

State has millions to spend on research

Is \$1 fee a ticket to a breakthrough?



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

Alessandra Drago, 3, receiving a reward for her efforts at speech on the first day of school at Tri-Valley Academy in Bergenfield.

By **ELISE YOUNG**
 STAFF WRITER

The Governor's Council on Autism is looking at a record number of grant applications from New Jersey labs and hospitals studying gene sequences, the environment – anything that might trigger so much disorder in the brain.

Its job is to give away \$10 million – the fruits of a \$1 state surcharge on traffic tickets. This is no easy task.

The council, in existence since 1999, hired its first full-time director, Mike Gallo Jr., just last month.

And as Gallo knows all too well, he's under a strict deadline to turn around a years-long morass of administrative and budget problems.

"If we're still having this conversation a year and a half, two years from now," he said, "tar and feather us."

Over the next several months, New Jersey's public policy on autism has the potential to evolve like never before.

For 2007, Governor Corzine gave public schools \$15 million to serve autistic students and to train their teachers.

"We have a bigger focus than al-

most anyplace in the country," Corzine said in an interview this month. "New Jersey's rate is alarmingly high. There have always been concerns there are environmental elements associated with it."

In autism's grip

Six-part special report

In addition to what he called "a responsibility of one human being to another," Corzine said the need to fund autism research and therapies is a financial imperative.

"This is a cost-benefit issue," he said. "Generally, physical health is strong in these individuals. They are going to live long lives. It is at a very high cost of failure that we

try to do the best we can to integrate and to provide a pathway for full participation in everyday life."

In the Legislature, bills would allocate more than \$20 million for an autism registry, education council and other services. One lawmaker, concerned about a possible link between sonograms and autism, is proposing that the Department of Health and Senior Services regulate pregnant women's exposure to ultrasonic waves. Another wants New Jersey to join the 17 states that compel health insurers to cover autism-related costs.

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Heidi Roger of Fair Lawn, a board member of the Governor's Council on Autism, and her son Andrew, who is autistic.

Research could get big boost from state

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In truth, some of those bills have languished for years. But autism advocates see Corzine as the force to make them a priority.

"We have a governor who is committed to this — who really understands the autism issues and wants them to move forward," said Paul Potito, executive director of the New Jersey-based Center for Outreach and Services for the Autism Community, one of the country's oldest such groups. "Also, we have legislators who have an interest and a concern. I see us as building momentum."

For the autism council, the next 36 months are crucial. Board members must prove that their work has led to bona fide research and clinical treatments. If lawmakers aren't happy, they'll refuse to reauthorize funding and the council will go out of business.

"We really put our credibility on the line," said board member Judah Zeigler, a former Leonia mayor whose son has autism. "Finally, we have the money for the

treatments. I'm really hopeful that by getting started now with these clinical research grants, when the time comes up for reauthorization, the only question legislators ask is, 'Where do I sign?'"

Heidi Roger of Fair Lawn, another board member whose son has autism, imagines where the council will be in a year.

"I'm hoping we have something exciting to present to the public," she said. "That we can hold a conference that highlights what has been funded and what the results have been — even if it's baby steps toward the ultimate answer."

Money trouble

The Governor's Council for Medical Research and Treatment of Infantile Autism, within the University of Medicine and Dentistry of New Jersey, came about in 1999, when Christie Whitman was in office. The council was headed by a seven-member board of four parent advocates and the rest from UMDNJ. It had \$1.5

million to distribute.

A year later, though, bad news came from the Legislature: The state was heading into fiscal crisis and the Governor's Council would get no funding at all. In 2001 lawmakers came up with \$1.5 million, according to the state Office of Management and Budget. But in 2002, the council again saw nothing.

Meanwhile, the council was operating without a director. Day-to-day record-keeping fell to a secretary who was "borrowed" from the university, according to Lawrence A. Feldman, a UMDNJ vice president who was the council's first chairman.

"We did what we thought was best, and that was to spend money on kids and research," Feldman said. "When I sent out a letter to a bunch of people, all the postage and all the paper — I just used university funds that were available. The university really subsidized, to a great extent, the working of the Governor's Council."

Some board members say that when the budget problems materialized, they should have been devising a strategy to meet with legislators, talk to the governor — anything to keep going. Instead, the monthly meetings schedule fell by the wayside. The chairman, they say, didn't seem interested in convening. Feldman said that wasn't so.

"We published the meeting dates at the beginning of the year. The board members [didn't] come," he said. "Is it true that we didn't have meetings enough? I don't know."

Whatever happened when the board did get together is something of a mystery.

