

# Staten Island Advance

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## Controversy raises doubts about research at Willowbrook

By SYDNEY FREEDBERG

The disclosure that at least 20 identified hepatitis carriers are attending city public schools has focused attention once again on nearly two decades of human experimentation into that troublesome disease at Willowbrook Developmental Center.

The carriers, three of whom are now being excluded from regular special education classes at PS 69, Merrymount Ave., New Springville, lived at Willowbrook when experiments into the nature and prevention of hepatitis were conducted.

It has not been established whether any of the pupils now identified as hepatitis carriers bear that medical distinction as a result of participation in the hepatitis experiments.

But a parent of a Willowbrook resident, whose admission to the institution in 1958 was "expedited," he says, by his child's participation in the experiments, says he is investigating the effect 16 years of research might have had in producing the present problems faced by the identified carriers.

Anthony Pinto of Bulls Head, a

member of Willowbrook's Consumer Advisory Board and a past president of the Willowbrook Benevolent Society, insists his most important goal is to ensure that mentally retarded hepatitis carriers — who do not have the disease but who can, under some circumstances, transmit it — are not subjected to any greater restrictions than would be placed on non-retarded carriers.

But he says he is interested in learning if the current situation has resulted, in part, from a lack of follow-up to the experiments, which began in 1956 and ended abruptly in 1969 when parents

gave pause to the idea of using mentally retarded children as experimental subjects.

Pinto says project investigators never told him what potential risks existed when his 10-year-old daughter was transferred from a specially constituted, 16-bed isolation unit in Building 2, the site of the research, to Building 23, a non-research facility.

He says no one was ever clear about explaining either the long-term dangers of serum hepatitis to the patient or the types of precautions parents and staff should have taken if a child had become

a hepatitis carrier.

(Such precautions, according to state guidelines adopted in 1975, include making parents and personnel responsible for the care of mentally retarded persons aware of the need for good hygienic practices, especially after caring for open wounds and before eating and handling food.

(Personal toiletry items, the state guidelines say, should not be shared, but no other restrictions should be imposed on carriers when they participate in routine activities such as special education programs.)

What happened to the carriers referring to the hepatitis experiments, "is hard to explain to people who did not experience it themselves. But it was almost as if they didn't want you to ask any questions and that they wanted to keep each parent isolated from the next.

"I was remiss in signing consent in the first place, but I did so because I was told that was the only way to expedite her admission. But I, and I assume other consenting parents, was ill-ad-

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vised about the possible consequences," Pinto says.

Dr. Saul Krugman, chairman of pediatrics at the New York University Medical Center and the project's chief investigator, denies that by artificially inducing hepatitis in several hundred newly admitted children, ages 3 through 10, he created carriers who would not have become so living in non-research wards of the institution.

He insists that all patients with artificially infected hepatitis would have contracted "a more severe form" of the disease naturally, probably within six months of admission.

And as in Willowbrook's non-research population, which numbered about 6,000, some of those injected or fed hepatitis virus, obtained from the blood or feces of non-subjects, became chronic carriers.

"I've explained this over and over and over again," Krugman said in an interview, "and each time the point seems to get rather distorted. What's going on today has been going on at Willowbrook since 1949."

The pediatrician added that he assumes the percentage of children who became carriers as a result of deliberately induced hepatitis is about the same as among those who developed the disease naturally.

"I can see why it's a difficult problem," Krugman says, adding that "the parents have to blame someone for the carrier state. But the point is that if these children had lived at home, they wouldn't have become carriers at all."

The tests to pinpoint who was a carrier and who was not, Krugman explained, did not become available until the late 1960s, making it impossible to determine precisely which of his sub-

jects might have been affected this way.

A hepatitis carrier is a person whose blood shows evidence of exposure to the infection, called type B hepatitis, which can be transmitted through blood products or saliva and causes lethargy, nausea, jaundice and sometimes permanent liver damage.

The blood of carriers, sometimes for a period of years after exposure, contains a certain body protein not normally identified in non-carriers.

Hepatitis type B, as Krugman's studies confirmed, is separate and distinct from hepatitis A, which is more highly contagious and with which a carrier state is not associated.

"But these are things we learned during our experiments," Krugman said, "and now, of course, this information is useful."

Less than once percent of the general population, according to Krugman, are carriers of type B hepatitis, while the rate at Willowbrook is about 10 to 15 percent. This, Krugman says, results from Willowbrook's generally unhygienic conditions, but he adds: "It's absolutely no different from any other institution for the retarded."

Krugman admits, however, that long-term follow-up of some of the experiment participants became impossible because "they've been transferred all over the place — to other institutions across New York State."

But he added that ever since 1971, every Willowbrook resident, including those who participated in the study, has been subject to periodic blood tests to determine whether an individual has the disease, is a carrier or is immune.

The pediatrician insists that most important, his experiments derived a wealth of information about the nature and prevention of hepatitis, including benefit to some subjects by giving them

future immunity and protecting them from other diseases.

The series of experiments confirmed the efficacy of gamma globulin against type A hepatitis and developed and improved on an inoculation for control of type B hepatitis, Krugman said.

The vaccine is now being tested, although some scientists continue to question its value.

Dr. Charles Cherubin, an epidemiologist living on Staten Island who is familiar with Krugman's work, believes that

"it is a little difficult to know the rate of hepatitis carriers produced because of Krugman's studies because he never really addresses the question in his papers."

But like most experts in the field, Dr. Cherubin thinks Krugman "really couldn't have done much to alter the situation — he just speeded it up a bit."

"I don't think he created carriers who wouldn't have existed anyway," says Cherubin, director of microbiology laboratories at Brooklyn Jewish Hospital.

"But at the time we were unprepared, and completely unaware, that the institution had such an incredibly high rate of carriers."

Pinto points out it is inexcusable to restrict mentally retarded persons in any way because they are deemed carriers of hepatitis, adding that a particularly tragic situation exists for those who acquired the state as a result of experimentation or institutionalization.

"They should just have made people aware of the risks and told them of the precautions to take instead of keeping them in the dark," Pinto says.

And an official of the Department of Mental Hygiene, Karin Erickson, who is deputy director of the Metropolitan Placement Unit agrees, saying: "Our society made them carriers and now we're trying to exclude them."

"It's a Catch 22," says Ms. Erickson, whose job it is to find mentally retarded youngsters homes in the community, "and anyway you look at it, the little children are the victims."

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