



# THAT DARN TIC



## A NEWSLETTER BY AND FOR KIDS WITH TS

### SPECIAL EDITION

### Featuring the Stars of the HBO-TSA Documentary, *I Have Tourette's but Tourette's Doesn't Have Me*



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**Aungeni** (9 years old)  
Ohio

Hi, my name is Aungeni and I have Tourette Syndrome. I live with my grandmother and I will be in 4th grade. I go to an alternative school, where we study in both English and Spanish.

In April 2004, I flew to New York to be taped for "I Have Tourette's but Tourette's Doesn't Have Me." I stayed in the hotel called the Southgate. I went shopping with my Aunt and Grandmother. I saw the Empire State Building. I took the subway to see the Statue of Liberty. We also went to Battery Park and to Ground Zero. Later that evening we went to the producer's house in Tribeca. Her name is Ellen and she is very nice.

The next morning we went to the studio in Greenwich Village to be taped. It was really fun. I was really nervous and felt shy. But then Ellen explained what we were going to do. Ellen asked me some questions, and I talked about my Tourette's. Then I changed into my ballet clothes and danced.

I think the film is very good and it shows how special people who have Tourette Syndrome are. I think the film will show how hard it is for kids to have TS, but many kids with TS are smart and have a lot of talent. We are just regular kids that have Tourette. See you on HBO!



**Colin** (13 years old)  
Ohio



Tw'as quite some time ago but I'll try to remember... Ah yes it is coming back... Tw'as quite awesome yes it was... And here's the story to prove it.

I came home from school after another horrible, frustrating day and decided to watch TV instead of bashing my head in with one of those metal bats. My mom came home from work and after she got done yelling at me for being suspended from the school bus for the third time,

said she saw on the TSA website that HBO was looking for kids with TS to be in a documentary. Usually I would half listen but it involved three things I really like: TS, HBO and me!

So she sent them my info, and told me don't expect a call. But guess what? Yeah, they called! I talked with Ellen, the producer, for a long time. She asked me questions about what it is like to have TS, my friends and about school (aaahhh!). Before we finished our phone interview, she decided to fly me out to Miami for a taped interview in a studio. Yeah! Miami! So then I got that song stuck in my head by Will Smith, you know the one, "Goin' to Miami on the streets of Tamiami."

June of 2004 I was off to Miami. What a time that was. We stayed at a great hotel (better than Ohio, nothing wrong with Ohio but...it was better). I met two other people with TS, Jazz and Amanda, they were really cool. The night before our taping we got to ride in a limo to a fancy restaurant with a singer. At the restaurant, Jazz's tics were acting up (we all had different tics) so the two of us went outside to vent. This guy walking down the street gives him a dirty look, and mumbled something rude. Jazz was really hurt, not like the metal bat in the head thing, but like I'm sorry you've got cancer hurt. So because that's how I deal with things, I made a joke about it and everything was just peachy. Then all of us walked down to the ocean, and us kids went swimming. My mom freaked out because I went in too far! Honestly dude I'm from Ohio. How was I supposed to know the rules of the ocean!

The next morning we went to the studio and I was the first to be interviewed. The set was awesome. It looked like the Matrix! Everyone from HBO was really cool and knew a lot about TS. That was it. I went home and told everyone about the experience.

How did it go one might ask? Am I in it? What is it about, you might ask? Well you'll have to watch HBO in November! I hope everyone does or I'm just incomplete.

Til the next big documentary! May the tics be with you! Side effects may include people staring, dry mouth, rude comments, dizziness, school detentions, headaches, a lack of TS awareness, or other related issues that I have yet to experience.



**Michael** (14 years old)  
California

Anyone would think that being filmed for a television special would be a frightening and nerve-wracking experience. Many people dream of being in the spotlight, and being smothered by public admiration. But for me, it wasn't a career opportunity, or a chance at the big time; it was a chance to teach the world about a strange and terrifying disorder that ravages the body and mind. The symptoms of this disorder can vary, but however mild the case may be, it is a life-changing experience. This disorder, subject to many a cruel pun and the cause of senseless taunting, is known as Tourette Syndrome.

