people would read it, or that the response would be so positive. Many are claiming it is helping them to understand their own children more than anything else has. I don't really understand this, but I am happy it is helping, and that is why it is still online and still mentioned on the front page.

As long as it is doing some good, I will keep it there. The site has to be good for something.

Are you still gnawing on the teethers?

Yes. I have several that I have collected over the years, including four that are anointed. Two by Vicki Sides and two by JoAnn McFatter. These are my favorites. Teething calms several senses all at once. The autistic senses are easily excitable and can be easily overloaded. This is a very painful thing, as anyone who has experienced it knows.

I have found in my travels that a lot of autistic children (and some autistic adults) have a habit of chewing on just about anything. They are instinctively looking for the calming effect. A lot of them don't know this is what they want, other than at a primitive, instinctual level.

This raises problems because a lot of things are just dangerous to be chewing. Power cords are a prime example. Teethers are safe and are even designed for this. But a teether that works for one person won't necessarily work for the next, because we are all individuals and all have different needs.

Once we figure out what works, we find a teether suited to those needs.

There are people out there who would say this is the wrong thing to do, and I suppose in some ways it could be, but only because we live in a closed-minded society. We have to be careful not to do it in public.

In private, it meets a legitimate, neurological, sensory need, and should be allowed. I know there are people reading this who won't agree with me, but this is my take on the issue. Used in other ways, the teethers also help with the autistic proprioceptive dysfunction, something that many people don't consider.

Let's talk about your take on some other issues. What is your take on the vaccine issue?

This is a tough one. Tough because there is compelling evidence for both sides. As soon as one side proves it is harmful, another side proves it isn't. It seems to be a never ending back and forth kind of thing.

I was in the room during the original Senate hearings on this issue, back in 2000. I heard the evidence presented to the Senate, and I wasn't convinced.

But as time went on, I heard more evidence, and I began to wonder.

So my take on it right now is that I really don't know if the vaccines are causing autism or not. But I do know that the possibility is there, and that we need to do whatever we have to do to get a clear answer one way or the other, regardless of cost or resources.

I am in favor of any kind of research on this issue, both pro and con. Because, like many others, I want to know for SURE whether this is a problem or not.

You have done your own work with the Senate.

Yes. Years ago, back in my ASA days, I did have a few words with members of the Senate and Congress of the United States. I don't know if they heard me or not, and looking back, I don't know if I was far enough out of the autism at the time that I even made any sense. Of course, now that I am, I know better than to lobby or testify to them again. My political days are over.

Are you saying you have no desire to be involved with autism anymore?

Not at all. What I am saying is that I prefer grass roots advocacy. I know that for me, I am going to be more useful and beneficial if I am speaking at conferences and/or doing the private consulting that I used to do on a regular basis. I was once up there working at the national, even international level. But I have since found that I get better results working with one person at a time.

Talk a little bit about those "ASA days" as you called them. What was it like?

It was rough. I was thrown into a world that I wasn't ready for. Politics at the national level can be hard for anyone, autistic or not. And I had no clue what I was doing. I had to learn as I went along, and, as the people who were there would tell you, I made plenty of mistakes along the way.

I learned that I just didn't belong there. I also learned that I do belong at the more local levels, doing state conferences and helping individual families. That is where my own talents are most useful.

How do you feel about the so-called *Autism Liberation Front*?

I think it may be very dangerous.

These are radicals who claim to be the voice of autism. But they can also be extremist and that isn't going to help anyone. I am most troubled that they want the money that is going into research for themselves. A few of them are saying that it is wrong to look for a cure for autism and that the money needs to go directly to them so they can have a better quality of life. I have problems with this.

No one understands more than I do that the autistic population needs a source of income. I am not disputing this. The entitlements from the government, while generous, are usually not even enough to pay the most basic bills. I am blessed (and incredibly thankful) that I have other sources of income that help me with that. I know that most of the people with autism out there don't have this and that they struggle.

At the same time, it is very selfish to be demanding the money from research. That money is going to help the true voice of autism. Because the voice of autism is not only the *Autism Liberation Front*, as they claim, and it is not only the *Autism Society of America*, as they also claim. The true voice of autism is also that child in the institution who is wailing all day and rocking in the corner with terror in her eyes. It is the little girl I know who recently swallowed six AAA batteries (and I have the X-Ray to prove it), it is the kid in school who is terrorized by bullies during recess just because he is different.

