

UNFILTERED

Mason Fong turns Tourette's into a source of strength

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photos courtesy of
Mason Fong



In a silent testing hall, scratching pencils, rustling papers and the occasional cough fills the air. Then, a short, involuntary noise breaks through the tension, like a pebble dropped into still water. But Mason Fong (12) doesn't flinch. He stays focused, breathing steadily, eyes on his paper. For him, these moments weren't new. They were normal. And more importantly, they were manageable. But it hadn't always been that way.

The Diagnosis

Growing up in a Hong Kong-American household, Mason and his family had no idea what Tourette's was. Only after sixth grade, when the tics began to worsen, did he visit professionals. He was then promptly diagnosed.

"I found out since I was watching America's Got Talent with my family," Mason said. "There was this comedian with Tourette's, [and] he explained what it was. And I'm like, 'Mom, I think I might have that.' We went to the neurologist a couple weeks after, and they were like, 'Yeah, you definitely have it.'"

Tourette's is a neurological disorder characterized by involuntary movements or sounds called tics, which vary from person to person. According to the CDC, it affects around one in 162 children.

"It's random, it changes every couple months, but my main one is that I make noises," Mason said. "It's definitely how people know me. I don't hit myself or anything, but sometimes it's tiring to live with it. My muscles get sore from [the twitching] and my throat really hurts, but it's not crazy bad though."

Further, Mason's tics worsen when he's affected by emotions such as nervousness or anxiousness. To combat this, he turns his focus away from Tourette's and instead focuses on something else.

"If I really need to focus in a quiet situation, I take deep breaths to put my mind on something else," Mason said. "Definitely don't think about Tourette's at all. Take deep breaths and stop it from happening. When I'm very focused on something, it gets better."

Before the diagnosis, Mason's teachers and parents simply thought he was seeking attention, either with a sudden cough or other random noises.

"I didn't know what I was doing and I couldn't stop it, not knowing what the answer was," Mason said. "Now knowing what it is, I can live with it, but it was really difficult trying to live with it without knowing what it was, and everyone around me would get frustrated, and I couldn't explain why. I was like, 'I can't control it. I don't know what I'm doing.' I had no coping mechanisms for it. I accepted that I [couldn't] control it and no one in the world

would understand me. But turns out, I just had Tourette's."

After the diagnosis, Mason was encouraged by his family to present in front of his classmates, educating them about Tourette's. His classmates then branched out and told other classmates, and now mostly everyone in the school is aware of his condition.

"Other people stopped judging him," Mason's longtime friend Tommy Edrington (12) said.

Finding Strength

Along with dealing with his own condition, Fong also has to deal with others not aware of Tourette's. Therefore, whenever meeting a new person, Mason always makes sure to immediately tell others what his condition is.

"I'm very straightforward with them," Mason said. "[I say], 'Yo, if you hear any noises or anything weird, just know that's me. I have Tourette's.' And I explain what Tourette's is. Keep it short and sweet."

However, this confidence didn't come naturally. Originally, Mason felt that his condition was something to be ashamed of; it was something he needed to hide.

"I was not comfortable living with my condition, and I was embarrassed about it," Mason said. "I was embarrassed showing my face in front of us. I [got] so many looks in the hallways all the time when people [told] me to be quiet or [were] mean to me."

What made those moments especially painful was the misunderstanding behind them. While everyone could hear the tics, they couldn't feel Mason's struggle and frustration underneath.

"It's hard to understand, especially if you don't have it as well," Mason said. "You don't know what the feelings are or how frustrating you are [with] yourself. People who have Tourette's are as frustrated as the other people in the room with them."

Since there's no cure for Tourette's, Mason's family took him to see specialists, providing him with therapy and medication, which often didn't remedy his condition.

"I hated the fact that I had to live with it and that there's nothing I could do," Mason said. "I felt I was cursed. But, after a few years, it's really not that bad compared to what other people are living with. It's very minor, so I'm pretty grateful, and I see it as a way for me to grow. It was a really big accelerator for my growth back in middle school."

A big shift in Mason's attitude can be attributed to his transitioning from dealing with Tourette's to rather accepting Tourette's as simply being part of him.

"One of the biggest things is [Mason] accepting who he is, and not letting his condition become his identity," Edrington said. "He's worked really hard for school and

"He's a very calm person, and he's very confident."

Kenix Fong
mother



Scan to listen to Mason Fong's (12) story

he's been able to separate his struggle with Tourette's with his passion for academics and other things."