It was a year ago that I first walked into that bright, airy studio, dressed in my best, and prepared for the worst. I tried not to be nervous, and I never stopped smiling in attempt to calm myself down. I sat down on the couch and the cameras started rolling. I was scared out of my wits at the thought that this very film might soon be viewed on national television. But as the questions were flung at me, I realized what this could mean to all the kids out there who have TS just like me, and struggle daily to retain their sanity. I began reaching deep into my soul for the answers, and answered the questions in more detail. I wasn't nervous anymore, and I wasn't afraid to be myself. I knew what that tape could mean to all those unfortunate children just like me.

I wasn't yet sure whether or not I was going to even be on the show, but I knew that if I was selected, that I, along with all the others, would make an enormous impact on all who watched it. The future will be bright for all those children out there who have TS, and I feel enormously satisfied knowing that I will have played a part in that. This show is a milestone, it symbolizes the coming of a new era; a golden era of understanding. We are a symbol and a promise of the acceptance and support that will soon come. And with that, I proudly say, I have Tourette's, but Tourette's doesn't have me!



**Matthew** (10 years old)  
New York

When I was being taped for the film, everyone was very helpful and made it seem so easy for me to do. I knew what I wanted to say, but it was hard to put into exact words for the interview.

I wasn't nervous, because all I had to do was tell about my experiences. It was helpful when I actually showed what my tic was. That was the best way to explain it! Some of the things I had to talk about were hard, like the problems I used to have from other people. But now I have more patience to explain to people what I have. It was good to be able to get all my thoughts out.



I thought it was very important to participate in the film because I thought I could give some information to people that might never have been through what I used to go through. Some people may not even know they have Tourette's. I am proud that I was part of the film.

About the final film, I think that more people will now be aware of Tourette Syndrome. I thought some parts were very touching and my mom cried. I showed it to my class one day, and by the looks on their faces, I could tell they liked it a lot! They all asked me a lot of questions when it was over. My teachers cried!

When the film is on TV, I hope a lot of people will see it and will become more aware.



**William** (11 years old)  
California

I thought it was important to participate in the documentary so that I could share what I know about Tourette Syndrome with people who are friends of people with TS. This way, if

someone has a friend with Tourette and the friend is too shy to talk about it, then they will learn about it from the documentary. I was already used to sharing about Tourette Syndrome because I get up in front of my class every year and share what I know. This prepared me for doing the documentary. I don't mind talking about or answering questions about TS.

It was a fun experience doing the documentary. I met a lot of fun people like Beth and Ellen. I met a couple of really good friends, Seth and Michael, and we still kind of keep in touch. The taping took a long time, but it was pretty easy for me because I got to just be myself. My family and I made a vacation out of our trip to Hollywood.

My friends still treat me the same because they all know that I have Tourette Syndrome. They were really excited to come to my birthday party because some of the documentary was taped at my house on my birthday.

I really like the documentary. I thought it turned out good. They only used part of what we taped, but that makes sense since it is only a 30-minute documentary. My mom cries every time she sees it. I hope the film will inspire people who have Tourette's to share it with the world. For me, it's always better if people know that I have TS so we can just move on from there. I figure that if I tell one or two people about it then they can share it with other people. The more people who know about TS the better. It's always better if people understand what's going on. Pretty soon they get used to you having Tourette's and you can just go on being friends.

I have just moved into my new house and I am making new friends in the neighborhood. My new friends also don't care about my Tourette Syndrome. I am looking forward to going to sixth grade next year.



**Jasper** (12 years old)  
North Carolina

I am 12 years old and have Tourette's. Sometimes it's really hard to live with, mostly because of the way others react to me. Last fall HBO gave me and a few others a chance to maybe make things a little easier by letting us teach others about what Tourette's is. I would like to tell you about this experience with HBO.

I was a little confused when my mom told me HBO called and asked me if I was interested in being in an HBO movie about TS. After a couple of weeks I talked to Ellen at HBO on the phone, she had a lot of questions and was really nice. I kind of forgot about everything, and then a few months later my mom told me HBO was flying us to Miami to film the movie. I was feeling excited and awestruck. I didn't think they'd choose me.

