

URMC will expand care for Tourette

Center joins consortium that will treat tic disorders

PATTI SINGER

STAFF WRITER

Families dealing with Tourette syndrome will have what amounts to an all-star team to coordinate care as the University of Rochester Medical Center joins a consortium to treat tic disorders.

The Tourette clinic at URMC will be partnering with three downstate hospitals to form a center of excellence, as designated by the national Tourette Syndrome Association. The group is one of 10 designated centers of excellence in the nation. Of those, the URMC group is one of three that is receiving up to \$50,000 a year for three years from the organization to improve care for people living with the disorder.

"It expands the reach of our expertise and our alliances, and at the same time provides more access and expert care for families who live throughout upstate," said Dr. Jon

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Dr. Jonathan Mink

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athan Mink, director of the Tourette clinic and chief of the Division of Child Neurology at URMC.

Mink said the consortium has two main goals. One is to raise awareness of tic disorders among primary care providers and train them to manage the less-complicated symptoms of Tourette and other tic disorders in children and adults. The other is to use teleconferencing so that families don't have to travel every time they need an expert.

Diana Pratt, whose 12-year-old was diagnosed with Tourette syndrome when he was in first grade, said the consortium can benefit families by having doctors more knowledgeable about tic disorders. "The more you educate the physicians, the more they educate the parents," said Pratt, who is vice chairwoman of the support group through the Tourette Syndrome Association of Greater Rochester and the Finger Lakes. Pratt said that at the start of each school year, she writes letters to her son's teachers, explaining how Tourette affects his ability to learn. "If more physicians understand, they can write notes to teachers. If I had a letter from a parent or a letter from a doctor, I would take the letter from the doctor more seriously."

Collaboration is becoming more common in all aspects of health care. It allows institutions to expand resources and reach more people than if each institution were going it alone. Mink said part of the consortium's role is similar to what URMC is doing now with telemedicine in the treatment of Parkinson's disease, particularly with nursing home patients who are unable to travel.

But the Tourette initiative involves three other centers — Icahn School of Medicine at Mount Sinai, North Shore-Long Island Jewish Health System and Weill Cornell Medical College — and will blanket the state.

URMC's territory, which already covers much of western New York and the Finger Lakes, would extend to Albany and most of the Southern Tier.

"It expands the reach of our expertise and our alliances and at the same time provides more access and expert care for families who live throughout upstate," Mink said.

Each hospital applied to the Tourette Syndrome Association. The consortium seems like an odd alliance, reminiscent of the Saul Steinberg cover for the *New Yorker* magazine that showed the view from 9th Avenue west of the Hudson as uninhabited desert clear to the Pacific.

"It was an interesting discussion," Mink said. "They're based in New York City. Like most people who don't travel much outside New York City, they think of Rochester as being somewhere on the other side of the Hudson River." The Tourette Syndrome Association formed three other regional centers of excellence elsewhere and wanted to serve all of New York, and Mink said all the hospitals were in favor.

Even before the consortium there was some collaboration. Mink said that he and Dr. John Walkup of Weill Cornell appeared on the WXXI-TV show *Second Opinion* to discuss the mass psychogenic illness that occurred in Le Roy, Genesee County last year.

Mink said URMC consulted on cases of conversion disorder, and the format of the consortium will allow the institutions to broaden such expertise in all aspects of tic disorders.

Mink said the hospitals are planning an educational conference in May in Ithaca for pediatricians and primary care providers.

Mink said approximately 1 percent of the population has Tourette syndrome or another tic disorder, characterized by uncontrolled involuntary movements and sounds. It's not uncommon for those affected to also have anxiety, obsessive compulsive disorder or attention deficit hyperactivity disorder. Mink said about 20 percent of children with a tic disorder have a learning disability.

Because other aspects of health are involved, Mink said the most effective care involves several medical, occupational and educational specialties. He said the URMC clinic provides a comprehensive approach, but the consortium will provide access to more experts. "We'll support each other with referrals or videoconferencing. Patients in Rochester could receive care at the same time from a psychiatrist in New York City."

PSINGER@DemocratandChronicle.com [Twitter.com/PattiSingerRoc](https://twitter.com/PattiSingerRoc)



Diana Pratt