These are the ones who desperately need help. These are the ones that research is trying to find an answer for.

I am not against a cure for autism. I support the research 100% and I have contributed to it on occasion. There are those who do not want to be cured, and that is their choice. I can respect that because each package is different. Some of them get the savant abilities and are still able to function to a large degree in society. These are the lucky ones. But to think that everyone is like that, and that no one is feeling pain from this disorder, is wrong. Just as I respect the decision not to desire a cure, so they also need to respect that in many cases, a cure can definitely be beneficial.

The bottom line is that there are two separate, very delicate issues here. And the *Autism Liberation Front* is seeing only one of them. That troubles me.

Still, a lot of what they want is valid. If they would take a more appropriate approach to making these needs known, they might get somewhere. It begins, I should think, with them realizing that not everyone with autism is like they are. Some are in unbearable, unspeakable pain.

Once they realize this, I think they can change the world. But they need to understand this one, simple fact first.

Getting back to your site, can you tell us what is in the "protected" area?

Right now just some archived files. Powerpoint backups and things like that. Useful if I am at a conference and there is a problem with the data I have brought along.

What do you have currently in the [download section](#) of the site?

I have decided to limit the download section to my own original works. Because anything I put up there that isn't mine, you can find elsewhere.

I have a cursor up there that I designed and programmed. It is a Christian cross cursor for Windows compatible computers. The spot where you click (the "hotspot") is right where the cross hairs connect.

I have a program that I wrote in 1995 for the [TRS-80 Model 100 Laptop Computer](#). This is a program called, *Music to Vacuum Your House By* and that's pretty much what it is. The program comes complete with documentation. I have always meant to write a Windows version, maybe I will get around to that one of these days.

I also have a program I wrote for the [Proteus Light & Sound System](#). This is a quick ten minute session that puts you to sleep and then wakes you up, leaving you feeling refreshed and energized. A few people around here have tried it and they say it works well. I did research brain wave entrainment before I wrote this. I wanted to be sure what I was writing was not only effective, but also safe.

The program is called, *Cloud By Day*, after JoAnn McFatter's album. I have plans to write more sessions, the next one of course will be called, *Fire By Night*, after her matching album.

I will be adding to the section as time goes by.

Speaking of JoAnn, let's talk about that. It is known that you are friends with William Christopher and JoAnn McFatter. So of course people reading this will want to know...

...what are they really like?

I don't see Bill Christopher as much as I would like to, we live on opposite ends of the country. He and I met in Albuquerque, NM, when I literally crashed a party for the Deveroux Foundation, in 1992. I knew he was going to be there and I wanted to meet him after reading his book, [Mixed Blessings](#). The party was invite only, so I "invited myself" and walked right

in. I tried to look like I belonged there, and it worked. No one asked me to leave and he and I got to talking.

He was here in town recently to tour the D-Day Memorial (which used to be in my backyard) and I spent a little time with him and his wife, Barbara. I enjoyed that.

What you see on M*A*S*H with Father Mulcahy, Bill is pretty much the same person. Kind, generous, great sense of humor. Wonderful guy. There are differences between them, but it seems to me that Bill put a lot of himself into that character.

As for JoAnn, we talk on the phone and e-mail often. Sometimes when she is not off somewhere in the world leading worship (and also sometimes even when she is), she is one of the three people who keep me grounded in reality and keep me more normal and less autistic. I am very grateful for this, and I think she knows. She is a good friend to me and I love her for that.

When I am talking to people who have heard [JoAnn's music](#), I tell them that as good as she is with the worship, she is even better as a friend.

Who are the other two who keep you grounded?

Two people here in Bedford. Vicki and Danielle. The three of them together are interesting in both their similarities and also in their differences. They are kind of a Kirk/Spock/McCoy thing when you put them together. Between the three of them, I get the friendship and support I need to function even with the autism. And in return for that, I try to be a good friend back to all of them. If they need something from me, I make sure that I make time for them.

Let's go spiritual for a moment. You are very involved with *Lion of Judah Ministries*.