On the airplane ride one of the other girls from the film was on the same flight. I didn't know for sure, but I suspected, because she had similar tics like I did. When she went to the same hotel as we did after we got off the plane we started talking. The hotel was awesome.

Right after we got settled in our room, Ellen and Beth from HBO wanted to talk to us. This is also when I got to meet Colin. As suddenly as we met we were automatically friends, and we automatically "ticced" a lot more when we were together.

That night we went out to dinner at South Beach. The restaurant picked us up in a limousine. Amanda, Colin and I went with our parents. Dinner was great. We had great conversations and talking about "tics," about how others reacted to them, and we really bonded. Being with each other made all our tics a little worse. Mine were really bad. I was yelling "die" and "metal" (you can imagine this isn't the greatest thing to be yelling in South Beach). Then a man walked by and cussed at me. It was really upsetting to me but really nice to have friends with me that truly understood how I felt and were there to support me. We continued to walk around South Beach and had fun looking at the stores and all.

On Saturday we went to the studio for the filming. I felt very nervous but a little excited, too. Beth and Ellen made me feel really good and calm. When I saw the set I thought it was amazing. I never thought I would ever get to be involved in something like this before. I was thinking that this might really make a change just like in my class when I did a presentation on TS and now everyone understands why I do the things I do. Now we have the same chance with this movie coming out so everyone can find out.

So, now I've seen the movie and I really like it. I think it can really make a difference in our world. I liked how it showed lots of different types of kids and their normal lives to show they are just like everyone else. They have just one thing that makes them a little more unique, Tourette's.

**Chasen** (11 years old)  
California



I have known that I have Tourette Syndrome since I was 5 years old. It is very difficult to have this problem. Not many people understand and it can really make me feel like I stand out.

People who know me are usually supportive but new people can be mean and make fun of me.

Last year, I was lucky enough to be chosen by HBO to film a documentary about TS. In the beginning, there were lots of phone calls with two nice people, Beth and Ellen from HBO. They even came to visit me at my house in California. We talked about music, bands, sports, all kinds of things. It was pretty exciting and scary when I found out I would be in the filming. Ellen even helped me pick out what to wear!

We drove to Hollywood one morning. It was totally cool to be on a real studio lot. They showed us around. Bruce Willis was there the day before filming and we saw the cars that were used in his film. When it was my turn to film, I was surprised at how huge the room was. It was cool because there was a little set with comfy chairs and rugs for us. It was a very long day and I was very tired at the end. Ellen asked a million questions about my TS and how it affected my life. It's hard because I don't remember not having it and it's just a part of who I am. There are lots of days when I wish I was like everybody else. It's very hard to sit still and not make noise in school. I hate being the only one jumping around on the football field.

My third grade teacher Mrs. Rude told me I have this because someday I will be able to help someone else like she was able to do when she had cancer. My mom tells me I'm really strong and I know my family is supporting me.

I was disappointed I was not in the HBO film more since they filmed me for hours and hours. I enjoyed watching the other kids though. I wish we could all meet someday. I'm happy I could be a part of it and hope people will learn a lot from everyone. I want people to know we may have some problems, but everybody has problems—just treat us like you would everybody else!!



**Kimberly** (14 years old)  
Utah

Being in this film was an amazing experience for me because it made me realize that I am not the only one who has Tourette's. Everyone was so nice. I loved it. It was so fun. I love being in front of the camera. Someday I want to be an actress and a singer and I think this has been a big step for me and I hope it takes me further. Well all I have to say is to all of you reading this is that all the struggles you may have in life will be hard, but I just want you to know that you are not alone and you will get through it someday. Hold on, be strong, trust me.



**Michael** (12 years old)  
Massachusetts

My experience being taped was a memorable one. There are so many great memories. It all started when my mom told me about this opportunity and I said, "Yes!" and eventually was off to

New York to film the HBO film. When my grandmother and I finally got to the set after a long cab ride, they welcomed us right away. The producer was there to personally greet us, and then we waited to enter the set. While waiting I was nervous and did not know what to expect. I was dying of anticipation. When I got to the set I had mixed emotions; the set was cool and comfortable, but it was also very small. The directors asked me questions, and I answered them as best as I could. For the first couple of questions I was a little hesitant, but then I loosened up. Some of the questions were hard to answer, but after some deep thought, I got them. I thought it would be sort of embarrassing. It was, but once I got in to it, it was better. All in all, I'm glad I did this and wouldn't have done it any other way.

