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Wanted: Volunteers, All Pregnant



Suzanne DeChillo/The New York Times

ON BOARD Alejandra, a 30-year-old waitress in Queens, is part of a government study of children's health that will follow her and her daughter, Isabella, shown with her husband, José, for 21 years.

By PAM BELLUCK

Published: February 15, 2010

The woman sent by government scientists visited the Queens apartment repeatedly before finding anyone home. And the person who finally answered the door — a 30-year-old Colombian-born waitress named Alejandra — was wary.

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EARLY START Alejandra agreed to be part of the study when she was pregnant. Isabella was born in August.

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Although Alejandra was exactly what the scientists were looking for — a pregnant woman — she was “a bit scared,” she said, about giving herself and her unborn child to science for 21 years.

Researchers would collect and analyze her vaginal fluid, toenail clippings, [breast milk](#) and other things, and ask about everything from possible drug use to depression. At the birth, specimen collectors would scoop up her placenta and even her baby's first feces for scientific posterity.

“Nowadays there are so many scams,” Alejandra said in Spanish, and her husband, José, “initially didn't want me to

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Suzanne DeChillo/The New York Times
FRESH START Isabella's mother said she was taking part to "help the next generation."

Spanish, and her husband, José, initially didn't want her to do the study." (Scientists said research confidentiality rules required that her last name be withheld.) But she ultimately decided that participating would "help the next generation."

Chalk one up for the scientists, who for months have been dispatching door-to-door emissaries across the country to recruit women like Alejandra for an unprecedented undertaking: the largest, most comprehensive long-term study of the health of children, beginning even before they are born.

Authorized by Congress in 2000, the [National Children's Study](#) began last January, its projected cost [swelling](#) to about \$6.7 billion. With several hundred participants so far, it aims to enroll 100,000 pregnant women in 105 counties, then monitor their babies until they turn 21.

It will examine how environment, genes and other factors affect children's health, tackling questions subject to heated debate and misinformation. Does pesticide exposure, for example, cause [asthma](#)? Do particular diets or genetic mutations lead to [autism](#)?

"This is a very important study for understanding the health of our nation's children and for identifying factors that may play a role downstream in adult health," said Dr. [Francis S. Collins](#), the director of the [National Institutes of Health](#), which is overseeing the study.

But while the idea is praised by many experts, the study has also stirred controversy over its cost and content.

In August, the Senate committee overseeing financing for the study [accused](#) it of "a serious breach of trust" for not disclosing that the initial price tag of \$3.1 billion would more than double, and said the study needed to release more information if it wanted to get "any" financing in the next budget year.

And an independent [panel](#) of experts and some members of the study's own advisory committee say it misses important opportunities to help people and communities — emphasizing narrower medical questions over concerns like racial and ethnic health differences, leaving unresolved crucial ethical questions concerning what to tell participants and communities about test results.

"This study is of the magnitude of the accelerator in [CERN](#), or a trip to the moon — a really big science issue," said [Milton Kotelchuck](#), a professor at the [Boston University](#) School of Public Health and a member of the independent panel. "But if you have a flawed beginning, then you've got 20 years of working on a flawed study."

Officials are making changes, putting all but the pilot phase, to involve 37 locations, on hold while conducting an inquiry into the cost and scientific underpinnings, Dr. Collins said. Some data may no longer be collected if "we can't afford" it, he said, and every aspect will receive "the closest possible scrutiny."

The study is far from its plan of recruiting 250 babies a year for four or five years in each community. By December, 510 women were enrolled and 83 babies were born in the first seven locations, including Orange County, Calif., and Salt Lake County, Utah.

That was after knocking on nearly 64,000 doors, screening 27,000 women and finding 1,000 who were pregnant and in their first trimester (and therefore eligible).

Dr. Collins said there were "unexpected difficulties in the number of houses that have to be visited to get enough babies" — 40 houses per enrolled woman, instead of the expected 14.

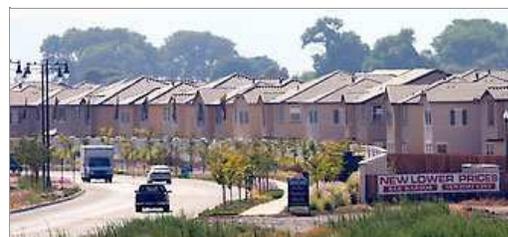
The time and information required from families could also make the study "too burdensome to be conducted the way it is," said Dr. Susan Shurin, former acting director of the National Institute of Child Health and Human Development, part of the National

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Institutes of Health and the study's supervising agency. The fear is women will "go 'Oh no, you again,' and slam the door in your face."