Even through these immense challenges, Mason never lets these negative experiences bring him down.

"I think he's mentally very strong to have to deal with all these issues," Mason's mother Kenix Fong said. "For the people that don't know him, when he [goes] to restaurants or on an airplane or on public transportation, people look at him weird, but he is so strong that he shuts those negative feelings out and just lives his normal life. Mentally, he is stronger than most of the kids that I know."

Mason's challenges with Tourette's has further motivated him to take a more positive stance on approaching life, using those experiences to grow.

"They don't know," Mason said. "They're not really aware of the surroundings and the challenges that people go through. I feel it's good to be a little kinder, more understanding to people. You don't know what they're going through, you don't know what they have or what's going on at home or what's going on mentally for them. It's good to be more understanding, especially in high school, a time where people are still trying to find out who they are."

For Mason, understanding goes both ways. If people are more open-minded, they're more likely to meet honesty with empathy, and honesty starts with him.

"Being open is a good thing to have because you want people to understand [Tourette's]," Mason said. "If you're open to telling them about your experience with it, they'll definitely understand, and they'll know where you're coming from. People don't know; that's why they're mean."

Even though Fong is very open to others joking about his condition, the nature of tics has often allowed the media to paint it in a comedic picture.

"Whenever I watch movies or go on Instagram to see Tourette's, it definitely hurts the reputation of Tourette's," Fong said. "I feel the media puts Tourette's in light of it being a joke. No matter how minor it is, it's still a challenge for everyone who has it, and I wish people were more accepting and aware about what it is."

The Road Ahead

For a long time, Mason wanted to be the first person to find a cure for Tourette's. However, he is reconsidering this option, as the path to become a doctor requires countless years of hard work, which could cause him to miss out on other valuable life opportunities.

"I definitely want to help spread the word for [Tourette's] in some way," Mason said. "No matter how big or small or how many people I tell, I definitely want to spread the word about it and make people more aware of it; we need to inform people more about [Tourette's]."

To work towards this goal, Mason is currently the president of Student Council and vice president of National

Honor Society. This has allowed him to speak in front of a crowd at a variety of events such as prom, homecoming and the Coaches vs. Cancer basketball game.

"I enjoy speaking," Mason said. "I think it's fun. Don't think about it too much, don't get too nervous and relax and go with the flow. I don't really have any coping ways, but I go out there and do it. It's [like] when you play an instrument: you're nervous before you play, but once you start playing, all your nervousness goes away because you're focused on your performance."

Mason's confidence in front of a crowd greatly aligns with what his mother has always hoped for. With Tourette's, Mason needs to work even harder to fit into a world where socializing is key for success.

"I want him to learn how to socialize with friends, to communicate with other people," Kenix said. "I think that's more important than getting straight A's or being at the top of everything. You can be the top [of] your class, but if you don't know how to handle people, that's not going to go well."

Further, Mason's confidence when speaking isn't because of talent, but instead because of his many years of learning how to live with something that once felt like a burden. Now, he is always looking for ways to turn Tourette's into a source of strength.

"[Tourette's] definitely is a challenge," Mason said. "It's tiring, it's frustrating, it's very frustrating sometimes, but I feel I would not be here without living with Tourette's. I'd be a completely different person, and I'm just thankful for my experience with it."

Captions: Mason Fong (12) poses in front of the Jahnke Student Entrance. Mason views his condition as a strength, allowing to grow from the variety of experiences in his life. "[Tourette's] is definitely the biggest factor in shaping my life," Mason said. "I feel I'm more aware of my surroundings and more empathetic towards people. It's definitely made me better in general." Photo by Vincent Hsiao. (on page 8)

The Fong family attends a Chelsea game Dec. 27, 2022. Mason's family has closely supported him throughout his journey with Tourette's, even when others might be judging towards his condition. "When he goes to restaurants or on an airplane or on public transportation, people look at him weird," Mason's mother Kenix Fong said. "I feel bad for him, but he is so strong that he [shuts] those negative feelings out and [lives] his normal life." Photo courtesy of Mason Fong. (on page 11)

Mason dons a felt mustache during his years at Spoede Elementary School. At that point Mason had not yet been diagnosed, which often led to misunderstandings. "We thought he was trying to get attention, when [he's] making noises," Kenix said. "We thought he was one of those kids trying to get attention from teachers. Photo courtesy of Mason Fong. (on page 11) 📷



"Before, I was way less confident in myself. I was never as social as I am right now."

Mason Fong (12)