I feel that it is important to participate in things like this because for one, it educates people in the world about Tourette Syndrome. I'll bet you that if you asked five people in your hometown or city, people that you didn't know, they'd give you one of those "blank" stares. Things like this help educate the general public, and they should know. Also, I think that it is more important to participate for your own personal reasons. After doing this you feel a sense of pride. I mean all those feelings before a thing like this happens: anticipation, fear, nervousness. In the end, after getting over those fears, a whirlwind of relief and self accomplishment come over you. It's a great feeling to have. Believe me, I know.

Also, I have not yet seen the film! I don't know why, but it's just weird watching yourself talk about your personal feelings on TV. You just feel weird watching it, but that could also be just me. I think that the film will open the world up to Tourette's. I mean, I don't know one single person who knew what it was before I told them. This film will help take care of the telling part. When more people know, more people may want to help, and that can go a far way. Maybe if people understand why this is happening, they may think twice before pointing and laughing. And even if this film doesn't do that, I know in one way or another, it will do something.

I want to say that people with Tourette's should feel like the toughest people in the world. If you think a football player is tougher than you, than you're wrong. I mean, does a football player jump around all night, or get embarrassed when you speak randomly, or can put up with ticcing 24-7? People with TS should feel proud; not because you have the disorder, but because of how you deal with it. Now, I want to end my story with a phrase. Always keep this phrase in mind when something bad happens. It will always be true: Something comes out of everything.

**Julian** (13 years old)  
Washington



This is my experience with the HBO filming. It all started when the HBO people called us about the Tourette Syndrome documentary and we were going to go to Los Angeles to be interviewed and be filmed. At first I didn't want to do this, because I didn't want people to see that I had Tourette's, but then I decided that it would be good, since I thought that this would be a great opportunity to educate children and people in general about Tourette Syndrome. So, instead of going to Los Angeles, Ellen and Beth decided to come to Yakima to film me for three days (and what great three days!!!)

The HBO producers and crew came to Yakima and came to my house and it was awesome! For three consecutive days they followed me in my house, at my school, all the places I went. They were always focusing on me to do this documentary, and I really liked this attention a lot. Since I want to be an actor when I grow up, this experience was so cool because I felt like a celebrity!

So they came over and they were always filming and filming they never stopped. We started early in the morning and we didn't finish until 10:00 p.m. or later at night—pretty intensive! They interviewed some of my friends and they really never focused on my mom and dad it was always on me. During the documentary filming we really did not have time to eat, so we would eat while we were doing the filming and we just did a whole bunch of work. They were filming me all the time, they even filmed me on the track where I do cross country.

Later on, like two months ago, Beth and Ellen sent me a DVD with the last product of the documentary and I thought it was really cool! At the beginning I thought it would be too strong for my friends to watch it, so I started to show it to little groups of people, my most closer ones and the more I see it the more I am ready to show it to my class and all the staff and I am more ready to talk about it to other people.

When I first watched the DVD, I told my mom that I wanted to meet all those children; that finally I have someone to share my feelings, my being me without no fear of judgement without needing to hold my movements all the time! When my mom told Beth and Ellen about my desire to meet the other children in the documentary, they told her that there is a possibility for me to go to New York before the documentary is broadcast and that made me feel very, very happy!

I think that Ellen, Beth and the crew were great people and did a really good job in putting this documentary together the way they did. Thank you guys!!

So, as you can see I loved the experience! I think it was a great experience and I hope some people will learn something about TS when they watch this documentary.



**Amanda** (14 years old)  
Mississippi

My experience being taped for the HBO documentary was such a surprise. I never dreamed that I would be considered to be in an HBO documentary on TV. It all started when

my mom responded to an e-mail asking who might be interested in making this documentary and she told them my story. Mom didn't tell me that she had replied to the e-mail, because she didn't want me to get my hopes up.

