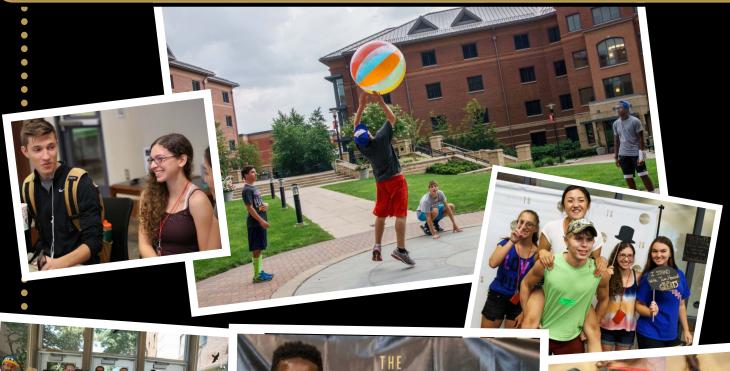


THE TEENAGE GUIDE

TO LIVING WITH

TOURETTE SYNDROME









The Teenage Guide to Living with Tourette Syndrome

and the

The GreaTS

are brought to you by



NJ Center for Tourette Syndrome and Associated Disorders, Inc.

The nation's first Center of Excellence for Tourette Syndrome

For more TS resources visit www.njcts.org, call 908-575-7350, or visit www.standwiththegreats.org



Introduction

The following pages represent the experiences, strengths, advice, and creativity of teens who attended the 2016 NICTS Tim Howard Leadership Academy hosted by the NJ Center for Tourette Syndrome and Associated Disorders at Rutgers University in Piscataway, NJ. Teens worked together in small teams and were given a situation that a teen with TS might realistically come across at some point in their lives. What they did next was think through what they were learning from the experts they heard from, the discussions they participated in, and the experiences they shared to consider how they might respond in that situation particularly in a way that reflects that they are One of The GreaTS! What does it mean to be "One of The GreaTS?" It is our hope that as you read through this book, you won't only read a description—but you'll see what it looks like in action!

As a participant in the NJCTS Tim Howard Leadership Academy, the contributors to this book had the opportunity to join an exciting community of The GreaTS. The GreaTS is a global platform dedicated to breaking down social stigmas, creating awareness, and providing support resources around Tourette Syndrome. This global platform was created in partnership with NJCTS and legendary goalkeeper Tim Howard, who was diagnosed with Tourette Syndrome at age 10 and never let it hold him back. It is a call to arms for those

with TS to rise above the challenges and embrace their own personal greatness. The teens who attended the Academy and contributed to this ebook composed and performed scripts that show, based on everything they learned at the Academy, how to address a particular situation a teen with TS might face. They also added tips, suggestions for dealing with tics, friends, teachers, and others, for each scenario. In short, this is advice FOR teens, BY teens—people who have definitely "been there" and are offering their best advice of how to handle any situation that gets thrown your way!

An Introduction to the Academy

The NJCTS Tim Howard Leadership Academy is a 4-day residential learning program for teens with Tourette Syndrome who have had varied experiences with leadership—some have a little, some just have a lot of interest in being better leaders, and others have a whole lot of experience already. Admission to the Academy is competitive, and applicants are selected to attend after having passed through a rigorous application process. Teens who attend connect over a variety of different experiences, including team-building activities, recreation, large and small group discussions, chances to ask questions of some of the most expert individuals in the field

of TS, and attend workshop sessions led by doctors, professors, and others.

The Four Pillars of the Academy

At the heart of the Academy, and echoed in the GreaTS movement, are four goals we think are pretty key to living your best life as a teen with TS. Each moment of the Academy is carefully constructed to explore and reflect the core goals, values, and themes.

- Self Leadership—the ability to know your own strengths, weaknesses, and needs in order to be one's best self
- Self Empowerment—the ability to recognize what you need and advocate for it in order to succeed
- Resilience—the idea that you can face adversity, obstacles, and difficulties, but remain positive and overcome them to emerge stronger
- Grit—this is the ability to "stay the course," to maintain determination and motivation despite experiences of failure or opposition

Tourette Syndrome, and other disorders commonly associated with it like ADHD, OCD, and anxiety, are often misunderstood by people who think that tics are controllable or that Tourette Syndrome is just something that means you curse a lot. But the truth is, having Tourette Syndrome is much more complicated than that and it can be difficult to understand and really hard to explain. The NJCTS Tim Howard Leadership Academy—and this ebook—

provide a place to build the critical skills of self-leadership and resilience so that young people with TS, like Tim Howard, will ultimately excel and, through their success, become an inspiration to others.

One of the GreaTS!

These four pillars of the Academy are echoed in The GreaTS campaign. The GreaTS empowers individuals with Tourette Syndrome—especially kids and young adults—to develop the confidence, leadership, and self-advocacy skills necessary to overcome their challenges. What follows is an attempt to uphold The GreaTS mission of breaking down social stigmas, generating awareness, and providing support. We hope it provides you with inspiration and language to help others understand. We hope you share it with others to generate better awareness. And we hope it provides guidance and support that you or someone you know might need.

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STARTING A NEW SCHOOL



Tips:

"Recognize your condition, learn to love it and accept it. Don't fight it or hate yourself for something you can't control."

-Sharif W., Elkins Park, PA

"Don't wait for it to become a problem before you talk to your teachers about TS. It's a good habit to troubleshoot problems before they occur."

—Fox C., Davis, CA

The Scene

The school year has just begun, and you're in an entirely new school. In your old school, everyone there was pretty understanding and supportive of your TS. Turns out, there were a few students before you who had TS, and they did a pretty good job of ensuring every faculty and staff member understood what TS is. But in your new school, your teachers don't understand. They've given you detention, accused you of acting out and interrupting class, and they're not consistently following the guidelines of your Individualized Education Program (IEP).

You know this isn't right and isn't fair. Your parents have offered to help you, but you'd like to try to encourage others to understand on your own, without your parents' help. You know that when you go to college or off to work in a few years, your parents won't be there in the same way to help—you'll have to be able to talk to others on your own.



Starting a New School: In Action!

Narrator: Starting a new school can be a daunting transition for anybody, especially for students with Tourette and its co-occurring conditions such as ADHD, OCD, and anxiety. Students with these conditions might have needs that other students don't have, and teachers might not always respect or understand these needs, or may not even be aware of them. My friend Andrew has Tourette and when he started a new school, one of his teachers failed to understand his needs, even though he had a 504 plan, and at first he found it very difficult to stand up for himself.

(Bell rings.)

