

# THAT DARN TIC

A NEWSLETTER BY AND FOR



KIDS WITH TS



tourette syndrome association, inc.

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*David Pauls, Ph.D., is Principal Investigator for the TSA International Genetics Consortium (researcher).  
Harvard Medical School, Cambridge, Massachusetts*

## INTERVIEW WITH DAVID PAULS, Ph.D.

**Q: What exactly is genetics?**

**A:** It's the study of characteristics or behaviors that run in families. It's why we look like our parents.

**Q: How does this relate to TS?**

**A:** We know that TS runs in families. We're trying to find the genes that are responsible for TS running in those families.

**Q: What are the newest discoveries about TS?**

**A:** As part of the work of the TSA International Consortium, we think we're honing in on where two genes that cause TS may be located.

**Q: What does this mean for my future?**

**A:** If we know which genes cause TS, we'll be better able to figure out ways to treat it and, as the former TSA President (Paul Devore) said, "We can make TS irrelevant."

**Q: Is there anything kids with TS can do to contribute to the study of genetics?**

**A:** They can volunteer with their families to be part of the ongoing studies of genetics. This means giving blood samples and talking about yourself. If you think your family might be interested, have your parents call TSA for more information.

**Q: What kind of education would a kid interested in science need in order to become a genetic research scientist?**

**A:** If they are interested in genetics, they need a college degree in biology, chemistry or genetics and either an advanced degree or a medical degree specializing in genetics or molecular biology.

## TICS

*by Jacob Chatzky, Sixth Grade*

If I could be guaranteed one thing in life, it would be to help people with Tourette Syndrome. The reason why I want to help people with Tourette Syndrome is because I have it myself. I want to help people emotionally. I also want to help people physically. I dislike tics and want to help other people with them.

I could help people because I know what it is like to have Tourette Syndrome. Sometimes when I have a tic and people are over, I can't take the tics any more so I lock myself in my room. I feel like staying there until the next day, but I don't. Sometimes things like music, movies or sports will soothe my tics, but that doesn't always stop the tics. I think tics are a bad thing because it gets people to think that you are annoying. The best advice is to ignore the tics.

I will help people deal with the emotions that they feel because they have tics. I think the world would be a better place if people would not make fun of other people. This goes for people who have other disabilities, too. It makes me sad when I think of people with disabilities. The best advice here is when someone makes fun of you ignore them.

I don't like to see people getting hurt when they have tics. I know what it is like to jerk your head, and I myself have to say tics are frustrating. You have to try to make tics not such a big deal. That is how you have to think about it. A tic is like when a person sneezes, think about it! When someone massages my back or head it helps me think about other things. I wish I could create a robot that helps by massaging my back. I would give other people with Tourette Syndrome the robot for free! Other things I do to help my tics is suck on candy and bite the candy instead of clicking my jaw. There are many things I do to try to help my tics.

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I like when people are nice to people with TS and when they understand people with Tourette Syndrome. It helps me a lot when people understand me when I am having a tic. I think people with tics are very special people. When I grow up, I would like to be a psychologist, so I can help people with Tourette Syndrome.

I think people with Tourette Syndrome can be anything they want to be.

## POETRY

### **My Tourette's Syndrome**

*by Conor Woods, Fourth Grade*

I hate the burning in  
my brain  
I can't control it.

The tics  
reek and smell like old sneakers  
I need to plug my nose  
I can't control it.

It's like being in jail.  
It's impossible to run away.  
I can't control it.

I cannot express my hate.  
It's like pollution,  
Polluting me.  
I can't control it.

If I could taste it,  
Vinegar and canola oil  
mixed up.  
I can't control it.

It takes up people's time.  
Like a buzzard picking the meat  
Off their bones.  
I can't control it.

Sometimes I get fixated on  
medication,  
food,  
anxiety.  
I can't control it.

Burning in my brain,  
Kids tease me and I say  
"Hey, I can't control it."