Ellen from HBO called my mom and said she would like permission to talk to me. That's when my mom told me about the e-mail and that Ellen would call me, but she didn't know when, since she was in New York and I was in Memphis, TN at the time plus the different time zones and with school. I think she called me that same day in February, 2004. I thought "Oh my gosh! This was so exciting!" I felt very special that I was chosen to get a phone interview, but I was also nervous because I didn't know what she would ask me.

Ellen and I talked several times over the phone and the next thing I knew they wanted to fly us to New York for me to be taped, but it was the weekend my mom was getting married. I thought "Oh no, I'll never get this chance again." But HBO said they would be doing more interviews around the country and that they would try to make other arrangements. Guess what? They flew us to Miami in June, 2004 for my taping interview and I was very excited. There were two other boys in the hotel when we got there for the taping and we met at the pool. It was so good to meet other kids my age with TS. The boys, our moms and I went to eat that night in South Beach in a limousine. It was such fun and relaxing and the boys kept us all laughing. The sad part is that one of the boys started ticcing and some inconsiderate man made fun of him. That really upset me and the other boy as well as our moms. I mean, come on, TS is involuntary and we wouldn't do stuff just to attract attention because sometimes our tics are embarrassing. It was dark after we ate and we walked down to the beach and got to wade into the ocean and then we went back to our limo because we had to get to bed early as the boys were taping the next morning.

Taping day. Wow the day was finally here. The next big decision—what to wear? I picked out a couple of tops and of course I tried a little bit of makeup. I mean I was almost 13 and I might make it into the documentary! We were told that not all of us could be in it, but they definitely wanted us to be honest and not hold back anything. At first I was nervous and shy, but I was very excited to be chosen for the taping interview. I wasn't scared about the interview because I had talked with Ellen so much already.

I thought it was important to tell people about TS because we are just normal people with a chemical imbalance in our brains that we can't control. Having TS is actually a real disability and it has made me more sensitive

to other people with handicaps. Also I wanted people to know that in non-stress situations, we kind of behave normally. I wanted people to know that all TS people don't curse like the TV and movies show. I think this documentary is important because it's real people who really have TS. It's not actors who are trying to pretend they have TS.

I thought it was important to let people know that having TS is something you don't need to be scared of and that it does not make you any different from any other person on this earth. Not many of my friends have seen the video, but my family has seen it and thought it was very good and emotional. I was glad to see that the boys I met in Miami are in it too. I don't like having TS, but I'm glad that I had an opportunity to share some of my experiences in the film. I thank Ellen and HBO for giving me the chance to explain and share my feelings about having TS.



**David** (12 years old)  
Connecticut



I first met Ellen when I attended the Connecticut annual TS conference. She was nice and asked me questions and said she would probably be contacting me again. She called a few months later and wanted me to go down to New York and be interviewed in a studio! I was pretty excited and thought this might be my chance to be famous, my big debut! I had to get some nice clothes on for the interview and prepare to be asked a bunch of questions.

I traveled to New York with my parents and sister and was pretty excited. We waited for a while and when they were ready I was interviewed and my family went for a walk. The hardest part of the interview was trying to decide which chair to sit in! Ellen asked me questions such as explain TS. They also said if I had to tic to just tic away. At the end of the interview Ellen said she and her assistant Beth might want to interview me again, maybe at my house or school. They called a few weeks later and wanted to film me at my school. My principal was very excited about HBO coming to the school. My classmates were, too. Ellen and Beth came to my house after school and interviewed me more. Some of my friends came over to the house too (my friends were annoyed they didn't show up in the DVD).

When Ellen sent a copy of the documentary I was excited to watch it. I was a bit disappointed when I realized they didn't use much of what they filmed of me but realized also that it was put together well. Lots of kids were in the film. It was interesting to see other kids individual personalities and tics and how they feel about having TS. Having other people see the documentary is important because it shows how kids with TS feel and how they are alike and not alike other kids. I am proud to have been a part of the process.



**Seth** (12 years old)  
California

My name is Seth and I'm 12 years old. I was diagnosed with TS at age 7. I had an opportunity to participate in the HBO documentary about kids with TS and thought it would be a fun way to talk about TS and experience something new. I also wanted to talk about it to overcome my awkwardness about discussing the disease and to help others understand how it feels to have TS.