Teacher: Andrew, I'd like to speak with you. You have been extremely disruptive in class this week. I understand that starting a new school can be stressful, but the level of disrespect you are showing has no excuse. You will change your behavior, or find yourself in detention.

(Andrew sulks out of the room.)

Narrator: Andrew knows that the way his teacher responded to his tics is not right, and even though he feels hurt he isn't sure what he can do to help himself.

(Andrew walks in.)

Andrew: Finally! Lunch time!

Jackson: Hey Andrew. My name is Jackson, you are new, right?

Andrew: Yeah, I'm having a rough first week. I have Tourette Syndrome, which means that I can't always control the way I behave in class because I can't control my tics. My teacher doesn't understand and I don't know what I'm going to do. I thought she would be more understanding.

Jackson: Have you talked to her about it?

Andrew: I don't know how.

Jackson: You know, Andrew, you can't expect others to anticipate your needs if you haven't spoken to them about them. It sounds like

you need to be an advocate for yourself. If your teacher doesn't understand your situation, you can't expect things to change on their own. If you have a 504 or IEP, you should make sure to go over what that means with your teacher in person. It's important that they hear what your needs are and what accommodations you are entitled to.

Andrew: Gee... I sure feel stupid. I just didn't know what to say.

Jackson: That's OK Andrew. It's never your fault if your needs are not being met or if a teacher doesn't respect your accommodation or your limitations, so don't be discouraged. Just remember to be proactive when entering a new situation in the future and don't give up.

Andrew: But what if someone doesn't have an accommodation set up for them, or what if my teacher continues to ignore or disregard my accommodation?

Jackson: If a student needs to be accommodated for in ways most students do not, they should speak to their counselor about setting up a 504 plan or IEP. These guarantee certain things that will help students with TS, ADHD, and other such conditions with certain accommodations to help them succeed. If a teacher refuses to comply with either of these, it is no small problem, and the student involved should talk to their counselor, principal, or school nurse to advocate for themselves and protect their rights. If a teacher refuses to comply with an accommodation, a student and their family can even take the issue to court if they wish.

Andrew: Golly! Thanks!

(Next day before class.)

Andrew: Hey teacher, I realize I have been disruptive in class lately, but I have a condition called TS which causes me to say and do certain things I can't control. My condition makes it hard to participate in class sometimes, and it might seem like I'm behaving disrespectfully when I can't help it.

Teacher: Gosh Andrew, I had no idea. I'm sorry I should have paid more attention to your paperwork. I see you have a 504 that explains your accommodations. Thank you for talking to me about this in person. See you in class!

(Andrew and teacher high five.)
End scene.

Take a deep breath Only assertiveness wins Understand your needs Respect others' boundaries Eat well - bewell Tell the world your story urn your failures intolessons Explore your options Self-advocate III

Tips:

"When attending a new school, always meet with your teachers to explain your situation and/ or reach agreements on certain accommodations you need to be successful in school. Try building a strong relationship with teachers. Those teachers with which you have built a bond can also help you in the long run when it comes to having an advocate.The one thing that is paramount is becoming your own self-advocate."

-Sharif W., Elkins Park, PA

Tips:

"Tell others about your symptomsdon't expect people to know." —Andrew P., Batavia, NY

"Don't let stressful situations intimidate you. The only way to deal with stress is to confront it even though it is stressful. Ignoring a challenge such as a large assignment, starting at a new school, or taking a difficult class will not make the challenge go away!"

—Fox C., Davis, CA

STANDING UP FOR SOMEONE ELSE

The Scene

Your friends understand your TS and are very accepting. You can tic freely in front of your classmates, and people rarely seem to notice anymore. It wasn't always this way but now that others understand, you find school and your social life to be quite comfortable, regardless of your TS.

But there's a kid a few grades younger than you who isn't having nearly as easy a time. She is getting picked on by her peers. Classmates mock her tics, people in the hallways sometimes tell her to stop ticcing, and even her friends seem less and less supportive or interested in hanging out. She doesn't appear to know what to do and she definitely doesn't have the confidence, nor the comfort speaking out that you have.



Dakota witnesses "The Crew" bullying Sarah.

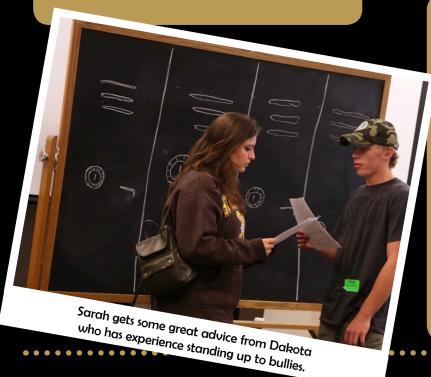
Tips:

"Don't let other people step on you! Speak up and talk about your TS with pride."

-Ben S., Morristown, NJ

"Be extremely kind to guidance counselors, doctors, teachers, and others who are in a position to help you and show them you appreciate their support."

-Michael L., Chesterton, IN



Standing Up for Someone Else: In Action!

(Sarah has a head shaking tic. Sammy and her crew walk up.)

Sammy: What are you a dog or something? It looks like you have fleas.

(Sarah does a tongue tic.)

Sammy: Are you kidding me? Are you trying to start something here? You're just a twitchy freshman that tries to get attention for twitching like a dog. Stupid freshman...

Sarah: (faintly) I'm sorry I'm not trying to start anything.

(Sarah and Sammy both take three steps and then freeze.)

<u>Dakota:</u> (to audience) This looks familiar. I went through the same thing back in freshman year when I was bullied for my tics and I still remember the feeling of being picked on.

(Sammy walks off stage, Dakota and Sarah walk closer to each other.)

<u>Dakota:</u> Hey I saw what was going on earlier and I just wanted to let you know that it doesn't matter what they think because you're a wonderful person and it clearly doesn't define you. Tourette is just a little part of you.

Sarah: Thanks. It's really tough going through this whole bullying thing. They say something to me at least a couple times a week.
I feel so embarrassed and what's worse is that they'll bully me in a large crowd which makes my anxiety even worse. It's been pretty tough because I don't really have anyone to talk to. A lot of my friends started to leave me once my tics started getting really bad. It seems as if they only cared about themselves and the people they hang out with.

<u>Dakota:</u> I know. I remember those days and they were really hard and confusing but they didn't stop me from living my life because those kids don't know the real me. Once I showed others that my Tourette didn't get the best of me, people started to care less about my tics.

Sarah: So what should I do?

<u>Dakota:</u> Well, it's not just you. We can both confront her, you don't have to do this alone.

(Next scene. Dakota, Sarah, Sammy and the crew enter.)