"We were never given the files of the minutes in electronic form, for the Web page," Zeigler said. "I made that request on any number of occasions. I don't think the secretary was intentionally hiding anything. For whatever reason, this was just a sideline to her normal job."

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Clock ticking on legislation

By **ELISE YOUNG**
STAFF WRITER

The Combating Autism Act is Congress's \$1 billion effort to chase down the cause of the disorder and treat those in its grip.

Onboard are New Jersey's two senators and 11 of its 12 representatives – Rep. Scott Garrett, R-Wantage, has not taken a position and the 13th seat is vacant. It has huge support from the country's most influential autism groups and advocates.

The legislation passed unanimously in the Senate on Aug. 3. Yet it is running out of time in the House of Representatives, where sponsors have mere days to introduce it before Congress goes into recess Oct. 6. The bill needs a majority of 218 representatives to pass. It has 190, according to a list compiled by CombatAutism.org, a coalition of advocates.

"We would like to pursue this this year," said Lisa Cohen, chief of staff for Rep. Diana DeGette, the Colorado Democrat who is a primary sponsor. "We're hopeful, because the bill has broad bipartisan support both in the House and the Senate."

Over five years, the bill aims to direct \$643 million for research through the National Institutes of Health, \$210 million for therapy and other services for autistic youth and adults and \$75 million for public education. It calls for the screening of every child in America, because therapies

for autism work best when started at a young age. It demands that the director of the National Institutes of Health make autism a priority, with annual reports to Congress.

The research money could be a boon for autism specialists at the University of Medicine and Dentistry of New Jersey and Rutgers and Princeton universities.

"Clearly, New Jersey, as a leader in this field for more than four decades, would benefit both in the health-related context as well as in the potential biomedical research and related sciences that are actually being conducted here," said Sen. Robert Menendez, D-N.J., one of the bill's sponsors. "If it went through the full Congress this year, it seems like the benefits could begin to flow at the end of next year."

Of course, President Bush's signature is crucial – and he has not publicly committed to the legislation. And some believe that election-year politics is making some House members leery of committing to a \$1 billion expenditure.

"The reason it's being held up in the House has to do with how much money the present majority wants to spend on health care in general," said Rep. Steve Rothman, D-Fair Lawn. "They don't want to come up with a figure before the election."

Rep. William J. Pascrell Jr., D-Paterson, said his colleagues have no time to spare,

particularly when some research suggests that autism is caused by environmental factors – a great concern in a state with the country's highest number of Superfund sites.

"I think that while this is far from what we need, we need to get it passed immediately," Pascrell said of the bill. "The House of Representatives is like a dinosaur. It needs its tail whacked so many times."

New Jersey's one holdout is Garrett. "It's still under consideration for him," said his press secretary, Audrey Jones. "Often he doesn't say how he's going to vote ahead of time."

A Republican colleague and longtime advocate of autism causes, Rep. Christopher H. Smith of Mercer County, said the House could save time and scrap its version of the bill.

"At this point, this late in the game, just take the Senate bill and pass that," he said. "Avoid a conference. I'm saying, 'Mr. Speaker, post the Senate bill.' The sooner this gets down to the president, the better. Get it down to the president. He'll sign it in an instant."

But the Bush administration wouldn't confirm that.

"We don't have an official position on the bill," said Peter Watkins, a White House spokesman.

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The whole setup aggravated the parents on the board. Zeigler went to Loretta Weinberg, the Democratic assemblywoman who now is a senator, and asked for a fundamental change in the council's funding: Rather than rely on a fluctuating amount each year, the council should have a dedicated revenue stream, independent of tax revenue.

In 2003, Gov. James E. McGreevey signed Weinberg's law, mandating a \$1 surcharge on traffic tickets for moving violations.

For the first time, the council began to see serious money: \$4 million to \$5 million a year.

With that kind of cash, the council allotted \$110,000 to hire a director and a part-time staff of its own.

More change was on the way. The parents wanted a chairman who had clinical or research ex-

pertise in autism. Feldman, they pointed out, was a microbiologist and a UMDNJ executive, with primary duties in the school president's office.

In October 2005, he was replaced by Dr. Kendell Sprott. "I'm a pediatrician," Sprott said. "I've had a number of kids who have autism and I've been concerned about the services they've gotten. I saw this as an opportunity to move things forward."

In August, the council hired its first director, Gallo, who for 14 years had been director of an environmental science program at Rutgers University.

In all, the council handed out \$6 million through 2005, Gallo said. The idea now is to distribute more money.