A special thank you to GATE Pharmaceuticals  
for its generous contribution to this publication

### **The Brick Wall**

*by Evan Kleinman*

I sit in class quiet.  
Nothing is bothering me.  
All of a sudden a sudden voice comes through my head.  
This thought controls my body.  
I smash my hands on the desk,  
Looking for something to hold on to.  
My mind goes dead.  
Then I just let it go.  
The tics take over me for a long moment.  
Clenching my jaw and squeezing my hands; I get through it.  
There is nothing to do to help myself.  
It's like something has taken over me.  
I make no progress.  
I do it over and over again, until I am satisfied.  
It's like painfully climbing up a steep hill and getting nowhere.  
The frustration makes tears go down from the corner of my eyes.  
Kids look at me and laugh.  
I feel no shame.  
Why should I?  
I have no control over it.

### **TSA CHILDREN'S GROUP**

*New York, New York*

### **TIC MONSTER**

*by Joriel Sharp, 11 years old*



*The above drawing shows Joriel as a puppet with the "Tic Monster" pulling the string.*

In the group, kids get together in a small room. It is really fun! First, we talk about our problems. Then, we try and give the person suggestions. When we are done with that, we play a game. Our favorite game is volley ball.

*by Anthony Fico*



## JOKES

by Jacob G. Dilson

What do you call dinner when none of the food falls on the floor?

A carefully balanced meal!

Why didn't the people attack the Hunchback of Notre Dame?

He was already revolting!

What is the saying of ice cream parlors in Texas?

"Remember the Ala mode!"



My friend can't help to curse but  
he's still a good guy.

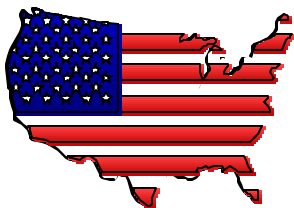
### Feelings are Important

*A letter from Andréa Naulls to her brother, Nick*

Dear Nick,

Feelings are as important as you. I care for you, I follow your steps in life, too. We lie to each other, but we still love each other? I love you, I'll die for you, I'll cry for you. I'll fight with you, but you fight back. But that's what brothers and sisters are for aren't they? But hey, I love you back.

Love,  
Andréa



9/11/01

The tragic events of September 11, 2001 touched us all. The editorial staff of "That Darn Tic" would like to extend condolences to the many children who lost parents or other family members. We hope that 2002 brings peace to the United States and the entire world.



*Tim Howard, Goalie for the New Jersey Metrostars Soccer Team was recently interviewed for the TSA quarterly newsletter. The following is excerpted from that story:*

### INTERVIEW WITH TIM HOWARD

- Q:** While you were growing up, what was the impact of TS on your life?
- A:** It was difficult. It wasn't about making friends but trying to have them understand or trying to hide from them. There are physical setbacks as well, especially in the classroom. TS can hinder the learning process. Spreading awareness to teachers is an important part of what we're trying to do.
- Q:** Do you have any advice for young athletes with TS?
- A:** The athletic field was my sanctuary. I wasn't judged by my TS but my athletic performance. I have fun with athletics, even now that it's my job, I continue to have fun. Fun is important in anything in life but especially in sports. TS shouldn't be a boundary for sports. A few of us had made it professionally. Sports can be more than just recreation.

My motto on TS – "Never let it be a stop sign; it's just a speed bump – another obstacle to overcome."



“Simon’s Special Sneeze Test,” text by Candida B. Korman, with illustrations by Jacob Ospa, will soon be available from TSA’s Publications Department. This children’s story demonstrates how one boy explains his TS to his teacher and classmates, with humor and a little help from his friends. “Simon’s Special Sneeze Test” is currently in production. It is expected to be available in late Spring 2002. Please contact TSA in late Spring if you would like to receive a copy. Forward your request to Tourette Syndrome Association, 42-40 Bell Boulevard, Suite 205, Bayside, New York 11361. Telephone: (718) 224-2999, Extension 231 or email to [ts@tsa-usa.org](mailto:ts@tsa-usa.org), Attention: Publications Department. Please be sure to give us your name, address, telephone and email with your request.



**SEASONS  
GREETINGS  
&  
HAPPY NEW YEAR  
TO ALL**