Specimens include blood, urine, hair and saliva from pregnant women, babies and fathers; dust from women's bedsheets; tap water; and particles on carpets and baseboards. They are sent to laboratories (placentas to Rochester, N.Y., for example), prepared for long-term storage, and analyzed for chemicals, metals, genes and infections.

Participants provide the names and phone numbers of relatives and friends, so researchers can find them if they move. As children grow, scientists, including outside experts, can cross-reference information about their medical conditions, behavioral development and school performance.

Clues could emerge if, for example, developmentally disabled children in both rural Alabama and suburban California show similar genetic patterns or chemical exposure.

"The task in selling this study is going to be to say we realize that this is audacious" and "seriously hard to do, but this is hugely important," said Dr. Ellen Wright Clayton, director of the Center for Biomedical Ethics and Society at [Vanderbilt University](#) and part of the independent panel and the study's advisory committee. "I'm hopeful some of the deficiencies can be addressed."

Selling the study presents different challenges everywhere.

In affluent, highly educated Waukesha County, Wis., the study is advertised on movie screens, yard signs and parade banners.

But in the hog-farm-and-Butterball-turkey-plant territory of Duplin County, N.C., where scientists have to enroll nearly a third of the 800 babies born each year, some women are "concerned about questions they may be answering and how they may sound answering those questions," said Dr. Roland Draughn, a local obstetrician.

Nancy Dole, a co-principal investigator in Duplin, said "we had to reassure" residents that "the purpose is not to make the county look bad."

Organizers have visited child car-seat installation events, church groups, even Latino men's soccer teams. Some women have volunteered, even ones who are not pregnant, bringing their children to the study's Duplin headquarters, a former video store.

But others would hesitate if approached.

"Twenty-one years, that's a long time," said Wanda Johnson, 37, a nursing-home aide with four children. "I may say yes, and then tomorrow, I don't want to be bothered."

In Queens, with over 2 million people and 30,000 births a year, recruiting 250 might seem easy. And some pregnant women, like Amy Saez, 28, said that if asked to participate, "I would totally be down with that because I'd become a part of science and history." But recruiters confront a jumble of languages and cultures, calling telephone translation lines to communicate in Urdu, Nepalese and Russian, for example.

And they have to "knock on each and every door in a building until they learn who lives there," said Dr. Philip Landrigan, chairman of [preventive medicine](#) at Mount Sinai medical school and the principal investigator in Queens. They buzz random apartments to get into buildings, "buttonhole people coming out, talk to doormen, supers," he said. For recruiters' safety, door-knocking stops at 8 p.m.

Soon, said Dr. Steven Hirschfeld, appointed the study's director when the original leader left under criticism, new recruiting methods will be tried, including having doctors encourage patients to enroll. That was previously rejected because investigators felt doctor-referred patients would exclude some women, like those not getting prenatal care.

Besides looking at widespread conditions, like [diabetes](#), the study will consider regional differences. Maureen Durkin, principal investigator in Waukesha County, Wis., wonders if

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radium in the county's water, and houses built on "farm fields that may be contaminated with nitrates and atrazine," have different health consequences than pollution or industrial chemicals in Queens.

Health authorities in Duplin County, N.C., are concerned about "so many hog lagoons and poop everywhere," said Shannon Brewer, a health department nurse, who also worries that many women there fail to [breastfeed](#) because "at the turkey factory, they just can't step out of line to pump."

In Flushing, Queens, Alejandra, who gave birth to Isabella in August, is [breastfeeding](#). But she said she was "afraid of the baby getting too many vaccines." She [quit smoking](#) after getting pregnant, but her husband, 34, a golf instructor, smokes in their bathroom.

Joseph Gilbert, a study employee who has been interviewing and collecting samples from Alejandra, said study protocol limited his ability to urge participants to change health habits.

But study officials are trying to determine what information to give participants and when. Some experts say people should get results of their chemical or genetic tests only if medical treatments exist because otherwise it only causes [anxiety](#). Others agree with [Patricia O'Campo](#), a member of the study's advisory committee and the independent panel, who says the study should be "less ivory towerish" and disclose more information to families and communities.

In this and other aspects of the study, "changes have to be made, and maybe some very big changes," Dr. O'Campo said. "I think it could be so much more."

Dabrali Jimenez contributed reporting.

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