<u>Dakota:</u> I heard you were being rude to Sarah. What's going on?

Sammy: What do you mean? She was trying to start something! She's always doing something weird.

<u>Dakota:</u> Well she can't control this. She has this thing called Tourette Syndrome. It forces her to make movements and sounds she can't control.

Sammy: So she has no control over the movements and sounds she makes? I don't buy that. Why can't she just try to be normal? Is she just trying to get attention?

<u>Dakota:</u> Well it doesn't work that way. As I said before she can't control it. It's nothing she can help. She has intense urges to make sudden noises and movements uncontrollably inside her body. Have you ever tried to suppress a sneeze? It's like trying to suppress a tic.

Sammy: You can use any excuse you want but she's still an attentionseeking freshman.

(Sammy and the crew walk off.)

Sarah: Great, now what? It didn't work.

<u>Dakota:</u> Listen Skippy, you need to have more faith in yourself. You have such an amazing personality and as I said before your Tourette doesn't define you, it's just a little part of you.

Sarah: But she doesn't believe us. She thinks I just want attention.

Dakota: So what? Who cares what she thinks of you? The only thing that matters is how you view yourself. There's nothing better than being yourself, and once you find the people who like you for you, it's so much better than being with the people who only like the fake you.

Sarah: Thanks Dakota. I've never thought of it that way. That really helped.

(Dakota and Sarah start to walk off but Jackie from the crew stop Sarah. Dakota keeps walking.)

Jackie: Hey Sarah! Wait, do you have a second?

Sarah: Um, yea, sure I guess...

Jackie: Listen, I really wanted to apologize about before. I'll be honest, I always thought Tourette was some cursing disease. I feel really bad about what we did. I didn't know that you had no control over this. People really shouldn't be making fun of disorders like this. You're really lucky you have a friend like Dakota to stick up for you like that. I wish we did the same.

End scene. Tips: "Keep a positive attitude. Tics are annoying but they're NOT the end of the world. Your tics can't limit you unless you let them." —Anna B., Mantua, NJ Together, Dakota and Sarah will stand up to "The Crew." we are Jackie apologizes to Sarah. She admires Sarah's friend who helped her tackle a bad situation.

YOU'RE JUST DOING IT TO BE FUNNY



Tips:

"Ask a teacher or friend to help you explain that with TS, it may seem you are just trying to be funny when you are not and that you don't feel comfortable when others laugh and accuse you of ticcing to get attention or to be funny."

-Luke D., Andersonville, TN

"Remain calm and use breathing techniques to help ease your anxiety."

-Logan A., Little Egg Harbor, NJ

The Scene

Your teacher, classmates, and friends all know you have TS. For the most part, when you tic, others don't comment or remark and they seem to accept that your tics wax and wane. However, recently you developed a new tic which has you repeating a sentence your peers seem to find funny. Initially, they tried to hide their laughter, but as time wears on, their laughter is more and more evident.

You aren't trying to be funny. In fact, you find the new attention your tic is drawing to be a little embarrassing and unwanted. Eventually, one of your classmates accuses you of "just doing that tic to be funny and get attention!" Others nod their heads in agreement. You can understand why it might appear that way to them, but it isn't at all what you intend.



You're Just Doing it to Be Funny: In Action!

Dr. Phil: Hello all and welcome to the Dr. Phil show. In our scene, you will witness Logan being bullied by JPP. In the classroom, we have seen various accounts where Logan is ticcing, a symptom of Tourette Syndrome which he was diagnosed with as a child. However, our other student, JPP, does not understand this disorder and thinks Logan is making these noises just to be funny and to get extra attention from his classmates. And here's the clip...

(Cut to the clip.)

Teacher: Okay Logan, it's your turn to summarize chapter 9 of "The Crucible."

Logan: The Crucible is about the Salem witch... Boo, chicken don't get greedy ...trials.

JPP: HAAAA whaaat was that?!?!?!

(End clip. Cut back to Dr. Phil.)

Dr. Phil: So there's the clip, now let's give Logan a chance to explain what's been going on.

Logan: Boo, chicken don't get greedy... Boo, chicken don't get greedy. I am not just making noises to be funny. I have a neurological condition called Tourette Syndrome, and you knew that JPP! It causes me to make sounds and movements I cannot control. Boo, chicken don't get greedy.

JPP: But who says that?! Where did that come from? C'mon Dr. Phil.

Logan: Listen, I can agree it's a little funny and I can see how it distracts everyone but I can't help it. When you point it out, it just makes my tics worse. I need JPP to stop laughing when I tic because it makes me upset.

Your sounds are funny and make me want to laugh. Why can't you just accept that?

<u>Dr. Phil:</u> Well let me just stop you there for a second. Logan, I think you handled yourself quite well especially when all eyes were on you.

Logan: Mmhmm Boo, chicken don't get greedy...

Logan: It does feel mean Dr. Phil. I feel like my boundaries are being violated.

<u>Dr. Phil:</u> Logan, I'd like to commend you for standing your ground and being assertive. It's hard to do when you have the whole class against you. The important thing to remember is to know and respect your boundaries, as well as JPP's, even though it wasn't mutual.

JPP: But I don't understand why he can't stop it or at least...

Dr. Phil: JPP, what would you do if this were you?

JPP: I wouldn't let anyone mock me! I'd FIGHT THEM!

Logan: Easy for you to say...

<u>Dr. Phil:</u> Violence isn't the answer. What can we do to solve the problem instead? JPP, what I'd like you to do is think about what you'd feel like if you were in Logan's position. Put yourself in his place.

Logan: Although it may be tempting to fight, I'm mature enough to know that it's not the right thing to do. I don't always know how to stand up for myself but I want to be able to talk to people about what it's like to have TS and say what's right in tough situations.

<u>Dr. Phil:</u> Wonderful! That's a step in the right direction. You're on your way to being a self-advocate!

JPP: What's a self-advocate?

<u>Dr. Phil:</u> A self-advocate is someone who tries to create awareness for their own cause; someone who knows themselves and can educate others through their experiences.

Logan: Maybe I can do that.

JPP: Yea, that makes sense...

Dr. Phil: Logan you've been through some hard times but you've overcome a lot of adversity, I'm glad you're able to show your grit.

JPP: Wow, I've never realized what I put you through.

Logan: There's a place I went last summer called the NJCTS Tim
Howard Leadership Academy. I learned how to stand up for myself and
overcome challenges that I face every day.

<u>Dr. Phil:</u> Logan, by remaining positive despite your struggles you turn your ideas into actions by showing great resilience and grit.

Logan: I never knew my words could make such a difference.

