



A NEW DIR

by Tracy Vonder Brink

The kids and teens
of the Mayo Clinic's
Pediatric Advisory
Board are changing
how research is done.

RECEPTION

Physician Paul Croarkin is testing a new treatment for depression in kids and teens, and he's come to a hospital advisory board for help. He presents a slideshow explaining his research, then asks the board members what they think of his presentation. He also wants to know how he could find volunteers for his project, something he's had trouble doing. The board members ask questions and give suggestions, and Croarkin, a psychiatrist, listens carefully and plans how to use what they tell him. But these board members aren't other doctors or scientists; they're not even adults. This board is a group of kids ages 11 to 17. They're the Mayo Clinic's Pediatric Advisory Board.



Xavier Felder, fourth from left in the top row, poses with fellow members of the Mayo Clinic Pediatric Advisory Board.

Why Kids?

An advisory board is a group of volunteers who give suggestions and guidance. A business might use an advisory board to find out if people like a new product. In science and medicine, advisory boards are often used to give recommendations and direction on studies and projects about health. For example, an advisory board might suggest how a researcher could make volunteers feel more comfortable during a study. But most advisory boards are made up of

adults. The Mayo Clinic's Pediatric Advisory Board is the first of its kind. Why set up a board of only kids?

The Mayo Clinic already had an adult advisory board, but more and more topics that involved kids were being brought to it. So Christi Patten, a doctor at the Mayo Clinic, thought it might be valuable to put together a pediatric version. (Pediatric is the medical term for kids.) After all, if studies are focus on health topics that affect young people, who better to ask than the kids themselves? Patten and

other board organizers decided to run the board just like the adult one—the only difference would be the age of the volunteers. A community outreach coordinator at Mayo Clinic reached out to teens to invite them. At first the board organizers wanted teens ages 14 to 17. But younger kids were also interested in joining, so they expanded the age range down to 11.

Xavier Felder, 14, has been with the board from its start, since April of 2019. He says he decided to join “because I wanted to know about diseases and what they’re doing about them, and new treatments.” The young board members went through the same training as adult advisory boards, learning about the rules doctors and scientists have to follow and what the different types of research are.

How It Works

The Pediatric Advisory Board gets together four times a year to give their advice to researchers. Each meeting lasts close to two hours. Before researchers go before the



After a presentation to the group, Dr. Paul Croarkin asks for feedback on aspects of his study on kids and teens.

Xavier Felder listens as Logan Holt (left) and his big sister Jade Holt (below, center) share their ideas.



board, they meet with the group's organizers to talk about how they'll present. They're limited to five slides and are reminded to make topics clear and understandable. They might also plan to break into smaller discussion groups after the presentation.

Xavier says his favorite part of the meetings is talking with the researchers. "I like when we can ask them questions about their topic. I get fascinated by the different diseases they study . . . things I've never heard of before," he says. Does talking to doctors and scientists ever make the kids nervous? Xavier says no. "The first couple of times I didn't know everybody in the group, so we did some ice breakers," he explains. "Now that I know the people in the group, I'm not nervous. If someone else asks a question I was thinking of, I just think of another question."

Helping Researchers

When Croarkin presented to the board, he asked for suggestions on reaching kids and teens who might want to try his treatment for depression. He showed the advisory board flyers he'd

printed that described the treatment. Instead of the flyers, they suggested he use social media and places where kids already were—like school—to help get the word out. So he presented to a local school board and was given permission to post information about his project on the school's resource page. He admits he wouldn't have thought of using a school to look for volunteers if the group hadn't suggested it. "They were even more on point with their advice than the adult advisory board," he says.

Physician Sarah Atunah-Jay and health care analyst Gladys Asiedu were also impressed by the Pediatric Advisory Board. They're studying how doctors can support kids who are bullied about their race, ethnicity, or weight. "The board brought up that talking about these issues can be very stressful and wanted to know how we'd make kids participating in the study feel safe and supported," Asiedu says. Atunah-Jay adds, "They gave great feedback on the focus group guide and will also be involved with data analysis."

The Future of the Advisory Board

Folks at the Mayo Clinic hope other hospitals and research centers will start their own pediatric advisory boards. They've found that kids have different experiences and insights than grown-ups, so their feedback is different from an adult advisory board. For example, when Atunah-

THE MAYO CLINIC

The Mayo Clinic started in the 1880s as a small clinic run by the Mayo brothers in Rochester, Minnesota. The brothers were surgeons, and they wanted to create a group practice where patients could see a team of specialists all in one place. Within 30 years it had become known around the world for its quality of care. Today more than a million patients go to the Mayo Clinic every year, and it has locations in five states.



Jay and Asiedu presented to the two boards, the adults wanted to know how the study information would be used, but the younger group had questions about how kids who joined the study might be affected. Both types of feedback are important for researchers. Atunah-Jay explains, "Our work isn't valid unless we consult kids. This is research that has an impact on them, so they need to be involved."

Being on the board has made Xavier interested in a career in science. "It opened my eyes to other careers in science than just being a doctor," he says. "You can work in a lab or be a researcher." What would he say to kids if a pediatric advisory board comes to their community? "I'd tell kids to get involved," he says. "If more kids join things like this, you have more voices, so the feedback and ideas are more diverse. It might sound like it would be boring, but it's not. It's fun, and you get to help people."

Tracy Vonder Brink is a writer from Cincinnati, Ohio. She would've loved to join a Pediatric Advisory Board as a kid. (What could be cooler than learning about science and telling researchers what to do?) She thanks the Mayo Clinic community members who lent their voices and insights to this article.