I didn't really prepare for the documentary, the words just came naturally because that's how I feel. I was really nervous about being interviewed by strangers and having the microphone in my face, but I got over that quickly enough. Beth and Ellen from HBO made me feel very comfortable during the interview process. At first, I have to admit I was embarrassed to talk about TS on camera but I decided to just go for it and speak from my heart.

My friends and family love the documentary. I have received the most positive feedback from everyone who has watched it. The video helped them understand TS and it helped them to understand me. Now I can talk to my friends more openly about TS because they know about the disorder and its symptoms. I loved the final film because they got unique information from each kid to bring it all together. We all have different talents and abilities but we share one thing TS. I don't feel so different anymore because of watching the documentary.

I hope the film will reach out to people, touch them in a positive way and help them to understand TS. I hope and pray that people are more accepting of TS by realizing that we can't help the things we do, and that it will help another kid struggling with TS that may be afraid to talk about it.

Overall, participating in the documentary was a great experience and it was fun! I made some new friends and helped educate people on a disease that is misunderstood by many. I feel better about myself and TS because of the documentary.



**Conor** (13 years old)  
Washington, D.C.

I wanted to make the movie because I wanted to let people know that having Tourette's is no setback for having an awesome life—look at all those sports players who have Tourette's.



Making the movie was really funny especially the first time they filmed me, because I couldn't look at the camera, but whenever I saw it I would smile and laugh. It was tiring to make sometimes. The people were really nice who filmed it, especially the cameraman, who was really cool. He has three fingers and a son my age.

My friends who have seen it have thought it's funny to see me on screen, but they also were really interested and started asking me lots of questions about TS. I just want to make sure that no one feels sorry for me.

I think the movie is cool and interesting. I hope it teaches lots of people about Tourette's.



**Riley** (15 years old)  
California



Hi! My name is Riley. I have severe Tourette Syndrome. I was recently filmed for the "I Have Tourette's but Tourette's Doesn't Have Me" documentary. I had a great experience working with everyone involved. However, it was weird having a camera up to my face and sharing my story to everyone. The producer and crew who filmed me were all very nice, but unfortunately I didn't get to share as much as I wanted to.

I can't blame them though, I mean the filming took almost a year and the whole movie had to be less than 30 minutes! But it was really cool meeting people with the same problems as me, just as well meeting people like Ellen Goosenberg and Tony Shalhoub.

I'm sad so many suffer the same disorders I do, but the TSA has really helped out a lot of kids, and that's including me, too.

After the premiere screening (at the TSA West Coast Dinner) I felt more confident in sharing my message about Tourette's and making new friends. I feel good, because now I'm going to a better school and getting A and B grades, when I used to earn no credit. My summer school just ended and I'll be looking forward to a three week vacation, but after September 6th, it's another semester. I'm working up new comic strips too, so hold your toes! I'm still ticcing like crazy, but I'm drawing comics and doing karate to keep my mind among other things.

In conclusion I want to say thank you all for allowing me to shout out my message!



**Marcus** (8 years old)  
New York



Making the Tourette's movie was very hard because sometimes I got distracted. I had fun jumping on the furniture, but never run your face into the wall.

It was fun to be in New York City with my sister Anna and my mother. I hope you like the movie. I sure do. My friends and teachers liked it too.



**Michaela** (7 years old)  
Colorado

I liked being in "I Have Tourette's but Tourette's Doesn't Have Me" because it felt like I was in front of a lot of people. It was cool and exciting to go to Hollywood, and to go to a studio and meet Ellen Goosenberg-Kent. I went in the hotel and when my brother Mackenzie turned the radio up in Ellen's room really high, I got scared! It was really funny, because he kept doing it and it made me laugh. When I was in the show, I saw the microphone above me. It was a really long microphone, and I looked at it sometimes and it looked funny.

I got to buy some pretty clothes to wear on the show and I got to play for a while before it started. When it started, I had to sit down in a chair and talk about what tics I had. I felt like a movie star! My friends saw the DVD and they liked it. It was really important to be in this show so people know what Tourette's is like to have. I really liked being a part of it. It was fantastic!



