

THAT DARN TIC

A NEWSLETTER BY AND FOR



KIDS WITH TS



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INTERVIEW WITH JESSICA COURTNEY COHEN ON SING FOR A CURE



Eleven-year-old *Jessica Courtney Cohen* sings to raise money to find a cure for TS. Her best friend, Micah, has it and she's helping to raise money for research as part of *Sing for a Cure*, a review with songs from the 1940s to the present. Jessica and company have performed in Los Angeles and in New York City.

Q: What got you started in *Sing for a Cure*?

A: Once I found out that Micah had TS, I thought maybe I can help raise money to find a cure. I really want to help people, and I figured out something that I can actually do to help them. One day, when they find a cure, I'll know I was part of it. I've loved singing since I was very, very little. I started when I was three.

Q: How did you choose the songs for the show?

A: We voted on our favorites from each year in the show.

Q: What's your favorite?

A: I like a lot of the songs, but mostly *That's What Friends are For*. It's dedicated to my friend with TS.

B. Is it a lot of work?

A: It's difficult to learn all the songs. And we only had specific times to see our director to do the choreography. For some songs, it's just bobbing around, but for most it's choreography. It's a challenge. I had to learn the choreography to *You Can't Hurry Love* the day before the show. It's really difficult. We could have done a whole lot more if only we had a couple of weeks more.

Q: What do you want to do when you grow up?

A: Actually I want to be a singer. I also like ice skating and I want to be a writer too.

Q: Do you have anything you'd like to say about kids with TS?

A: I don't want them to go through pain or feel different or feel weird and that they don't fit in.



A thought from *Jeremy West* (age 9):
"Listen to your brain; it has lots of information."

EMILYby *Emily Ellis* (14 years old)

Sometimes we are happy, sometimes we are sad.
 Sometimes we get teased, so sometimes we get mad.
 Although we may seem different
 Because of the tics u see each day,
 Just know that the disease chose us and not the other way.
 So when you see me twitch and curse, please never forget .
 It isn't me that's doing it but a disorder called Tourette.

**SMELLING**by *Anthony Quagliano* (age 10)

I have a tic that isn't so chic.
 I have to smell, and it's not so swell.
 Sometimes my friends ask "why?"
 And I feel like I could cry.
 One time I smelt my shoe, and it smelt like pool!
 I know it's not right,
 It's a tic that I try with all my might not to do.
 My teacher says not to get blue!
 "You are a very good person, and a bright student, too!"

Coping With My OCDby *Zachary (Zak) Hollis*, 12 years old

My name is Zak and I have Tourette Syndrome and Obsessive Compulsive Disorder. I just turned twelve years old and my TS has been bad since I was eight. My OCD is hard to live with because it affects my social life, it affects my schooling, and it affects my family.

Right now I am in a treatment program for OCD. I have a great doctor. His name is Dr. B and he has helped me for two and a half years. I need to learn how to cope with my OCD so I can be with my family. The OCD took me away from my family.

I have mental obsessions about a lot of negative things. Living with my OCD was like trying to hide a big, bright, colored elephant in the room. It is like that because it is a big part of my life that I always tried to hide because I would get embarrassed. But when I would come home from school, it would all come out. I would feel like a volcano erupting. My rages were bad.

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

In my treatment program I am learning to use different tools. I am learning different tools to help me relax so that I can take back control of my brain.

I think of the OCD as one big monster. This monster wants to take over my brain. My doctor is teaching me how to push the monster off my brain.

I know I will be able to go home and live with my family. I will take control of my brain. I am excited about my new treatment.

Advice from The Tic Advisor

Dear Tic Advisor:

My older brother's friends make fun of me and he doesn't defend me. When we're alone he's a great older brother, but when they're around it's like he's another person. What can I do? I think he's ashamed of me.

Defenseless Little Brother

Dear Defenseless Little Brother:

It sounds like your brother is afraid that his friends won't like him if he sticks up for you. If they really are his friends, they'll like him even more. Some people would tell you to talk this over with your parents, but I think you should try to talk to your brother directly. Tell him he really is a great big brother -- most of the time -- and that you'd like him to try to be a great big brother all the time -- even when his friends are there.



Dear Tic Advisor:

Last year I had the best teacher in the school. She really understood my TS. But this year's teacher doesn't get it. When my tics get bad she thinks I'm just trying to get attention. I look across the hall and wish I was back in the other teacher's class every day.

Attention-Getter

Dear Attention-Getter:

Why don't you try asking last year's teacher to talk to this year's. Sometimes the only person a teacher will listen to is another teacher.