<u>JPP:</u> Logan, I give you a lot of credit for getting up in front of the class and speaking, I happen to be a pretty bad speaker, you think you can give me some pointers?

Logan and JPP: Yea, together we can STAND WITH THE GreaTS!

End scene.



ROOMIES!

The Scene

High school graduation has come and gone, and as summer vacation is nearing an end, you are just a few short weeks away from moving in to your college dorm. Your friends have told you all about their roommates but you've not been in touch with yours at all, even though she has reached out.

Your roommate doesn't yet know that you have TS. You are concerned that since you will be living in such close quarters, she won't be happy to know you have TS and that it might affect her life. You're worried she might find out and march straight to the RA to demand a roommate change.



Tips:

"Don't be bothered by what uneducated people say. Just stay calm and tell them what TS is. They're more likely to stop being mean once they know the circumstance."

-Mike H., River Vale, NJ

"Think of the positive effect TS has left on your life and ignore the negatives. Make sure people know you have TS and what it is so they will be more understanding. It is always best to tell the peers closest to you."

—Trevor S., Randolph, NJ



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Roomies: In Action!

<u>Narrator:</u> Jessica just found out the name of her new roommate. She decided to text her to let her know about her Tourette Syndrome. She thinks this year will be great and her roommate will completely accept her. It is now 2 weeks later and they are meeting for the first time.

(Jessica walks into the room, ticcing.)

Jessica: Hey!

Candace: Hey you're that girl with Tourette Syndrome, right? Well I watched a movie, so I'll just swear back at you.

Jessica: Oh no... eh heh heh. (awkward laugh)

Candace: What's wrong with you? Is that one of your...bugs?

Candace: Well, is it contagious? Because I really don't want that.

(Candace goes to get the RA.)

Candace: I just can't! I can't! I do not want bugs in my room!

RA: I'll see what I can do.

(Candace storms out.)

RA: I thought maintenance already took care of the bug problem.

<u>Narrator:</u> Ok. So that was what not to do. Now you get to know what you should do. Again, Jessica and Candace are roommates. But this time Jessica is taking an assertive route instead of a passive one. She just arrived at her college.

(Jessica approaches her RA.)

Jessica: Hey, you're my RA right?

RA: Yea that's me!

<u>Jessica:</u> I have Tourette Syndrome, a neurobiological disorder, and I'm a little nervous about how my roommate will react.

CA: Oh you don't have to worry about it. I'll even go with you if you want.

Jessica: Thanks!

(RA and Jessica go to Jessica's room.)

Candace: Hi! I guess you're my roommate.

RA: Yes, this is Jessica.

(Jessica and Candace shake hands.)

Jessica: I'll be right back. I need to put my bag down.

(Jessica steps away but continues ticcing.)

Candace: Is she ok? Why is she making those noises?

RA: She has Tourette Syndrome, a neurobiological disorder. She can't control it.

Candace: Oh, is it contagious?

(Jessica returns)

Jessica: No, it's not contagious. It's really no big deal sometimes.
I move a little or make weird noises. I'm very open about it. If
you have any questions, just ask!

Candace: Well, is there anything that I can do to help you out?

Jessica: Actually, yeah. Just remember to try to be accepting of it.

If I'm having a bad tic day just try and ignore it.

Candace: Sounds good. Here, let me help you unpack.

End scene.

Tips:

"Meditation and yoga are two of the best medicines for tics."

—Matthew T., Abington, PA

"The best way for me to calm down is to flex all my muscles one by one."
—Bennett S., Rumson, NJ





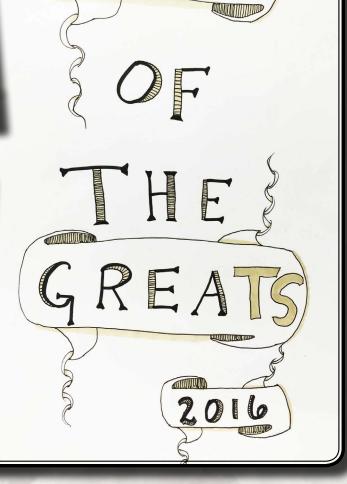
Now that Candace understands that Jessica's tics aren't contagious, she knows how to help her new friend.

Tips:

"Know when you need a break.

Most people will understand that when you have a day or moment that is particularly bad for your tics, you need a break. Take a walk, get a drink of water, go outside and get some fresh air, just calm down. There's no need to get worked up about tics and the anxiety will likely only make them worse."

—Maggie-Lu M., Ennismore ON, Canada



TICCING WHILE DRIVING



Tips:

"Always have a space or place where you know that you can take a break—whether at home, work, or wherever you go."

-Chris M., Oaklyn, NJ

"Make sure to never let your TS limit what you can do. Always be confident in yourself."

-Kyle O., Lawrence, NJ

The Scene

You are a new driver, and for the past few weeks, you've been loving the freedom of being able to hit the road on your own! But allergy season is here. And in past years, allergy season brings with it an increase in your motor tics. What would happen if your tics increased while you were driving? Sometimes your leg kicks and your shoulder shrugs. Would this affect your and others' safety on the road?

You've been able to shrug off this concern until this one bright and lovely day, what you dreaded happens: you are behind the wheel and your tics are increasing. You are fighting the urges to tic, but you're not sure how long you can suppress them. You find yourself focused on not kicking your leg or shrugging your shoulder, which could take your hands off the wheel.



Behind the wheel, Bennett struggles between listening to his good conscience and his bad conscience.

Ticcing While Driving: In Action!

<u>Narrator:</u> Bennett was at his friend's house for the day but it's starting to get late and he needs to go home. Allergy season is here and Bennett's tics are flaring up. He is going to debate the best way to get home safely.

Bennett: Thanks Mrs. Smith for having me over! I am going to go now.

Mrs. Smith: Hey Bennett. Thanks for coming. I know it's getting late and I noticed your tics have been worse today. Do you want me to drive you home?

Narrator: Bennett doesn't feel comfortable asking for a ride home. He feels if he asks he will feel embarrassed and that he would be a burden by leaving his car at his friend's house. Bennett is going to weigh the pros and cons between his good conscience and bad conscience.

<u>Bad Conscience</u>: Bennett, you know you'll feel silly asking for a ride. You've driven plenty of times before. The last thing you want to do right now is be a burden to Mrs. Smith.

Good Conscience: Asking for a ride from Mrs. Smith is a good idea. You won't have to worry about your tics and you can always get your car tomorrow.

Bennett: It's OK Mrs. Smith. Thank you very much for the offer. I've driven home plenty of times before and I know I need the car in the morning. I'll just drive myself home.