**Mackenzie** (8 years old)  
Colorado

When my mom asked me if I wanted to be in a documentary and talk about Tourette's, I thought it would be really cool to be in a show on TV, so I said yes. To get ready to be in the film, my mom helped me decide what tics I have that I could talk about and how to speak up so they could hear me good. We got to fly on a plane to Hollywood and that was fun. We stayed in a hotel with a kitchen and we played the stereo really high in the Director's room. The next day we went to a studio and they taped me and my sister Michaela for the show. I was excited, because I've never been on a show.

When my best friend saw the show, he said he thought it was good. He knew I did stuff but didn't know I had Tourette Syndrome. I think it's good he knows about it now. They cut me out of the film because they had to make it shorter, but I was in it at the beginning for a tiny bit. They showed me doing my blinking tic that I don't do anymore. I thought the film was ok, but it would be better if more kids got to stay in it.

I think the show was important so that other people can stop making fun of kids with Tourette Syndrome. If they don't know what Tourette's is, they'll tell you to stop doing it sometimes when you can't stop doing it. It's important for teachers so they know you aren't trying to distract the kids on purpose. The show will help kids know that other people have Tourette Syndrome, too and not just them.

I feel proud and thankful that I got to be a part of "I Have Tourette's but Tourette's Doesn't Have Me."



**Jacob** (11 years old)  
Massachusetts



Hi, my name is Jacob and I am eleven years old and I can't believe its been almost two years since I went to New York to film my part of the HBO special, "I Have Tourette's but Tourette's Doesn't Have Me." It's a bit difficult to remember all the details but I do remember my feelings and my impressions. It is hard to talk about them because I was so deeply honest then and it is hard to be like that now.

I am very proud to have been a part of this special. I guess this was a "once in a lifetime" thing. I flew to New York for one day. It was one of the busiest days I had ever had. I had some fun. They gave me my favorite food and drink and then it was time to start talking about my life. Everyone is different but I think I'm a lot like other kids with Tourette Syndrome. I have tics and sometimes it's hard in school and at home. I have a sister, named Rachel, who tries to help but doesn't always make things easy for me. I also shared how my neighbors have said some very mean things to me. Some people will never understand Tourette Syndrome.

I sometimes like having Tourette and other times I don't. I like a few of my tics, especially the animal noises. Some kids think I am very talented and others think I'm weird until I tell them that I have TS and explain what it is. I hope this special helps me and others with TS teach people about it so they will treat me and you just like everyone else.



## That Darn Tic

*That Darn Tic* is TSA's newsletter by and for children up to 15 years old.

All submissions will be edited for length, grammar and content. Please don't send us your only copy. Drawings, photos and cartoons reproduce best when they are black and white on white paper. We may alter the size to fit the art on our pages. We will publish as many as we can fit—so send us your best and we'll do the rest! Submissions are due by December 1, 2005.

Please send your short stories, poems, essays, drawings, riddles, cartoons and jokes to:

**TSA**  
**That Darn Tic**  
**42-40 Bell Boulevard, Suite 205**  
**Bayside, NY 11361**  
or email: [tracy.flynn@tsa-usa.org](mailto:tracy.flynn@tsa-usa.org)

The next *That Darn Tic* issue will be coming your way soon!

Thanks to the other stars of  
"I Have Tourette's but  
Tourette's Doesn't Have Me."

You, along with your other  
co-stars, have provided  
unique insight and given a  
powerful voice to this much  
misunderstood disorder.

We applaud you all!

You are an inspiration  
to all those—young and  
old—living with Tourette  
Syndrome.



Brian



Katelyn



Veronica



Megan



Trent



Stephanie



tourette syndrome association, inc.

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Assoc. Inc.

**Watch**  
**"I Have Tourette's but Tourette's**  
**Doesn't Have Me"**  
**Saturday, November 12 at**  
**7:30 p.m. ET/PT on HBO!**  
**Catch replays on HBO Family**  
**and HBO In Demand or order**  
**the DVD (with extras!) from**  
**the TSA website!**