Like many, I am searching for the truth. But in some ways, even at 41, I still don't know what a lot of the truth is.

I'm still working on that. But I have found a home and a family with *Lion of Judah*. They are what I always felt a church should be, in that they are there not only on Sundays, but available the rest of the week. There are many people there with different talents and being a part of that church kind of includes an unwritten rule that you be available to the rest of the membership if they need something you can provide. You give freely, but you also take from others what you need, so it is a very healthy

relationship. I like it that way. I don't think I'd be able to be here in Bedford without them.

Do you agree with their doctrine?

Not all of it. Some of it seems to me to be a bit extreme on the conservative side. But I do agree with enough of it to stay there, and I know that you are never going to find the perfect church that matches your ideals completely, because each one of us has a different concept of who God is.

I have also seen that the people who attend are genuine in their love for the Lord. I have been to more than one church where I have not felt this is so. They truly want to please Him here, and they want to be like Him

I suppose one or two of them might take offense that I wrote an outline for a novel based on an Egyptian goddess. Such things are an evangelical no no. One thought I had was to write a sequel that addresses this. I thought it would be interesting to have some fundamentalists, charismatic fundamentalists, take umbrage at Isis for being a false goddess. They would rise against her in the name of Jesus. That might make an interesting story.

I also want to write a story, probably not Isis based, that looks at evangelicals and homosexuality. There are some real problems in the churches of this country when it comes to this, and it also needs to be addressed.

You were also involved with the martial arts for a time.

I carry the rank of 5th Gup in Tae-Kwon-Do and I have studied Tai-Chi and Ninjitsu. When I was doing the Ninja training, I learned some of the dangerous stuff. Camouflage, Espionage, Sabotage, and Assassination. I studied martial arts weaponry, too.

As I have said many times in other places and other interviews, this is information I now regret having.

There is a younger guy at our church who is currently into Ninjitsu. He walks up to people, strikes what he really does seem to think is a threatening pose, and says, "*You know, I could kill you right now.*"

He thinks he looks cool doing that, but he absolutely doesn't. The scary thing is that could have been me. So in a sense, I am glad that the fibromyalgia came along when it did, or I may have been in a very dark place now.

Do you still have the weapons?

Some of them. I have the [Balisong](#) that I studied in Tae-Kwon-Do. We had to choose a weapon to master and I chose that one. I chose it because I admire the elegant simplicity of the design, and the multiple ways it can be used, open or closed.

Somewhere in a drawer in the house, I have maybe two or three of the Ninjitsu weapons and tools, too. But I got rid of most of all of those martial arts weapons a couple of years ago when I moved into the new house. I am just not that interested in it anymore and many of those weapons are far more dangerous to yourself than to others if you don't know what you are doing.

You mentioned the fibromyalgia before. Is this on top of the autism?

The fibro came along in early 1996. I believe it may have happened because I overdid it a bit with the martial arts, but I can't know that for certain.

I am, off and on, trying the [guaifenesin protocol](#) to see if that helps. It does seem to be helping a lot of people. The problem is that it is costing me \$45.00 a month or more, and I have a problem with that. (I'm sure I am not the only one?)

Back when this first started, I can remember walking along and then sometimes this "weakness" would come over me out of nowhere and I wouldn't even be able to stand. I had heard I was heading for a wheelchair at that point, but thankfully that didn't happen. I am not 100% better by any means, but the sudden weakness is gone and I am still walking on my own. I am very thankful for this, because by all rights I should be heavily drugged or in a chair.

But I'm not. :)

Of course I can't end this interview without asking what you are doing now, and your plans for the future.

Currently I have a few writing projects going. I am working on two outlines, one is a Star Trek story called, *Descent of the Gods* (this is with the original crew), and one is an all original autism fiction novel. This outline I will actually be able to write the complete novel for because it is all my own creation and not licensed. I am hoping I will be able to find a publisher for it. Autism fiction is out there, but it is rare. And this novel tells the story from the point of view of a child with autism, so it will be educational as

well as entertaining, in that it will give insight into the more personal aspects of autism.

As for the future, I want to go back to doing conferences again every now then, and I want to write more, which I am beginning to do again.

Except this time I am getting it right.

Thomas, thanks for doing this interview with me.

Your welcome. :)