<u>Narrator:</u> Bennett gets to his car and begins to drive home. He starts to feel his tics coming on and debates if he should rush home by taking the busy highway or the local back roads with less traffic.

<u>Bad Conscience</u>: Don't worry about other cars on the highway. Just get on at the next entrance and you'll get home much faster. You won't have to tic until you get home!

Good Conscience: You know it's not safe on the highway. What will you do if you start to tic and you can't get off the highway? What if there are lots of cars?

Bennett: I think I'll take the highway. I want to get home as soon

- as I can. Plus my tics are getting worse.
- Good Conscience: You're making a bad decision!!! You know, if you're going to drive on the highway, you should at least keep to the slow lane where there will be less traffic and you'll be safer.
- Bad Conscience: But the left lane will get you there faster! What's the difference if you tic in the slow lane or the fast lane? You still tic no matter what.
- Bennett: I have already begun my shoulder tic and can't seem to let it go. I even feel my leg tic coming on and probably can't hold it in any longer. I would feel safest in the slow lane because I already risked my safety by getting on the highway in the first place.
 - Narrator: As Bennett continues to drive on the highway, he can't suppress his leg tic anymore and his foot comes off the gas pedal.
 - Good Conscience: Bennett, you need to put on cruise control. With your leg tic you can't keep a consistent speed.
 - Bad Conscience: You don't need cruise control! Just speed up and when you have a leg tic your car will slow down to the speed limit.
 - Bennett: I think I'll put on cruise control. The last thing I want to do is speed and attract attention from a police officer on the road.
- Narrator: Bennett's shoulder tic and leg tic won't calm down. Even with driving in the slow lane and with cruise control on, Bennett still doesn't feel completely safe driving on the road alone. His good conscience and bad conscience are going to sway his decision to pull over on the side of the road.
- <u>Bad Conscience:</u> No need to pull over, Bennett, you are almost home.
 You said it yourself, you didn't want to be a burden to Mrs. Smith.
 Plus, if you pull over and a police officer comes up behind you he will be very suspicious about your tics.
- Good Conscience: At this point, your tics are really bad. Don't listen to your bad conscience. What's more important, your safety or the slight chance an officer approaches you and you have to deal with that? You need to pull over to try and calm your tics down.
- Bennett: I think the best thing to do at this point is pull over. My hands keep coming off the wheel due to my shoulder tic. In case

I need to slow down, my leg tic is preventing me from pressing the brake. I need to calm down because I'm in no condition to drive.

Narrator: Bennett finally pulls over and tries to calm himself down. After about 15 minutes, he has not calmed down. If anything, his tics have gotten worse. He knows he needs to call for help and is trying to figure out the best person to call.

Bad Conscience: Who could you possibly call? You can't call law enforcement. They won't understand your tics!

Good Conscience: Listen, if you call emergency services, explain the situation to the dispatcher. Be brave and advocate for yourself. Give them a heads up about your tics.

Bennett: I don't know any officers in the area. I would rather call someone I am comfortable with.

Bad Conscience: Why are you even debating this? Just stay here and drive again after you calm down.

Then you need to call your parents or a friend. You Good Conscience: are in no condition to drive.

Bad Conscience: That's so embarrassing!

Bennett: I'm going to call my parents. I honestly regret not asking Mrs. Smith for a ride. I know I'm in a tricky situation now, but in the future I will always make sure to put my safety over my pride.

End scene.



Bennett should have put his safety first and accepted Mrs. Smith's offer to drive him home.

lips:

"Be confident and don't listen to negativity! If anyone makes fun of you, it just means they have problems of their own." -Ben S., Morristown, NJ

"To smooth over the school experience, reach out to your teachers before school starts to tell them about your TS and maybe give them some of the resources about TS."

-Blair, Hillsdale, NJ

GETTING PULLED OVER

The Scene

You've had your license for a little while now. You consider yourself a comfortable driver, and you have skills in place for managing your TS symptoms while driving. Occasionally, when traffic gets bad, or someone cuts you off, you have a momentary increase in tics brought on by the anxiety of those rare and uncomfortable situations. But these moments are few and far between!

One day, while taking a different route home, you neglect to notice a dramatic drop in the speed limit. But the nearby police officer most certainly did not neglect to notice! Before you know it, the officer pulls behind your car and flashes the lights. You're being pulled over. Already you can feel your tics increasing from the anxiety of the situation. The officer, not knowing you have TS, begins questioning your behavior immediately and believes you are being insubordinate.



Tara is being pulled over for speeding and is prepared to explain upfront that she has TS.



James gets pulled over for speeding and his tics make the police officer think he is behaving aggressively.

Tips:

"Stay calm and relaxed. Explain to the officer why you may demonstrate suspicious behavior. Have "I have TS" cards available to hand to the officer. Fully cooperate with what the officer tells you to do. Act completely normal, as if you were talking to your parents or best friend."

-James P., New Milford, NJ

Getting Pulled Over: In Action!

Narrator: James is driving down the highway going 80 mph in a 65 mph zone.

Police Officer: License and registration? You were speeding and ran through a stop sign.

(James punches the seat next to him.)

Police Officer: Please calm down.

(James keeps ticcing, sniffing, punching, blinking.)

Police Officer: Have you had any alcohol? Are you under the influence of any drugs?

James: (aggressively, still ticcing) How dare you! I'm so offended!
What's your badge number? I'm going to report you!

Police Officer: I need you to calm down.

James: I'm sorry, I can't help it.

Police Officer: What do you mean?

James: I have Tourette Syndrome, give me a break. All the nice cops do.

Police Officer: You didn't answer my question. Are you on drugs?

James: Do you have a hearing problem? I already told you no!

Police Officer: Stay in your vehicle. I will be right back.

(The police officer calls in to the station and asks what TS is. He returns to the car with a basic understanding.)

James: Jeez, what took you so long?

Police Officer: Sorry I was asking and checking what TS is.

<u>James:</u> Did you not pay attention at the academy? You're supposed to know these things.

Police Officer: I do apologize sir, but you are still getting a
ticket for reckless driving. Maybe next time you'll be more
compliant.

James: Maybe next time you can be more knowledgeable.

(James drives away.)

Police Officer: (sighs) I don't get paid enough for this.

(Next scene.)

Narrator: Tara is driving down the highway going 88 mph.

<u>Police Officer:</u> License and registration, please? Do you realize you were speeding a ran a red light?

(Tara punches and kicks the seat next to her.)

Police Officer: Have you had any alcohol? Are you under the influence of any drugs?