Dear Readers:

Do you have a question for the Tic Advisor? Or would you like to answer the questions sent by other kids? Let us know. Send a letter to Peggy, TSA, 42-40 Bell Boulevard, Suite 205, Bayside, New York 11361 or email to peggy.harford@tsa-usa.org.

INTERVIEW WITH
PETER HOLLENBECK, Ph.D.
PURDUE UNIVERSITY



Q: What does the Scientific Advisory Board (SAB) do for TSA?

A: The main job of the SAB is to advise TSA about what areas of research hold the most promise for helping to understand, treat, and ultimately cure TS. We ask scientists and doctors working in these promising areas to submit proposals to TSA to fund their research. The SAB has also been involved in TSA efforts to get the U.S. Government (through the National Institutes of Health) to put much more funding into research on TS since their resources are much greater than ours.

Q: How does the board decide which research projects to recommend for funding?

A: We read a lot of proposals - 50 or so in most years - and then the whole SAB meets for a weekend each winter and discusses them at length. We identify the best, most promising science in several areas related to TS and recommend to the TSA Board that they fund these studies. We also make a special effort to try to fund young scientists with the hope that we can get them interested, early in their careers, in the effort to understand, treat, and cure TS.

Q: What do you think will be the next big discovery?

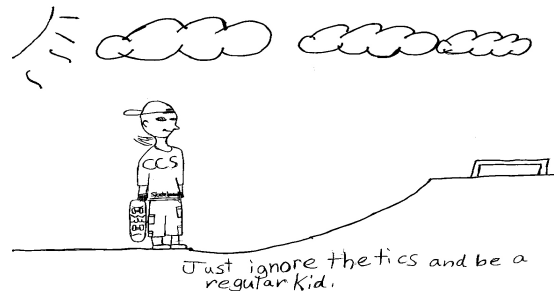
A: I wish I could predict things like that! Perhaps the coolest thing about science is that it is extremely unpredictable. You can decide to go to the moon, build the rocket, and get there - because it's really just an engineering problem. But scientific problems -- How does the brain work? How does it cause behaviors? How is the TS brain different from everyone else's? -- are very open-ended. You just don't know what area of study will suddenly shed light on the things that you are trying to learn. In the past 50 years the answers to big problems have again and again come from unexpected places. I think that there are several very promising areas, and the TSA has tried to put funding into these: the genetics of TS, the use of neuroimaging. We'll see.

Q: Do you have any advice for kids who are interested in science as a career?

A: Yes - learn absolutely everything that you can in K-12! Scientists don't just need good science and math skills, they need to be able to speak and write well, to read and think very critically. Be interested in the natural world, and study it, but don't neglect English, history, foreign languages, etc.

Q: Why should people participate in research projects?

A: Without willing volunteers, there would be practically no clinical research, and no advances in most major areas of human suffering. Someone who participates in a study may benefit themselves, but they may also help open the door to better treatment of thousands of other people.



Seventh-Grader, *Sean Stigall*, sent us the above drawing.

Quit it

by *Marcia Byalick*



Read *Quit it* for the inside story on TS.

Marcia Byalick follows Carrie, just an average kid with TS, as she copes with her eccentric older sister, concerned but out-of-it parents, best friend with obsessive fears, goofy teachers, a lead in the school play, and all the usual craziness of getting through a year at school with tics. *Quit it*, by Marcia Byalick, is available from Delacorte Press: www.randomhouse.com. \$15.95. Call TSA for a discount.

Simon's Special Sneeze Test, text by Candida B. Korman, with illustrations by Jacob Ospa, is 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. Please contact TSA 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, Attention: Publications Department. Please be sure to give us your name, address, telephone and email with your request. The cost is \$4.00 plus shipping & handling.

TSA would like to express our sincere gratitude to Zachary Ashinoff from Westchester, New York, for being the first Editor of the national TSA kids' newsletter - *That Darn Tic*. Zachary helped to get this most important publication off the ground and we are fortunate that he will be remaining as a consultant on the newsletter's Editorial Board.

As we say thank you to Zachary, we welcome our two new Co-Editors: Zachary Hollis from New Mexico and Micah Smith from California. We look forward to their participation and thank them for agreeing to take on this responsibility.

Joining the Editorial Board of the newsletter are Jonny Ospa, the creative force behind *Touretteville* and his brother, Jacob Ospa, the illustrator of TSA's new children's book *Simon's Special Sneeze Test*.

Candy Korman and Peggy Harford will continue to provide technical support to our team.

If you do not already receive *That Darn Tic*, call Peggy at the national office: (718) 224-2999, Extension 225 or send an e-mail to peggy.harford@tsa-usa.org and get on the mailing list (please include full name, address and date of birth). You can also download past copies on our website: www.tsa-usa.org.



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