By mid-September, the council had received about 30 grant requests – and expected about 20 more – for research. Each recipi-

ent will get \$300,000 over two years. In November, it will open another round of requests, for clinical therapy grants of up to \$500,000 each.

Combined, Gallo said, the grants should amount to \$10 million. He's hoping that lawmakers remember this in three years.

In the meantime, the board isn't done retooling itself. Weinberg has sponsored another bill to alter the makeup of the council, eliminating the strong ties to the UMDNJ administration, which now has the power to appoint the chairman and some board members.

UMDNJ is under the supervision of a federal monitor after the U.S. Attorney's Office alleged corruption and mismanagement among some top administrators. In July, the monitor cited at least \$243 million in overbilling, double billing and waste, a lack of oversight for more than \$104 mil-

lion in no-bid contracts and no valid purchase orders for \$88.3 million paid to vendors.

There is no indication the council's money was ever mis-spent. But Roger, the board member and Fair Lawn parent, said that as New Jerseyans become aware of the autism council's work, they should have no questions about its operations.

"We're trying to do everything without even the appearance of impropriety," she said.

Weinberg agrees. "It is the governor's council – not the UMDNJ council," Weinberg said. "I think that it's sort of moribund. With a little more autonomy they would be able to get a new view, a new outlook, a new passion to move ahead."

Zeigler said that he and Gallo are talking about giving the Legislature an update.

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"We have an obligation to publish an annual report," Zeigler said. "That hasn't been asked for. You know what? We shouldn't wait until it's asked for. We have an absolute need to be transparent. We have an obligation to do the right thing. Finally we can hold our heads up to the people of New Jersey and to the autism community and say, 'Here's what we've been doing.'"

Gallo calls the changes "a hopeful story."

"Yes, this council had problems," he said. "It still succeeded in getting some work done. At some point, the past is the past. What I would say to the autism community is, you have some top-notch people in place now. Give them a chance to move this ball forward."

Other legislation

With more money coming in to the autism council – and a governor with a history of funding autism causes – some legislators say they have a greater will to turn their own autism bills into law.

In the Assembly, one bill would require health insurers to cover autism-related treatments, including speech, physical and occupational therapies.

The legislation has come up every year since 2002, most recently in January.

In June, the state Pension and Health Benefits Commission recommended that it not be enacted because it "does not address the overall issue of providing coverage for developmental disorders." One of its sponsors, Assemblyman Louis M. Manzo, D-Jersey City, said the benefits commission – which reviews proposals that could affect public workers' health and pension packages – did all New Jerseyans a disservice.

"No. 1, it just shows their lack of knowledge on what drives cost in insurance," he said. "No. 2, it's just, basically, 'Oh, we let this whole thing run wild on pensions over the past couple of years so now it looks like we're going to be the reformers over here.' We could go right to the Assembly floor and ask the Legislature to establish a law and disregard what I feel is a self-serving opinion."

Another bill would appropriate \$500,000 to set up an autism registry, such as those in Delaware,



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Mike Gallo Jr., the first full-time director of the autism council, will oversee the disbursement of about \$10 million in grants.

West Virginia and elsewhere that compel physicians to report diagnoses just as they do with cancer, HIV and some birth defects. The legislation has been posted each year since 2000.

"Such a small percentage of bills make it to the governor's desk," said Assemblyman John F. McKeon, D-Essex, one of the sponsors. "It just sometimes gets lost in the morass of other pieces of legislation."

A third measure, introduced last year, would establish the Autism Education Council to award grants to public schools, encourage the hiring of specialized school aides and start recreation and social programs. Like the others, it remains in committee, with no hearings scheduled.

The slow pace has frustrated Assemblyman Joseph Pennacchio, R-Morris Plains, a dentist who came upon a study in the Aug. 22 edition of the Proceedings of the National Academy of Sciences that linked sonograms, or ultrasounds, to abnormal brain development in embryonic mice.

Neurologists told him that some researchers suspect the same problem can occur in humans.

The neurons of the mice, they said, seemed to show abnormalities similar to those in autistic children's brains.

"I did some research, called some doctors," said Pennacchio. "I asked about the protocol for taking sonograms. There isn't any."

He wrote letters to state Health and Senior Services Commissioner Fred Jacobs and Corzine, suggesting that New Jersey study the autism rate among children of mothers who didn't have the scans while expecting. In the meantime, he said, regulators should consider a policy to standardize sonograms, including the number of times a woman is scanned, for how long and at what wave frequency.

"It's a lot faster for the governor to make this happen through edict than through a bill," Pennacchio said.

Jacobs' office referred Pennacchio's suggestion to the Governor's Council on Autism.

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