Tara: I'm sorry officer. I am not under the influence of any drugs or alcohol. I have Tourette Syndrome. It's a neurological disorder that causes me to make sounds and movements that I can't control. Is it OK if I reach for my wallet and get my card?

Police Officer: Ok.

(Tara passes a card to the police officer which states that she has Tourette Syndrome and briefly explains what it is.)

Police Officer: Oh, Tourette Syndrome? I think I've heard of this. I think my neighbor's son has this. Let me double check with my Chief.

(Police Officer steps away from Tara's car and dials her Chief.)

Police Officer: Hello, Chief? I just pulled someone over who says she has Tourette Syndrome...

(Police Officer returns to Tara's car.)

Police Officer: My Chief confirmed that it's something you can't control.

Tara: Thank you for understanding. Most people don't understand how hard it is to deal with.

Police Officer: Actually, my Chief would like for you to come in and talk to all of the officers about what Tourette Syndrome is and what it's like for to live with it.

Police Officer: Just take this as a warning. We'll be in touch. Just drive safe and watch your speed.

Tara: Thank you officer and have a wonderful day.

Tips:

"Don't get angry if the officer does not know about TS. Be cooperative if the officer is impatient or annoyed with your behavior. Don't be disrespectful in your tone or manner.

And don't try to suppress your tics."

—James P., New Milford, NJ

End scene.



Tips:

"Chewy necklaces are helpful fidgets that can help with redirecting vocal tics better than using a manual fidget."

—Maggie E., Whippany, NJ

THE DATING GAME



Tips:

"Remember that your Tourette Syndrome doesn't define who you are. Sure, it's a part of you. But Tourette Syndrome is a part of so many individuals! It may feel like it's your defining feature, but it definitely isn't. Find what makes you "you" and go with it. You are so much more than a Tourette Syndrome label."

—Maggie Lu M., Ennismore ON, Canada

The Scene

Your friends all seem to have boyfriends and girlfriends. You've been shy about dating, but there is this one person who has been catching your eye for weeks now. You'd LOVE to go on a date with him or her, but every time you imagine asking this person out, your tics increase. You finally build up the courage, and one glorious day, you swallow your fear and you ask him or her out—and they say yes! You're not sure they know you have TS, but you're so over the moon excited, this is the furthest thing from your mind!

That is... until the night of the big date. You begin running through all of your fears. What if you accidentally kick him or her if your leg tic acts up? What if your vocal tics take them by surprise, or what if they laugh? What if it turns out they don't want to see you again because of these things?



The Dating Game: In Action!

<u>Host:</u> Ladies and gentlemen! Boys and girls! Children of all ages!
Are you ready for...the dating game? I'm your host, JRay. Now, let's meet our lucky lady. Come on out Jojo!

Jojo: Hi mom! Hi dad! I'm on TV!

Host: So, Jojo, what do you look for in a man?

Jojo: Someone who can be confident, truthful, and of course, make me laugh. And a sprinkle of handsome wouldn't hurt!

<u>Host:</u> Well, we'll see what we can do. Contestants, come on out! [applause] All right, you all know how this works, Jojo you will ask our contestants any questions you want. You can ask one, two, or all three of them. Contestants, your answer must be truthful.

<u>Jojo:</u> Contestant number one, what is a strength and weakness of yours?

Contestant 1: I've faced a lot of challenges from being different from others but through my advocating I've been able to help change my weaknesses into strengths.

Jojo: Contestant number two what would you cook me for a meal?

Contestant 2: I don't know! My mom can cook us something. I'm really dependent on her. (audience laughs)

Jojo: Contestant number three what you do in stressful situations?

Contestant 3: I drown my sorrows in a tub of ice cream!

<u>Jojo:</u> This question is for all the contestants. What is your perfect first date?

Contestant 3: Working out at the gym. You can be my spotter.

Contestant 2: My mom will drive us to the movies and buy us popcorn,
 but you'll have to pay for the ticket.

<u>Contestant 1:</u> A group date, because I like having a support team to ease the pressure.

<u>Host:</u> All right, that's all the time we have for today. Jojo, have you decided who you like to date?

Jojo: Well, JRay, I mostly do! I choose...Contestant number one!

Contestant 1: Yes! I knew we were soulmates!

(Jojo and Contestant 1 walk off stage skipping next to each other.)

Narrator: Contestant 1 began the group date by explaining he had TS. Jojo was excepting of Contestant 1's TS and found it endearing that he was upfront and honest. His tics were more noticeable at the beginning of the date, but as everyone became more comfortable his tics became less noticeable. Contestant 1's confidence earned him a second date with Jojo. They will be going on a movie date to watch "Front of the class."

End scene.



Tips:

"Don't think about what you can't do in a conflict, instead think about what you can do."

—Lysso S., Bar Harbor, ME



INTERVIEW ANXIETY

The Scene

It's the summer, and you've done the leg work of applying for a bunch of jobs. You can't wait to be bringing in some of your own money, and you're excited at the prospect of building up your savings account. About a week after your resumes have been submitted, you get a call for an interview and are THRILLED to find that it's for your favorite job of all the ones you've applied for! What could be better?

The morning of the interview comes, and your excitement and anxiety over the interview definitely have you feeling nervous and on edge. By the time you sit down face-to-face with the person who is interviewing you, your tics have increased; they are visible and audible. You know it's iust a matter of time until the interviewer notices, and you're worried it will interfere with your ability to land the job.



Tips:

"Always start the day with a deep breath and a smile. Find an organizational method you like and stick to it. Planners, bullet journals, apps, etc."

-Maggie E., Whippany, NJ



Lia takes the professional approach and addresses her TS up front with Steven.

Interview Anxiety: In Action!

(Steven is waiting at a table for the arrival of Lia. Steven checks his watch, making it clear that Lia is late)

Steven: Where is Lia? She's at least 20 minutes late!

(Lia bursts into the room, clearly distressed, drinking coffee.)

Lia: I'm so sorry I'm late! Oh this is so embarrassing. I totally overslept.

Steven: That's fine. Please sit down. Why do you want to work at Costco?

Lia: (flustered) Umm...I've heard you give good breaks?

Lia: No, my nose is just itchy, but thank you.

Steven: Why do you think you'd be good as a Costco cashier?

<u>Lia:</u> (tics noticeably increase) I just really need the job, and I saw you were hiring.

Steven: Are you alright? You seem pale and shaky.

Lia: Yes, I'm fine. I'm alright. Can we please just continue?

Steven: Anyway, what days are you available?

(Car alarms begin to go off outside.)

Lia: (Tics continue and Lia becomes very stressed out and uncomfortable) Whenever really. It doesn't matter, um...just when you need me to work.

Steven: (Sees something is clearly wrong and becomes concerned.) How about we schedule this meeting for another time? You seem a little agitated. We'll keep in touch.

(Both stand, shake hands, and Lia exits.)

NARRATOR 1: So, as you can see, there are several things wrong with this picture. First, Lia came in late, making a bad first impression. This stressed her out, causing an increase in tics. It didn't help that she was drinking coffee—which can exacerbate tics even more. Second, the interviewer noticed her tics, and when he commented, Lia chose to lie. This stressed her out, and could lead to problems down the road—her employer may not trust her and may hesitate to provide accommodations in the future. Finally, Lia uses poor interview practices by being ill-prepared for her interview. She arrived in



casual dress and answered questions timidly, without asserting herself. By not practicing assertiveness, her stress increased the tics even more. By making these mistakes, Lia did not get the job, which created undue stress and—surprise!—increased her tics even more. Now let's see how the interview could have played out with better preparation.

(Steven is sitting at his table, waiting for Lia. Lia stands behind a door, doing deep breathing exercises. This time, she's wearing a blazer.)

Steven: Lia! You're here early.

Lia: (shakes Steven's hand) Thank you sir, I like to be punctual.

Steven: Please, take a seat. So, why do you want to work for Costco?

Lia: My family have been Costco members for years, so I thought it would be great to work for a great company I'm already familiar with.

Steven: That's great to hear. I see you want to be a cashier. Why do you think you're more qualified than other applicants?

Lia: Well, I've had cashier experience before, and I'm rather good with money and math.

(Lia has a bunny nose tic during her response.)

Steven: Miss, are you okay? Would you like a tissue?

Lia: I'm fine, but thank you. I actually have Tourette.

Steven: I see. That's that swearing disease, right?

Lia: That's actually a common misconception. Less than 10% of people with TS swear. Most people have things like uncontrollable movements and sounds. About 1 in 100 people have Tourette, so it's actually quite common.

Steven: That's so interesting. That must be difficult for you.

Lia: Most people see it as a disability, but it has actually had a positive influence on my life. It's taught me resilience and grit, and I've also gained leadership skills from working with my local TS association.

Steven: That's so amazing that you can overcome your challenges like that. We need leadership skills like that here at Costco.

<u>Lia:</u> Thank you so much, sir. Even if I'm not hired, I'm glad I could spread some awareness about TS.

Steven: That's quite alright. When can you come in for training?

Lia: I'm free as soon as possible! Thank you so much!

Steven: Thank you for educating me on Tourette.

(Lia leaves, takes out her phone, dials a call.)

Lia: Hey mom. Thanks for helping me prepare! I got the job!!!

NARRATOR 2: As you can see, this interview was drastically improved. She got the job this time! In the first interview, Lia was late and drinking coffee. This stressed her out and exacerbated her tics. This time, she arrived on time, perhaps a little early. She practiced deep breathing ahead of time to calm her anxiety and tics. She also

drank water instead of coffee. Water doesn't increase her tics because it's unsweetened and non-caffeinated. This time, she also dressed appropriately. This made her look better to her employer and made her feel and look more confident. By talking openly about her TS, and the leadership experiences she's had as a result, she proves her strength and resilience during her interview. This time, she also planned ahead and worked with her mom beforehand to better her interview skills. This helped reduce



stress and made her feel more comfortable during her interview. With proper self-advocacy and interview etiquette, Lia had a smoother interview, enjoyed herself more, and had a higher chance of getting the job.

End scene.





MOVEMENT AT THE MOVIES



Amanda and Jenn act out how to go to the movies and stand up for yourself if your tics become a problem.

Tips:

"See a movie that REALLY interest you! Sometimes if you a really focused on something you enjoy, your tics will decrease. Take frequent bathroom breaks or step out if needed for a minute."

-Amanda S., East Brunswick, NJ

The Scene

Your friends have invited you to hang out with them. It's a Friday night, school's not in session, you don't have to work your part-time job tomorrow: you've got nothing but time! You eagerly accept, only to find out someone has suggested you all go see a movie. You have wanted to go see that film for weeks now, but what happens if your tics increase in the theater? You shrug off this thought and decide to go join your friends.

A few hours later, what you dreaded happens: you're at the movies and your tics are increasing. Your legs are kicking the chair in front of you and you are repeating lines from the movie, loudly, so that others in the theater turn around and look at you. Even your friends begin to whisper, "Hey, can you stop doing that?"

Tips:

"If all else fails, have a backup plan!
Suggest watching a movie at home or a
new show on Netflix because everything
eventually comes out on DVD!"

-Jenn H., Old Bridge, NJ

Movement at the Movies: In Action!

Narrator: It is a Friday night and two friends are going to the movies to see "Frozen." It was the first day this movie came out, so Amanda and Jenn were only able to find two seats together up in the first row.

Amanda: I've been waiting to see this movie for months! I really hope my tics don't get in the way. I'm kinda worried they will, especially in the front row.

Narrator: The movie begins and both girls get really excited for the opening song... when suddenly...

(Amanda starts to have a motor tic: arm goes up in the air, both girls try and ignore it, but it continues.)

Amanda: I think I should step out for a minute. I can't help but think I'm distracting everyone.

Jenn: But you'll miss the best part! Pleaseeee stay!

<u>Narrator:</u> Both girls stay and the tics continue. They continue to increase in frequency and volume as the girls get more excited about the movie's best scenes. This time Amanda's motor tics won't stop, and as she becomes more aware of the possible distraction, they increase with her anxiety.

Person sitting next to Amanda: Hey, could you please stop? I'm trying to watch and hear the movie.

Amanda: I'm sorry but I have Tourette Syndrome, which means that I can't control my movements and sounds sometimes. It's something neurological and telling me to stop can sometimes just make me nervous and make my tics worse.

<u>Jenn:</u> We've been looking forward to seeing this movie for a long time, too, and didn't think it'd be fair for her to miss it over the chance of some possible tics.

Person sitting next to Amanda: No, I'm sorry, I had no idea, I

thought you guys were just trying to be like some of the teenagers at the movies can be sometimes.

(Amanda and Jenn turn back towards each other.)

Amanda: I do have to go to the bathroom anyways, so I'm going to step out for a minute and by the time I come back I should be more relaxed. Pay close attention to the movie for me, I want updates when I come back!

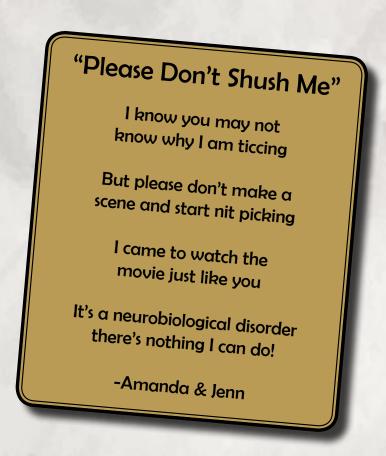
(Amanda comes back in and her tics settle down.)

Narrator: The movie finishes and the girls head out to their cars.

Jenn: Sorry you had to deal with that lady before, she was so rude!

Amanda: Hey, not everyone knows what TS is, so I'm actually thankful I got to educate another person on it today. Hopefully now she'll be more aware of how TS works if she ever encounters someone with it again.

End scene.



Dr. Cox's Tips for Thriving Academically



1. Identify Your Strengths & Weaknesses:

Do you have creativity, good communication or computer skills, a tenacious work ethic? Or, are you challenged by time management, procrastination, or perfectionism?

2. Establish Academic Goals:

Each school year, decide and work toward achievable goals—certain grades, the honor roll; doing better in a certain class, etc... Stretch yourself in setting goals then celebrate achieving them. Without goals, you may find it too easy to miss assignments or not try your best.

3. Develop A Time Management System:

Electronic gadget, paper planner or calendar. Keep track of important dates and deadlines; prioritize your time.

4. Stay on Top of Assignments:

Don't rely on your parents or teachers to remind you about homework and tests. When you get to college or the workplace, professors and supervisors are rarely empathetic regarding late work. Start good habits now and keep track of your tasks on your own.

5. Get to Know Your Teachers:

Let them know you too! At least connect with teachers in the subjects you think you want to pursue in the future. They can help you select colleges, give you valuable advice about the college application process, and guide you in the right direction.

6. Find a Study Partner in your Classes:

"Study buddies" can help you by sharing class notes, doing review sessions together, studying for tests and partnering on homework and labs. Pick a mutually beneficial partner.

7. Schedule Study Time and Breaks:

Don't cram! Study daily, over a long period of time, with short breaks taken between assignments or subjects. Study for an hour, then take a 10-minute break, etc... You'll retain material longer this way; and there's a connection between a healthy body and a healthy mind.

8. Work Hard, Play Hard:

The end of high school is about transitioning from a teenager to an adult! Seek balance! Avoid burnout by giving yourself personal rewards.

- ONE OF THE -

GREATS

"I am One of The GreaTS because I can stand up for myself when needed. I am able to overcome great obstacles, even ones I think are greater than me."

-Luke D., Andersonville, TN





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GREATS.

"I'm One of The GreaTS because of the fact that I can advocate for myself, teach others to do so, and can follow tips shown to me in presentations to better myself."

—Logan A., Little Egg Harbor, NJ





"Over the past couple years, I have started to advocate for myself a lot more than when I first knew I had TS which is a huge concept that is talked about consistently at the Academy. Most of the time, when trying to study, it is really tough for me to overcome some of the tics but I push through mentally and physically in order to perform well. I have learned a lot at this Academy from what to do with bullies, more methods to suppress the tics a little and how to further explain TS to people not only for me but others. This Academy has given me more confidence and will make me a better advocate for TS which makes me feel like One of The GreaTS." —Trevor S., Randolph, NJ



Click to listen to Trevor's "Gangnam Style" TS rap



"I am one of the GREATS because I've learned perseverance and self-love through the fiery baptism of bullying and struggles in school." —Sharif W., Elkins Park, PA



"I believe that I am one of the GreaTS because of how I use courage, resiliency, and grit to respond to adversity. Throughout my life, I have been through many situations where my morals and beliefs were challenged by the outside world. Yet, by using courage to stand up for what I believe in, resiliency to construct physical, mental, and spiritual strength, and grit to strengthen my character, I am able to successfully face all of the opposition that comes into my life."

-James P., New Milford, NJ





It's your turn to Stand With The GreaTS!

We hope the scenarios and the suggested strategies for confronting the challenges they present provide you with the tools and language to navigate social interactions as a teen with TS. One of the key takeaways for teens who attend the Academy is the sense that they are not alone. Rather, they have a community of individuals who understand exactly what teens with TS are going through and are anxious to make a difference in the lives of others. Echoed time and again is the sentiment that participating in communities and activities that are intended to generate understanding, awareness, and strategies for others has the bonus of strenathening and helping participants themselves!

The Academy is entering its fourth year, and we are overwhelmed by the wonderful feedback we've received from Academy participants, their parents, and the coaches and presenters who mentor participants throughout their stay at the Academy. Comments like: life changing, better performance in school, an easier time forming and keeping friendships, and a stronger sense of self. What teen doesn't deserve an opportunity like this?

It's a common misconception that the NJCTS Tim Howard Leadership Academy is underwritten, but the Academy, which welcomes teens from around the world to participate free of charge, is funded strictly

through donations, fundraising events, and corporate sponsorships. We hope that you consider donating to this initiative to broaden our reach to the hundreds of other teens who will gain confidence from this one-of-a-kind learning experience. Nowhere else is this extraordinary opportunity available.

Please join us in our efforts to extend this global community of GreaTS, so that the social stigma, misunderstanding, and misconceptions around TS are eradicated, and individuals who live with TS and associated disorders may live their best lives possible!

Melissa Fowler, MA, MEd Director NJCTS Tim Howard Leadership Academy

Faith W. Rice Executive Director NJ Center for Tourette Syndrome & Associated Disorders, Inc.

For more T\$ resources, visit:

www.NJCTS.org

standwiththegreats.org

NJCTS · TIM HOWARD



The Teenage Guide to Living with Tourette Syndrome

Tourette Syndrome is often misunderstood by people who think that tics are controllable, or that TS is just something that means you curse a lot. But the truth is, having TS is much more complicated than that, and it can be difficult to understand, and really hard to explain.

The Teenage Guide to Living with Tourette Syndrome is brought to you by the NJCTS Tim Howard Leadership Academy Class of 2016, offering advice, guidance, tips, and suggestions for dealing with tics, friends, teachers, and others, for ALL teens living with TS.

This is advice FOR teens, BY teens—people who have definitely "been there" and are offering their best advice of how to handle any situation that gets thrown your way. The contributors are also representatives of The GreaTS movement which empowers individuals with Tourette Syndrome—especially kids and young adults—to develop the confidence, leadership, and self-advocacy skills necessary to overcome their challenges. What follows is an attempt to uphold The GreaTS mission of breaking down social stigmas, generating awareness, and providing support. We hope it provides you inspiration and language to help others understand; we hope you share it with others to generate better awareness; and we hope it provides guidance and support that you or someone you know might need.

